

HEALTH

SENIOR Q&A

Planning for a disabled child's future

Q: I have been caring for my son who has a learning disability. As I get older, I worry about who will provide care for my son after I no longer can. I know I need legal advice and help from someone who can help me plan for that day. What would you advise?

A: There are two concerns - financial and legal and resources for your son. The first step is meeting with an elder law attorney who has a specialty in disability law. Once you have the legal and financial information, you will be able to put together a plan of care. It is important to know what finances are available when looking at options in the community. If you search National Association of Elder Law Attorneys or NAELA, you will find a list of attorneys in your state. Also, ask friends for recommendations. The elder law



Linda Sullivan and Debbie Gtner

attorney should be able to recommend a geriatric care manager who knows the resources in the community and will allow you to put together a plan for your son. Prepare now, research all options, tour and ask questions when you are not in a crisis.

Q: My father is depressed and was recently diagnosed with dementia. He owns several guns. I do not believe he would harm himself, but I think about the guns in the house. When I have asked my father if we can get rid of the guns, he refuses. Any ideas on what I should do

to keep my father safe?

A: Speak with your father's physician about your thoughts. Your father may listen to the physician if he/she tells your father to remove the guns. If the guns are in a locked area, maybe your father will give you the key. This way he has no accessibility to them. If they are not locked up, suggest your father lock them up and give you the key. Some people feel safe keeping guns at their bedside, but with dementia it is never a good idea. You should notify the police that your father has guns at home and the diagnosis of dementia.

Q: My mother has expressive dementia - difficulty expressing her thoughts. She appears to understand what I am saying but is not always able to express what she wants to say. This is frustrating for her. Do you

have any ideas on how my mother can better make her needs known?

A: One idea is to put together a picture book of items such as her favorite foods, cookies, candy, water, etc. In another section, you can have words such as pain and then either words or pictures of body parts. Also, ask your mother's primary care physician if he/she will arrange for a speech therapist to complete an evaluation and suggest other ideas. You may also want to put a note in your mother's wallet that she has difficulty speaking. If she is ever brought to the hospital the staff will immediately assume the speech issue is new. Your telephone number should be clearly available for all EMTs. We recommend putting a notification on the refrigerator with a list of medications, diagnoses,

important information, allergies and family phone numbers.

Q: My sister and I do not agree about the care for my mother. I believe my sister is nonchalant when it comes to getting my mother to the doctor and she minimizes everything. My sister lives with her and information about my mother is filtered through her. I live out of state, and I am limited to what I can do. I feel my sister is not doing enough for Mom. Any ideas for a sibling living at a distance?

A: It is very hard to live at a distance and be directly involved in caregiving. Maybe the next time your mother has a medical appointment, the doctor can have you on the phone so you can listen in and at the same time voice your thoughts and opinions. Ask the doctor if they have medical records online.

This way you and your sister can be looking at the same reports. Consider setting up Skype on the computer with your sister so you can see each other when you talk about your mother. This way you may feel like you are closer. Seeing each other online is different than a phone call. Also, you can see your mother on Skype. Gently remind your sister that you may live at a distance but there are still things that you can do.

Debbie Gtner, LCSW, C-SWCM is Vice President of the Geriatric Care Managers. Linda Sullivan Nurse and Care Manager Certified, RN, CMC. Together they are owners of ElderCare Resource Services helping families navigate resources for seniors. Contact them at 508-879-7008; toll free at 866-280-2308.

SPINE & SPORTS

Do you have runners' butt?

Runner's butt is characterized by pain along the upper hamstrings and buttock. It is caused by repetitive strain to the hamstring tendon and its attachment to the bottom-most bone of the pelvis, which is called the ischial tuberosity, or the "sit bone." Also referred to as "high hamstring tendinopathy," this condition is most common in runners and ultimately causes some to give up running altogether.

The simplest way to test for runner's butt is with a hamstring isometric test. While standing on your good leg, elevate your painful leg and place your heel on a chair or step. This puts your hamstring into a stretched position. Contract your hamstring by pressing your heel downward. If you get a jolt of pain, odds are you've got runner's butt.

Unfortunately, most common approaches for alleviating the pain, such as using a foam roller or sitting on a tennis ball, ice or heat applications, stretching or physiotherapy modalities like electric stimulation, don't work. Excessive stretching often makes the condition worse. Painkillers like ibuprofen provide only temporary pain relief and are not worth the side effects of long-term use.

