



**College of Psychiatrists
of Ireland**

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UNDERSTANDING ECT

A Perspective Paper

REFOCUS and ECT

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This paper has been published as a College of Psychiatrists (CPsychI) Perspective.

The function of a CPsychI Perspective is to stimulate discussion and reflection amongst members of the College, the general public and other stakeholders. It does not represent the position or policy of the CPsychI but will contribute to further CPsychI policies and positions

UNDERSTANDING ECT CPsychI REFOCUS PERSPECTIVE

The College of Psychiatrists of Ireland (CPsychI) was formed in 2009. It is the professional body for psychiatrists in the Republic of Ireland. The Mission of the College of Psychiatrists of Ireland is to promote excellence in the practice of psychiatry. The Recovery Experience Forum of Carers and Users of Services (REFOCUS) is a committee of the College of Psychiatrists of Ireland. REFOCUS is made up of 10 service users and 10 family members, who have given of their time to work with the College in improving training of psychiatrists, and in identifying ways to improve our mental health services.

INTRODUCTION

This paper aims to address the common fears service users and family members have about ECT. We believe that it will also give psychiatrists a better understanding of the concerns of users and families about the treatment. We also hope that the paper may dispel many of the myths surrounding ECT for the general public.

Doctors should use this perspective paper on ECT together with the CPsychI position paper on ECT to facilitate informed discussion with patients and their families in the process of getting agreement to treatment with ECT.

All members of REFOCUS have an interest in ECT and its place in modern psychiatric treatment. Dr. Consilia Walsh from the College ECT committee gave a presentation on ECT to REFOCUS early in 2014. This stimulated further discussion among the group. Some have had the treatment, some have relatives who received it and some have seen good results while others have seen it cause problems. However, we all wanted to have more information about ECT.

The most common experience we all had was lack of information and fear - fear that it would cause serious damage, fear that our doctor might prescribe it against our will and fear, not just that this meant our condition was very bad, but that we would never be the same again. Fear was experienced by individuals and there was also a fear within the family. These fears seemed to lead to a conspiracy of silence as in the past services were not volunteering information and so the fear persisted.

The College of Psychiatrists of Ireland's position paper on ECT states that ECT is an effective, safe treatment, that it is given in well regulated situations and that it is now accompanied by a lot of information which is provided to those who have the treatment prescribed. Nevertheless, we felt there was a need for a paper with more information.

Six members of REFOCUS, including members who have had ECT and members whose family member had been treated with ECT, used a semi structured interview technique to interview two psychiatrists about ECT. Each interview took two and a half hours. One of the psychiatrists has conducted a lot of research in ECT and works in a specialist centre for treatment resistant depression, the other psychiatrist is a community-based psychiatrist who works as part of a multidisciplinary team.

The first psychiatrist uses ECT commonly, the second uses it rarely. In the interests of clarity, it is important to point out that some questions were replied to by only one psychiatrist. This was a function of the semi structured interviewing approach. It was clear during the interviewing that each psychiatrist had the patients' best interest in mind, despite their differing approach and uses of ECT. We set out the questions and answers below, with answers from the first consultant psychiatrist, CP1 and those of the second consultant psychiatrist, CP2.

Questions and answers are grouped together under a number of themes to facilitate understanding.

CONSENT AND COMMUNICATION

Q1. We are aware that people need to give informed consent for ECT. Our experience is that, when you are in the mental health system, it can be difficult to get enough information to make an informed decision and that, when a person is depressed, they may not be able to assert their own wishes. How can you ensure it is informed consent?

A1. CP1. There is very little research or information on mental capacity and ECT. We do know that less than 10% of people who receive ECT do so on an involuntary basis. It is important that the person is given good information, so that they can weigh up the pros and cons of treatment and be able to indicate their consent or not.

A1. CP2. This is an area where an advance healthcare directive (AHD) could be used. I feel an AHD should be completely respected. It is a human rights issue. (AHD is written when the person is well and identifies what treatments they want or do not want if they become incapable of choosing). The relationship between the patient and the psychiatrist is important. There is a cultural shift to providing information and improving communication, this all makes for a better informed decision. Treatment becomes collaborative.

Q2. What if they are not able to communicate?

A2. CP1. Well it depends what the problem is. If the problem is severe depression, or catatonia, then ECT is the best treatment. If the problem is schizophrenia, ECT would not be used here in Ireland. In the 1940s and 1950s, before antipsychotic medication, ECT was used for schizophrenia. A recent study compared ECT use in Bangalore in India and in London, and in Bangalore 50% of ECT use is for schizophrenia, whereas in London it is rarely used for schizophrenia.

A2. CP2. In an ideal situation there would be an AHD. Certainly family members would be consulted. If the situation was life threatening, all efforts must be made to understand the person's wishes and to review any treatment alternatives once the person is able to communicate.

