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NIH MedlinePlus

WINTER 2016

the magazine

Benjamin King

Star of Disney Channel's *Liv and Maddie* helps others—especially kids—learn to live well with Crohn's disease.

Living with Crohn's Disease

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The U.S Surgeon General leads us all in a Call to Action on Walking.

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Managing Parkinson's Disease

New research offers hope for better diagnosis and treatments.

A publication of the **NATIONAL INSTITUTES OF HEALTH** and the **FRIENDS** of the **NATIONAL LIBRARY OF MEDICINE**

Confronting Violence, Improving Women's Lives Special Display Opens at NLM

Photos: Lisa Helfert

◀ *Confronting Violence, Improving Women's Lives* is on display in the NLM History of Medicine Division (Building 38, first floor) through August 19, 2016.

▼ (From L) Acting NLM Director Betsy Humphreys joins nurses Dr. Barbara Parker, Dr. Jacquelyn Campbell, Dr. Doris Campbell, and Dr. Daniel Sheridan, along with exhibition curator Dr. Catherine Jacquet, WJLA-TV's Kimberly Suiters, and Patricia Tuohy, head of the Exhibition Program, NLM History of Medicine Division.

The National Library of Medicine (NLM), with the support of the Friends of the National Library of Medicine, marked the opening on September 17 of a new special display, *Confronting Violence, Improving Women's Lives*, which is on view until August 19, 2016. The display is also the subject of a companion Web site (www.nlm.nih.gov/exhibition/confrontingviolence) and traveling banner display.

It details the history of nurses and nursing in relation to domestic violence and related research. Activists and reformers in the United States have long recognized the harm of domestic violence and sought to improve the lives of women who were battered. During the late 20th century, nurses took up the call. Beginning in the late 1970s, nurses were in the vanguard as they pushed the larger medical community to identify victims, adequately respond to their needs, and work toward the prevention of domestic violence.

Confronting Violence was developed by the Exhibition Program at NLM and guest curated by Catherine Jacquet, PhD, an assistant professor of history and women's and gender studies at Louisiana State University. Nurses Dr. Jacquelyn Campbell and Dr. Dan Sheridan, both of whom are featured in the exhibition, gave personal accounts of their involvement in the movement and offered advice for how to stem the tide of domestic violence today.

Kimberly Suiters from ABC7/WJLA-TV emceed the opening event. In welcoming attendees, Acting NLM Director Betsy Humphreys said, "You don't solve a problem by turning your head aside and ignoring it. … We're very lucky to have people here today who didn't turn their heads aside and actually went to work on an important problem."

The full program can be viewed at: videocast.nih.gov/Summary.asp?File=19163&bhcp=1

Sincerely,

Glen P. Campbell, Chairman

Friends of the National Library of Medicine

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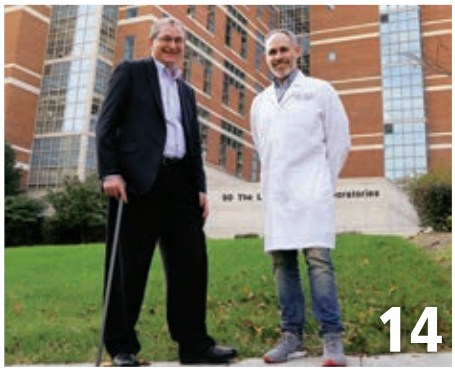

▲ Arturo Porzecanski (left), who has a rare disease called systemic capillary leak syndrome, and Dr. Kirk Druey of the National Institute of Allergy and Infectious Diseases.

▲ Probiotics are live microorganisms present in some foods, supplements, and skin creams that are intended to have health benefits.

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Photos: (Cover, Top) Laura King, (Cover Inset) Benjamin King, (Center) Bill Branson, (Bottom) Pixabay

The National Institutes of Health (NIH)—the Nation's Medical Research Agency—includes 27 Institutes and Centers and is a component of the U.S. Department of Health and Human Services. It is the primary federal agency for conducting and supporting basic, clinical, and translational medical research, and it investigates the causes, treatments, and cures for both common and rare diseases. For more information about NIH and its programs, visit www.nih.gov.

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Living with Crohn's Disease

Benjamin King, star of Disney Channel's hit TV series *Liv and Maddie*, helps others—especially kids—learn to live well with Crohn's disease. He spoke with ***NIH MedlinePlus*** magazine about his own long journey with this condition.

Photo: Benjamin King

▲ King on the set rehearsing for *Liv and Maddie*.

Photo: Laura King

Why have you chosen to speak out about Crohn's disease?

For many years I really didn't talk about it. But I always figured at some point I could turn what was a very dire situation in my life into something for the greater good. As our show *Liv and Maddie* began to take root in so many homes that watch the Disney Channel and have children—especially considering the number of pediatric cases of Crohn's—I knew the time was right for me to speak out. Our show has become a platform for me to open up to children and adults with this disease and say "you can fulfill your wishes" … "you can live your life." It has been a real honor for me to work with the Crohn's and Colitis Foundation of America to raise awareness.

Can you share with us your journey with this condition?

It started when I was 15 and was diagnosed with proctitis. It was mortifying. But I was given mild medications in combination with other therapies that seemed to work. And I was able to manage to live my life and go to college.

Get social with Benjamin King!
Twitter: @SirBenjaminKing
Instagram: @SirBenjamin213
Snapchat: Sirbeej213
Facebook: Benjamin King

Photo: Benjamin King

▶ A healthy King vacations in 2015 with his family in New York City.

Photo: Nautica Malibu Triathlon, 2010

▲ Coping with Crohn's didn't stop King from competing in a triathlon in 2010.

When I was 24, I got really sick with severe pain and bleeding. I ended up in the hospital with ulcerative colitis. They were going to remove my colon but as a last ditch effort they put me on cyclosporine and it worked. I was sent home with a new life. And for 13 years I took medications and had some mild symptoms, but lived a productive life with only rare problems.

Then in late 2008 and into 2009, I got sick again and had to go back to the hospital. This time they had to remove my colon. I went through nine months of hell with three surgeries. I am a big guy—6 feet 4 inches, 220 pounds—but I was down to 157 pounds. I didn't know about my future and was frightened and depressed.

When did you finally get a diagnosis of Crohn's disease?

While I was effectively "cured" of ulcerative colitis because my colon had been removed, I still wasn't right. Finally, in 2010, I saw a great doctor and underwent extensive testing and he diagnosed me with Crohn's. This leveled me. I was shaking. I thought I had been cured. But at the same time I thought now maybe they can really figure this out and get me well.

And four and a half years after my surgeries and trying two medications, suddenly the clouds lifted, the sun began to shine, and I started to feel like myself again. I just felt re-energized. I was able to direct an episode of our television show, which was great.

You've called Crohn's a "hidden disease." Why?

It's not like a broken arm where people can see the cast. People don't know the struggles we have unless we come out and say something about it. And this is a disease that carries with it great personal embarrassment and shame. Why would you want to talk about a condition that revolves around the time you spend in the bathroom? I hear of so many people, friends, family who are being diagnosed, that I have to wonder how many suffer in silence. How many more are there who really need help but aren't getting it?

How have you benefited from the support of others with Crohn's?

When I got really sick in 2009, I found great comfort in a support group through the IBD Support Foundation (ibdsf.org). As I became healthier, I wanted to get involved in facilitating pediatric support groups. Helping kids by sharing my story in a way they could identify with has become a powerful ingredient in my own recovery. Their spirit, their willingness to laugh and cry about these crazy experiences we all go through, is humbling, and very inspiring for me personally.

What message do you have for kids and their families dealing with these issues?

First, it is OK to feel that this stinks and is not fair. It's part of the healing process to say you have been dealt a bummer hand. Second, you are not alone. If you can, try to talk with someone who has dealt with these conditions. That has really helped me. Third, there is hope. Life gets better and there are many options that can help you. I am not a physician, but I do believe for children, there will be a cure in their lifetime.

FastFacts

- ✔ Crohn's disease is a chronic, or long-lasting, disease that causes inflammation—irritation or swelling—in the gastrointestinal (GI) tract.
- ✔ The exact cause of Crohn's disease is unknown. Researchers believe that factors such as an autoimmune reaction, genes, microbes in the GI tract, and environment may play a role in causing Crohn's disease.
- ✔ Crohn's disease can occur in people of any age. However, it is more likely to develop in people between the ages of 20 and 29.
- ✔ The most common signs and symptoms of Crohn's disease are diarrhea, abdominal cramping and pain, and weight loss.
- ✔ Good nutrition is important in the management of Crohn's disease. A health care provider may recommend that a person make dietary changes.

What Is Crohn's Disease?

Crohn's disease causes inflammation, or swelling, and irritation of any part of the digestive tract—also called the gastrointestinal (GI) tract. The part most commonly affected is the end part of the small intestine, called the ileum, and the part of the large bowel (colon) attached to the ileum.

In Crohn's disease, the inflamed parts of the GI tract can become scarred (strictures) and cause blockage, or can cause penetration through the bowel wall causing inflamed tracts (fistulas) or infected pockets (abscesses). Both types of problems can cause pain and change in bowel habits.

Crohn's disease is one of two main forms of diseases of the GI tract named inflammatory bowel disease (IBD). The other form, called ulcerative colitis, only affects the large intestine, which includes the colon and the rectum—the lower end of the large intestine, leading to the anus.

Who Gets Crohn's Disease?

Both men and women can get Crohn's disease, and it can run in families. People with Crohn's disease may have a blood relative with the disease or another type of IBD. Crohn's disease can occur at any age, and most commonly starts in adolescents and young adults.

As many as two-thirds to three-quarters of people with Crohn's disease will require surgery at some point during their lives. While surgery does not cure Crohn's disease, it can conserve portions of your GI tract and return you to the best possible quality of life.

