

Futuremakers: Brain and Mental Health

Episode 1: Brain injury and rehabilitation

Belinda Lennox:

Welcome to this season of future makers, brain and mental health. I'm Professor Belinda Lennox. I'm a psychiatrist and a researcher here in Oxford, and this season you'll be joining me as we demystify the science behind the most complex object in the known universe, our brains. And look at the wide-reaching impacts of mental illness on individuals and society. I'll be introducing you to some of Oxford's best academic minds, working to solve the greatest challenges in brain and mental health, and I'll also be speaking to guests from beyond the university to bring their perspectives and lived experience and get a sense of the impact of what we're doing. Join us as we discover how Oxford is shaping the future of brain and mental health research.

Hello. I'm Belinda Lennox, and in this episode of Future Makers, we'll be talking about brain injury and particularly around the consequences and sequelae of brain injury and the current research around brain rehabilitation.

I'm delighted to be joined by Jenny Clarke, the Co-founder and CEO of the Brain Injury Recovery Charity, SameYou. And Heidi Johansen Berg, Professor of Cognitive Neuroscience and Director of the Welcome Centre for Integrative Neuroimaging at the University of Oxford.

Jenny, could you start by telling us a little bit about the work that SameYou does?

Jenny Clarke:

Certainly. It really started when my daughter, completely out of the blue, suffered her first brain haemorrhage. She was 23 and she had just started to film Game of Thrones. The first season had happened, and she was doing a press trip. She said, 'I'm really a bit nervous as this is not something I've done before', and there was a lot of strain in her life. But as all actors do, they have to keep fit, so she was at the gym, and she suffered a very large brain haemorrhage. We knew straight away that it was going to be a fight for her life. So, we went through that and then two years later, she had a preventative calling, and it went catastrophically wrong. She had open head surgery, and it was about 12 hours before we knew whether she was going to live or not? But as in many stories, it has a happy ending. She was fine despite all of the pronouncements and the scares she has come through both experiences with no cognitive deficits, no physical deficits, but she has come through a very different human. She was 25 when the second near death experience happened, and it made us realise the trauma that particularly young people go through, and it made us realise the fragility of our human brain. And after looking into what possibly we could try and do to use her voice and her global reach to take some action to tell people that this is a problem and that it's such a neglected problem. So, it really all started there.

Belinda Lennox:

So SameYou is about raising awareness and about campaigning for better rehabilitation services.

Jenny Clarke:

Exactly. So, we started off in a very informal way, she told her story to The New Yorker. And we had a website and that was pretty much it. We had some visions about what we wanted to do, and then the website crashed because of the amount of people wanting to respond to her because she said 'I've told you my story, now you tell me yours'. This really is not a fluent remark, it underpins one of the major issues.

There's so much stigma about brain injury. There's so much shame. And there's so much uncertainty about the reaction people will get if they admit and have to use that word. Isn't it shocking that you have to admit that you've had a brain injury? And we have seen from, probably just over 10,000 people who have communicated, written to us, emailed, and told their stories to us because they say that Emilia has normalised it.

So, this is again not a small conversation; this is just an indicator of the work that must be done. To show the need that people have to have at least somebody to explain to them what's happened to them and to share their journey as they go through all sorts of really difficult chronic conditions.

Belinda Lennox:

Yeah, I find it surprising you say that there's shock in a way or surprise that so little is known about what happens after brain injury or after a stroke. I suppose, well, it's not a surprise to you, Heidi, as you spend a long time researching this area. But is that true? Do you get the sense that really people just have no idea?

Heidi Johansen-Berg

Yes, I think people have certain preconceptions about, you know, the types of people who have strokes. We've got an idea that it tends to be older people, for example, who have strokes. And as we've just heard from Emilia's story, it can be people of all ages, of any age, can experience a stroke or other types of brain injury. The common occurrence of these, because they are a potentially an invisible thing, obviously some people who have experienced brain injury have very visible difficulties afterwards and for others much less so. It's not always something that people necessarily know about.

So I think raising awareness, both of the scale of the challenge that people face, and how every type of brain injury is different and how much variability there is and know that every stroke survivor is different. Every person who's experienced a brain injury is different and the circumstances behind those different types of injury are so variable.

Jenny Clarke:

So really where you asked me a question and I gave you a very long answer about why still. But what we're here to do is to amplify the voices of survivors and to make clear the needs of survivors, because there is a very big gap between what clinicians, rehabilitation therapists and clinicians are able to provide and also think that they should provide. And then what people who have gone through the experience and what their families have gone through, tell us that what they need.

