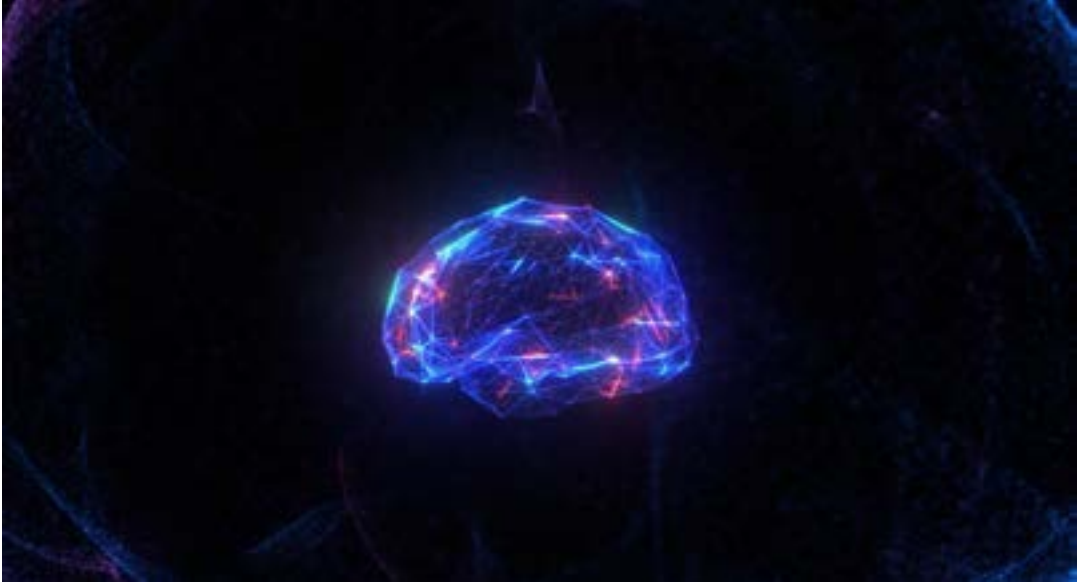


Out of sight, out of mind. Rights, consent, and electroconvulsive therapy

Lisa Morrison



This article is a commentary on an audit of Electroconvulsive Therapy (ECT) patient information leaflets in Northern Ireland, Scotland, and Wales, which found that they do not comply with the ethical principle of informed consent. Stigma, rights, and trauma are discussed through the authors personal experience of multiple ECT treatments and research, and potential actions to address these failings are suggested.

Keywords: ECT; Electroconvulsive therapy; Informed consent; Patient information leaflets; Rights; Safety; Efficacy; Trauma; Regulation; Monitoring.

Context

THIS article is an extended commentary on a paper I co-authored with Professor John Read and Dr Chris Harrop ‘An independent audit of Electroconvulsive Therapy (ECT) patient information leaflets in Northern Ireland, Scotland and Wales’, published in the scientific journal *Psychology and Psychotherapy: Theory, Research and Practice*. It concludes ‘ECT information leaflets in these three nations are barely more accurate than those in England, and do not comply with the ethical principle of

informed consent. Patients and families across the UK are systematically being misled about the risks they are taking and the limited nature of ECT’s benefits’ (Read et al., 2023, p.2). Consent to a medical procedure is a human rights issue. Without accurate information, informed consent cannot be given.

Background

Why did I co-author this paper?

Approximately twice as many women as

men are given ECT. I know of women from a generation past, robbed of precious memories of their children, significant life events, dignity, and a sense of self because of electroconvulsive therapy. I would have been a teenager at the time, taking on my first 'psychiatric label' and swallowing my first pill. Many more of both were to come. It's a watershed year for me turning fifty. I did not think I'd live this long and no longer define myself as 'mentally ill'. Although I remain in the mental health system I no longer understand 'complex trauma and dissociation' as 'disorders'. Bad things happened and I found creative, resourceful solutions to get through.

Now I am the mother who cannot remember my children's birthday parties, first days at school, significant events in their lives, my wedding, graduation and so much more. I wasn't told this could happen or that there were alternatives. Professionals have a duty to give people all relevant information, benefits and risks, and any alternatives to the treatment being recommended. Consent is about the right to self-determination and autonomy and key principles of trauma-informed practice. I do not want this story repeated in thirty years.

