



HD & Covid



It has been a difficult and scary time for many of you over the past six months. Aside from having HD in your families you or your loved ones may have many other health issues that make you concerned about catching Covid. People who are symptomatic with HD are no more at risk of contracting the virus but their behaviours could make them more susceptible if they are unable to reliably practice social distancing, hand and respiratory hygiene. They may be unable or unwilling to wear a mask when outdoors but there are medical exemptions from having to do so. We suggest you or they carry your HD card or lanyard if you are worried about confrontation. If you need one, please let us know.

While people with HD are clinically no more at risk of contracting the virus they can be more prone to complications if for example they tend to get chest infections or have a lowered immune system. The best thing to do is to be safe now rather than sorry later. Follow the public health advice, avoid crowds, maintain a social distance, wash/disinfect

hands regularly and avoid touching your face and eyes. You should be mindful of high-touch areas like shopping ATMs, credit card machines, door handles, public bathrooms. It can be helpful to carry a glove or a disinfectant wipe for such areas and you should make use of disinfectant sprays in shops when using trolleys and baskets. You need to trust that every person in your household and anyone you choose to have contact with is acting responsibly to protect each other.

This virus will be with us for some time and there is much talk of the 'new normal', which is far from normal. You cannot lock yourself away in fear indefinitely but find a way to continue to live your life as best you can while protecting yourself and your community. We know this has been an incredibly lonely time for some with many people turning to their phones and computers. If this is something you are wary of, please get in touch as there are projects to help people use technology and in some cases even free equipment.

Covid has obviously affected how our health and social services are operating with many appointments being cancelled. There is info in the newsletter about genetic services and how testing has been affected. The latest update from the HD Regional Movement Disorder Clinic is that most consultations are being held by phone and then it is decided whether a face to face visit is required based on clinical need. Of course Covid restrictions on social distancing etc mean less availability for face to face appointments. If you feel an urgent appointment is needed contact your GP or your neurology dept. This is frustrating for clinicians and families alike but it is the reality for now so we all need to make the best out of it.

Contact Us:

Sorcha McPhillips/Chief Executive
Zelie Leech/Support Worker
Kathryn McCready/Support Worker
Ashley Clarke/Youth Events & Fundraising

079 8284 3907
077 3393 5863
079 2151 3561
078 1033 0949

sorcha@hdani.org.uk
zelie@hdani.org.uk
kathryn@hdani.org.uk
ashley@hdani.org.uk



Report from the CEO

Hi to all our service users and friends,

These past six months or so have found us plunged into the strangest of times. Some days it can seem like we're living in a sci-fi movie with the social distancing and masks. We understand that Covid 19 is particularly difficult for those living with or caring for someone with HD. We have tried our best to make the most of this difficult situation by using the time we are 'grounded' to make contact with as many families as we can. We have over 825 individual 'service users' on our secure database – these include patients, people at risk of inheritance, carers and their family members. We called, emailed, texted, reached out on social media to hundreds of people and wrote to those we had no other details for. We wanted you to know that although our practices would be changing to protect them and staff, we would still be at hand for help and advice. We re-designed our social media to include daily themes, like #Mental Health Monday and Workout Wednesday, with specific tips, advice and info to help our followers best manage their life with HD and in the content of Covid. We've also been working on new materials to put on our website, making connections with other health professionals and service providers and working on new programmes.

Our monthly support groups and events remain cancelled for the time being but we have moved to the virtual world where we are busier than ever. We have weekly Zoom support groups open to all service users, fortnightly family fun youth events, fortnightly online meet ups for 18-35 age group, and a new fortnightly men's only group. We hope to also have carer specific groups too.

Unfortunately, a lot of our plans have been put on hold because of Covid- our annual conference which had a great line up of speakers and exhibitors planned has been postponed until next September. Instead we have been busy

creating content to put online, putting together this newsletter to send out to all our service users and our #CovidCareWellbeing packs to help service users deal with the isolation and impacts of the pandemic.

We are incredibly proud of how well so many of you have been doing in the face of such uncertainty and love to hear about your walks, gardening, writing, exercise, art projects, baking and family time. We know it can be a real struggle to face the day and for many of you Covid has meant separation from loved ones, friends, community and is especially hard when people you love are in homes and hospitals with limited if any chance to visit. You will find below our contact details and those of trained counsellors ready to listen 24/7 if you are feeling low or lonely.

Our thoughts are with those of you who have felt the ultimate loss during these past six months. We hope you find comfort in the memories of the special times you spent with those friends and family. There are some excellent bereavement support services to help you understand and manage your feelings of grief and loss. We always welcome the opportunity to commemorate those within the HD family who have died so please consider sharing your memories and photos for our Facebook Album and newsletter.

We don't know what the road ahead looks like but we want you to remember that we are at the other end of the phone or computer if you need anything. Hopefully we will see you before long and in the meantime stay safe and stay connected.



Sorcha McPhillips
Chief Executive

Our Work

Where do HDANI work?

