



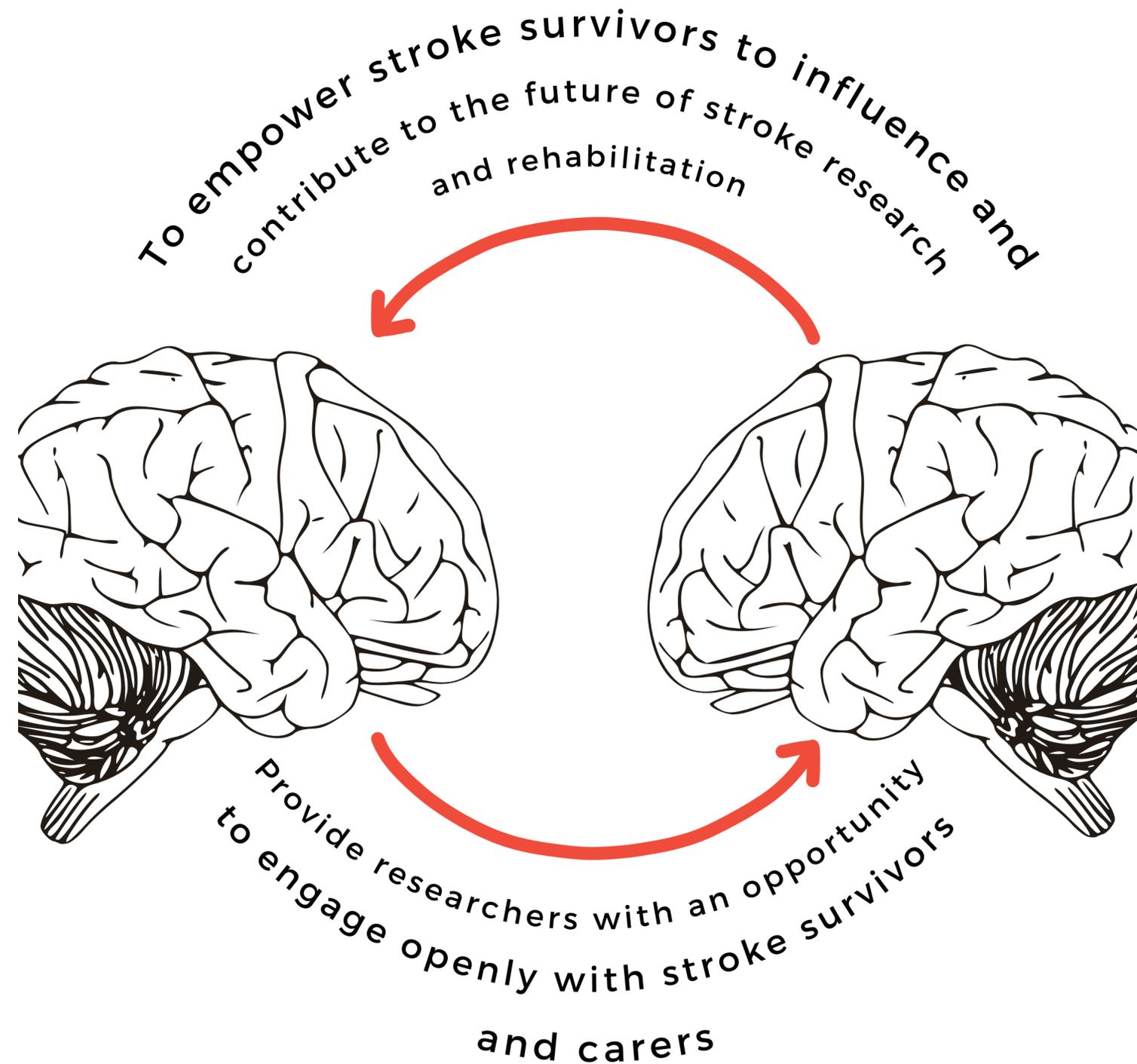
UCL
WORLD
STROKE
DAY
FORUM

2021

Aims

A series of online events run over the course of a week, including panel discussions, workshops, art exhibitions, and a showcase of digital tools.

25th-29th
October 2021.



Stroke Research



ARM LAB

Research Leads: Prof. Sven Bestmann & Prof. Nick Ward

We are interested in how we can radically improve upper limb recovery after stroke in humans, through high dose, high intensity physiotherapy and occupational therapy focused on those with upper limb dysfunction.



ASPIRE CREATE

Research Lead: Prof. Rui Loureiro

Our rapidly growing centre investigates the applications of engineering and robotics technologies to rehabilitation and assistive technologies for conditions such as spinal cord and nerve injury, stroke, muscular dystrophy, and more.

COGNITION & GRAMMAR LAB

Research Lead: Prof. Rosemary Varley

We devise new therapies for people with aphasia following stroke. Our research is funded by the Stroke Association. We are working on a new therapy directed at everyday language sentences. We use computers to achieve high dose intervention, as well as non-invasive brain stimulation.



EFFORT LAB

Research Lead: Dr Anna Kuppuswamy

We investigate the neural basis of perceptual fatigue in neurological conditions using a range of techniques, including: behavioural paradigms, non-invasive brain stimulation, brain imaging and computational modelling.

HYPER ACUTE STROKE UNIT



Research Lead: Dr Richard Perry

The Hyper-acute Stroke Unit (HASU) of UCLH brings experts and equipment together to provide world-class treatment, reducing death rates and long-term disability. Dr Richard Perry is the clinical lead for hyperacute research and his main focus is developing safe and clear protocols for excellence in hyperacute stroke care and embedding research trials into those protocols.

NORTH CENTRAL LONDON INTEGRATED REHABILITATION PROJECT



Research Lead:
Dr Robert Simister

Our project aims to support delivery of coordinated rehabilitation to stroke survivors at home following hospital discharge, and develop a program to evaluate stroke survivors' actual and perceived recovery after treatment. Dr Robert Simister recently led work with the London Hospital Ambulance service to improve pre-hospital selections of possible stroke patients using a formalised video, helping to ensure patients are taken to the correct hospital first time.



NEUROTHERAPEUTICS GROUP

Research Leads: Prof. Jenny Crinion & Prof. Alex Leff

Our research focuses on the rehabilitation of acquired language and cognitive impairments, in individuals who have had a stroke and those with dementia. We specialise in developing novel digital interventions for aphasia and other neurological conditions.

PLORAS TEAM

Research Lead: Prof. Cathy Price



Our goal in the Predicting Language Outcome and Recovery After Stroke (PLORAS) team is to provide a model of the neural basis of language that predicts and explains speech and language difficulties and their recovery after brain damage (from stroke or neurosurgery).



SWAN TEAM

Research Lead: Prof. Chris Donlan

We are the Sequences in Words and Numbers (SWAN) team. We work with Children with developmental language disorders and people with aphasia to develop the SWAN app. This is game-based therapy to help adults and children with difficulties with communication and numeracy skills.

