



Hypermobile Ehlers-Danlos Syndrome (hEDS) and Hypermobile Spectrum Disorders (HSD) in Scotland:

A SCRAPBOOK OF LIVED EXPERIENCES



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<https://books.ed.ac.uk/edinburgh-diamond> | @EdinDiamond

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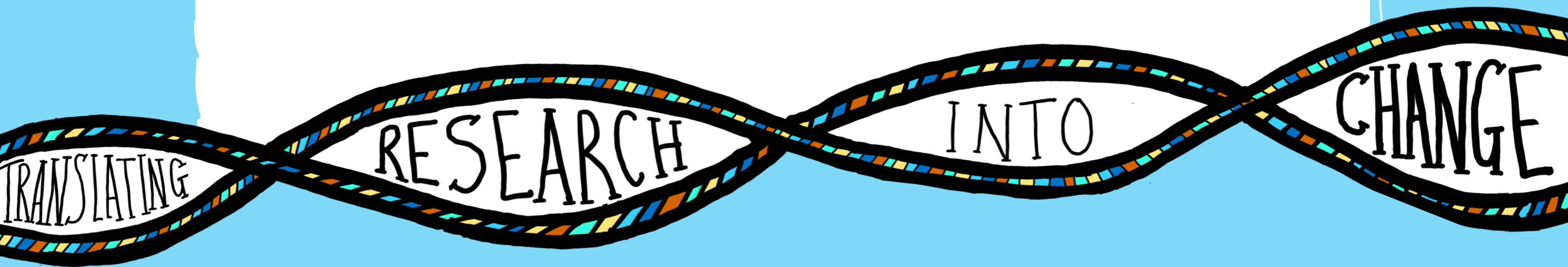
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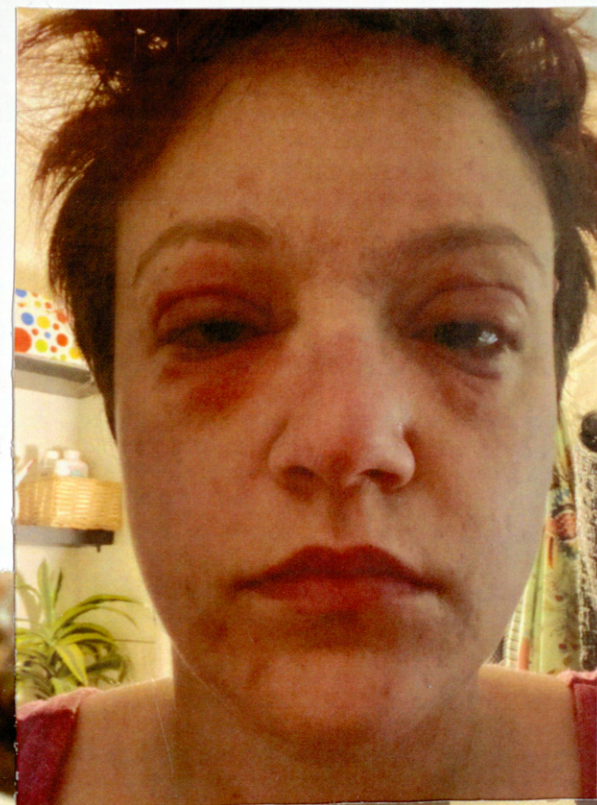
This scrapbook documents the lived experiences of people with Hypermobile Ehlers-Danlos Syndrome and Hypermobile Spectrum Disorders in Scotland.

The following pages were created by participants of the “Translating Research Into Change” patient engagement event, on the 8th February 2024 at the University of Edinburgh, as part of the hEDS-START project.





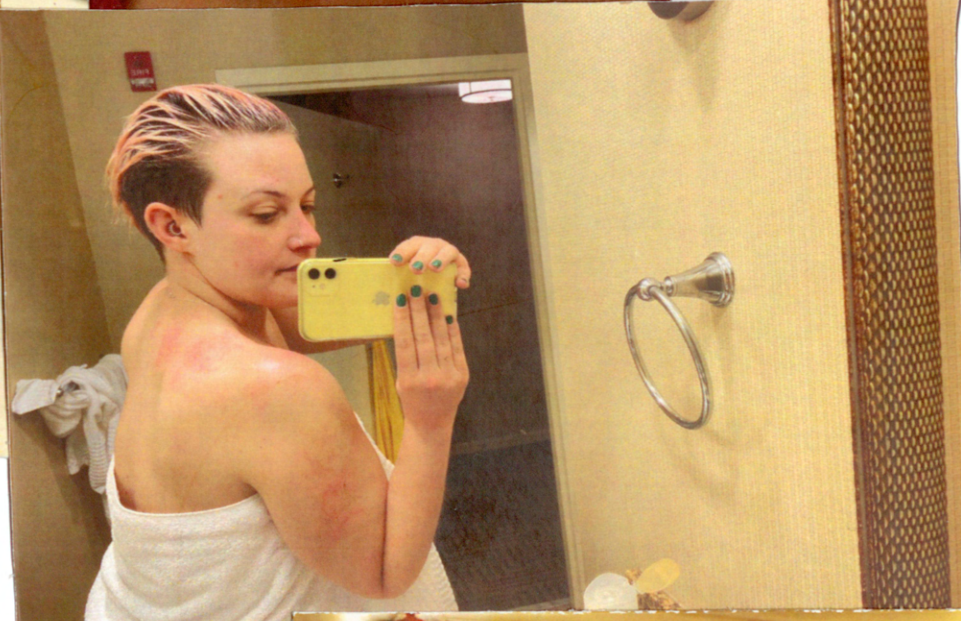
I SPEND MUCH OF MY TIME CRAFTING TO HELP WITH MY MENTAL HEALTH AND GIVE ME A SENSE OF ACHIEVEMENT



ECZEMA & FRAGILE SKIN CAN BE A BIG ISSUE. MY FACE ACTUALLY LOOKED WORSE THAN THE PHOTO SHOWS. THE PHOTO BELOW SHOWS HOW MY SKIN RIPS WHEN I USE SUPPORT TAPE - NO MATTER HOW MUCH I SOAK IT - IT RIPS THE SKIN AS I TAKE IT OFF. I NEED THE TAPE TO SUPPORT MY JOINTS



30 SECONDS FROM MY HOME. NATURE IS SO IMPORTANT FOR MY MENTAL WELLBEING.



ENJOYING A TRIP TO THE BEACH WITH MY FRIEND

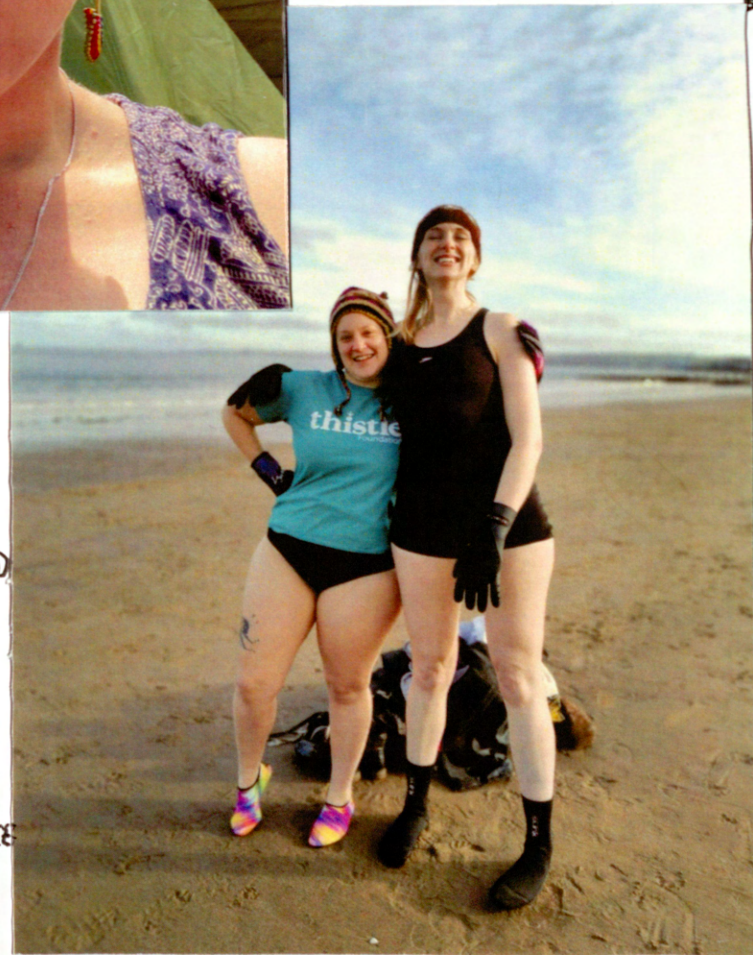
FESTIVAL TRIPS ARE IMPORTANT, BUT THE IMPACT ON MY PHYSICAL AND MENTAL HEALTH IS TOO MUCH AND I DON'T GET TO ENJOY THEM ANYMORE



