

We Are HDSA!



 **Huntington's Disease
Society of America**

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Navigating the Health Care Maze

By Lift Caregiving (www.liftcaregiving.com)

Most people – whether as patients, family caregivers, or health professionals – do not have a good idea of what medical insurance will pay for until the need arises. Family members and patients are often shocked to find that insurance will not pay for many services and items needed at home that are routinely paid for in the hospital. Unless your relative has specific long-term care insurance, many home care needs, especially home care aides or attendants, will not be covered at all or beyond an initial short-term period.

Know What Your Insurance or Managed Care Company Is Responsible for Covering

- If your loved one has been hospitalized, insist on being consulted by the discharge planner about the care plan before decisions are made. Explore all the options, not just the one the discharge planner recommends.
- Find out what your insurance company will approve for your loved one's care, why, and for how long.
- Try to get one person from the insurance or managed care company (a case manager) assigned to your loved one's case and make sure that person fully understands your loved one's condition so that the correct home care services and equipment are provided.
- Look out for inconsistencies or vaguely described benefits. Do not let your insurance company deny coverage for something that has been covered in the past or that you believe should be covered.

Make sure you have been assigned the correct level of home care assistance. Registered nurses, practical nurses, and home health aides or personal care workers have different skills and limitations. There are also different types of agencies, only some of which are Medicare – Medicaid certified.

Identify and Use All Available Resources

- Get to know your local pharmacist, who is an excellent and readily available resource.
- Familiarize yourself with print and Internet resources. Both books and websites provide excellent resources and can put you in touch with other people and community agencies that can help. There is a vast amount of information on the Internet, so be selective and use credible sources.

- Discuss your options with people outside of your network who have experienced your situation.
- Have friends and family help with some of your managerial chores – sorting out bills, reviewing insurance policies, etc. Do not let bills pile up.

Be Assertive About Your Rights

- You can say no if hospital discharge planners want to send your loved one home and you feel you are not prepared to provide the necessary care at home. Be flexible but firm as you negotiate a feasible plan.
- Request an aide or home care nurse to come to the hospital and help you bring your loved one home, including riding in the ambulance, setting up the bed and other medical equipment.
- Make sure your loved one has the proper transportation to and from outpatient visits.
- Ask for a re-evaluation of the situation at a specified time (a few weeks or months).

Recognize How the System Can Work Against You

- Administering the best possible care (i.e., changing dressings daily, using the most appropriate medications and providing other necessities) may be very costly. Such care may not be covered by your insurance policy. You will almost certainly have out-of-pocket expenses for things that are not considered “medically necessary.”
- Instead of providing greater coverage, having two insurance policies could actually mean less coverage. Each plays against the other – delaying or actually curtailing benefits. Make sure you have a clear agreement as to which payer is “primary.”

A spouse is legally responsible for the partner's bills and his/her income is included in determining Medicaid eligibility. Unmarried couples are considered as single individuals, making it easier to get Medicaid benefits, which may include home care.

For more information on how to navigate the health care system, visit liftcaregiving.com.

Educational Events:

October 1:

Houston, TX

October 8:

Baton Rouge, LA

Tampa, FL

Columbus, OH

October 22:

Birmingham, AL

King of Prussia, PA

October 28:

Northwest Chapter

November 4:

Tucson, AZ

November 5:

Indianapolis, IN

New England Region (Providence, RI)

November 8:

Miami, FL

November 12:

Christiana, DE

Caregiver's Corner:

October 19:

Care for the Caregiver:

A Social Work Perspective

November:

Gait & Balance

December 6:

Safety in the Home

For more information on Caregiver's Corner, please contact Jane Kogan at

JKogan@hdsa.org.

Shining the Light

By Tara LoCastro

Steering Committee Community Member, 2CARE Clinical Trial, Huntington Study Group; former Vice President, HDSA Upstate New York Chapter

I remain inspired by the *We Are HDSA* article from September, 2011 entitled "One Mans' Story: Entering the Light" by Kenneth P. Serbin. Exiting the proverbial "HD closet," retreating from and hiding the truth speaks volumes about the far reaching impact that HD has on a family and its members. It takes extraordinary courage to face the deep fear and hardship that come with HD. There are several very complicated emotions and decisions forced upon those touched directly or indirectly by the chronic disease. These complex factors warrant that we also shine the light on evolving models such as Patient & Family Centered Care (PFCC), which is not a novel concept but has emerged as healthcare providers of all types seek to find new ways of engaging their constituents. In the wake of healthcare reform, patient satisfaction measurement will be one of the methods that determine provider pay-for-performance. Therefore it continues to be 'the right thing to do,' and now carries a financial weight with corresponding and overdue priority.

