

Spring Newsletter



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Living with HD in the time of COVID-19

By Dr Arik Johnson

Living with Huntington's disease (HD) can bring numerous challenges to a person's life. Living with HD during a pandemic can magnify those challenges. While HD itself does not make a person more susceptible to this novel coronavirus, some of the symptoms seen in HD (like swallowing issues) can complicate the care of someone with HD and COVID-19.



The good news is people all over the world have made changes, like staying home and limiting contact with others, to minimize exposure to the virus and to stay healthy. For people living with HD, this could potentially make life more difficult, especially if the person with HD has behavioral symptoms. Irritability, forgetfulness, perseveration (getting stuck on an idea/obsessing), anxiety and depression can all be magnified during this time.

When dealing with behavioral issues, you want to first make sure there isn't an obvious cause, or trigger, that is leading to the issue. Triggers can be environmental (ie: what is going on in the world, other people) or internal (ie: pain, hunger). If you can identify a trigger, you may be able to modify it to lessen the behavioral symptoms. For example, if the kids are home instead of at school, the environment may be more stimulating. You might be able to modify this by setting several "quiet times" with the kids to limit noise and activity.

It is also important to communicate when dealing with life changes like those associated with COVID-19, and to do so regularly. Setting up regular "family meetings" where everyone sits down and talk is one option. Schedule these meetings and use tools like lists, calendars, and even whiteboards to make sure the information is recorded and available for all to see. Refer back to those tools as a reminder, for example, "we will go to the market on Tuesday at 10:00 and it's right here on the calendar."

Cont. on page 3



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www.southdakota.hdsa.org

Find us on Facebook

@SDHDSA



HDSA VIRTUAL TEAM HOPE WALKS!

The battle against #HuntingtonsDisease rages on and we need you to join TEAM HOPE - VIRTUALLY! A virtual walk is a real walk, but on your terms. You get choose your own course. Now, you can take part wherever you are...from the comfort and safety of your own home, around your yard, or even your neighborhood (following social distance guidelines, of course).

There are 2 options to join the TEAM HOPE – VIRTUALLY!

JOIN THE #HDSAFamily NATIONALLY ON Saturday, May 2nd

or

JOIN THE #HDSASouthDakota ON Saturday, May 23rd

There is **NO CHARGE** to register or walk in a Virtual Team Hope Walk, but everyone is encouraged to fundraise. You can set up your fundraising pages at: www.hdsa.org/thwsd

And, on your Virtual Walk Day – share photos on social media and video/Facebook Live/Instagram themselves walking and sharing their HD story and why they're walking for HDSA.

Use the hashtags #VirtualTeamHopeWalk. #HDSA #HDSASouthDakota #FamilyIsEverything

Of course – there are contests & prizes!

- Most \$ raised! The team that raises the most \$\$\$ by Memorial Day – Monday, May 25th on www.hdsa.org/thwsd will receive a prize package from your South Dakota Chapter President, Debbie Augustad.
- Design your own Team Hope t-shirt! The best Team Hope T-shirt design will receive a prize package from your South Dakota Chapter President, Debbie Augustad.
- Design a sign of “what does HDSA” means to you! The best sign will receive a prize package from your South Dakota Chapter President, Debbie Augustad.
- Do a dance & post on social media (practicing social distancing)! Best dance wins a prize package from your South Dakota Chapter President, Debbie Augustad.
- Raise a \$100 individually by Monday, may 25th & win a National Team Hope t-shirt.

Our HELP TODAY provides so much HOPE for TOMORROW for HD families. THANK YOU for your efforts and dedication in support of the HDSA mission during this incredibly challenging time.

#LetsTalkAboutHD



May is HD Awareness Month

May is HD Awareness Month and a great time to educate people outside the HD community about the disease and how they can join us in our efforts to provide “**Help for Today and Hope for Tomorrow**” to everyone affected by HD. Watch your emails for more information.



