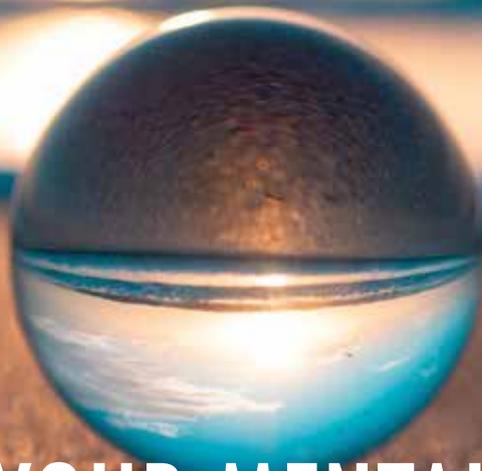


HPD News

SPRING 2021

RESEARCH 3
Diagnosis based on Education

YOUTH 6
Coping with Lockdown 2021



TUNE IN TO YOUR MENTAL HEALTH

Caregiving Is stressful. **WORDS** AMANDA DICKEY

Compassion is a natural trait present in most caregivers: family and professionals alike. Caregivers focus on the needs of the person they are caring for and tend not to notice signs of their own physical and mental distress.

Burnout, compassion fatigue, secondary traumatic stress and vicarious trauma are very real conditions that can impact any caregiver at any time. Recognising the warning signs and symptoms could help reduce a caregiver's distress and their recovery journey.

If you identify with any of these signs and symptoms, please ask for help. Reach out to a friend, family or seek professional help through your GP, a mental health professional or contact us on 9874 9777.

This Association acknowledges that Mental Health safety is paramount in regard to our clients, staff and volunteers, and underpins this through new Workplace policies and support practices.

SELF ASSESSMENT FOR BURNOUT AND COMPASSION FATIGUE		
BURNOUT	COMPASSION FATIGUE	VICARIOUS TRAUMATISATION
SIGNS <ul style="list-style-type: none"> • Fatigue • Anger • Frustration • Negative reactions towards others • Cynicism • Negativity • Withdrawal 	SIGNS <ul style="list-style-type: none"> • Sadness and Grief • Avoidance or dread of working with some patients • Reduced ability to feel empathy towards patients or families • Somatic complaints • Addiction • Nightmares • Frequent use of sick days • Increased psychological arousal • Changes in beliefs, expectations assumptions • Detachment • Decreased intimacy 	SIGNS <ul style="list-style-type: none"> • Anxiety • Sadness • Confusion • Apathy • Intrusive imagery • Loss of control, trust and independence • Somatic complaints • Relational disturbances
SYMPTOMS <ul style="list-style-type: none"> • Physical • Psychological • Cognitive • Relational disturbances 	SYMPTOMS (mirror PTSD) <ul style="list-style-type: none"> • Physical • Headaches • Digestive problems • Muscle tension • Fatigue • Psychological distress • Cognitive shifts • Relational disturbances • Poor concentration, focus and judgment 	SYMPTOMS (mirror PTSD) <ul style="list-style-type: none"> • Physical • Psychological distress • Cognitive shifts • Relational disturbances
TRIGGERS <ul style="list-style-type: none"> • Personal characteristics • Work-related attributes • Work organisational characteristics 	TRIGGERS <ul style="list-style-type: none"> • Personal characteristics • Previous exposure to trauma • Empathy and emotional energy • Prolonged exposure to trauma material of clients • Response to stressor • Work environment • Work-related attitudes 	TRIGGERS <ul style="list-style-type: none"> • Personal characteristics • Previous exposure to trauma • Type of therapy • Organisational context • Resources • Re-enactment

Source: Transitional Support



FROM THE DESK *Lewis Kaplan*

LEWIS KAPLAN, CEO Huntington's NSW ACT

As we near the end of another challenging year, we can at least look back on some modest successes in 2021. The Association generated a small surplus in the previous financial year thanks to generous donors, Commonwealth Government JobKeeper and a successful national conference run by our Association. Our NDIS Support Coordination service continues to grow and is close to breaking even.

ADVOCACY

Our policy advocacy work has increased on a number of fronts, particularly in relation to the NDIS where people with HD (and other progressive neurological conditions) continue to struggle like square pegs in round holes. Even though people with HD (at least those under 65) generally qualify for the NDIS, the NDIS Act was designed with either stable or improving disabilities in mind, so those whose condition

is worsening and those with episodic issues (like people with HD moving in and out of crisis) do not fit the "normal" client profile and often struggle to have their needs properly met.