Although our staff are based from home, saving us the cost of running a building, we support hundreds of individuals and families right across the province. This includes patients, those at risk of HD, carers, partners, other family members as well as children and young people. The map to the right is a snapshot of the over 500 family members we are currently engaged with.



What do we do?

Kathryn and Zelig are our family support workers who each cover different Trust areas. They both facilitate support groups and provide one to one information, advice and support. They act as advocates to patients and their families to help them navigate the health and social care system, deal with issues like benefits, housing, employment, education and care services. They bring together service providers to make sure that patients and families are receiving the most appropriate care and support and this can include working with other charities that provide counselling or deal with issues like addiction support, family conflict, debt management or bereavement care. Not everything we do is directly related to HD but in many cases HD makes it more difficult for individuals and their families to deal with everyday issues like health, housing, education, relationships, employment and finance so we provide a listening ear and helping hand or the tools to enable people to deal with things themselves.



**CRUSE NATIONAL
HELPLINE**
0844 477 9400
Monday – Friday
9.30am – 5.00pm
Website: www.cruse.org.uk



Ashley works in two roles- firstly helping to connect children and young adults from HD families by providing them with information and opportunities to get together. She works closely with HDYO and our family support workers as well as outside specialists to ensure we have age-appropriate, accessible and fun resources and events. Ashley also acts as our Fundraising and Awareness Officer by helping anyone wanting to raise money for HDANI, selling merchandise through our new online charity shop and seeking to promote the charity for example through #LightItUp4HD.



Sorcha, is our Chief Executive, her job is a little bit of everything and includes developing and running projects, managing staff, ensuring the care of service users, writing policies, serving the board, applying for and maintaining grants, overseeing the finances, developing links with other organisations, creating resources and training and engaging with policymakers and politicians. You might not see very much of her but she is always working away in the background making sure things are running well, chasing money and badgering people to do a better job for the HD community.

Crisis Telephone & Counselling Service

Lifeline

0808 808 8000

24/7
365 days a year

www.lifelinehelpline.info

Samaritans

SAMARITANS

116 123

24/7
365 days a year

Jo@samaritans.org

www.samaritans.org

HD Specialist Nurse



HDANI continues to lobby politicians and policy makers so that regardless of where you live in Northern Ireland you will have access to a HD Specialist Nurse. We see this role as an expert gatekeeper to health and social care services for families living with HD and a way to help people best manage their condition and maintain their independence. At the minute there is only one nurse, Majella explains her role;

My name is Majella McConville and I work as a Huntington Disease Specialist Nurse. The geographical area of my work remit, covers the Belfast Trust and South Eastern Trust only.

My role is to help and support those affected by Huntington Disease. It is a familial disease so everyone is affected, be it physically, emotionally, mentally or socially.

Huntington Disease can be and is a very complexed and complicated disease and is certainly not "one size fits all" approach.

It has to be a Multi-disciplinary approach, so therefore I work very closely with other health professionals e.g Neurologists, Psychiatrists, Occupational Therapists, Speech and Language Therapists etc. This is to ensure that each

individual is holistically given the best help and support available.

I would attend regular multi-disciplinary team meetings, to discuss each individuals needs and requirements and collectively we plan ahead to provide the most appropriate care available.

I also carry out visits in the community sector. Be it clients own homes or in residential or nursing home settings.

Another important aspect of my role is education. I would arrange education talks to give people a better understanding of the disease and allow them the opportunity, to ask questions about managing people with HD.

Affected individuals can be referred to me through various channels. It can basically come from anyone as long as the person referred has given their consent to do so.

Once referred, I will make contact and organise a visit. At this point an assessment will be carried out, to ascertain what help, if any they require at that time. The individual will then be given the opportunity to be further referred to the Familial Movement Disorder Clinic.

Familial Movement Disorder clinic is a regional clinic centred at Belfast City Hospital. Any HD affected individual from across NI can be referred to this clinic.

From point of referral the waiting time is normally 6/9 months until seen by the Neurologist. Once seen, reviews are annually, but can be sooner if required. Many individuals however are happy to remain in their own Trust and be reviewed by the local Neurology team.

Anyone living in the Belfast Trust and South Eastern Trust wanting to access my services can call the HD Department **028 95 047 930**.

Did you know that Huntington's Disease causes Dementia?



Huntington's disease (HD) is an inherited neurological condition that causes difficulties with movement and coordination. It also causes cognitive impairment that gets worse over time. Symptoms usually develop when people are between 30 and 50 years old and dementia can occur at any stage of the condition. People typically lose their short-term memory and their planning and organisational skills. They can also develop obsessive behaviour. Research has found that people with the HD gene can be experiencing issues with behaviour, mood, memory and thought processes long before they show any physical signs of HD.

What are the signs and symptoms?

The early signs and symptoms of dementia can vary from one person to another and may differ depending on the type of dementia a person has. Some people find they experience physical as well as mental changes. Below are some of the common early signs and symptoms of dementia. We hope it gives you a better idea of the things to look out for.

Memory loss that disrupts daily life

One of the most common signs of dementia is memory loss, especially forgetting recently learned information. Others include forgetting important dates or events; asking for the same information over and over; increasingly needing to rely on memory aids or family members for things they used to handle on their own.

