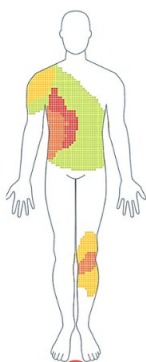


Your Pain Through Story



Manchester
Digital
Pain Manikin

A zine exploring patients' experiences of pain and using the Manchester Digital Pain Manikin



The Manchester Digital Pain Manikin

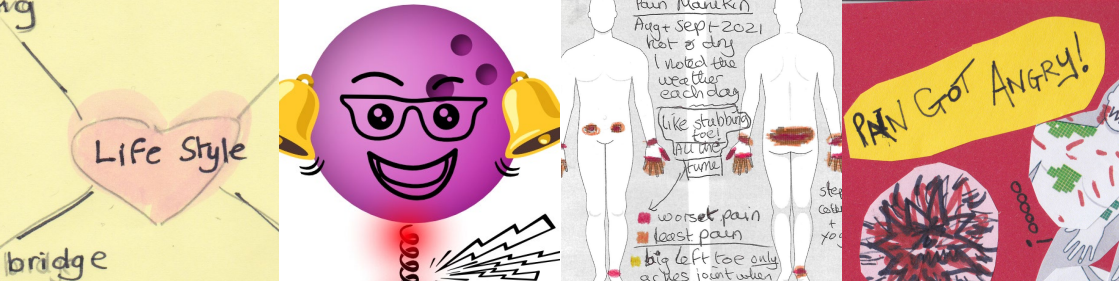
The Manchester Digital Pain Manikin is a research programme from the University of Manchester. The programme aims to improve the quality and equity of digital tools to help people from diverse backgrounds to self-report their pain.

Our Collaborators



CHRISTABEL PANKHURST INSTITUTE
FOR HEALTH TECHNOLOGY RESEARCH AND INNOVATION



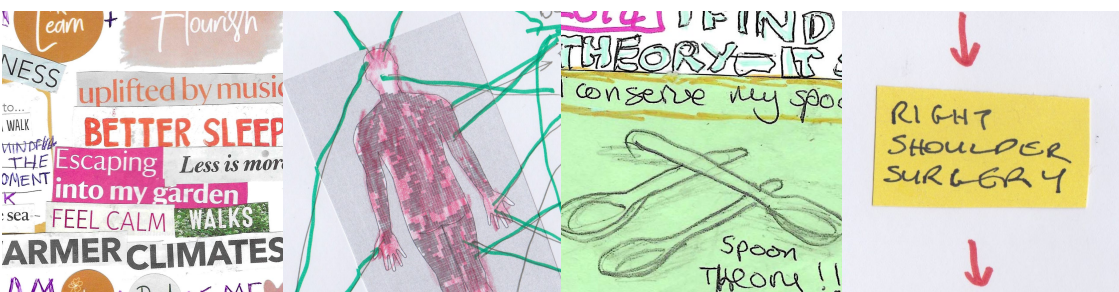


About the project

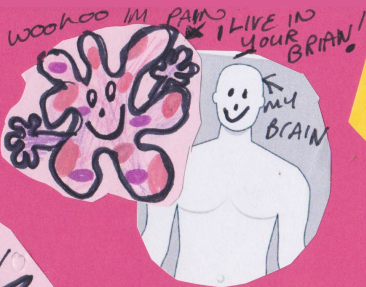
Pain manikins, such as the Manchester Digital Pain Manikin, are also known as pain drawings or pain diagrams. Pain manikins are human-shaped figures where people can shade areas to self-report the location of their pain more accurately.

In a recent study, we found that people with lived experience of chronic pain found it easy and acceptable to use the Manchester Digital Pain Manikin to daily report their pain for 30 days. 11 people who took part in this study came to 'Your Pain Through Story' events. During these events, run by Anna Ploszajski and Hana Ayoob, we asked them to tell the story of their pain through words, drawings and pictures, including their own pain manikin drawings. The results can be found in this booklet.

Our next step will be to see how we can use people's pain stories and manikin drawings to explain how our Manchester Digital Pain Manikin research programme could help people with expressing and communicating their pain experience.



ONCE UPON A TIME.....



PAIN LIVED IN MY BRAIN!

TELLING ME IF I NEEDED HELP



OH NO!

AND GUARDED ME FROM ACCIDENTS



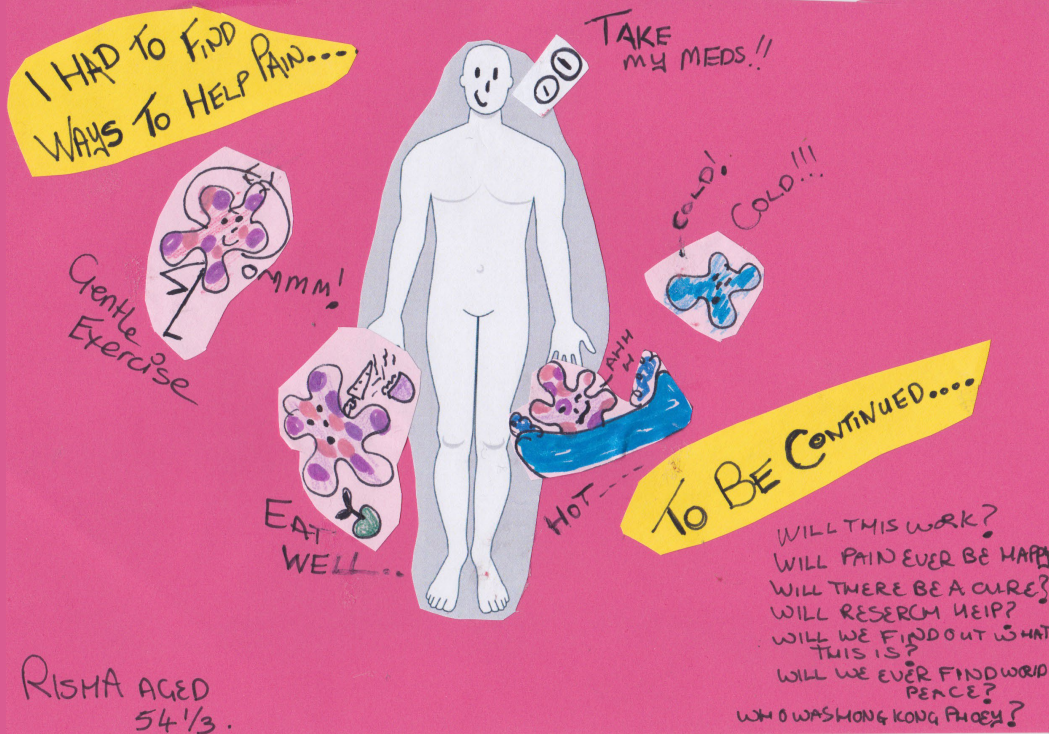
OR IF I WAS ILL!