This is not to say that everyone with HD is unhappy with the NDIS. There are many for whom the NDIS has been a godsend, whose service providers take the trouble to learn about HD and who really care about providing high quality service. But the Association believes this should be the case for everyone, not just a lucky minority.

COVID-19 VACCINATIONS

While the COVID-19 pandemic lockdowns continue across Greater Sydney and many parts of NSW we remain active to the extent possible. Our client-facing staff are classified as essential workers, and all staff are now double vaccinated, but we must continue to be super cautious and not contribute to spreading COVID-19, particularly as those with HD are at higher risk of serious illness if they do catch it.

MOVEMENT DISORDERS

For those of you who read the detail of the NSW Health budget, this will not be news: \$8.6 million has been allocated over four years to support community care for people with movement disorders, such as Parkinson's

Disease by delivering specialist nurses and allied health staff in 15 Local Health Districts (LHD). I was invited to a consultation videoconference by NSW Health along with representatives from Parkinson's NSW, Dystonia Network and Multiple Sclerosis Australia. We were told that each LHD would have flexibility to decide how to spend its funding which was roughly equivalent to 1 full-time allied health professional or clinical nurse consultant. Some LHDs already have such a role and would be expected to do more, others might create a number of part-time roles spread across a larger geographic area. We hope that at least some of this additional resourcing will help people with HD.

PRE-IMPLANTATION GENETIC TESTING (DIAGNOSIS) – PGT

We have received clarification from the federal Minister for Health that the new PGT funding available from 1 November will cover the genetic testing but not the IVF process which surrounds it, which at least for one cycle is partly covered by Medicare if undertaken by a bulk-billing service.

<http://mbsonline.gov.au/internet/mbsonline/publishing.nsf/Content/Factsheet-Pre-imp-Gentest>.

2021 ANNUAL GENERAL MEETING

The **2021 Annual General Meeting** of Huntington's NSW & ACT Inc. will be held on **Saturday 27th November 2021 at 12noon**.

The AGM will be available via video conference only due to uncertainty about COVID-19 lockdown restrictions.

Nomination forms for Board positions are available upon request. Completed forms should be returned to Huntington's NSW & ACT no later than Friday 5th November 2021.

Please note that you need to be a financial member to be able to nominate or be nominated for the Board or to vote.

Closer to the event more information will be available on our website at:
<https://huntingtonsnswact.org.au/events/notice-of-2021-annual-general-meeting/>
or by contacting us on 02 9874 9777.

DIAGNOSIS TENDS TO COME EARLIER FOR THOSE WITH MORE EDUCATION

WORDS MARISA WEXLER MS

People with Huntington's disease who have had more formal education tend to be diagnosed earlier and have milder symptoms than those with less formal education, a new study indicates.

The study, "The effect of education on symptom onset and severity of Huntington's disease," was published in *Movement Disorders Clinical Practice*.

While the role of disease-causing mutations in affecting Huntington's severity is well-established, little is known about how environmental and lifestyle factors, such as education, influence the course of Huntington's. In the study, researchers at the University of Virginia and Virginia Commonwealth University analyzed data from a global patient registry, called Enroll-HD, to better understand how education affects the disease's course.

"The primary objective of our study was to determine the effect of education on the age of onset of motor symptoms," the researchers wrote. "Secondary objectives included determining the effect of education on the age of onset of depression, irritability, and cognitive impairment; and determining the effect of education on functional status after HD [Huntington's disease] diagnosis."

Little is known about how environmental and lifestyle factors, such as education, influence the course of Huntington's.



In total, the team assessed data for 4,537 people with Huntington's, most of whom resided in Europe or North America. Based on education level, these patients were divided into three groups: 1,115 had completed only pre-secondary education, 1,491 had completed secondary education, and 1,931 had gone on to post-secondary education.

Statistical analyses were used to compare various disease-relevant measures between the three groups. These models revealed that individuals with more formal education tended to be significantly younger at diagnosis, and at the onset of motor symptoms, depression, irritability, and cognitive impairment.

"Our results show that HD participants with higher education level report earlier onset of participant-reported HD associated symptoms and have earlier age of HD diagnosis," the researchers wrote.

"We suspect that these findings may be explained by increased self-awareness and/or insight and thus earlier recognition of mood, motor symptoms, irritability, and cognitive symptoms in more highly educated individuals," the team added. "In the same way, earlier age of diagnosis in HD participants with higher education levels may arise from earlier recognition of symptoms and earlier evaluation by health care providers."