Challenges in planning or solving problems

Some people may experience changes in their ability to develop and follow a plan or work with

numbers. They may have trouble following a familiar recipe or keeping track of monthly bills. They may have difficulty concentrating and take much longer to do things than they did before.

Difficulty in completing tasks at home, work or leisure

People with dementia often find it hard to complete daily tasks. Sometimes, people may have trouble driving to a familiar location, managing a budget at work or remembering the rules of a favourite game.

Confusion with time or place

People with dementia can lose track of dates, seasons and the passage of time. They may have trouble understanding something if it is not happening immediately. Sometimes they may forget where they are or how they got there.

Trouble understanding visual images or spatial relationships

For some people, having vision problems is a sign of dementia. They may have difficulty reading, judging distance and determining colour or contrast, which may cause problems with driving.

New problems with words in speaking or writing

People with dementia may have trouble following or joining a conversation. They may stop in the middle of a conversation and have no idea how to continue or they may repeat themselves. They may struggle with vocabulary, have problems finding the right word or call things by the wrong name.

Misplacing things and losing the ability to retrace steps

A person with dementia may put things in unusual places. They may lose things and be unable to go back over their steps to find them again. Sometimes, they may accuse others of stealing. This may occur more frequently over time.

Decreased or poor judgement

People with dementia may experience changes in judgment or decision-making. For example, they may use poor judgment when dealing with money. They may pay less attention to grooming or keeping themselves clean.

Withdrawal from work or social activities

A person with dementia may start to remove themselves from hobbies, social activities, work projects or sports. They may have trouble keeping up with a favourite sports team or remembering how to complete a favourite hobby. They may also avoid being social because of the changes they have experienced.

Changes in mood and personality

The mood and personalities of people with dementia can change. They can become confused, suspicious, depressed, fearful or anxious. They may be easily upset at home, at work, with friends or in places where they are out of their comfort zone.

What should I do if I suspect dementia?

Just because you think you, or someone you love, may be experiencing some of the signs, does not necessarily mean that you or they have dementia. If you have any cause for concern, it is a good idea to make an appointment to see your doctor and discuss it with them. Seeing a doctor early on can reduce the anxiety and worry you may be feeling and provide you with answers.

What help is there for people living with dementia or their carers?

HDANI can support you and your family and also help you connect with specialist dementia services. Just because you have been diagnosed with HD or had a positive predictive test does not mean that you cannot access dementia services nor do you need a HD diagnosis to do so. We believe that you should take all the help and support you can get as early as possible. There are a range of services in Northern Ireland that you may be able to access including;

Alzheimer's Society Northern Ireland

028 9066 4100

Dementia helpline and advocacy service, also information, advice and support across Northern Ireland.

Causeway Dementia Support Service

(Coleraine) 028 7035 8887

Young people with dementia and their carers - young carer support group meets on the 2nd Monday of every month at 2.30pm in Coleraine Rugby Club, Rugby Avenue, Coleraine.

Dementia NI

028 90686768 or email info@dementiani.org

Dementia NI is an independent group of people living with dementia within Northern Ireland. Group members come together to support each other through friendship and understanding, particularly new members who may have been recently diagnosed. The groups which run throughout Northern Ireland, empower people living with dementia to have a voice, and to remain active and part of their community. The groups raise awareness by telling others what life is like to live with dementia and engage with organisations throughout Northern Ireland, to inform them of how to make their services, policies and practice more suitable for people living with dementia.

DEEP Groups

The Dementia Engagement & Empowerment Project (DEEP) brings together groups of people with dementia from across the UK. DEEP supports these groups to try to change services and policies that affect the lives of people with dementia. Whilst not young onset specific, many of the DEEP groups are well attended by younger people with dementia. Dementia NI have a DEEP group. For more information contact tara@dementiani.org

Mid Ulster Office - Alzheimer's Society

(Maghera) 028 8676 5888

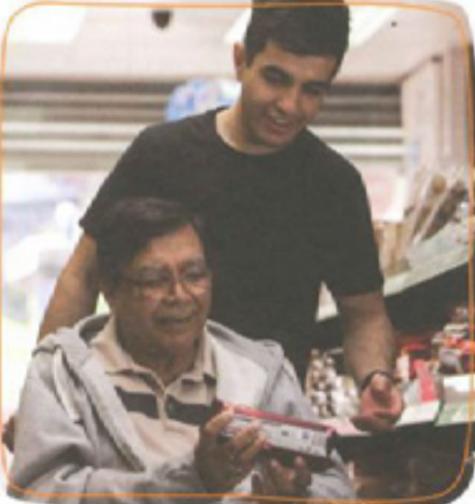
A support group for carers of people with young onset dementia meets on the fourth Friday of every month, 2.00pm-3.00pm in Mitchell Hall, Station Road, Maghera.

What is Palliative Care?

