

ARTWORK EXPLORING FUTURE HEALTHCARE
FOR ENERGY LIMITING CONDITIONS

ANOTHER
FUTURE
IS
POSSIBLE

EDITED BY JULIAN GRAY

ACKNOWLEDGEMENTS

Thank you to all participants who took part in this project.

This zine was produced as part of a project funded by the Arts and Humanities Research Council (AHRC) as part of their programme of public engagement programme to mark the 75th anniversary of the NHS: AH/X012263/1.

The project is led by Bethan Evans (University of Liverpool), Ana Bê Pereira (Liverpool Hope University) and Morag Rose (University of Liverpool), working with researchers Alison Allam, Stephanie Davis, China Mills, Anna Ruddock, and Aaliyah Shaikh, and artists Khizra Ahmed, Khairani Barokka, Julian Gray, Mish Green and Louise Kenward.

Project partners are Healing Justice London and Chronic Illness Inclusion.

Find out more about the project here:

<http://disbeliefdisregard.uk/ahrc-project/>



FOREWORD

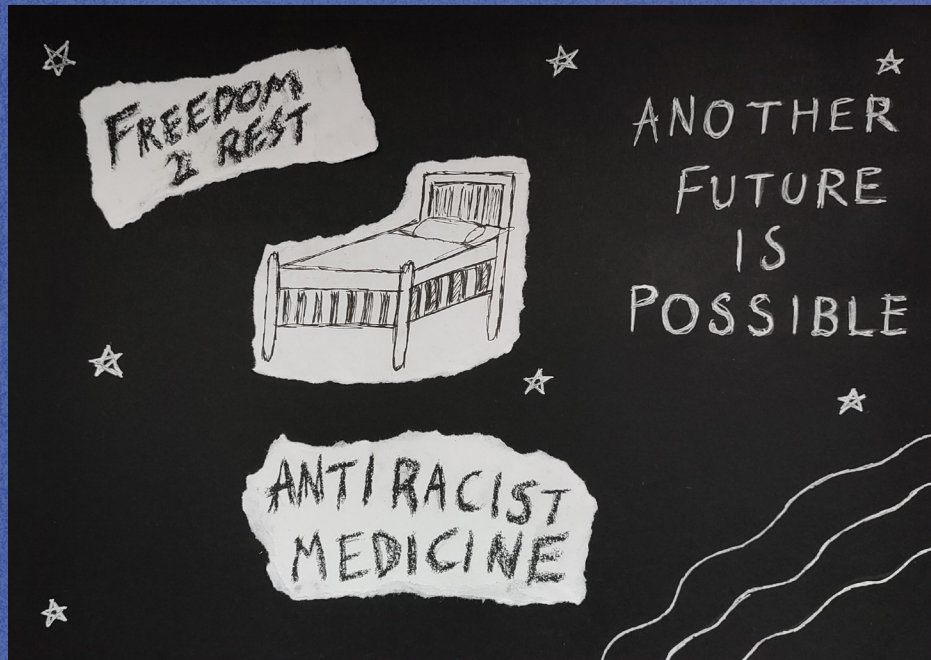
Welcome to *Another Future is Possible*.

This zine is a collection of artworks made during a series of creative workshops facilitated by myself as part of a wider project exploring possible future healthcare for those with ELCs (Energy Limiting Conditions, including but not limited to ME/CFS, Long Covid, Fibromyalgia, etc). Some of the pieces are sombre, some are hopeful; all are open, honest depictions of the artists' feelings about living with these very real conditions.

Some of the artists have provided commentary alongside their pieces, while others allow their pieces to stand alone. My sincere thanks to everyone who has contributed.

The title of this zine is taken from Zainabb's piece *Another Future* - an optimistic, hopeful and inspiring quote which represents what all of us with ELCs hope is true.