Causes

Researchers are studying the possible causes of Crohn's disease. Your body's natural defense system, called the immune system, protects you from infection by fighting against bacteria, viruses, and other things that can make you sick. Researchers believe that with Crohn's disease, the immune system is triggered by bacteria in the GI tract, leading to chronic inflammation and ulcers, or sores, and damage to the intestines. Other factors that researchers think are important in Crohn's disease are:

- genes—the traits passed down from your parents
- diet
- stress
- smoking

Symptoms

Crohn's disease symptoms can be different for each person. The most common symptoms of Crohn's disease are:

- diarrhea
- abdominal cramping and pain
- weight loss

Diagnosis

A doctor will perform a physical exam and tests to diagnose Crohn's disease.

The doctor may order blood tests, which can show anemia caused by bleeding. Anemia is a condition in which red blood cells are fewer or smaller than normal, which means less oxygen is carried to the body's cells. Blood tests can also show a high white blood cell count, a sign of chronic inflammation.

You may also be asked for a stool sample. A stool test is commonly used to rule out other causes of GI diseases, such as infections.

Other tests may be needed to diagnose Crohn's disease. The following tests are all performed at a hospital or outpatient center.

- **Colonoscopy.** Colonoscopy is the most commonly used test to specifically diagnose Crohn's disease. This test is used to look inside your rectum, entire colon, and ileum.
- **Upper GI endoscopy and enteroscopy.** Your doctor uses these tests to see inside your upper GI tract.
- **Capsule endoscopy.** For this test, you swallow a capsule containing a tiny camera that allows your doctor to see inside your GI tract.
- **Computerized tomography (CT) scan.** A CT scan uses X-rays and computers to create images of the inside of the body.
- **Upper GI series (X-rays).** An upper GI series may be done to look at the small intestine.

Treatments

Treatment for Crohn's disease depends on:

- where the disease is located in the GI tract
- what problems you already have from the disease
- what past treatments you have had for the disease

The goals of treatment are to:

- decrease the inflammation
- relieve symptoms such as abdominal pain, diarrhea, and rectal bleeding
- correct nutritional problems

Treatment may include:

- medicines
- surgery
- eating, diet, and nutrition

Medicines

One or more of the following medicines may be used to treat Crohn's disease:

- Anti-inflammation medicines may be used first to treat your Crohn's disease. These medicines help reduce inflammation in the intestine and relieve pain and diarrhea. Sometimes anti-inflammation medicines cause side effects, so you should talk with your health care provider about what to expect.
- Corticosteroids also help lower inflammation. Steroids are similar to natural chemicals in the body. However, steroids are used only for a short time because long-term use can lead to serious side effects.
- Immune system suppressors. Azathioprine and 6-mercaptopurine work by keeping your immune system from attacking harmless foreign substances. Immune system suppressors also cause side effects, so you should talk with your health care provider about what to expect.
- Biological therapies. Biological therapies are medicines that are given by an injection in the vein, or an injection in the skin. There are currently five FDA-approved biological drugs that treat inflammation in Crohn's disease.
- Antibiotics. Antibiotics are used to treat infectious complications of Crohn's disease, such as fistulas or abscesses.
- Antidiarrheal medicines and fluid replacements. Diarrhea and abdominal cramps are often relieved when the inflammation improves, but more medicine may be needed. Antidiarrheal medicines include diphenoxylate, loperamide, and codeine. People with diarrhea should drink plenty of fluids to prevent dehydration—loss of fluids from the body. If diarrhea does not improve, the person should see the doctor promptly for possible treatment with fluids given through a small tube inserted into an arm vein.

Surgery

As many as two-thirds to three-quarters of people with Crohn's disease will require surgery at some point during their lives.

While surgery does not cure Crohn's disease, it can conserve portions of your GI tract and return you to the best possible quality of life.

Surgery becomes necessary when medications can no longer control symptoms, or if you develop a fistula, fissure, or intestinal obstruction. Surgery often involves removal of the diseased segment of bowel (resection), and then the two ends of healthy bowel are joined together (anastomosis). While these procedures may cause your symptoms to disappear for years, Crohn's frequently recurs after surgery.

Sometimes you need to have more than one surgery because the disease returns next to where the intestine was removed. Because Crohn's disease can return after surgery, you can talk with your health care provider and other patients to get as much information as possible before having surgery.

Eating, Diet, and Nutrition

Your health care provider may start you on a special diet, so you get extra nutrition and calories. High-calorie liquid supplements are often used to give you the extra calories and right amount of vitamins and minerals to keep you healthy. During acute phases of the disease, you may need to receive intravenous nutrition to give the intestine a rest.

No foods are known to cause injury or inflammation to the intestine. But foods such as hot spices, alcohol, greasy foods, and milk products may make diarrhea and cramping worse. You should eat a healthy diet and avoid foods that make symptoms worse. Your health care provider may refer you to a dietitian to help you with meal planning.

Crohn's Disease and Stress

People with Crohn's disease sometimes feel more stress in their lives, which can make symptoms worse. Eating well, getting enough rest, and learning to relax may help you through stressful times. Support groups may help lower stress for people with Crohn's disease. Ask your health care provider for help finding support groups.

Even though you may need medicines and other treatments, you may feel well and be symptom-free for long periods of time. Most people with Crohn's disease are able to work and live full lives. Women with Crohn's disease can have successful pregnancies.

NIH Research

The National Institute of Diabetes and Digestive and Kidney Diseases Division of Digestive Diseases and Nutrition supports research into digestive conditions, including Crohn's disease. Researchers are working to better understand genes and Crohn's disease. They are also studying new medicines and ways to deliver medicines that might be more effective than current treatments.

Participants in clinical trials can play a more active role in their own health care, gain access to new research treatments before they are widely available, and help others by contributing to medical research. For information about current studies, visit www.ClinicalTrials.gov.

Meeting the Challenge of Crohn's Disease

During the early stages of her diagnosis, Donna Hoffman was treated by a protégé of Dr. Burrill Crohn, the gastroenterologist who identified the disease that now bears his name.

Photos: Elliot Siegel

Donna Hoffman, a South Carolina resident originally from the Northeast, has met the challenges of Crohn's disease for 40 years. After a slow initial diagnosis, she has kept the disease under control with the right medications, healthy foods, plenty of sleep, low stress—and compassionate gastroenterologists. She recently spoke with ***NIH MedlinePlus*** magazine about dealing with Crohn's disease.

How old were you when you first experienced the symptoms that would later be diagnosed as Crohn's disease?

I was 18, and it was the summer I graduated from high school in 1969. I had been a healthy teenager up until then. I started having stomach problems. Then I began to lose weight and have trouble with certain foods. I didn't think much of it at first.

But then I got persistent diarrhea, and the other symptoms got worse. And I continued to lose weight and have stomach pains. I was going to community college and living at home with my parents. It got to the point that I would go to school and then come home and sleep the rest of the time. I was totally exhausted.

And it became totally isolating. It was terrible; very depressing. That fall my parents and I decided to have something done. I was in and out of at least three or four hospitals that fall. They kept admitting me. They did a barium enema. There were just a limited amount of tests back then.

Crohn's disease is sometimes difficult to diagnose because it's similar to some other conditions, including ulcerative colitis or IBS (irritable bowel syndrome). How long did it take for you to get a correct diagnosis?

It was not diagnosed right away. I went through at least two years of hospitals. At one point they sent me to a psychiatrist because they thought it might be psychosomatic.

It got to the point that in the summer of '71—I was 20—I was 90 pounds—and I'm 5 feet 5 inches. My mother was feeding me baby food because I couldn't digest anything. I was so physically emaciated and exhausted. But they couldn't find out what was wrong with me.

Fortunately, one weekend, we were over at a friend's house. I was having a bad attack, and they thought maybe I had appendicitis. They put me in the back seat of a car, and my dad drove me to a nearby hospital I had not been to. Our friend's

doctor there did exploratory surgery that same day.

They ended up removing two inches of my ileum [the final section of the small intestine], and told me it was as hard as a rock. Then I developed a dangerous inflammation of my abdominal wall—peritonitis. And I almost didn't make it. I was in the hospital for weeks.

It was a long recovery, but a wonderful comeback. I was treated by Dr. Daniel Present, who happened to be a protégé of Dr. Burrill Crohn, the gastroenterologist who identified the disease that now bears his name.

Dr. Present treated me with some then-experimental drugs. And he treated me with high doses of prednisone, an anti-inflammatory drug.

What have been the biggest lifestyle challenges you've faced with Crohn's disease? Diet? Exercise? Travel?

I had to change my diet. And I had to get plenty of sleep and avoid high levels of stress. After I was married, one of the things that helped me recover was my pregnancy. Throughout my pregnancy—and for 20 years after—I was in remission. The Crohn's disease only came back when I went through a period of very high stress.

In terms of food flare-ups, I've found I'm better eating foods with no chemicals and no other additives. That, and low stress have been the answer.

Are there any foods you like that are definite no-no's?

Anything with lactose; I do miss pizza and ice cream; I do cheat once in a while.

Aren't there non-lactose substitutes?

For me, it's not the same. [laughs]

Are there medications you take to help manage your symptoms?

I take Pentasa (mesalamine), an anti-inflammatory medication daily. My doctor also gives me methotrexate, a breast cancer drug, which in minute doses keeps the immune system from attacking itself and keeps my intestine from attacking itself.

What advice might you give to someone who has just been diagnosed with Crohn's disease and wants to manage it?

Find a compassionate, knowledgeable gastroenterologist. The best must have a special gene that makes them compassionate. I've had four doctors in 40 years, and they have all been compassionate.

Then, I would tell them to consult a dietitian. You really are what you eat.