BUT....



PAIN GOT CONFUSED?



A LIFE THAT CHANGED

IN THE LATTER PART OF 2000'S MY LIFE CHANGED DUE TO A ROAD TRAFFIC INCIDENT. I WORKED A LOT! I WAS INDEPENDENT. NOT MARRIED. A TEAM LEADER - I THOUGHT I WAS IMPORTANT TO OTHERS PROFESSIONALLY. I DIDN'T HAVE TIME FOR HOBBIES - WORK WAS THE MAIN EVENT.

I WAS BADLY INJURED IN THE INCIDENT. I HAD SEVERE ARM INJURY & LESS SEVERE BACK INJURY. I WAS IN HOSPITAL. I HAD SURGERY. I TOOK ANALGESIA. I WAS IN PAIN. WHEN I CAME HOME I NEEDED HELP FROM MY PARTNER, I COULD NOT DRIVE & CERTAINLY COULD NOT GO BACK TO WORK. I HAD A LOT OF PAIN STILL & TOOK ANALGESIA - I FELT DEPENDENT ON THE TABLETS. THE PAIN & THE LACK OF INDEPENDENCE BECAME THE MAIN EVENT. THE DAYS AT HOME DRAGGED - I FELT DEPRIVED OF SELF IMPORTANCE. AFTER FOUR MONTHS I DECIDED I HAD TO GO BACK TO WORK. IT FELT SO IMPORTANT TO BE 'SOMEBODY' AGAIN. MY FORMER JOB WOULD HAVE BEEN IMPOSSIBLE. THE PAIN PERSISTED BUT I BEGAN TO FEEL MORE HOPEFUL. I STARTED TO WORK PART-TIME IN A POST WITHIN A

HOSPITAL. I COULDN'T DRIVE BUT TOOK PUBLIC
TRANSPORT. I KNEW I COULD DO MORE, TAKE MORE
RESPONSIBILITY, WORK MORE HOURS. THE PAIN PERSISTED
BUT BECAME LESS IMPORTANT. MY JOB BECAME
FULL TIME - I DID TRAINING FOR OTHERS.
THE PAIN BECAME MORE OF A PROBLEM - MORE
SURSELY. THE PAIN PERSISTED BUT MORE MANSEABLE.
AS TIME WENT ON I REALISED THAT PAIN WAS A
PART OF MY LIFE - I COULDN'T GET RID OF IT
SO BEGAN TO ACCEPT THIS. MY (NOW) HUSBAND
HAD CHANGE IN HIS HEALTH STATUS & I NEEDED
TO TAKE ON MORE PHYSICAL TASKS AT HOME.

I STARTED TO DRIVE AGAIN. ALTHOUGH I HAD
COUNSELLING IT CAME FROM WITHIN ME THAT
I NEEDED TO CHANGE MY OUTLOOK. I DISLIKED BEING
A 'PATIENT'. THE STRONGER ANALGESIA WAS
ANATHEMA TO ME.

OVER TIME, OVER YEARS REALLY, I GRADUALLY
REDUCED MY WORKING HOURS & RESPONSIBILITY. I
HAVE LEARNED TO 'ESCAPE' INTO BOOKS, GARDENING,
MUSIC & TO HELPING OTHERS ON A VOLUNTARY BASIS.
PAIN IS A PART OF MY LIFE. I TAKE REGULAR
ANALGESIA BUT THE STRONGER STUFF HAS GONE.
ACCEPTANCE THAT, IF THINGS CAN'T BE 'CHANGED'
LIFE HAS TO CHANGE.

ACCEPTANCE OF THIS IS NOW THE MAIN EVENT,

OSTEO-ARTHRIS
= DAILY CONSTANT
FLUCTUATING

PAIN + FATIGUE

IT NEVER STOPS

+ PAIN KILLERS
AREN'T THE ANSWER
THEY TRASH YOUR

GUTS - GELS FOR
HELP ← PAIN

JOINTS CLOSE TO
THE SKIN FOR 4 HRS

HOW IT BEGAN

I WOKE UP ON MY
BIRTHDAY - Agony

COULDN'T TURN
OVER OR BEND MY BACK

HIP JOINTS SCREAMING
HAD A SICKNOTE - EVENTUALLY

POSH TYPING chair BUT
2010 FINGERS + TOES IN PAIN

STILL DOING YOGA

2013 AMYTRIPTALENE
HELPS WITH SLEEP/INSOMNIA

STRICT BEDTIMES + MINIMAL BUT

2014 I FIND THE SPOON
THEORY - IT SPEAKS TO ME
I conserve my spoons I ♥ PACING



NO 2 DAYS
THE SAME
PLANNING
LOOK IT UP!!!



