Understanding dementia: a conversation with caregivers

WHAT TYPE OF MEMORY LOSS IS NORMAL? Should I be worried? Where do I go from here?

These questions – among many others – were addressed during a March 20 seminar, “I’m Having Trouble Remembering: A Discussion on the Difference Between Normal Aging and Dementia,” presented by Erin Stevens, DO, MGH geriatrician and Palliative Care physician.

The program, open to caregivers, patients and staff, kicked off a four-seminar “Conversations with Caregivers” education series at the MGH. Sponsored by the Dementia Caregiver Support Program, this new initiative was created by the Division of Palliative Care and Geriatric Medicine to offer support to those navigating the often-difficult path of caring for an aging parent, spouse, friend or loved one.

“We are here to help educate, support and provide for those caring for someone with dementia,” said Lorie Smith, MD, medical director of the Dementia Caregiver Program. “We hope, as our program continues to develop, participants will find it a source of compassion and collaboration.”

NORMAL AGING OR DEMENTIA?

“Let’s think about our cars,” Stevens said. “It can be perfectly normal to park your car in a garage and then forget where it might be parked. What is not normal, however, is to forget what type of car you have or not remember why you drove there.”

Normal memory changes – such as briefly forgetting where a car is parked – are signs of cognitive aging, a process that occurs in every individual as they age. More concerning situations are when an individual starts frequently getting lost in once-familiar places, forgetting routine tasks, losing weight, and if they seem depressed, make inappropriate comments or experience changes in their sleep or spending habits, Stevens says.

“Dementia isn’t just memory loss; it can be an impairment in any one of six main mental process domains – complex attention, executive function, learning and memory, language, perceptual-motor and social cognition,” said Stevens. “When the memory loss or behavior effects the ability to function daily or to be independent, it is more concerning for dementia.”

CAUSES AND TYPES OF DEMENTIA

“There are many causes of dementia, but the biggest risk factor is age. The older we live, the more of a chance we have of getting it,” Stevens said.

Other causes of memory loss may include vascular disease, head trauma, degenerative disorders or a hereditary

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Fiancée’s cancer care inspires marathoner

MIKE TRIPALDI WAS AT A TIKI BAR with friends on Memorial Day weekend in 2015 when his life changed forever. It should have been an early night — he needed to get up the next morning to train for an Ironman competition. But when Lauren Dudley walked through the door, Tripaldi knew he couldn’t go home.

“We made eye contact immediately,” Tripaldi says. “And the rest is history.” Three years later, Tripaldi has joined the 2018 Mass General Marathon Team to raise funds for pediatric hematology oncology in honor of Dudley, who is now his fiancée. In April 2017, Dudley discovered a lump after exercising. The next day, she went wedding gown shopping with her mom and sisters. “I thought I’d just pulled something going to the gym,” Dudley recalls. “I showed it to my mom, and she said, ‘Oh, my God. You need to get this checked out right away.’”

Within days, Dudley had a mammogram and ultrasound at her local hospital. “We fell in love with Mass General,” Tripaldi says. “The experience couldn’t have been more welcoming. Doctors looked her in the eye. She felt like she was the only patient in the whole hospital.”

Tripaldi, a longtime athlete, saw how innovative treatments at the MGH can improve cancer patients’ lives — and how frustrating it is to watch a loved one struggle despite these medical advances.

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MGHfC celebrates 10 years of child health research

THE OUTLOOK FOR CHILD HEALTH RESEARCH – both in federal funding and at the MassGeneral Hospital for Children (MGHfC) – is a bright one, was the message from speakers at the 10th anniversary of MGHfC Pediatric Research Day. In a talk aimed at the next generation of early investigators and clinician-scientists, keynote speaker Diana Bianchi, MD – director of the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD) – urged participants to look at the funding glass as “half-full.”

Bianchi discussed challenges and opportunities related to child health research during the March 20 event at the Starr Center. She correctly predicted the healthy rise in National Institutes of Health (NIH) funding in the omnibus budget bill subsequently passed by Congress and also described an array of online tools provided by NICHD and other federal funding sources. Bianchi encouraged young investigators to reach out directly to NIH program directors early in their careers and to broaden their search for federal pediatric research funding, which has grown from $3.28 billion in 2011 to $4.18 billion in 2017.

David Torchiana, MD, Partners HealthCare president and CEO, spoke about the vital role that pediatric research plays at the MGH. “You’re punching above your weight,” said Torchiana. Total funding for pediatric research at the MGH was approximately $90 million in 2017, making up nearly 10 percent of the total research budget of $912 million.