You need to learn to read your body. I can tell when I'm going downhill.

And just remember, as one of my doctors told me, not every day is going to be a good one. But we're very fortunate to live in a time when we have these treatments. I have a healthy 32-year-old son.

I've never let Crohn's disease affect my travel. I'm planning a trip out of the country right now.

Find Out More

- ✔ **National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK):** www.niddk.nih.gov/health-information/health-topics/digestive-diseases/crohns-disease/Pages/ez.aspx
- ✔ **MedlinePlus:** www.nlm.nih.gov/medlineplus/crohnsdisease.html
- ✔ **National Human Genome Research Institute (NHGRI):** www.genome.gov/25521854
- ✔ **NHGRI Clinical Research on Crohn's Disease:** www.genome.gov/25521854#al-6
- ✔ **Clinical Research Trials:** www.clinicaltrials.gov search "Crohn's disease"
- ✔ **Crohns and Colitis Foundation of America (CCFA):** www.ccfa.org

Tips for a Healthy New Year 2016

Photo: iStock

Photo: National Institute on Aging

Follow Surgeon General's advice on benefits of walking to boost your fitness

As you ring out the old year and ring in the new, you may be considering changes you'd like to make to improve your health in the upcoming months. If you're thinking about making exercise a part of your New Year's resolution, you might be glad to know that small changes in your routine can lead to big results. In fact, the key to improving your overall health and preventing chronic diseases may be as simple as adding just 22 minutes of physical activity—such as brisk walking—to your day.

Time to Take Action and Move

According to a recent U.S. Surgeon General's Report, less than half of all U.S. adults get enough physical activity each day to reduce their risk of developing a chronic disease—including diabetes, cancer, or heart and lung disease. What's more, only a quarter of high schoolers were found to get the recommended daily amount.

To combat these low rates, Surgeon General VADM Vivek H. Murthy, MD, MBA, has issued a Call to Action to encourage individuals to make walking a priority in their daily lives. *Step It Up! The Surgeon General's Call to Action to Promote Walking and Walkable Communities* endorses walking as a safe, affordable, and effective way for everyone to exercise. This Call to Action also encourages local community leaders to maintain public spaces so that people can walk in an environment that is safe and accessible for all.

Ready, Set, Go!

Whether your New Year's resolution includes walking or another form of physical activity, continue reading for more tips

Surgeon General VADM Vivek H. Murthy, MD, MBA, in photo at left, joins the director of the National Institute on Aging, executive director of the White House Conference on Aging, fitness expert Donna Richardson, ***Go4Life***® partner organizations, and older adults for a fitness walk in the nation's capital to celebrate ***Go4Life Month*** last September and to highlight *Step It Up! The Surgeon General's Call to Action to Promote Walking and Walkable Communities.*

Photo: National Institute on Aging

on how and why you should incorporate physical fitness into your daily life for the upcoming year. Need a motivational boost? Start by downloading the Surgeon General's walking playlist on Pandora at www.surgeongeneral.gov and get moving!

Know the Basics

Regular physical activity can help prevent chronic diseases, but there are many other health benefits you can achieve by getting your daily dose of physical activity. For example, exercise can help:

- Control your weight
- Strengthen your bones and muscles
- Improve your mental health and mood
- Improve your ability to do daily activities and prevent falls, especially if you're an older adult
- Increase your chances of living longer

Target Exercise Amounts

How much physical activity you need depends on your age. The Centers for Disease Control and Prevention (CDC) recommends:

- **Children ages 6 to 17 years old** should get 60 minutes of physical activity each day. This should also include a vigorous-intensity activity (such as running) three days per week, and muscle strengthening (such as gymnastics) three days per week.
- **Adults ages 18 and older** should get 150 minutes of moderate-intensity activity (such as brisk walking), or 75 minutes of vigorous-intensity activity (such as running), each week. Adults should also do muscle-strengthening exercises that work all muscle groups two days per week.

Fitting exercise into your daily life may seem tough at first, but according to the CDC, you don't have to do it all at once. In fact, exercising in 10-minute increments can be enough to reap the health benefits.

Tips for Getting Started

If you think fitting in a daily workout is expensive, think again! You don't need a costly gym membership to jumpstart an active lifestyle. The National Institute of Diabetes and Digestive and Kidney Diseases recommends simply picking an activity you enjoy. Start by listing the activities you would like to do, like walking, joining a sports league, exercising with a video, dancing, biking, or taking a class at a fitness or community center. Then, you can start to plan your workout schedule. For example:

- Set short-term goals that are specific and that you can track. Instead of saying "I'm going to be more active this week," set a goal of walking 30 minutes a day, three days a week.
- Think of the days and times you could do the activity, such as first thing in the morning, during lunch break from work, after dinner, or on Saturday afternoon. Look at your calendar or planner to find the days and times that work best, and commit to those plans.

Keeping Active at Work

When you're looking to add more physical activity to your routine, it's important to practice healthy habits at work, as well as at home. For you, this might mean simply moving more at your workplace. The CDC encourages the following activities to keep you moving at work:

- Print to a different printer. Try printing to a printer located further away from your work area. Consider printing one floor up or down and take the stairs.
- Take the stairs rather than the elevator.
- Park at a remote parking lot and walk to the office. The further away you park, the more activity you can include in your day.
- Walk and talk. Have a walking meeting or step in place while talking on the phone.
- Start meetings with five to 10 minutes of stretching or activity, or add in stretch or activity time mid-way through long meetings.
- Do 60- to 90-second standing breaks for every hour you sit.
- Keep a set of hand weights by your desk. Use them three or four times a day for muscle strengthening.

In addition, many employers offer weight management programs and on-site fitness programs to encourage and support employees with establishing and maintaining healthy lifestyle behaviors. These programs can offer even more opportunities for you to engage in healthy workplace activities.

Fitness for Those with Disabilities

Physical activity is great for individuals of all sizes, shapes, and abilities—including those with disabilities. The same physical activity recommendations apply: For adults, 150 minutes of moderate-intensity activity, or 75 minutes of vigorous-intensity activity per week. Children with disabilities should aim for 60 minutes of physical activity each day, and muscle-strengthening activities for both age groups two or more days per week can offer additional health benefits.

The following are some ideas on how to get active:

- Wheeling yourself in a wheelchair
- Wheelchair basketball, tennis, football, or softball
- Aquatic therapy
- Hand-crank bicycling
- Rowing
- Seated volleyball
- Horseback riding
- Working with a resistance band
- Adapted yoga
- Swimming or water aerobics

If you have a disability and cannot meet the recommended guidelines, engage in regular physical activity based on your abilities and—most importantly—avoid inactivity. Some physical activity is always better than none.

Photos: iStock

Exercise for Older Adults

Exercise is safe for almost everyone, and older adults are no exception. According to the National Institute on Aging, being physically active can help you continue to do the things you enjoy, boost your mood, and help you stay independent as you age. It can reduce the risk of developing some diseases and disabilities that develop as you grow older, yet it's also an effective treatment for many chronic conditions.

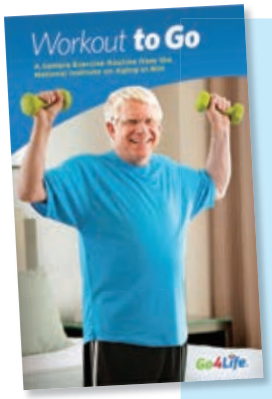
If you haven't worked out in a while, it's important to start out at a low level of effort and work your way up slowly. Starting slow will help prevent injury. You may want to talk with your doctor if you start an exercise program or significantly increase your physical activity, especially if you have a medical condition, such as arthritis, diabetes, high blood pressure, or heart disease.

As you exercise, make sure you listen to your body. For example, during a moderate-intensity activity (such as brisk walking), you can sense that you are pushing yourself but that you aren't near your limit. You can begin to increase intensity slowly as you become more fit.

There are plenty of opportunities each day to fit in more physical activity. For example:

- When you unload the groceries, strengthen your arms by lifting the milk carton or a one-pound can a few times before you put it away.
- When you go shopping, build your endurance by parking the car at the far end of the parking lot and walking briskly to the store. Or, get off the bus one or two stops earlier than usual.
- Take a few extra trips up and down the steps at home to strengthen your legs and build endurance.
- Try to do some of your errands on foot rather than in the car.
- While you're waiting in line, practice your balancing skills by standing on one foot for a few seconds, then the other. Gradually build up your time.
- While you're talking on the phone, stand up and do a few leg raises or toe stands to strengthen your legs.

No matter your age, health history, or fitness level, it's important to make physical activity an important part of your daily routine.



Workout to Go

Designed to fit easily into your purse or travel bag, ***Workout to Go*** from the National Institute on Aging can help you stay in shape for the activities you enjoy most. And you can do the 13 easy-to-follow strength, balance, and flexibility exercises in this booklet anytime, anywhere. Take it with you to the gym, on vacation, or even to the office.

Order your own copy by visiting go4life.nia.nih.gov/workout-to-go.

Find Out More

- ✔ ***Go4Life* from the National Institute on Aging:** go4life.nia.nih.gov
- ✔ **The National Heart, Lung, and Blood Institute's Guide to Physical Activity:** www.nhlbi.nih.gov/health/educational/lose_wt/phy_act.htm
- ✔ **Tips to Help You Get Active:** www.niddk.nih.gov/health-information/health-topics/weight-control/tips-help-get-active/Pages/tips-help-you-get-active.aspx
- ✔ **The World Around You: Use What You Have to Stay Healthy and Fit:** www.niddk.nih.gov/health-information/health-topics/weight-control/way/Documents/TheWorldAroundYou.pdf
- ✔ **Exercise and Physical Fitness:** www.nlm.nih.gov/medlineplus/exerciseandphysicalfitness.html
- ✔ **Occupational Health:** www.nlm.nih.gov/medlineplus/occupationalhealth.html
- ✔ **MedlinePlus — Exercise for Seniors:** www.nlm.nih.gov/medlineplus/exerciseforseniors.html
- ✔ **The Surgeon General's Call to Action to Promote Walking and Walkable Communities:** www.surgeongeneral.gov/library/calls/walking-and-walkable-communities/index.html

It's Not Too Late to Get Vaccinated Against Flu

Photos: iStock

Cough. Sore throat. Muscle aches. Flu season is here, and the best way to avoid those dreaded symptoms is to get your flu vaccine.

