Support is mutual at HD Support Group

By Amanda Miller, LMSW
UI HDSA COE Social Worker

Have you ever attended a support group meeting? Some of you will think “of course!” But many readers will respond with “no, I should, but I haven’t yet because (insert string of justifications).”

The reality is, most people impacted by diseases like Huntington disease, whether they are caregivers, at risk, presymptomatic or living with HD, have never been to a support group meeting. The reasons for not attending vary from individual to individual and family to family. Among the many reasons, the most common beliefs (and I’d go as far as to say misconceptions) about the value of support groups fall into one or more of these categories.

1. I don’t really need it yet, but when I do, I’ll look into it. Perhaps you just found out HD is in your family, but you’re not “sick” and don’t know anyone who is. Perhaps you are just beginning the caregiving journey and you do not yet feel that your stress is to the level of needing peer support. Whatever your stage in the lifelong journey with HD, I assure you, it is never too soon to discover others like yourself.

2. I’m not really comfortable talking about my feelings with strangers. The second most common reason for not joining an HD support group is the fear of vulnerability in a room full of strangers. With time, the room is no longer full of strangers, but rather a collection of individuals with whom you’ve had the opportunity to develop meaningful, mutually supportive relationships. Yes, the first time you walk into support group, you will be with strangers. Fear not! There are not any requirements to share restructure your view of what a support group can offer. The group isn’t simply a mechanism for responding to problems. It offers the chance to build relationships with those who can help you before you find yourself elbow-deep in crisis. For the financially savvy, consider this your savings account for support; you build it now so you have it later.

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HD Family Conference
May 3 in Des Moines

Iowans will have a chance this May to hear about popular HD topics from several experts at the 2014 HDSA Iowa Chapter Family Conference.

The event will take place May 3 starting at 8:30 a.m. in Des Moines at the Holiday Inn Des Moines Airport. HDSA Iowa Chapter President Brandon Rogers said the education day will be an opportunity for those affected by HD, their families and community health care professionals to learn more about cutting-edge research, HD advocacy and more day-to-day topics like genetic testing and nutrition and HD.

“This event is being held to provide those who are fighting HD a chance to gather and grow together,” Rogers said.

Center for Cell and Molecular Therapy at Children’s Hospital of Philadelphia Director Dr. Beverly Davidson will talk about her ongoing RNA interference research. UI HDSA COE Director Dr. Jane Paulsen will provide updates on cognition and HD. And UI Professor of Psychiatry Dr. Peg Nopoulos will discuss the challenging issue of driving and HD. Several other topics will also be discussed in breakout sessions.

There is no cost to attend the education day, and breakfast and lunch will be provided.

For more information, contact Rogers at bjrogers@healthcare.uiowa.edu.
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your deepest, darkest secrets and fears. In fact, I counsel potential support group members to come to the meeting with the main goal of simply listening. Hear the experiences of others, let yourself be open to the idea of meeting others impacted by HD, but know that there are no rules of engagement (beyond showing respect to those around you). All you have to do is simply be. Be present in the room, and be mindful of those around you and their circumstances. If you feel comfortable, share your reasons for attending. Perhaps you have a specific question (about a symptom, for example); perhaps you don’t know why you’re there. The most beautiful part of an HD support group is that you don’t have to know the answers. All you have to know is your level of participation is completely up to you; we will respect your entry into the group and support you as you figure out your comfort level.

3. I talk to my family and friends about the issues, so I’m pretty well supported. A theme present in so many HD families is the beautiful existence of informal support from family and friends. Support groups are not, in any fashion, designed to replace this. Rather, support groups augment the love and comfort you find in your personal life. They provide the opportunity for people experiencing similar life struggles to share with each other their successes, failures, and everything in between while not having to worry about burdening their friends and family. In a support group setting, members can even ask about experiences they may not feel comfortable asking other members of the family (picture having a conversation with your mother about your partner’s changing intimacy). I don’t discount the value that informal support provides, but I do emphasize the value of exposure to others outside of your own circle.