IT'S IMPORTANT TO ME LIVE A LIFE AND ENJOY LIFE WHEN I CAN. THIS WAS MY FIRST BIRTHDAY AFTER MY FIRST SUICIDE ATTEMPT. IT TOOK ME A WEEK TO RECOVER



I LOVE BEING OUTSIDE. WHEN I WILD SWIM MY WRISTS DISLOCATE, BUT MY GOOD FRIEND ALWAYS HELPS ME. EVERY DISLOCATION, SUBLUX ETC HURTS A LOT. BUT I EXPERIENCE THE PAIN SO I CAN HAVE A LITTLE LIFE





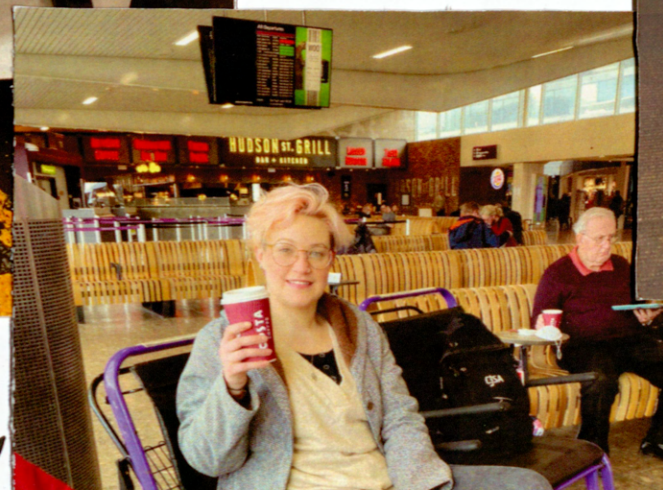
PEOPLE PARKING IN ACCESSIBLE BAYS WITHOUT BLUE BADGES MEANS IT HARD TO GO OUT WHEN THERES NO WIERE TO PARK OR THE PARKING SPOTS ARE TOO FAR AWAY



I COULDN'T LIVE WITHOUT MY CATS, MAISIE AND PIP. THEY ARE A HUGE COMFORT. I HAVE TRIED TO WORK, BUT BEEN ~~ON~~ UNSUCCESSFUL LIVING ON DISABILITY BENIFITS MAKES IT VERY DIFFICULT TO AFFORD LOOKING AFTER MY CATS PROPERLY.

IT CAN BE HARD KEEPING ON TOP OF MEDICATION. MAISIE JUST THINKS THEY'RE CAT TREATS.

SOME AIRPORT ASSISTANCE IS GREAT AND MAKE SURE YOU GET WHAT YOU NEED



IN SOME AIRPORTS THEY DON'T EVEN PROVIDE A CHAIR



SOME MOBILITY AIDS CAN BE COOL



SOMETIMES THEY LEAVE US IN CORRIDORS FOR AN HOUR



MY MUM, WHO HAS WEDS AND IS MY CARER. SHE IS THE ONLY PERSON IN MY LIFE WHO CONSISTANTLY LOOKS AFTER ME. SHE HAS HEALTH CARE PROBLEMS HERSELF AND SOMETIMES I HAVE TO BE HER CARER. WE HAVE NO CHOICE.

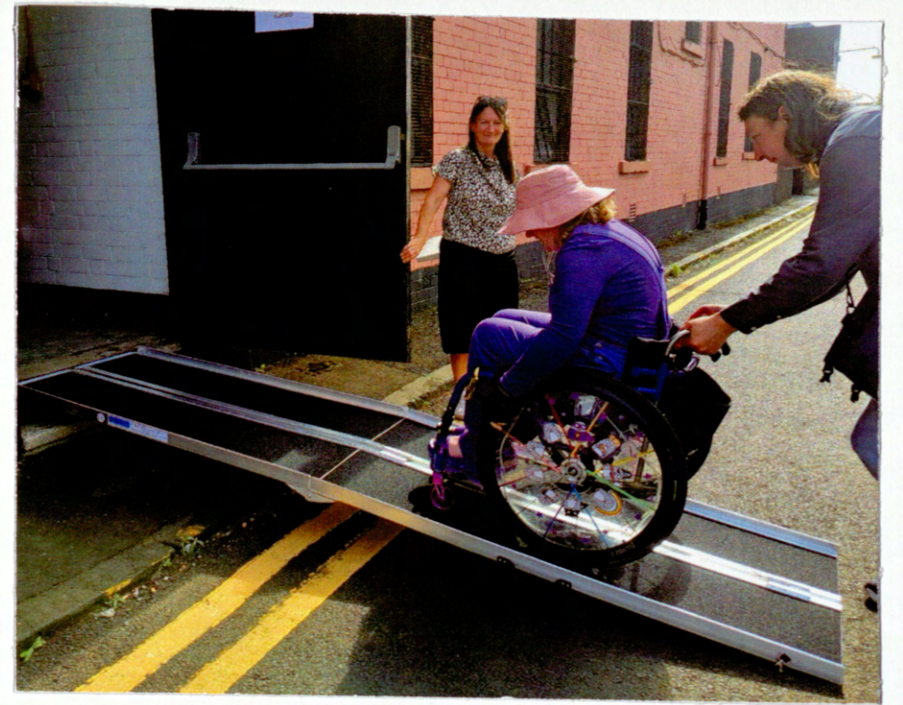




Playing tennis with my brothers
- I'm part of a wheelchair tennis club



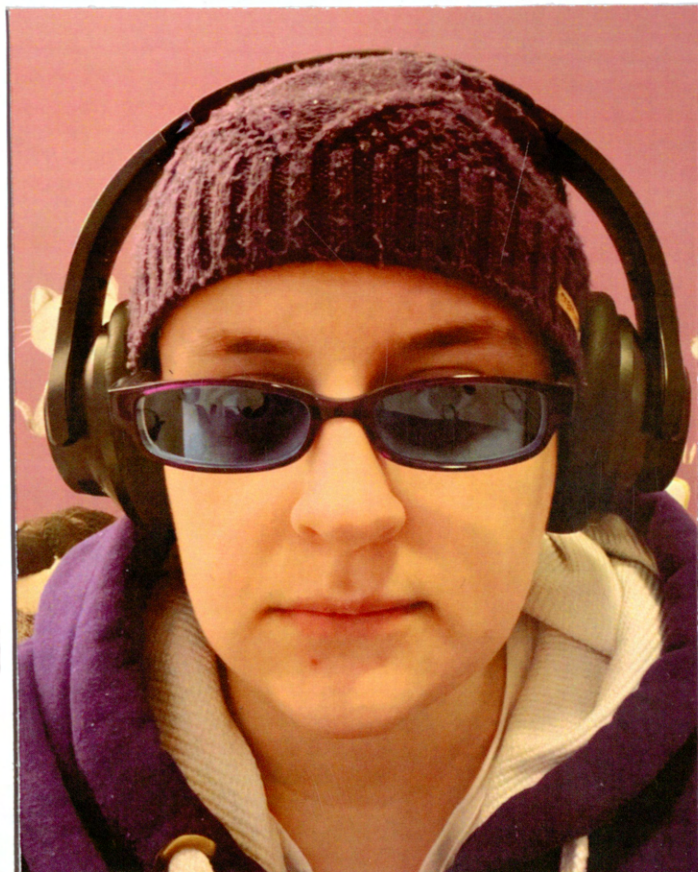
Back when I had regular
pain meds & didn't need
my wheelchair



Struggling to get up a ramp
into an inaccessible building



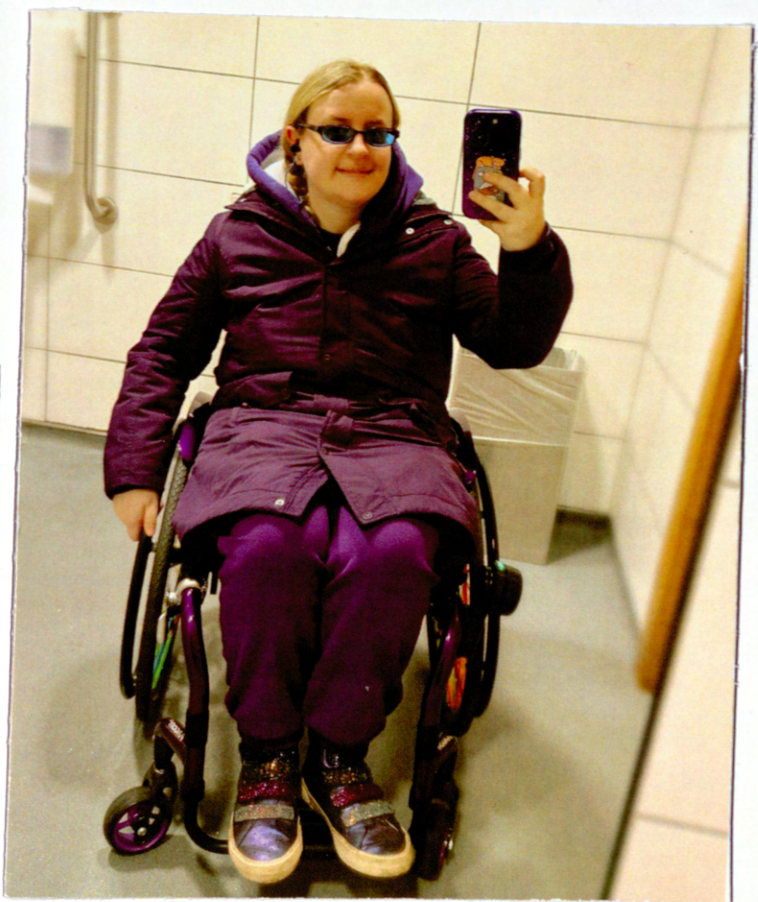
Taking part in a
screenprinting workshop
- trying to clean the
screen myself was very
challenging