Flu season occurs primarily in the winter, but outbreaks can begin as early as October and last until May. Everyone 6 months of age or older should get the flu vaccine each year. It usually takes two weeks after you are vaccinated for antibodies to develop and provide flu protection, so it's best to get your vaccine as soon as it becomes available. But it's not too late to get protected. Your vaccination can also help protect others who may be more vulnerable to serious flu illness.

The 2015-2016 Season

Three kinds of flu viruses commonly circulate among people today: influenza A (H1N1) viruses, influenza A (H3N2) viruses, and influenza B viruses. Each year, experts predict what flu viruses will be the most common during the upcoming season. For the 2015-2016 season, the vaccine is made to protect against the following three viruses:

- an A/California/7/2009 (H1N1)pdm09-like virus
- an A/Switzerland/9715293/2013 (H3N2)-like virus
- a B/Phuket/3073/2013-like virus (this is a B/Yamagata lineage virus)

Some of the 2015-2016 flu vaccine will also protect against an additional B virus (B/Brisbane/60/2008-like virus). This is a B/Victoria lineage virus.

Typically, one dose of the flu vaccine can protect you for the duration of the flu season, even as your antibody levels decline over time. Children 6 months to 8 years may need two doses of the vaccine for ample protection from the flu bug.

Fighting the Flu

Flu viruses are spread mainly by the droplets made when people with the flu sneeze, cough, or talk. These droplets can land in the mouths or noses of people who are nearby. You might also become infected by touching a surface or object that is contaminated with the flu virus and then touching your own mouth, eyes, or nose.

But there are preventive steps you can take to stay healthy. To limit your exposure to the virus, avoid contact with others who are sick. Wash your hands often with soap and water, or use an alcohol-based sanitizer if soap and water are not available. Try not to touch your eyes, nose, or mouth, and frequently disinfect surfaces or objects that may be contaminated with flu germs.

If the Flu Does Strike

If you do catch the flu, you may be able to pass it along to someone else before you start to experience symptoms, and between five to seven days after becoming sick. Young children—and those with weakened immune systems—may be able to infect others for a longer period of time.

When symptoms hit, antiviral drugs may reduce their severity, help shorten the time you are sick, and prevent serious complications.

But the single best way to prevent the flu? A flu vaccine each season.

Flu Signs and Symptoms

If you do become sick with the flu, you may experience some or all of the following symptoms:

- **Runny or stuffy nose**
- **Fatigue (tiredness)**
- **Vomiting and diarrhea (more common in children than adults)**
- **Headaches**
- **Sore throat**
- **Cough**
- **Muscle or body aches**
- **Fever or feeling feverish/having chills (though not everyone with flu will have a fever)**

Find Out More

- ✔ **National Institute of Allergy and Infectious Diseases:** www.niaid.nih.gov/topics/Flu
- ✔ **MedlinePlus:** www.nlm.nih.gov/medlineplus/flu.html
- ✔ **U.S. Department of Health and Human Services:** flu.gov
- ✔ **Centers for Disease Control and Prevention:** www.cdc.gov/flu/
- ✔ **ClinicalTrials.gov:** www.clinicaltrials.gov search"influenza"

Photo: Bill Branson

Social media brought together Arturo Porzecanski (left), who has a rare disease called systemic capillary leak syndrome, and researcher Dr. Kirk Druey of the National Institute of Allergy and Infectious Diseases. Together, they have expanded clinical knowledge about the condition.

Patient *Power!*

Thanks to the Internet, the "crowdsourcing" of disease information among patients and doctors is becoming a valuable lifeline around the globe. For patients with serious rare diseases, crowdsourcing can mean the difference between life and death.

"Indispensible" is the way NIH researcher Dr. Kirk Druey describes the actions taken by one of his research patients in spreading awareness of a deadly but very rare disease.

Ten years ago, systemic capillary leak syndrome (SCLS) almost took the life of then-56-year-old economist and American University professor Arturo Porzecanski. Parts of his vascular system suddenly leaked out plasma into other parts of his body. In trying to save him before his organs could fail, doctors flooded his system with too much replacement fluid that damaged his leg and arm muscles.

When the attack occurred, Porzecanski and most doctors knew nothing about SCLS. Realizing that another bout of the disease would probably kill him, Porzecanski set out to discover more about SCLS and any other patients who had experienced it.

Through his tenacity and smart use of the Internet, Porzecanski was not only able to find information on new treatments but also identify other patients seeking help in the United States and across the globe. He set up an SCLS community group on a social website

called RareShare (www.rareshare.org). Patients, their loved ones, and health care professionals were sharing contacts, treatment information, and the latest research.

The NIH Connection

In 2008, having built up a network of patients and front-line physicians who could provide medical histories and blood and tissue samples needed to carry out research on SCLS, Porzecanski sought out investigators at NIH's National Institute of Allergy and Infectious Diseases (NIAID). With research already under way on other, related vascular diseases, NIAID's Druey made use of Porzecanski's virtual community to enable a research protocol on SCLS. For a rare disease that has fewer than 1,000 known cases, to recruit patients and their doctors to collaborate with researchers is very difficult yet crucial to eventual success.

Photo: Kathleen Cravedi

▲ Porzecanski and Druey have worked together since 2008 to help connect patients with systemic capillary leak syndrome, a rare disease that has only about 100 known cases. They aim to spread life-saving information to those with the disease.

"Arturo's efforts were indispensable," says Druey. "And we now have the largest registry of patients for that disease in the world."

Through Porzecanski's efforts on RareShare, he quickly became the go-to patient resource for those with SCLS. He also helped get blood samples from patients to assist Druey and his colleagues in their research at NIH.

"Arturo came to NIH as an inpatient and stayed several days in the Clinical Center hospital here in Bethesda," Maryland, says Druey.

Porzecanski also came to NIH to show Druey and his colleagues all of the research he had put together on SCLS—to pass along his knowledge in the hope that it could help speed along life-saving information to others.

Some 40 SCLS patients and their physicians have provided Druey with blood and tissue samples, or at least medical histories, to further knowledge of the rare disease. He has already published 10 research articles that shed more light on SCLS, with more papers in the pipeline.

Porzecanski has also helped spread the word to SCLS patients that French researchers have developed a treatment of high-dose intravenous immunoglobulins (IVIg) that can be effective in stopping SCLS and lengthening the lives of patients—including Porzecanski.

Porzecanski and Druey have made quite a team in their efforts to understand and defeat SCLS.

"I'm fully invested in this research," says Druey. "I feel this is something I owe to these patients."

In fact, Druey and his colleagues have already applied for a grant to help fund a gathering of scientists from across the globe who are now studying SCLS.

Porzecanski couldn't be happier that such "patient power" efforts will help SCLS patients who otherwise would be without hope.

Find Out More

- ✔ **MedlinePlus — Rare Diseases:** www.nlm.nih.gov/medlineplus/rarediseases.html
- ✔ **Genetic and Rare Diseases (GARD) Information Center:** rarediseases.info.nih.gov
- ✔ **How to Find a Disease Specialist:** rarediseases.info.nih.gov/resources/pages/25/how-to-find-a-disease-specialist
- ✔ **Rare Diseases Clinical Research Network:** www.ncats.nih.gov/rdcrn

In Their Own Words: Dealing with Dyslexia

Dyslexia occurs in people of all backgrounds and intellectual levels.

People with dyslexia can be very bright. They are often capable or even gifted in areas such as art, computer science, design, drama, electronics, math, mechanics, music, physics, sales, and sports. Some of our nation's most well-known and successful individuals have confronted the challenge of dyslexia. Below is a sampling of celebrities who have spoken up about their experiences as individuals with dyslexia.

Jennifer Aniston

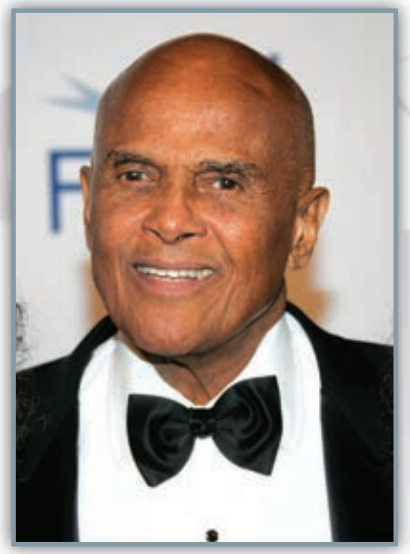
(Actor, producer, and businesswoman)

"The only reason I knew [I had dyslexia] was because I went to get a prescription for glasses … My eyes would jump four words and go back two, and I also had a little bit of lazy eye … Until then, I thought I wasn't smart. I just couldn't retain anything. Now I had this great discovery. I felt like all of my childhood 'trauma-dies'—tragedies, dramas—were explained."

Harry Belafonte

(Singer, songwriter, actor, and social activist)

"I grew up in a school system … where nobody understood the meaning of learning disorder … I was constantly being physically abused."



