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## CHAPTER 6

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# ECT: The facts psychiatry declines to mention

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**E**LECTROCONVULSIVE THERAPY [ECT] was introduced in the 1930s by an Italian psychiatrist, Ugo Cerletti (see earlier chapter by Newnes) and involves an electric current being passed through the brain in order to produce a grand mal seizure. In many hospitals in the 1950s and 1960s, ECT was the treatment of choice for people diagnosed as having schizophrenia (Oxlad and Baldwin, 1996). ECT is now more commonly used to ‘treat’ depression. Technological advances have led to the modification of ECT techniques, the modern procedure involving administration of a muscle relaxant and an anaesthetic, to prevent the types of problems that were previously associated with the treatment such as broken bones and teeth. Modified ECT machines deliver a string of high voltage electric pulses (about 150 volts) either unilaterally, (electric current delivered to one side of the brain) or bilaterally (electric current delivered to both sides of the brain simultaneously). Breggin (1991) states that most people receive 6–10 sessions of ECT and MIND (1995) report that most people have a course of 4–8 treatments. The ECT Handbook (Freeman, 1995) states that a set number of treatments should not be prescribed and that a patient should be re-assessed after each treatment to see if further ECT is necessary. The Handbook suggests that 2 to 3 treatments should be given a week and that ECT should not be given daily.

### **ECT facts and figures**

Two (Freeman, 1995) to 4.5 (MIND, 1995; Rogers, Pilgrim and Lacey, 1993) ECT treatments in every 100,000 are reported to prove fatal. ECT has been banned by psychiatrists in Germany, Holland and

Italy (Baker, 1995; MIND, 1995) and there are restrictions on compulsory treatment in Canada (MIND, 1995). In the UK the National Association for Mental Health has called for a ban on the use of ECT with children under the age of eighteen years and on all compulsory use of ECT (Baker, 1995). Many people today believe that ECT is used rarely, if at all. In fact, approximately 20,000 to 22,000 people receive ECT treatment in England every year (Baker, 1995; ECT Anonymous, 1996; Johnstone, 1989; MIND, 1995). In the year ending March 1991 (the year in which the method of collecting data changed and the last year for which accurate statistics are available) approximately 105,000 treatments were administered. This is likely to be an underestimate as not all ECT treatments are reported and the statistics do not include ECT administered in private or special hospitals. ECT Anonymous (a self-help group for ECT survivors and their carers) estimate that 140,000 treatments are given every year in British hospitals. Figures for children are also high, with an estimate of between 500 and 3500 minors being given ECT in the U.S.A. every year (Thompson and Blaine, 1987) and at least 60 young people aged 12 to 17 being given ECT in the UK in the ten years up to 1992 (Jones and Baldwin, 1996). The youngest child reported to have received ECT was 34.5 months old (Bender, 1955).

Approximately two-thirds of people given ECT are women; Pippard and Ellam (1981) suggest a ratio of 2.27 women to every man. There has also been a dramatic increase in the number of elderly people receiving ECT (Jones and Baldwin, 1992; Oxlad and Baldwin, 1996). Karagulla (1950) documented that in the 1940s only 4% of people given ECT for depression were over 66 years of age. Current figures in the USA indicate that over half of the people receiving ECT are over 65 years of age (Oxlad and Baldwin, 1996). A recent study of death certificates by U.S.A. Today in Texas found that one in 200 elderly patients died shortly after ECT, many from heart attacks or brain haemorrhaging brought on by the treatment (see Johnston, 1996). In the same article the author also cites a study by a British psychiatrist which found that deaths from ECT in an elderly population could be as high as one in ninety.

### **ECT and informed consent**

To give informed consent to any medical treatment individuals must fulfil three criteria. They must possess the capacity to make the decision in question; they must possess the relevant information required to make the decision; and they must give their consent

voluntarily, free from pressure (Appelbaum, Lidz and Meisel, 1987). ECT can only be given *without* an individual's consent under Part IV of the Mental Health Act, 1983 and if authorisation is given by a second opinion doctor appointed by the Mental Health Act (MHA) Commission (see MHA Code of Practice, Department of Health, 1993). A recent report published by ECT Anonymous (1996) analysing the official reports for the Royal College of Psychiatrists (RCP; Pippard and Ellam, 1981; Pippard, 1992) states that 10% of people who are given ECT are treated without their consent. This appears to suggest that 90% of people who receive ECT fulfil the criteria for having given an informed consent i.e. they are competent, volunteer their consent and possess adequate information about the treatment to be given.