THE FACTS

I'M 56 NOW
HAD OA PAIN
FOR NEARLY
20 YEARS

WHAT I KNEW THEN

OA WOULD COME FOR ME
ALL THE WOMEN ON BOTH
SIDES OF THE FAMILY HAVE
IT - THEY TROOP ON INTO
THEIR 90s STILL WALKING
GARDENING + KEEPING
ACTIVE. THE MIND TOO

I HAD TO PREPARE

YOGA + WALKING
SINCE 2005 IN NATURE

HILL WALKING HEALTHY FOOD self-care

OFF WORK 3 WEEKS - NEVER
BACK AT WORK/
PAIN ALWAYS THERE IN

2010 XRAY DIAGNOSTICS
HIPS

BONE CRUSHING
FATIGUE +

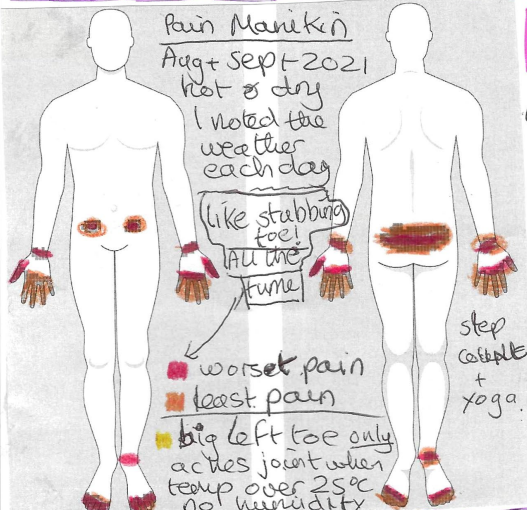
INSOMNIA

2015 STILL DOING YOGA
+ MINDFULNESS!!

BOTH HELP ME
BOX OFF THE
yoga mind PAIN Strong

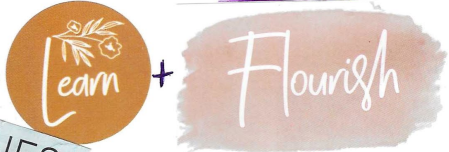
2016 CITIZEN SCIENTIST 'CLOUDY WITH
 I WAS ONE 10K PEOPLE WITH A CHANGE OF
 ARTHRITIS PAIN WHO TRACKED PAIN + SYMPTOMS
 WELLBEING → **IMPACT OF WEATHER**
 I KNEW **RAIN + DAMP** MADE MY **PAIN WORSE**
 I FOUND OUT **HUMID + HOT** WORSE PAIN TOO

2017 I WATCH THE WEATHER TO PLAN MY
 WEEK + SPOON THEORY + **YOGA** + **NATURE**



2021 PAIN MANIKIN
 RESEARCH PROJECT - TRACKING
 LOCATION WITH AN APP -
 LIKE CLOUDY IT WAS
HARD PAIN + FATIGUE
 WORSE + COVID LOCK DOWN
 = MANY PHONE ALARMS
 'BELLING ON THE **PAIN**
 WAS **HARD** BUT I NOTED
 THE WEATHER + STEP
 COUNT. THIS HELPED ME

WHAT I KNOW NOW



the **WI**
 INSPIRING WOMEN

My special people are...

HUSBAND +
FAMILY +
FRIENDS +
CRAFTERS

thoughts + **WELLNESS**

I will take the time to...

START A SMALL CRAFTING PROJECT

TAKE A WALK

BEMINDFUL IN THE MOMENT

Slow Adventures

COOK

Wellbeing by the sea

uplifted by music

BETTER SLEEP

Escaping Less is more
 into my garden

FEEL CALM **WALKS**

THE PAIN IS EVERY DAY
 FOREVER BUT I SHALL
 KEEP GOING 1 STEP AT
 A TIME!!

WARMER CLIMATES

I AM **Happy** + **Proud** OF ME

2023 → **ONWARDS** LOVE FROM

by Rebecca

My Pain Story -

Living with Fibromyalgia, is a total nightmare.

Its not a life that anyone choose.

I spend every minute trying to hide it as it costs and affects friendships, relationships, I've lost both. My pain can be triggered by the weather, cold and windy can elevate me to a 9 pain or even into a 10. I fight physical, immensurable pain on a daily basis it is emotionally draining both physical and mentally.

I get up everyday feeling shaky, unsteady on my feet my body feeling like a tin man. Most Mornings

I wake with pins and needles in my hands or not feeling my hands, making it hard to grip anything like a tooth brush or hair brush. Starting my day already feeling exhausted, with a low mood due to not having a restful night. Having to sit on the bath so I can try to have a wash. It takes me around half an hour to come around in the morning.

My Mouth is constantly dry due to my medication I take. I constantly feel chronically Exhausted.

My bones feel like they are bruised, I have back ~~cramps~~ spasms ~~not~~ which can be debilitating.

My first alarm will go off to prompt me to take my morning medication. I have this as I am very forgetful. If I didn't I wouldn't know if I had taken it, I have this set for 4x a day for all medication.

I ~~not~~ suffer badly with brain fog. I also struggle with recalling words mid sentence, I often use wrong words while having a conversation or totally forget what I am talking about.

I constantly struggle taking in information in letter form and my son now has to read it for me.

I struggle with multi tasking and don't have a long attention span. I easily get distracted. I am unable to perform simple maths or remember numbers, I constantly forget my pin numbers for my bank card which then is embarrassing. Thank god for contactless!!

I struggle with wide spread pain throughout ~~the day~~, my body where I feel like I have a vice around my rib cage that feels like it's constantly squeezing and going tighter and tighter

~~from~~ ~~there~~ ~~and~~ I also suffer with non cardiac chest pain on a regular occasions I do take medication for this it suppressed but is still there along with side effects from the medication.