What is ECT?

ECT involves passing an electric current through the brain, large enough to induce a seizure. There is still no generally accepted theory that explains how it works. Approximately 70 per cent of people who are given ECT are women. The Royal College of Psychiatrists 2020 leaflet which rated very low in the audit of patient information leaflets in England, prompted the College to review its leaflet but it still has seven inaccurate statements and nine omissions (Harrop et al., 2021).

Why is it used?

MIND states on their website 'Repeated ECT is only recommended if you have previously responded well to it, or if all other options have been considered'. The Royal College of Psychiatrist states, 'ECT is a treatment for

some types of severe mental illness that have not responded to other treatments.'

Key Findings from the Audit Summarised (Read et al., 2023, p.12–13)

Accurate statements frequently omitted:

- cardiovascular risks
- it is not known how ECT works
- risk of mortality
- risks of multiple general anaesthetic procedures
- how to access a legal advocate

Only two leaflets reported that they had been co-produced with patients.

Most frequently omitted facts:

- no evidence of long-term benefits
- that ECT efficacy studies find high placebo rates
- information about how much electricity is involved

Nineteen of the 23 (83 per cent) made misleading statements minimising memory loss, blaming the memory loss on depression, claiming that ECT is the 'most effective treatment', and asserting that it has very high response rates (with no mention of similar placebo response rates). All 23 claimed, despite lack of supporting evidence, that ECT saves lives. *Evidence linked to all the above points can be found on p. 17 – 21 of the journal article.*

Three areas for reflection:

1. ECT, Power and Human Rights

It is concerning that proponents of ECT can fail to acknowledge power differentials in the 'patient' and 'doctor' relationship. Power differentials remain significant in a mental health system built on an illness and deficit model. Social, economic, and environmental conditions drive how much choice, control, and sense of agency people feel in their lives (WHO, 2022). I had 96 ECT treatments in total, mostly in Northern Ireland, the most recent in 2016. I spent 8 years in and out of the local psychiatric inpatient unit and the Emergency Department (ED) following

self-harm and suicide attempts. I did not have choice, control, or agency. A lifetime in mental health services had stripped me of my personhood and often, unintentionally, dehumanised me. I was 'treated' as a diagnosis and set of symptoms and multiple traumas poorly understood.

I know many people, including carers/supporters who have felt equally powerless and hopeless. In the most difficult times, we depend on professionals to ensure our rights are respected and upheld. I never knew my medications should be regularly reviewed and the ECT patient information leaflet in my Trust has one of the worst scorings for accuracy. I might still have chosen to have ECT if I had had all the facts. But I didn't. Knowing I could not have made an informed decision and living with the devastating consequences of the treatments, feels like yet another violation.

My advance directive to never have ECT again can be overruled under the Mental Health (Northern Ireland) Order 1986. A treatment which induces a seizure in the brain for which there is no clear evidence for how it works, can be forced on me. How is this not discrimination based on perceived ability? Article 3 of the Human Rights Act 1998 is the right to freedom from torture and inhumane treatment. There were occasions in the ED when I wasn't offered anaesthetic for internal and external stitches and my dignity not respected in many ways. I believe that shocking my brain because of deep distress caused by things that had happened to me, is a violence I should not have had to endure.

2. Extreme distress

The Royal College of Psychiatry (RCPsych) states on its website 'ECT is an effective treatment for some types of severe mental illness. It is usually considered when other treatment options, such as psychotherapy or medication, have not been successful or when someone is very unwell and needs urgent treatment'. It is of concern that in their disclaimer it says '... we make no representations, warranties or guarantees, whether express or implied, that the content in this leaflet is accurate, complete or up to date'.