*Possession of information and voluntary consent*

The Mental Health Act Code of Practice (Department of Health, 1993) recommends that people should receive full information about the purpose and nature of any treatment; the likely effects and risks of that treatment; the likelihood of its success; and any alternatives, including the alternative of no treatment at all. Similar regulations have been outlined in the American Psychiatric Association Task Force Report (1990; see Leong and Eth, 1991). Despite such recommendations, a survey of service users conducted by MIND (1995) found that only 14% of people had been given any information about ECT and only 9% remembered being told of any adverse effects. A further study by Jenaway (1993) found that although over 85% of the people in their study were satisfied with the consent procedure for treatment with ECT, fewer than 50% could recall being told of certain side effects including memory difficulties, headaches and confusion. Similar figures were found by Riordan, Barron and Bowden (1993) when interviewing 49 people about to undergo treatment with ECT. Fifty-seven percent of their sample recalled details of the procedure, 50% recalled that an anaesthetic would be involved, 38% recalled the use of electricity and only 10% recalled that a fit would be induced. In the same study 40% of people had no recollection of being told of any side effects and over a third felt that they had not been given adequate opportunities to discuss their treatment.

In order to give a valid consent an individual must do so voluntarily and free from coercion. However, a study of patients' perceptions of ECT at one hospital (Malcolm, 1989) found that nearly half of the patients who had experienced ECT thought that they

could not refuse it and some did not know whether they could or not. Forty-five percent knew that it was possible to refuse, but many commented that it was futile to do so because they would be given the treatment anyway. Older people and women were found to be the least aware of their rights. Johnstone (1999) interviewed twenty people who reported having found ECT upsetting. She concludes that many people may consent to ECT despite inadequate explanations about the treatment due to their feelings of extreme desperation and powerlessness. She quotes one person as saying 'they asked me if I would agree to it, but they did say if I refused they'd go ahead with it anyway . . . being forced to stay there is bad enough but being forced to have something that you don't want is ten times worse, so I did agree, yes.'

### **The Royal College of Psychiatrists' fact sheet on ECT**

The ideal opportunity to remedy this situation arose when, in 1995, the Royal College of Psychiatrists published their ECT Handbook. This provides practical guidelines on the clinical use of ECT, its administration and the position with regard to the law and consent. The guide includes in its appendices a fact sheet to inform patients and their families about the nature, purpose, and likely effects of ECT, as well as alternatives to treatment with ECT. On first sight this document appears to provide a comprehensive guide to ECT. On further examination a very different picture emerges.

*What the Royal College of Psychiatrists' fact sheet says — and what it leaves out*

- 'Most people who have ECT are suffering from depression'

Historically ECT has been used to treat many kinds of mental distress. Although the fact sheet is correct in suggesting that it is now most commonly used to treat depression, the Handbook endorses the use of ECT for a large number of diagnoses including mania (2–3% of people receiving ECT according to MIND, 1995), some cases of schizophrenia, catatonia, postpartum psychosis and even neuroleptic malignant syndrome. MIND (1995) also report the use of ECT in neuropsychiatric conditions such as epilepsy and Parkinson's disease. The fact sheet makes no allusion to this, leading the reader to believe that treatment with ECT for any condition other than depression is rare.

- '[The] current produces a seizure which affects the entire brain, including the centres which control thinking, mood, appetite and sleep. Repeated treatments alter chemical messages in the brain and bring them back to normal'

This is stated as a fact which most people consulting the information sheet are unlikely to question. However, the truth about how ECT works is far from clear. Shock treatments were initially developed to be used with patients diagnosed as schizophrenic on the basis that epilepsy and schizophrenia could not coexist. Although many theories exist (Johnstone, 1989; Fink, 1990; Gordon, 1948), the actual mechanism by which ECT works is not known (Frank, 1990). Dr Green (cited in MIND, 1995, p. 13) agrees with the RCP that ECT has its effect through changes in brain chemistry, but goes on to say:

*... comparing this favourably with the current generation of pharmacologically specific drugs would be similar to the assumption that a broken television could be mended as readily with a sledgehammer as with a screwdriver: you might jog the right bit.*

Breggin (1991) argues that ECT works by causing organic brain damage, with memory loss, confusion and disorientation disabling the brain — an argument that was widely accepted in the early years of its use, even by some proponents of ECT. As recently as 1973 Dr Max Fink, a leading proponent of ECT in the USA, has stated that 'where there is no evidence of impaired mental function and no electroencephalo-graphic alteration [changes in brain waves indicating damage] clinical improvement does not occur' (MIND 1995, p. 13).

- 'Once you are fast asleep a small electric current is passed across your head and this causes a mild fit in the brain. There is little movement of your body because of the relaxant injection that the anaesthetist gives.'