Partners



AbilityNet believe in a digital world accessible to all. They support anyone living with any disability or impairment to use technology to achieve their goals at home, at work and in education.



abilitynet.org.uk | Charity number 1067673



Aphasia Re-Connect aims to improve the lives of people with aphasia through building on people's strengths. Their mission is to create a peer support network of people living with aphasia to enable them to live life, discover opportunity, develop confidence and find wellbeing.

aphasiareconnect.org | Charity number 1176125

The ARNI Institute is a stroke charity which provides specialist rehabilitation and exercise support after hospital and community physiotherapy finishes. Their approach to stroke rehabilitation is dynamic, innovative and linked directly to the very latest neurorehabilitation evidence base.



arni.uk.com | Charity number 1116130

a stroke / of luck

A Stroke of Luck offers advice and access to exercise-based Stroke recovery. Their mission is to provide stroke survivors with the opportunity to access fitness professionals training services to aid their recovery and rehabilitation.

astrokeofluck.co.uk | Charity number 1186213



Brain Research UK is the UK's leading dedicated funder of neurological research. They fund the best science to achieve the greatest impact for people affected by neurological conditions, to help them live better, longer.

brainresearchuk.org.uk | Charity number 1137560

The Brain & Spine Foundation's mission is to improve the quality of life of people affected by neurological problems by providing expert information, support and education. Their expert services are there for people at every stage, from first symptoms, diagnosis, treatments and in the long term.



brainandspine.org.uk | Charity number 1098528



Capgemini is a global leader in consulting, digital transformation, technology and engineering services. The Group is developing a prototype of a speech therapy app (SpeechFirst) using artificial intelligence to give user feedback as part of their Tech4PositiveFutures initiative.

capgemini.com

Nikki May is a yoga instructor dedicated to showing stroke survivors that life can be amazing with their new normal. Her online videos explain how meditation and yoga twists can help brain injury.

**FINDING YOUR
NEW NORMAL**
With Nikki May

[instagram.com/finding_your_new_normal/](https://www.instagram.com/finding_your_new_normal/)



the brain injury association

Headway is the UK-wide charity that works to improve life after brain injury by providing vital support and information services, including a free helpline, website, publications and an emergency fund, a Brain Injury Identification Card and a directory of rehabilitation and respite facilities.

headway.org.uk | Charity number 039992

**The National
Brain Appeal**
Funding advances
in neurology and
neurosurgery



The National Brain Appeal help provide much-needed funds to support one of the world's leading centres for the diagnosis, treatment and care of patients with neurological and neuromuscular conditions.

nationalbrainappeal.org | Charity number 290173

The Neurological Alliance is over 70 organisations working together to transform quality of life for people with neurological conditions by improving treatment, care and support.



neural.org.uk | Charity number 1039034

NHS
University College London Hospitals
NHS Foundation Trust

UCLH provides first-class acute and specialist services in six hospitals in central London. Their mission is to deliver top-quality patient care, excellent education and world-class research.

uclh.nhs.uk | Charity number 1165398

The Royal College of Speech and Language Therapists is the professional body for speech and language therapists in the UK. Their mission is to create better lives for all people with communication and swallowing needs.



rslt.org | Charity number 273724



The Stoke Association provide specialist support, fund critical research and campaign to make sure people affected by stroke get the very best care and support to rebuild their lives.

stroke.org.uk | Charity number 211015

Think Ahead is dedicated to improving the lives of stroke survivors, their carers and families by rebuilding health, hope and confidence through support, advice and friendship.



think-ahead.org.uk | Charity number 1128934



DISCOVERY RESEARCH

How researching the brain post-stroke improves health outcomes

Panels

Five panels focusing on major themes in stroke research and rehabilitation were held across the Forum week. Each panel consisted of a documentary screening and an open Q&A with the audience. The panels were illustrated by a scribe to capture important conversations explored during the session.



It can take several years and significant funding to make small steps of progress in science. Yet studies that focus on the intricate details can lead to big changes in the long term. This panel explored how improving our understanding of basic brain processes can ultimately revolutionise stroke care and rehabilitation.

Currently, stroke receives significantly less public funding compared to other common health conditions such as cancer. But stroke charities are campaigning to change this, according to **Georgina Hill** from the **Stroke Association** and **Katie Martin** from **Brain Research UK**. In the meantime, charities play an important role in funding discovery research projects, such as those at UCL Queen Square Institute of Neurology.

Discovery research studies can take many forms. For example, UCL's **PLORAS team**, led by **Professor Cathy Price**, is currently working on a prediction tool which will give stroke patients more information about their most likely course of speech and language recovery. Different strokes have different consequences, and personalised predictions account for this. Cathy believes it is important for

patients to understand that their own recovery may take a different journey to other stroke survivors, and that predications allow patients to prepare for their future and choose the optimal treatments available.

Understanding the brain post-stroke relies on stroke survivors taking part in research studies, which can feel daunting. PhD student **Haya Akkad** frequently works with stroke survivors for her research into speech production recovery, which is funded by Brain Research UK. After asking about their health and experiences of rehabilitation, she scans their brains with various forms of brain scanning technology including MRI and MEG, as well as using non-invasive brain stimulation techniques.

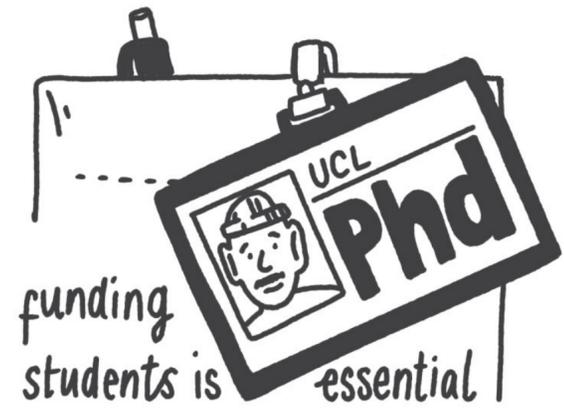
Researchers can help volunteers identify a suitable study to take part in, according to **Professor Sven Bestmann**. Sven studies movement in stroke survivors to develop better approaches to stimulate specific brain regions and aid recovery. Even if somebody had a stroke a long time ago and has received lots of rehabilitation therapy, they can still contribute to stroke research. They may even see further improvements in their recovery.

DAY ONE

UCL WORLD STROKE DAY FORUM

DISCOVERY research

HOW RESEARCHING THE
BRAIN POST-STROKE LEADS
TO BETTER HEALTH OUTCOMES



funding students is essential



WE CAN LEARN
SO MUCH WITH THE HELP
OF STROKE SURVIVORS

SCIENTIFIC STUDIES CAN TAKE A
LONG TIME AND BE VERY EXPENSIVE



WE RECEIVE LESS
FUNDING THAN OTHER
AREAS.

currently, strokes only receive
1.2% of public and charity spend

IF WE KNOW
EXACTLY WHAT
HAS HAPPENED,
WE CAN...

discover
new treatments,
like non-invasive
brain stimulation.

and better predict
outcomes in stroke
cases to help patients
meet their potential!

PLORAS

There's still a
lot we don't know
about stroke
recovery

We'll only understand
how to repair the brain
if we know exactly how
it's been disrupted

understanding
why
treatments work

The more we spend on
research,

the less we need
to spend on
long term care!

DAY TWO
UCL
WORLD STROKE DAY FORUM
REHABILITATION APPS AIDING RECOVERY FROM HOME

One to one in person therapy is best, but it's not always an option.



Numerical learning is often overlooked in patients with aphasia

SWAN was developed to be similar to children's numerical games and was proven to significantly improve both numerical recall and confidence.

We need to focus on creating apps people **WANT** to use

IReadmore is a single word reading app that's been 14 years in development

Smart features adapt to your personal ability

Improves reading ability in just 4 weeks.

Designed with people with aphasia, for people with aphasia.



Apps can put the patient BACK IN CHARGE

SpeechFirst

using ai to give feedback to users as they continue therapy

TOTAL

- the NHS cannot -
- provide the level -
- of support that -
- is needed.

- Private therapy is -

- available, but -

£ INACCESSIBLE

Apps could also free up therapists to work in more engaging, personalised therapies with patients



IT'S VERY HARD TO CREATE SOMETHING THAT WORKS FOR EVERYONE

giving AUTONOMY in recovery & REDUCING inequality in healthcare

REHABILITATION APPS

Aiding recovery from home

Research suggests stroke survivors typically require significant hours of speech and language therapy to see a marked improvement in their recovery. Yet NHS services can only provide a fraction of what is needed. This panel discussion explored how app-based therapy aims to help bridge this gap.