Q3. I had ECT in the 70's. I was 17. It was never discussed with me. The doctor identified that I needed it, and I had no say. I had been abused, and maybe should not have had ECT?

A3. CP1. Under the Mental Health Act, 2001, a person under 18 is regarded as a child. In these circumstances permission is given by the parent /guardian.

A3. CP2. It depends on the quality of the relationship with the psychiatrist. That relationship can help tease out when it is appropriate to use ECT or not. I would like to think that in today's world such a scenario as you describe would never happen.

Q4. Would it be good to have an advocate? Families are not always the best, in that they can have very strong views one way or another.

A4. CP1. Certainly a trained advocate who can ensure the person is given all the necessary information in order to make an informed decision would be desirable. It is important that all centres where ECT is given provide good written and verbal information, and that families are also given information. This information should be user friendly and there needs to be a Clinical Nurse Specialist (CNS) who can go through all the information in detail with the patient.

A4. CP2. Yes, having an advocate can help, but the most important thing, as I said already, is the relationship with the psychiatrist. It can be difficult to understand ECT, particularly when you are unwell. In these circumstances, a booklet alone or “information” would not be sufficient. Again, sorry for repeating myself, but treatment needs to take place in a collaborative and not a prescriptive setting.

MEMORY LOSS

Q5. What about the memory loss?

A5. CP1. Memory loss is transient and it is for events that occurred around the time of the ECT. We don't have the research information on retrieval of longer term memories, or autobiographical memories, where people lose memories they had already formed. Yes there are a lot of practices in medicine that we do not know exactly how they work. With ECT there is a tiny amount of electricity used. All the trials have been focussing on modifying the technique in order to minimise the cognitive or memory effects. It is important to be honest with people on the effects on cognition.

There are a number of difficulties, firstly there is confusion after the treatment, and 80% of people will have recovered fully in 40 minutes. The rest recover fully over the next 24 hours. There will be transient memory problems around the time of ECT and 97.5% recover within two weeks.

A5. CP2. There do seem to be quite polar views on this, but trying to be as objective as possible, there is certainly a high incidence of memory problems in the short term, and a low incidence of longer term memory problems. There is good evidence that unilateral ECT causes less memory loss than bi lateral (unilateral ECT is where the electrode is applied only to one side of the brain).

Q6. I was worried that the ECT could have caused damage by blocking out memories of abuse.

A6. CP1. It is very unlikely that ECT would block out memories of a trauma. However, we do know very painful memories can be blocked out psychologically.

A6. CP2. ECT does not suppress memories from childhood. There may be some suppression of psychotic experiences that people were going through at the time of ECT. ECT effectiveness is nothing to do with blanking out unpleasantness. In my experience, people don't always remember severe depressive symptoms, or psychotic symptoms, even if they have not had ECT.

Q7. What about effects on the memory after 20 years?

A7. CP1. We do know that 97.5% of people will return to baseline ability to remember within two weeks of ECT, so it would be extremely rare for anyone to continue to have a problem making new memories after twenty years.

Q8. What about the effects on cognitive ability over the longer term?

A8. CP1. There are no really long term studies. St Patricks Hospital has just completed a 12 month follow up study of patients who had received the treatment and who consented to participate in the study. It is hoped to extend that research.

HOW EFFECTIVE IS ECT AND HOW DOES IT COMPARE TO OTHER TREATMENTS SUCH AS MEDICATION AND PSYCHOTHERAPY.

Q9. What are the 12 month effects of ECT?

A9. CP1. We have found that 40% of people relapse after 6 months, and 50% relapse after one year.

Q10. Is ECT cheaper than other treatments?

A10. CP1. It costs €500 per treatment session. The average course is about 8 sessions with two sessions per week and the person needs to be in hospital for about three weeks. At follow up at 6 months people needed less healthcare following ECT, than those who were on medication, so that would make it cheaper. We have seen people who have been severely depressed for months, in hospital; once they are referred for ECT they get well and go home. It is important not to leave people depressed for too long; recurrent depression has a negative effect on the brain.

Q11. If a person had psychotherapy at an earlier stage would they be less likely to need ECT? What about psychotherapy twice a week for two years?