Photos: iStock

Anderson Cooper

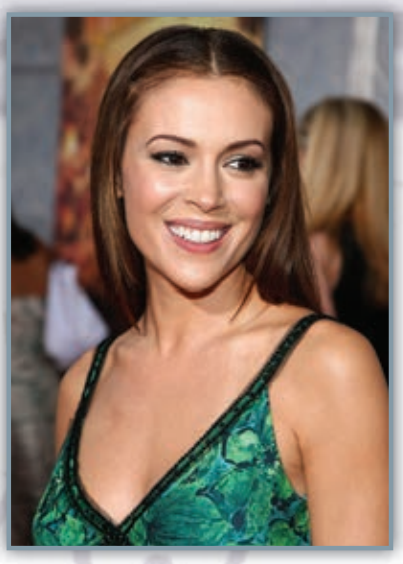
(CNN anchor and talk show host)

"As a child, I had … a mild form of dyslexia where I would see some letters backward, and I had to go to a special reading instructor. One way she helped was to encourage me to find books that I was really passionate about."

Whoopi Goldberg

(Actor, comedian, writer, social critic, and television host)

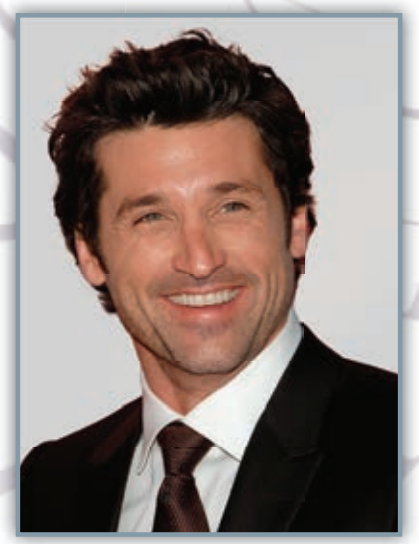
"I'm dyslexic, so there weren't a whole lot of books in my early life … I still like to be read to."



Patrick Dempsey

(Actor and race car driver)

Diagnosed with dyslexia at age 12 after spending years in a special needs class, Dempsey has said, "I have never given up." In a 2006 interview, he told Barbara Walters, "I've gone back and started to learn to read on a very basic level."



Alyssa Milano

(Actor, singer, and songwriter)

"I've stumbled over words while reading from teleprompters. Sir John Gielgud, whom I worked with on *The Canterville Ghost* years ago, gave me great advice. When I asked how he memorized his monologues, he said, 'I write them down.' I use that method to this day. It not only familiarizes me with the words, it makes them my own."

Decoding Dyslexia, a Common Learning Disability

What Are Learning Disabilities?

Learning disabilities affect how someone learns to read, write, speak, count, and perform calculations. They are caused by differences in the way the brain processes information. They do not reflect a person's intelligence. Also, they are not the same as learning problems due to intellectual or developmental disabilities, or emotional, vision, hearing, or motor skills problems.

Learning disabilities usually are discovered after a child starts school and has difficulty in one or more areas. People can have more than one learning disability. Learning disabilities may last a lifetime, but they can be managed with the right educational supports.

Is There a Cure?

Learning disabilities have no cure but early intervention can lessen their effects. People with learning disabilities can be successful in school, at work, and in their personal lives.

Diagnosing Learning Disabilities

A full evaluation for a learning disability includes:

- A medical examination, including a neurological exam, to identify or rule out other possible causes of the child's difficulties, such as emotional disorders, intellectual and developmental disabilities, and brain diseases
- Exploration of the child's developmental, social, and school performance
- A discussion of family history
- Academic achievement testing and psychological assessment

Usually, a team of specialists, among them a psychologist, special education expert, and speech-language pathologist, performs evaluations. Many schools also have reading specialists who can be part of a team that can diagnose a reading disability.

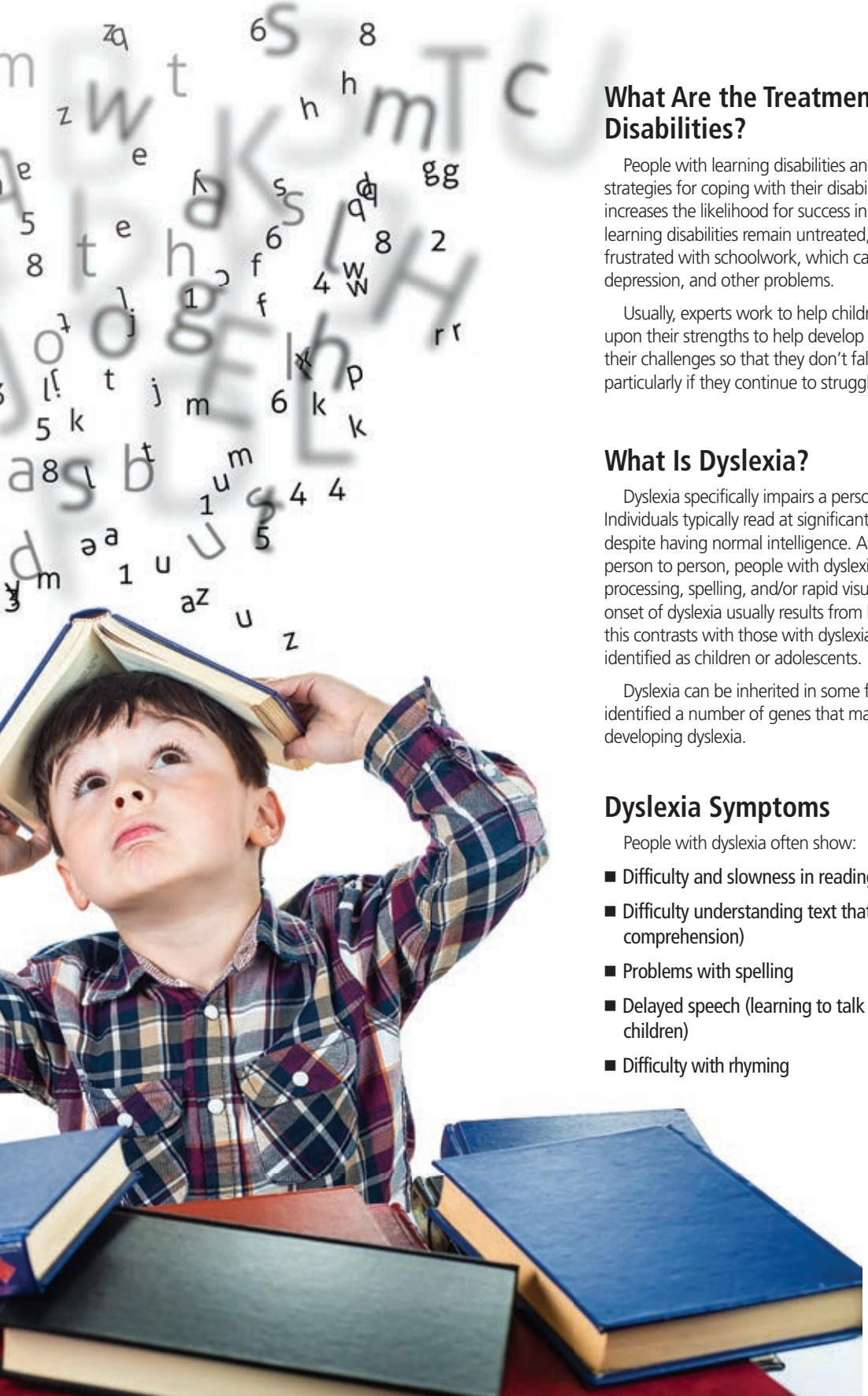


Photo: iStock

What Are the Treatments for Learning Disabilities?

People with learning disabilities and disorders can learn strategies for coping with their disabilities. Getting help earlier increases the likelihood for success in school and later in life. If learning disabilities remain untreated, a child may begin to feel frustrated with schoolwork, which can lead to low self-esteem, depression, and other problems.

Usually, experts work to help children improve skills and build upon their strengths to help develop ways to compensate for their challenges so that they don't fall behind in other areas, particularly if they continue to struggle.

What Is Dyslexia?

Dyslexia specifically impairs a person's ability to read. Individuals typically read at significantly lower levels than expected despite having normal intelligence. Although it varies from person to person, people with dyslexia have difficulty with sound processing, spelling, and/or rapid visual-verbal responding. Adult onset of dyslexia usually results from brain injury or dementia; this contrasts with those with dyslexia who simply were never identified as children or adolescents.

Dyslexia can be inherited in some families. Recent studies have identified a number of genes that may predispose an individual to developing dyslexia.

Dyslexia Symptoms

People with dyslexia often show:

- Difficulty and slowness in reading words
- Difficulty understanding text that is read (poor comprehension)
- Problems with spelling
- Delayed speech (learning to talk later than most other children)
- Difficulty with rhyming

Photo: iStock

What Is the Prognosis?

For those with dyslexia, the prognosis is mixed. The disability affects such a wide range of people and produces such different symptoms and varying severity that predictions are hard to make. Prognosis is generally good, however, for individuals whose dyslexia is identified early, who have supportive family and friends and a strong self-image, and who are involved in proper remediation.

Treating Dyslexia

The main focus of treatment should be on a person's specific learning problems, typically by modifying the teaching environment and methods.

- **Special teaching techniques.** The use of explicit, systematic instruction to teach and directly support children's efforts to learn to read and recognize words. This occurs over time.
- **Classroom modifications.** For example, teachers can give students with dyslexia extra time to finish tasks and provide taped tests that allow the child to hear the questions instead of reading them.
- **Use of technology.** Children with dyslexia may benefit from listening to books on tape or using word-processing programs with spell-check features.

Special Education Services

The Individuals with Disabilities Education Improvement Act (IDEA) requires public schools to provide free special education supports to children with learning and other disabilities. They must be taught in the least restrictive, most appropriate environments for them.