Palliative care is the active, holistic care of patients with advanced, progressive illness. Palliative care aims to improve the quality of life for patients facing serious illness and for their families, through the assessment and management of physical symptoms, and psychological, spiritual and social issues. Each Trust has their own palliative care services which includes a range of health and social care professionals from doctors and nurses to pharmacists and physiotherapists. HDANI will be carrying out a piece of work with Marie Curie in the coming months to identify the particular palliative care needs of people with HD and their families and we will be in contact to seek your views and experiences on what you feel is needed. In the meantime, here is some information about the services Marie Curie provide in Northern Ireland.



Marie Curie Helper
Northern Ireland



Someone who's
there to help you

Support when you need it if you or
someone you care about is living
with a terminal illness

Care and support
through terminal illness



Marie Curie

How our service works

Contact us if you'd like support from our Helper volunteers.

Phone: 0800 304 7404

Email: nihelper@mariecurie.org.uk

We can help if you're aged 18 or over with a terminal illness, or if you're looking after someone who is terminally ill.

Our service is free of charge and is available in Northern Ireland.

We'll find out more about you and your situation before matching you with a Helper volunteer who's right for you.

All our carefully selected volunteers have completed specialised training for their role.

Once matched, you can arrange with your Helper volunteer when you want to meet and what you'd like to do together.

Your volunteer can visit you in your home, or talk to you on the phone, for a few hours every week – on any day of the week.

Our service is entirely based around you. You may want a friendly face to turn to, a question answered or help with something practical – how you spend that time with your volunteer is really up to you.

Marie Curie – what we're here for

We're here for people living with any terminal illness, and their families. We offer expert care, guidance and support to help them get the most from the time they have left.

Our nurses work day and night, in people's homes across the UK, providing hands-on care and vital emotional support. Our hospices offer specialist round-the-clock care.

And we support people throughout their illness by giving practical information, support from trained volunteers and being there when someone wants to talk.

Marie Curie Support Line
0800 090 2309*

Ask questions and find support.
Open Monday to Friday 8am to 6pm,
Saturdays 11am to 5pm.
mariecurie.org.uk/help

You can also visit community.mariecurie.org.uk to share experiences and find support by talking to people in a similar situation.

*Calls are free from landlines and mobile phones. Your call may be recorded for quality and training purposes.

Testing for HD



How do you test for HD?

Since the early 90's it has been possible to accurately detect whether a person will develop HD in later life through analysis of a blood sample. In line with international guidelines, this 'predictive' test can only be conducted after a person has turned 18 and generally as part of a genetic counselling process. In some instances, children or adults who are exhibiting potential symptoms of HD may be tested for a clinical diagnosis.

Should I get tested?

HDANI recognise that the decision to get tested is hugely personal and so we feel no one should be pressured into it. There may well be benefits to testing in terms of accessing research and potential drug therapies and to help decide about your future for example family planning. However, you should consider why you want a test and if it is the right time in your life to do it. Ideally you will have a strong support network in place to help you consider your options deal with whatever the result may be. We encourage people to be as open as possible with family and close friends so that you can benefit from their support and avoid stigma.

What happens if I want to get tested?

The process, according to the guidelines, should involve getting an appointment from your doctor for the genetic clinic local to you. Then you will be assigned a genetic counsellor who will meet with you at least twice before you would take your blood test. Once the blood

is taken it usually takes a few weeks to get your results. You should know arrangements for receiving your result i.e. the date and time and who will be there. It is recommended practice that results are given in person. At any time, you may stop the process without finding out your results.

Testing in Northern Ireland

The Regional Genetics Service investigates genetic conditions, including Huntington's Disease, affecting patients across Northern Ireland. In addition to testing, the team also provide information on family planning, advice, guidance and genetic counselling.

To access this free service, you need to be referred by a GP or specialist doctor. The referral can be made before or after a genetic diagnosis in you or any at-risk relatives.

The Regional Genetics Service is based on A Floor of the Tower at Belfast City Hospital. There are also a number of genetics clinics in hospitals across Northern Ireland including Antrim Area Hospital, the Ulster Hospital, Altnagelvin area Hospital, Southwest Acute Hospital, Craigavon Area Hospital, and there are also clinics in Knockbreda Health centre. Due to current Covid restrictions there are only limited face to face appointments in some clinics at present and it is generally not good practice to give results over the phone.

For more information about the service please contact:

genetic.medicine@belfasttrust.hscni.net
or call 02890329241

Monday to Friday: 9am to 5pm (excluding public holidays)

Check out this article on HDYO
<https://en.hdyo.org/you/articles/570>

HDANI Youth

Over 18 Catch up

Sadly, due to Covid-19 HDANI have been unable to host their annual Summer camp and other youth day's out.

We have started hosting a fortnightly HDANI Over 18 Catch Up via Zoom, this is open to HDANI Youth members 18 – 35 Years old.

This Zoom takes place Thursdays @ 6.30pm, please confirm with Ashley if you can attend.

If no one confirms the Zoom will be cancelled and the next one will be in two weeks

Zelie, our support worker and Ashley will facilitate the catch up and if anyone requires support Zelie will be available.

