

Mr Matt Hancock MP
Department of Health & Social Care
Ministerial Correspondence and Public Enquiries Unit
39 Victoria Street
London
SW1H 0EU

July 10th 2020

Dear Secretary of State,

CALL FOR A REVIEW OF THE USE OF ELECTROCONVULSIVE THERAPY (ECT)

Following the publication on 8.7.2020 of the Independent Medicines and Medical Devices Safety Review led by Baroness Cumberlege, we call for a comparable and urgent review into the practice of Electroconvulsive Therapy (ECT).

We write as a group of mental health professionals, carers, and patients who have received ECT. The lead signatories are Dr Sue Cunliffe, a former paediatrician who has been diagnosed with brain damage following ECT in 2004-5, and Dr Lucy Johnstone, a clinical psychologist who has extensive experience of adult mental health work. Most of us have been campaigning about this issue for many years. We have received no official acknowledgement of our serious concerns, let alone action on the numerous failures of clinical practice, informed consent, governance, and sound evidence for the use of ECT. As a result, the ECT recipients among us have been left with severe psychological trauma and lifelong impairments to their cognitive functioning, along with a range of other consequences such as visuo-spatial difficulties, seizures, cardiovascular problems, and the loss of precious memories of family, friends and significant personal events.

The main themes arising out of the Cumberlege review also apply in relation to ECT, as we illustrate below with a brief sample of some of the obstacles faced by Dr Cunliffe and others:

'No one is listening' – the patient voice dismissed.

As Dr Cunliffe has powerfully attested on a number of occasions, those harmed by this procedure are rarely listened to, and frequently dismissed. Both professionals and service users have been subject to sustained social media denial, harassment and trolling, principally by a small group of psychiatrists, for describing their serious difficulties. Their experiences have been dismissed with blunt statements that they are mistaken about or inventing their reports, that ECT does not cause brain damage, and that their memory loss must be due to ongoing depression. 70% of ECT recipients are women, with older women the largest single group. As with pelvic meshes, the words 'defensive', 'dismissive' and 'arrogant' apply to some professional responses, in which an already vulnerable group is often given additional diagnostic labels and more rounds of ECT if they complain.

'I was never told' – the failure of informed consent.

In 2003, NICE recommended that national information leaflets for patients should be developed. This has not happened. We have discovered that NHS Trusts across the country are using leaflets based on false information – such as that ECT 'corrects imbalances in the

brain', a theory now abandoned by the Royal College of Psychiatrists itself. The RCP has refused to address this, and we have had to put pressure on individual Trusts to remove the leaflets. A new patient information leaflet from the RCP has been promised for over a year. Patients are thus not giving informed consent as described in GMC guidelines. Moreover, they are very rarely informed about the risks. In 2014 ECTAS (a non-independent, self-appointed, group of ECT providers coordinated by the Royal College of Psychiatrists) published a study identifying 18.75% of ECT patients as suffering severe permanent brain damage. In 2018 Thymatron, ECT manufacturers, was required to include brain damage as a side effect in its product information leaflet. Meanwhile the College continues to issue unsupported statements about ECT being safe and effective in the majority of cases.

Redress – 'We want justice'

Patients like Dr Cunliffe have been forced to give up jobs and careers due to brain damage and to rely on partners and families for care and support. Dr Cunliffe met former RCP President Dr Wendy Burn last year to ask for guaranteed access to rehabilitation for ECT recipients, but despite promises, there has been no action, and no means of getting an accurate diagnosis of people's impairments.

'We do not know who to complain to'

Complaints have got nowhere. Hospitals and Trusts are primarily concerned with protecting their reputations, and there is a pattern of simply referring complainants to other agencies. Recently a group of 40 clinicians and researchers into ECT, along with patients and their families, wrote to the Care Quality Commission, which monitors consent, safety and governance, only to be told that they were not the relevant body.

Conflicts of interest – 'We deserve to know'

Financial conflicts of interest in relation to ECT are more common in privatised healthcare systems as found in the US. However, we have met sustained denial and resistance from complaints managers and from professionals who have used ECT which appears to be based on a wish to deny evidence, even if it was produced by their own profession, and avoid culpability. The former RCP president, Dr Wendy Burn, recently stated that it was the College's view that 'there is no evidence that ECT causes brain damage.'

'Holding to account' – Guidelines and quality

In 2003, NICE made a series of best practice recommendations, including implementing an audit cycle in all ECT units to ensure NICE guidelines are being met. This has not happened. A standard defence is to claim that an ECT unit is accredited by ECTAS. However, evidence available on the ECTAS website shows that monitoring for cognitive impairment was not essential for ECTAS accreditation, and was in fact the most commonly missed standard. The same website demonstrates ECTAS has not suspended the accreditation of units that are failing in two of the most important areas, namely safety and informed consent.

Guidelines obviously need to be based on the best quality evidence. Despite claims to the contrary, there has never been sound evidence that ECT is effective except perhaps for a minority of patients in the short term. A recent review concluded 'Given the high risk of

permanent memory loss and the small mortality risk, the longstanding failure to determine whether or not ECT works means that its use should be immediately suspended until a series of well designed, randomised, placebo controlled studies have investigated whether there really are any significant benefits against which the proven significant risks can be weighed' (Read, Kirsch, McGrath, 2020.) A senior researcher has described ECT as 'a classic failure of evidence-based medicine.'