THIS WEEK IN
HUNTINGTON'S
DISEASE
RESEARCH
WITH DR. LEORA FOX

Keeping you up-to-date on HDSA research activities, recently published work about Huntington's disease, historical moments in HD research and more.

Check out:

<https://hdbuzz.net>

<https://hdsa.org/blog/>



Stay up-to-date on the latest HD research! Dr. Leora Fox is the Manager of Mission and Research Programs at HDSA. Dr. Fox writes a weekly blog about HD research for everyone to understand. Also check out HDBuzz! HDBuzz is a website about HD research. In plain language. Written by scientists. For the global HD community.

HUNTINGTON'S DISEASE

Huntington's disease is a fatal genetic disorder that causes the progressive breakdown of nerve cells in the brain.

Every child of a parent with HD has a 50/50 chance of inheriting the faulty gene that causes the disease.

HD deteriorates a person's physical and mental abilities usually during their prime working years.

HUNTINGTON'S DISEASE IS DESCRIBED AS
ALS, PARKINSON'S & ALZHEIMER'S - ALL ROLLED INTO ONE.

THERE IS NO CURE...YET

Huntington's Disease Society of America
FOR MORE RESOURCES VISIT
HDSA.ORG

*Help for Today,
Hope for Tomorrow.*

Dr. Arik Johnson, continued from page 1.....

Additionally, try to normalize what people are feeling. This is a scary, confusing, and frustrating time, and people will react emotionally. Acknowledging that can allow people to realize they are not alone in what they are thinking and feeling. You can then try to shift the focus from things that you can't control (ie: what's going on in the world), to things that you can (ie: doing a project at home, finding a show for everyone to watch together). Redirection or distraction can be a useful strategy for anyone, not just a person living with HD.

Finally, reach out if you feel like you are not able to manage the situation yourself. Whether you are a person living with HD or caring for someone who has it, remember there are resources available for assistance during this time. This could be contacting your local healthcare team, joining an online support group, using telehealth counseling, or even calling a good friend. You can find numerous resources on the Huntington's Disease Society of America (HDSA) website (www.hdsa.org) or connect directly with your local HDSA Chapter representatives and HDSA social worker.

The current COVID-19 pandemic has certainly impacted the way people are living their lives, but there are ways to try to cope with these changes. People who are living with HD have often been practicing the types of strategies discussed, but it can be helpful to review them and practice them actively during this time.



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HDSA MISSION

**To improve
the lives of
everyone
affected by
HD and their
families.**

A Note From Our Social Worker - Michelle Wenge

Self-care is tricky but so important when you are a caregiver. It is Spring-is anyone still doing New Year's resolutions or have you moved on? Sometimes self-care doesn't even seem possible with life happening. Just like a good home or relationship, self-care needs a solid foundation to grow from. Maybe you are already good at self-care-is there room to improve or add another area of life to grow in?

Here are some solid places to develop/enhance your self-care.

1. Have a stable, daily routine. This can start out as something small and grow. It can be as simple as making a commitment to wash your face every night before bed, putting lotion on your feet before you start your day, or reading for 10 minutes in the morning.
2. Exercise-this also can start small and grow. Whether it is a 10 minute walk or an hour at the gym, exercise has a ton of benefits.
3. Consistent Sleep-anyone feeling a theme to this? Go to bed and get up at the same time every day. Of course life happens and this isn't always realistic but the more you practice this habit the more your body will be able to feel rested.
4. Intentional relaxation-this is NOT screen time. This is where you take a moment to be present, take a deep breath and BE in your body.
5. Food-consistency is the key again. Food is the fuel that keeps our body and brain going! Is your body getting what it needs? Is it running on fast food? Could you benefit from simply taking a vitamin supplement every day? Small actions can produce big results.
6. Avoid isolation if you are in a rut. Alone time can recharge you, but isolating so others don't know how it is going, or so you aren't the "downer" in the group is the opposite of self-care. (Did you know we have a support group every month?)
7. Life is bigger than.... (Fill in the blank)!

