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Research Paper

The self-reported positive and negative effects of electroconvulsive therapy: an international survey

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ABSTRACT

Background: When assessing the efficacy and safety of any medical procedure the experiences of patients need to be considered. This paper adds to the growing body of studies asking recipients of electroconvulsive therapy about their treatment experiences.

Methods: Open questions about the positive and negative effects of ECT, in an online international survey, were responded to by 776 ECT recipients, from 41 countries.

Results: About half (48.8 %) spontaneously reported one or more positive effects and almost all (96.9 %) spontaneously reported one or more negative effects. About half (51.2 %) reported only negative effects, 45.6 % reported a mixture of positive and negative effects and 3.2 % reported only positive outcomes. Content analysis found that the most reported positive effects were: 'Improved Mood' (23.2 %), 'Reduced Suicidality' (12.6 %) and 'Reduced Psychosis' (3.1 %). The most reported negative effects were: 'Memory Loss' (81.6 %), 'Cognitive Decline' (29.0 %), 'Headache' (11.1 %), 'Abused/Violated/Traumatised' (7.9 %), 'Fear/Anxiety' (6.8 %), 'Impaired Relationships' (5.4 %), 'Brain Damage' (5.0 %), 'Can't Work' (4.9 %) and 'Pain' (4.9 %).

Limitations: This convenience sample may have been biased towards those with negative or positive attitudes about ECT. Some of the negative and positive effects attributed to ECT may have been the result of other factors (such as illness and age, or placebo, respectively).

Conclusions: These results, in conjunction with previous studies, suggest the need for new, more robust, independent research into safety and efficacy. The safety component of such studies should probably include adverse effects beyond memory loss and cognitive decline.

1. Introduction

1.1. Electroconvulsive therapy

Electroconvulsive therapy (ECT) is the administration of electricity to the human brain, under general anaesthesia, to cause tonic-clonic seizures. Typically, between six and 12 treatments are given, at a rate of two or three times a week. ECT is recommended primarily for severe depression, but is also sometimes given to people diagnosed with schizophrenia, bipolar disorder or catatonia. It is given predominantly to women and older people (Leiknes et al., 2012; Morrison et al., 2025). An international review found 'large variation between continent, countries and regions in utilization, rates and clinical practice' (Leiknes et al., 2012). An audit in England found a 47-fold (Read et al., 2021) difference in the rates of ECT usage between the highest and lowest using areas. 'Significant regional variation in provision of ECT' also occurs in the USA (Peltzman et al., 2020).

Such variability is unsurprising given that since its introduction in 1938 ECT has become one of the most controversial procedures in the history of medicine (Funk et al., 2025; Meechan et al., 2022; Read et al., 2019a, b). The controversy has at least a dozen components: (i) is there any robust evidence that ECT is better than placebo, in either the short or long-term? (ii) does ECT prevent suicide? (iii) for how many recipients is the memory loss following ECT permanent? (iv) does that permanent memory loss, and other cognitive dysfunction, constitute brain damage? (v) does ECT have other significant adverse effects? (vi)

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what is the mortality rate as a result of ECT? (vii) should the procedure ever be given to children? (viii) should it be given against the will of patients? (ix) should standardised, replicable performance measures be developed and registered with the FDA etc.? (x) should there be so many different dosing methods and dosages? (xi) by what mechanism(s) is ECT supposed to work? and (xii) do critiques regarding the efficacy and safety of ECT represent stigmatising of the treatment, as sometimes claimed?

Traditional quantitative studies, including randomised, placebo-controlled trials, have yet to resolve most of the questions fuelling the controversy (Meechan et al., 2022; Read and Arnold, 2017; Read et al., 2019b).

Most ECT researchers and reviewers conclude that ECT is an effective treatment (Espinoza and Kellner, 2022; Meechan et al., 2022; Mutz et al., 2019; Pagnin et al., 2004; Rönnqvist et al., 2021; UK ECT Review Group, 2003). Nevertheless, a review, co-authored by Dr Irving Kirsch, Associate Director of Harvard Medical School's Placebo Studies Programme, found no placebo-controlled studies of ECT for depression since 1985, and no evidence of any benefits compared to placebo beyond the end of the treatment period (Read et al., 2019b). The UK's national guidelines state that ECT 'is not recommended for general use in managing schizophrenia' (National Institute for Health and Care Excellence, 2014). The USA's Food and Drug Administration requires notices to be displayed next to ECT machines stating: 'The long-term safety and effectiveness of ECT has not been demonstrated' (Food and Drug Administration, 2018). A meta-analysis reported that:

> Views on ECT vary, from researchers who consider that it is probably ineffective but certainly causes brain damage, through to those who think it is the most effective treatment available in psychiatry and is completely safe. The substantial geographical variation in rates of use of ECT suggests uncertainty about its efficacy and safety. (UK ECT Review Group, 2003, p. 799).

1.2. Asking patients

Meanwhile, there is an important and growing body of studies directly asking ECT recipients about their experiences. By 2003 a review of such studies had found a huge range, 29 % to 83 %, describing ECT as helpful, with an even greater range, 18 % to 98 %, saying they would have ECT again (Rose et al., 2003). The reviewers concluded that 'Studies where the interviews were conducted soon after treatment, in hospital settings, by the treating doctor, were more likely to report positive views of electroconvulsive therapy'. Other reviewers have pointed out:

> In hospital, they are not exposed to even minimally taxing actions such as shopping and driving. There are no environmental cues as to what they are expected to know and remember in their roles outside the hospital. In a few days or even weeks, patients cannot gain enough experience of using their minds and memories to accurately assess their altered capacities… . . In the longer term, i.e. 2–6 months, patients who initially rated their memory and cognition as improved, experience and accurately report impairment. (Roberston & Pryor, 2006)

For example, the largest study (418) in the 2003 review, was a questionnaire distributed by Mind, a British NGO, at various points of time after discharge from hospital. It found that only 36 % of ECT recipients reported ECT to be helpful (Pedler, 2000). The second largest (308), distributed by British service-user organisations, also after discharge, found that only 30 % reported ECT to be helpful and only 18 % said they would have it again (UK Advocacy Network, 1995).