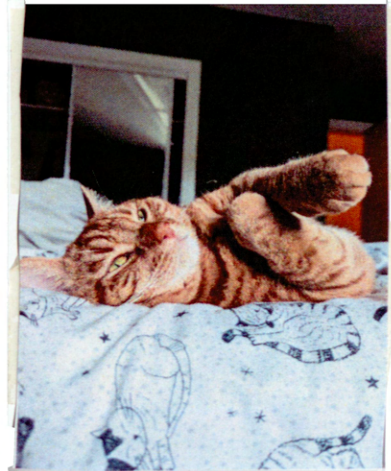
On a bad pain day
- can't move without
screaming



In the Project Ability
Studios - an amazing
disability arts charity



Happy to get out with
the assistance of my
wheelchair & power pack
- they give me freedom



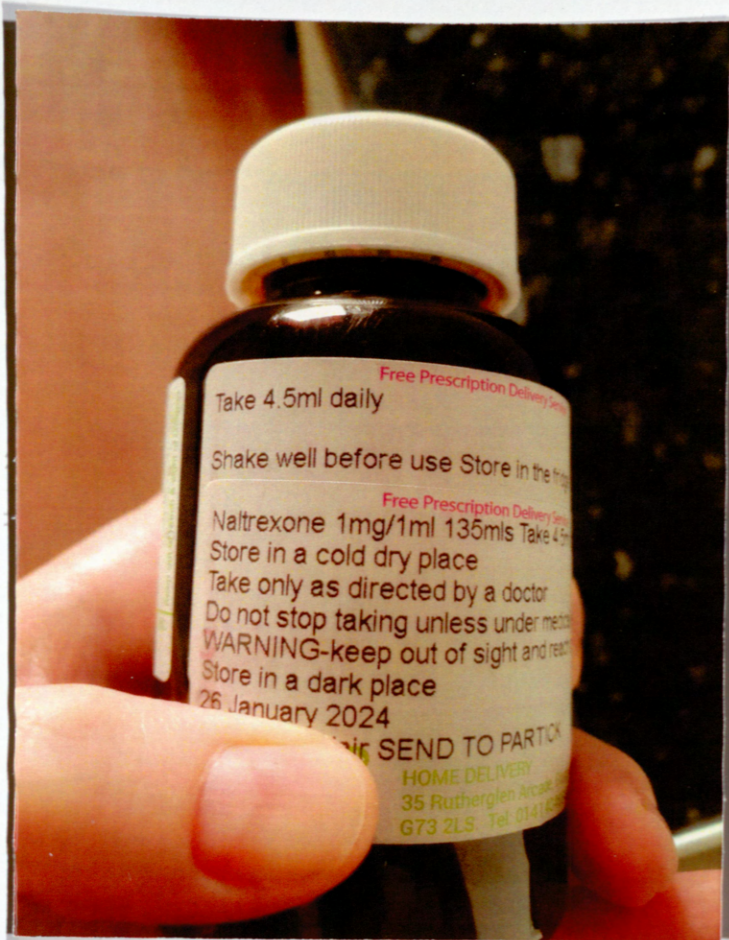
Quote from my GP:

"Wow, I should read up on this. It's not as rare as we think, is it?"

I visited a physio for knee pain after pushing myself too far hillwalking. I use this to keep myself mentally + physically well and was looking for advice to build muscle + continue hillwalking more sustainably. My physio had never heard of hypermobility. His advice was to stop hillwalking.



The best support I have had is from a private osteopath. NHS Support options have not been aware of HSD/hEDs. I should not have to spend money to access healthcare.

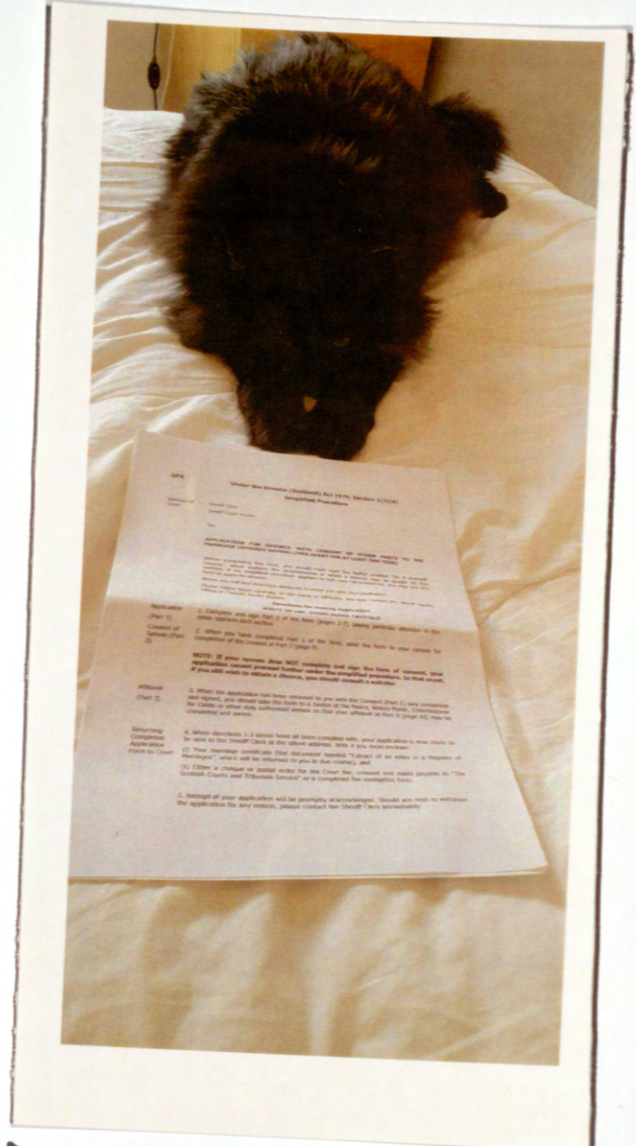


NHS
Greater Glasgow and Clyde

Referral to other forms of support (please specify) N
 Have absence reporting procedures been followed? Y
 If no, why were procedures not followed? N/A
 Has the employee been given contact details for Employee Counselling Services? N
 Last 12 months sickness absence:

Date From:	Date To:	No. of Days:	Reason
27/01/2023	27/01/2023	1	Fatigue, Stress & Subluxations
14/11/2022	16/11/2022	3	Mobility
10/10/2022	12/10/2022	3	Subluxations/hyper mobility
12/07/2022	12/07/2022	1	Joint pain & Hyper mobility
10/06/2022	10/06/2022	1	Potential Virus
19/05/2022	19/05/2022	1	Hip Subluxation

Is the employee nearing a trigger point? Y
 If yes, has the employee been made aware of the outcome of reaching a trigger point? Y
 Has the employee reached a trigger point? Y
 If yes, advise employee that a Formal Absence Review Meeting will be arranged in accordance with Attendance Management Policy)
 If yes, please enter date of Formal Absence Review Meeting? 24/03/2023
 Summary of other outcomes of discussion:
 Meeting organised for 24/03/2023. Line manager to confirm



HAVING TO PAY FOR PRIVATE PRESCRIPTIONS NOT AVAILABLE ON NHS = FINANCIAL BURDEN.