Be aware that other problems can cause buttock pain, including arthritic hips, hip bursitis, lumbar spine disc herniations and pelvic organ diseases. Also, large tears in the hamstring tendon are common and make runner's butt impossible to treat. Sometimes an MRI is required to rule out these conditions.

For self-help, try self-massage. Find the most tender spot along the hamstring. Firmly press and rub it with a fingertip for up to three minutes. Don't roll or squash it on a tennis ball or foam roller. Exercise the hamstring by doing one-leg dead lift repetitions with moderate weight. Or, while on your back, place your heels on top of a gym ball and while keeping knees bent about 30 degrees, lift your butt off the ground. This is called a "supine ham bridge" (go to www.drgillman.com to watch a demonstration of these exercises). Avoid stretching. If you must run,



Scott Gillman

shorten your stride. If possible, take a break from running. If these options don't work, seek professional help. A credentialed sports chiropractor is ideally suited to properly evaluate and treat your condition.

When you search for skilled healthcare providers, find those who are certified and experienced in both sports medicine and soft tissue treatment. Graston Technique, FAKTR (Functional and Kinetic Treatment with Rehabilitation) or deep transverse-friction therapy are methods that can help, as can kinesiology tape, such as Rocktape. Follow through with exercises that condition the hamstring.

Since the hamstring attaches to the pelvis, expert joint manipulation to the pelvis to promote better pelvic joint movement is important. (A chiropractor is best suited for this treatment.) Therapeutic ultrasound or low-level laser therapy over the tendon, when combined with other soft-tissue methods, can help. Last, platelet-rich plasma (PRP) injection has been successful in resolving stubborn tendon problems. Unfortunately, there is no research that shows who will respond best to what treatment.

Sports chiropractors and orthopedists are among the most expert at diagnosing your pain before embarking on treatment. You can eliminate runner's butt with appropriate treatment and time, but if buttock pain doesn't improve after approximately 10 sessions of professional therapy, then get a second opinion.

Scott Gillman is a doctor of chiropractic in Natick, in practice since 1991. He is also a chiropractic sports medicine specialist with a Diplomate from the American Chiropractic.

'Coffee spots' could be a sign of neurofibromatosis

Q: My son's doctor said the rashes on his back were "coffee spots" and that meant he may have some kind of nerve disease. We see the specialist in a couple of weeks, but I am hoping you can tell me something about this.

A: From your description it sounds like your pediatrician noted café-au-lait spots and suspects neurofibromatosis (NF), so that is what I will discuss in today's column. Please verify with your pediatrician that this is the correct diagnosis. NF is a disorder that can cause tumors (most often benign, but sometimes malignant) of the nervous system.

There are three types of NF, but I will concentrate on type one (NF1) in today's column since this is by far the most common type; it affects about 1 in 2,500 children, whereas the other types (NF2 and Schwannomatosis) affect less than 1 in 25,000 children.

NF1 is due to a defect in one of the genes on chromosome 17. This gene code for the protein neurofibromin helps regulate the growth of nerve cells. When it is abnormal, the nerve cells may grow in an uncontrolled fashion, hence causing the growth of tumors. The abnormal gene that causes NF1 is inherited in about half the cases and occurs spontaneously in about half the cases.



DR. JEFF HERSH

Patients with NF1 are usually identified in childhood when one or more of the characteristics of the condition begin to manifest. These characteristics include:

- More than 6 café-au-lait spots: having a few of these harmless brown skin lesions (the color of coffee with milk, hence the name) is extremely common (a quarter of people have between one and three café-au-lait spots), but having more than six is very suggestive of NF1
 - "Freckling" of the skin of the armpits or groin area: the name freckling is a bit misleading since this is NOT the classic freckles so many people have
 - Two or more neurofibromas: these are benign tumors and feel like small "lumps" under the skin
 - Two or more Lisch nodules: these are tiny bumps of the colored part of the eye (the iris)
 - Certain bony deformities
 - A family history of NF1
 - Tumor of the optic nerve (called an optic glioma)
- Having any one of these

What's up Doc?

findings triggers a suspicion of NF1, and having two or more are enough to make the diagnosis of NF1.