What people are not told is that the 100–150 volts passed through their brain, if applied to the chest, would have serious consequences (Frank, 1990). The ECT Handbook (Freeman, 1995, p. 73) states that the minimum instrument setting required to induce a seizure ranges from 25 millicoulombs (mC) to 800 mC depending on the individual, implying a 40-fold inter-individual variation in seizure threshold. This suggests that great care is needed when assessing

the requirements of each person undergoing treatment. However, recent audits of ECT (Duffett and Lelliott, 1998; Pippard, 1992) indicate that much confusion exists concerning instrument settings and the timing of seizures, practice varying greatly between clinics.

Anaesthetics and muscle relaxants are central nervous system depressants, sedating the brain and necessitating the administration of higher voltages of electricity in order to produce a convulsion. It has been argued that this can increase the risk of amnesia and damage to the brain (Breggin, 1991; Jones and Baldwin, 1992). Further worrying evidence comes from a report compiled by Pippard and Ellam (1981). The authors found that 50% of clinics regularly used trainee anaesthetists, that in 68% of cases the anaesthetist met the client for the first time in the clinic and that in 19% of cases they had not been advised of the client's current medication regime. The authors witnessed several incidents where muscle relaxants were administered while the client was still conscious and some cases where no muscle relaxant was administered at all because 'they couldn't find a vein'. Although the recent audit of ECT (Duffett and Lelliott, 1998) indicates that there has been some improvement in this area, 15% of clinics still report difficulties in obtaining anaesthetic cover resulting in cancelled clinics or people being transported between hospitals for treatment.

- 'Some people wake up with no side-effects at all and simply feel very relaxed. Others may feel somewhat confused or have a headache' (and later in the fact sheet) 'Some patients may be confused just after they awoken from treatment and this generally clears up within an hour or so.'

The fact sheet provides an abbreviated version of the information provided in the Handbook which states 'immediately after treatment patients may experience headaches, muscular aches, nausea, drowsiness, weakness, anorexia and amenorrhoea . . . in the first week after ECT, memory problems and headache have been found to be the most prominent side-effects' (p. 67). The Handbook also informs us that 'some patients may switch into a manic illness during treatment with ECT' (p. 68), but patients are not informed of this. Abrams (1988) states that 'a patient recovering consciousness from ECT understandably exhibits multiform abnormalities of all aspects of thinking, feeling and behaving, including disturbed memory, impaired comprehension, automatic movements, a dazed facial expression and motor restlessness' (pp. 130–1). However, the

most reliable information regarding side-effects is likely to come from people who have actually experienced ECT. Rogers, Pilgrim and Lacey (1993) found that many people report memory loss. One client reported 'terrible loss of memory of considerable duration. I had to retrain my brain to remember things. Mainly the worrying aspect was long-term memory loss where I could not remember things which I knew that I knew'. Other quotes include: '[the] only side effect was that final treatments pushed me into a hypermanic state. Memory loss and headaches at the time'; 'headache, temporary amnesia, concussion'; and 'loss of memory which *didn't* right itself, bad headaches and sickness directly afterwards'.

The fact sheet also fails to address the psychological side effects of ECT. Johnstone (1999) found her participants to describe a wide range of emotional responses including 'feelings of humiliation, increased compliance, failure, worthlessness, betrayal, lack of confidence and degradation, and a sense of having been abused and assaulted.' One person said: 'afterwards I felt as if I'd been battered . . . I was just incapacitated, body and mind, like a heap of scrunched-up bones.' A survey of 306 people who had received treatment with ECT (United Kingdom Advocacy Network, UKAN, 1996) also reported many psychological effects including loss of confidence, dignity and self-esteem; fear of hospitals and psychiatry; anger and aggression; loss of self; and nightmares.

- 'Your memory of recent events may be upset and dates, names of friends, public events, addresses and telephone numbers may be temporarily forgotten. In most cases this memory loss goes away within a few days or weeks, although sometimes patients continue to experience memory problems for several months. *ECT does not have any long-term effects on your memory or your intelligence.*' (my italics)

The Handbook itself states: 'the evidence suggests that neither new learning nor memory for information from the past are permanently impaired. Objective memory impairment (on specific memory tests) is reversible. Some patients may, however, be left with discreet memory gaps for specific autobiographical events, the explanation for which is unclear' (p. 68). Although possible memory problems following ECT are acknowledged in the fact sheet, we are not told of the large body of evidence (including both subjective reports from people who have experienced ECT and the findings of empirical studies) that confirms the frequency of long-term negative effects of ECT on a wide range of cognitive abilities, predominantly memory function (Breggin, 1991; Frank, 1990; Freeman and Kendall, 1980;