If this list seems overwhelming, pick one of these and make a plan. Plan your change and work your plan! Remember you are worth it!



Calendar of Events 2020

	<p>It's a Golf outing like no other! Come out to the Spring Creek Golf Course on August 22, 2020. Join our 5th Annual Tee Off for HD! Shotgun Start at 8am, 18 holes of golf, team play, awards lunch, and a raffle! It's guaranteed to be a fun time, and you will be supporting the South Dakota Chapter for HDSA!</p>
<p>September 19th, 2020 Team Hope Walk – South Dakota</p> 	<p>Team Hope Walk is HDSA's signature grassroots fundraising event. Since its inception in 2007, more than \$12 million has been raised across the country. The 2020 South Dakota Team Hope Walk features a walk, 5K and 10K run. Join the cause! You can create your own team or make a donation to support HD! Help for Today, Hope for Tomorrow</p> <p>www.hdsa.org/thwsd</p>
	<p>Fall Education Event Dr. Arik Johnson is our featured speaker. Dr. Johnson is a psychologist at the Los Angeles Center of Excellence. It will bring people from all over South Dakota and the surrounding area together to hear about scientific research in regard to HD. Come join us on September 20, 2020. A panel discussion will also be held on September 21, 2020 at the University of South Dakota.</p>
	<p>BINGO & BREWS FOR HD! STAY TUNED FOR MORE DETAILS NOVEMBER 2020!</p>



The Huntington's Disease Society of America

HDSA is the premier nonprofit organization dedicated to improving the lives of everyone affected by Huntington's disease. From community services and education to advocacy and research, HDSA is the world's leader in providing help for today and hope for tomorrow for people with Huntington's disease and their families.

HDSA's network of chapters, affiliates, HDSA Centers of Excellence, social workers and support groups provides a seamless connection for help, education and outreach to HD families and health care professionals across the United States.

#HDTips: Meal Size & Frequency

Smaller, more frequent meals can solve many problems. Offering six to eight small meals a day can solve several of the problems associated with nutrition and HD. More meals equal more calories, which can help prevent weight loss.

Smaller meals may take less time and may cause less frustration; however, be careful as some people with HD eat too quickly. Hunger can make anyone irritable and anxious. People with HD can be unaware of their own hunger. Frequent meals can help prevent emotional outbursts.

Ask for a referral to a dietician or nutritionist familiar with HD who can assist in developing a menu that will provide the nutrients and calories needed by your loved one to maintain weight.



FOR MORE RESOURCES VISIT
HDSA.ORG

AmazonSmile

Shop AmazonSmile and Amazon will make a donation to the Huntington's Disease Society of America Sioux Valley Chapter.

Up to 0.5% of your purchase will benefit HDSA.

www.smile.amazon.com



#HDTips

MAKING YOUR HEALTH A PRIORITY AS A CAREGIVER

You cannot care for another if you don't care for yourself. Caregivers often neglect their own health, setting aside things like going to the doctor when they are ill or filling their own prescriptions. Taking care of yourself is not a luxury – it is essential to the well-being of the person you are caring for. Eating healthy food, getting sufficient sleep and engaging in physical activity will help you to reduce your stress levels, get more done and perhaps most importantly, maintain the sense that you are an important player in your life story.





TEAM HOPE WALK / 5K & 10K RUN

SATURDAY, SEPTEMBER 19TH, 2020
SERTOMA PARK – SIOUX FALLS, SD

8:00 AM – REGISTRATION
8:45 AM – 10K KICKS OFF
9:00 AM – 5K WALKERS KICKS OFF
9:45 AM – LIVE AUCTION

For More Info Contact

Debbie - 612-816-0145 / debstadley@gmail.com
Vanessa – 605-310-0440 / vlanderson.slp@gmail.com

All Proceeds Will Benefit
Huntington's Disease Society of America - South Dakota Chapter

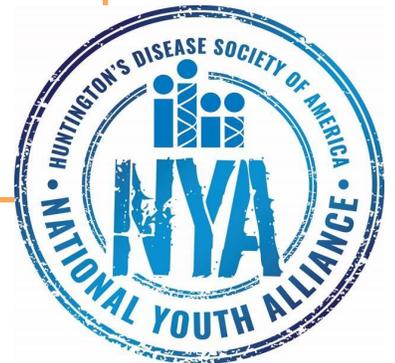
NATIONAL SPONSORS





The 35th Annual HDSA Convention is going VIRTUAL!
 WATCH FOR DETAILS IN THE UPCOMING WEEKS!