The catch up is a relaxed way to make friends, catch up with old friends and check in with HDANI. It is a chance to talk about stay cations, University, returning to school or even your favourite Netflix show.

If those attending would like to discuss a HD topic this can be done in a Zoom meeting and will be pre-arranged, giving people notice if they would like to attend.

If you would like to suggest a topic or attend any of the meetings please contact Ashley. The link needed to access the Zoom will be sent once you have contacted Ashley to confirm attendance.

For information on youth, events or fundraising

Email: ashley@hdani.org.uk

**Text/Call/WhatsApp:
078 1033 0949**



HDANI Youth Quiz

Ashley has been hosting a HDANI Youth Quiz fortnightly on Thursdays @ 6.30pm – 7.00pm for all members of the HDANI Youth Programme (5-35 year olds).

If you would like to attend please contact Ashley, for updates on the HDANI Youth Zoom please search Facebook for the private Facebook group – HDANI Youth Quiz.

Here you can keep up to date with when the Zoom is happening. If no one confirms the Quiz will be cancelled and move to the next date.

HDANI Youth Quiz takes place using Facebook messenger Rooms, you can use your mobile, laptop or PC, simply download the Facebook Messenger App. The link needed to access the Quiz will be sent once you have messaged Ashley to confirm attendance.

HDANI Youth Email

Once a month Ashley sends an email to members of the HDANI Youth Programme containing information you may find useful.

If you do not receive these emails, please check your junk folder or get in contact with Ashley.

Some topics which have been covered include

- HDYO Congress
- Social Media
- Young Carers
- HDYO
- Smarties Campaign
- AWARE Resources and Video's

Get Involved with HDANI

If you or your children do not attend the youth events, but would like to receive information please contact Ashley. These emails share information you might find useful, accessing support, services or keeping up to date on HD information.

**ANYTHING. ANYWHERE.
ANYTIME.**
HDYO VIRTUAL SUPPORT
Skype: hdyofeed@gmail.com



HDANI Virtual Conference

We have some fun content planned for the HDANI Virtual Conference for our youth members. The week beginning Monday 5th October we have teamed up with HDYO to share content with our youth members.

If you would like to get involved and receive more information please contact Ashley our Youth Events and Fundraising Officer.



Monday 5th October

Motivation Monday making Gratitude Jars

Wednesday 7th October

Wisdom Wednesday - Looking towards the future. *Scheduled Zoom*

Friday 9th October

Feel good Friday – Feeling good talking about Huntington's Disease. *Scheduled Zoom details to follow on our Facebook page*

An email was sent out with information on these events which will be hosted by Ashley our Youth Events and Fundraising Officer and Matt from the Huntington's Disease Youth Organisation (HDYO).

CARERS ACTIVITIES PROGRAMME

Autumn/Winter 2020

DATE	TIME	COURSE TITLE AND CONTENT	DELIVERY AND REGISTRATION
One Day Course			
15th October 2020	10.30 - 12.30	<p>Carers rights and entitlements with Carers Northern Ireland</p> <ul style="list-style-type: none"> • Who we are and what we do • Who are carers/facts and figures/impact of unsupported caring • Carers Allowance • Carers Credit • Rights in work • Supports available to carers • Jointly Carers assessments 	<p>Registration is essential.</p> <p>Places are limited and will be allocated on a first come first serviced basis.</p> <p>How do I register?</p> <p>To register for one of the three dates</p> <p>Email: geraldine.green@carersni.org Or Contact Carers NI (028) 9043 9843</p> <p>All sessions are delivered via ZOOM so you will need access to a computer, tablet or smartphone and internet/4G.</p>
11th November 2020	10.30 - 12.30		
24th February 2021	10.30 - 12.30		

CARERS ACTIVITIES PROGRAMME

Autumn/Winter 2020

DATE	TIME	COURSE TITLE AND CONTENT	DELIVERY AND REGISTRATION
Three Day Course over consecutive Wednesdays			
25th November 2020	10.30 - 12.30	<p>Carers Self Advocacy Training delivered by Carers NI <i>Consecutive Wednesdays</i></p> <p>Day 1: The System</p> <ul style="list-style-type: none"> • Carers in NI • Introduction to advocacy • Carers and the System • Carers Rights • Carers perspective <p>Day 2: Communicating effectively</p> <ul style="list-style-type: none"> • Recap • Assertiveness • Influencing and negotiating • Making a complaint <p>Day 3: Language and Thinking</p> <ul style="list-style-type: none"> • Recap • Words, voice and language • Thinking about your thinking • Empathy • Next steps - Carer involvement in local Forums 	<p>Carers must attend all 3 dates.</p> <p>Registration is essential.</p> <p>Places are limited and will be allocated on a first come first serviced basis.</p> <p>How do I register?</p> <p>To register for one of the three dates</p> <p>Email: geraldine.green@carersni.org Or Contact Carers NI (028) 9043 9843</p> <p>All sessions are delivered via ZOOM so you will need access to a computer, tablet or smartphone and internet/4G.</p>
2nd December 2020	10.30 - 12.30		
9th December 2020	10.30 - 12.30		



HDANI have created a new space for those who wish to share photos and memories of those they have lost through HD on Facebook, album, "In Loving Memory." You can also include birthdays/anniversary dates you would like us to remember.