A more recent meta-synthesis, of 16 qualitative studies of patients' perspectives (Wells et al., 2020), found a range of experiences, including long-term benefits, short-lived improvement, no positive effects, and damage to cognitive functions. A recent Swedish survey asked 1917 recipients 'Would you consider having ECT again if you would fall ill again?'. 51.1 % said yes, 21.3 % said no, and 27.6 % were undecided (Kronsell et al., 2024). Negative responses were correlated with memory loss and failure of ECT to alleviate depression.

The current study was designed to add to this body of literature, and to give a large number of ECT recipients the opportunity to have their experiences heard, by conducting the first ever online, international survey.

2. Methods

The study was approved by the University of East London's Ethics and Integrity Sub Committee (ETH2324–0053). It involved the same method as previous online surveys about other psychiatric treatments (Cartwright et al., 2016; Horowitz et al., 2025; Larsen-Barr et al., 2018; Moncrieff et al., 2024; Read, 2025; Read et al., 2014, 2023a, b; Read and Sacia, 2020; Read and Williams, 2019).

2.1. Instrument

A questionnaire was developed, from previous research and the experiences of the three research team members who are ECT recipients. Mind, the UK's largest mental health charity, commented on a draft. Participants had to be at least 18 and have had ECT (>4 weeks prior to survey participation).

Other papers have reported the responses regarding effectiveness (Read et al., 2025a), effects on memory (Read et al., 2025b), information given to patients and families before ECT (Read et al., 2025c), other adverse effects (Read et al., 2025d), the self-reported causes of the problems for which ECT was prescribed (Read et al., 2025e) and sex differences (Morrison et al., 2025). The current paper reports on the ECT recipients' responses to two open questions: 'Please name up to three positive effects of your ECT, if any' and 'Please name up to three negative effects of your ECT, if any'. These questions were asked near the beginning of the survey, so as not to influence responses with the later questions, such as lists of possible adverse effects.

2.2. Procedure

The questionnaire was open, on Qualtrics, from January to September 2024. It was disseminated on social media. The researchers also contacted numerous mental health organisations in all six continents. For example, the 44 national group members of Mental Health Europe (www.mentalhealtheurope.org) were asked to disseminate the survey to their members and other mental health groups in their countries.

2.3. Data analysis

Of the 844 ECT recipients who responded to the survey, 776 reported at least one positive or negative effect. These were counted and divided into one set of positive responses and two sets of negative responses (see Tables 2–4).

2.3.1. Content analyses

Three content analyses were conducted (one for responses to the positive effects question and two for the more numerous responses to the negative effects question). One of the researchers carefully read both data sets in their entirety, developed draft categories and subcategories, and coded the items into them. Responses could be coded into more than one category/subcategory. Only categories with 8 (1 %) or more examples are reported. A second researcher was given 25 randomly selected positive responses and assigned them to the categories/subcategories developed by the first researcher, without knowing how the first researcher had coded the 25 items. A third researcher similarly blind coded 25 randomly selected items from each of the two sets of

negative responses.

2.3.2. Coding of positive effects

The two coders concurred on 24 of the 25 items (96 % agreement). The disagreement occurred because although both researchers agreed that 'Lifted my depression' was an example of the category 'Improved Mood', one assigned it to the sub-category 'unqualified' but the other assigned it to the 'significant/large' sub-category. The disagreement seemed to arise because 'significant/large' was seen by one coder to include any elimination of the depression while the other was using 'significant/large' to indicate something more extraordinary. This led to the introduction of two new subcategories, 'eliminated' and 'improved', with the six items referring to depression being 'lifted' recoded as 'eliminated' instead of 'unspecified'. Of the 127 items originally coded as 'unspecified' 75 were recoded as 'improved' and 32 as 'eliminated'. The 'significant/large' theme was renamed 'large/extreme' to differentiate it from 'eliminated'.

2.3.3. Coding of negative effects

Of the 25 examples from the first set of negative effects ('Memory loss, Cognitive decline and Brain damage') 23 were coded into the same categories/subcategories by both coders (92 % agreement). When examples that were coded into more than one category/subcategory were included, however, the agreement rate was 25 out of 35 (71.4 % agreement). In several instances coders had coded by content but not severity/duration, or vice versa. For example, 'Temporarily lost ability to read' had been coded by one coder only as 'reading difficulty' and by the other only as 'temporary' when both categories should have been used. The data set was rechecked for similar omissions.

Of the 25 examples from the second set of negative effects ('Other') 22 were coded into the same categories/subcategories by both coders (88 % agreement). When examples that were coded into more than one category/subcategory were included the agreement rate was 26 out of 30 (86.7 %). Three of the disagreements related to the subcategories of 'Mistrust of Professionals', leading to a new subcategory of 'Other doctors', to differentiate these from 'Psychiatrists/mental health services'.

A fourth member of the research team, when reviewing a draft of the paper, suggested that a subcategory of the Abused/Violated/Traumatised category be created to recognise 'retraumatization' (see Table 4).

3. Results

3.1. Sample characteristics

The majority of the 776 ECT recipients were female (74.1 %) and most identified as 'white' (88.8 %). The average age at the time of their last ECT ranged from 14 to 77 and averaged 37.2 (SD = 13.6). The year of their last ECT ranged from 1958 to 2024, with a mean of 2012.2 (SD = 13.0). More than half (55.7) had last received ECT in the last ten years (2015 – 2024). The respondents were from 41 countries. Most (73 %) had received their most recent ECT in the USA (48 %), the UK (14 %), or Australia (11 %).

Of the 734 responding to the question about courses of treatments, 252 (34.3 %) had received only one course, 206 (28.1 %) had received between two and five courses, 93 (12.7 %) between six and ten, and 183 (24.9 %) 'more than 10'. Of the 703 people responding to the question about individual ECTs in the most recent course, 99 (14.2 %) had received between one and five ECTs, 233 (33.1 %) between six and ten, 245 (34.9 %) between 11 and 20, and 126 (17.9 %) '>20'.

Of the 495 people who knew which electrode placement was used for their most recent treatment, 109 (22.0 %) reported unilateral and 386 (78.0 %) bilateral. When asked to choose one or more of six reasons why ECT was prescribed, 80.2 %% selected 'Depression', 16.9 % 'Bipolar disorder/mania', 13.8 % 'Psychosis/schizophrenia', 4.1 % 'Catatonia, 14.2 % 'Other' and 6.2 % 'Don't know'.