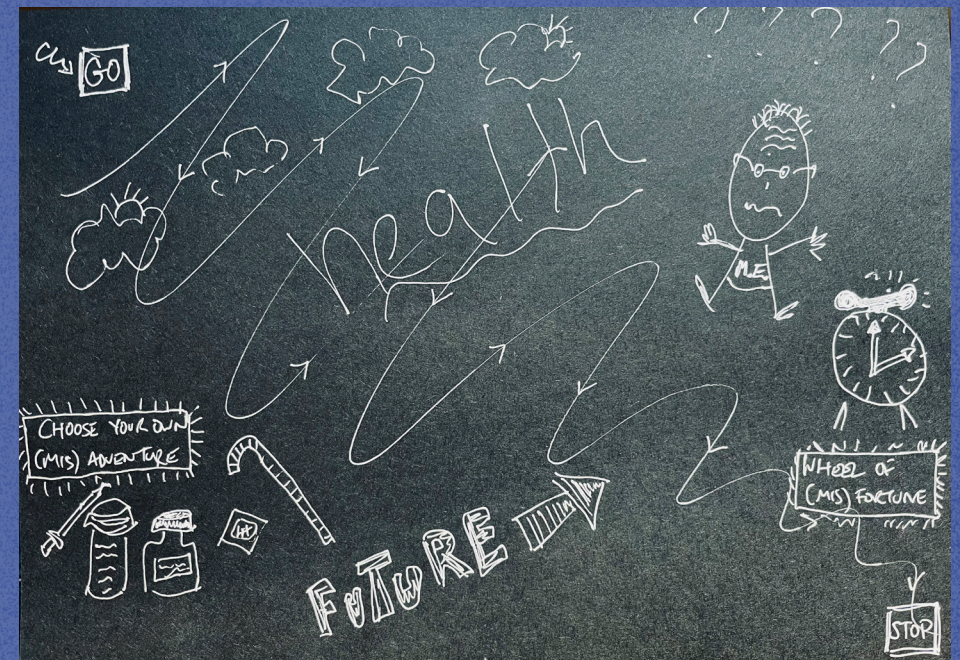
JULIAN GRAY
20TH FEB 2024



ANOTHER FUTURE
ZAINABB

FORTUNETELLING