In most states, children are entitled to these services beginning at age 3 and extending through high school or until age 21, whichever comes first. The teaching environment should be designed to meet the child's specific needs and skills. It should minimize restrictions on the child's access to typical learning experiences. The specific rules of IDEA for each state are available from the National Early Childhood Technical Assistance Center.

Qualifying for Special Education

To qualify for special education services, a child must be evaluated by the school system and meet specific criteria outlined in federal and state guidelines. To learn how to have a child assessed for special services, parents and caregivers should contact a local school principal or special education coordinator. Parents can also visit these Web resources:

- The Parent Technical Assistance Center Network (www.parentcenternetwork.org)
- The Parent Guide to IDEA (www.ncld.org/parents-child-disabilities/idea-guide)

What Research Is Being Done?

The *Eunice Kennedy Shriver* National Institute of Child Health and Human Development and other institutes of the National Institutes of Health support dyslexia research through grants to major research institutions across the country. Current research avenues focus on developing techniques to diagnose and treat dyslexia and other learning disabilities, increasing the understanding of the biological and possible genetic bases of learning disabilities, and exploring treatments to improve outcomes for children and adults with dyslexia.

Photo: iStock

Find Out More

- ✔ ***Eunice Kennedy Shriver* National Institute of Child Health and Human Development:** nichd.nih.gov
- ✔ **MedlinePlus:** www.medlineplus.gov
- ✔ **Understood:** understood.org

"Talk with your child, read to your child every day!"

Brett Miller, PhD, directs the Reading, Writing, and Related Learning Disabilities Program in the Child Development and Behavior Branch of the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development. He oversees research focused on development of reading and written-language abilities for learners across the lifespan. He spoke recently with ***NIH MedlinePlus*** magazine about dyslexia.

Photo: Courtesy Brett Miller

Brett Miller, PhD

Is there a key to helping people with dyslexia?

Early, systematic, and explicit reading instruction—teaching the link between the written word and its specific sounds—is critical for dyslexia. The written word maps directly onto spoken language. So the challenge is to link the sounds of English, for example, to the specific letters of the alphabet.

How can parents help their children?

Since learning begins at home, the best thing parents can do is to talk with their children and read to them every day. Let them soak in what they're hearing and learn how to converse. This is a great opportunity to bond with your children and helps them build their oral vocabulary and learn the structure of language, which are part of the foundation for reading.

What is the goal?

The goal is to build a foundation for reading and that takes lots of time and practice.

When should special instruction begin?

The earlier the better for children who are struggling to read. Some children need more time to learn, while others do better in smaller groups. So parents should build relationships with their children's teachers and school administrators to advocate for the best possible support.

Early intervention reduces long-term problems. Children who are not improving by the fourth or fifth grade may need continued instructional support on foundational skills of reading in later grades.

Photo: Pixabay

The Basics of Probiotics

What Are Probiotics?

Probiotics are live microorganisms (such as bacteria) that are intended to have health benefits. Products sold as probiotics include yogurt and other foods, dietary supplements, and topically applied skin creams.

Although people often think of them as harmful "germs," many microorganisms help our bodies to function properly. For example, normal intestinal bacteria digest food, destroy disease-causing microorganisms, and produce vitamins. Large numbers of microorganisms live on and in our bodies. In fact, microorganisms in the human body outnumber human cells by 10 to 1. Many of the microorganisms in probiotic products are the same as or similar to the ones in our bodies.

Why Do People Take Probiotics?

People take probiotics in the hope of gaining health benefits, including improved longevity.

What Kinds of Microorganisms Are in Probiotics?

Probiotics may contain a variety of microorganisms. The most common are bacteria that belong to groups called *Lactobacillus* and *Bifidobacterium*. Each of these two broad groups includes many types of bacteria. Other bacteria may also be used as probiotics, and so may yeasts such as *Saccharomyces boulardii*.

How Popular Are Probiotics?

Data from the 2012 National Health Interview Survey show that about four million U.S. adults had used probiotics or prebiotics in the past 30 days. Other than vitamins and minerals, probiotics or prebiotics were the third most commonly used dietary supplement. Their use quadrupled between 2007 and 2012. The survey also showed that 300,000 children ages 4 to 17 had used probiotics or prebiotics in the prior 30 days.

What the Science Says About the Safety and Side Effects of Probiotics

Whether probiotics are likely to be safe for you depends on your health.

- In people who are generally healthy, probiotics have a good safety record. Side effects, if any, usually consist only of mild digestive symptoms such as gas.
- On the other hand, there have been reports linking probiotics to severe side effects, including dangerous infections, in people with serious underlying medical problems.
- People most at risk include the critically ill, those who have had surgery, very sick infants, and people with weakened immune systems.

Even for healthy people, there are uncertainties about the safety of probiotics. Most of our knowledge about safety comes from studies of *Lactobacillus* and *Bifidobacterium*. Less is known about other probiotics. Also, information on the long-term safety of probiotics is limited, and safety may differ from one type of probiotic to another.

For example, even though a National Center for Complementary and Integrative Health-funded study showed that a particular kind of *Lactobacillus* appears to be safe in healthy adults age 65 and older, this does not mean that all probiotics containing *Lactobacillus* would be safe for people in this age group.

NIH Supports Research on Probiotic Products

The National Institutes of Health has established the Human Microbiome Project to study the many microorganisms and their genes (called the "microbiome") that share our body space. These microbes outnumber our own cells by 10 to 1 and one of the most important things they do for us is to help with digestion. Part of this project is an initiative to study probiotic products, including their health benefits, how they work, and their long-term effects. Several NIH agencies are involved in this effort. For example, the National Institute of Diabetes and Digestive and Kidney Diseases is encouraging new research projects to study probiotics and the development of diseases such as inflammatory bowel disease, obesity, and diabetes.

Find Out More

- ✔ **NIH National Center for Complementary and Integrative Health — Probiotics:** nccih.nih.gov/health/probiotics
- ✔ **MedlinePlus:** www.medlineplus.gov search "probiotics"

Five Things to Know About Probiotics

Probiotics are available in oral products such as dietary supplements and yogurts, as well as other products such as suppositories and creams. It is important to be aware that the U.S. Food and Drug Administration has not approved any health claims for probiotics. Here are some other things you should know:

1. Some probiotics may help to prevent diarrhea caused by infections or antibiotics. They may also help with symptoms of irritable bowel syndrome.
2. Although some probiotic formulations have shown promise in research, strong scientific evidence to support the use of probiotics for most conditions is lacking.
3. Studies suggest that probiotics usually have few side effects. However, the data on safety, particularly long-term safety, are limited, and the risk of serious side effects may be greater in people who have underlying health conditions.
4. Probiotic products may contain different types of probiotic microorganisms and have different effects in the human body. The effects also may vary from person to person.
5. If you are considering a probiotic dietary supplement, talk with your health care provider first. Do not replace scientifically proven treatments with unproven products or practices.

Are Probiotics Good for Your Health?

Photo: NIH

Josephine P. Briggs, MD, Director, National Institutes of Health National Center for Complementary and Integrative Health

Probiotics are gaining in popularity, and chances are you've heard about them as "good bacteria" or seen them advertised in your supermarket's yogurt aisle. But what are probiotics, and do they have any real health benefits?

Probiotics are live microorganisms—bacteria, for example—that are either the same or similar to microorganisms found naturally in our bodies. Although we tend to think of bacteria as harmful "germs," many bacteria actually help the body function properly. Probiotics are available as dietary supplements and in dairy foods, and our research tells us that probiotics/prebiotics are among the top five natural products used by both adults and children. It is important to note that the U.S. Food and Drug Administration has not approved any health claims for probiotics; however, there is some evidence that probiotics may be helpful for conditions such as diarrhea caused by antibiotics and infections, as well as symptoms of irritable bowel syndrome.

— Josephine P. Briggs, MD

Parkinson's Disease

New research offers hope for better diagnosis and treatments

Photo: iStock

Parkinson's disease (PD) belongs to a group of conditions called motor system disorders. It happens when nerve cells in the brain don't produce enough of a brain chemical called dopamine.

The primary symptoms of PD are:

- tremor, or trembling in hands, arms, legs, jaw, and face
- rigidity, or stiffness of the limbs and trunk
- bradykinesia, or slowness of movement
- postural instability, or impaired balance and coordination

As these symptoms become more pronounced, patients may have difficulty walking, talking, or completing other simple tasks.

PD usually affects people over the age of 60. Early symptoms of PD are subtle and occur gradually. In some people the disease progresses more quickly than in others. As the disease progresses, the shaking, or tremor, that affects the majority of people with PD may begin to interfere with daily activities.

Other symptoms may include depression and other emotional changes; difficulty in swallowing, chewing, and speaking; urinary problems or constipation; skin problems; and sleep disruptions.

The disease can be difficult to diagnose accurately. There are currently no blood or laboratory tests that have proved to help in diagnosing sporadic PD. Therefore, the diagnosis is based on medical history and a neurological examination. Doctors may sometimes request brain scans or laboratory tests in order to rule out other diseases.

FastFacts

- ✔ As many as one million Americans live with Parkinson's disease (PD), which is more than the combined number of people diagnosed with multiple sclerosis, muscular dystrophy, and amyotrophic lateral sclerosis (ALS).
- ✔ Approximately 50,000 Americans are diagnosed with PD each year, and this number does not reflect the thousands of cases that go undetected.
- ✔ An estimated seven to 10 million people worldwide are living with PD.
- ✔ Incidence of PD increases with age, but an estimated five to 10 percent of people with PD are diagnosed before the age of 50.
- ✔ Men are one and a half times more likely to have PD than women.