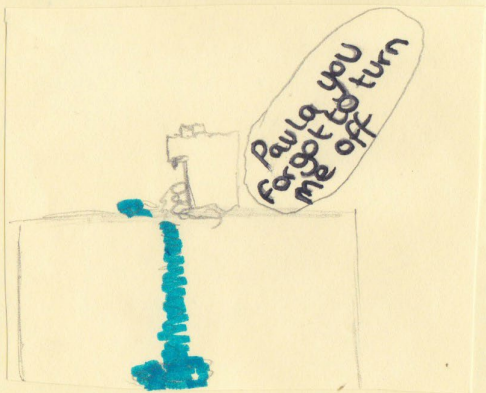
I've noticed that I suffer from sensory overload I don't cope well with noisy environments this makes me feel very overwhelmed and panicky, my chest goes tight and I feel very emotional.

I also don't cope well with bright lights. as they make my eyes hurt. I don't drive when it has gone dark as I now struggle to see and the lights give me headache.

Paula Jones

This pain story
contain the effect
it can sometime
cause having
fibro and the
effect it has on
me and my youngest
daughter.

amy.p.i



My Pain Story!

Strength
Change
Pains
Fighting
Determination
Fibro-fog
Emotions

The Negative's

- Chronic fatigue
- fibro fog
- Mental health
- Weight gain
- Shaves



Thing's What
upset me?

- Relying on my Kids.
- Can't plan day's
- feeling a let down.
- Not always being able to walk the dog!

How it affect's my youngest daughter?

was heartbreawing not to be able cuddle my mum when she was having bad day and the Pain was debilitating!

Osteoarthritis + Jo

2009

LEFT HIP
REPLACEMENT
SURGERY



RIGHT
SHOULDER
SURGERY



LEFT FOOT
SURGERY



LEFT THUMB
SURGERY



BUT!

ANTI
INFLAMMATORIES

TRYCyclics

SWIM

PILATES

MEDITATION

MASSAGE

OPIATES

YOGA

CBT

RIGHT KNEE
SURGERY



*I will not let it RULE

Joint Hypermobility

PARACETAMOL

MUSCLE
RELAXANTS

NORDIC
WALKING

PHYSIO

RELAXATION

- GYM

STEROID
INJECTIONS

RIGHT THUMB
SURGERY



LEFT SHOULDER
(watch this space)

2023

RIGHT HIP
REPLACEMENT
SURGERY



LEFT BIG
TOE SURGERY



RIGHT BIG
TOE SURGERY



LEFT HIP
REVISION
SURGERY

or RUIN my life *

aching
throbbing
pulsating
pulsing
flashing
numbing
tingling
'pins + needles'
burning
itching
electric shock sensation

What I do

I conflict with

pain killers
TENS machine
massages
heat patches
joint replacement
weather

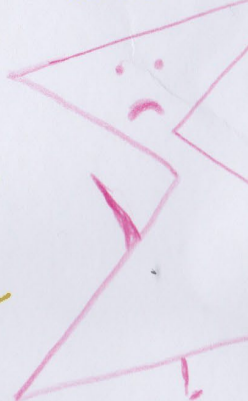
How I am

periodic
post-operative
chronic pain

acute
random

following a fall,
an accident
'wear and tear'
menstruation pain

Who am



PAI

Who do I affect

Potentially anyone
(→ injury, accident,
arthritis, fibromyalgia,
cancer, chronic pain,
acute pain, multimorbidity
.... etc) -

I ?

When do I operate

anytime
24/7, 365 days/yr
day/night
whether your body
is active or not

How do I operate

on a pain intensity scale
of 1 to 10.

Carrol

Life

Family

Hospital

Blood
Tests

NAPS.

Dog

Walk.

Pain

Keds.

Friends

Bed.

Rest

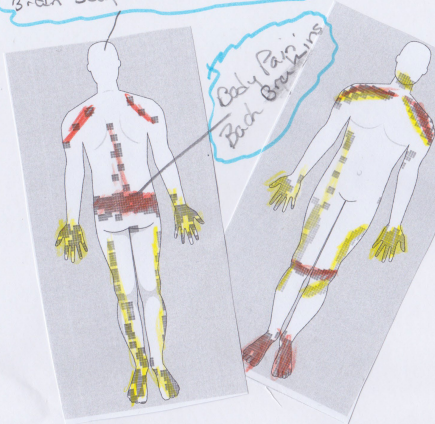
My Journey started 8th Sept 2008. Pain
hospital tests. life changed. Two years later
able to go home. To try and fit in with family
and start different life with my husband. My issues
asking for help, the small things cutting toe nails.
Drying me after shower. Open bottle .e.c.t. Now
15 years later, able and knowing what I can do.
But Husband firmly telling me what they think I
cannot do or should do. ^{their} ~~there~~ worry does not stop
Has my illness is worse, now my body is not
fighting back. Hospital is now more like home than
home. When at home friends who I can cry talk
laugh with, are my release. Also I need time to
myself. I have a small dog Milo. He was
bought, so would make me take him walks. So
have a reason to get out of bed each day.
Able to just spend time when walking with him, no
pressure. He ask's just for food and love.
There is not enough paper to explain how life
did change that day. If I can help one person
understand, how to cope I would.

Day of Shopping

Feel Great - then think
go shopping - get their
and as the day goes on
things get bad

Brain say's Push on through

Body Pain's
Bad Bruising



Day After

Well day in bed cant move Body
Broken feel like a cripple cant keep
awake had enough.
Like this for about 3 days.

