

Introduction

‘You still do that to people?’

This is a common question when I tell people what I do as an ECT consultant psychiatrist in our local hospital. Often, this is coupled with a look of bemusement, or even disapproval.

Electroconvulsive therapy (ECT) is the most controversial treatment in psychiatry and is an unknown area for most people. It has been nearly fifty years since *One Flew Over the Cuckoo’s Nest* appeared on cinema screens, depicting Jack Nicolson undergoing a torturous treatment at the hands of the cruel Nurse Ratchet, yet this image persists in people’s minds when ECT is mentioned. Depictions of a painful, barbaric, archaic treatment that can cause brain damage are at the forefront when ECT is suggested as an option for patients. This negative image persists, even among healthcare professionals: plenty of my colleagues are still perplexed by our role in the hospital. ‘Does it even work?’ they ask in wonder, as if we would continue to be employed if it did not.

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ECT was first developed in Rome, in 1938, following observations that induced epileptic seizures could bring improvements in some mentally unwell patients. At that time, antidepressant and antipsychotic medications were not yet available, and it would be nearly two decades before these were developed. Patients with mental illnesses were largely living without any effective treatments, and when they became very unwell, they could stay unwell, with many of them confined in asylums.

ECT was found to be highly effective in patients suffering with schizophrenia or depression. The use of ECT rapidly spread around the world, as its effect was noted quickly by psychiatrists, who administered it to their patients. After the development of medications in the 1950s, the use of ECT began to decline, although it remains the most effective treatment for certain types of mental illness, such as psychotic depression and catatonia, as well as for many patients with mania, schizophrenia and depression who do not improve with other treatments. The use of ECT continued to decline over the years, after a strong backlash from groups that did not understand its role in modern psychiatry. The negative portrayal in the media also played a significant role.

Despite that, ECT has survived globally, to the present day, as it remains highly effective for those with very severe illness who do not improve with other treatments. In recent years, around 2,000 patients received ECT annually in the UK. The rate is higher in some European countries (for example, Sweden), but lower in others, such as Italy, the country where it was first developed. The majority of patients receiving ECT in the UK are treated for depressive episodes, with fewer for schizophrenia, mania and other conditions. Just over 40 per cent of depressed patients achieve remission (nearly complete absence of symptoms), while two-thirds of patients are rated as being 'much improved' or 'very much improved'. ECT is prescribed to twice as many women than

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men, reflecting the higher rate of depression among women. Elderly people are more likely to benefit from ECT, and the average age of those receiving ECT in the UK is just over sixty years.

This book was conceived with the view of lifting the mystery surrounding ECT and reducing the misinformation and hostility that abounds in the media and tarnishes public perception. We felt that the public should hear the voices of patients and their relatives, as it is not sufficient for doctors merely to describe the procedure and its benefits. This is why we brought together a group of people who were willing to share their stories, with each one writing a chapter. There is, admittedly, a higher proportion of good outcomes among the participants, compared to the statistics listed earlier, but not all outcomes are perfect and there are detailed descriptions of some of the side effects they experienced.

None of the contributors has been able to witness the procedure, since they were anaesthetised when ECT was given to them or, in the case of relatives, would have been asked to stay in the waiting room. This has resulted in a lack of technical descriptions of the procedure, so the following section provides a short summary of what happens during ECT in clinics in the UK. For a more detailed description, readers can access the patient information leaflet available on the Royal College of Psychiatrists website: www.rcpsych.ac.uk/mental-health/treatments-and-well-being/ect.

What Is ECT?