A11. CP1. Cognitive Behavioural Therapy (CBT) is more likely to help depression. The combination of CBT and antidepressants has been shown to be most effective, but sometimes a person may be so severely depressed they may not be able to use psychological therapies. Not everyone drifts into depression, for some people it can come on very quickly, and be very severe. There is some evidence that staying on an antidepressant after ECT can reduce the risk of relapse. ECT would not be the first treatment we would use, but it is not just used as a last resort. That would be foolish, why leave the best treatment to last? It would often be the 3rd or 4th treatment. We know that only 30% of people respond to the first antidepressant they are given. Slightly less will respond to second antidepressants, and it is less than 15% by the time the fourth antidepressants are used. Response rates for ECT are between 45 - 70%, even after two or three antidepressants have failed. Response rates for ECT used earlier are up to 80%. So best practice is to treat a person with depressive illness with antidepressants but, if they are not responding after 4 or 5 changes in medication, then they are much more likely to respond to ECT than to another change in medication.

A11. CP2. The problem with ECT occurs if its users only promote a primarily biological focus on managing depression. If the message is "this is a biological treatment for 'broken brains' - getting to the point where people come to depend on ECT alone, then of course I have a problem with that. While certainly ECT may be very effective in treating severe depression, and a person can get him or herself out of a crisis with ECT, but getting themselves out of a dark place requires other approaches and further exploration to look at what has happened and why the person became depressed in the first place. A very biologically based psychiatrist may be less concerned about exploring the causes of the symptoms. My approach would be to suggest to the person that they look at more psychological therapies.

While using a biopsychosocial approach, there are times when, one or more of these approaches is more appropriate. Sure, if a person has a dramatic response to ECT and recovers fully, then, I agree there may be no need for psychological interventions, but these cases are rare.

Q12. So if a person was given ECT, would that mean they do not have to take medication afterwards?

A12. CP1. Being on medication after the ECT halves the relapse rate. In Ireland and the UK we tend to leave people on an antidepressant, even if they have not responded to it before ECT. There haven't been any trials comparing ECT with medication to ECT alone.

A12. CP2. There is the same problem with medication; in fact, it is even more of a problem than ECT, because it is used so much. People start to believe they have a long-term "broken brain" syndrome. I believe that antidepressants work by altering brain chemistry rather than by "correcting" it. Such alteration is associated with improved mood. This may seem subtle, but it is an important point. Does a cup of coffee "correct" your brain? No, it alters its activity. While drugs may work in the short term, in the longer term it may prevent individuals from learning the skills they need to recover. Building resilience, learning new skills for living, may occur better in a drug free environment.

Q13. If recovery is about relying on your own strengths, it is about moving away from medical treatments, where does ECT fit in?

A13. CP1. If recovery is about building resilience, then, that is what all the treatments do, they improve resilience through the plasticity of the brain. (This is where the brain can respond and grow through physical and environmental influences). ECT, CBT or drugs can all change the brain.

A13. CP2. I would have a major problem if ECT is bundled together with other positive interventions. I don't agree with the idea that medications/ECT are inherently healing on the brain. Going through a painful but complete grieving experience is not the same as not grieving and getting ECT instead.

HOW IT WORKS

Q13. How true is the popular perception that nobody knows how it works?

A13. CP1. There is a reasonable understanding of how it works. It is established that it is what is known as an “up regulator of neurotrophic factor”. It is known that it produces nerve regeneration in the hippocampus, the part of the brain associated with emotion, and we know that with depression and with stress this part of the brain shrinks.

A13. CP2. This is true; we don't know exactly how it works. I don't have a great problem with that in that there are a lot of treatments used in medicine and we don't know how they work. The fact that it does work is true; nevertheless, I believe it can't be good for the brain to have a seizure.

HISTORY OF ECT AND PUBLIC PERCEPTION

Q14. What is the history of ECT in Ireland?

A14. CP1. Rates are declining. Ten years ago 1,000 people were given ECT in a year; in 2011 the number was 332. The numbers of centres giving ECT has diminished considerably. For a centre to maintain expertise there needs to be at least 10 courses/year of ECT given. It makes sense to have a few centres of excellence; one should not accept anything else. It would be straight forward enough to have regional centres of excellence.

Q15. It would certainly improve the public perception of it if it were given in specialist centres of excellence?

A15. CP1. Yes, I think some people are being denied its use. Looking at trends in London, it is clear people are much more ill by the time they have ECT. I question why people should suffer longer. Many places in the UK and Ireland have stopped providing ECT. For many treatments in medicine, availability affects whether it is used or not.

A15. CP2. Yes, I agree, give it where people are giving it regularly. In ten years working as a consultant I have only used ECT three times, and on each occasion it was given in an external centre of excellence.

Q16. Was it ever the wrong treatment?

A16. CP1. The objections to ECT have always been ideological rather than scientific. There are times where a person needs ECT and could end up on a drip to feed them if they are left too long, as they might well be in a catatonic state of depression. The level of debate has been linked to fear of punishment, rather than seeing it as a therapeutic intervention.

A16. CP2. There are much better psychological treatments now, and so it is used less.

Q17. Are there countries where it is not available?

A17. CP1. In Italy; access is more likely if you are in private healthcare.