3.2. Total positive and negative effects

Of the 776 respondents who identified positive or negative effects, 379 (48.8 %) reported one or more positive effects (see Table X). 156 reported one positive effect, 81 two and 142 three; totalling 744 reports of positive effects. 752 (96.9 %) reported one or more negative effects. 110 reported one negative effect, 111 two and 531 three; totalling 1925 reports of negative effects. Thus, the average number of positive outcomes reported per person was 0.96, compared to a mean of 2.48 for negative outcomes.

Just over half (51.2 %) reported only negative effects, 45.6 % reported a mixture of positive and negative effects, and 3.2 % reported only positive outcomes.

3.3. Positive effects

Table 2 presents the content analysis of the 744 positive effects reported by 379 ECT recipients, with examples. Twenty categories met the criteria of having examples from 1 % (8) or more of the 776 that had provided at least one positive or negative effect. Five categories were further divided, into a total of 19 subcategories. The two most commonly reported effects, by far, were Improved Mood (23.2 %) and Reduced Suicidality (12.6 %). No other positive effect was reported by more than 3.1 % (Improved Psychosis).

3.4. Negative effects

Tables 3 and 4 present the two content analyses of the 1925 negative effects reported by 746 ECT recipients. Table 3 shows that Memory Loss was reported by 633 (81.6 % of the 776 reporting positive or negative effects), Cognitive Decline by 225 (29.0 %) and Brain Damage by 39 (5.0 %). The two larger categories are further subdivided, into 20 subcategories.

Table 4 presents 15 other types of negative effects, including five categories that are divided, into a total of 18 subcategories. The most commonly reported other effects were Headaches (90, 11.6 %), Abused/Violated/Traumatised (61, 7.9 %), Fear/Anxiety (53, 6.8 %) and Impaired Relationships (42, 5.4 %)

4. Discussion

4.1. Positive effects

Clearly, many people feel better after ECT, in various ways. The three most commonly reported positive effects were improved mood (23.2 %), reduced suicidality (12.6 %, with 2.4 % saying it saved their life), and reduced psychosis (3.1 %). Table 1 lists multiple other important benefits reported by smaller numbers, including increased energy, hope, activity and socialising.

Furthermore, cognitive improvement was reported by 1.7 %. None of the 776 ECT recipients, however, reported improved memory.

It should also be noted that two effects that might usually be considered negative are, for a few people, experienced as a good outcome, namely Forgetting Trauma/Why Depressed (2.3 %) and Emotional Numbing (1.4 %).

Table 1
Total positive and negative effects.

	Positives	Negatives
one or more	379 (48.8%)	746 (96.1%)
none	397 (51.2%)	30 (3.9%)
one	156 (20.1%)	103 (13.3%)
two	81 (10.4%)	109 (14.0%)
three	142 (18.3%)	534 (68.8%)

n = 776

Table 2
Positive effects.

Effect[1]		Examples (in their own words)	Age at last ECT, gender,* country
IMPROVED MOOD	180 (23.2%)		
unspecified	28	*Mood.*	37 m UK
improved	71	*Less depression.*	31 m Germany
		Mood improved.	38 m UK
eliminated	25	*Lifted my depression.*	57 f UK
		No longer depressed.	20 m Iran
		Hard to tell because it came at the same time as change to meds and other circumstances but I did recover from the deep depression.	38 f USA
temporary	20	*Brief improvement in mood.*	31 f Sweden
		Temporary depression relief.	79 m USA
slight	17	*Slightly improved mood.*	31 f Canada
		Minor decrease in depression.	61 m USA
temporary and slight	4	*Depression minimally improved but only for a couple of days right after ECT treatment.*	35 m USA
		Slight relief from my depression for a short while.	29 f Australia
large/extreme	13	*I came rocketing out of extreme depression.*	33 m USA
		Deep, long-lasting depression is gone.	35 f USA
		Went from severe depression to full remission.	44 f Norway
REDUCED SUICIDALITY	98 (12.6%)		
suicidality eliminated	41	*Stopped suicide ideation.*	51 f Ireland
		Suicidal attempts have stopped	35 f USA
		Elimination of suicidal ideation.	61 m USA
suicidality reduced	34	*Became less actively suicidal.*	66 f USA
		Lessened suicidality.	21 f N Zealand
		Less suicidal thoughts.	33 f Belgium
saved life	19	*Saved my life.*	43 m UK
		I didn't kill myself.	40 f USA
		I'm still alive in 2024, ECT is a lifesaver and I'm certain I would've taken my life without it.	33 m USA
temporary reduction or elimination	6	*For a couple weeks after I was less suicidal.*	59 f Australia
		Short term relief from suicidal ideation.	44 f USA
REDUCED PSYCHOSIS	24 (3.1%)		
eliminated	13	*Recovered from my period of psychosis.*	24 m UK
		The voices went away.	44 m Denmark
reduced	11	*Decrease of auditory hallucinations.*	31 f S Korea
		Less psychosis.	25 f Canada
GENERAL IMPROVEMENT	24 (3.1%)		
unspecified	11	*Effective.*	35 f UK
		Resolved psychiatric symptoms.	34 f Australia
slight	3	*Small amount of relief.*	56 f USA
		I had a slight improvement.	27 f UK
temporary	8	*Temporary/ 1 month improvement in symptoms.*	39 f Canada
		Short term effective.	47 f Australia
slight and temporary	2	*Slightly worked for a little while.*	35 m USA
		Felt slightly better short term.	56 m UK
INCREASED ENERGY	21 (2.7%)	*More energy.*	64 f UK
		Temporary more energy.	28 f Belgium
INCREASED ACTIVITY/ FUNCTIONING	20 (2.6%)	*Started doing things I used to enjoy.*	56 ? USA
		Able to function again.	49 f UK
FORGOT TRAUMA/WHY DEPRESSED	18 (2.3%)	*Couldn't remember why I was in hospital or why I was depressed.*	29 f USA
		Forgetting bad things.	28 f Australia
		Forgot some traumas and uncomfortable things from the past.	20 f Finland
		All those childhood traumas magically wiped away.	28 m Norway
		Forgot some trauma.	40 f USA
		Temporarily lost memories of my past abuse.	31 f Australia
		Memory loss makes coping easier in not ruminating or replaying things.	26 f USA
HOPE	17 (2.2%)	*Hopeful about future.*	28 m Australia
		Not feeling hopeless anymore.	27 nb USA
		Gave me hope that it could make me better (it absolutely did not).	23 f USA
INCREASED SOCIALISING	17 (2.2%)	*I was able to resume my relationships with family and friends.*	69 f USA
		Talking a little again. Small conversations.	29 f Canada
		Could see my family and go home.	52 m UK
REDUCED ANXIETY	16 (2.1%)	*Less anxiety.*	55 f Austria
		Huge reduction in anxiety.	62 m USA
		Less anxiety temporarily.	55 f Australia