Treatment

At present, there is no cure for PD, but a variety of medications provide dramatic relief from the symptoms. Usually, affected individuals are given levodopa combined with carbidopa. Carbidopa delays the conversion of levodopa into dopamine until it reaches the brain. Nerve cells can use levodopa to make dopamine and replenish the brain's dwindling supply.

Although levodopa helps most parkinsonian cases, not all symptoms respond equally to the drug. Bradykinesia and rigidity respond best, while tremor may be only marginally reduced. Problems with balance and other symptoms may not be alleviated at all. Anticholinergics may help control tremor and rigidity.

Other drugs, such as pramipexole and ropinirole, mimic the role of dopamine in the brain, causing the neurons to react as they would to dopamine. An antiviral drug, amantadine, also appears to reduce symptoms. In 2006, the U.S. Food and Drug Administration (FDA) approved rasagiline to be used along with levodopa for patients with advanced PD or as a single-drug treatment for early PD.

Deep Brain Stimulation

In some cases, surgery may be appropriate if the disease doesn't respond to drugs. A therapy called deep brain stimulation (DBS) has been approved by the FDA. In DBS, electrodes are implanted in the brain and connected to a small electrical device called a pulse generator that can be externally programmed.

DBS can reduce the need for levodopa and related drugs, which in turn decreases the involuntary movements called dyskinesias that are a common side effect of levodopa. It also helps to alleviate fluctuations of symptoms and to reduce tremors, slowness of movements, and gait problems. DBS requires careful programming of the stimulator device in order to work correctly.

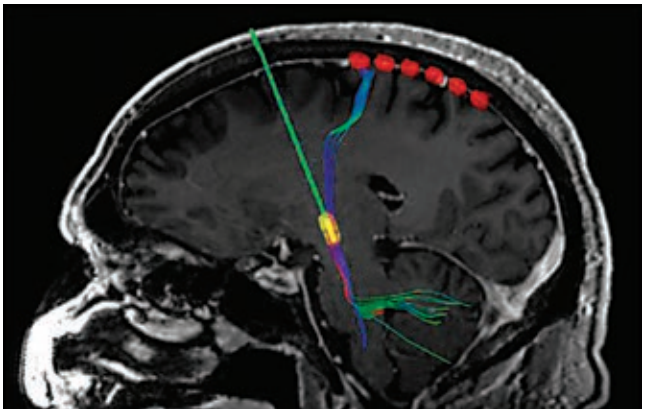


Photo: Coralie de Hemptinne

▲ This image shows a deep brain stimulation electrode (green cylinder with yellow tip) in place during surgery. The red dots are detectors that recorded cortical activity as part of an NIH-supported study to identify abnormal brain rhythms associated with Parkinson's disease.

Parkinson's Symptoms

- MEMORY LOSS, DEMENTIA
- ANXIETY, DEPRESSION
- HALLUCINATIONS

- SLOW BLINKING
- NO FACIAL EXPRESSION
- DROOLING
- DIFFICULTY SWALLOWING

- SHAKING, TREMORS
- LOSS OF SMALL OR FINE HAND MOVEMENTS

- PROBLEM WITH BALANCE OR WALKING
- STOOPED POSTURE
- ACHES AND PAINS
- CONSTIPATION

Illustration: iStock

Award-Winning Help

Fundamental to the success of DBS was the pioneering work of Mahlon DeLong, MD, of Emory University School of Medicine. He recently received the Distinguished Medical Science Award from the Friends of the National Library of Medicine (FNLM) for his work on DBS.

What Is the Prognosis?

PD is both chronic, meaning it persists over a long period of time, and progressive, meaning its symptoms grow worse over time. Although some people become severely disabled, others experience only minor motor disruptions. Tremor is the

major symptom for some individuals, while for others tremor is only a minor complaint and other symptoms are more troublesome. It is currently not possible to predict which symptoms will affect an individual, and the intensity of the symptoms also varies from person to person.

Research

The National Institute of Neurological Disorders and Stroke (NINDS) conducts PD research in laboratories at the National Institutes of Health and also supports additional research through grants to major medical institutions across the country.

Current NINDS-funded research programs are studying how the disease progresses with a goal of developing new drug therapies. Scientists looking for the cause of PD continue to search for possible environmental factors, such as toxins, that may trigger the disorder, and study genetic factors to determine how defective genes play a role. Other scientists are working to develop new protective drugs that can delay, prevent, or reverse the disease.

Find Out More

- ✔ **National Institute of Neurological Disorders and Stroke (NINDS):** www.ninds.nih.gov/disorders/parkinsons_disease/parkinsons_disease.htm
- ✔ **MedlinePlus:** www.nlm.nih.gov/medlineplus/parkinsonsdisease.html
- ✔ **Parkinson's Disease: Hope Through Research – NINDS:** www.ninds.nih.gov/disorders/parkinsons_disease/detail_parkinsons_disease.htm
- ✔ **Parkinson's Disease Research:** www.ninds.nih.gov/research/parkinsonsweb/index.htm
- ✔ **National Institute of Environmental Health Sciences:** www.niehs.nih.gov/health/topics/conditions/parkinson

Parkinson's Disease Research

No breakthroughs, but steady progress

The NIH's National Institute of Neurological Disorders and Stroke (NINDS) is the nation's leading funder of research on Parkinson's disease (PD). Researchers are working to better understand and diagnose the disease, develop new treatments, and, ultimately, prevent PD.

> "[I]ndividual research groups are coming together to identify other symptoms—sleep problems, anxiety, and depression—that may appear before movement symptoms."
>
> —Beth-Anne Sieber, PhD, National Institute of Neurological Disorders and Stroke, NIH

As these efforts continue, one outcome may be earlier diagnosis of the disease.

"Although there have not yet been definitive research breakthroughs in the identification of diagnostic biomarkers for PD, one important advance is that individual research groups are now coming together to identify other symptoms—such as sleep problems, anxiety, and depression—that may appear before the movement symptoms," says Beth-Anne Sieber, PhD, chair of the Parkinson's Disease Working Group at NINDS.

"The research I see coming together may well help us use these signs and symptoms to help in earlier diagnoses of PD before the tremors and rigidity," she adds.

There are clinical trials under way to help alleviate symptoms. "Another area of clinical trials is in how to halt the progression of PD," Sieber says. Other clinical trials relate to exercise and the quality of life for PD patients.

Still other PD research is being carried out through a bold new NIH project that aims to revolutionize understanding of the human brain. It is called the BRAIN Initiative—short for Brain Research through Advancing Innovative Neurotechnologies.

NINDS conducts PD research in laboratories at the NIH in Bethesda, Maryland, and also supports additional research through grants to major medical institutions across the country.

Parkinson's Patient Active as Research Advocate

About three years ago, Joel Grace, then 75, noticed twitching in the fingers on his left hand as he sat at his computer. Mild at first, the twitching made him suspicious that something was going on that he ought to have checked out. His doctor quickly diagnosed him with Parkinson's disease (PD).

Today, the widower who lives in southern New York state says that he is "mildly impaired" by PD, mostly left-side weakness, with difficulty in his trunk movements, such as turning over in bed or getting in and out of cars. Buttoning shirts can be an issue, and he walks for exercise now, rather than jog.

"I do everything I used to do; it just takes me three times as long," he says with a laugh.

Gaining and Sharing Knowledge

From his diagnosis, Grace made up his mind that he did not want to be a passive PD patient.

"I didn't like Parkinson's, and I wanted to do something about it," he says.

He read as much as he could about the disease, and decided that he would like to help others find out information and deal with their own PD as he was doing himself.

He now attends three different Parkinson's support groups in his area, passes along to fellow patients medical and legislative news about PD, and has become an active research advocate through the University of Rochester Medical Center, a Center of Excellence for PD research, and the Parkinson's Disease Foundation, a national nonprofit research organization.

Clinical Trials

With a PhD in psychological counseling, Grace is also able through that training to help as an assistant monitor in clinical trials. Recently, he was selected to help as a data safety and monitoring board member for a clinical trial funded by the NIH's National Institute of Neurological Disorders and Stroke.

Photo: Parkinson's Research Foundation

> "My involvement as a volunteer has made me feel like part of the research team, not just a passive subject."
>
> –Joel Grace

"The University of Rochester researchers recommended me to the Parkinson's Research Foundation to be a research advocate for them, which has been wonderful," he adds. "Being diagnosed with Parkinson's makes you feel somewhat victimized. My involvement as a volunteer has made me feel like part of the research team, not just a passive subject."

The specific clinical trial that involves Grace as a monitor for patient safety is a 60-site clinical study to investigate whether the drug inosine can slow early PD. The University of Rochester Medical Center was selected as the coordinating center for data collection.

"I can't say enough about the University of Rochester Medical Center research team," says Grace. "They have been wonderful."

The Biology of Addiction: Drugs and Alcohol Can Hijack Your Brain

People with addiction lose control over their actions. They crave and seek out drugs, alcohol, or other substances no matter what the cost—even at the risk of damaging friendships, hurting family, or losing jobs. What is it about addiction that makes people behave in such destructive ways? And why is it so hard to quit?

NIH-funded scientists are working to learn more about the biology of addiction. They've shown that addiction is a long-lasting and complex brain disease, and that current treatments can help people control their addictions. But even for those who've successfully quit, there's always a risk of relapse. Research shows that many people will relapse before they overcome addiction—it is not failure, but often a step in the road to recovery.

"A common misperception is that addiction is a choice or moral problem, and all you have to do is stop. But nothing could be further from the truth," said George Koob, PhD, director of NIH's National Institute on Alcohol Abuse and Alcoholism. "The brain actually changes with addiction, and it takes a good deal of work to get it back to its normal state. The more drugs or alcohol you've taken, the more disruptive it is to the brain." The good news is that both behavioral treatments and medications can help bring the brain back into the normal state, noted Dr. Koob.