People's distress manifests in different ways,

for many reasons. The World Health Organisation (WHO, 2014) and extensive research, identifies social determinants as causal factors for poor mental health and suicide. This compels us to reconsider how we understand and make sense of people's suffering. Given the prevalence of anti-stigma campaigns and public messages about mental health; stigma and fear about 'mental illness' remains strong and influences people at every level in society (Abbott, 2022; Allen et al., 2020; Buckland, 2016; Karban et al., 2021 and Morriss, 2016). What are we doing to challenge and address this? It is more than 'what happened to you?' It is also why? For example, why is violence against women and girls so endemic and what causes poverty. What are the conditions that allow these injustices to happen? Collective action is needed wherever we are. For me, this is being part of Participation and Practice of Rights (PPR), a Human Rights Organisation in Northern Ireland. This social movement is calling to change the script on mental health and inviting conversations about many of the issues discussed in this article. Using our skills, experience and knowledge in whatever way works for us, collectively we can drive much needed change.

Although I could not have given informed consent, I did agree to having ECT. The reason being anaesthetic provided momentary but desperately needed relief from the unbearable madness in my head and despair and hopelessness in the core of me. There was little else being offered (see more about this in point 3). Between 2009 and 2016 I received 12 treatments, six times over seven years. By 2017 I was barely functional. ECT and a concoction of medications were failing to address the causes of my malaise. It is argued that ECT is only ever used as a last resort. But how and who monitors this? Nobody it seems.

Regulation and monitoring

Key Points Summarised (Read et al., 2023, p.22–23)

- The American Psychiatric Association (2001), acknowledges that 'ECT can result in persistent or permanent memory loss'

- An ECT machine manufacturer includes 'permanent brain damage and permanent memory loss' as risks (Somatics, 2018)
- Findings of two recent audits about how ECT is administered and monitored in England (Read, Harrop, Geekie, & Renton, 2018; Read, Harrop, Geekie, Renton, & Cunliffe, 2021) suggest, in conjunction with the two audits of information leaflets, that no official body is effectively monitoring or regulating ECT
- The RCPsych's 'ECT Accreditation Service' (ECTAS) has recently stressed that it has no monitoring or regulatory responsibilities (Read, Harrop, Geekie, & Cunliffe, 2022; Sivasanker, Thompson, & Baugh, 2021)
- Membership of ECTAS is voluntary
- One ECTAS standard requires that patients are 'provided with an ECT patient information leaflet' with no specification of what it should contain or that it should be evidence-based and co-produced with patients' groups
- SEAN's (Scottish ECT Accreditation Network) only states 'Information should be given both verbally and in writing' (SEAN, 2019) to patients

Strict regulation and monitoring should be a given. If this were a physical health treatment, would such vastly differing standards across Trusts in the UK exist or be tolerated? (Read independent audit 2019). ECT induces a seizure in the brain where there is no agreed theory or scientific evidence for how it works, can cause permanent memory loss and brain damage, yet is allowed to continue with such negligent 'standards'. People on the margins, seen as 'severely unwell', are easily forgotten or ignored. My husband, a well-resourced businessman, was rendered powerless with fear for my wellbeing and trusted the professionals to ensure a proper duty of care was being honoured. People are repeatedly being failed. A recommendation from the audit is that:

Psychologists, and all other mental health professionals, share the responsibility with psychiatrists to ensure that patients and families are given accu-

rate, evidence-based information so that informed consent is meaningful. They should intervene at a clinical and managerial level if that is found not to be the case'. (Read et al., 2023, p.21)

3. Talking therapies as an alternative

The RCPsych state ECT is considered when other options such as psychotherapy and medication have been unsuccessful. Access to psychological and talking therapies are notoriously limited, short term, not offered or, people are deemed too unwell to engage. This all needs reviewed and monitored through rigorous data collection then acted on. How many inpatient units have access to psychological therapies? What are the waiting lists? What is accessibility in GP's and the community like?

Lack of funding and resources continue to create barriers, and nobody questions that mental health deserves more equitable investment. But how are the finances that are available being spent?

- NICE give a figure of 6 treatments of ECT estimated cost = £2475
I had 6 x 12 sessions = 72 treatments = £29 700
- I was an inpatient many times between 2009 and 2017.
In 2014 I spent 23 weeks as an inpatient over 4 admissions
Average £450 a day for a bed therefore 161 days = £72 450.
This is without the cost of medications, ED visits, ambulance services and ICU.