But why apps? **Professor Alex Leff** explains that apps offer something different by providing a narrow focus on a specific skill. This “intensity” of apps is an advantage, as well allowing autonomy in therapy, according to **Professor Rosemary Varley** – with a caveat that computer therapy should be supported by recommendations from a trained specialist.

But some people can benefit more from practising at home with an app, without the pressure of someone watching, according to **Dr Carolyn Bruce**. Carolyn's research team is developing an app called SWAN,

which allows stroke survivors to practise their numerical skills by playing number games. This is one of several rehabilitation apps being developed at UCL. For example, iReadMore, a language-focused app developed by Prof Alex Leff's group has recently been released to the public.

Holly Brown, who was part of the team who developed the SpeechFirst app at **Capgemini**, has seen for herself how rehabilitation apps could help stroke patients. Holly's dad had a stroke 14 years ago, and still practices his speech therapy as part of his recovery. She believes app-based therapy would make this even more accessible for him and others, even so longer after their strokes and when NHS support has come to an end.

But is there a limit to the extent of recovery one can achieve through apps? “No, there isn't,” says Prof Carolyn Bruce, stressing that people are constantly learning and changing.

HOW TECHNOLOGICAL ADVANCEMENTS BOOST RECOVERY



While the COVID-19 pandemic has been difficult for stroke survivors in many ways, it also accelerated the development of new technologies designed to improve stroke treatment, care and rehabilitation.

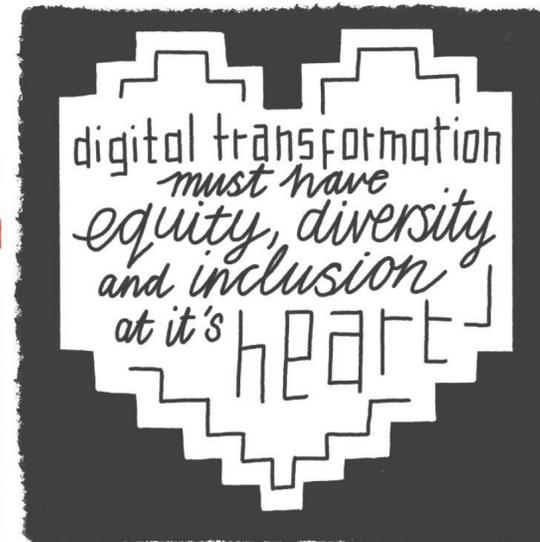
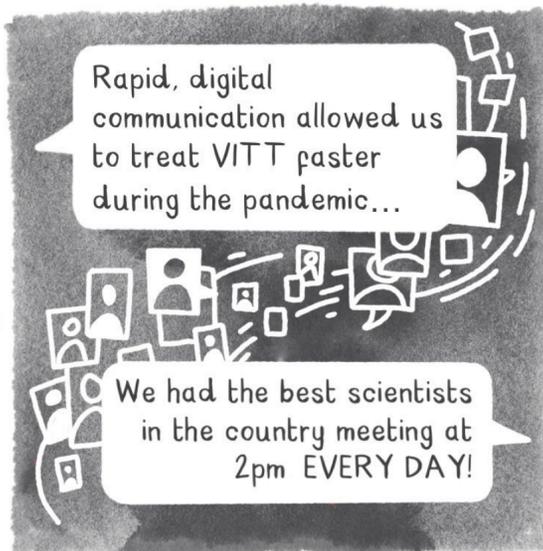
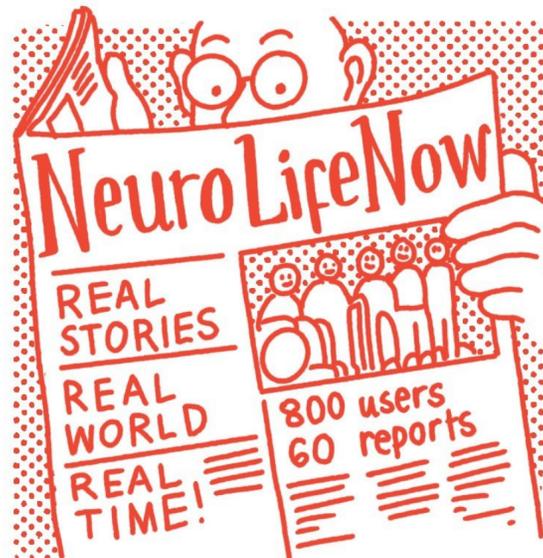
In April 2021, incidences of very rare, stroke-related side effects of COVID-19 vaccines began to be reported. Luckily, a team of stroke experts rapidly developed treatment recommendations thanks to regular video calls enabling them to convene during lockdown. One of these experts was **Dr Richard Perry**, who credits technology with facilitating better communication among healthcare professionals in the pandemic.

Technology was also utilised to directly interact with patients during lockdown. NeuroLifeNow is an app and website for people living with neurological conditions to share their experiences of health and care services. Lockdown meant the app could be released earlier, even with limited functionality, according to **Marc Smith** from the **Brain and Spine Foundation** and **Georgina Carr** from the **Neurological**

Alliance – the two charities behind the project. This allowed them to respond to feedback from users and improve it. This shift in focus towards home-based systems and low-cost technology, such as apps, was seen throughout stroke research including for **Peter Snow**, whose research focuses on the applications of robotics for rehabilitation at UCL.

But technology has also transformed on-the-ground emergency care for stroke patients. **Dr Robert Simister** worked closely with the **London Ambulance Service** to develop a pilot project which remotely triages stroke patients with the input of doctors via video conference.

As lockdown lifts, what does the future of stroke technology look like? Stroke experts believe continued collaboration between healthcare providers, researchers and patients is crucial, and predict more personalisation of therapies. However, in our technical world, digital exclusion and the impact of health inequalities are important considerations.

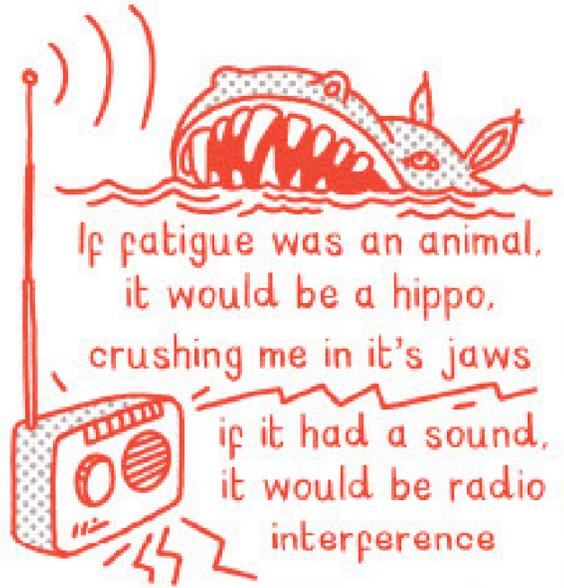


A collaborative arts and neuroscience project with artist Sophie Layton, made in collaboration with stroke survivors and neuroscientists Dr. Anna Kuppuswamy and Dr William De Doncker

what does **FATIGUE** feel like?