Squire, 1977; Squire and Slater, 1983). Freeman and Kendall (1980) interviewed 166 patients who had had ECT during either 1971 or 1976. They concluded: 'we were surprised by the large number who complained of memory impairment [74%]. Many of them did so spontaneously without being prompted and a striking 30% felt that their memory had been permanently affected' (p. 16). Squire and Slater (1983) found that some people who had received ECT were still complaining of memory loss three years after the last shock, forgotten events spanning an average of seven months surrounding treatment. A survey conducted by the UK Advocacy Network (UKAN, cited in Johnston, 1996) found that one third of 300 respondents believed that ECT had damaged them. Eighty percent of these claimed that it had irreparably destroyed their memory. Many said that the treatment had made them more depressed. In a recent case a woman from Scotland sued her Health Board for negligence due to memory loss following treatment with ECT (McKay, 1998). She said 'I found it almost impossible to remember anything that happened prior to the ECT treatment . . . I'm also unable to retain and remember new information. If someone tells me something it vanishes from my mind. My memory for years after the treatment is blanked too'.

ECT Anonymous (1996) summarise the conclusions of the 1981 and 1992 official reports by the Royal College of Psychiatrists. They conclude that 1) excessive currents of electricity can cause brain damage; 2) routine settings are bound to be excessive for many patients and as clinics cannot determine safe doses, dangerous routine settings are frequently used; and 3) brain damage is routinely caused to many patients. The RCP fact sheet does not adequately reflect the above research.

- 'Over eight out of ten depressed patients who receive ECT respond well, making ECT the most effective treatment for severe depression' (and later in the fact sheet) ' . . . severely depressed patients will become more optimistic and less suicidal.'

A number of research studies have shown that ECT does produce short term improvements on depression rating scales for some patients, but that this is not sustained beyond four weeks (Buchan, Johnstone, McPhearson, Palmer, Crow and Brandon, 1992; Weiner, 1984) or at three and six-month follow-up (Johnstone, Deakin, Lawler, Frith, Stevens, McPhearson and Crow, 1980). This is not mentioned in the fact sheet. One of the studies most frequently cited to confirm the efficacy of ECT is that of Freeman, Basson and

Crichton (1978). However, on closer inspection the methodology of this study is shown to be unsound. The authors 'felt it ethically unjustified to withhold for a complete course a treatment generally regarded to be effective' (p. 738). Despite the protocol of the study they gave the simulated ECT group real shocks for their third and subsequent treatments, thus rendering the study flawed and invalid. A reputedly 'double-blind controlled study' by West (1981) made a similar error, allowing ten of the eleven non-ECT patients to transfer to the ECT group during the research. Such studies are not good advertisements for scientific research or for ECT.

Wide regional variations in the rates of treatment (Rogers, Pilgrim and Lacey, 1993; Newnes, 1991) suggest there to be little consensus as to the efficacy of ECT. Jones and Baldwin (1992) cite discrepancies in prescribing rates as wide as 125 treatments per 100,000 population in Oxford to 400 per 100,000 in Wessex. It could be argued that these figures reflect regional differences in the number of people presenting with depression. However, a study by Gill and Lambourn (1981), which found very large differences in the prescribing rates of ECT between consultants working in the same geographical area, suggests that differences in consultants' attitudes towards ECT is a more likely explanation.

Fink (1990) provides further evidence to refute the above statements from the fact sheet, reporting that ECT patients who are not receiving medication relapse at rates as high as 70%. The Handbook acknowledges that nearly half of the depressed patients who recover from ECT will relapse within twelve weeks without drug treatment (Barton, Mehta and Snaith, 1973) and MIND's booklet on ECT (1995) raises doubts about whether ECT can prevent suicide. The fact sheet fails to provide patients with such information.

- 'If you choose not to accept your doctor's recommendation to have ECT, you may experience a longer and more severe period of illness and disability than might otherwise have been the case.'

There is a noticeable lack of conclusive evidence to support the truth of the latter part of this statement, there being few valid studies comparing people who have had ECT with those who have not or with those who have had simulated ECT. Of the studies that do exist, many do not report results in support of long-term benefits from ECT above no treatment or simulated ECT (Johnstone et al., 1980; Lambourn and Gill, 1978).

- ‘People who have responded to ECT report it makes them feel “like themselves again” and “as if life is worth living again”’.