Based on scores on the UHDRS (unified Huntington's disease rating scale), patients with more formal education tended to have significantly less severe motor symptoms, as well as significantly

greater functional ability. More education also was associated with better scores on multiple measures of cognition.

"Interestingly, and somewhat counter-intuitively, lower motor scores and better functional status were present in those with a higher level of education despite an earlier age of onset of motor, cognitive, and mood symptoms," the researchers wrote. Lower motor scores on the UHDRS indicate better motor function.

The researchers posited several possible explanations for this finding: for example, it's possible that these patients may have had milder symptoms simply because they were diagnosed and subsequently evaluated earlier in the course of their disease. It is also possible that education provides protection against Huntington's symptoms by improving aspects of cognition or other processes, which the researchers said requires further investigation.

A limitation of this study is that socioeconomic status, which has a substantial effect on both education and health outcomes, was not available in the analyzed dataset.

Analyses of medication use showed high rates of chorea treatments among less-educated individuals, which "could suggest that healthcare access is not a significant factor influencing baseline motor symptoms, although this cannot be concluded with confidence given that this is an indirect measure of healthcare access," the researchers wrote.

WALK 4 HOPE WRAP UP

This year we are again impacted by COVID-19 but still asked people to Walk 4 Hope in their own communities. With almost half of our income (excluding NDIS) coming from fundraising activities like the Walk 4 Hope, we were relying on people to register and show support.

Even though we were physically unable to get together, our walkers kept active and walked to create awareness of HD in their own neighbourhoods. Some people chose to walk on the set Walk 4 Hope dates, others set a challenge to walk 3 to 4km every time they went out, others chose to complete 40km throughout the month. We are extremely grateful for every single person who walked, registered, and donated. By the end of September, we had raised \$58,000 and there are still some donations coming in.

A big thank you to our team captains Rachael, Peta, Glen, Glenette and Veronica for all the help and support they provide. Each of these people volunteer time to assist with planning, searching for prizes, sourcing vendors, selling merchandise and being an ambassador at their Walks.

Such a wonderful result for a virtual event!



NEW REGIONAL HD SOCIAL WORKER FOR ILLAWARRA

WORDS LEWIS KAPLAN

Huntington's NSW ACT is very pleased to welcome Vita Solano to the newly created (part-time) position of HD social worker based in Wollongong.

The regional social worker will support people with HD, their families, and carers throughout the progression of HD. We will be working closely with the HD Outreach Service at Westmead Hospital to ensure we complement rather than compete with each other.

Our sincere apologies again to our members and the HD community in Canberra where we initially expected to establish the position. We were unable to attract suitably qualified staff so could not proceed in this location. If we are in a position to extend funding for regional HD social workers in the future, you will not be forgotten.

It is our view that these specialist HD social worker positions should

be funded by government in all regions of NSW and the ACT. Currently, in addition to the hard working team at the Westmead Hospital HD Outreach Service, the only other HD Social Worker in the state is based in Newcastle, funded by Hunter New England Local Health District. John Conaghan has been in this role for many years and is known to and highly valued by many HD families in the Hunter region.

A big thank you to John for sharing his position description and thoughts about his role which helped enormously in creating both the successful funding proposal and position description Vita is now about to fulfil.

And a very big thank you to The Co-Group for committing funding for this position and for bearing with us over so many months while we worked on implementing the project.



WELCOME

Vita

Vita has worked in the community services sector for over a decade, working in the aged care & dementia care sectors. Enjoying working in the community & for the community in a variety of capacities.

She has a passion for working with people with chronic illness & disability, with a particular dedication to providing advocacy.

Vita looks forward to supporting people with HD & their families in the Illawarra & Shoalhaven areas.

HUNT 4 HOPE OP SHOP RE-OPENS

We received a message from Matina that they re-opened on Monday 11th October. After being closed for 3 ½ months due to COVID lockdown, the retail store has opened their doors once more.

If you are in or around Maroubra and are looking for some great bargains whilst shopping, make sure you call in to the shop.

MEMBERSHIP RENEWAL

Membership renewal is now overdue.

Memberships cost just \$22 per year and are valid for one year. We really value your membership.

To renew your membership, visit our website or call the office to get a paper copy sent to you.
<https://huntingtonsnswact.org.au/get-involved/become-a-member/>





HOW WE'VE COPEd IN LOCKDOWN, 2021

YOUTH CONNECTION PROGRAM

WORDS AMY HALE

As the NSW COVID lockdown looks like it's coming to an end and life is slowly returning to some kind of normality, I have been reflecting on how these last 15 or so weeks have been for the kids and young people in our Huntington's community. For most people living in NSW this lockdown has been hard, but for kids experiencing lockdown with a parent affected by HD, in lots of cases it has been even harder.