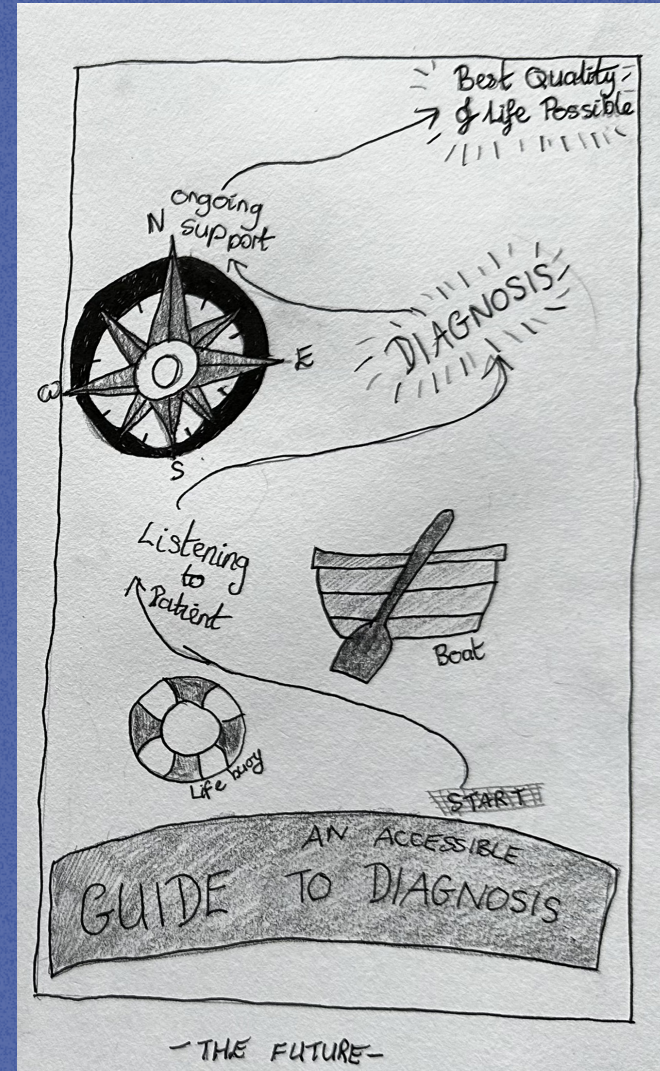
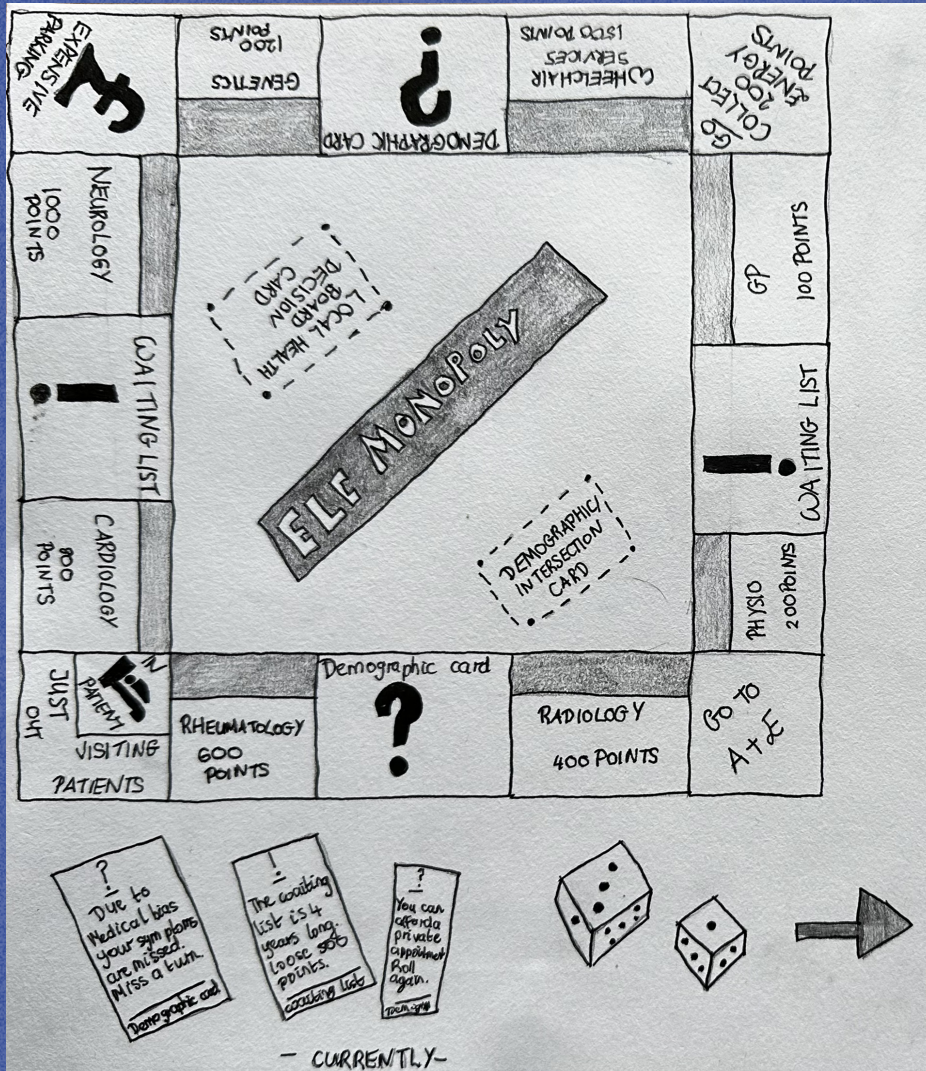
JP SEABRIGHT