There is mixed opinion amongst people who have experienced ECT as to its benefits. Rogers, Pilgrim and Lacey (1993), in a survey of service users, found that 43% of people said ECT had been helpful or very helpful and that 37% reported it as unhelpful or very unhelpful. A further 20% reported no effects. The fact sheet does not provide quotes from people who said ‘I permanently lost all memory of myself and my family. I couldn’t even remember how to read and write. The person I used to be died the day I had ECT’ or ‘please inform others never to have this treatment. I had ECT many years ago and am still trying to recover’ (ECT Anonymous, 1996) or ‘I never want ECT again, I’m afraid of it’ (Rogers, Pilgrim and Lacey, 1993). Many such statements exist.

- ‘The alternative is drug therapy which also has risks and complications, and drug treatment is not necessarily safer than ECT.’

The only alternative treatment mentioned in the fact sheet is antidepressant medication. Other ways of helping depressed people, such as psychotherapy, are ignored. It is likely to be difficult for a patient to refuse treatment with ECT if they believe that this is their only chance of a cure. Unless, that is, they opt for the alternative of medication which also has ‘risks and complications’. The RCP Handbook on ECT acknowledges that little is known about the combined effects of many drug groups and ECT on seizure thresholds and on cardiac function. Few clinical studies have been undertaken in this area, most research being conducted on animals, particularly rats (Freeman, 1995, p. 55). The RCP accept that the effects of psychotropic and anaesthetic drugs on the efficacy and safety of ECT are neglected areas of research. However, the fact sheet does not mention possible concomitant use of other medication for diagnoses such as schizophrenia, a subject that merits seven pages of discussion in the Handbook.

- ‘You can refuse to have ECT and you may withdraw your consent at any time, even before the first treatment has been given. The consent form is not a legal document and does not commit you to have the treatment . . . withdrawal of your consent will not in any way alter your right to continued treatment with the best alternative methods available.’

The fact sheet is clear about patients’ rights to withdraw consent. However, patients are likely to find it difficult to refuse ECT in the light of the information that is provided in the fact sheet and with

the only alternative treatment offered being medication. Riordan, Barron and Bowden (1993) questioned 49 people undergoing ECT. They conclude that ‘. . . although patients had a low understanding of treatment, they were still compliant, with most rating highly the doctor’s role in decision-making. This may reflect a high level of trust, or a resigned lethargy, in part reflecting mental state, but also a feeling of lack of involvement in their own management’ (p. 533).

### **The need for adequate information**

The issue of informed consent is complex. It is not easy to define *adequate information*. How much should people be told? Too much information may be overwhelming, but too little may be inaccurate and misleading. A compromise is obviously needed. What is not in debate is that people should have access to the facts about the treatment they receive. Although individual quotes have been selected from the fact sheet to illustrate my arguments, much of its content has been included in the above discussion. It is clear that the information presented to patients about ECT is inadequate and, at times, inaccurate. It could be questioned whether patients who have only read the fact sheet would be able to give truly informed consent to treatment with ECT. Many people who agree to have ECT will be completely unaware of issues which should have played a part in the decision and are unlikely to have access to literature exposing the risks. It is important to note that the RCP fact sheet is intended to be used as an adjunct to information about the purpose, nature and implications of treatment presented by the psychiatrist prescribing ECT. There is thus an opportunity for discussion to take place in order to address any questions and concerns that an individual may have. However, research exploring the nature of additional information given in such a consultation appears to be lacking and it is not clear whether people are ever presented with adequate information on which to base a decision about treatment with ECT.

### **Why conceal the truth about ECT?**

Jones and Baldwin (1992) argue that ECT has been repackaged in a way that is designed to censor public and user opinion. ECT is routinely sold as a harmless intervention with no serious long-term side effects, the only alternative to which is medication. Reasons for this are unclear. Some possibilities are explored below.

*Time pressures and a belief in the efficacy of treatment*

With the increasing pressure placed on all professions by escalating case loads, increased bureaucracy and the complexities of peoples' presenting problems, it is arguable as to whether people are offered adequate explanations about all sorts of medical and psychological treatments. Psychiatrists are likely to suffer the same pressures, with little time to spare and ever-increasing responsibilities. When professionals possess a belief in the absolute efficacy and the minimal risk of harm relating to their offered treatments they may not feel it possible, or even necessary, to spend valuable time ensuring that consent from their patients is fully informed.