With home visits and school visits not able to take place, zoom has kept lots of the kids involved in the Youth Connection Program able to access our support. Over the last 100 days I've heard about the ups and downs of what's going on for them. I've been told by almost everyone I've spoken to about how hard it is to get motivated for home learning, how frustrating and sometimes impossible it has been to find a quiet place to learn, and for quite a few, how far behind in schoolwork they are and how stressful it feels thinking about how hard it might be to catch up once school goes back into the classroom.

This one has proven to be really tricky for a lot to talk about - and knowing that, I've been so impressed with the honesty so many kids have found in telling me how hard it has been not having a break from experiencing Mum's or Dad's HD and how this has worn them down. For so many kids, lockdown has meant they have missed out on regular HD 'circuit breakers' like going to school, seeing friends, or playing sport - things that get them out of the house and get their batteries re-charged. Some kids and young people have had to balance their schoolwork with taking on extra care roles for Mum or Dad as drop-in support care workers have cancelled shifts at the last minute and have also told me how hard it's been not having the extra informal support they had been used to from family and friends dropping round.

It has proven to be particularly hard for families in areas with stricter lockdown rules. Some young people in our HD community have caught COVID, some have been working long hours as nurses and support staff in hospitals on the front line in

Western Sydney, taking on extra work, risk, and responsibility as colleagues test positive to COVID and are required to self-isolate. Others haven't been able to return to work for weeks and are struggling financially. Care facilities in Greater Sydney having faced strict visiting rules has meant that kids and young people with a mum or dad being cared for out of the home are dealing with the emotions and logistics of not being able to visit and all of the often complex feelings that come from this.

For some of the young people involved in the program that have tested positive to HD, another lockdown has been a hard thing to cope with. I've listened to how frustrating it is to be wanting desperately to get out and live lives, travel, have relationships, and spend time with friends and people they love. Time is precious for all young people, but for someone knowing they will develop Huntington's, being emotionally OK with spending time, often alone, in lockdown and not being able to make the most of the time they feel

they have before symptoms begin is a unique challenge.

Thankfully not everyone I've spoken to has had a negative HD lockdown experience. I've heard from families about how much they've valued spending more time with their HD affected parent and how much it has meant to them having that time to connect that they wouldn't otherwise have had. Some kids have also expressed how much more relaxed their parents with HD have been without the stress of going out and how calm they have been in lockdown enjoying more quiet and less busyness in their days.

Overwhelmingly though, be it in expressing positive or negative lockdown experiences, the resilience and coping I have seen day-to-day really is inspirational, as kids, young people, and their families have adapted the best way they can. I have been in awe of the self-reflection the kids and young people I have spoken to have shown. Whether it be in telling me how they have been coping, or telling me with such honesty about how they've not been coping at all. I know there's lots of processing and talking to come in the next few months as everyone works out how to be out in the world again. I can't wait to get out and see all of your lovely faces soon. It's been too long! If you're already involved in the program and I haven't spoken to you for a while, reach out and let me know how you're going. If you're not involved but think you'd like to be, get in contact too. Hopefully we can get some groups up and running again soon too. Onwards and upwards!

If you are a child or young person affected by Huntington's and you'd like to be involved in the Youth Connection Program, reach out and let us know.

Call Amy on 0499 031 231 or email amy@huntingtonsnsw.org.au.

THE HD SPOTLIGHT ON

Amy Hale

Youth Social Worker

Huntington's NSW ACT
Youth Connection Program



Q Why did you decide to become a social worker?

A When I was a kid I used to love going to work with my grandma in the holidays. She was a community social worker in Kings Cross. We would drive around the Inner Sydney in the 80's stopping and speaking to people who were having a hard time - often experiencing homelessness. I used to love watching the way she listened to them and worked with them. She taught me the value in each and every person and showed me how much of a privilege it is to be let into someone's world with them when they're struggling.

Q How did you get involved in the HD world?

A When the HNSW ACT youth work position was advertised in 2017, the ad just jumped out at me. It was exactly what I was looking for. Not being from an HD family, I became involved in the HD world in a different way. I've always been interested in science and genetics, and my specific interest in HD started many years ago through trying to understand folk singer, Woody Guthrie's poems and lyrics. He grew up watching his mum's HD progress and sometimes wrote about how that felt for him. Listening to him made me want to learn all I could about Huntington's disease, and I've had a fascination with it ever since.

Q What keeps you enthusiastic about your job?