(*continued on next page*)

Table 2 (*continued*)

Effect[1]		Examples (in their own words)	Age at last ECT, gender,* country
HOME	15 (1.9%)	*It enabled me to get out of hospital.*	33 f UK
		Discharged home.	50 f UK
		According to my journal (because I cannot remember) agreeing to have it meant I could leave the locked unit and eventually be discharged–it was the only way they would let me go.	34 f USA
		I did it to get out!	
COGNITIVE IMPROVEMENT	13 (1.7%)	*Better concentration.*	46 f UK
		I was able to think clearer.	47 f USA
		Temporary more focus.	46 f Belgium
RETURN TO NORMAL/SELF	13 (1.7%)	*Felt myself again.*	47 m UK
		Resumed my normal life.	34 f Australia
FAST	13 (1.7%)	*Efecto rapido.*	29 m Columbia
		I came rocketing out of extreme depression.	33 m USA
		Instant euphoria.	30 m Net'lands
REDUCED CATATONIA	13 (1.7%)		
eliminated	8	*Removal of catatonic symptoms*	64 m USA
reduced	5	*Reduced catatonia*	29 m Australia
EATING MORE	12 (1.5%)	*Appetite was better.*	32 f Finland
		I could eat and drink again.	20 f UK
		I was also anorexic at the time, so it stunned me enough to eat to a healthier weight.	39 f UK
EMOTIONAL NUMBING	11 (1.4%)	*Numbing. felt no emotions.*	41 f Canada
		Dulled emotions and thoughts.	22 m USA
		I was so disorientated that it almost rendered me emotionless so I therefore did not feel the level of heightened depression I did at the time I entered the hospital.	32 f Australia
WORK/EDUCATION	11 (1.4%)	*I was able to return to work.*	44 f UK
		Finished school.	26 m Iceland
ANAESTHESIA	11 (1.4%)	*The anaesthetic provided a break from life.*	31 f Australia
		I like being given an anaesthetic because it felt like dying peacefully and being totally free of my pain for a short time.	42 f UK
		I got to get off the planet for a few minutes with the anaesthetic. That was only benefit.	27 ? Australia
		While having the course I had some improvement in symptoms but these were more from the medication given to put me under.	19 f Australia
INTERACTIONS WITH STAFF	8 (1.0%)	*There was more personal attention when getting ECT so I felt more cared for.*	42 f UK
		The routine of going to the hospital socializing with the nurses etc.	41 f USA

? = no answer
1 Quotes could be coded into more than one category/subcategory
* nb = non-binary,

4.1.1. Commentary

Just as some of the reported negative effects attributed to ECT may have been caused by other factors (see Limitations), the same may be the case for some of the positive effects. The current study cannot determine what proportion of those experiencing improved mood are due to ECT or to placebo effects. From the participants' perspective a placebo explanation would not diminish or detract from their experience that ECT helped them. Nevertheless, a review focussed on placebo responses to ECT (Rasmussen, 2009), found 'an unexpectedly high rate of response in the sham [SECT] groups'. Reviews of ECT for depression have found only 11 placebo-controlled studies comparing ECT with 'sham'/'simulated' ECT (SECT), in which the general anaesthetic is administered but the electricity, and therefore the convulsion, are withheld (Read and Bentall, 2010; Read et al., 2019b). There have been none since 1985 (Gregory et al., 1985). The reviews found that all the studies fell well short of today's methodological standards.

Furthermore, a meta-analysis by the UK Government's ECT Review Group (2003) stated: 'Although ECT is sometimes thought to be a life-saving treatment, there is no direct evidence that ECT prevents suicide'. The New Zealand Government found 'no definitive randomised evidence that ECT prevents suicide' (Ministry of Health, 2004). Multiple studies find that people receiving ECT are more likely to kill themselves than people not receiving it (Munk-Olsen et al., 2007; Tsai, et al., 2021). Others find either a slight difference in favour of ECT (Kaster, et al., 2022; Ronnqvist, et al., 2021), or no difference (Jorgensen et al., 2020; Watts et al., 2022).

A recent meta-analysis, of 17 studies involving more than 40,000 ECT patients, concluded that ECT 'was not consistently associated with a reduced risk of suicide', because it was associated at 3 months follow up but not at 1, 6, or 12 months (Rhee et al., 2025).

Nevertheless, all of the reported experiences of our respondents in terms of decreased suicidality must be accepted at face value. If you believe something saved your life, it probably did.

4.2. Negative effects

By far the most common effect, positive or negative, was memory loss, reported by 81.6 %. It should be noted that these were responses to an open question about 'negative effects', not responses to a specific/closed question such as 'Did you experience memory loss?' Of the 633 people spontaneously reporting memory loss, 150 (23.7 %) went on to spontaneously describe the loss as 'severe', and 55 (8.7 %) as 'persistent/permanent'. It is not clear how long-lasting or severe the loss was for the majority who did not comment on duration or severity. These figures

Table 3
Negative effects 1: Memory loss, cognitive decline and brain damage.