While there are various definitions and adaptation, PFCC is defined by the Institute for Patient & Family Centered Care as ... *"an approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among health care providers, patients, and families...Patient- and family-centered practitioners recognize the vital role that families play in ensuring the health and well-being of infants, children, adolescents, and family members of all ages."* (www.ipfcc.org/faq.html) In short, PFCC recognizes the importance of including families in important healthcare decisions.

PFCC is a means to promote the understanding and sensitivity required of healthcare providers in serving any community. It engages the 'person' and seeks to include family for information, decisions and care needs. This approach to healthcare acknowledges that it is very much a two-way street. A person-centered approach considers the unique needs and preferences of the individual and their family. The emotional, social and developmental needs are often managed as separate and discrete care needs instead of being incorporated into the overall plan of care. Healthcare reform is forcing a critical review of how care is coordinated and this is creating new guidelines for care such as PFCC and numerous state and federal grants that promote better integration and synergy of healthcare services.

Many healthcare providers have created Patient & Family Advisory Councils to directly engage patients and/or family members for feedback and partnership to improve their experience. This type of forum changes the dynamic and brings the stakeholders (customer and/or patients) to the table for input on decisions or activities being pursued by the provider. Ask your primary care provider and/or healthcare system where they stand with PFCC and to learn more visit the Institute for Patient & Family Centered Care website, www.ipfcc.org.

Publications

For more information on Juvenile-Onset HD (JHD), please visit the HDSA website. HDSA has several publications on JHD, including:

Juvenile Huntington's Disease: A Family Guide

The Juvenile Onset HD Resource Directory

The Juvenile HD Handbook: A Guide for Families and Caregivers

Juvenile Huntington's Disease and the School Experience (for schools interested in learning more)

To find out more about these and any other HDSA publication, contact Anita Mark-Paul, Information and Fulfillment Aide, at amarkpaul@hdsa.org.

Care Coordination Portal

HDSA is pleased to offer the HDSA Care Coordination Portal, powered by Lotsa Helping Hands. The HDSA Care Coordination Portal is a free, private, web-based tool that caregivers can use to manage the care and administrative needs of their loved ones as well as the outpouring of support from their network of family and friends. Create your caregiver community today at www.hdsa.org/carecoordination.

H.R. 718 Reaches 100 Cosponsors:

This September, H.R. 718 reached the 100 cosponsor mark thanks to an aggressive home office visit campaign during the August Recess. Thank you to all of the HDSA advocates who educated Congress! ***It is not too late to visit your Representative about H.R. 718, and your two Senators about S. 648.*** Contact Jane Kogan at jkogan@hdsa.org to learn more.

By Karen Tarapata

The new school year can be an exciting time for children – new teachers, different classmates, fresh challenges. For children with Juvenile-Onset HD (JHD), the new school year can also be a source of anxiety. Changes to routine and unfamiliar situations can be unsettling to children with this disorder and may worsen some symptoms. Below are suggestions a parent or caregiver of a child with JHD can provide to the school.

Strategies to reduce stress in children with JHD

Students with JHD often feel tremendous stress. They sometimes blame themselves for things that are really symptoms of the disease. Sensitivity and positive reinforcement from teachers can reduce classroom stress and improve results.

- Changes in routine can cause stress in students with JHD. As much as possible, maintain a structured environment with established daily routines.
- The student with JHD may also have obsessive thoughts or irrational fears that create stress. People and situations that act as “triggers” should be identified, controlled, or eliminated.

Cognitive management

JHD causes degeneration of nerve cells in the brain. New information becomes difficult to learn and old information may be forgotten.

- Understand that the student cannot simply “try harder.”
- Keep information concise and simple.
- Use calendars and checklists for required tasks.
- Give directions in writing. Include examples for the student to follow.
- Break assignments into steps. See that each step is completed before assigning the next task.

