



Experiencing Fatigue

Dr Anna Kuppuswamy, Effort Lab, UCL
and Sofie Layton

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Talk Transcript – Dr Anna Kuppuswamy

Hello, and welcome to the **Experiencing Fatigue** public engagement panel discussion.

I'll start off with some background to the project. Now, I am a scientist who is interested in understanding how the **brain contributes to development of fatigue** in the long term of **stroke**.

Now, this was something that I was interested in, immediately after finishing my PhD, and I started thinking about ways of addressing this question. So the first thing I looked into was **how do we measure fatigue?** And the obvious answer was **questionnaires**. So you give either 10 to 15 questions, or depending on what questionnaire we use, it's either short or long. And we get information from the **stroke survivors** about their **fatigue levels**. And I thought, 'Ah, hey, we have got a good tool for measuring fatigue.'

And slowly over the last eight years, I have come to realise that the **fatigue questionnaires**, although **extremely useful** in getting an overall picture of the levels of fatigue, it **doesn't give** you the **full picture** in relation to the **experience of fatigue**.

How do **patients** actually **experience** the **symptom**? It's not simply a question of **tiredness**, there are lots of other **elements** to it, specifically, **sensory processing** seems to be altered quite significantly.

Now, this is not necessarily captured in all of the questionnaires that we use. And I set about thinking, **how** do we **understand** this **experience** of **fatigue**? Now, why do we **need** to **understand** it, the critical thing is, unless we get a **full picture** of the **experience**, we are not going to be able to **pin down** what it is that the **brain** is doing to **contribute** to these **experiences**.

Now, that's when I thought, well, **questionnaires** – although extremely useful – are **not serving** the **purpose** for what I am interested in, which is to **understand** the **underlying mechanisms** of **fatigue**.

I need to **learn more** about **experience**, how do we go about doing this? And this is when at this point in time, I attended a UK Stroke Forum day, which was organised by Cassie Hugill. And that's when I thought, well, I need to start **interacting** with **patients** more exclusively just for the **purpose** of **understanding** their **experience**, as opposed to just bringing them in to do experiments.

And that's where the **arts project** was born. And of course, I'm very grateful to Cassie who has helped me put this whole idea together and obtain funding from the Wellcome Trust for this project.

Once the project was funded, of course, the entire team has chipped in, importantly, William and Sian and Sofie our artist. So this is a **hugely collaborative work**. And I'm very excited about the outcome of this project, and looking forward to taking it to the next level. So hopefully now we will hear from **Sofie** about her **experience**, and then you'll get an **opportunity** to ask her some **questions** about more about this project ([register for the panel session here](#)).

Talk Transcript – Sofie Layton

Working on the **Experiencing Fatigue** project with **post-stroke survivors** has been an extraordinary experience, and an **amazing privilege** as an artist.

Our process started back in March, and I did **one work face to face workshop** with a group of **five participants** who were incredibly generous and began to **illuminate** what the **reality** of what **fatigue** was for them.

Over the coming sort of three to four months, we had to **convert** everything to **online workshops** where we worked with **narratives**. I sent out packs of **metal embossings** with tools, and I also sent out **embroidery** to certain individuals.

And the idea behind the project was very much to **explore metaphors**, and begin to get an **insight** into what the **reality of living with fatigue** is like.

The experience that **post-stroke survivors** have of **fatigue** is something that is **incredibly visceral**, and it's quite **shocking to imagine**.

One of the participants said to me,

“I **get up** in the morning, I have a **shower**, I get **dressed**, and I have to go back to **bed**”.

And the idea that what for most of us is the **start of our day** and something that **wakes us up** and **punctuates** our day, is in itself an **enormous chore**. It began to give me an **insight** into what this very **difficult condition** is.

I sent out **embossing kits**. An **embossing** is done on an **aluminium sheet**. And people were encouraged to **emboss elements** of the **brain**. And also some people sent back **embroideries**.

What was lovely was this **process of exchange** that went on where I would send something out by post, and it would come back.

Obviously, during COVID, we had to be very careful about how we monitored infection and allowed sort of time for quarantine to happen with the materials.

And in the meantime, we were also working on **narratives** and some of the narratives that emerged through the **workshops** and through the **writing** are things like:

“Fatigue is a molten quagmire slowly creeping at a distance,
constant, unstoppable rumble.”

“Fatigue is an incessant throb felt in your chest
and through every fibre of your being.”

“Fatigue is an uninvited guest, a demanding visitor, a merciless
parasite, a dark looming presence.”

“Fatigue,
a sparrowhawk appearing from nowhere,
swooping down grabbing its prey,
and leaving a wake of devastation and trauma.”

What I've done with the narratives that were collected is that I've assembled them into a series of **three artwork panels** that combine the **embossings** and the **participative elements** that were created haptically, along with the **metaphorical written** and **spoken narratives**, to create a piece that can then be reflected on a later date.

The artworks are created using an **embossing process**, which is an **aluminium metal**, which I've **printed** on to. And then it's **combined** with the **metaphors** that emerged from the **writing workshops** that we did online, **exploring metaphors**.

And this has always also been the **starting point** for the **animation** and some of the ideas that go into the **soundscape** and things that are developing as part of the project.

So one participant said that if fatigue was an animal, it would be...

“...a sparrowhawk appearing from nowhere,
swooping down grabbing its prey,
leaving a wake of devastation and trauma.”

“Fatigue is insect-like,
a colony of ants,
a swarm of locusts
clouds of blackness appearing from nowhere
overwhelming
devastating.”

“Colour is in the mind
Crepusculo
Dusk grey, twilight
Powder pink, fragile dawn.”

“If fatigue was an animal, it would be a hippo,
lumbering
slow
lethal
crushing you within its jaws.”



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<https://the-effort-lab.wixsite.com/fatigue>

<https://www.experiencingfatigue.org/>