Effect[1]		Examples (in their own words)	Age at last ECT, gender, country
MEMORY LOSS	633 (81.6%)		
unspecified	308	*Memory loss.*	33 m India
		Memory impairment.	27 f USA
retrograde/long-term/auto-biographical	170	*Can no longer remember parts of my life.*	27 m UK
		Long term memory loss. I can't remember chunks of my life before ECT.	27 f UK
		Memory loss of several years.	33 f USA
anterograde/short-term	164	*Loss of short-term memory.*	20 f USA
		I have almost no ability to maintain train of thought or recall what transpires which I have been told is called working memory disorder.	24 m USA
		Difficulty forming new memories. New things don't seem to stick as easily as before.	34 nb USA
		No working memory.	62 ? USA
severe	150	*I lost 19 years of memory including my children growing up.*	37 f USA
		Lost 4 years of long term memories completely. It is as if those years of my life did not happen.	20 f Australia
		Most of my memories are gone.	25 f Australia
		I have lost a significant amount of my long term memories. Approx. 4-6 years prior to the treatments, I have no clear memories beside the ones I can "Force through" with photographs and other people retelling the story.	25 f Denmark
		Years of memories of academic and biographical content are gone.	19 m USA
		Very difficult to return to work as I couldn't remember any of the procedures or even where my desk was.	33 f Canada
		I could not teach any more, as I had forgotten whole chunks of information that had been garnered over 30 plus years.	46 f USA
		Severe problems with remembering things and learn new things. Its like I have no storage, or its in there but cant find it cause its stored in a blacked out room in my head.	18 f Norway
slight	17	*Slightly worse memory.*	29 f Iceland
		I think it had a negative effect on my memory slightly.	29 m Australia
persistent/permanent	55	*Permanent loss of memory and memories.*	47 m USA
		Permanent memory loss.	28 m Australia
		Loss of years of memory, permanently.	21 m USA
		Even years later, I still cannot recognize people I've known for years when I see them.	35 f USA
		Memories of significant events with my children permanently erased. Hard to remember much at all about their early lives, birthdays, first days at school, activities … I also don't remember my wedding.	42 f UK
temporary	18	*Transient amnesia.*	32 f Finland
		Issues with memory in the few months afterward.	25 m Australia
		Severe but temporary memory loss.	53 m USA
COGNITIVE DECLINE	225(29.0%)		
unspecified	67	*Cognitive impairments.*	22 f Hungary
		Loss of cognition.	32 f Ireland
confusion	37	*Confusion.*	48 f Spain
		Confused.	36 m N Zealand
concentration/focus problems	36	*Problems with concentration.*	32 nb Germany
		Short term memory problems, concentration.	19 f UK
		Inability to focus.	40 f USA
brain fog	17	*Brain fog.*	66 m USA
		Constant brain fog.	17 f USA
reduced intelligence	17	*Lowering of IQ.*	54 f USA
		Lower intelligence.	28 f Turkey
reading difficulty	16	*Can't read a book.*	41 f Canada
		Reading problems.	33 f UK
reduced executive function	13	*Impaired executive functioning.*	39 f Canada
		Executive dysfunction.	16 m USA
reduced maths ability	10	*Can't do math or any of the things I have studied.*	30 f USA
		My IQ level has dramatically declined, university graduate having to relearn basic English and math.	25 f Australia
processing problems	10	*Cannot think nor process information.*	57 m USA
		Impaired my cognitive skills like ability to process info.	46 f USA
severe	14	*Forced to resign from working as a registered nurse due to loss of cognition.*	24 f USA
		Debilitating loss in executive function, especially concentration.	64 m USA
mild	4	*Sporadic cognitive issues: searching for words and losing track of where I am in a conversation.*	61 m USA
		I believe my overall cognitive functioning worsened slightly.	18 f UK
permanent/persistent	9	*Processing issues I still have all these years later.*	25 f USA
		Struggled with memory loss and poor concentration for years after, and memory/intelligence had always been an important part of my identity, so identity loss.	27 f Australia
temporary	4	*Temporarily lost ability to read.*	18 nb USA
BRAIN DAMAGE	39 (5.0%)	*Brain damage.*	55 m USA
		Brain damage with extreme memory loss including executive function disorder.	54 f Canada
		TBI [traumatic brain injury] with severe headaches.	26 f Australia
		Permanent brain damage.	50 f USA
		Loss of job, permanent SSA disability, brain changes per several MRIs.	35 f USA

*nb = non-binary, ? = no answer

should be contrasted with the 17 (2.7 %) who described their memory loss as 'slight' and the 18 (2.8 %) who said it was 'temporary'. So, of the 167 commenting on severity, 89.8 % (150) described the loss as 'severe'. Of the 73 who mentioned duration, 75.3 % (55) described it as 'persistent/permanent'.

More than one in four (29.0 %) in the current study spontaneously reported a range of other types of cognitive impairment. One in 20 respondents spontaneously reported suffering 'brain damage.'

Headaches were reported by 11.6 %. Of the 24 spontaneously commenting on severity, most (87.5 %) described the headaches as severe. Of the 26 commenting on duration, most (61.5 %) described them as short-term, i.e. only immediately after the treatments (see Table 3).

Responses coded as 'Abused/Violated/Traumatised' were made by 7.1 %. Of these 61 people, 23 % described their experience of having ECT as triggering previous trauma and abuse and, thereby, as 'retraumatizing'.

4.2.1. *Commentary*

There are at least four possible explanations why our findings are less positive about ECT than those of other ECT researchers (Espinoza and Kellner, 2022; Meechan et al., 2022; Mutz et al., 2019; Pagnin et al., 2004; Rönnqvist et al., 2021; UK ECT Review Group, 2003). All four may be partially true.

Firstly, our sample may have been biased towards negative responders and/or responses (see Limitations).

Secondly, it may be that asking people weeks, months or years later produces more negative, and accurate, outcomes. As mentioned earlier "Studies where the interviews were conducted soon after treatment, in hospital settings, by the treating doctor, were more likely to report positive views of electroconvulsive therapy (Rose et al., 2003). Other reviewers put it this way:

> There are many reasons why hospitalised patients who have received ECT might overestimate their abilities… . . In hospital, they are not exposed to even minimally taxing actions such as shopping and driving. There are no environmental cues as to what they are expected to know and remember in their roles outside the hospital. In a few days or even weeks, patients cannot gain enough experience of using their minds and memories to accurately assess their altered capacities (Robertson and Pryor, 2006).

Thirdly, Rose et al. (2003) also found that 'Patient led studies reported lower rates of perceived benefit than clinical studies'. Our survey was explicit about half the research team being ECT recipients. People may be more candid about personal experiences with others who share similar experiences. Furthermore, those three researchers helped make sure the right questions were asked, questions less likely to be asked by people who have not experienced the effects of ECT, which in turn may have elicited increased openness in some participants.

