Parenting:
Teaching Children to Care for Their Own Health Needs

It’s never too early for parents to teach their children about their disease, how to live a healthy life and how to take an active role in their treatment.

By Mark T. Haggard

CHRONICALLY ILL CHILDREN face greater challenges than other kids their age. One of the biggest challenges is to learn to care for their own special health needs so they are prepared for adulthood. And, parents play a crucial role in this process. It starts by educating children about their condition and what is happening inside their bodies, and then teaching them how to treat themselves and be proactive about their care.

Educate Them About Their Disease

Education is key to helping kids understand what they are going through. Fortunately, there are many educational resources. Many pediatric immunologists are able to translate the advanced language of immunology into a language that kids can understand as they grow older. The Immune Deficiency Foundation has a “Kids Connection” page on its website to educate children (primaryimmune.org/patients-and-families/idf-kids-connection). IG Living recently launched “IGL Teen,” a section on its website for teens being treated with immune globulin (IG) therapy to connect (www.IGLiving.com/IGLTeen.aspx). The Jeffrey Modell Foundation website offers literature at www.info4pi.org. And, author Sara Le Bien has published a book titled Our Immune System.

Teaching children to understand their bodies is important. Knowing which signs may signal that they are becoming sick allows them to seek treatment immediately before a small illness gets out of hand. Parents can detect certain signs that even kids might not recognize. For instance, when one of my children becomes irritable for no reason, it is an indication of a coming infection; my son used to burst out in tears if I just looked at him wrong because he knew I thought it meant he was getting an infection. I also know that when one of my kids wakes up on the couch, they are likely getting an infection.

Also, once children know what is going on in their bodies, they understand why the medications and their unique delivery systems are important. (It doesn’t make an injection any easier, but it helps to understand its importance.)

Teach Them to Live a Healthy Lifestyle

It is especially important for parents to teach kids to be proactive about their condition rather than reactive. A healthy lifestyle decreases opportunities for pathogens to reach kids’ immune systems. Therefore, parents should be models of healthy lifestyles by maintaining a healthy diet, washing hands with soap and water, using hand sanitizer, brushing and flossing.
teeth, refraining from smoking, avoiding secondhand smoke, fastening seat belts in the car, and using protective equipment while riding bicycles or engaging in other outdoor sports.

The National Institutes of Health (NIH) provides a number of suggestions for ways parents can help kids learn to live healthy lifestyles: 1) Involve the entire family in activities such as walking, hiking, bicycling or other recreational sports; 2) Take a trip to the zoo or the park, which can involve a lot of walking; and 3) Make children responsible for household chores that involve vigorous activity such as mowing the lawn, walking the dog or washing the car. Most importantly, kids need to see their parents having fun performing these activities; if parents look like they are enjoying the activities, the kids will likely enjoy them.

Unfortunately, “screens” have become a huge roadblock to healthy lifestyles. Getting children out from in front of a screen, whether it’s a television, computer monitor or a handheld game, is important. The NIH recommends limiting television watching and not allowing televisions in children’s rooms. They further recommend that families eat dinner together with the television off, have family game nights with the television off, and not use television or video games to reward children. Parents need to be mindful about how much they watch television and use computers themselves, since children’s lifestyles will likely mimic theirs.

To promote physical activity, parents can look for outdoor fun in their hometowns. Fortunately, our local area offers a plethora of opportunities, including fishing, biking, hiking and skiing. While my wife and I are leery of the play structure at the local fast-food restaurant, we let our kids do as much as possible otherwise. For instance, my daughter is a ballet dancer and my son plays football. We know there is the possibility that the slightest injury can be aggravated by an infection, so we keep a specialized first-aid kit on the sideline during practices and games, and give our son extra padding to cushion any potentially injurious blow. Obviously, kids should abstain from activities that their doctors prohibit, but if there are no concerns, the upside of improved immune health from being physically fit far outweighs the possibility of an infection from an injury.

Teach Them to Be Active in Their Treatment

Involving kids in their treatment is another way for parents to prepare kids to care for themselves. Rather than letting Mom or Dad do all of the work, children should be encouraged how much children can be involved in their treatment, depending upon whether they are prescribed intravenous IG (IVIG) or subcutaneous IG (SCIG). For instance, my son’s IVIG requires a home health nurse, so he is limited in how much he can manage in his treatment. My daughter started SCIG when she was 6 years old. For now, I put the tubing together and prime the pump, my wife accesses my daughter, and my daughter de-accesses herself when she is finished. We hope to eventually give her the reins entirely, but at 10 years old, she is not yet able to handle everything.

It’s entirely possible that while children are learning to be active in their treatment, they will have a setback. For instance, Michael, who has selective IgA deficiency and takes antibiotic prophylaxis, was given the reins to be responsible for taking his medicine soon after he turned 13. His mother stopped giving him daily reminders. And, while he was responsible for a few weeks, his regimen became sporadic for another week, and he got a sinus infection. After a few rounds of higher-potency antibiotics, Michael recovered. The lesson he learned has made him more loyal to his prophylaxis regimen, and he has not been struck by any more major infections.

Like teaching kids to brush their
teeth, parents can’t harp on them every morning and night. A once-in-a-while reminder doesn’t hurt, but if parents do that too often, they start to sound like Charlie Brown’s teacher: “Wah wah, wah wah wah.” As a teacher, I know that kids learn best on their own, and they will eventually learn to be responsible. For Michael, it was a hard lesson, but it was a lesson learned.

Don’t Dash Their Dreams
Parents have to allow their kids to dream as well. From the time my son started talking, he wanted to be a U.S. Navy Blue Angel pilot. His story is similar to another child with common variable immune deficiency (CVID) who desperately wanted a career in the Navy. But conventional wisdom told his mother that the Navy would not take a candidate with CVID, and she told him as much. “Mom,” he replied, “it’s OK for someone else to take away my dream, but it’s not OK for you to do it.” He didn’t need his mother’s advice; he needed her unconditional love and support. In reality, this is all parents can do for their children: Encourage them, not tell them what the world says they cannot do.

It’s Never Too Early for Independence
Some parents want their children to perpetually remain 5 years old. Other parents feel they need to protect their children from their illness, thereby making their children dependent on them. It’s not OK to do either of these things. Children will eventually leave the nest, and they will have to act on their own. Success or failure will be up to them. It is never too early to begin teaching children to care for their own health needs. If they fail as children, their parents can help them; if they fail as adults, most times, their parents cannot.

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