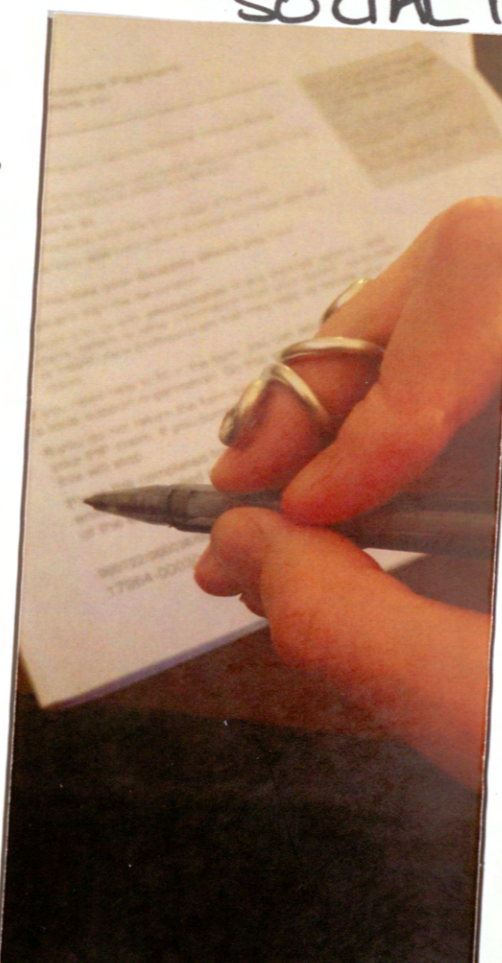
CONSTANT SICK DAYS FROM WORK BUT UNABLE TO TAKE TIME TO HEAL

DIVORCE, LOSS OF SOCIAL LIFE. SOCIAL ISOLATION.

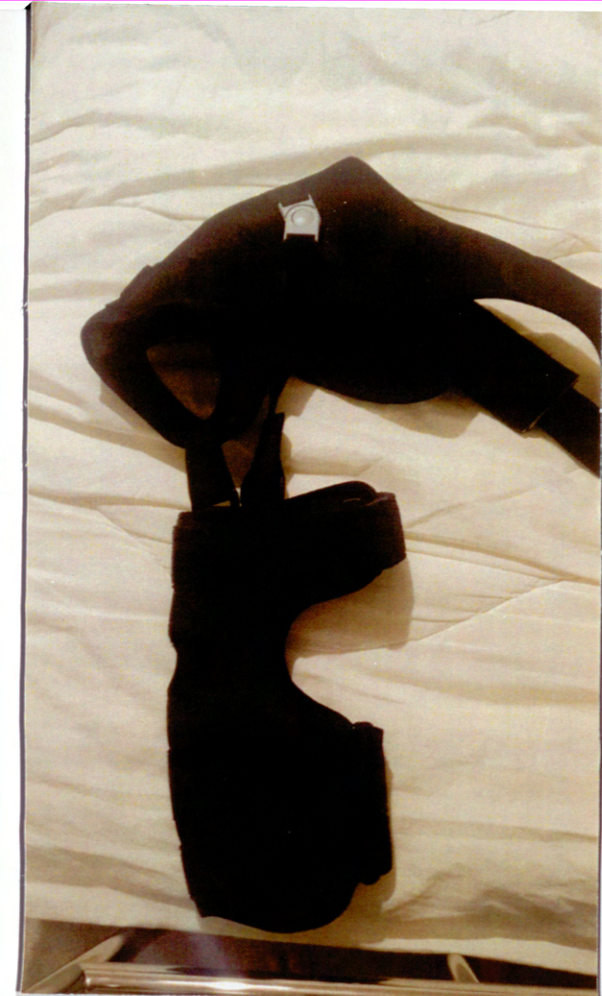
LOVE NATURE. RARE DAY OUT. CHERISH EVERY MOMENT



BATCH COOKING, WHERE POSSIBLE. CANT COOK FOR MYSELF.



MAKING MY OWN. FINGER SPLINTS TO TRY & HELP PAIN.



CONSTANT OVERWHELMING,
RESEARCH TO EDUCATE.
DRS.

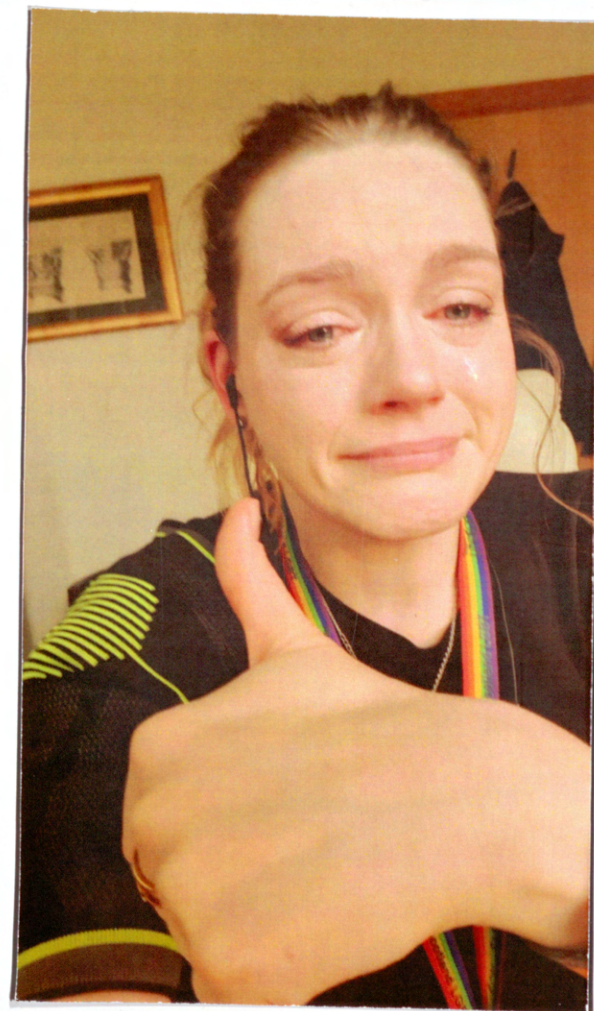
CONSTANT PURCHASES
TO TRY HELPS SYSTEM
SYMPTOMS.
FINANCIAL RUIN.

CANT WALK WITHOUT
AID, TOO SHORT BUT
BETTER THAN NOTHING.

SHOULDER BRACE,
NOT FIT FOR PURPOSE
BUT BETTER THAN NOTHING.



WHEELCHAIR UNABLE TO
USE AS NOT ASSESSED CAN'T USE.



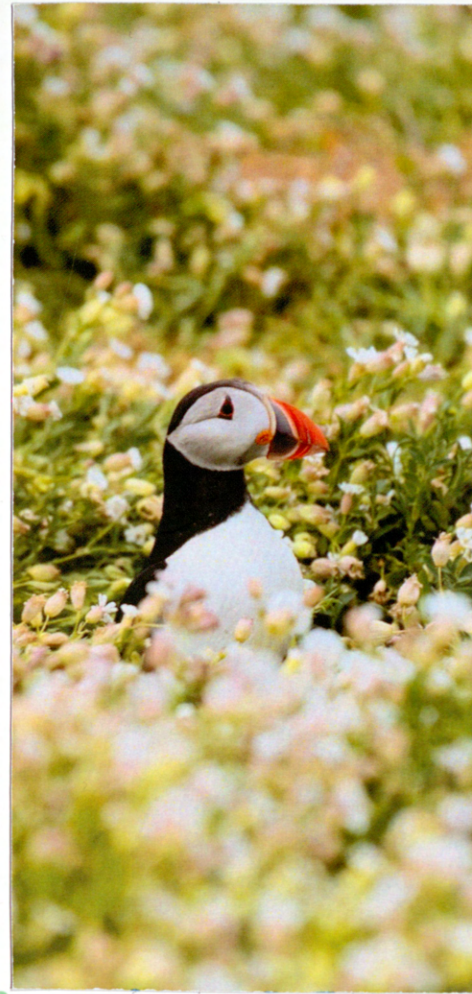
WORKING FULLTIME .
IN CONSTANT PAIN
LISTENING TO PATIENTS
IN PAIN, TRYING TO
HELP OTHERS, NO
ONE TO HELP ME .