So the gap is really wide and what we're trying to do is to be talking about it by trying to build a community around this is to narrow that gap. And to shift the balance from the obvious evidence-based therapies and solutions, and not change it, but add to it, because there's so many things that can be done that people don't necessarily consider should be done by clinicians, the NHS, whichever country you're in. We really think that's vital.

And then the other very big thing that we do is we raise funds. We find donors and supporters to catalyse innovations. What we want to do is to seed fund innovations in research, and that's biopsychosocial as opposed to any other research.

What we've been doing is to try and understand, to show people, the need through funding research programmes and to look at the training and education because the resourcing of any rehab therapist is very, very poor. People have left their professions and there is not enough people to go around. There's certainly not enough funding to build up that pool of experts that will help people sensitively through the mental health process that people need to recover.

And we've been funding technology, we've been funding research, and we've been funding education, and we have a major nurses training programme that we funded. But the technology piece is really interesting. You talk to anybody and it's we've got the tech answer and the world has moved and changed so much.

What we feel strongly about is how do we use tech to reach people on a really human level. So we at the moment are not supporting apps or anything like that, but we have started something which is a rehabilitation tool online, a group rehabilitation and maybe later I can tell you a bit more about it.

Belinda Lennox:

Ohh yeah, I'd love to hear about that. I suppose we're both talking about sort of hidden aspects of stroke recovery. But could you tell me a bit more, sort of flesh it out a bit more. What are the most common things that people have problems with?

Heidi Johansen-Berg

Yeah. Well there there's huge variation in the difficulties that people experience and as I'm sure many listeners will know, different parts of the brain do different jobs and have different functions, so the type of difficulties that someone will experience after brain injury very much depends on where in the brain has been affected by that and how badly it has been affected.

So, the difficulties can include problems with movement, with speech, with understanding speech, with vision, with any possible function of the brain, but the particular the constellation of difficulties will depend on exactly where the damage is, and one of the problems is that every individual is different, because every type of damage is different.

So that causes a real challenge when it comes to the rehabilitation. That the approach to rehabilitating these different aspects of somebody's experience tends to then be siloed to different types of health professional, whereas who you're trying to support is a whole individual.

So, trying to have that holistic approach to what does this individual need and how can this rather specialised traditional healthcare system support that is quite a challenge because there are a whole range of different difficulties as well as, psychological and other factors of regaining one's life, that that you've experienced before the damage.

So, I think it's a huge challenge and it's really exciting to hear about the work that you're doing. In that I think looking at innovation and how we can harness technology to try to really enhance the sort of traditional model of realisation is the future direction that we should all be trying to follow.

Jenny Clarke:

And also, at the same time we're looking at the role of nurses, because most people I've met in multidisciplinary teams in rehab don't have nurses, and when we went through what we went

through the key resource that we found invaluable, after Emilia left Queen Square, was the nurse, her nurse. And Queens Square have, I think last time I checked funding for 1 1/2 nurse positions to take you on the journey from when you were admitted right through what happens in rehab and beyond, which is quite remarkable and shocking.

There's also a lot of work that the WHO are trying to do and a wonderful organisation that was set up, called Nursing Now, that we've been involved with, which is really trying to upskill early career nurses and to find ways for nurses to take part and influence the recovery journey for people, whatever trauma they've been through.

So I think it's very much our point of view is let's get as much technology that can help but also, it needs to have that personal touch because we're all human and the touch on the hand is worth a lot.

Belinda Lennox:

Of course. I would love to hear more about the technology solutions though. What are the really exciting things that are being developed?

Heidi Johansen-Berg

Well, I think there's all sorts of different innovations coming out of the research side. I think one of the really key things to emphasise, though, is that despite the excitement around these technologies, by far the most important factor that will determine the extent of somebody's recovery following an injury, is the amount of practise and rehabilitation that they can do. So the standard model for rehabilitation you might think of somebody trying to have physiotherapy to retrain an arm movement, for example, after a stroke. What is needed is just many, many hours of practise in order to relearn those movements. That's the core thing that you need, and you can't replace that with technology, but potentially what you can do is boost that with technology, give you sort of more bang for your buck if you like. And, or, try to scale up that traditional model of rehabilitation.

The traditional model for that type of physiotherapy is that the stroke survivor would be working one to one with a highly trained physiotherapist in these sessions to retrain the movements. And that's the sort of gold standard of the therapy approach. But it's obviously a very, very resource intensive type of intervention and that's one of the key reasons why people, particularly in the UK, don't get the degree of care that they need in order to reach their recovery potential. It's just too expensive to provide that degree of one-to-one care.