"I'm not an artist, so this features words and diagrams and something approaching asemic writing, showing my stream of consciousness journey when thinking about my future health."

HEALTHCARE MONOPOLY

FERN



“Accessing healthcare with an Energy Limiting Condition can feel like landing on a monopoly board. The system doesn’t always recognise that people are not homogenous resulting in multiple barriers to overcome while simultaneously running out of energy and resources in a quest for medical help.

“Hopefully in the future a clear, accessible, linear pathway will replace this, with a focus on the end goal being each patient having the optimal quality of life in their individual circumstances.”

LONG COVID AS AN ELC FEELS LIKE A GAME OF 'ALL SNAKES, NO LADDERS'

KERSTIN

LONG COVID ALL SNAKES NO LADDERS

RULES
 YOU ROLL A SPECIAL DICE, SINCE YOU NEED TO MOVE SLOWLY.

YOUR DICE HAS THREE 1'S, TWO 2'S AND ONE 3 (BECAUSE YOU DO HAVE GOOD DAYS SOMETIMES).

YOU PLAY UNTIL YOU REACH 100. IT WILL TAKE FOREVER, BUT DON'T LOSE PATIENCE - IT'S ALL PART OF THE GAME.

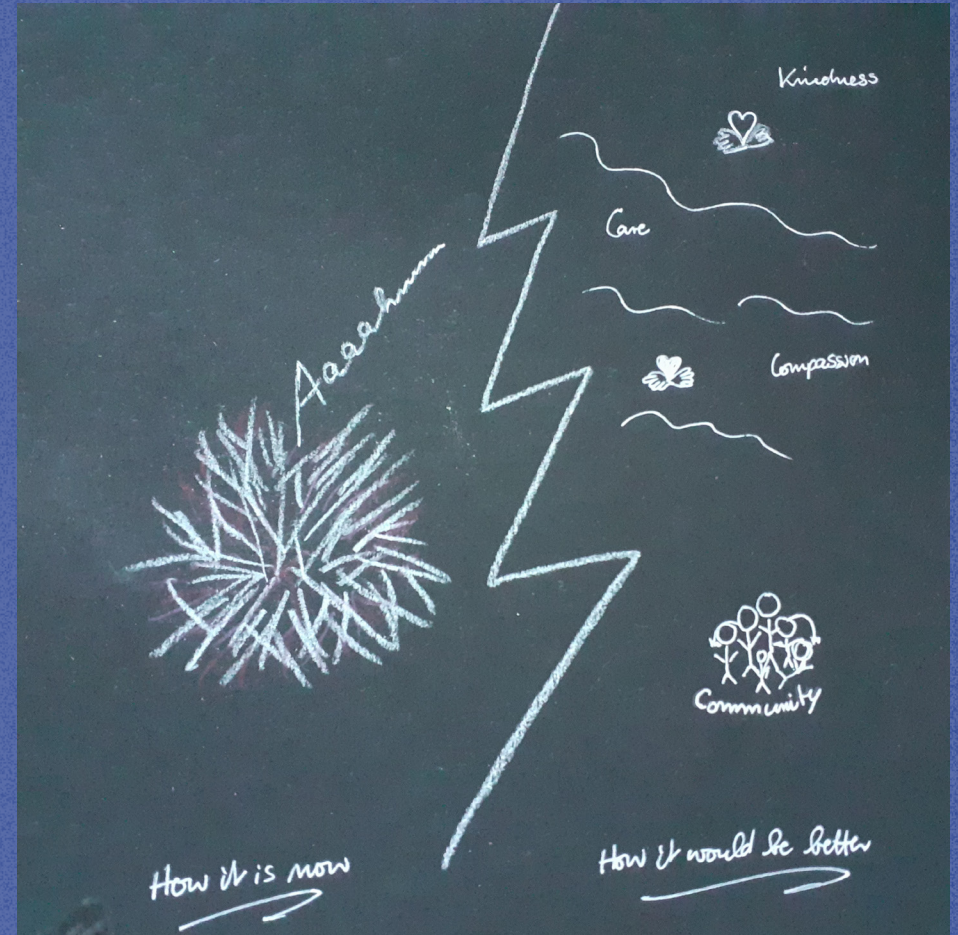
WHEN YOU LAND ON A SNAKE'S TIP OF THE TAIL, YOU SLIDE DOWN TO ITS HEAD.

THERE ARE NO LADDERS FOR SHORTCUTS - MEDICAL RESEARCH TAKES TIME, YOU KNOW. GOOD LUCK!