FRIENDSHIP



STRESS RELIEF, BREATHING SPACE



NATURE



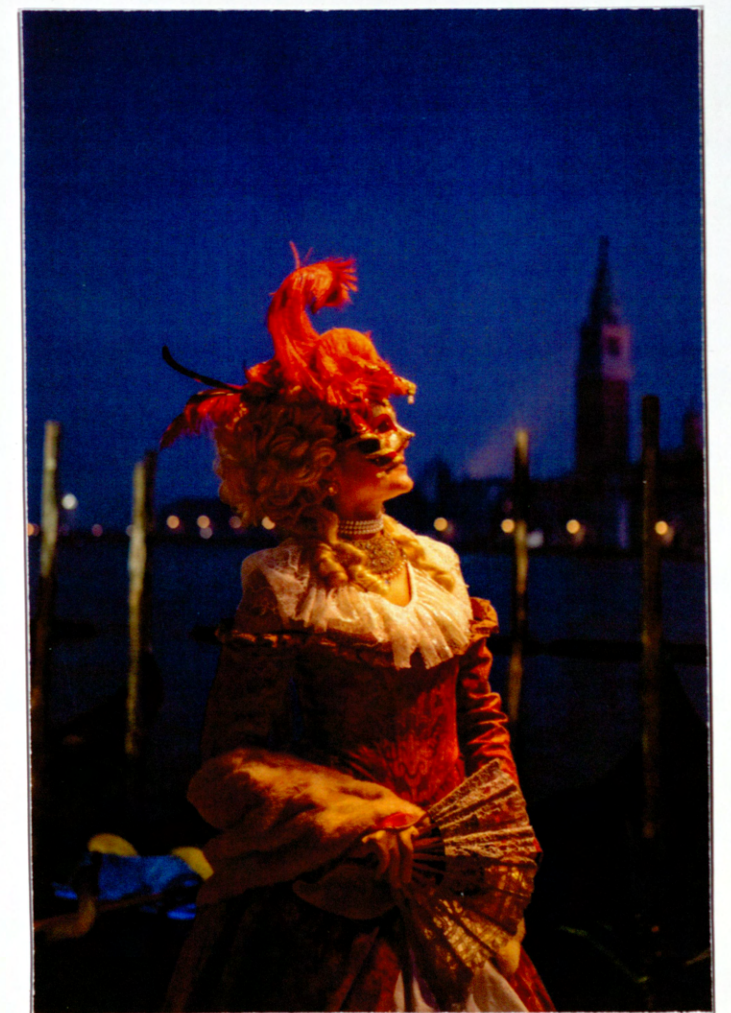
LEARNING



PASSION, DISTRACTION



SOCIALISING



TRAVEL

36 YEARS TO GET
A DIAGNOSIS FOR HEDS

WAS ASKED BY A MIDWIFE
WHY DID I THINK I WAS FIT
TO HAVE A CHILD AND LECTURED
FOR AN HOUR ON MY IRRESPONSIBILITY

WAS ALMOST GIVEN MEDICATION
I WAS ALLERGIC TO, BECAUSE
A DOCTOR DIDN'T READ THE
PRE OP NOTES AND WROTE ME
UP FOR THE WRONG MEDS

PHYSICALLY DAMAGED DURING A
PIP ASSESSMENT AND HAVE NEEDED
STICKS / SMART CRUTCHES / WHEELCHAIR
NOW. ORTHOPEDICS WON'T REPAIR
BECAUSE THEY SAY WE ARE POOR TO HEAL

BECAUSE OF MY NEED FOR A
SINGLE, SEPERATE ROOM IN
HOSPITAL, I WAS PUT IN THE
LOCKED WARD FOR THREE DAYS



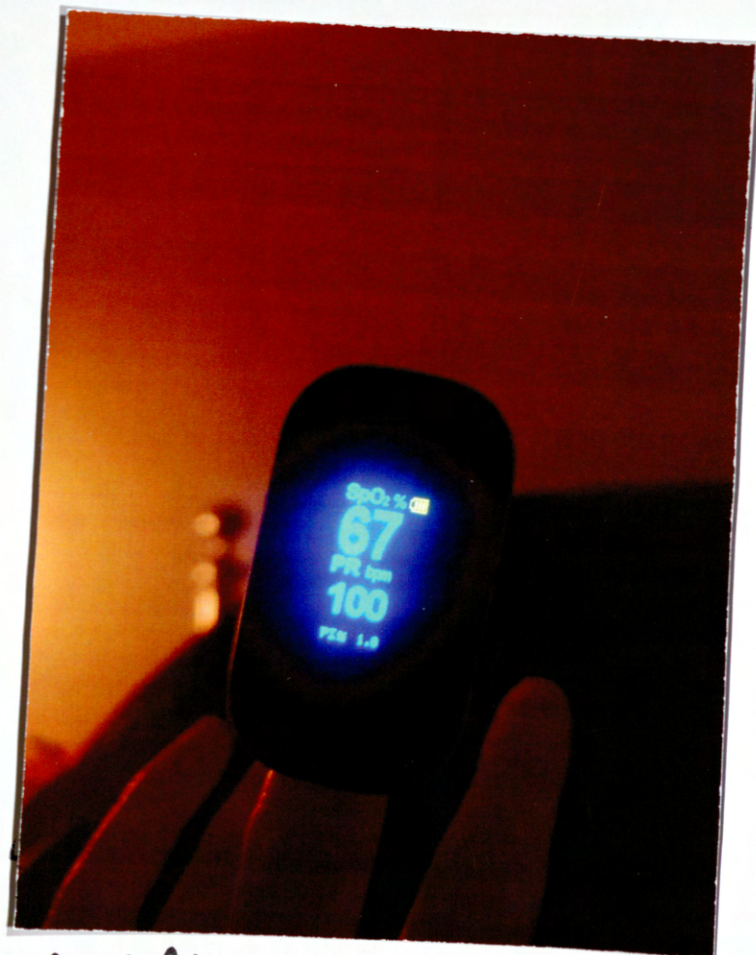
BATHROOM ADAPTATIONS .



UNTREATED
HEART CONDITION .
CANT GET HELP FROM
GIP .
"NOT A CARDIOLOGIST
WHO WILL TAKE YOU
SERIOUSLY" .



CHURCH FROM
HOME AS CANT
GO . PRAYING
THINGS WILL GET
BETTER . ITS THE
ONLY HOPE .



UNABLE TO SEEK MEDICAL
ATTENTION IN EMERGENCY/
AS I KNOW I WONT BE TAKEN
SERIOUSLY | LACK OF KNOWLEDGE .



HELPING FLYER FOR EVENTS
BUT RESTRICTED IN MY MOVEMENTS



PERFORMING IS A LOVE
OF MINE, I LOVE TO SING
BUT DANCING CAN BE A
STRUGGLE. BRUISING IS AN ISSUE!

HOBBIES KEEP ME MOTIVATED
BUT BRAIN FOG AND PAIN MAKE IT
A DAILY STRUGGLE.

LACK OF EMPATHY FROM MANY
SOURCES MAKES IT HARDER.

MEDICAL PROFESSIONALS CAN BE HARSH.

MOST OF MY ISSUES WERE PUT
DOWN TO OBESITY TILL MY LATE 30s.



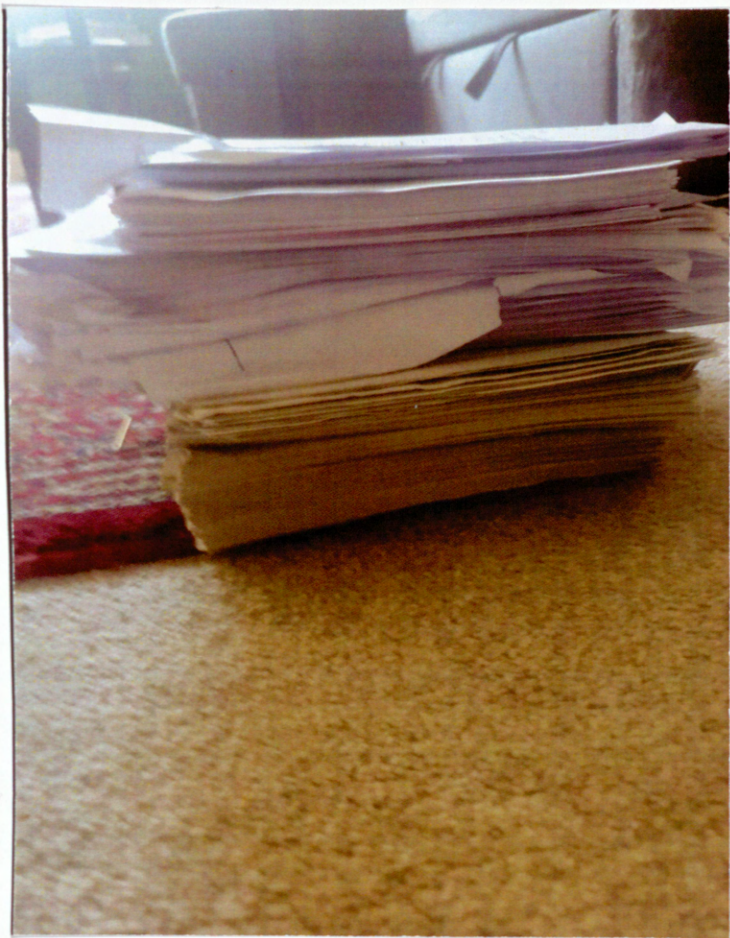
COSPLAY AND FANCY DRESS
IS A LIFE LONG HOBBY.
I CAN BECOME A CHARACTER
AND MASK ISSUES, HOWEVER
AFTER A DAY ON MY FEET
IT CAN TAKE DAYS TO
RECOVER ESPECIALLY AFTER
A SHOW.