Brain Broken
So Tired

Body lost
Brain lost



SYMPTOMS

- EYES - SORE BLURRY.
- JAW - SORE & DYSFUNCTION
- SKIN - ITCHY SORE DRY
- URINARY - HAVE ACCIDENTS
- BOWL - HAVE ACCIDENTS
- JOINTS - STIFFNESS SORE
- MUSCULAR - SORE PAIN
FATIGUE TWITCHING
SPASMS.
- CHEST - PAIN
- Stomach - Being Sick.
- CENTRAL - HEAD HURTS
CANT SLEEP
SLEPT TOO MUCH
MEMORY PROBLEMS
COGNITIVE PROBLEMS
DIZZINESS
ANXIETY
DEPRESSION.
PTSD.

THEY SAY you will get
BETTER BUT you don't it
JUST GETS WORSE!

CAUSES.

WEATHER
STRESS.

THEY SAY SEEK HELP

BUT THEY DONT HELP

JUST MORE TABLETS THEY
SAY DO EXERCISE BUT VIP YOU
GOT IT RIGHT DONT HELP.

SO NOW HERE ARE MY QUOTE'S
TO MYSELF.

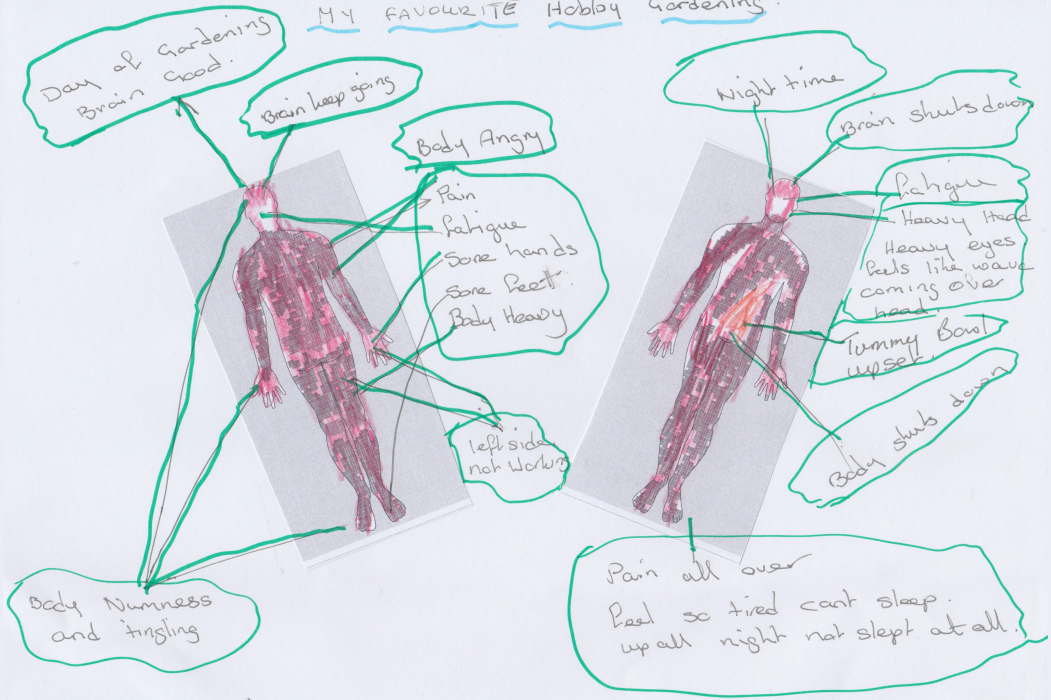
DONT CRY OVER
THE PAST IT'S
GONE. DONT STRESS
OVER THE FUTURE,
IT HASN'T ARRIVED.
LIVE IN THE PRESENT
AND MAKE THE MOST
OUT OF IT. ♥