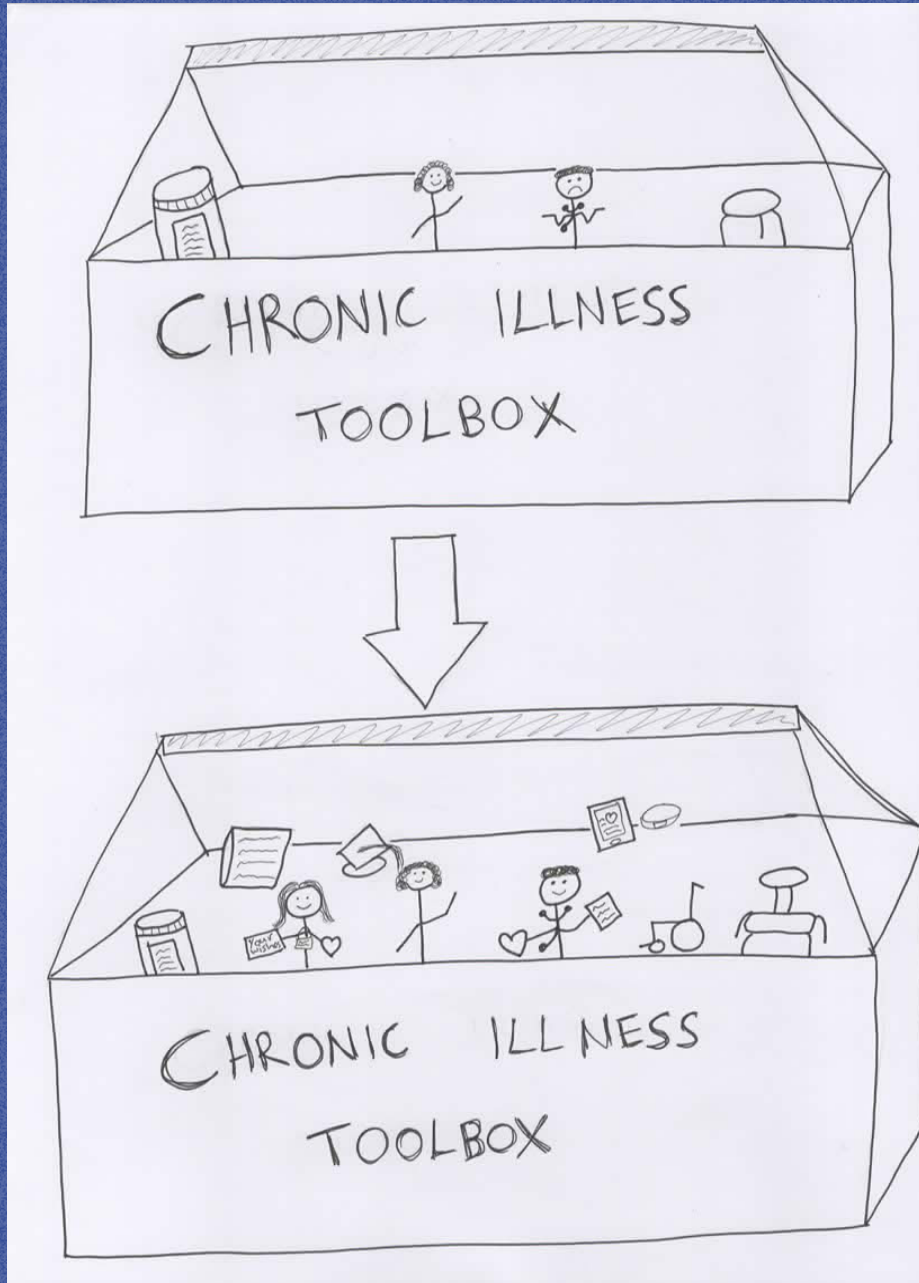
SEPT 2022

“Living with Long Covid feels like a never-ending game of Snakes and Ladders, only someone has taken away all the ladders (there are no shortcuts, medical research takes time) and thus there are only snakes left.”

You play with a special dice only showing 1s, 2s and a single 3 since you need to move slowly. Beware all the triggers (=snakes) that may hurt your baseline.”



HOW IT IS NOW AND HOW IT COULD BE BETTER
 ANONYMOUS



TOOLBOX FOR THE FUTURE

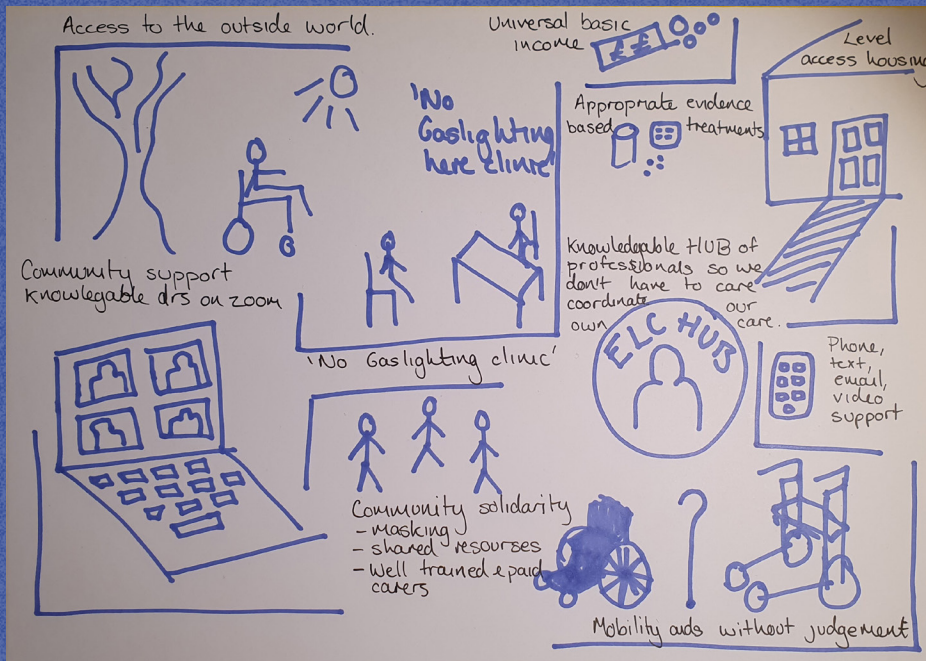
MEL

"At the top you have a mostly empty toolbox, where you have some things to help but not a lot, and the Dr doesn't really know how to respond to you.