*The need for reassurance and illusion*

Patients and their relatives place a great deal of faith in the medical profession; they have to. Desperate for a cure, it is understandable that they are willing to place their faith in a professional person who promises to provide an explanation for, and a solution to, their distress. The consultant (also desperate for a cure and acutely aware of the respect and responsibility the role brings) is under pressure to maintain the confidence placed in the profession. This is likely to involve protecting patients from the uncertainty surrounding the likelihood of a cure. Psychiatrists alone hold the power to prescribe a course of ECT and have been doing so since the 1940s. Not surprisingly there is a reluctance to acknowledge the potential damage that ECT can cause — it would be unthinkable to suggest that psychiatrists (for over 50 years) have been administering a treatment that is destructive to those whom they aim to cure. Psychiatrists are also in the unenviable position of carrying the responsibility for dealing with emergency psychiatric cases. It is often with a sigh of relief that other professions place at their door those people in extreme distress or who are the most difficult to help, with the expectation that they will be 'treated'. With such pressures and expectations placed upon them, and very few options available, it is possible that ECT is embraced by psychiatrists with a similar sigh of relief, providing them with at least 'something' that can be done for people in extreme distress. The hope of patients, relatives and professionals for a 'cure', especially a rapid, dramatic cure, is therefore not dashed.

*The Medical Model of distress*

Much of psychiatry is based on the medical model which holds that depression is a physical illness caused by a chemical imbalance

in the brain and is genetic in origin. Patients are encouraged to believe they have an illness which will remain with them for the rest of their lives. If their symptoms decrease or disappear they are in remission, the depression waiting to return with a vengeance and without warning. An organic illness begs an organic cure and it is not therefore surprising that the interventions offered by psychiatry are medication and ECT. To offer alternatives such as psychotherapy would not make sense. It is therefore imperative that patients accept the physical treatments on offer as there is nothing obvious to take their place. However, not all clients are able or willing to consent to treatment with ECT. As ECT is often claimed to be used as a last resort when drug treatment has failed, refusal of treatment exposes the lack of an alternative and may leave psychiatrists feeling helpless to intervene. It is possible that this results in an increased number of people being administered ECT *without* their consent. Statistics compiled by the Mental Health Act Commission (1993; 1997) do indicate an increase in ECT treatments given to patients detained under section 58 of the MHA 1983. In the two year period from 1985 to 1987, 3362 people were given ECT under the provisions of the Act. In the period from 1993 to 1995 (when overall ECT figures showed a gradual decline) this figure had risen to 4607.

#### *Lack of knowledge*

For any treatment there exists a wealth of conflicting information as to its relative benefit and harm. The possibility that professionals in any discipline are unaware of the extensive body of literature that undermines their practices cannot be ignored. In any profession it is difficult to keep up-to-date with current literature. The RCP Handbook does provide a fairly comprehensive literature review on ECT, but it seems unlikely that everyone prescribing ECT is fully conversant with the listed studies. A recent audit of ECT (Duffett and Lelliott, 1998) confirmed this. Fifty-five ECT clinics in Great Britain were visited and interviews were conducted with the consultant psychiatrists identified as responsible for each. Only 36% of consultants claimed to have read the ECT Handbook (Freeman, 1995). Even those reading the Handbook may look only at the conclusions at the end of each chapter and these are generally more positive about ECT than the literature referred to in the main body of the text.

### **The way forward**

A movement against the use of ECT in Great Britain is slowly gaining force. People who feel they have been damaged by ECT are coming forward and are being given a voice. Organisations such as ECT Anonymous are organising demonstrations and lobbying the Royal College of Psychiatrists in London. Health Trusts are being sued for damages. Two major positions appear to exist within the anti-ECT lobby: some people feel strongly that ECT should be banned and others that ECT practices, including those around the provision of adequate information, should be reviewed and improved.

#### *Should ECT be banned?*

In my opinion the answer is 'yes'. ECT Anonymous (1996) eloquently dispel what they term the 'myth of the ECT controversy'; that is, the case for and against ECT. They argue that there is in fact no controversy — when examining ECT there is evidence that it both provides help and causes harm. The questions that we should be asking are 'what is the degree and frequency of help and of harm?' and 'is the ratio of one to the other acceptable?' They reveal that treatment with ECT provides a 50:50 risk of real harm: it appears to harm as many people as it helps. Is this an acceptable risk? Should such a treatment be so widely prescribed in the 21st century? Is it not time for ECT to be confined to the past and regarded with the same condemnation as treatments such as insulin coma and Metrazol shock (seizure's induced by the injection of Metrazol into the bloodstream)? It will perhaps be some years before this debate reaches the highest levels of policy-making, current emphasis appearing to remain on monitoring treatments and making the existing procedure as non-aversive as possible.