So one of the areas of focus of some of the research is how can we scale that up, either by adapting elements of the rehabilitation such that survivors can continue to do that practise at home and in their own time, guided by a professional, but then with things like remote monitoring, or technology to practise at home as well as how can we optimise the conditions of the rehabilitation session to really maximise that output, and there's a lot of focus on what's happening in the brain. When you're experiencing a rehabilitation session, your brain is active in that process, your brain is relearning, your brain is undergoing what we call brain plasticity, the changes that happen in our brains whenever we practise a new skill or learn a new skill. We know that learning is cemented through changes in the brain, literally through rewiring of our brain cells and brain circuits.

As neuroscience researchers understand a lot now about those processes of brain plasticity there are potentially things that can be done to try to boost that process, to try to optimise the conditions in the brain so that you can maximise the amount of brain plasticity that can occur. But those would

always be things, in my view, to be added to the active practise. The survivor needs to be putting in the hours doing the practise, but then if we can do that in a condition where the brain has been primed for maximum plasticity, then, hopefully that will improve the outcomes.

Jenny Clarke:

And I think that our experience and the research that I've done travelling around, particularly the US, and seeing innovations happening over there, is that motivation is one of the critical success factors, because if you're lucky enough, use that. If you are fortunate to have the rehab therapy, if you've got physical impairments. You've said it already, you know brain injury doesn't just happen to the brain, it happens to the whole person.

And so, while it's incredible to feel that people can start to, for instance, hold a glass when they haven't been able to before. The numbers of thousands and millions of repetitions needed to get them there is very soul destroying and demotivating.

I've seen quite a few solutions where people are using Pixar animated quality game to give people a simpler way of doing these repetitions. There's many of those in the market.

But I also think that the most important thing is to combine this in a holistic way, because whatever is wrong with you, whether you've got cognitive speech and language issues, whatever it is, if you don't have that neuropsychological support, you will not have people believe that they can get better, and especially when neurosurgeons tell people, you know, you're lucky to be alive. You're not really gonna get better. I've had this time and time again. People tell me right now, today, that's what people around the world are still saying.

So what we need to do is to really help people understand that with neuroplasticity and using different ways for them to engage their brains, they will find all sorts of ways that they can improve their quality of life.

Heidi Johansen-Berg

I completely agree the importance of those psychological factors of expectation and motivation are enormous, and we know across all of medicine that the power of what the doctor tells you to expect, it's the same with pain drugs, if they say, oh, this is probably not going to work, but give it a go, you know. For sure it won't work. Whereas if you know it's this so-called nocebo effect, the opposite of a placebo effect. If they tell you that you're not gonna get better, you're not gonna get better. And it's very prevalent in brain injury and stroke survivors that almost everybody I've met who's had those experiences at some point. Somebody has said to you oh well, you know it's a year or two now since your brain injury, you're not gonna get any better. You just need to accept where you're at now and move on.

And yet we know that there does continue to be some degree of capacity for recovery and many people will never regain their original level of function, but there's continues to be this capacity for recovery just like there continues to be capacity for brain plasticity in all of us throughout life. It's always there. It's a core feature of the brain that it will change with experience. But we need to drive it through that experience, as you've said, driving the motivation to put in the hours to do those repetitions is absolutely key. And we know how much now the tech industry understands about how to manipulate our motivation and reward systems through gamification and other types of feedback, that should absolutely be harnessed for good in the context of rehabilitation, and as you said Jenny, it very much is starting to be but not yet really fully impacting, I think.

Jenny Clarke:

And so we're on the pioneering front, breaking down barriers to try and get this sort of thing put into mainstream. And if I could add one other thing. Even though people might not be able to regain their full functionality.

When you have a brain injury, you pretty much immediately feel you've lost your identity. And it's this identity issue that is the heart of a lot of the pain and sorrow that goes through people's minds when they've had a brain injury, or they are with family members who have. So I think it's quite important. We call our charity SameYou because everyone wants to be recognised as the same. Now they might not seem it to other people, but I think it's also beholden on all of us, whether we're clinicians, or friends, or family, to really understand that the person is still there and deserves acknowledgment that they are still there. And everything that we try to do is to reinforce that and really talk about it because it's really vital in the road to recovery.

Belinda Lennox:

Hello, I hope you're enjoying this episode of Future Makers, Brain and mental health. If you'd like to learn more about our work here in Oxford, head to ox.ac.uk/brain, or let us know what you think on social media using the hashtag #OxfordBrain.

You're both giving such a positive, hopeful message, and as you said at the beginning, Jenny, it's a distinct contrast with the sort of popular perception of stroke and brain injury. I suppose what's the ambition, how will a future health service treat people differently?