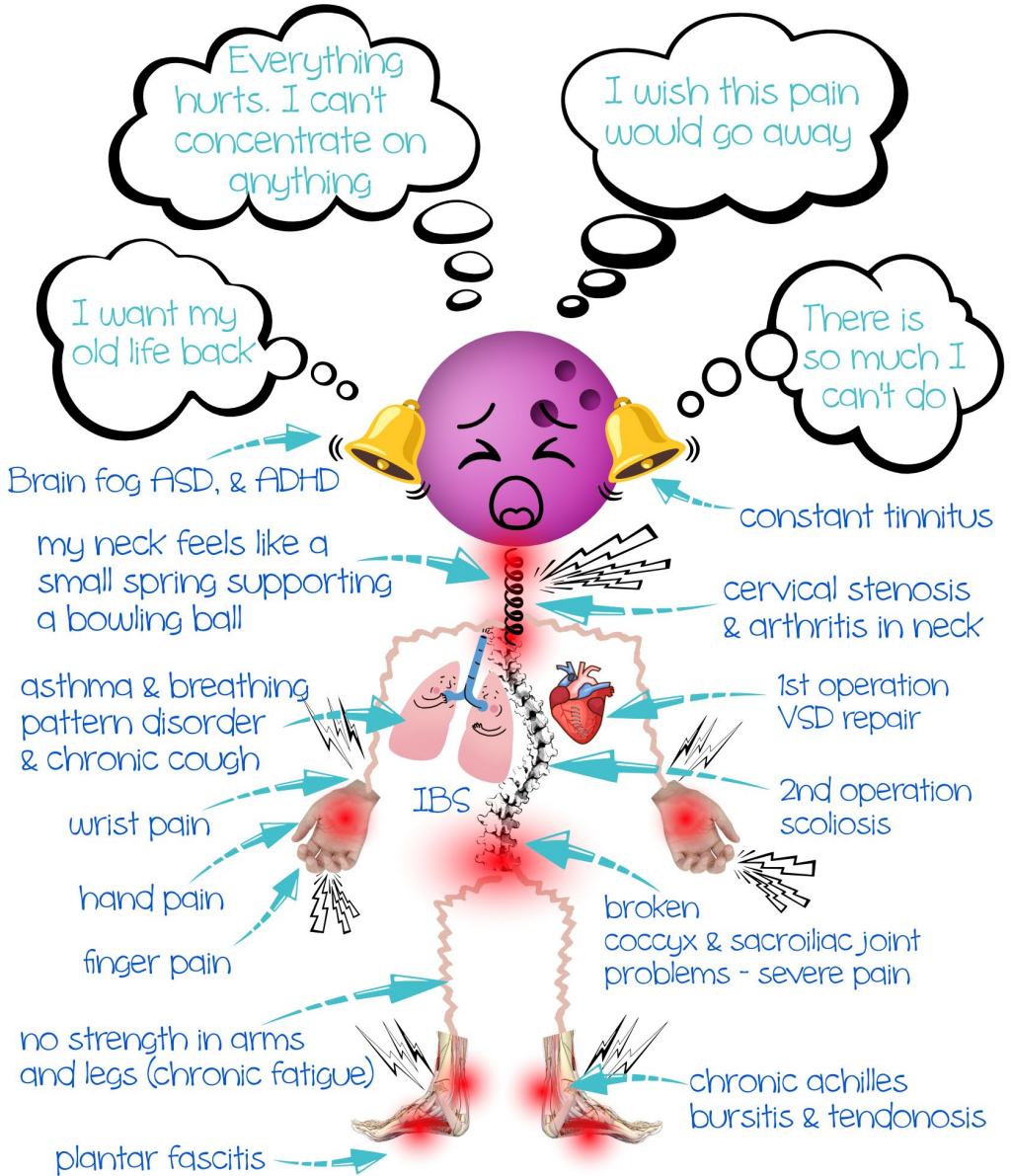
BE A
BUTTERFLY

WALK AWAY FROM PEOPLE
WHO PUT YOU DOWN.
WALK AWAY FROM FIGHTS
THAT WILL NEVER BE
RESOLVED.
WALK AWAY FROM TRYING
TO PLEASE PEOPLE WHO
WILL NEVER SEE YOUR
WORTH.
THE MORE YOU WALK
AWAY FROM THINGS THAT
POISON YOUR SOUL
THE HEALTHIER YOU
WILL BE.