The HD community has been gearing up for May, HD awareness month with the #LetsTalkAboutHD campaign on Facebook. The hashtag is a way for people to share their touching and personalized stories. The NYA encourages people to let their story be known to create awareness. Additionally, the NYA released an attractive new logo before May comes. There are upcoming NYA events in Chicago, August 7, Nashville on September 25, and Seattle on November 6.



Huntington's Disease Society of America
Free Online Support Groups

Connect with other members of the Huntington's disease community to help navigate you and your family's journey with HD.

For more info visit [HDSA.org/osg](https://www.hdsa.org/osg)

ONLINE SUPPORT GROUPS

The Huntington's Disease Society of America provides FREE, professionally-run Online Support Groups for you to get the help you need from the comfort of your home.

Go to <https://www.supportgroupcentral.com> for the full schedule and to register.

HDSA VISION

A world free of HD.

The Society is a National, voluntary health organization dedicated to improving the lives of people with Huntington's disease and their families.

To promote and support research and medical efforts to eradicate Huntington's disease.

To assist people and families affected by Huntington's disease to cope with the problems presented by the disease.

To educate the public and health professionals about Huntington's disease.

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 57101-2675
 Phone # contacts below.



Resources

Social Worker
South Dakota Chapter
 Michelle Wenge
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Sanford Huntington's Disease Clinic

- Dr. Matos
Neurologist
- Lior Borovik
Genetics Counselor
- Diane Johnson
Mitchell – Family
Therapist
Sanford Health -
Sioux Falls, SD
605-312-8500

Content for the HDSA South Dakota Spring 2020 Newsletter was provided by: Dr. Arik Johnson, Michelle Wenge, Becky Word, Debbie Stadley Augustad and www.hdsa.org.

South Dakota Chapter Board of Directors

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Honorary Board Member – Kevin Sandbulte

#HDTips

HDSA PROVIDES **FREE ONLINE RESOURCES** FOR FAMILIES TO GET THE HELP THEY NEED FROM THE COMFORT AND SAFETY OF THEIR HOMES.

ONLINE SUPPORT GROUPS
 HDSA.ORG/OSG

TELEHEALTH
 HDSA.ORG/TELEHEALTH

HELPLINE
 (800)345-HDSA



 **Huntington's Disease Society of America** FOR MORE RESOURCES VISIT **HDSA.ORG**

#HDTips

HYGIENE & HUNTINGTON'S DISEASE

Difficulty with motor control and sequencing tasks can make even the most routine activities seem insurmountable. Though some people with HD lose interest in personal hygiene as a result of depression, the inability to start, stop and sequence tasks may also be the cause.

TIPS
 Write out separate lists of morning and evening hygiene tasks.
 List steps for completing each task and post the list in a visible place.



 **Huntington's Disease Society of America** For more resources visit **HDSA.org**



Friend of SOUTH DAKOTA Chapter Appeal Name: _____

Mailing address: _____

Phone: _____ Email: _____

Amount of NEWSLETTER Appeal Contribution: \$ _____

Please make checks payable to: SOUTH DAKOTA HDSA

Credit card payment available: Visa / MasterCard / Discover / Amex (please circle)

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Exp date:_____/_____ Code on back of card:_____

HDSA is a 501(c)(3) non-profit organization. HDSA's Federal Tax ID Number (EIN) is 13-3349872.

Your contribution is tax deductible to the full extent of the law.



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