The arrow represents progress to the future, where you still have the helpful person (this could represent any kind of care or support) and meds, but you have an empathetic Dr who has something useful for you (information, diagnosis, tests results), another health professional who will work in partnership with you (could be physio, OT, specialist nurse), you have proper equipment, you have new technologies and you have research."

A BETTER FUTURE...

AMY



“Anyway the hub would have multidisciplinary professionals who are knowledgeable about ELC. They would know about pacing, they wouldn’t push us beyond our limits. They would do home visits REGULARLY (not just once then forget about you). They’d contact us by whatever method we chose and we’re capable of.

“There would be research clinics trying out the latest clinics.

Mobility aids would be encouraged and supported and they would be cool!! (Funky colour options)

Community care would be encouraged. We would have access to online support to meet our peers (finding this has been so important for me).

They would wear well fitting FFP3 masks to protect us and to protect themselves from getting post viral illness. The clinics would be HEPA filtered.

They would have comfortable resting spaces and resting would be celebrated.

There’s so much more I want to say but I’m out of spoons.”

“I imagine many things which are health and social care related because the two are impossible to separate for me. So much of my health is determined by my lack of access to the basic things I need to live. Like a stable income, an accessible home, mobility aids.

“Thinking about health specifically the long covid clinics have been the perfect example of how not to do a ELC hub. It frustrates me that I’m not well enough to get involved and improve stuff. I used to try so hard as a care coordinator to tie up the threads of people’s lives. If they were getting their benefits or able to pay their rent we couldn’t even look at their health.

UNTITLED INDIGO



“Drawing 1 is my current experience with healthcare for my ELC. It is non-existent. It is me sitting in my bed, on my own, feeling a bit fed up, isolated and trying to cope the best I can on my own.”



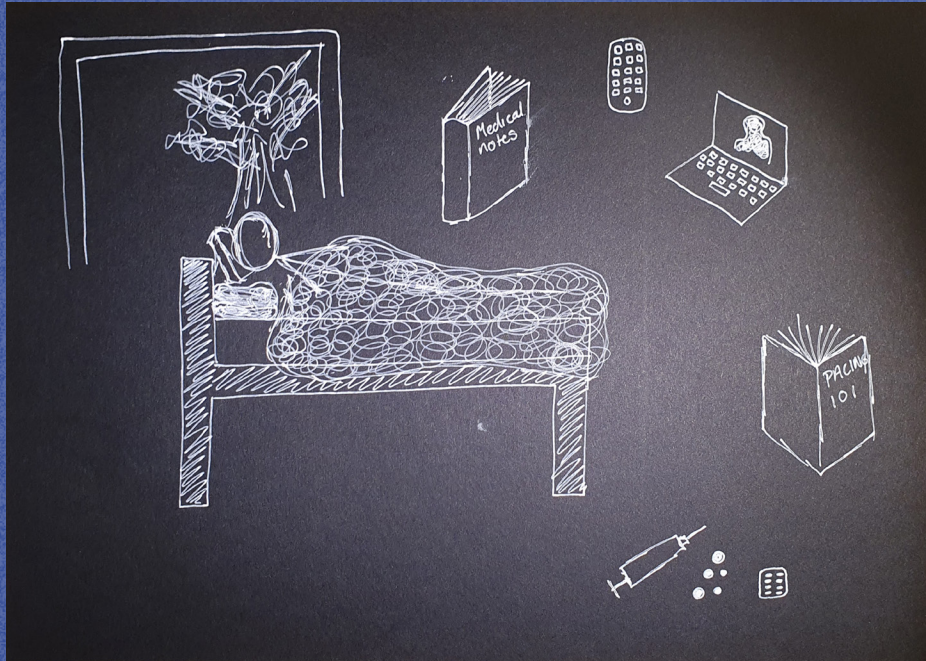
WHAT NEEDS IMPROVING IN ELC HEALTHCARE INDIGO

“Drawing 2 is what an improved, and ideal healthcare for my ELC could look like. I am at a ‘holistic care clinic’, using my active manual chair and SmartDrive and discussing options with a team of specialists who also include disabled people like me. My partner is with me and he is also supported in his role.