Faculty keynote speaker Randy Buckner, PhD, director of the MGH Psychiatric Neuroimaging Research Division, proposed that many ailments are caused or mediated by the fundamental mismatch between our brain’s evolution in an intimate hunter-gatherer society with tightly proscribed relationships and roles and the complex, modern society that “we’ve evolved into.”

Four junior faculty members also presented talks. Peggy Settle, RN, PhD, nurse director of the Neonatal Intensive Care Unit, described a research study that led to implementation of a successful infant-driven feeding method. Lauren Fiechtner, MD, director of the Center for Pediatric Nutrition at MGHfC, talked about the importance of including parental feedback and direct participation in a weight management study on children. Vibha Singhal, MD, pediatric endocrinologist, presented on marrow fat and bone across the nutritional spectrum; and Hongmei Mou, PhD, of the MGH Center for Regenerative Medicine, talked about the development of a stem cell model to study airway diseases.

More than 150 posters were presented, and travel awards were given to Jafari Gholamali, MD, PhD; Vibha Singhal, MD; and Mai Uchida, MD. Thirteen finalists also were selected to submit applications for an MGHfC pilot and feasibility award.

A touching tribute

MGH STAFF JOINED TOGETHER in the Thier Conference Room this week to celebrate the life and legacy of Rev. Dr. Martin Luther King Jr. Sponsored by Nursing and Patient Care Services and the MGH Spiritual Care Department, the April 4 event – on the 50th anniversary of King’s death – featured readings of the activist’s famous sermons, photos of the Civil Rights Movement and a live gospel singalong.
Cardiologist ‘merits’ notice by giving back

AS DIRECTOR OF THE MGH CARDIAC INTENSIVE CARE UNIT and “co-director” of three young children at home, David Dudzinski, MD, will tell you he has his hands full on a weekly basis.

But that hasn’t stopped him from mentoring other cardiologists coming up through Ellison 9, serving as assistant Cubmaster to his 7-year-old’s troop or volunteering at a local science night at his two eldest kids’ Belmont school.

“I half-jokingly call these activities my best prevention against burnout, but it’s true,” says Dudzinski. “And it feels great to see the wide-eyed reaction to science from these children.”

Dudzinski says wide – and wary eyes – greeted him at the March 15 Winn Brook Elementary School Science Night. A local grocery store had donated animal hearts, which Dudzinski dissected, to show students the chambers and valves similar to those of the human heart.

“About a third of the kids were afraid to even touch the hearts at first. But then almost all of them got right in there, picked them up and really studied them quite intently,” says Dudzinski. “And interestingly, a couple of parents disclosed their own experiences with heart surgeries and also stopped by to take a look and ask questions.”

SCIENCE NIGHTS AND “SCOUTING” OUT POTENTIAL CAREERS

Just a few days later on March 19, Dudzinski took the show-and-tell up a notch, during his second year of hosting a Medicine Merit Badge Night for Boy Scouts of the Boston Council.

Twenty-two Scouts ages 12 to 16 visited MGH for a night of learning through conversation and demonstrations. In keeping with the Boy Scout motto, the group learned how to “be prepared” for a path in school that might lead to careers in medicine, asking questions of Dudzinski and the MGH Heart Center’s Vlada Usherenko, NP and Shauna Sullivan, RN.

“MGH has state-of-the-art technology, but we also discussed the art of the conversation and making a connection through taking a full patient history and conducting the physical exam,” says Sullivan.

“We wanted the Scouts to learn not only about modern medicine and our careers but also something special about their own health,” says Dudzinski. He led the Scouts through an echocardiogram – or ultrasound of the heart – using the transducer on five of the Scouts to allow them to see and hear their hearts beating and blood flowing across the valves in real time.

Adds Dudzinski, “We may have inspired a few future cardiologists.”

Dual-space training room offers hands-on learning opportunities

THE MGH LEARNING LABORATORY recently piloted an in-situ simulation space in the Emergency Department, as part of the Department of Emergency Medicine’s Quality and Safety Olympics. The clinical bay houses an adult or pediatric mannequin simulator along with easily accessible equipment to provide training and education opportunities for emergency care team members.

The Feb. 12 exercise included a number of MGH staff, including attending physicians, resident physicians, nurses, physician assistants and unit coordinators. Participants cared for a simulated critical patient then discussed the team’s clinical approach and ways to improve team communication during challenging cases.

“The goal moving forward is to make realistic training more routinely available to busy clinical staff in their own unit,” says James Gordon, MD, director of the MGH Learning Laboratory and chief of the Emergency Department’s Division of Medical Simulation.