Finally, asking people open questions about their 'negative' experiences may uncover more damage than the tools traditionally used to assess for cognitive deficits. For example:

> Claims that ECT does not have permanent adverse effects on memory and cognitive ability have been based on extremely gross measures of mental function such as the Mini-Mental State Examination and other dementia screening scales … . Even people with severe brain injury or lobotomy can perform well on simple tests of overlearned verbal material that require culturally common information, for example the Wechsler Memory Scale. However, clinicians who conclude from this that there is 'no memory loss' have not measured memory loss at all, and certainly not the type of memory and cognitive disability that people can experience after ECT. (Robertson and Pryor, 2006).

Our findings on memory loss are broadly consistent with previous studies which have asked patients directly. Memory loss was the most common spontaneously reported side effect by 389 British ECT recipients (49 %) (Rayner et al., 2009). Of 30 other British recipients, 24 (80 %) reported memory loss when interviewed (Guruvaiah et al. 2017). When questionnaires were distributed by British and Irish ECT staff to their patients, 121 (63 %) of the 192 who responded reported memory loss (Hailey et al., 2015).

A 2003 review identified four studies that had asked 597 patients about memory loss at least 6 months post-ECT. The review found a range of 51 % to 79 %, with a weighted average of 70 % (Rose et al., 2003). The review also found four (n = 703) that had asked explicitly about 'persistent or permanent memory loss', producing a range of 29 % to 55 %, with a weighted average of 38 % (Rose et al., 2003).

Subsequently, a study of 'long-term subjective memory' assessed 277 patients in Sweden, on average 73 days after ECT, and found that 55 % reported a 'negative' effect on memory and 23 % a 'very negative' effect (Sigström et al., 2020). Of the 192 British and Irish patients approached by their psychiatrists, 36 (19 %) reported 'Severe/long-term memory loss' (Hailey et al., 2015). A meta-synthesis of 16 qualitative studies (Wells et al., 2020) found that:

> … in 15 papers, participants described complete erasure of their memory of events and experiences that occurred prior to, and sometimes immediately after, having ECT. Some participants described not remembering specific important life events, like a son's birth or their mother's death. For others memory loss was extensive: "the past 25 years are missing". This memory loss was usually considered permanent.

The memory loss, and some of the other cognitive effects reported by our respondents, are acknowledged in the A.P.A. Task Force Report (2025, pp. 253–264), although they are described as 'transient' and 'do not appear to be persistent' etc., and as largely caused by the 'psychiatric illnesses' for which the ECT was prescribed. The Report does not acknowledge that these cognitive deficits can, and often do, impact on all aspects of life, including activities of daily living, work and relationships (see below).

A recent review of nine studies (Mathiassen et al., 2025) concluded that:

> Our systematic review suggests that ECT causes autobiographical memory loss in patients with depression. This is supported both narratively and by our meta-analysis revealing an overall moderate effect of ECT on autobiographical memory compared to controls. The autobiographical memory loss remains stable between end-of-treatment and long-term follow-up (6–12 months), indicating that lost memories are not regained.

Our data cannot, of course, resolve the controversy about whether the memory loss and other cognitive dysfunction, experienced by so many patients, constitutes "brain damage." The observation that if one's brain functioned better prior to ECT therefore one's brain has indeed been damaged by ECT does not seem unreasonable. While scanning and imaging studies produce inconsistent results there is some evidence that our ECT recipients' observations are not unfounded.

Some computerised tomography scans have found frontal lobe atrophy following ECT (UK ECT Review Group, 2003). An MRI study found that the number of ECTs administered correlates with reduced grey matter density (Shah et al., 2002). A review of >100 imaging studies concluded that:

> The temporarily improved scores on depression instruments following ECT reflect the combination of frontal and temporal lobe functional impairments and activation of the hypothalamic–pituitary–adrenal axis (HPA axis) and the mesocorticolimbic dopamine system. These effects as well as other detailed changes observed in structures such as the hippocampus appear consistent with those typically seen after severe stress-exposure and/or brain trauma. (Fosse and Read, 2013).

A 2024 longitudinal study quantifying longitudinal volumetric

Table 4
Negative effects 2: Other.