Jenny Clarke:

Well, I've got strong views about that and we've got some strong opportunities to take part in that change and being one of a group of people who can change that. But may I just talk a little bit more about our neuro rehabilitation online because you were talking about tech? Would that be?

Belinda Lennox:

Of course.

Jenny Clarke:

In the COVID lockdown we had an office in Queens Square and so I worked with UCL a lot. And it was a real crisis, as everybody knows and remembers, for people to be cleared out of wards, to use a very unkind expression. But the reality was people needed bed space, hospitals needed bed space, so when people had had a stroke or brain injury they would be discharged very early. It was a real crisis to make sure that people were safeguarded and there was some way of having care when community nurses and therapists, not that there are many of them, we're unable to help.

We suggested that because I've got a tech background, though you wouldn't notice it, I've worked for big tech companies all my life, we looked at how tech can change things. So what we did, with UCL, was to create a group rehabilitation programme. This was through, with a lot of screaming and shouting, and no, no, we can't possibly do that.

I'll give you the end story as opposed to the process that went through it for speed. But you were talking about really good professional physiotherapists. What the team worked out is if they had 10 or 12 people in their online clinic and if there were two physiotherapists, one giving the instructions about the exercises, and the other one noting and monitoring what each individual was doing, and

they were able to do that over the hours, days and weeks of the programme, that was really successful.

The other real barrier about the group online was that people have got the idea that it has to be one to one, that people need this one to one because it's so traumatic and so private.

Guess what? All our research, and we've had through it third party research, is after we did the programme for six months with UCL, and now we've got lottery funding, and it's in five National Health trusts in Lancashire, all the research is that it's such a bonus. That the people have come together in groups of 10 or 12 or whatever, can be accommodated because it immediately gives you a buddy group, a buddy system, and people of all ages and of all different stages in their journey, whether it's immediately after discharge, which of course is ideal, or it could be wait months down the line. What people are telling us and telling their therapists, who are giving them the online treatment, is that the sense of watching other people struggle and achieve gives them a sense that they're OK, they can do it too. And afterwards they form clubs and groups to keep on with self-mentoring each other and giving people support.

This is a really big thing to find out. And what we're trying to do is to get more funding and it's on the verge of being commissioned in certain areas in Lancashire. And we are supporting the people we're working with to try and get it right across the UK.

Heidi Johansen-Berg

That's a really nice example of how you take what we might think of as the gold standard model of physiotherapy but then think of ways to scale that up and to boost its effect.

You know you scale it up through making it group based. Making it online. And then you add these other layers of efficacy through things like the social dynamic and the cohort that then persist beyond that one-hour training session. You continue to see the benefits and that's really exciting.

I mean, I think there's ways of how we take the model but then optimise its effects through, you know, adding things on these so-called adjunctive therapies, things that we can add to the basic training. It is a real focus area for much of the research currently, so looking at things like, you know, directly stimulating the brain while you're undergoing the therapy, potentially using drugs which boost these processes of brain plasticity.

But even very simple approaches can help. One of the things that we're particularly interested in at the moment is the effect of sleep on rehabilitation outcomes in particular. We'll all be aware that how well we sleep has a huge impact on our well-being and on our function in general, and that's also true for somebody who's experienced brain injury.

But it goes even further in the context of rehabilitation in that your sleep quality happening in the background of your rehabilitation experience is going to directly impact on the quality of that rehabilitation, both because it will impact on things like your motivation to engage with the rehabilitation but will also impact on the process of brain plasticity.

So from a neuroscience perspective we understand very well that the way that your brain learns is not only to do with the processes of change that is happening when you're practising a skill, but that also there's a process of what we call consolidation that is happening in the brain after you stop practising. After you practise something, your brain literally continues to rehearse those things, and you can see that particularly during sleep. In the sleeping brain after you've practised something, you can, and there's many neuroscience experiments, demonstrate how the brain cells are literally

replaying those experiences during sleep. And it's that sort of neuronal replay which really cements the learning in your brain.

We're also interested in whether looking at the quality of sleep that an individual is experiencing around a rehabilitation session is another opportunity to boost the effects of the rehab. If we can optimise their sleep quality following a session, can you really maximise the amount of this consolidation that would be happening in the brain. So sort of trying to bring that neuroscience understanding to bear on how we can design our rehabilitation interventions to make the most of everything, all this fantastic knowledge we have about the brain, and how it works, can we really apply that to design the sort of perfect holistic rehabilitation intervention that considers all of these different aspects not just what's happening during the one hour session.