They are affirming towards mobility aid use, offer holistic therapies, proper pain relief, support with benefits and housing and Access to Work. They provide advocacy and follow the social model of disability and disability justice.”

UNTITLED

AMY



"I'm my own care coordinator. I have an enormous file with all my notes, every appointment letter and clinic letter and notes I've made before and after. I was a care coordinator before I got ill so I'm lucky to have this skill but advocating for myself is exhausting and its depressing how much of it is just records to send to PIP and the DWP to beg for scraps to live off.

I read up on treatments and ask Dr's to prescribe them. There is no central person helping me and every non disabled person who I say that too thinks I must be lying because they can't imagine you could be in this state and just be left to your own devices."

"This is kinda my life now. It mostly revolves around my bed. I speak to Dr's on the phone and by zoom but I have to beg for that sometimes and I don't have access to the same level of care as if I went in person.

TWO POSSIBLE FUTURES

KERSTIN

“Justice lies in the hands of everyone. Justitia, the goddess of justice with her two scales is open to either possible future for people suffering from ELCs (and everyone else feeling frail and sick).

Justitia represents society and thereby all of us. Society’s decisions will determine which side of the future will materialise.”





How ELCs WILL BE DIAGNOSED AND TREATED IN THE FUTURE

KERSTIN

“Either the current state continues and people with ELC are confused and left alone, or healthcare is organised as a network, where a healthcare professional, possibly a GP takes us by the hand and leads us through the process. They would be the grown-up in the room and take on initial leadership.

They would have the perfect network in mind of who could help and assist in treatments and diagnoses but eventually the network works decentralised around the patient needs, in which the patient meets everyone else on equal terms as an expert in their own condition. The network is fully connected, so everyone is up to speed and aware of what is happening in other parts of the network.”



HOW I SEE MYSELF AS I AGE

KERSTIN

"Either I might age alone in my armchair, or I might be as fit as everyone else of my age and I sit, content and white-haired on a never-ending park bench next to my partner and we're all resting and caring for each other as we enjoy our time together.

The bench continues to show that we're all on the same page now: no one is rushing anymore and I'm not left behind because I'm slow and need to rest."