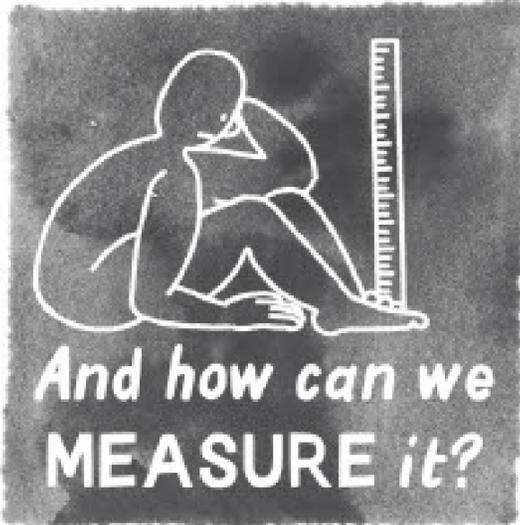
If fatigue was an animal, it would be a hippo, crushing me in it's jaws
if it had a sound, it would be radio interference



CREATIVITY that's accessible to **all!**



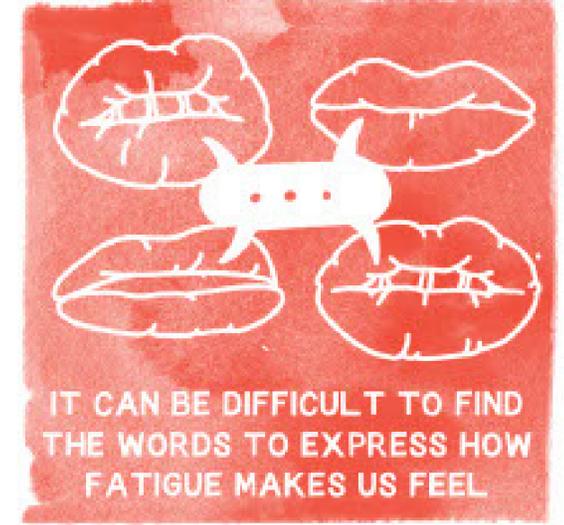
And how can we **MEASURE** it?



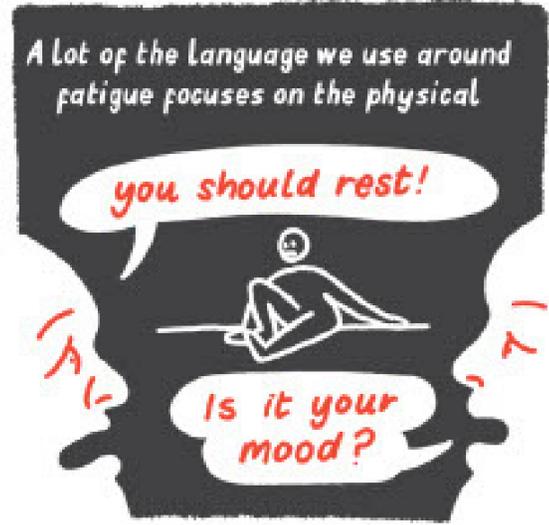
Using clay to make a portrait that expresses our fatigue



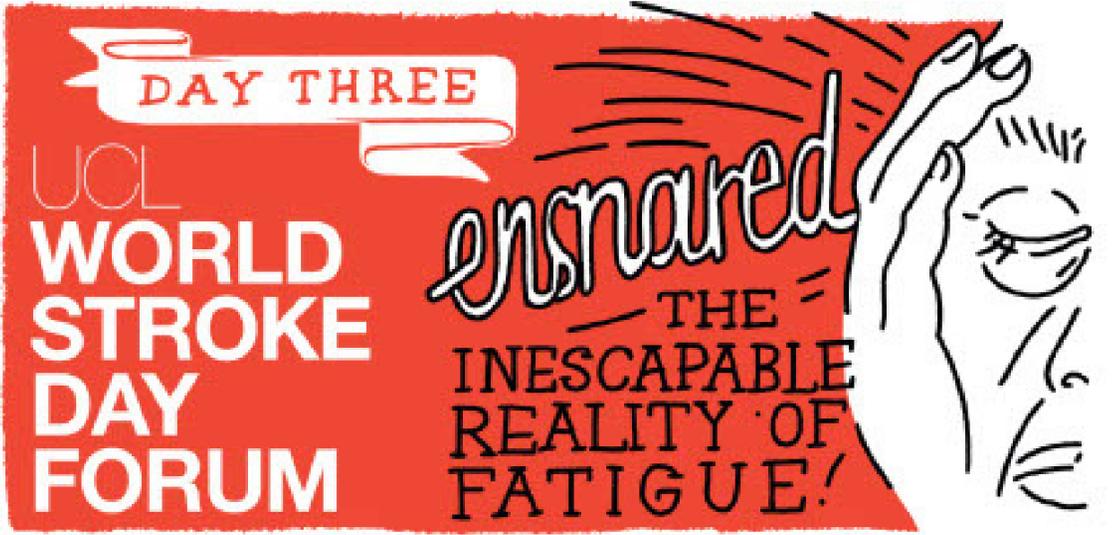
IT CAN BE DIFFICULT TO FIND THE WORDS TO EXPRESS HOW FATIGUE MAKES US FEEL



A lot of the Language we use around fatigue focuses on the physical
you should rest!
Is it your mood?



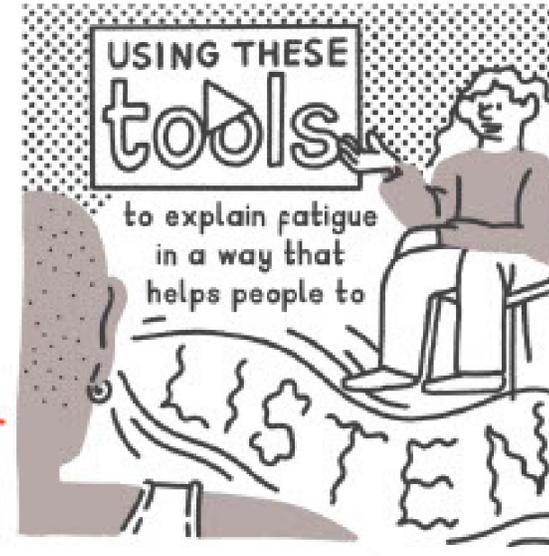
DAY THREE
UCL WORLD STROKE DAY FORUM
ensnared
THE INESCAPABLE REALITY OF FATIGUE!



If we understand better, can use our findings to influence treatment in the future



USING THESE tools to explain fatigue in a way that helps people to



ENSNARED

The inescapable reality of fatigue

ENSNARED is a collaborative arts and neuroscience project, which transformed stroke survivors' metaphors for post-stroke fatigue into a series of digital artworks. This panel session formed the official launch of the ENSNARED artwork.

The story of ENSNARED began with **Dr Anna Kuppuswamy**, who found that her research participants had many different ideas about their fatigue. Anna felt that a new more explorative medium was needed to understand fatigue, as the conversations within the lab were limited in what could be captured.

This was the birth of a collaboration with artist **Sofie Layton**, who ran creative workshops with stroke survivors to find ways to visualise fatigue, including modelling a blind self-portrait out of clay, embossing images of MRI brain scans, and embroidering metaphors for fatigue. Sofie then worked with these metaphors alongside a team of artists to develop a digital series of artworks, including performance photography, film, animation, and soundscape.

For the stroke survivors who took part, viewing the artworks was an emotional experience. They found a powerful sense of community in working with others living with post-stroke fatigue, feeling pride and ownership over the project.

ENSNARED was also a learning experience for the neuroscientists involved. Working on the project sparked a recognition in **Dr William De Doncker** that fatigue is related not only to movement, but also how the brain processes auditory and visual signals.

While the metaphors and artworks resonate with many stroke survivors, others may not find them relatable. According to Anna, this reflects the wide variety of experiences of fatigue. In future, she hopes that the project will be expanded to include the voice of more stroke survivors and people with fatigue from other conditions. Ultimately, ENSNARED provides an opportunity to unpack and listen to other's stories, improving understand of an often elusive condition.