Finally, there is an aspect of the support group that is often overlooked: the value that you as a member provide to the group. You have the opportunity to have a magnificently positive impact on others who are living with circumstances not unlike your own. Many group members value their role in the group as it relates to what they can do for others, and in that service, they find peace.

In my decade as a support group facilitator, I’ve had the privilege to meet hundreds of families. Every person with whom I’ve spoken has started out having at least some reservations about joining support group. Many people cite the reasons listed above, others have their own, but my message is the same to all of them: This disease isn’t easy and you don’t have to do this alone. Find a support group near you. Hear about the experiences of others. Contrary to the myth, seeking support isn’t a sign of weakness; it’s one of the best indicators of the strength a person carries. HD is a long and challenging opponent; give yourself the opportunity to have as many resources as possible in your fight. I challenge you to consider bolstering your corner of the ring, and I would like to extend my personal invitation to join our supportive circle.

Research on effect of exercise on HD continues

Everyone from the first lady of the United States to your high school gym teacher will tell you that physical activity and exercise are good for you.

It stands to reason that physical activity and exercise would be beneficial specifically to those with Huntington disease, or those looking to do something to delay onset of certain HD symptoms.

That assumption may very well be accurate, but researchers say at the moment, there’s work to be done to find the definitive proof that physical activity is directly beneficial in this way. That doesn’t mean people shouldn’t be physically active, says Nancy Downing, Ph.D., an assistant professor with the University of Iowa College of Nursing who is currently researching physical activity and diet as it relates to body composition in HD.

“What we say to all of our patients, eat well and exercise, that’s no different for any person with HD,” Downing said. “The problem is for any recommendations specific to a disease population, to tell them this will help you, we can’t really do that until we have good scientific evidence. Right now, we generally say that exercise is good for everybody.”

While promising, studies haven’t proven that exercise or physical activity can prevent or slow HD progression. More studies need to be conducted, and eventually, Downing said researchers would want to know exactly how physical activity interacts with the biological factors at play in HD.

For instance, Downing said there is evidence that exercise alters how our genes operate, and knowing more about exactly how this works could be impactful for a genetic disorder like HD.

Meanwhile, very preliminary analysis of data collected in Downing’s “Body Composition in Prodromal HD” indicate a decrease in lean muscle mass for those who are closest to estimated HD diagnosis when compared to gene-negative individuals, which may be a factor in unwanted weight loss. Other data indicates a small but statistically significant correlation between better cognitive (thinking ability) functioning in individuals, which may be a factor in unwanted weight loss. Other data indicates a small but statistically significant correlation between better cognitive (thinking ability) functioning in those who exercised more as measured by Fitbit activity trackers.

The end goal of this type of research will be to provide recommendations regarding exercise and diet specific to HD. Until that point, Downing says its best to follow the exercise guidelines for the general population as research continues.
SSRI may improve mood; no effect on functioning

By Jolene Luther
Public Relations Assistant

A recent clinical trial found the drug citalopram was not successful in improving executive functioning in those with HD. However, the researchers say that although the trial’s outcome was negative, there are many positive outcomes of the study.

Treatment trials of Selective Serotonin Reuptake Inhibitors (SSRIs), like citalopram, in HD mice have shown improved motor symptoms and delay of onset of cognitive and behavioral symptoms, leading researchers to test the effectiveness of SSRIs to improve functioning in humans. In a recent study published in Movement Disorders, “Results of the Citalopram to Enhance Cognition in Huntington Disease Trial,” Leigh Beglinger, associate professor at the University of Iowa and neuropsychologist at Elks Rehab Hospital in Idaho, and coauthors tested the effectiveness of citalopram to improve executive functioning (e.g., multi-tasking, organizing, problem solving,) in those with HD. They examined 34 adults who had been diagnosed with HD or tested positive for HD at the UI HDSA COE and two other sites.

No significant improvements in functioning were found in those that took citalopram compared to those that took a placebo. Even though the desired outcome didn’t occur, this study has several positive outcomes.