#### *How could current practices be changed?*

Increasing pressure is being placed on psychiatry to question and change its practices. Sadly, such initiatives have not yet had a major impact. The recent audit of ECT in England and Wales (Duffett and Lelliott, 1998) failed to show a marked improvement in standards of administration from the previous audit of Pippard (1992). Only one-third of clinics were rated as meeting the Royal College of Psychiatrists' standards, only 16% of responsible consultant psychiatrists attended their ECT clinic weekly and only one-third of clinics had clear policies to help guide junior doctors to administer ECT effectively. The report concluded that 'these problems have not been resolved by 20 years of audit and College

activity. There should be a continuing debate as to what further interventions might be considered' (p. 405). Recommendations are made regarding improvements to practice, however the issue of informed consent is not addressed. This must also be an area for further consideration. The RCP fact sheet needs to be revised to provide patients with a more balanced and accurate picture of ECT. Below is an alternative fact sheet that addresses some of the above issues and that provides patients with at least some of the facts which psychiatry declines to mention.

### **An alternative fact sheet**

This alternative fact sheet (see below, pages 114-118) follows the outline and format of the Royal College of Psychiatrists' fact sheet which can be found on pages 103-105 of the *ECT Handbook* (Freeman, 1995). The reader is also referred to the MIND Booklet '*Making Sense of Treatment and Drugs: ECT*' (1995) which provides a comprehensive and balanced guide to ECT. (Readers may photocopy the fact sheet on pages 114-18.)

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## **ECT: A Fact Sheet for You and Your Family**

### ***Introduction***

This leaflet tries to answer some of the questions you may have about electro-convulsive therapy (ECT). For example, what is ECT? Why is it used? What is it like to have ECT and what are the risks and benefits?

Don't worry if you find it difficult to read through the whole leaflet at once. You can come back to it later. You may need someone to help you to understand some parts of the leaflet and you may wish to use the information below to help you to ask questions of staff, relatives or other patients.

### ***Some facts about ECT***

- Over 20,000 people a year are given ECT.
- ECT has been banned by psychiatrists in Germany, Holland and Italy and there are restrictions on compulsory treatment in Canada.
- In the UK the National Association for Mental Health has called for a ban on the use of ECT with children under the age of eighteen years and on all compulsory use of ECT.
- Approximately two-thirds of people given ECT are women; there has been a dramatic increase in the number of elderly people being given ECT.

### ***Why is ECT used?***

Most people who are given ECT have been diagnosed with depression. However, ECT is also sometimes prescribed for people with a number of other diagnoses including mania, schizophrenia, catatonia, postnatal psychosis, epilepsy and Parkinson's disease.

ECT is often suggested for people who have not been helped by tablets, although this is not always the case. Some people believe that ECT is the best treatment in cases of severe depression and that it can be life-saving. MIND state that 'although ECT does sometimes prevent death when someone is profoundly depressed, no longer eating and drinking and is in a critical state, there is no evidence that ECT prevents suicide'.

***How does ECT work?***

Nobody really knows how ECT works, but there are many different theories. The Royal College of Psychiatrists believes that repeated treatments with ECT alter chemical messages in the brain and bring them back to normal. Other psychiatrists argue that ECT works by causing brain damage, with memory loss, confusion and disorientation disabling the brain.

***How well does ECT work?***

ECT has been shown to produce short term improvements on depression rating scales for some people, but this improvement has not been found to continue beyond four weeks and has not been found to be present three and six-months later. ECT patients who are not receiving medication have been found to relapse at rates as high as 70% and research has also shown that nearly half of the people who receive ECT for depression will relapse within twelve weeks without treatment with medication.

There is mixed opinion amongst people who have experienced ECT as to its benefits. In one study 43% of people said that ECT had been helpful or very helpful and 37% reported that it had been unhelpful or very unhelpful. A further 20% reported no effects. People who have found ECT helpful report that it makes them 'feel like themselves again' and 'as if life was worth living again'. Other people have said 'please inform others never to have this treatment. I had ECT many years ago and am still trying to recover' and 'I permanently lost all memory of myself and my family. I couldn't even remember how to read and write. The person I used to be died the day I had ECT'.

***What ECT cannot do***

The effects of ECT will not help all of your problems. The way you are feeling may be the result of a whole number of problems, for example at home or at work. These problems may still be present after your treatment and you may need further help with these. ECT will not prevent future 'episodes of depression'.

***Why has ECT been recommended for me?***

ECT is given for many reasons. If you are not sure why you are being given ECT, don't be afraid to ask your doctor. It might be possible to have an advocate with you if you need support in

asking questions.