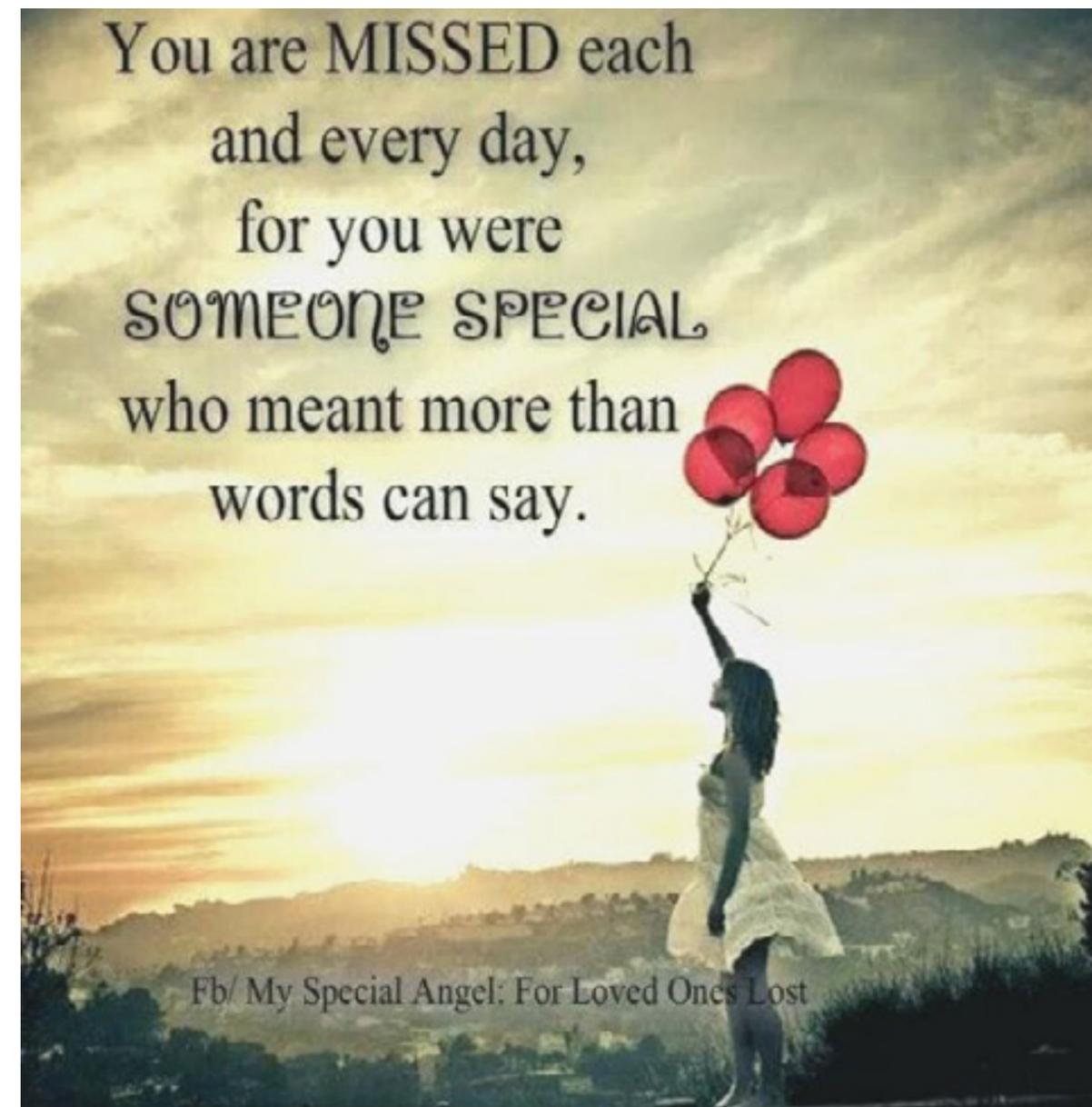
We have been contacting all service users on our current database and been adding HD family members who have been mentioned in our newsletters over the years, but wanted to ensure everyone was given the opportunity to share their own memories.

If you would like to share memories, please get in touch via email info@hdani.org.uk or via Facebook [@HDANorthernIreland](https://www.facebook.com/HDANorthernIreland) with photos, messages, dates and we will add to the album but it won't be shared as a public post on the newsfeed.

If you require any support from HDANI please do not hesitate to get in touch.

In Memory of recently lost loved ones

- **MAGEE**, Lorna, 12th January 12 2020, passed peacefully at Railway Lodge Care Home, Dunmurry. Daughter of the late Kenneth and Dorothy and beloved sister of Elaine. Also sister-in-law of Trevor and devoted aunt of Craig & Ross.
- **CAMPBELL**, Margaret (Millie), 13th January 2020, passed peacefully at Foyle Hospice. Dearly beloved Wife of the late Sammy. A loving Aunt to Jack, Austin, Samuel, and Malcolm.
- **TURNER** (Swatragh), 12th March 2020, Liam R.I.P. beloved father of Jack and Rachel, son of Willie and the late Philomena and dear brother of Barry, Paula, Tracy, Martina and Joseph.