“When study results don’t support the positive outcome researchers were hoping for, it does help inform doctors about which drugs may not be beneficial so that they may choose another way of treating symptoms for future research,” said Beglinger.

But knowing what doesn’t work was not the only positive outcome. The study showed citalopram was safe and possibly helpful for mood in HD, which had not been shown before, Beglinger said.

“This may give doctors more confidence in using this type of drug to treat others symptoms of HD, for example, mild depression,” Beglinger said.

Mice-human similarities led to study

The road to this study was paved with mouse-model research. Although hard to believe, human brains are not all that different from mice brains. Why? According to the National Genome Research Institute, the protein-coding regions—the regions that have the important information necessary to make our bodies’ proteins—of DNA in mice and humans are 85 percent identical. Therefore, research in mice often provides a good first step in the process of discovering treatments for human diseases. Beglinger and coauthors suggest it’s possible they may not have found improved functioning because the citalopram dosage size was too small, the treatment period may have been too short, or the measures used to determine cognitive functioning improvement were not sensitive enough. However, they also point out this is the second HD treatment trial with SSRIs that has failed to show improvement in functioning.

All studies, whether the results are negative or positive, contribute to guiding researchers along the path to finding effective treatments for HD. And without participants, researchers would be halted along their path.

“I would like to thank all the people who participate in research or help their family members participate in studies,” Beglinger said. “The HD community continues to inspire me with their commitment and strength. We would not have answers about treatment without you.”

HD awareness “Alive and Well” in Dubuque

HD studies currently enrolling at the UI

- PREDICT-HD: An observational study of pre-symptomatic individuals. Contact Sean Thompson, predict-hd@uiowa.edu, 319-384-4094
- HDQLIFE: An observational study for adults diagnosed with HD, or PREDICT-HD participants who are gene positive. Contact Courtney Shadrick, courtney-shadrick@uiowa.edu, 319-353-5443
- First-HD/CREST-E: Clinical drug trials for symptomatic, diagnosed individuals. Contact Amanda Miller, amanda-c-miller@uiowa.edu, 319-353-4357
- Enroll-HD: An observational study for anyone in the HD community. Contact Jane Kerr, jane-kerr@uiowa.edu, 319-353-4955.
Science unsure whether brain workouts work


“I’m not convinced there is a huge difference between buying a $300 subscription to a gaming company versus you yourself doing challenging things on your own...

Dr. Murali Doraiswamy
Duke Institute for Brain Sciences

For a $14.95 monthly membership, the website Lumosity promises to “train” your brain with games designed to stave off mental decline.

While Lumosity is perhaps the best known of the brain-game websites, with 50 million subscribers in 180 countries, the cognitive training business is booming.

An effective way to stave off memory loss or prevent Alzheimer’s — particularly if it were a simple website or video game — is the “holy grail” of neuroscience, said Dr. Murali Doraiswamy, director of the neurocognitive disorders program at Duke Institute for Brain Sciences.

The problem, Dr. Doraiswamy added, is that the science of cognitive training has not kept up with the hype.

“Almost all the marketing claims made by all the companies go beyond the data,” he said. “We need large national studies before you can conclude that it’s ready for prime time.”

A series of studies in recent years has suggested that certain types of game training can improve a person’s cognitive performance. In February 2013, however, an analysis of 23 of the best studies on brain training, led by the University of Oslo researcher Monica Melby-Lervag, concluded that while players do get better, the increase in skill hasn’t been shown to transfer to other tasks. But other studies have been more encouraging.

In January, the largest randomized controlled trial of cognitive training in healthy older adults (Advanced Cognitive Training for Independent and Vital Elderly [Active]) found that gains in reasoning and speed through brain training lasted as long as 10 years.

While there is no real risk to participating in the many unproven brain-training games available online and through smartphones, experts say, consumers should know that the scientific jury is still out on whether they are really boosting brain health or just paying hundreds of dollars to get better at a game.

“I’m not convinced there is a huge difference between buying a $300 subscription to a gaming company versus you yourself doing challenging things on your own, like attending a lecture or learning an instrument,” Dr. Doraiswamy said.