***How many treatments will I be given?***

ECT is usually given two or three times a week. It is not possible to say exactly how many treatments your psychiatrist will prescribe. Some people are given as few as two or three treatment sessions, others are given as many as twelve and sometimes more. ECT treatments should not be given daily.

***What will happen immediately before treatment?***

Before having ECT you will be given an anaesthetic and a muscle relaxant. You will therefore need to fast (have nothing to eat and drink) from about midnight the night before each treatment. This will involve having no breakfast on the morning that you have ECT. Anaesthetics and muscle relaxants sedate the brain. They prevent your bones being broken during treatment with ECT, but mean that higher voltages of electricity will have to be administered to produce a seizure than was previously the case. Some psychiatrists have argued that this can increase the risk of memory loss and damage to the brain.

***What will actually happen when I have ECT?***

Treatment with ECT will take place in a separate room and other patients will not be able to see you having it. The procedure itself takes a few minutes. The anaesthetist will ask you to hold out your hand so you can be given an anaesthetic injection. This will make you go to sleep and cause your muscles to relax completely. You will be given some oxygen to breathe as you go off to sleep. Once you are fast asleep a current of 100–150 volts will be passed across your head and this will cause you to have a grand mal seizure. This is equivalent to an epileptic fit. The seizure affects the entire brain, including the centres which affect thinking, mood, appetite and sleep. There will be little movement of your body because of the relaxant injection that the anaesthetist gives.

When you wake up you will be back in the waiting area. There will be a nurse with you to offer you reassurance and make you feel as comfortable as possible. Once you are wide awake you will be offered a cup of tea.

For the treatment you should wear loose clothes, or night-

clothes. You will be asked to remove any loose jewellery, hairslides or false teeth if you have them.

***How will I feel immediately after ECT?***

Immediately after treatment you may experience headaches, muscular aches, nausea, drowsiness, weakness, a lack of appetite, and amenorrhoea (loss of periods in women). Other reported effects include disturbed memory, impaired comprehension and motor restlessness.

***What are the longer term side-effects of ECT?***

In the first week after ECT, memory problems and headache have been found to be the most prominent side-effects. One research study found that 74% of people who had had ECT complained of memory impairment and 30% felt that their memory had been permanently affected. Another study found that people were still complaining of memory loss three years after treatment.

ECT may also exacerbate existing psychological problems. Psychological after-effects can include loss of confidence, dignity and self-esteem; fear of hospitals; nightmares, anger and feelings of depression.

A survey by the UK Advocacy Network found that one third of their sample believed that ECT had damaged them and that many said the treatment had made them more depressed. Some people may become very manic during treatment with ECT.

***Are there any serious risks from the treatment?***

The Royal College of Psychiatrists state that the risk of death or serious injury with ECT is about one in 50 000 treatments. MIND cite a figure of 4.5 deaths per 100,000 treatments. Older people are at a much higher risk than younger ones and one study by a British psychiatrist found that deaths from ECT in an elderly population could be as high as one in ninety. Deaths are usually because of heart problems. If you do have heart disease it may still be possible for you to have ECT safely with special precautions such as heart monitoring. Your doctor should ask another specialist to advise if there are grounds for concern.

***What other treatments could I have?***

Alternatives include medication, talking therapies (e.g. counselling and psychotherapy) and complementary therapies (e.g. acupuncture, aromatherapy and homoeopathy). MIND have published a series of booklets which will inform you about all of these different approaches.

***Will I have to give my consent? Can I refuse to have ECT?***

Your doctor must have your consent to give you ECT. ECT can only be given *without* your consent if you are sectioned under Part IV of the Mental Health Act (1983) and authorisation is given by a second opinion doctor appointed by the Mental Health Act Commission.

At some stage before the treatment you should be asked by your doctor to sign a consent form for ECT. If you sign the form you are agreeing to have up to a certain number of treatments (usually six). Before you sign the form your doctor should explain what the treatment involves and why you are having it, and should be available to answer any questions you may have about the treatment. You can refuse to have ECT and you may withdraw your consent at any time, even before the first treatment has been given. The consent form is not a legal document and does not commit you to have the treatment. It is a record that an explanation has been given to you and that you understand to your satisfaction what is going to happen to you. Withdrawal of your consent to ECT should not in any way alter your right to continued treatment with the best alternative methods available.

***What if I decide not to have ECT? Are there any risks in not having ECT as recommended?***

If you decide not to have ECT this should in no way alter your right to continued treatment with the best alternative methods available. Some people would argue that refusal of treatment may lead you to experience a longer and more severe period of disability that might otherwise have been the case. Others would argue that by refusing ECT you are avoiding the possible negative side-effects outlined above and may find better ways of coping with your difficulties.