The treatment is administered in hospital. The patient is given a short-acting general anaesthetic that is injected intravenously by a consultant anaesthetist. When the patient is fully asleep, they are given a short-acting muscle relaxant which reduces the strength of the muscle contractions. An electric current is passed

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through the head via two electrodes, typically one over each temple (bilateral ECT) or one over the right temple and one over the top of the head (right unilateral ECT). Right unilateral ECT causes less confusion and fewer memory problems. The muscle relaxant causes partial paralysis of the muscles, including those involved in breathing. As a result, the patient stops breathing and the anaesthetist delivers oxygen via a face mask. A foam mouthguard is inserted to prevent damage to the teeth. The electric stimulus consists of short pulses of electric current, each of 1/1,000 of a second or shorter, given for up to eight seconds. The amount of electricity required to induce an epileptic seizure varies between people, with older people requiring higher doses. The required dose changes during the course of treatment and is affected by certain medications that the patient may be taking. The electric current induces an epileptic seizure, which presents only with muscular twitches due to the partial paralysis caused by the muscle relaxant. Electroencephalogram (EEG) electrodes are attached to the head, to record the electrical activity in the brain. The modified seizure lasts typically between twenty seconds and one minute. Shorter seizures are less likely to be therapeutic, while those lasting more than two minutes should be stopped with medication.

In the UK the treatment is usually given twice a week, while in some countries, such as the USA, it is done three times a week. During the seizure, the blood pressure and pulse rate of the patient increase, and sometimes the pulse rate can become irregular. These changes are monitored and settle typically within a few minutes. The patient regains orientation after around fifteen to thirty minutes. Improvement in depression may start after only a few treatments. Recovery from depression is seen on average after eight sessions, but these numbers can vary quite widely between individuals. Relapses are common, with about half of all patients relapsing within twelve months. These patients might

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need additional courses of ECT, or a few additional sessions (continuation ECT), along with medications. A small proportion of patients who continue to relapse may require longer-term treatment (maintenance ECT), which can be given at intervals ranging between one and six weeks.

The most troubling side effect is temporary memory problems, reported by up to 40 per cent of patients while they are having ECT. Typically, people can forget some events that occurred during, or shortly before, the depression started and covering the time during the ECT course. For example, they may forget conversations with visitors during this time. Sometimes these memories return fully or partially, but in other cases these gaps can be permanent. A small proportion of people report some persistent memory loss for a number of months after the ECT. There are reports of patients who experienced gaps in memories stretching back for several years prior to the ECT course, and I have witnessed accounts of people who forgot some significant events that had happened several years before the treatment. The type and range of memory problems are covered extensively by the contributors throughout the book.

Despite its dramatic nature, the effects on the heart and the use of a general anaesthetic, the treatment is remarkably safe. Numerous brain imaging studies have shown that ECT doesn't cause brain damage and, if anything, there is evidence that it promotes new nerve growth in certain areas of the brain. This might play an instrumental role in how ECT works, although there are other potential mechanisms.

Patients who have capacity provide written consent before starting ECT. This is done after discussions with clinicians about the benefits and side effects of the treatment to support their informed consent. A large proportion of patients treated in the UK are so ill at the start of treatment that they are not able to make decisions about this treatment – that is, they lack capacity to

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consent. For such very ill patients (typically those who have become mute or are severely psychotic or disorientated), ECT can be given without consent, after a second opinion is given by an independent consultant psychiatrist. We hope that the information within this book will help some prospective ECT users make their informed decisions about this treatment.

These are the dry facts that you might hear from the psychiatrist. So, let us give the voice to the patients and their relatives, to see how things look from their point of view. I can promise that the tone will change, the emotions will become palpable, and you will learn a lot, just like I did.

George Kirov, October 2024

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A Mother's Journey Jan's Story



Part 1: 1999

4th May

I am thirty-one weeks pregnant with my first child. It is 5 o'clock in the morning and I awake to find my bed soaking wet. Knowing that urinary incontinence is not unusual in the later stages of pregnancy, at first I think I must have wet the bed. But there is a lot of liquid and it keeps coming. I begin to think that my waters may have broken. Up until this point, my pregnancy has been uneventful. Robert, my husband, and I have only just attended our first antenatal class and our baby is not due until July. I ask Robert what he thinks we should do; he reckons it is probably nothing as the baby is not due for another two months, and so I should just try to go back to sleep.