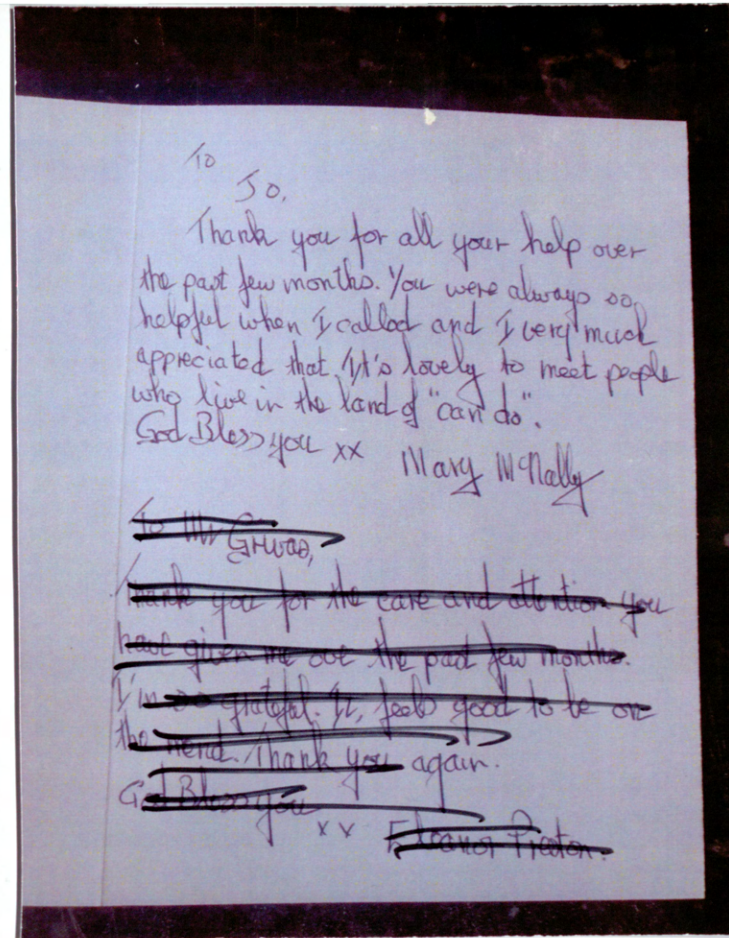
BECOMING A CHARACTER IS
LIBERATING BUT DAILY LIFE CAN
BE A STRUGGLE, PHYSICALLY +
MENTALLY



I LOVE TO VOLUNTEER & CROSSOVER
MY INTERESTS, RAISING FUNDS + GIVING
BACK MAKES ME HAPPY, BUT SIDE
EFFECTS FROM STANDING/SITTING/WALKING
TAKE THEIR TOLL



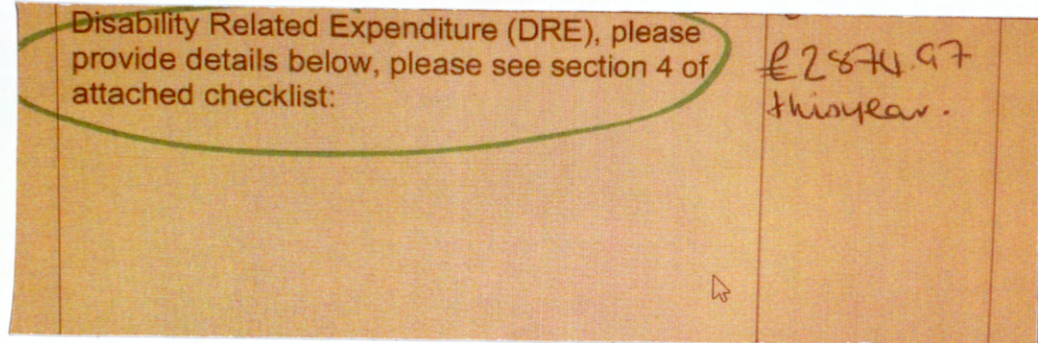
MANAGING
OWN MEDICAL
RECORDS
+ CONSTANT
ADMIN IS
EXHAUSTING
& STRESSFUL.
NO DAYS
OFF.



To So,
Thank you for all your help over
the past few months. You were always so
helpful when I called and I very much
appreciated that it's lovely to meet people
who live in the land of "can do".
God Bless you xx Mary McNally

~~Thank you for the care and attention you
have given me over the past few months.
I'm grateful. It feels good to be on
the mend. Thank you again.
GRT xx Eleanor Treator~~

A THANK YOU
CARD FROM A
GRATEFUL PATIENT.
MAKES ALL THE
PAIN WORTHWILE.



Disability Related Expenditure (DRE), please
provide details below, please see section 4 of
attached checklist:

£2871.97
this year.

CONSTANT FINANCIAL RUIN
FROM PAYING FOR HEALTHCARE
MEANS CANT SOCIALISE OR LIVE
INDEPENDENT LIVE DESPITE WORKING,
FULLTIME & DETERIORATING HEALTH.



MY BEST FRIEND
SLEEK. ♡.



UNABLE TO SHOP FOR
FOOD DUE TO UNTREATED
ALLERGIES, GI SYMPTOMS.

Some of my lived experiences.



Unexplained bruising.
People ask where I got them or what happened and I have no idea how I got them, most of the time.

Lack of knowledge of EDS in Primary care Professionals



I have equipment that I have bought to help stretch and correct Postural problems and help relieve Pain in joints.

Being tired ALL the time.



I always have music playing or the radio on in the background to help with feeling connected to the world when I'm at home alone.



Wrist pain from previous injury that was not healed properly due to having HEDS. This caused me to give up my career as a Massage/Beauty therapist.

Brain fog and memory problems due to HEDS and medication to help with pain and depression.



Crocheting is my form of art therapy, especially when I have an injury.

I crochet blankets and toys.

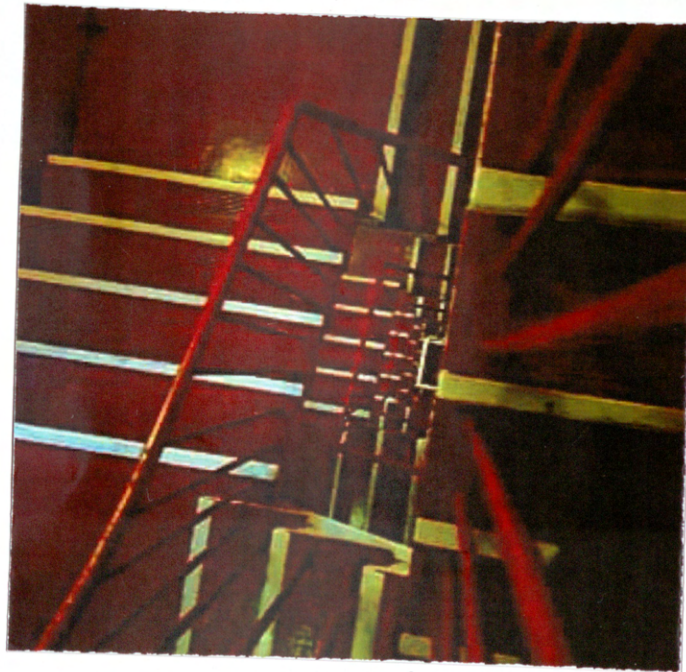
I crochet memory hearts for my funeral home and try to raise money for EDS.



Pain, recovery, braces, no mobility. After surgery no 3 on this knee.



Peace, tranquil, in nature, taking photos.



Work, climbing 8 flights of stairs due to no disabled access.



Painting scenic art is difficult due to the pain and long hours.

30 YEARS TO DIAGNOSIS

NO JOB FOR THE PAST 2 YEARS
STRUGGLING FOR THE PAST 20

I STRUGGLE TO
GET TO SLEEP EVERY
NIGHT AND IT MAKES
ME FUZZY + ACCIDENT
PRONE THE NEXT DAY



PAIN
SUCKS

I CONSTANTLY HAVE
TO RESEARCH MY OWN
ILLNESS TO TEACH
MY DOCTOR / A+E
SO THEY DON'T
HURT ME

I'M FED UP OF BEING
TIRED ALL THE TIME

NO-ONE ASKS ME TO
GO RACES ANY MORE
BECAUSE I STRUGGLE

BATCH COOK ON
"GOOD DAYS" SO
I HAVE SOMETHING I
CAN EAT ON BAD
ONES

MY HANDS AND KNEES
AND FEET HURT
ALL THE TIME.
I WISH I WASN'T
SO BROKEN.

MASSIVE LOSS OF
SOCIAL LIFE / FRIENDSHIPS
LEADING TO MORE
DEPRESSION, INABILITY
TO COPE THEN SUICIDAL
IDEATION.