Belinda Lennox:

Ohh, that's so fascinating. We need a whole extra session on sleep, but I suppose it is a powerful intervention, so it sort of makes sense that improving the quality will improve recovery from all brain conditions.

Heidi Johansen-Berg

Yes, I think it would. It would likely have very generalised, very general positive effects through things like mood and motivation, and energy and focus. In addition, potentially to the quite specific impact on the relearning and brain plasticity processes.

Jenny Clarke:

Absolutely. That's really exciting. We haven't worked with anybody on sleep. I think to draw it back down to helping people now, today, on the ground is challenging, is that each team in each neuro rehab centre in the NHS have different skills, and there's not really a complete suite even in the very largest of academically linked neuro hospitals.

I don't think there's enough research that's been underway on cognition, for instance. There are so many different issues with cognition, and I haven't met anybody yet, and I'd love to talk to you in Oxford, which I haven't done up till now, and see what you are working on because that's that seems to be so important.

My experiences with looking at Emerald, which is newer rehabilitation online, is that the way its working is that each trust, and each therapy group, the rehab specialist teams, are tailoring it to their own resources.

So we have a carers café in London, for instance, where because there's a neuropsychologist that really has got a deep understanding about the impact that your immediate circle, whether they're carers, or family members, and how they need support and help as well. And then you have different speech and language classes, et cetera.

What we are really challenged with as an issue in the whole, is how can, for instance, even brain injury be linked more clearly with a stroke pathway? There's lots and lots of brilliant work being done and we sort of say well, excuse me, what about, you know, acquired brain injury? There is a lot more to it. And that's one of the challenges that I think we all need to come together to realise is an issue and to see how we can band together and to try and make change. So that was just something as a non-academic nonclinical person I can just see where some of these gaps really are.

Belinda Lennox:

Yeah. And Heidi for you for the future, what's the really exciting things on the horizon?

Heidi Johansen-Berg

Yeah, well, I think as we were discussing, it's a bringing together. There's been these phenomenal advances in neuroscience and how well we understand the brain, both the effects of injury to the brain, and the possibilities and opportunities of plasticity in the brain. And yet there's a big distance between that degree of understanding of the system and how that's applied or not applied in the healthcare setting.

I think trying to bring those things closer, ideally to a joined-up system. If you had the joined-up system of the type that we were just discussing such that the different elements of the care are brought together, along with the understanding of how the brain recovers biologically, such that you could design those interventions to be optimally able to make use of that plasticity. At the moment that it feels like a huge, missed opportunity. We could be getting better outcomes if that neuroscience were brought to bear on the way in which the interventions are delivered.

Belinda Lennox:

Sorry, Jenny. Go ahead.

Jenny Clarke:

I was just going to agree completely. From our perspective, what we're trying to do is to push forward to develop a mental health pathway for ABI. We see that others are not doing that, and we think that there are some really good models that we can take from other chronic diseases. We're doing it with UCL, and with great teams in UCL that we can really try and make a difference.

So we we're really at the start of that journey, and so that is an adjunct to the existing therapies, and we hope that we can really develop a blueprint that people can take on, adapt, and improve.

Belinda Lennox:

So, Jenny, what's next for the charity?

Jenny Clarke:

Well, we are launching a campaign that's focused on mental health recovery needs after brain injury, and I'm sure that not everybody realises the scale of the problem. For instance, in 2022, the research shows us there's about two and a half million people in the UK, and 155 million people globally, living with the consequences of brain injury, which are huge numbers. This is not niche, this is not a small health problem. And so, we're showing people that one in three people will suffer some type of brain injury at some point in their life, whether that's concussion, whether that's a traumatic brain injury, or stroke, or whatever. 'One in Three, 33'

So, for the last couple of years, we've started to raise awareness about trying to use '33, One in Three', and this year '33 steps to brain injury recovery'. What we've done is to put together assets, videos, and information to help people look at recovery through nutrition, through exercise, and through mindfulness and mental health well-being pieces. We have a challenge where we're asking our followers and our supporters to try and do 33 of something. Our campaign gives lots of advice and tips and we're building out our resource page on sameyou.org.

We're a very small charity, we've got only two or three people working, so we haven't got all the information that we could put on there, but we think that this is a great start, as you've been saying earlier, to holistically approach the recovery process, because it's so important.

Belinda Lennox:

Well, thank you both so much. What a fascinating conversation and a really important area. I can think of some things I wouldn't mind doing 33 times other things that might be a bit more tricky.

I hope you enjoyed this episode of Future Makers, Brain and Mental Health. You can find more episodes of future makers wherever you get your podcasts and more on Oxford's research at ox.ac.uk/brain. Thanks for listening.