Once NF1 is diagnosed, certain evaluations and tests may be done to look for other manifestations of the disease. This will include a thorough physical examination with special focus on blood pressure, skin, ears, growth (including checking for early puberty), learning and memory development (including evaluation of how the child is doing in school) and the eyes (often by a specialist). Imaging may be indicated, such as an MRI to look at the brain/optic nerves and/or x-rays of any bones suspected of having an abnormality. This evaluation will need to be done on a regular basis (at least yearly, although some experts recommend more frequent screening in some cases) since different aspects of NF1 may manifest at different times for individual patients.

Patients with NF1 may have complications possibly including short

stature, learning disabilities, seizures, cognitive dysfunction, increased incidence of autism, vision problems (for example as a complication of an optic glioma), high blood pressure, large head size (when corrected for their age, weight and height) and/or certain cancers (less than 10 percent of NF1 patients develop a malignant tumor from their condition). Overall life expectancy in patients with NF1 is decreased compared to the general population, with expected median life expectancy of about 60 years old for NF1 patients compared to about 74 for the general population.

Treatment must be individualized for each patient, and is determined by what, if any, symptoms and/or complications they develop; treatments may include surgery, medications and/or supportive care. For this reason it is important that NF1 patients be followed by a team of healthcare providers which have experience and expertise with this condition.

Since NF1 may be an inherited condition, counseling of the family (and the child when they grow to adulthood) is an important aspect of care. Very close evaluation of siblings is also indicated.

Jeff Hersh, Ph.D., M.D., can be reached at DrHersh@juno.com.

SUPPORT GROUPS

PARKINSON'S DISEASE SUPPORT GROUP — Second Wednesday of each month, 10 a.m.-noon, for persons with Parkinson's disease and their caregivers. Meetings include speakers, support, refreshments, and conversation. At Community VNA, 10 Emory St. Attleboro. To learn more, call the coordinator at 508-695-6569 or visit www.communityvna.com. **PARKINSON'S SUPPORT GROUP** meets every third Tuesday, 1:30-2:30 p.m. at 535 Union Ave., Framingham. Call the Social Services Department at 508-532-5980, ext. 4108 for details.

PARENTS HELPING PARENTS, hosted by Parents Helping Parents and Early Childhood Alliance, meets at Little Footprints in the Sand, 592 Waverly St., Framingham, 6:30-8 p.m. Mondays. For information, call Michelle

at 860-877-9227 or Silvia at 508-304-4090 or visit www.parentshelpingparents.org. Also meets at 82 Brigham St., Marlborough, 6:30-8 p.m. Mondays. For information, call Meg at 617-926-5008, ext. 102.

SOUTHEASTERN MA PARKINSON'S DISEASE SUPPORT GROUP meets the second Wednesday, 10 a.m.-noon, at Community VNA, 10 Emory St., Attleboro. The group is designed for caregivers and their loved ones. Meetings include speakers, refreshments, conversation and support. Free. Open to all communities. To learn more, call 800-220-0110 or visit www.communityvna.com and click on Calendar.

PARENT SUPPORT GROUP Wayside Youth & Family Support Network's parent support groups for parents of children with behavioral, emotional or

mental health challenges. The groups are held on second and fourth Monday of each month, 7-9 p.m. at Wayside Youth & Family Support Network, 88 Lincoln St., Framingham. Contact Dodi Hardsog, parent support coordinator, at 508-620-0010, Ext. 339, or lois_derusha@waysideyouth.org.

PARENTS WITHOUT PARTNERS A nonprofit organization that supports single parents and their children by providing educational and social activities. To contact the Auburn Chapter, call 508-721-0707. **PFLAG/MetroWest (Parents, Families, and Friends of Lesbians, Gays, Bisexuals, and Transgender people)** invites all to an evening of conversation, sharing, support, and connection on the fourth Monday of each month, 7-8:30 p.m. at Rice House

on the campus of the Unitarian Universalist Church of Wellesley Hills, 309 Washington St., Wellesley Hills. Information: metrowestpflag@verizon.net; www.gbpfllag.org.

PROSTATE CANCER SUPPORT GROUP meets the last Thursday of each month from 7 to 8:30 p.m. at the MetroWest Medical Center, School of Nursing Building, 85 Lincoln St., Framingham. No meetings in July and August. A group also meets on the first Tuesday, 9-10:30 a.m. at Callahan Senior Center, 535 Union Ave., Framingham. Call Melissa Hayon at 508-383-8529 or Linda Mario at 508-383-1378.