Photography - Stephen King
Performers - Erike Poole, Robert Clark



Photography - Stephen King



Animation - Babis Alexiadis



Workshop Participants



Photography - Stephen King
Performers - Erike Poole, Robert Clark



Photography - Stephen King
Performers - Erike Poole, Robert Clark



Workshop Participants



Animation - Babis Alexiadis

DAY FOUR

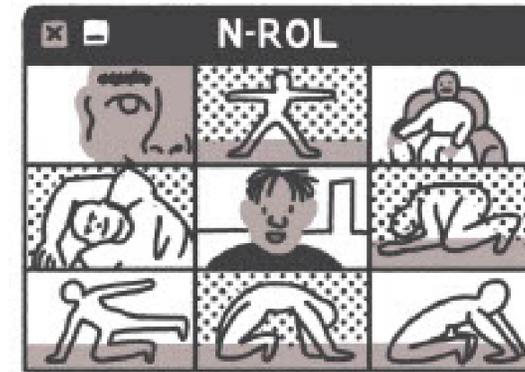
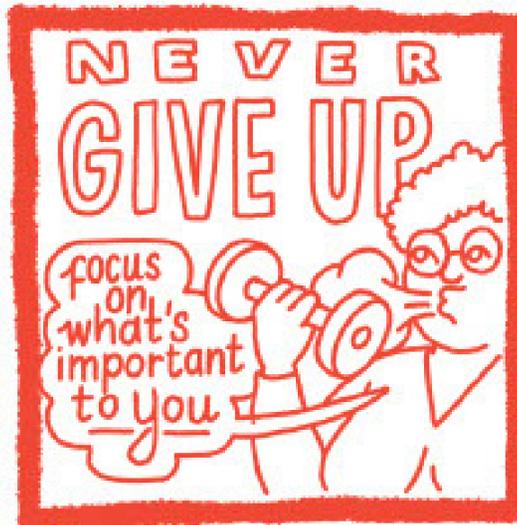
UCL WORLD STROKE DAY FORUM

IT'S NEVER TOO LATE FOR recovery

HOW NEW MODELS OF REHABILITATION
ARE HELPING STROKE SURVIVORS
YEARS AFTER A STROKE



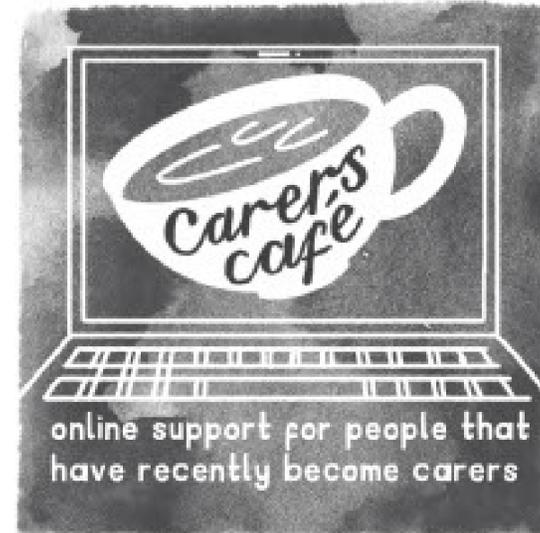
Many survivors feel that once their NHS rehabilitation is over they no longer have support



a comprehensive online
rehabilitation programme that
allows people to work in groups



rehab at home means
people can avoid the
fatigue of travelling to
sessions, and so are more
likely to do it more often

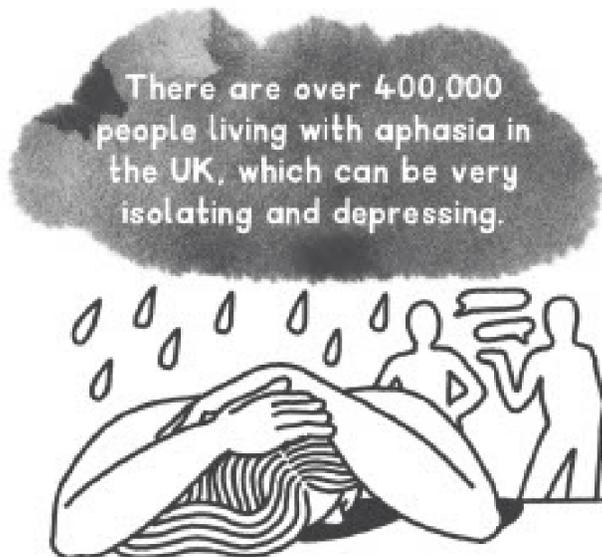


online support for people that
have recently become carers



There is no plateau in
rehabilitation

and we
need to prove it so
people can access the
care they need



There are over 400,000
people living with aphasia in
the UK, which can be very
isolating and depressing.



PATIENTS AND DOCTORS NEED
TO LOBBY FOR SUPPORT!

IT'S NEVER TOO LATE FOR RECOVERY

Stroke survivors often feel that once their NHS-prescribed rehabilitation is over, their recovery reaches its endpoint. But researchers and charities aim to challenge this notion by exploring new models of rehabilitation.

The message is one that clearly resonates with stroke survivors, who may fear they have missed their recovery window. While **Professor Nick Ward** recognises that this can be a source of anxiety, he and many other researchers agree that improvements are possible indefinitely.

High dose, high intensity rehabilitation has been shown to be effective in a number of programmes at UCL. It is these types of programmes that charities like **The National Brain Appeal** aim to fund, according to CEO **Theresa Dauncey**, as they provide frameworks for people to make empowered choices about their own recovery. **Dr Tom Balchin, ARNI**, emphasises this importance discussing how retraining - rehab and training - is vital for further recovery.

As well as rehabilitation, wellbeing support should also be

available throughout recovery, adds **Dr Catherine Doogan**.

But, while charities can provide necessary support after discharge from NHS community teams, some stroke survivors may be unaware of these services, or are unable to access them where they live. **North Central London Stroke** is a community project aiming to address this. Anyone in the North Central London area can access their care services at any point after their stroke, says **Rachel Okin**, who works on the project.

Being proactive is crucial. Stroke survivors and their carers can seek out new initiatives and request a referral from their healthcare providers. While this can be difficult, **Professor Jenny Crinion** encourages people not to give up on asking for what they need. Ultimately, underfunding and unequal access across the country are problems that patients, charities, researchers, and clinicians must continue to fight together.



Workshops

A series of interactive workshops focused on topics ranging from emotional support to staying active after stroke. These workshops prioritised active audience engagement, and stroke survivors' participation was crucial to their success.

"Stroke is like a rock dropping in the ocean. Those ripples spread far and wide, affecting friends, loved ones and family."

"Put your favourite song on and dance."

"Have someone who is close to you, a person who has patience."

"Neurorehabilitation is not one intervention. It has lots of components that can all be deployed at different times."

"The wellbeing of the carer is correlated to the wellbeing of the person who had the stroke."

"I'm 10 years down the line and it gets better."



SUPPORT GROUPS

AND HOW TO FIND THE RIGHT ONE FOR YOU

After a stroke, many survivors need long-term support to navigate changes to their lives. Peer groups can be invaluable sources of comfort and guidance, according to the **Stroke Association** and **Aphasia Re-Connect**.

Peer support is defined as drawing on shared experiences, characteristics or circumstances to support others to improve health and wellbeing. It can take many varying forms, such as conversation groups, art workshops, music classes, photography, reading and exercise classes.

As well as group activities, **Beth Scrimshaw** from the Stroke Association explains that the charity offers one-to-one telephone support and an online My Stroke Guide which serves as an information hub.