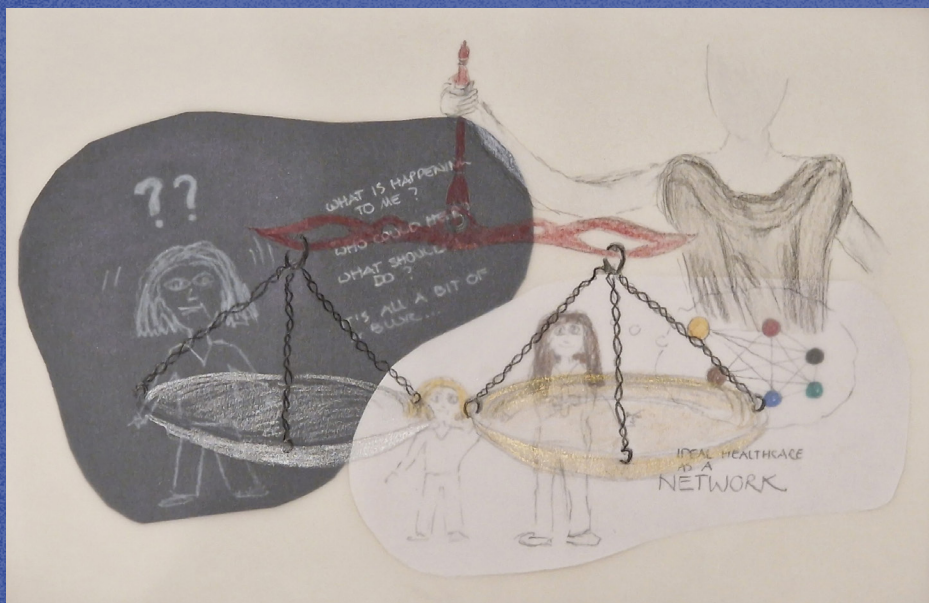


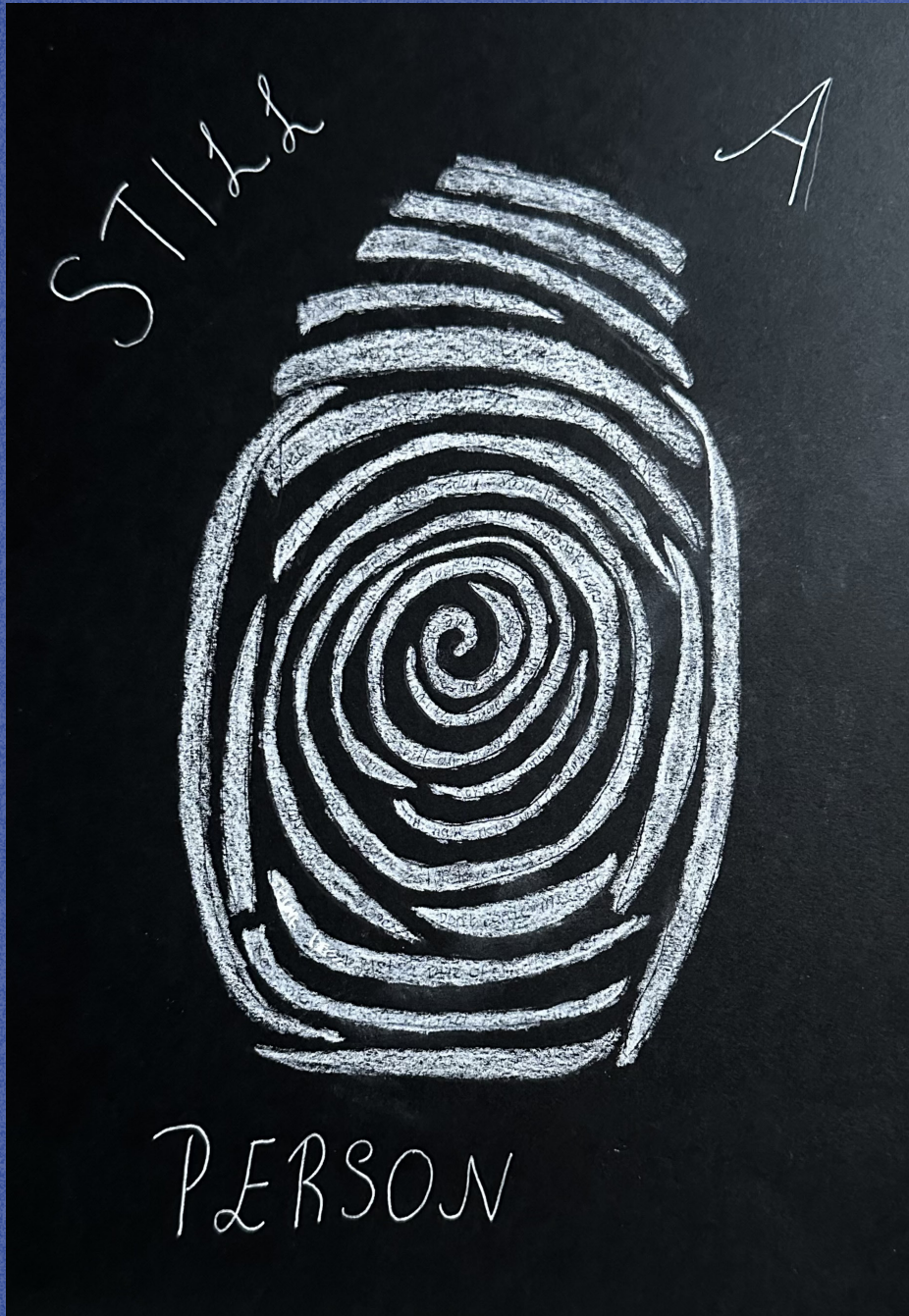
THE FUTURE OF ELC DIAGNOSIS AND HEALTHCARE

KERSTIN

“Either people with ELCs and other disabilities are forgotten and left behind while society marches on.

Or in a brighter future, society has taken action to include the ‘millions missing’ and has invested in research so that people with ELCs are no longer ignored. Scientific breakthroughs have enabled an understanding of what is going awry in the bodies of people suffering from ELCs and there are proper diagnostics, therapies and treatment available. Societal empathy ultimately makes our lives easier and more livable, not just by financing solutions but also by offering true care through understanding and inclusion.”





STILL A PERSON

FERN

"My hope is that when people with ELC age both health and social care will remember we are as unique as individual fingerprints."

We are not simply caseloads and files to be forgotten about. Our lives still have value."



A LIGHT WITHIN REACH

BRI

A light within reach
So I know which way to swim
Signposting safety
Not a siren on the rocks.

Bri