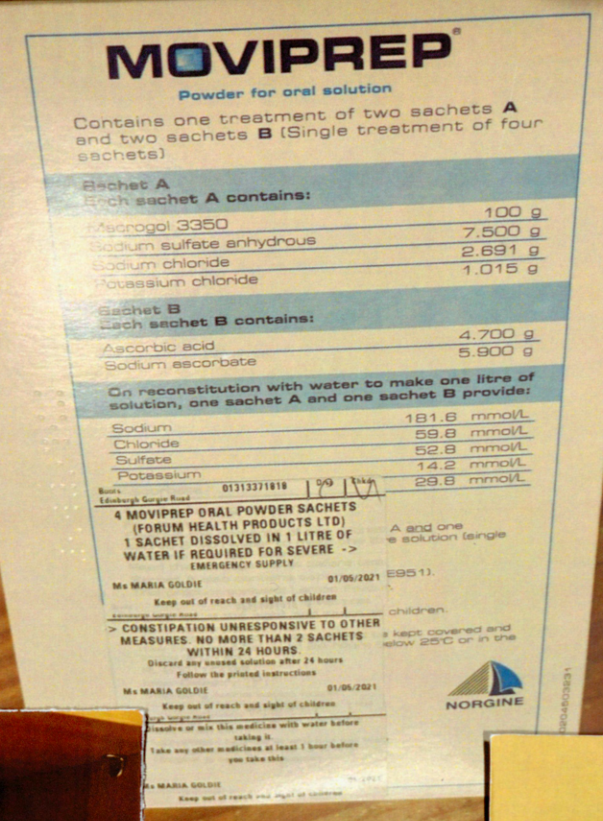
I STRUGGLE CONSTANTLY
TO FEEL I AM
WORTHY + NOT A
BURDEN. ☹️

I'D LOVE TO HAVE A PET
BUT I'M TOO SCARED I
WOULDN'T BE ABLE TO
LOOK AFTER THEM
SO I LIVE ALONE IN
SADNESS.



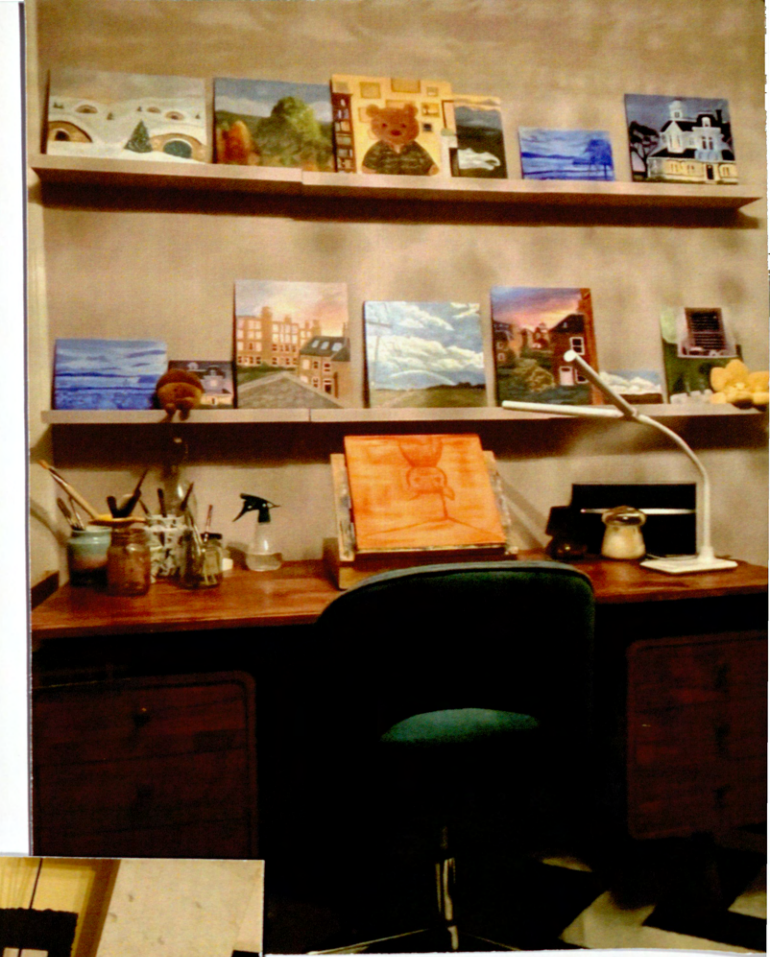
↳ wearing supports to stop my fingers from dislocation

When nothing else works! →



Hobbies at home →
Painting brings me joy, it relaxes me but it exhausts me too.

Lots of time at home means that I have lots of hobbies.



↳ no energy to wash my hair so I use dry shampoo



my lived experience



↳ warm baths help me to relax and help with my joint pain



↑ my 2-monthly repeat prescription

organising my weekly pills →



↳ It takes lots of time and effort to even get the sofa ready to relax and watch TV



HUSBAND KISSED
FOREHEAD +
BRUISED BEFORE
ARRIVING AT WORK



BAGS OF MEDS
GP'S NOT ENGAGING
WITH DISCUSSIONS
FOR ALTERNATIVE
TOLD TO BUY OWN
TENS MACHINE OR
TAKE MEDS THAT
CAUSE SEIZURES

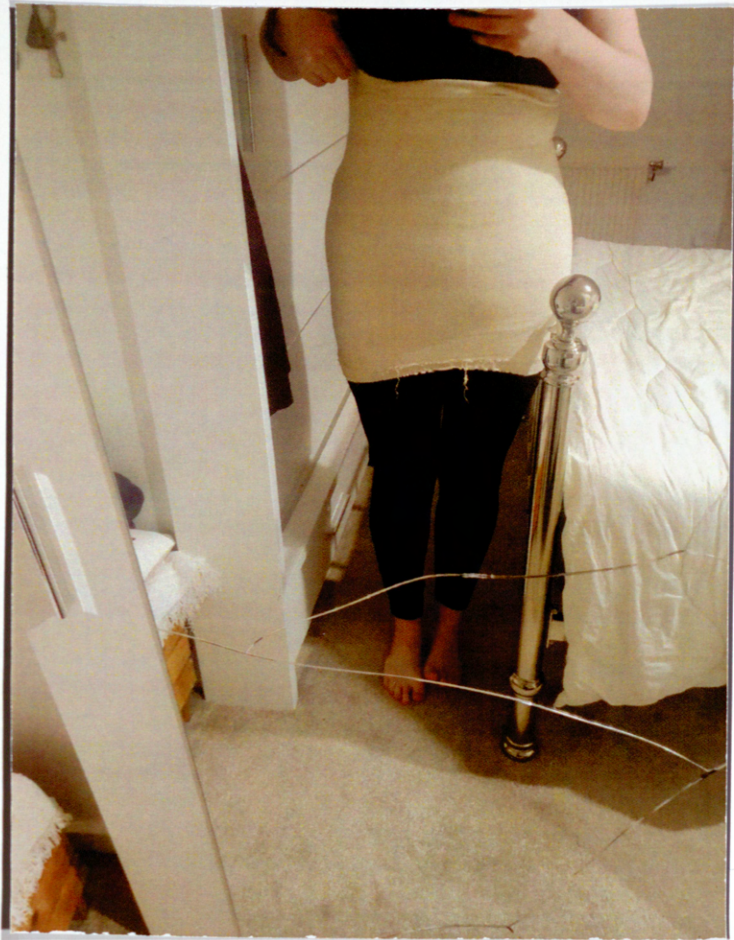
KIDS CONSTANTLY
WORRIED
SCARRING ON
EVERY LIMB



POOCH LOVE
LOWERING ANXIETY
ENFORCED REST



ANXIETY ABOUT LETTING OTHERS DOWN



BODY TUBE TO HELP HOLD SUPPORT ORGANS FROM PHYSIO.
UNABLE TO ACCESS ANY PHYSIO FOR REPAIR



HAD TO MOVE TO GROUND FLOOR PROPERTY AS CANT CLIMB STAIRS.



MADE FUN OF AT WORK FOR BRAIN FOG - COLLEAGUES MAKE ME WEAR DUNCE HAT.



TRIED TO COOK A MEAL. DISLOCATED SHOULDER & WRIST. SELF MANAGED.



INVERSION
TABLE
PREDIAGNOSIS .
TRYING ANYTHING
TO HELP PAIN .
DIDN'T HELP
= FINANCIAL RUIN .