MY FAVOURITE Hobby Gardening

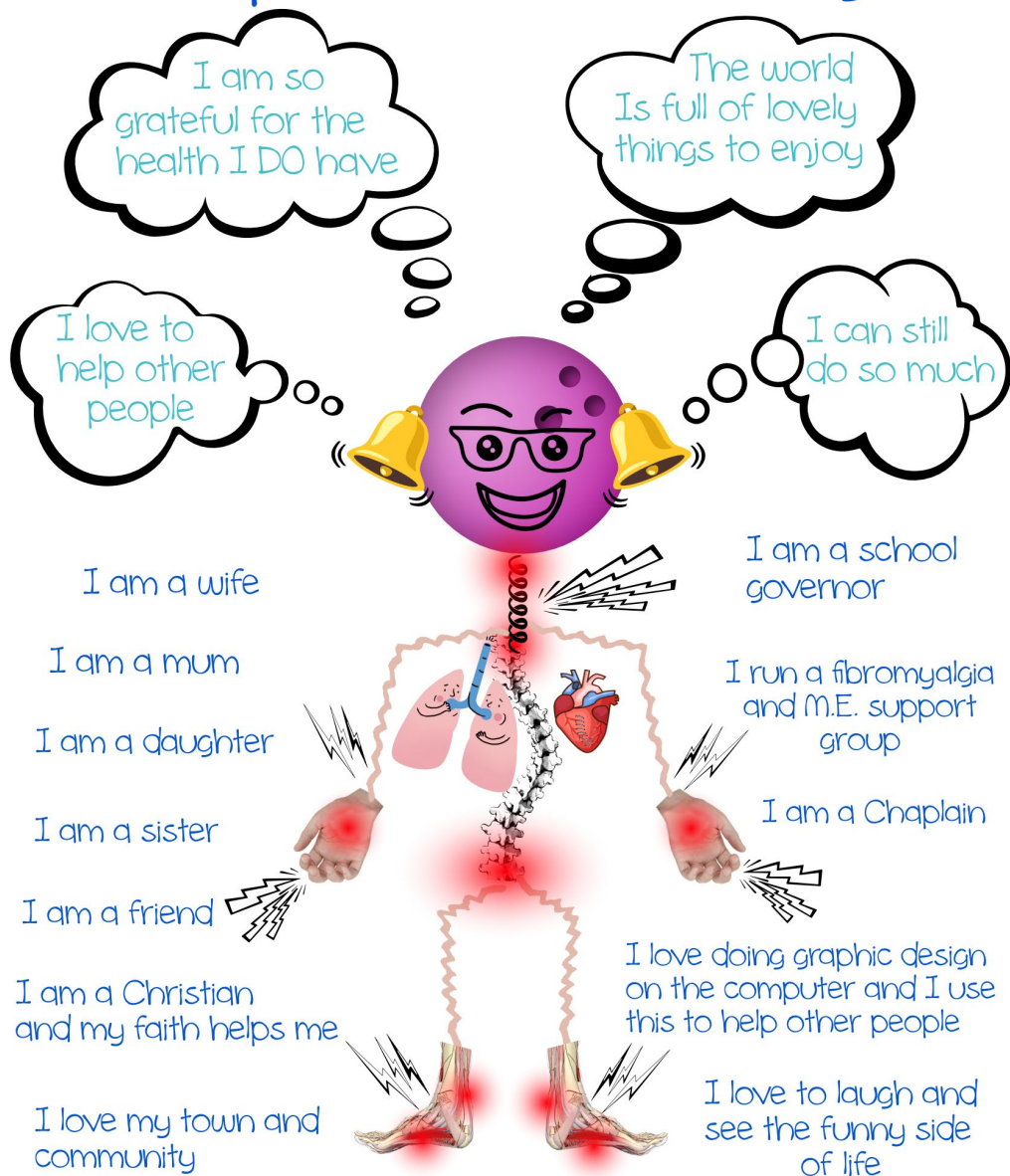


Chronic Pain is Constant



When I focus on the pain it makes me feel depressed and hopeless

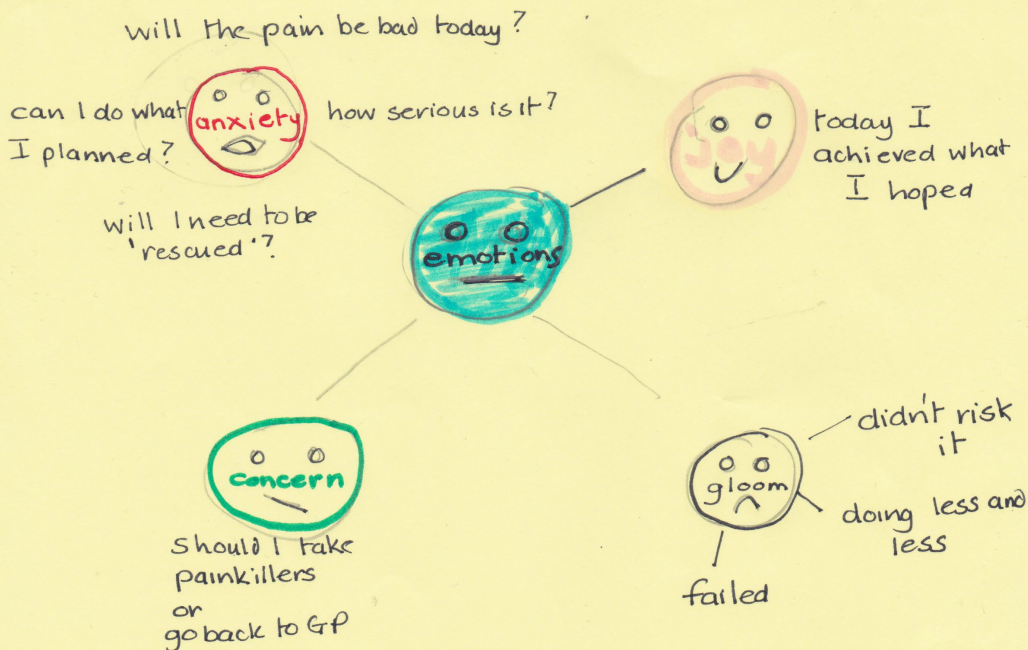
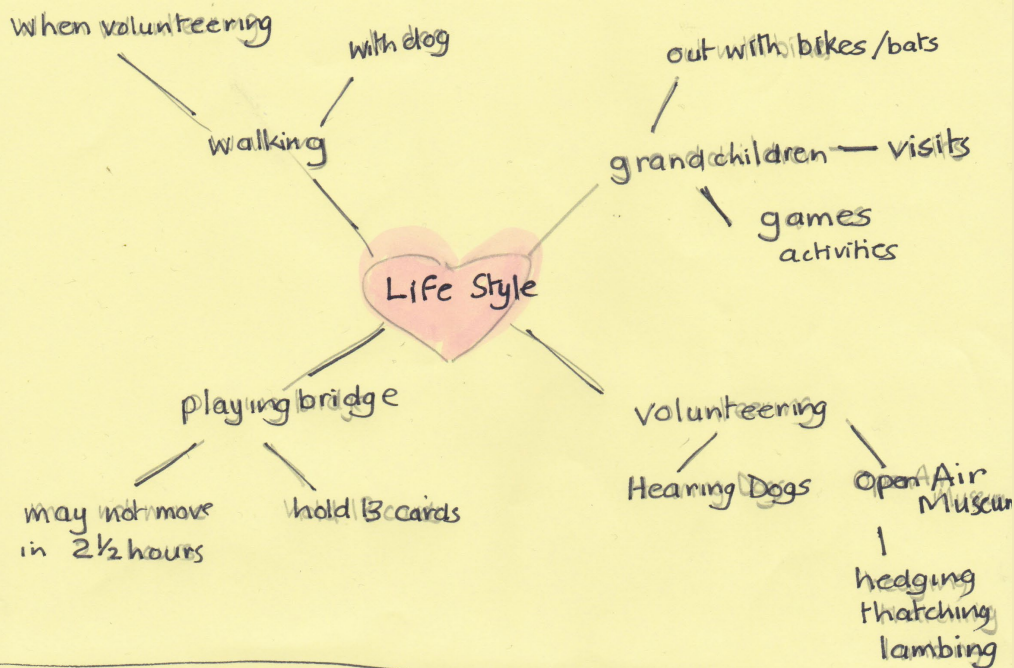
The pain doesn't change



But focusing on positive things and things outside myself helps take my mind off of it