A It's impossible not to stay enthusiastic when I am constantly being inspired by the strength, honesty, and resilience I see in the kids and families I work with. The Huntington's community really is like no other. Growing up in a family affected by HD can present such extraordinary and unique challenges for a young person. The privilege of walking that path with them while they're trying to work out and navigate these challenges is really very special.

Q What is your ideal Sunday?

A I think my ideal Sunday would just involve a long list of simple pleasures! I live in a rural area in the mountains outside Sydney, so weekends are quiet. I'd definitely start with a coffee outside in the sun watching the magpie gang - and if I'm really lucky, I'd see the two brown doves as well. I'd spend time with my kids and my dogs (who would all be behaving perfectly - for the entire day). We'd listen to lots of records and find creative things to do. Maybe we'd have a swim in the dam in the afternoon and definitely homemade pizza for dinner. As the sun goes down, we might light a little fire in the garden to sit around. That would be a pretty perfect day for me.



Huntington's NSW ACT

Huntington's NSW ACT Inc.
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Free Call: 1800 244 735 (Country NSW only)

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Web Site: www.huntingtonsnswact.org.au

Our team

LEWIS KAPLAN

Chief Executive Officer
0407 108 667

GISELLE BEAUMONT

NDIS Senior Support
Coordinator
0422 604 737

AMY HALE

Youth Social Worker
0499 031 231

MALISHA FERNANDO

NDIS Support Coordinator

AMANDA DICKEY

Community Programs Officer
0456 013 612

VITA SOLANO

Illawarra HD Social Worker
0413 195 398

STEWART SWALES

Administration Co-ordinator

ALISON WEIR

Fundraising & Marketing
0419 465 612

HD SERVICE

Westmead Hospital

**DR CLEMENT LOY
(DIRECTOR), DR SAM KIM,
DR FLORENCE CHANG**

Neurologists
(02) 8890 6793

**CECELIA LINCOLN &
FELICITY STEHOUWER**

Social Workers
(02) 8890 6699

TERRY MCGILL

Clinical Nurse Consultant
&

PETER KWONG

Clinical Nurse Specialist
(02) 8890 9960

HD Clinic Appointments
Outpatients Department
(02) 8890 6544

HUNTER HD SERVICE

John Hunter Hospital

JOHN CONAGHAN

Social Worker
(02) 4922 3076

HUNTINGTON'S UNIT

St Joseph's Hospital

(02) 9749 0215

PREDICTIVE TESTING

Find your nearest Genetics
Clinic at www.genetics.edu.au/genetic-services

EDUCATION RESOURCES

Huntington Study Group

Global HD cooperative
therapeutic research org.
<https://huntingtonstudygroup.org>

HDYO

Support and education to
young people (aged up
to 35) impacted by HD
around the world.
<https://en.hdyo.org/>

RESEARCH QUERIES

Dr Therese Alting

Enroll-HD Study
(Westmead Hospital)
(02) 8890 6310 or
0438 604 719

HDBuzz

Research news. In plain
language. Written by
scientists. For the global
HD community.
<https://en.hdbuzz.net/>

WHAT'S HAPPENING?

WE'RE
COVID
SAFE

Due to the COVID-19 pandemic and changing government restrictions, our support groups are meeting in a variety of ways. RSVPs are now essential for all meetings as there are COVID protocols that need to be followed to keep everyone safe. Take a look at how your region is choosing to connect.

CARER SUPPORT

CENTRAL COAST

Postponed. Seeking interest.

COFFS HARBOUR

Korora, 11:00am - 1:00pm
3rd Friday monthly.

NEWCASTLE

Jesmond, 10:00am - 12:00pm
2nd Thursday monthly.
Note: Meeting room limited to 12 attendees

SYDNEY

West Ryde, 10:30am - 12:30pm
3rd Wednesday monthly.
Note: Meeting room limited to 12 attendees

COMMUNITY SUPPORT

ACT

Ainslie ACT, 12:30pm - 2:30pm
1st Saturday bi-monthly.

CENTRAL COAST

Postponed. Seeking interest.

ORANGE & CENTRAL WEST

Orange, 10:30am - 12:30pm
1st or 2nd Saturday monthly.

PORT MACQUARIE

Port Macquarie, 11:00am - 1:00pm
2nd Friday monthly.
Note: Meeting room limited to 10 attendees

WOLLONGONG

Wollongong, 10:00am - 12:30pm
1st Monday monthly.

Latest detail and to register your interest can be found on our website at: <https://huntingtonsnswact.org.au/support-groups/> or contact us on 02 9874 9777.