- **MOFFATT**, April 20th 2020, passed peacefully at Hockley Lodge Nursing Home, Margaret Elizabeth (Betty), formerly of Drumnamether Road, Tandragee, beloved wife of the late Samuel (Sammy), loving mother of Heather, Arlene and David, mother-in-law of Graham and Peter and dear grandmother of Andrew, Nathan and Rachel.
- **SMYTH**, John James (Jackie), 20th August 2020, passed peacefully at The Foyle Hospice, beloved son of the late Jack and Margaret and a dear brother of Jennifer, Christine and the late David and William.
- **LEEMAN**, Brian, 26th August 2020, passed away after a long battle with Huntington's Disease, he never complained and was always smiling. Brian was 76, he will be missed dearly by Marta and Trudy, Charlie and Amelia.

HDANI Fundraising

Families in Northern Ireland need our help more than ever, so please help us to help them



#HELP HDANI FROM HOME

Fundraise
Donate
Raise Awareness



Thank you to Skipway and the Heatrick family for their donation of £1000 last December in lieu of company Christmas Cards

Birthdays

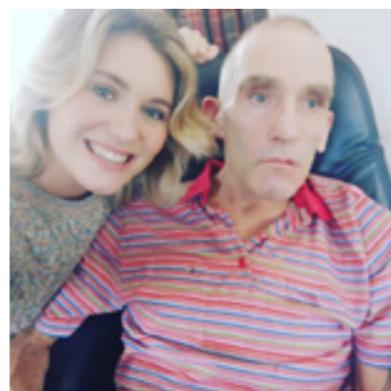
Is your birthday coming up? Why not turn your birthday into a gift to support local HD families.

Please contact Ashley if you would like to get involved.

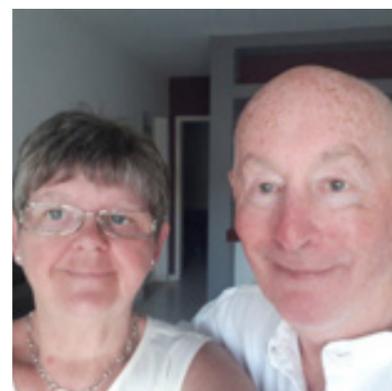
ashley@hdani.org.uk
07810330949



Ann Dorrington very kindly made a donation to HDANI for her 80th Birthday.



Ashley celebrated her birthday and raised an amazing £285 for HDANI



Marie celebrated her birthday and raised an amazing £670 for HDANI



HDANI have a fun and easy way to help raise awareness for Huntington's Disease and raise money for HDANI.

- Step 1 – Make a cuppa
- Step 2 – Take a selfie / picture of your cuppa
- Step 3 – Upload your picture to Facebook or Instagram, tag 4 friends to join in and use #Tea4HD
- Step 4 – If you can, text TEA4HD to 70085 to donate £4

Virtual Charity Shop

We have set up a virtual charity shop on Facebook. It's a very simple way to have a clear out and help raise money for HDANI. You can find the charity shop by searching 'HDANI Virtual Charity Shop'. It is basically a virtual car boot sale where you can buy and sell your items with all profits going to HDANI.



You can check out the Announcements at the top of the Facebook page for rules and instructions. You will also find HDANI merchandise for sale here, items include our new travel mug,

Price - £8 for service users / £12 for the general public plus £3.50 postage



A huge thank you to Cathy at BP McKeefrey Ltd for their repeat donation of £5,000 towards our youth work at HDANI.