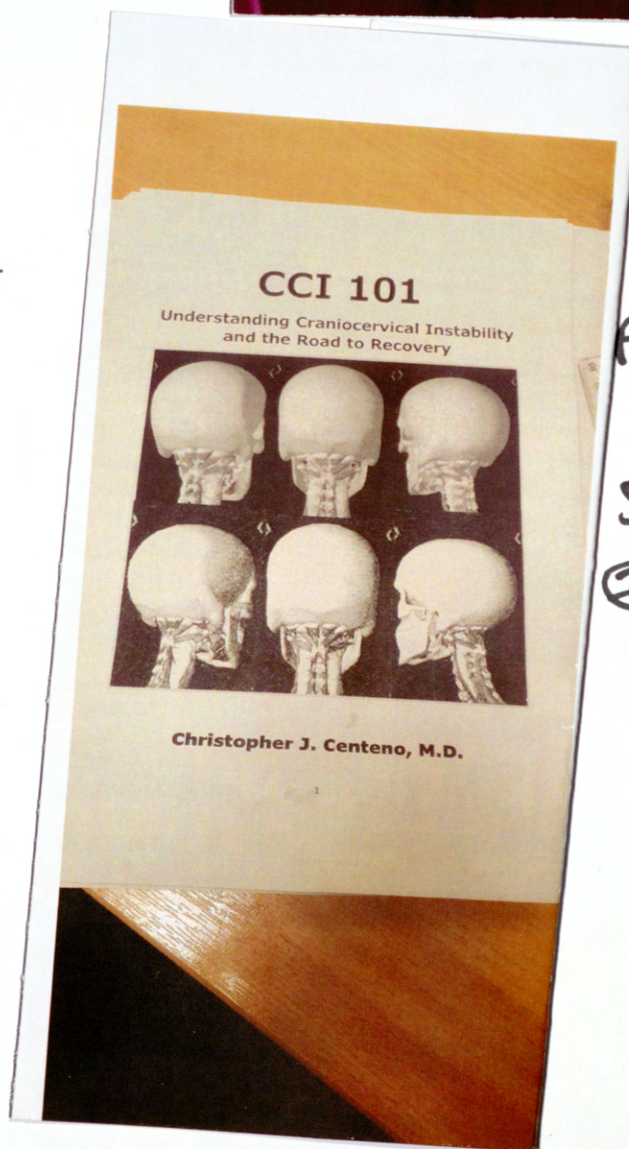
SAD LAMP
TO TRY &
INCREASE
MELATONIN
& SLEEP RHYTHM



WEE
BOOBY
PUTS
SMILE
ON
MY
FACE.
☺



BODY BRAID
TO TRY &
PROVIDE SOME
POSTURAL
FEEDBACK.



NEUROSURGICAL
CONDITION .
- NO NEUROSURGEONS
AWAKE .
I WORK IN NEUROSURGERY,
STIGMA & SELF
EDUCATION!



IT COULDN'T HELP
 SO I BOUGHT A
 NEW BED WITH
 BARS TO HOLD ON TO
 TO TURN & LIFT.
 ELECTRIC BLANKET
 ON CONSTANTLY.
 ROTATION OF
 PILLOWS BUT NEVER
 COMFY &
 CAN'T SLEEP.



CAR PARKED
 BLOCKING STREET.
 CAUSING FALL
 + BED BOUND
 DAYS.



SPINAL BRACE
 TO PROTECT
 PROTECT
 JOINTS IN
 CAR JOURNEYS.



CUPBOARD FULL
 OF AIDS &
 SPLINTS.
 = FINANCIAL ROIN.
 HELP 50%.

31 years
To be diagnosed

13 years unemployed

earlier diagnosis would allow for appropriate employment support

Education Interrupted

fully accessible ^{be a thing} education would and should

Mental health Negatively Impacted

Clinical psychology should be involved from the start

More information from other EDS patients than health care professionals.



The GP Almost Killed Me. They refused to explore my symptoms properly... I had cancer as well

I have lost so much of my life because I have never been properly supported. I was misdiagnosed at the age of 19 with fibromyalgia and borderline personality disorder. I HAVE EHLERS DANLOS SYNDROME AND AUTISM.

MY ANTIBODY
REPLACEMENT HOME
THERAPY KIT
I SET UP
EVERY WEEK
FOR 6 YRS
THANK YOU
BLOOD DONORS
♡ 😊!



HSD, HEDs
CAUSED MY
BONE MARROW
TO FUNCTION
POORLY.
ANTIBODY
TRANSFUSIONS
SAVED MY LIFE...

ASSISTANCE
DOG
SUPPORT,
COMFORT,
REMINDERS
&
SAFETY



COMPANION



MEMORIES
HOBBY, FAMILY
LOVE
MENTAL HEALTH

I WAS ADVISED TO PURCHASE "SMART CRUTCHES" AS THESE SPREAD THE WEIGHT GOING THROUGH MY UPPER JOINTS.



I USE PHYSIO TAPE REGULARLY TO "HOLD" AND "STABILISE" VARIOUS JOINTS. I HAD TRAINING FROM A PHYSIOTHERAPIST IN ORDER TO DO THIS SAFELY.



MY MOUSE MAT AND FOOT WEDGE ARE IN PLACE TO HELP MAKE WORK A LITTLE BIT MORE COMFY. MY WORK PROVIDED THESE FOR ME TO ALLOW ME TO CONTINUE IN MY CURRENT ROLE.



I HAVE WORN BI-LATERAL ORTHOTICS FOR 10 YEARS TO SUPPORT MY LOWER LIMBS AND BACK.

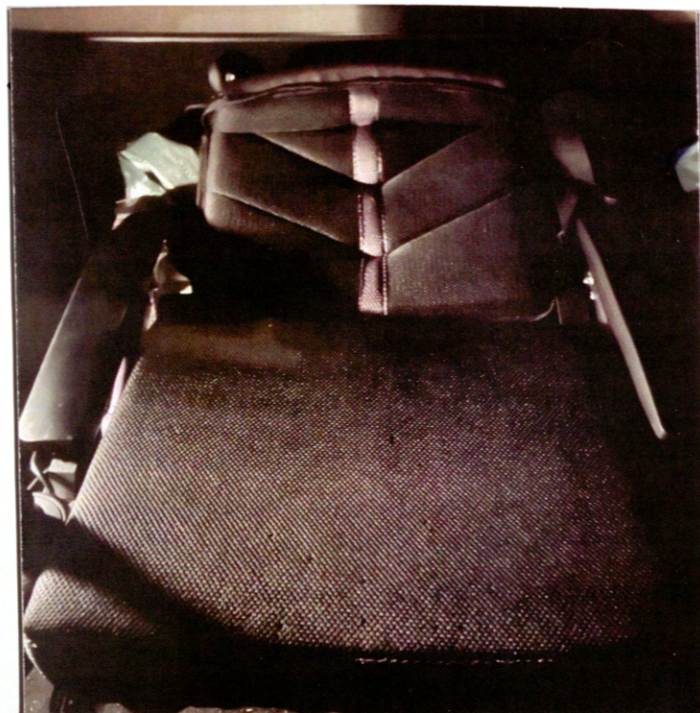
MOLLY THE CAT, MY WARM BED
AND MY BUBBLE BATH ARE MY
MAIN RELAXATION AND PAIN RELIEF.



I AM CURRENTLY PREPARING FOR COMBINED
SURGERY ON MY ABDOMIN, MULTI-ORGAN
PRO-LAPSE AND 7.5CM TEAR IN MY
ABDOMINAL WALL - "TENA" LADY IS ESSENTIAL
AT THE MOMENT.



IN THE LAST SIX MONTHS I
HAVE BECOME A PARTIAL
WHEELCHAIR USER DUE TO CONTINUAL
SPINAL & JOINT DAMAGE



I FEEL IT'S IMPORTANT TO NOTE THAT 95% OF
MY MOBILITY AIDS AND SUPPORTS ARE SELF-FUNDED
DESPITE BEING AT THE ADVICE OF MEDICAL
PROFESSIONALS.



I LIVE ALONE AND CANNOT SAFELY LEAVE THE HOUSE WITHOUT ASKING A NEIGHBOUR FOR HELP, THERE ARE ONLY 8 HOUSES IN MY VILLAGE. I STRUGGLE TO ATTEND APPOINTMENTS BECAUSE I CANNOT GET TRANSPORT. ALL MY SHOPPING HAS TO BE DELIVERED.

I WORRY ABOUT MY CHILDREN AND THE BATTLES THEY MAY HAVE TO FACE

I CAN'T EVEN GET THIS OUT OF THE HOUSE BY MYSELF, LET ALONE WHEEL IT.

I FEEL I HAVE TO CONTINUALLY BATTLE WITH CLINICIANS TO GET ANY UNDERSTANDING

I HAVE NO SOCIAL LIFE

I HAVE TO EXPLAIN EVERYTHING TO EVERY HEALTH PROFESSIONAL I AM REFERRED TO. MOST HAVE NEVER HEARD OF HEDS.



A RADIOLOGIST DISLOCATED MY HIP WHILST X-RAYING MY FOOT

I WAS ACCUSED BY A GP OF TAKING DRUGS.

THEY DID NOT BELIEVE ME WHEN I SAID ANAESTHETIC OR SEDATION DID NOT WORK AND DESPITE PROTEST, 2 NURSES HELPED ME DOWN FOR A PROCEDURE.

I HAVE NOW FOUND A GP WILLING TO BE OPEN TO MY IDEAS ABOUT MY CARE, BUT IT IS A JOINT PRACTISE AND DUE TO MISTRUST I DON'T WANT TO SPEAK TO ANY OTHER GP



With our thanks to all of those who attended the “hEDS/HSD: Translating Research Into Change” patient engagement event.



THE UNIVERSITY
of EDINBURGH