Peer support is a mutually beneficial experience, according to **Sophie Stribbling** from Aphasia Re-Connect. The charity runs a Peer Befriending scheme, which provides those who had a stroke a while ago a sense of purpose by offering support and advice to

somebody who had a stroke more recently.

For some, accessing peer support can feel intimidating. One stroke survivor, **Carol**, first believed she was too young to join a stroke support group. But when she went along, she met a variety of people from all walks of life and realised that every stroke is different. She later felt inspired to give something back and reach out to more stroke survivors.

Peer support means different things to different people, depending on each individual's stage in their recovery journey and motivations for joining a group. For some, this may be wanting advice and information, for others it may be about socialising, or helping others. Ultimately, peer support groups provide a safe space to learn and grow, with support from the stroke community.



COMMUNICATING BEYOND WORDS

Impaired language ability after stroke can make speaking or writing tricky. But there are other ways to communicate without using words.

First, it helps to consider what communication is. UCL **PLORAS team** researcher **Hayley Woodgate** thinks of communication as expressing thoughts and feelings, sharing information, sending a message, or telling a story.

The “total communication” approach acknowledges that communication takes many forms, and allows people with communication difficulties to communicate in the most accessible way to them. This may be a combination of things. Some common methods used by stroke survivors to assist their communication include drawings or photographs, gestures, emojis, and apps.

As an artist, **Sofie Layton** is interested in creative means of communicating. One particular medium is embossing. By pressing into metallic embossing paper with a pen, one can mark the shape of a symbol to represent a concept or idea.



For example, an ear with a hidden face could represent the interaction between hearing and responding.

Cyanotype paper is another artistic approach to communication. Instead of words, this technique uses patterns of shadows and light. By arranging objects into pattern on the cyanotype paper, then leaving it in sunlight for a few hours, the light leaves faded marks where the objects covered the paper.

While each artistic activity may not resonate with everyone, the workshop provided an opportunity to explore new ways to express themselves. In doing so, stroke survivors can discover what works for them, their abilities, and their specific communication needs.

HOW TO IMPROVE EVERYDAY COMMUNICATION



Communication difficulties are common after a stroke, and survivors may feel restricted in their activities due to difficulties talking to strangers. However, there are some great initiatives out there to help navigate these tricky conversations.

This is particularly important when interacting with institutions or systems. The criminal justice system has an overrepresentation of brain injury survivors, whether as offenders or victims of crime. **Holly Warner** from the charity **Headway** wanted to improve understanding of brain injury among police officers and other staff to ensure survivors receive appropriate responses and support.

Headway developed a Brain Injury Identity Card, to help people with brain injuries identify their needs without speaking. Anyone with a verifiable brain injury, including as a result of stroke, can apply for a card. It is personalised, to indicate how each person's brain injury affects them. The card is also applicable in a wide range of daily activities outside of a criminal justice setting, including using public transport or seeing a GP.

Elsewhere, businesses and institutions can be proactive in supporting people who struggle to communicate. The **Royal College of Speech and Language Therapists** and a range of partner organisations including the Stroke Association, developed an initiative called Communication Access UK, which offers training to organisations to become more accessible to people with communication difficulties. Organisations who complete the training are accredited as "communication accessible", and can display the Communication Access symbol to help people identify them.

Often, communication difficulties can mean stroke survivors are left out of conversations or treated poorly, according to **Derek Munn** from the RCSLT. Therefore, initiatives such as these aim to make a more inclusive society.

Users are also welcome to suggest ways to improve them, such as new organisations to partner with, or requesting a physical marker on the ID card so users can feel which side is the front. This gives stroke survivors a valuable opportunity to contribute to the design of services intended for them.

GETTING MOVING

Loss of motor control after stroke can be devastating. But practising movement can help stroke survivors see significant improvements during recovery, as well as maintain health and wellbeing.

As every stroke is different, so are each survivors' capabilities during recovery. **WeAreUndefeatable** is a campaign that recognises this. It is run by a collective of charities who support people with chronic health conditions and revolves around finding what works for each individual, and celebrating every achievement.

The ARNI Institute, founded by **Dr Tom Balchin**, also supports stroke survivors to regain mobility through a slightly different approach. Stroke patients receive varying amounts of rehabilitation in the NHS and this may be less than expected. Tom developed ARNI to help stroke survivors who felt they were stuck in limbo after their prescribed rehabilitation therapy via qualified therapists.

The Institute champions intensive functional task training, physical coping strategies and stroke-specific resistance training, with the goal of recovering motor control. A stroke survivor himself, Tom got to understand the power of repetitive motions over

time, to encourage brain plasticity. Stroke survivors use task-boards for upper limb retraining, which are laptop boards with items on. These help retrain a stroke survivor's reach, grasp and release ability.

Some stroke survivors struggle with rehabilitation due to lack of motivation to practise their exercises, or the movements can feel too difficult. Keeping a diary to keep track of activities can help, as can following a programme or plan.

Loss of motor control after stroke can be devastating. But being taught how to actively recover and self-manage limitations can help stroke survivors see significant improvements. Regular training can also reduce the chance of another stroke.

Tom emphasises the need to be careful and safe, without pushing oneself too far. He also emphasises the requirement to make sure survivors continually learn about potential therapies and how they can help themselves, which is a reason he supports UCL World Stroke Day Forums.



THE IMPACT OF STROKE

ON IDENTITY, RELATIONSHIPS & WORK

Trauma to the brain caused by stroke can change the way people think and feel, which in turn can impact stroke survivors' relationships with themselves and others. **Dr Catherine Doogan** works with stroke survivors to identify emotional challenges they might face. In doing so, she hopes to support this process of change.

Common changes experienced after a stroke include: difficulties with cognition, emotional and behavioural changes, impaired functioning, taking on new roles in relationships and an altered sense of identity. For stroke survivors, making comparisons to their pre-stroke self can emphasise discrepancy and cause distress. Ultimately, the key is accepting change.

Emotional support services provided by the NHS or charities

can help stroke survivors through the process of change.

The Stroke Association teaches people to recognise unhelpful coping styles (such as avoidance) and catch negative thought patterns. Sue Fitton, an Emotional Support Coordinator with the charity strongly believes that adjustment after a stroke is an ongoing process.

Moreover, adapting to change is rarely linear, according to Catherine. She draws similarities to the five stages of grief, explaining how people can move between the different stages at different times. In fact, many stroke survivors experience a sense of loss after stroke. One workshop participant struggled to reconcile their identity as a musician with their loss of ability to play their instruments.

Even through these changes, however, one way to find acceptance is for stroke survivors to identify the values that are most important to them. By thinking about how to maximise those aspects, survivors can re-connect to themselves and set new goals.

CARING FOR CARERS

Many stroke survivors require prolonged support from a carer - usually a member of their family or loved one. But while the wellbeing of the carer is directly correlated to the wellbeing of the person they care for, many carers feel unsupported and overwhelmed.

The **N-ROL project** at UCL was mostly aimed at stroke survivors, offering online neurorehabilitation during the COVID-19 pandemic. However, it also included a support group specifically designed for carers, to explore common stressors and introduce potential coping strategies.

Carers sometimes tend to minimise their own struggles, especially in relation to their loved one who had a stroke. But **Dr Catherine Doogan** advises against this. To get help, she emphasises, we have to understand the difficulties and challenges that carers face themselves.

One particular difficulty is a lack of information in the early days after a stroke. Many carers struggle to know what to do or where to turn for support in the beginning. They may also feel unprepared for the

psychological and emotional changes in their loved one after stroke.