Behavior control

JHD makes it difficult to regulate and prioritize stimulus. A child with the disease can easily become “worked up” and distracted, causing them to act out or shut down. The young person will need support to maintain focus and control behavior.

- Put the student's desk near the front of the room where they can focus on the teacher.
- Children with JHD are easily influenced. Separate the child from those who encourage inappropriate behavior.
- Recognize that the young person is not acting out “on purpose.”
- Designate a quiet place, such as the resource room or library, where the student can calm down. A music player with headphones has been used successfully in some instances.

Physical safety

JHD is a movement disorder that affects balance. Maintaining physical safety is paramount.

- A young person with JHD may begin to walk on their toes or develop a stiff-legged gait. They may lose their balance easily. An aide may need to walk with the child to prevent falls.
- As the disease progresses, loss of voluntary muscle control can make safe seating an issue in the classroom, lunchroom and the bus. An occupational therapist can make safe seating suggestions.
- Be aware that a child with JHD may be a target for bullies. Verbal, physical and sexual abuse may be a problem.

Eating Concerns

The multiple disabilities of JHD impact lunchtime at school. Choking is a constant

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Disability

Go to www.hdsa.org/disability to learn more about Social Security Disability (SSD), including benefits, eligibility, application tips, building your case, and more!

Ask the Social Worker

In October's *Ask the Social Worker*, Anne Leserman, social worker at the HDSA Center of Excellence at the University of Iowa, discusses Unawareness. To read this month's and previous month's *Ask the Social Worker*, visit www.hdsa.org/atsw. If you have any comments on *Ask the Social Worker* or would like to ask a question, send an e-mail to Seth J. Meyer at smeyer@hdsa.org with the subject "Ask the Social Worker." We look forward to your questions.

Going Green

Due to popular demand, *We Are HDSA!* is able to publish through the end of the year. There is still time to subscribe to the online edition of *We Are HDSA!*. Send an e-mail to Seth J. Meyer at smeyer@hdsa.org with your e-mail address and support group.

Thank you

HDSA thanks Lundbeck for the educational grant that made this newsletter possible.

Moving Together

Lundbeck

concern. The child may have difficulty using utensils and getting enough nutrition in the allotted time. Distraction is also a concern.

- The student should be monitored at lunchtime to see that they eat. Hunger is a known behavioral trigger in JHD.
- Consider moving lunchtime to the resource room or other quiet place. Allow additional time for eating, if possible.
- Additional scheduled snacktimes during the school day may aid nutrition and behavior.

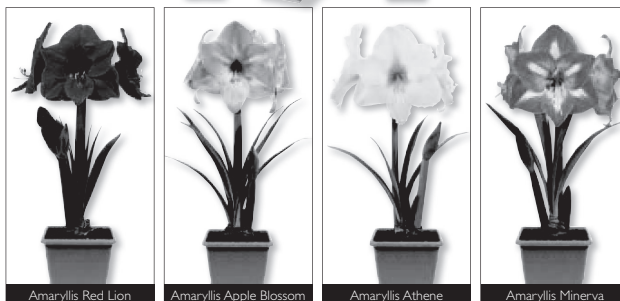
Build Hope for Huntington's Disease: Keep Groundbreaking Clinic Open

Lundbeck, Inc. recently announced its second *Build Hope for HD* donation campaign in support of a unique clinic in Venezuela that provides care for people affected by HD. This year, the campaign takes on even greater significance because the Casa Hogar Amor y Fe (House of Love and Hope) is at risk of closing its doors – unless necessary funds are found.

To trigger a donation from Lundbeck to help keep the clinic open, individuals simply click on the campaign icon at www.buildhopeforhd.com before the end of October. For your click, Lundbeck will donate \$10 to support the Casa Hogar (up to \$10,000).

The Casa Hogar provides treatment, food, care and an integrated nursing home to thousands of family members with HD who live along the shores of Lake Maracaibo, Venezuela. The clinic continues to be an important part of the HD community, serving as a model for patient care, despite extreme challenges of poverty. The clinic also serves as a potential clinical trial location and a home for genetic and neurological research that may impact the future of HD discoveries.

Fall Amaryllis Sale!



To place your Amaryllis order contact your local chapter or please go to www.hdsa.org/holidaystore

or call
1.800.345.HDSA