By 8 o'clock the liquid shows no signs of stopping, so I think it is best that I phone the maternity service at our local hospital.

'I'm thirty-one weeks pregnant and I think my waters may have broken', I say.

They tell me I need to go to the hospital. I do not quite understand the severity of the situation, so I ask if I should come sometime today.

The line is quiet for a second, a shocked pause in response to my lack of understanding.

'No. You need to come now.'

We pack ourselves into my silver Corsa Sport. I have nothing with me but a bag of sanitary pads as, what I now believe are my broken waters, are still flowing, and I presume I will be back home the same day.

We arrive at the hospital; my sanitary pad is getting increasingly sodden and heavy as we walk upstairs to the maternity ward. They take me for an ultrasound scan. After the scan the doctor comes in and says:

'You have a premature rupture of membranes. What this means is, most likely, you will go into labour imminently.'

1. A Mother's Journey

I am bewildered; my thoughts collide as I try to wrap my head around the situation. This is not my plan, I am supposed to be working until the start of July, I still have a conference that I am leading coming up, I have been working on it for months. Besides, we have taken only one antenatal class, the nursery is not ready, we have not bought most of what we need for the baby: no clothes, no nappies. None of this is supposed to be happening yet. I am not at all ready.

The doctor tells me that, as there are no signs of labour, I will be admitted to the antenatal ward. I will have scans on alternate days to see how long my pregnancy can be maintained. We are taken to see the special care baby unit. I am shocked by the sight of tiny, premature babies with their translucent skin, kept alive with tubes and wires.

The next two weeks are tempered, mainly, by a stirring mixture of anxiety and restless boredom. Each day is spent in anticipation of what the next monitoring or scan may show, with little else to do but sit on my bed in the mixed ante- and postnatal ward.

All day and night the shrill cries of newborns cut through the low, guttural shouts of women in early labour, backed by the rasp of struggling snores of exhausted new mothers. Despite the slowly rising humidity of mid-May, the heating is kept on high for the newborns not yet strong enough to maintain their body temperature. The room swelters in the thick hot air. Each night I lie awake, drenched in sweat as I struggle to peel the plastic sheets from my reddened skin.

18th May

It is 1 o'clock in the morning. A caesarean section has been planned for me later today. For the past twelve hours I have had dull nagging back pain. With the pain now intensifying, I press my bedside buzzer. A midwife comes to examine me and tells me that she thinks that I am going into labour. Following six hours of labour, I have an

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emergency caesarean section under general anaesthetic. Toby is born.

I have not yet seen my newborn son. I am confined to bed and hazy on morphine. Toby – four pounds, fourteen ounces and seven weeks premature – is in the special care baby unit. The midwives suggest that I should try to provide him with breast milk. I am given a small polaroid photo of my baby. Looking at this is intended to stimulate my breast milk. I am told that I will get the best supply of milk by using the breast pump every four hours throughout the day and night. The small quantity of creamy-yellow liquid that my body produces is given to Toby through a feeding tube.

Doctors tell us that Toby will remain in the special care baby unit until he meets three conditions: he must have regained his birth weight, be able to maintain his own body temperature and wake up at night to feed. This is likely to be close to his full-term date of 4th July.

23rd May

Five days after my caesarean section, I am sufficiently recovered to be able to go home. Still trying to maintain my breast milk, I set my clock radio alarm every three hours throughout the night. Sterilising the plastic bottle, breast pump funnel and tubing, then using the equipment, takes close to an hour. Each time, I go downstairs to my sitting room, assemble the pump paraphernalia on my coffee table and try to relax while listening to music. I always choose the same CD – Andrew Lloyd Webber’s greatest hits. I listen to endless repetitions of ‘Memories’, ‘Phantom of the Opera’ and ‘Don’t Cry for me Argentina’.

1st June

My post-operative belly is tender, my caesarean scar is inflamed and oozing and my breasts are sore from the frequent pumping. Getting out of bed is increasingly wearisome and my body is struggling to produce sufficient milk.