Effect		Examples (in their own words)	Age at last ECT, gender, country
HEADACHES	90 (11.6%)		
unspecified	51	*Headache.*	51 f UK
after treatments	16	*Headache on same day.*	32 f Finland
		Headache short term.	36 m Ireland
ongoing	10	*Chronic headaches.*	23 f France
		Onset of repeated severe migraine headaches ongoing.	15 f UK
mild	3	*Slight headache afterwards.*	22 f UK
severe/migraine	21	*Very severe headaches after each treatment.*	37 f UK
		Terrible and frequent migraines.	46 f USA
		Extreme physical pain in head after, like being hit with a 2x4.	21 f USA
ABUSED/VIOLATED/ TRAUMATISED	61 (7.9%)		
post traumatic stress disorder - new or exacerbated	21	*I developed PTSD now.*	45 f USA
		My PTSD got much worse.	44 m Norway
		The abuse at the hospital was extremely triggering and worsened my PTSD.	27 f Canada
trauma(tic), unqualified	17	*Severe trauma from the experience.*	47 f Sweden
		Traumatic experience with ECT.	42 m USA
retraumatizing	14	*Triggered past experiences of abuse.*	48 f UK
		Retraumatised. Held down and body 'done to' against my will.	50 f UK
		Fear and terror at having things done to me which reminded me of childhood assault and made my symptoms worse.	36 nb Australia
		Distress from being put under anesthetic, due to past trauma - very triggering and distressing, told to just suck it up.	31 f Canada
		The abuse at the hospital was extremely triggering and worsened my PTSD.	26 f Canada
		As someone with a history of childhood abuse and rape, knowing I was given ECT so many times without proper facts and other options for addressing the cause of my depression, self-harm and suicidality, feels like being raped all over again.	42 f UK
abuse/violation	13	*Feeling violated and assaulted.*	? m Australia
		I felt violated by the Doctor, who reneged on our agreement to stop treatments when I asked to.	50 m Canada
		I felt violated in a way that shouldn't be possible. Our memories should be inviolable. Over time I came to see that this was just another rape, but of my mind. Part of me was stolen, violently. ECT was abuse.	35 f Australia
coercion	7	*Trauma due to compulsory ECT.*	38 f Australia
		Trauma, because I was scared to but did it under pressure.	26 f Denmark
		Retraumatised. Held down and body 'done to' against my will.	50 f UK
FEAR/ANXIETY	53 (6.8%)		
unspecified	13	*Fear.*	46 f USA
		Terror.	24 nb USA
ongoing/new fears	23	*ECT made my anxiety worse.*	30 f UK
		Profuse sweating thinking about or talking about ECT.	27 m USA
		Terror of experiencing it again.	28 f Canada
		I live in fear of this happening to me again. Just 2 years ago I narrowly missed being detained by psychiatry and my GP was saying she thought I should have ECT. I was terrified.	31 f Australia
fear of/during treatment	17	*Mortal fear before getting the next ECT.*	18 f Austria
		Extreme anxiety I had going into treatment.	68 m Canada
		I was scared every time I did it.	44 f Norway
		I woke up in one session not able to breathe or move. Terrifying.	68 f USA
IMPAIRED RELATIONSHIPS	42 (5.4%)		
unspecified	7	*Relationship issues.*	53 f Ireland
		The ways ECT changed me harmed my relationships.	40 f Canada
		Lost who I was and it affects all my relationships.	36 f USA
loss/damage/mistrust	15	*Struggle with emotional connection and maintaining healthy relationships.*	19 f UK
		I lost trust in my family and most people and of course the medical system.	26 f Egypt
		Loss of trust in family and in almost any doctor.	21 f USA
		Relationship breakdown of marriage.	49 f Australia
not recognise	15	*I couldn't remember my family.*	25 m UK
		Even years later, I still cannot recognize people that I've known very well for years when I see them until they remind me of their name AND how we know each other.	35 f USA
memories lost	7	*Having memories of significant events with my children permanently erased.*	42 f UK
		Relationships are established by shared experiences, shared interests and shared memories–wipe the memories and the relationship no longer exists.	34 f USA
PAIN	38 (4.9%)		
unspecified	14	*Chronic pain.*	26 nb USA
muscle	11	*A few muscles would be sore.*	56 f USA
		Severe muscle pain.	44 f USA
jaw	6	*Sore jaw post session.*	24 m Australia
		Constant jaw pain, even on non-ECT treatment days.	61 m USA
CAN'T WORK	38 (4.9%)		
temporarily	5	*Inability to hold a job for two years.*	26 m Brazil

(*continued on next page*)

Table 4 (*continued*)

Effect		Examples (in their own words)	Age at last ECT, gender, country
		Couldn't work during the treatments.	35 f USA
permanently	24	*Severe memory loss causing loss of job & career as health care professional.*	48 f Canada
		Couldn't do my job anymore bc I forgot how to do it.	32 f USA
		Due to memory loss, lost my well-paying job of 12 yrs.	38 f USA
		Loss of my career as a medical doctor.	35 f Canada
		Loss ability to provide myself with an income.	31 m USA
work moredifficult	5	*Had to take lower position at work.*	57 f USA
		I had to teach myself how to learn new things again, which affected my work and university greatly. This caused huge career and financial effects.	20 f Australia
STIGMA	31 (4.0%)	*Stigma/discrimination/shame.*	16 f N Zealand
		Felt highly stigmatized for having "needed it" and having "undergone it".	28 f USA
		Social stigma, feeling like a "freak" who had her brain fried.	40 f USA
		Negative stigma surrounding ECT.	31 f Australia
		Stigma about ECT, including from the anti-psychiatry community.	25 f USA
EMOTIONAL NUMBING	30 (3.9%)	*Feelings deadened.*	36 f USA
		Emotional numbness.	26 f Canada
		Feeling like a zombie.	25 f Finland
		Unable to experience any joy.	38 f Canada
		Emotionally void for years afterwards.	47 f UK
MISTRUST OF PROFESSIONALS	18 (2.3%)		
psychiatry/mental health services	8	*Destroyed trust in psychiatry; too afraid to pursue further help.*	38 f Canada
		Later a large feeling of outrage at feeling so duped by psychiatry.	56 m USA
		No trust in services.	45 f UK
other doctors	5	*Fear of doctors.*	17 f USA
		I live in fear of this happening to me again. The threat of ECT means my physical health suffers because I have to avoid doctors during times of distress.	31 f Australia
other	5	*Distrust of the legal system.*	17 f USA
		Absolute mistrust of anyone in positions of power.	47 f UK
SUICIDAL	17 (2.2%)	*I became suicidal*	19 f Canada
		Increased suicidal for several years post ECT.	15 f UK
		Suicidality became worse.	59 m UK
HUMILIATION/SHAME	14 (1.8%)	*Degradation, shame.*	31 f Germany
		Humiliating and scary treatment.	32 f Sweden
		Humiliating procedure.	50 f USA
MANIA/EUPHORIA	11 (1.4%)	*Sent me manic, so depression went for a short time.*	22 f N Zealand
		Re-hospitalized within 24 hours of release, mania.	26 ? USA
		Dangerous Hyper Euphoria lasting one day.	55 m UK
PSYCHOSIS	10 (1.3%)	*Induced psychosis.*	38 f UK
		Delusional thinking increased.	28 m India
		Increased paranoia & suicidal thought but will never tell anyone about it for fear of more forced ECT.	48 f Canada
PHYSICAL INJURY	10 (1.3%)	*Bit tongue requiring stitches.*	50 f Canada
		Broken teeth.	26 f USA
		Jaw injury.	31 f USA
SEIZURES/EPILEPSY	8 (1.0%)	*Later diagnosed with epilepsy. Did not have epilepsy before ECT.*	26 m UK
		Frontal Lobe Epilepsy.	16 f N Zealand
FINANCIAL	8 (1.0%)	*High price even with insurance.*	42 m USA
		Large time and financial commitment for no gain.	56 m USA

*nb = non-binary, ? = no answer

changes in ECT recipients identified significant gray matter volume atrophy two years post-ECT (Borgers et al., 2024). Furthermore, the repetitive intracranial mild traumatic brain injury caused by ECT is not easily captured on standard brain scans (Traumatic Brain Injury Advisory Board, 2019). The neuropathology of repetitive high field strength electricity on brain tissue involves compounding microstructural damages that are only visible under microscope with proper staining technique (Chen et al., 2006; Schmidt et al., 2008).