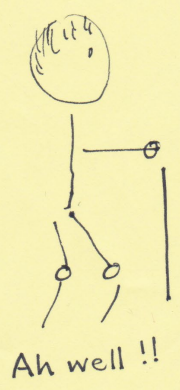
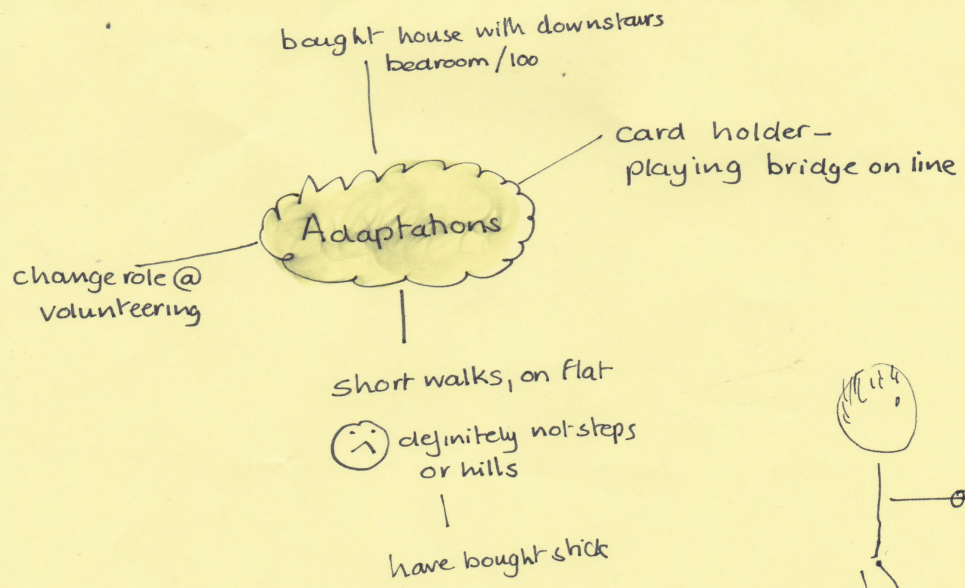
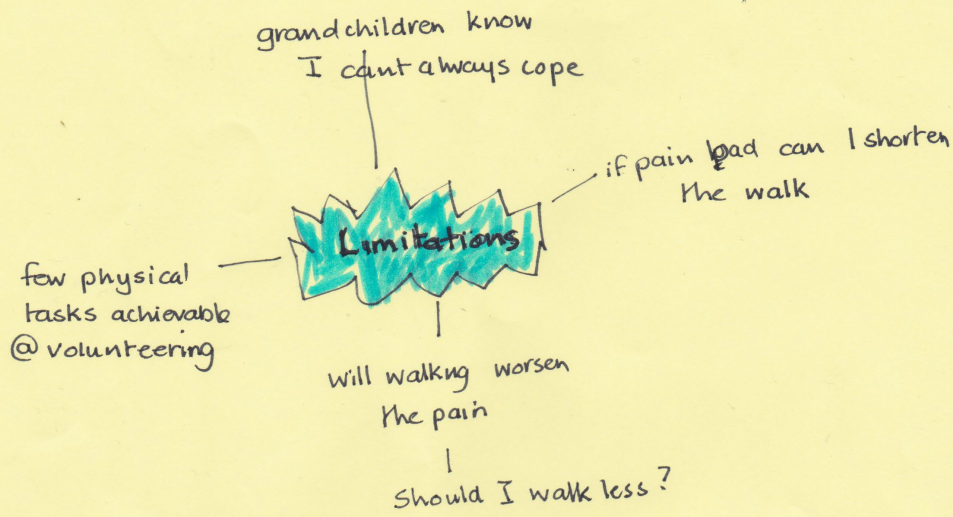
by Beckey Barton

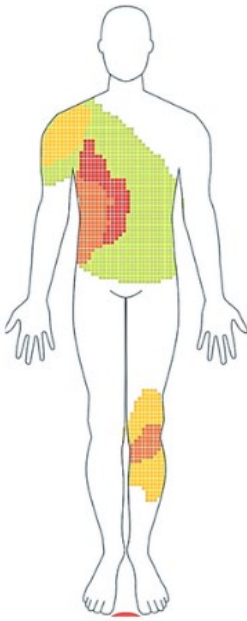
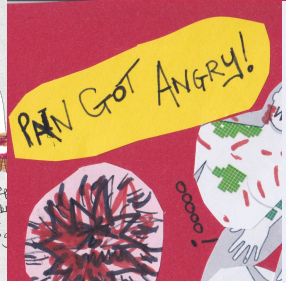
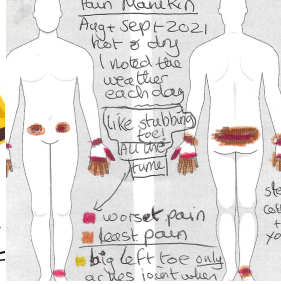
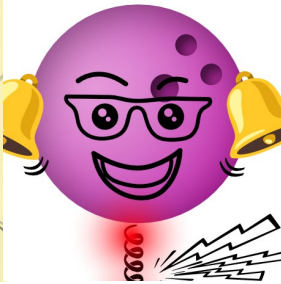
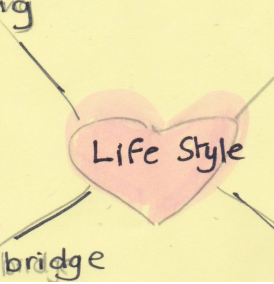
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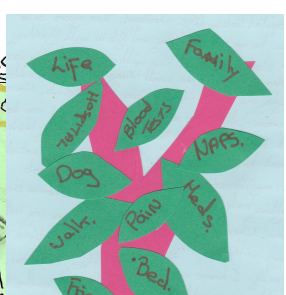
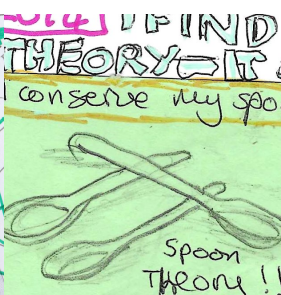
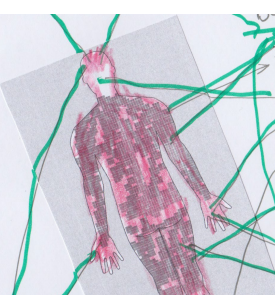
by Jennifer

2





Manchester Digital Pain Manikin





"I felt like describing my pain to someone. I thought someone's listening to me, someone's understanding it"

[South Asian woman describing her experience of taking part in the Manchester Digital Pain Manikin study]