“The creation of dual-use space to support both patient care and provider training offers exciting new opportunities to improve patient care at the point of service.”
Future support program offerings

**THE DEMENTIA CAREGIVER SUPPORT PROGRAM** will host three additional programs in this educational series. All are free and will take place in the Haber Auditorium. Call 617-724-0406 to RSVP. Seating is limited. Staff, patients, families and caregivers all are welcome.

**APRIL 18, 5:30 - 7 PM**

**After a Dementia Diagnosis: What's Next for Patients and Caregivers?**

Barbara Moscowitz, LICSW, Dementia Caregiver Support Program, MGH Division of Palliative Care and Geriatric Medicine

**MAY 16, 5:30 - 7 PM**

**Legal and Financial Planning Following a Dementia Diagnosis**

Steven M. Cohen, partner, Pabian & Russell, LLC

**JUNE 20, 5:30 - 7 PM**

**Caring for the Caregiver: Promoting Resiliency, Strength and Support**

Katie Brandt, director of Caregiver Support Services, MGH Frontotemporal Disorders

is constantly changing, so if there’s one thing I can’t stress enough it’s the importance of keeping your mind active.”

For more information about the Dementia Caregiver Support Program, contact Barbara Moscowitz, LICSW, program founder and associate director for Education and Support, at bmoscowitz@partners.org.

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**Marathon**

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“You see people fighting for their lives, just to have another day,” he says. “I knew I had to research anything I could do to get involved, so one day nobody will have to worry like us.”

Genetic testing found Dudley to be “mosaic” for the cancer-causing TP53 gene mutation, meaning the gene was found in some but not all of her tumor cells. “Mass General got back to me within two hours of my calling, and I was able to meet with an entire treatment team in one visit,” says Dudley, who was referred to Barbara Smith, MD, PhD, director of the Breast Program in the MGH Cancer Center, for a double mastectomy. She then received treatment at Mass General Waltham every three weeks and will continue with chemotherapy until September.

Tripaldi, meanwhile, trains for the Boston Marathon every day. He also is planning to host a fundraiser at his restaurant — Monument Square Market in Hollis, New Hampshire — the weekend before the marathon.

“My goal is to raise $10,000 — but really, my goal is to blow that away,” Tripaldi says. “This has been horrible to watch. My role is to keep Lauren positive, keep her going. But really, this girl didn’t even need me. There are no words to explain how unbelievably strong she is.”

And when Tripaldi reaches the finish line at the marathon, the couple will be able to focus on a new goal: their Memorial Day wedding.

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**Dementia**

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condition. Depending on the type of memory problem — whether it be neurodegenerative or age-related — the correct specialist can then work on a management plan. Different types of dementia present differently and can be helped — or worsened — by medications or treatments. “Depression is one of the top three causes of reversible dementia. So it is really important to have the correct initial evaluation and diagnosis so we can tease out and treat any reversible causes. It may end up the patient doesn’t have dementia at all, but instead has one of these other issues that can be treated,” said Stevens.

**DIAGNOSIS AND MANAGEMENT**

“We know that early advance care planning improves care for both patients and caregivers,” said Stevens. “We want to — for as long as possible — preserve our patients’ memory, maintain their function and independence, and support them and their caregivers.”

While there are medications to help slow the progression of dementia, they do not prevent, treat or cure the disease. In addition to or in place of medication, a number of other techniques also can be used to help with symptoms. These techniques include a proper diagnosis, removing and treating any reversible causes or exacerbations, managing behavioral symptoms and promoting brain health.

“A good rule of thumb is what’s good for your heart is also good for your brain,” said Stevens. “Adopting a healthy lifestyle with exercise, a balanced diet and mental activities is the best way to maintain a healthy brain. The brain is constantly changing, so if there’s one thing I can’t stress enough it’s the importance of keeping your mind active.”

For more information about the Dementia Caregiver Support Program, contact Barbara Moscowitz, LICSW, program founder and associate director for Education and Support, at bmoscowitz@partners.org.

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**Circle of support**

**THE MGH SPIRITUAL CARE DEPARTMENT** hosted a special “Circle of Concern: An Epidemic of Violence” service in the MGH chapel April 5 to honor and console those affected by mass shootings and recognize the fifth anniversary of the Boston Marathon attacks. At the service, employees were given a card to write their concerns and placed them in a vase on an altar table. Some employees read aloud the words or phrases written on their cards, others placed them in silence.

This was the first in a new monthly series reflecting on current events facing the MGH community.