I don't use the word treatment because it implies giving care to cure something and reinforces a them and us, doing to and people as problems to be fixed, mindset. But consider some alternative supports this could fund. Specialist trauma therapy, peer support, community-based arts programmes, an open dialogue approach, a 24-hour, homely crisis centre and more. Staff trained in trauma informed, responsive ways of working and the importance of regulation and meaningful activity. I was fortunate to mostly be given kind care. But there was a significant gap in understanding the impact of traumatic

events. Trauma informed and responsive is also so much more than this. It is the values and principles underlying how we are with people. A way of being and doing infused at every level and area of practice.

Compassionate relationship building where every person is recognised for their inherent worth, is essential. We don't 'give voice' to the voiceless. It's the conditions people find themselves in which allow them to be heard or not. I am fortunate to be in a place now where I feel I can speak up. Many people who journeyed with me are not so fortunate. How do you advocate for and relate to those considered severely unwell? People whose trauma is dismissed by multiple labels locating blame within the individual. Our systems can be traumatising for people working in and needing them. Our collective actions for change matter.

Conclusion

Trauma for me was about total powerlessness. A fear that's hard to describe and shame that permeated every cell in my being. The mental health system reinforced how 'wrong' I was and took away my power with a doing to, medicalised approach. Multiple medications and ECT silenced me. Many factors changed the course of my journey, and it was the courage of a Clinical Psychologist who was willing to review my diagnosis, listen, and explore what was really going on which resulted in finally getting my experiences validated and appropriate help sought.

A Psychiatrist and EMDR Consultant now walks beside me. In understanding my dissociation I've been given a new language to make sense of my experiences and with enough safety and stability created, we can do trauma processing. What seemed so disordered was very understandable and useful in the context of my experiences. I am now able to work again but lost years of my life and precious memories and time with my children. I had to relearn many skills after being rendered barely functional. It is a long road reclaiming me and there is much to grieve. But I am also so fortunate and grateful

for the many things which have supported me to be where I am today. Every person has the right to life. A quality of life meaningful to them. How do our actions support this?

I fail to comprehend how the issues being raised about ECT are not being acted on. Proper monitoring and regulation and accurate information given to patients and carers. Recognition of the harms ECT has done and actions to redress this. Adequate data being collected about issues relevant to those receiving the treatment. Where else in healthcare would such a lack of proper governance be tolerated and why do those with any powers not act? Informed consent is not optional. It is every persons right.

Links to articles and authors offering further commentary

- Read, J., Harrop, C. & Geekie, J. (2023). Efforts to improve the accuracy of information about electroconvulsive therapy given to patients and families. *Ethical Human Psychology and Psychiatry*. <https://connect.springerpub.com/content/sgrehpp/early/2023/08/11/ehpp-2023-0007>
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- Professor John Read profile: <https://uel.ac.uk/about-uel/staff/john-read> and blog
- Patients are still misinformed about electroconvulsive therapy <https://www.psychologytoday.com/us/blog/psychiatry-through-the-looking-glass/202307/patients-are-still-misinformed-about>
- Dr Chris Harrop profile: <https://www.madinamerica.com/author/charrop/> and blog
- Psychiatry's Loch Ness Monster: NICE shows nearly no evidence for ECT <https://www.madintheuk.com/2023/06/psychiatry-loch-ness-monster-nice-evidence-ect/>
- Lisa Morrison profile: www.lisamorrison.co.uk and 3-part blog about her experiences of ECT and wider systemic issue: <https://www.lisamorrison.co.uk/blog>

The author

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Biography

Lisa runs her own Training and Consultancy, bringing her extensive lived and learned experience to educate about the value and importance of trauma informed values and principles, both for people needing, and those

working across a range of services. She also works for Participation and Practice of Rights, a human rights organisation, campaigning for a #NewScript for mental health.

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Blogs and other resources

Life After ECT podcasts

<https://podcasts.apple.com/gb/podcast/life-after-ect/id1517617860>

Participation and Practice of Rights (PPR):
New Script for Mental Health Campaign
www.nlb.ie/campaigns/mental-health

PPR blog: Inequality and Mental Health

<https://www.nlb.ie/blog/2023-05-inequality-and-mental-health-joining-the-dots>

International Institute for Psychiatric Drug Withdrawal (includes a video on safe withdrawal) <https://iipdw.org/>