Charities and community organisations can provide advice and information for carers to support them as they take on this role. Regional stroke charity **Think Ahead Stroke** runs peer support groups specifically for carers to find community in others going through a similar situation. This shared understanding is crucial, according to **Alex Yoxall**, who works for Think Ahead Stroke. Alex speaks from personal experience: growing up, his father was his mother's carer after she had a stroke aged 41.

While the relationship between a carer and their loved one may be altered after a stroke, and tensions can sometimes arise, it is important that carers know support is available for them, and take to care for their own needs too.



ACCESSING DIGITAL TOOLS

The world has been transformed by digital technology, bringing with it many exciting opportunities in stroke rehabilitation. But for many stroke survivors, a lack of digital literacy can pose challenges.

According to a poll, the vast majority (85%) of workshop participants use digital tools every day. However, a majority also revealed that they experience difficulty using digital tools as a result of their stroke. Writing was voted to be the most difficult aspect.

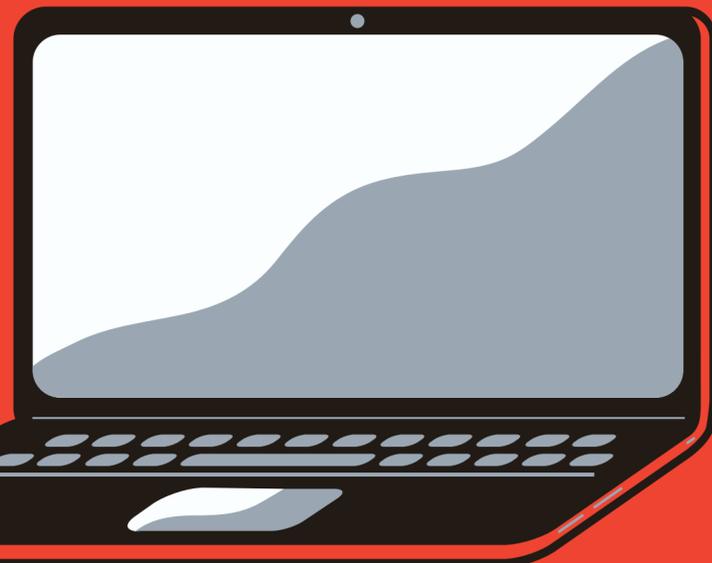
AbilityNet is an organisation working to combat digital exclusion by supporting people of all ages, with any disability or impairment, to use technology. They have a nationwide team of Tech Volunteers who support

disabled people at home to use their technology by providing specialist advice services and free information resources to build a more accessible digital world.

Some stroke survivors use specific tools designed for people with their condition. AbilityNet also works with Stroke Association support groups to see how technology can help those with communication issues after a stroke. For example, one particular intervention fits onto a pair of glasses and photographs text to turn it into speech. Another uses Bluetooth to connect a handset to a tablet for movement therapy.

Other make use of apps, such as the SWAN rehabilitation app which was developed at UCL. SWAN asks users to practise creating sequences of numbers and match numerical symbols with the corresponding spoken word. Gamifying the rehabilitation helps stroke survivors maintain motivation, according to UCL researcher **Dr Vanessa Meitanis**.

Contact AbilityNet for free by calling **0800 0487642** or use their online referral form for digital support. [Request free IT support at home.](#)



HOW MIGHT ROBOTICS TRANSFORM REHABILITATION?

Building a robot to help with rehabilitation therapy sounds like something from the future. But at the **ASPIRE Centre for Rehabilitation Engineering and Assistive Technology** at UCL, researchers are doing just that.

The ASPIRE Centre's research investigates how robot-mediated therapy can improve movement rehabilitation outcomes. However, they do not see robots as a replacement for clinicians. Instead, robots are a complementary tool that humans can use and learn from. For example, a robot can add a competitive element to improve motivation for rehabilitation exercises.

The definition of robot has been heavily influenced by industrial uses or science fiction portrayals, according to **Professor Rui Loureiro**. But robots are all around us; most of us carry around robots every day - our mobile phone.

This explains why some people may be happier to receive rehabilitation therapy from a computer-assisted system, but not a robot.

Rui and his PhD student **Peter Snow** both believe there is a trend of people becoming more open and comfortable with robotics today than 20 years ago. In a workshop poll, participants had more positive attitudes towards robotics than expected.

As robot-mediated rehabilitation therapy advances, the opinions of stroke survivors have never been more important. Researchers are eager to hear from stroke survivors about their priorities for new technologies, to guide the directions of future research.

STAYING ACTIVE AFTER A STROKE



Keeping physically active after having a stroke can be challenging for a whole host of reasons. **Nikki Evans**, founder of **Finding Your New Normal**, and **Craig Pankhurst**, founder of **A Stroke of Luck**, found this out for themselves when they both suffered strokes at relatively young ages.

When Nikki had a series of six strokes in 2013, she found comfort in yoga and meditation. She also found that it accelerated her recovery, and now she teaches others about the benefits. Craig, on the other hand, was a former international swimmer before having a stroke in 2018. He founded A Stroke of Luck to support others and championed a traffic light system for communicating his energy levels in relation to his post-stroke fatigue.

Both believe wholeheartedly in the role of a positive mindset, which can be hugely beneficial for finding motivation to recover. However, false positivity can be an unhelpful coping style. Instead of denying negative emotions, Nikki advises

stroke survivors to accept what they are feeling, and find healthy ways of dealing. Some such ways could be breathing exercises or guided meditation.

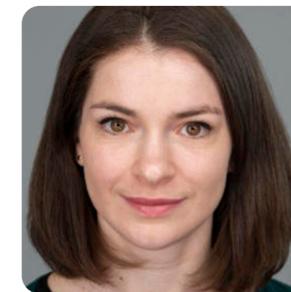
Anxiety surrounding sport or exercise can be a barrier for people who want to get back into physical activity after a stroke. People may worry that they have lost fitness or mobility skills. For others, the idea of pushing themselves too far may feel scary. Craig reassures that not everybody can go straight to the gym after a stroke. For those wanting gentler activities, his charity has put together a series of chair-based exercise for people with more limited physical capabilities.

So, what would be Craig and Nikki's number one piece of advice for staying active? For Craig, it is avoiding making negative comparisons to their pre-stroke selves. Instead, he advises, they should accept the changes. For Nikki, to be keep being proactive in your recovery.

Event Team



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INTERVIEW WITH CASSANDRA HUGILL



HOW DID THE IDEA FOR UCL WORLD STROKE DAY FORUM FIRST COME ABOUT?

The Forum was inspired by a conversation with one of the clinicians at Queen Square regarding the challenges of discussing limitations in rehabilitation with patients. They wanted to talk openly and honestly about the challenges of current rehabilitation programmes and how their research is hoping to improve this.

I wanted to create an event that brought people together in a positive way. Where researchers and people who have had a stroke could sit down with a cup of tea and discuss latest

advancements not as a professional but as a person. Both groups have so much to offer; from an academic and a lived expert perspective.

HOW HAS THE FORUM EVOLVED SINCE ITS FIRST ITERATION IN 2018?

In 2018, we launched the Forum with 100 stroke survivors and their family joining us. Held in Westminster, London, it was a mixture of workshops, talks and a large expo space with café style tables and tea and coffee on hand for those important one to one conversations. In 2020, in response to the pandemic, the Forum went entirely digital. This had many advantages including reaching a lot more people from the comfort of their own homes! However, we do miss those free flowing conversations, so are looking forward to offering some in-person events next year along with our digital programme.

"I WANTED TO CREATE AN EVENT THAT BROUGHT PEOPLE TOGETHER IN A POSITIVE WAY."

WHAT IS THE MOST CHALLENGING ASPECT OF RUNNING THE FORUM?