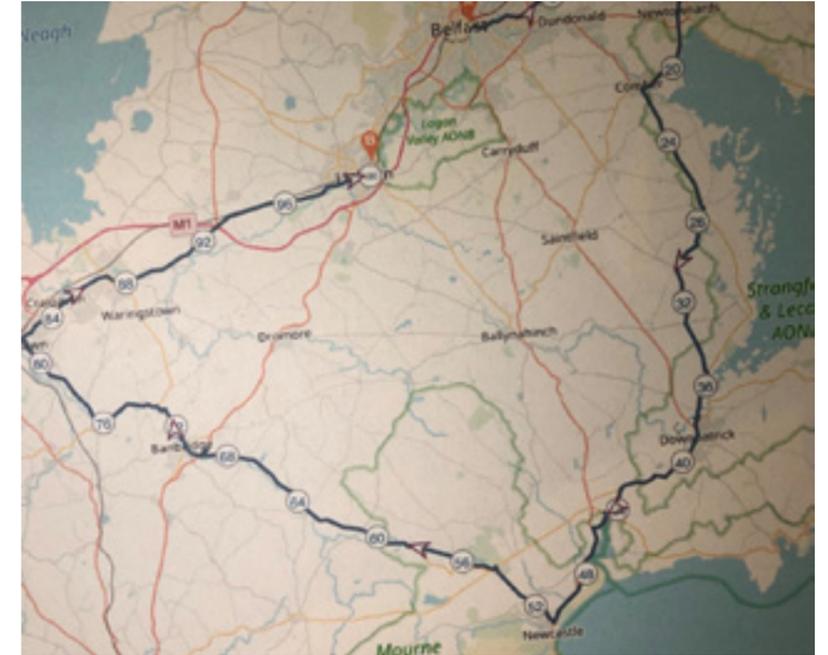
Janice and Colin – Walk a Marathon

Janice and Colin McCartney set themselves a lockdown challenge to walk a marathon for HDANI. Janice lost her father to Huntington's Disease and has been an active member for several years now. Janice and Colin have raised an amazing £ 3448.50 HDANI would like to thank Janice, Colin and everyone who took part or donated!



Nathan McCambley – 100 Miles

Nathan McCambley, Michael Parker and Lewis Irwin covered 100 miles on foot on 10th July 2020 in aid of Huntington's Disease Association Northern Ireland! These guys have raised an amazing £828.50, and HDANI would like to congratulate them for this tremendous effort and accomplishment. HDANI hope you all had a good rest afterwards and would like to thank you for raising awareness for Huntington's Disease and funds for HDANI.



Aidy Haywood

Aidy didn't let the fact that hairdressers were closed in lockdown stop him, he braved the shave for HDANI and became a HD Hero raising a fantastic £400 for HDANI. Thank you Aidy, you look great! Huntington's Disease is close to Aidy's heart as his family are affected by the condition.

Stuart Crombie – Mourne Walk Challenge

HDANI would like to congratulate Stuart and his 11 friends on completing the Mourne Wall Challenge. Stuart lost his mum just over five years ago to Huntington's Disease, and he wanted to raise more awareness for the disease and how it affects certain family's! Stuart also lost his grandfather to the disease a number of years ago.



Stuart and his friends took on the Mourne Wall Challenge in July to raise awareness for Huntington's Disease and raised an overwhelming £13658.75 for Huntington's Disease Association Northern Ireland.

HDANI would like to thank Stuart, the guys who took part with him and everyone who supported them in raising awareness for Huntington's Disease and funds for HDANI.

Dianne Leeman

We are overwhelmed to have received £1,000 from Dianne Leeman who raised donations by baking gorgeous treats and raffling them off to raise money for local charities including Huntington's Disease Association Northern Ireland. Diane lost her husband to HD and other family members are still battling the disease. Thank you so much to everyone involved and supporting us. We hope the winners enjoyed their treat!



Dianne has a Facebook page where she shares some of her beautiful bakes, you can find it by searching Facebook for 'Diannes home baking'.



Amy Dalglish

Amy Dalglish and her team had planned to run the Belfast Marathon Relay race, sadly due to Covid-19 the event was cancelled. This did not stop Amy and her team.

Team Not so Fast, Not so Furious have been fundraising from May through online donations and raffle's to raise an amazing £925 for HDANI. Each member of the team is completing their section of the



race at home safely.

Thank you to Amy and her

team and good luck in your fundraising

Donaghadee Young Farmers Club Sponsored Walk



Due to Covid 19, Donaghadee Young Farmers' Sponsored Walk, which was scheduled for 14th June 2020, has had to be cancelled. However, so their chosen Charity didn't miss out, the club have decided to hold a virtual

sponsored walk instead.

Members were been given the task of covering the distance of 10K that they would have been walking together, separately, while still raising money for their Charity for this year, Huntington's Disease Association NI.

This charity was chosen as it is close to the Clubs heart.

HDANI would like to thank the club members and all involved with this event, Donaghadee YFC have raised a remarkable £922.50 so far.

Dunmurry Golf Club

On Friday 28th February Dunmurry Gold Club hosted a Quiz night in aid of Huntington's Disease Association Northern Ireland. Our Youth Events and Fundraising Officer attended and spoke about Huntington's Disease. The night was a great success with dinner, an auction and the Quiz.

Thank you Dunmurry Golf Club and everyone involved and their kind donation.

Donations have also been received with thanks from

- Mrs Nell Sheppard
- Ann Campbell
- David & Margaret Devenny
- Josie Dennison
- Trevor Lamont

If you would like to fundraise for HDANI or have any questions about the information provided please get in contact with Ashley, Youth Events and Fundraising Officer.

07810330949

ashley@hdani.org.uk

Contact Us:

Sorcha McPhillips/Chief Executive
Zelie Leech/Support Worker
Kathryn McCready/Support Worker
Ashley Clarke/Youth Events & Fundraising

079 8284 3907
077 3393 5863
079 2151 3561
078 1033 0949

sorcha@hdani.org.uk
zelie@hdani.org.uk
kathryn@hdani.org.uk
ashley@hdani.org.uk

HDANI (for post only)
53 Andersonstown Road
Belfast BT11 9AG

www.hdani.org.uk



@HDANorthernIreland



@HDAssocNI