'Collect once, use often' and 'Collecting what matters'

It is almost impossible to find official data about ECT. An audit by members of our group (Read, Harrop, Geekie and Renton, 2017) used Freedom of Information requests and found a 12-fold variation in rates of ECT usage, and routine failure to keep records of whether, for example, other interventions have been offered first, as recommended by NICE. The same audit found that only 4 Trusts could provide outcome data, and others were using inappropriate measures, if any at all. None were using follow-up data. Virtually none could give information on adverse events, such as heart failure or unexpected death. Only a minority were assessing cognitive functioning post-treatment.

'Time to change focus' – Regulation of devices, and reforms

ECT machines came onto the market before the current MHRA regulations. They do not meet those standards, such as the requirement to have an accepted mechanism of action (there is none for ECT) and not to do harm if used correctly. We believe that on this basis, their license should be removed, in the light of substantial evidence and personal testimony that routine use can cause lifelong cognitive impairment.

In summary, we believe that the Cumberlege report conclusions and recommendations, rephrased below to apply to ECT, must be implemented urgently:

The Government should immediately issue a fulsome apology on behalf of the healthcare system to the patients and families adversely affected by electroconvulsive therapy.

The appointment of a Patient Safety Commissioner who would be an independent public leader with a statutory responsibility. The Commissioner would champion the value of listening to patients and promoting users' perspectives in seeking improvements to patient safety around the use of electroconvulsive therapy.

A new independent Redress Agency should be created based on models operating effectively in other countries. Networks of specialist centres should be set up to provide comprehensive rehabilitation, care and advice for those adversely affected by ECT.

The MHRA needs substantial revision, particularly in relation to adverse event reporting and medical device regulation. It needs to ensure that it engages more with patients and their outcomes. It needs to raise awareness of its public protection roles and to ensure that patients have an integral role in its work.

A central patient-identifiable database should be created, in order to research and audit outcomes both in terms of the safety and patient reported outcomes measures.

The register of the General Medical Council (GMC) should be expanded to include a list of financial and non-pecuniary interests for all doctors, as well as doctors' particular clinical interests and their recognised and accredited specialisms.

We urge you to address this unevidenced and damaging practice, which now dates back 80 years, as soon as a Patient Safety Commissioner is appointed, or failing that, by any other appropriate mechanism.

We would be happy to supply further information and look forward to your earliest response.

Dr Sue Cunliffe, ECT recipient and former paediatrician, Worcester
Dr Lucy Johnstone, Consultant Clinical Psychologist, Bristol
(Correspondence to LucyJohnstone16@blueyonder.co.uk)

Other signatories

Dr Fairuz Awenat, Consultant Clinical Psychologist, Wilmslow, Cheshire
James Barnes, Psychotherapist, Exeter
Jan Bostock, Consultant Clinical Psychologist, Northumberland
Professor Emeritus Mary Boyle, Clinical Psychology, University of East London (retired)
Dr Steven Coles, Clinical Psychologist, Nottinghamshire
Professor Rhiannon Corcoran, Dept of Primary Care and MHealth, University of Liverpool
Professor John Cromby, Clinical Psychology, University of Leicester
Jill Davies, partner of ECT survivor
Bob Diamond, Clinical Psychologist, Nottinghamshire Healthcare Trust
Ruth E Dixon, daughter of ECT survivor, North Lincolnshire
Emma Xxxxx, Wife of ECT recipient, Winchester
Baylissa Frederick, Psychotherapist, Paisley, Scotland
Dr Rex Haigh, Consultant Psychiatrist in Medical Psychotherapy, Berkshire
Dr Chris Harrop, Clinical Psychologist, West London NHS Trust
Professor David Harper, Clinical Psychologist, University of East London
Jenny Xxxxx, ECT recipient, Essex
Professor Peter Kinderman, Clinical Psychology, Liverpool University
Dr Warren Larkin, Consultant Clinical Psychologist, Lancashire
Andy Luff, ECT recipient, Farnham
Dr Aisling Mannion, Clinical Psychologist, Nottinghamshire
Joe Miller, Consultant Clinical Psychologist, Exeter
Dr Elizabeth Murphy, Research Clinical Psychologist, Manchester
Dr Gareth Morgan, Clinical Psychologist and Lecturer, University of Leicester
Una Parker, ECT survivor, Leeds
Dr Melissa Pyle, Research Psychologist
Professor John Read, Clinical Psychologist, University of East London
Dr Che Rosebert, Director of External Relations, Association of Clinical Psychologists UK

Dr Clive Sherlock, Psychiatry, Oxford
Dr Gary Sidley, Clinical Psychologist (retired), Rossendale, Lancashire
Cas Schneider, Consultant Clinical Psychologist
Sue Xxxxx, ECT Recipient, West Midlands
Dr Sara Tai, Senior Lecturer in Clinical Psychology, University of Manchester
Dr Akima Thomas OBE, Clinical Director of Women and Girls Network, London
Professor Sami Timimi, Consultant Child and Adolescent Psychiatrist, Lincolnshire
Emma Watson, Peer Support Development Lead, Nottinghamshire
Gilli Watson, Consultant Clinical Psychologist, Devon
Jo Watson, Psychotherapist, Birmingham
Dr Jennie Williams, Consultant Clinical Psychologist, Kent

References

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The manufacturer of ECT machines, *Somatics*, recently issued a Regulatory Update to add 'permanent brain damage'
http://www.thymatron.com/downloads/System_IV_Regulatory_Update.pdf

Dr Cunliffe's personal testimony can be found here:
<https://www.bmj.com/content/364/bmj.k5233/rr-9>