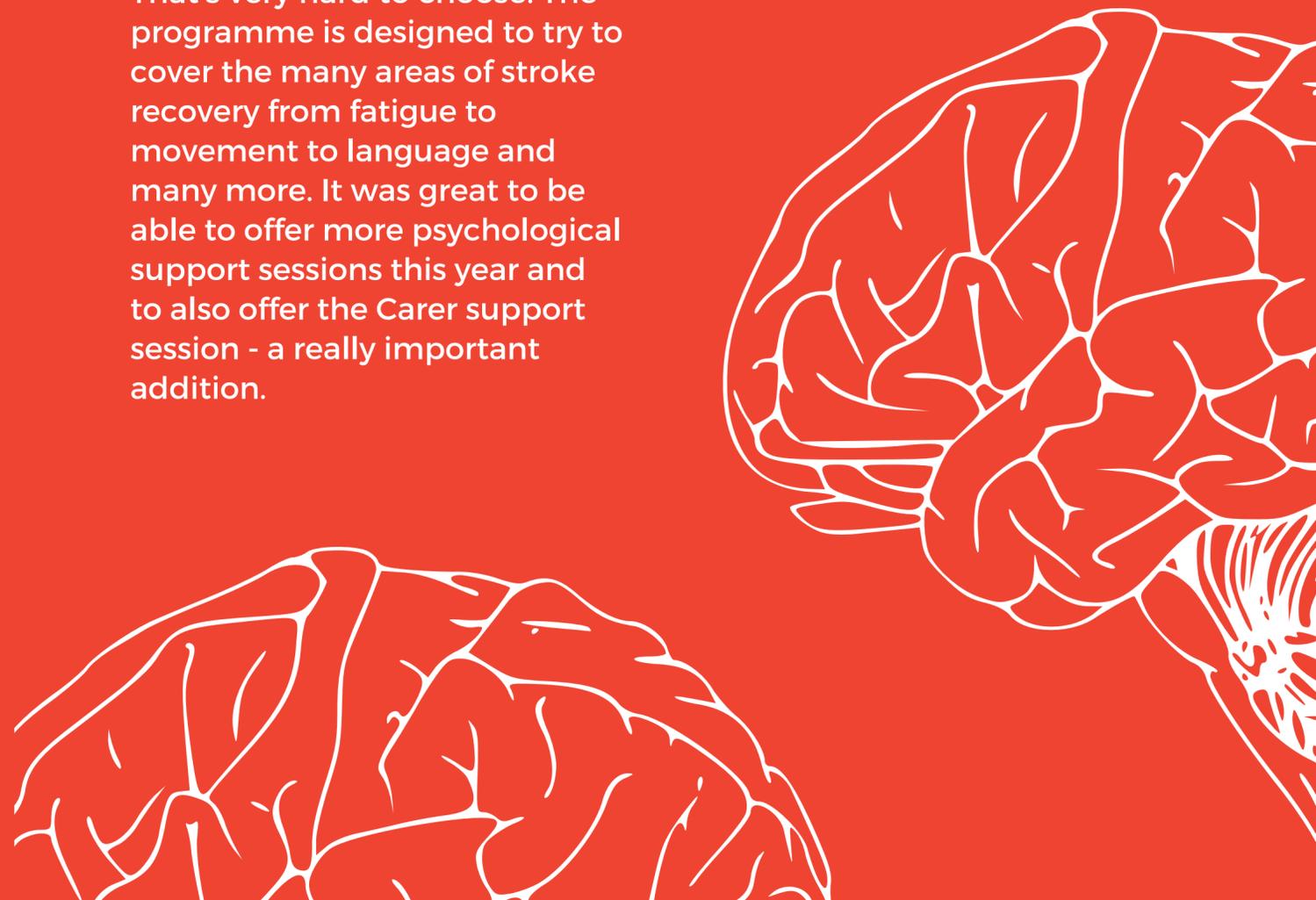
Getting the word out! We want to share the events with as many people as possible so really appreciate the incredible support of our partner charities in helping spread the word.

WHICH SESSION WAS YOUR FAVOURITE THIS YEAR AND WHY?

That's very hard to choose! The programme is designed to try to cover the many areas of stroke recovery from fatigue to movement to language and many more. It was great to be able to offer more psychological support sessions this year and to also offer the Carer support session - a really important addition.

WHAT ARE YOUR HOPES FOR THE FUTURE OF THE FORUM?

I hope that the Forum will continue to grow and evolve to meet the needs of the stroke community. Each year we bring together more people, more charities and more research teams - those connections are vital to ensure that research is meeting the needs of those they are trying to help.



Impact of the 2021 Forum



1,901

tickets booked across all events by stroke survivors, loved ones, and carers.

525

We forged new partnerships to include more collaborators than ever before:

15



Partners

9



Research Groups



77,080

total impressions across UCL WSD Forum social media pages.

112

tweets tagged #uclWSDforum.



98%



Increase in website traffic in October 2021 versus September 2021

The primary focus was to enable two-way engagement between researchers and stroke survivors. Attendees left the events feeling empowered.

Sessions with highest attendance:

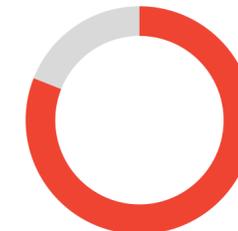
1. It's Never Too Late for Recovery
2. Rehabilitation Apps: Aiding Recovery from Home
3. The Impact of Stroke on Identity, Relationships and Work

"The Forum reinforced our determination both to persist with [physical rehab] and seek out opportunities for getting better help with [my husband's] speech & related issues." - Attendee



87%

of participants enjoyed or really enjoyed the Forum.



81%

of participants found the session topics relevant.

"I think the Forum's strength was the ability to bring all sectors together. There was such a broad range of researchers, practitioners and patients all able to share & learn together." - Attendee

Session voted most useful by attendees:
Staying Active After a Stroke

What motivated our contributors to join the Forum?



Researchers and charities also gained valuable insights from stroke survivors and carers to inform future research and public engagement opportunities.

"Being in touch with patients and their main concerns for what needs to be better understood is inspiring for me as a scientist, who likes to believe my work is useful for patients living with stroke." - UCL Researcher



The UCL World Stroke Day Forum is run by the Wellcome Centre for Human Neuroimaging at UCL. Now in its fourth year, the Forum is supported by a number of organisations.

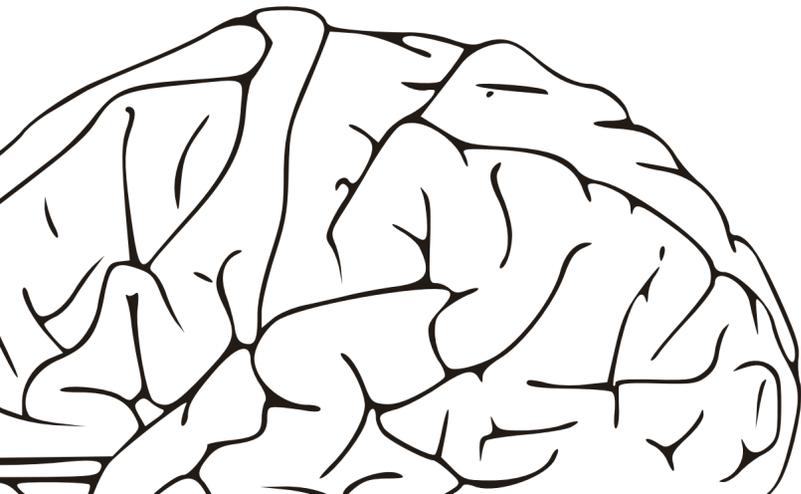
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www.bridget-m.com

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