The ECT manufacturer, Somatics (2018), includes 'permanent brain damage' in its list of risks from ECT. In 2023, a joint report by the World Health Organisation and the United Nations recommended that: 'People being offered ECT should also be made aware of all its risks and potential short- and long-term harmful effects, such as memory loss and brain damage' (World Health Organisation/United Nations, 2023).

4.2.2. Negative effects requiring more attention

Our respondents also identified a range of other negative effects which are rarely researched (Johnstone, 1999). When asked, later in the survey, about 25 adverse effects, 17 were endorsed by more than 50 % of both recipients and relatives (Read et al., 2025d). The adverse effects reported on in the current paper fall broadly into two types. The first are the secondary effects of cognitive dysfunction, including memory loss, on social functioning such as relationships and ability to work. When asked specific questions later in the survey 33 % reported having lost their jobs and 68 % reported relationship problems as a result of ECT (Read et al., 2025d). The second type relates to the emotional effects of

ECT, including fear, (re)traumatisation, shame and stigma, feeling humiliated, and emotional numbing. Losing trust in staff and mental health services is another important but unacknowledged issue.

None of these 'other' adverse effects are mentioned in the A.P.A.'s recent Task Force Report (A.P.A., 2025). All of them, we suggest, require urgent attention, from both researchers and clinicians, and some should probably be included in information leaflets given to patients and families (Harrop et al., 2021; Read et al., 2023c; Wand et al., 2024).

A small qualitative study, of 20 ECT recipients who reported adverse effects, addressed some of these unacknowledged, but important issues a quarter of a century ago:

> A variety of themes emerged, including feelings of fear, shame and humiliation, worthlessness and helplessness, and a sense of having been abused and assaulted. This had reinforced existing problems and led to distrust of psychiatric staff….
>
> Feelings of shame, failure, badness, unworthiness, self-punishment and helplessness are common features of depression, and in so far as ECT reinforces them, it will obviously be unhelpful. Perhaps most worrying were the cases of the two women survivors of sexual abuse who clearly experienced ECT as a re-abuse. Thirdly, ECT may be leaving some people with a distrust of psychiatric services that undermines any future attempts to form therapeutic relationships (Johnstone, 1999).

Finally, more attention could be paid to the possibility that even the positive effects are, for some people, due to erosion of trauma memories, emotional numbing or the temporary escape provided by the general anaesthetic.

4.3. Limitations

Sample bias towards those for whom ECT had a *negative* outcome may have occurred from the dissemination of the survey on social media by the researchers, some of whom have critiqued ECT in research papers and online. To minimise this, social media posts included phrases like 'Positive, mixed and negative experiences are all equally valued'. It is also possible that people who felt ECT had harmed them were particularly motivated to contribute. Having a mental health condition is likely to be independently associated with long-term difficulties and lower quality of life. It may have been hard for some respondents to differentiate these from the effects of ECT.

Sample bias towards people for whom ECT had a *positive* outcome was also potentially present, in three ways (although without the necessary data these remain speculative):

(i) Those for whom ECT had failed to alleviate the severe depression (for which it is typically prescribed) might be uninterested in, or unable to complete, a survey.
(ii) Patients who died during or soon after treatment due to cerebral or cardiovascular events (Duma et al., 2019; Read, 2024) did not participate.
(iii) Some of those in whom ECT caused cognitive deficits may have been unable to participate.

This survey relies on self-reports, which relied on memory, sometimes of events many years in the past, and the cognitive impairment caused by ECT gives additional reason to suspect possible inaccuracies in recall.

As noted earlier, some of the positive outcomes attributed to ECT by our participants may have been placebo effects (Rasmussen, 2009; Read et al., 2019b). Similarly, some of the negative effects they attributed to ECT may have been due to other factors, such as depression. Numerous studies, however, have found that the memory loss and other cognitive dysfunction found after ECT is not related to depression (McElhiney, et al., 1995; Neylan, et al., 2001; Shah, et al., 2002). A review concluded 'There is no evidence of a correlation between impaired memory/cognition after ECT and impaired mood, much less a causal relationship' (Robertson and Pryor, 2006). The A.P.A. Task Force Report states that 'depression symptom severity is unrelated to neurocognitive performance' (A.P.A., 2025, p. 25). Nevertheless, the relationship between depression and some of the other negative outcomes is unknown, and other factors such as age and illness, may have contributed to the negative effects attributed to ECT by our participants.

Qualitative research, including content analysis, is, by definition, a subjective process. The six researchers, including three who have received ECT, have a less positive view of ECT than many other ECT researchers, and this may have biased the coding process. The quotes, however, were characterized as 'positive' or 'negative' by the participants not the researchers. We have provided as many examples as space will allow (including 86 examples of 'positives') so readers can judge whether the categories and coding are reasonable.

Our samples had an average age at last treatment of 37 years, which is younger than the typical average age of ECT recipients (Leiknes et al., 2012; Read et al., 2021). This is important because there is some evidence that ECT is more effective for older people (Jelovac et al., 2021) but causes them more cognitive deficits than younger patients (Sackeim et al., 2007).

We did not recruit adequately from beyond English-speaking countries in North America, Europe and Australasia. The survey was written in English without translations.

In combination, these limitations clearly limit the generalizability of our findings.

5. Conclusions

All the limitations identified above must be kept in mind when drawing conclusions from our study.

Even allowing for these limitations, however, this large international group of ECT recipients, taken together with previous studies of patient accounts, points to the need for further research designed to better delineate the benefit/risk ratio of ECT. The safety component of such studies should, perhaps, include the adverse effects reported by our participants.

CRediT authorship contribution statement

John Read: Writing – original draft, Methodology, Investigation, Formal analysis, Conceptualization. **Sue Cunliffe:** Writing – review & editing, Methodology, Investigation, Conceptualization. **Sarah Hancock:** Writing – review & editing, Methodology, Investigation, Conceptualization. **Christopher Harrop:** Writing – review & editing, Methodology, Formal analysis, Conceptualization. **Lucy Johnstone:** Writing – review & editing, Methodology, Investigation, Conceptualization. **Lisa Morrison:** Writing – review & editing, Methodology, Formal analysis, Conceptualization.

Declaration of competing interest

The authors declare the following financial interests/personal relationships which may be considered as potential competing interests: JR has been a paid expert witness in several ECT legal cases in the USA and Canada

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