To learn more: newsinhealth.nih.gov/issue/oct2015/feature1

Lack of Sleep May Increase Diabetes Risk

A lack of sufficient sleep reduces the body's sensitivity to insulin, impairing its ability to regulate blood sugar and increasing the risk for diabetes, according to researchers from the University of Colorado. Their new study adds to a growing body of information linking a lack of sleep to a range of ailments including obesity, metabolic syndrome, mood disorders, cognitive impairment, and accidents.

"We found that when people get too little sleep it leaves them awake at a time when their body clock is telling them they should be asleep," said the study's lead author, Kenneth Wright Jr., PhD, professor of integrative physiology at CU-Boulder. "And when they eat something in the morning, it impairs their ability to regulate their blood sugar levels."

Diabetes rates are skyrocketing nationwide, noted study co-author Robert Eckel, MD, an endocrinologist and professor of medicine at CU-Anschutz. By 2050, he noted in a press release about the study (bit.ly/1RRJ3kI), as many as 33 percent of all Americans may have type 2 diabetes.

The study, funded in part by NIH, appeared online in the journal *Current Biology* (bit.ly/1lgXHaR).

Keep Your Mouth Healthy: Oral Care for Older Adults

Oral health is important for people of all ages. But the simple routine you learned as a kid—brush your teeth twice a day and floss regularly—can become more of a challenge as you get older. Among adults ages 75 and up, about one in four has lost all natural teeth, largely because of gum disease and tooth decay.

You can take steps to keep your mouth healthy throughout your lifetime. And if you're a caregiver for an older adult, you can help ensure that he or she gets proper oral care. Tooth decay and gum disease don't have to be a part of getting older.

"We have to worry about the same conditions throughout life, although some conditions are more prevalent at certain ages," said Dena Fischer, DDS, MSD, MS, a dental health expert at the National Institute of Dental and Craniofacial Research. "Gum disease is more common when you're older," Fischer explained. "But cavities can happen at any age, as long as you have natural teeth." Both are largely preventable with proper care.

To learn more: newsinhealth.nih.gov/issue/oct2015/feature2

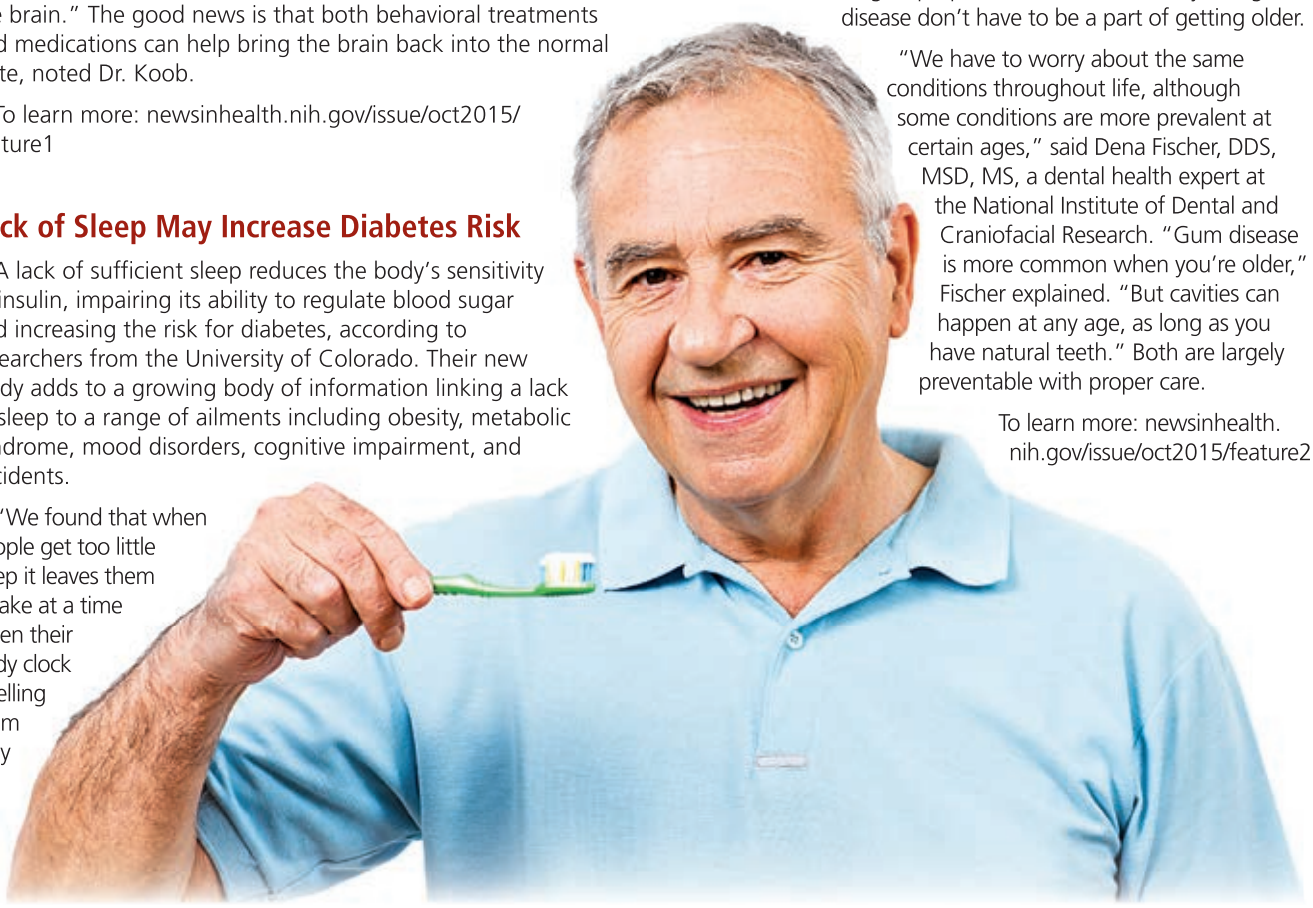


Photo: iStock

Info to Know

NIH Quickfinder

For more information or to contact any of the following NIH Institutes, centers, and offices directly, please call or go online as noted below:

Institutes

- **National Library of Medicine (NLM)**
  www.nlm.nih.gov
  1-888-FIND-NLM (1-888-346-3656)
- **National Cancer Institute (NCI)**
  www.cancer.gov
  1-800-4-CANCER (1-800-422-6237)
- **National Eye Institute (NEI)**
  www.nei.nih.gov | (301) 496-5248
- **National Heart, Lung, and Blood Institute (NHLBI)**
  www.nhlbi.nih.gov | (301) 592-8573
- **National Human Genome Research Institute (NHGRI)**
  www.genome.gov | (301) 402-0911
- **National Institute on Aging (NIA)**
  www.nia.nih.gov
  Aging information 1-800-222-2225
  Alzheimer's information 1-800-438-4380
- **National Institute on Alcohol Abuse and Alcoholism (NIAAA)**
  www.niaaa.nih.gov | (301) 443-3860
- **National Institute of Allergy and Infectious Diseases (NIAID)**
  www.niaid.nih.gov | (301) 496-5717
- **National Institute of Arthritis and Musculoskeletal and Skin Diseases**
  www.niams.nih.gov
  1-877-22NIAMS (1-877-226-4267)
- **National Institute of Biomedical Imaging and Bioengineering (NIBIB)**
  www.nibib.nih.gov | (301) 451-6772
- ***Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD)**
  www.nichd.nih.gov | 1-800-370-2943
- **National Institute on Deafness and Other Communication Disorders (NIDCD)**
  www.nidcd.nih.gov
  1-800-241-1044 (voice)
  1-800-241-1055 (TTY)
- **National Institute of Dental and Craniofacial Research (NIDCR)**
  www.nidcr.nih.gov | (301) 480-4098
- **National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK)**
  www.niddk.nih.gov
  Diabetes 1-800-860-8747
  Digestive disorders 1-800-891-5389
  Overweight and obesity 1-877-946-4627
  Kidney and urologic diseases
  1-800-891-5390
- **National Institute on Drug Abuse (NIDA)**
  www.nida.nih.gov | (301) 443-1124
- **National Institute of Environmental Health Sciences (NIEHS)**
  www.niehs.nih.gov | (919) 541-3345
- **National Institute of General Medical Sciences (NIGMS)**
  www.nigms.nih.gov | (301) 496-7301
- **National Institute of Mental Health (NIMH)**
  www.nimh.nih.gov | 1-866-615-6464
- **National Institute on Minority Health and Health Disparities (NIMHD)**
  www.nimhd.nih.gov | (301) 402-1366
- **National Institute of Neurological Disorders and Stroke (NINDS)**
  www.ninds.nih.gov | 1-800-352-9424
- **National Institute of Nursing Research (NINR)**
  www.ninr.nih.gov | (301) 496-0207

Centers & Offices

- **Fogarty International Center (FIC)**
  www.fic.nih.gov | (301) 402-8614
- **National Center for Complementary and Integrative Health (NCCIH)**
  www.nccih.nih.gov | 1-888-644-6226
- **National Center for Advancing Translational Sciences (NCATS)**
  www.ncats.nih.gov | (301) 435-0888
- **NIH Clinical Center (CC)**
  www.cc.nih.gov | (301) 496-2563
- **Office of AIDS Research (OAR)**
  www.oar.nih.gov | (301) 496-0357
- **Office of Behavioral and Social Sciences Research (OBSSR)**
  obssr.od.nih.gov | (301) 402-1146
- **Office of Rare Diseases Research (ORDR)**
  rarediseases.info.nih.gov
  Genetic and Rare Disease Information Center
  1-888-205-2311
- **Office of Research on Women's Health (ORWH)**
  orwh.od.nih.gov | (301) 402-1770

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