Q18. Why are more people not getting it?

A18. CP1. I am not here to claim it works for everyone, people with long term problems don't respond very well to it, but I do think there are a large group of people who are being denied it. When used appropriately it can be very effective. At present, ECT is not available in some parts of Ireland. There are also a generation of psychiatrists who have never been trained in ECT administration. There is a stigma and mythology around mental illness. But it is barbaric to let people die when there is an effective treatment to stop this. Objection to ECT is often a statement for something else. For example, the movie *The Changeling* was about events 5 years before ECT was first used, and yet there is a scene in it where a woman is given ECT as an apparent punishment. People often conflate the issues together, punishment and ECT. No one would ever think of cardioversion (an electric shock to return the normal rhythm to the heart) as a punishment. It is the stigma of mental illness.

A18. CP2. I think we treat people quicker now. We get people thinking about wellness - so they don't become so severely depressed. If care is delivered only as a purely medical service, that does not offer advice on lifestyle, then ECT might be used more. Using a psychological and social approach to managing depression, along with the medical approach, from the start helps, as people are steered away from expecting a magic pill to recover, with a consequent reduction in the use of medication. It is the case that the elderly often respond well to ECT which begs the question why is this so and why is severe depression seen so often in the elderly? I think of it as, if people push the boulder of distress along over the years, never actually dealing with it, until their ability is lost, and then they do not have the resilience to cope. This is an unproven theory based on my experience over the years.

Q19. I think if people were given the clear facts and the odds about the effects of medication versus ECT, they would see there is humility in this. Do doctors use it inappropriately?

A19. CP1. Psychiatrists follow an algorithm, or schedule of treatments, depending on the person's response. When ECT is being discussed with a patient, they should be given all this information. An advocate or family member should also be given verbal and written information.

Q20. Why is there such public hostility?

A20. CP1. I think, as we said before, it is related to stigma. Steroids are drugs that cause a lot of problems as well as treating a lot of illnesses. You don't see people campaigning against steroids.

A20. CP2. I think this arises particularly around the issue of consent. ECT is seen as suppressive or punitive. This is linked to the public idea that all mental illnesses can be treated with "counselling", and not physical treatments, such as tablets or ECT. While not supporting the "broken brain" concept, I do accept there are times when only medication or only ECT can help.

Q21. Are there other invasive treatments, and do they get the same bad press?

A21. CP1. Yes there is Deep Brain Stimulation for Parkinson's disease. This does not have the same negative connotations. It is new and modern, given under controlled and regulated conditions. In fact, ECT is given in controlled and regulated conditions. There is no money in ECT; no one is interested in promoting it.

CONCLUSION

This paper aimed to set out the concerns of members of REFOCUS in relation to, what some would see as, the controversial treatment, ECT. All those involved have direct or indirect experience of ECT. One role of Refocus is to bring the point of view of service users and their carers to bear on the promotion of best practice that is the function of a professional body. We hope that this paper will facilitate further informed discussion on the role of ECT as a treatment in modern psychiatry.

We felt the best way to do this was to consult with acknowledged experts and we are very grateful to the two doctors who answered our many questions so painstakingly. We believe this paper will promote thoughtful debate on ECT; help inform psychiatric training and also serve as a helpful tool to patients, family members and clinicians whenever it is proposed that an ECT treatment programme be given.

PERSONAL NARRATIVES

Psychiatrist: *“The ideas concerning ECT are simply based on the misconception that ECT is barbaric - like the late Henry Rolin, I do not want this valuable treatment to be unavailable if I need it (it doesn't mean I have to like it) - anyone who has treated people with psychotic depression knows that ECT is invaluable - I'm afraid that psychiatrists are being de-skilled in this area by the need to refer cases elsewhere - I published a study back in the 1980s showing that most people get their information from non-psychiatric sources, most notoriously the movie 'One Flew over the Cuckoos Nest' - only those people who knew someone who got ECT had positive views on it.”*

Service User/Patient *“I was 17 when I had ECT. I always believed it had caused permanent damage. It was only after speaking to CP1 that I understood it had not caused permanent damage. I had managed to go to college and get a degree since having ECT, but for years I had it in my head that I had been damaged. After the session with CP1 I felt a weight had been lifted off my shoulders. It would have helped me to have this conversation about ECT years ago.”*

Family Member/Carer *“I recall as a young 15 year old being made aware of ECT by my mother (a widow) that my brother was going to receive the treatment; it was spoken about in 'hushed' terms. Indeed it was just going to happen and it was going to make my brother better - it didn't! The sad part of this story is no-one to my knowledge within the family or otherwise discussed this treatment or its effects with my brother. As a teenager I didn't have an idea of what was really going on. All I knew or understood about the treatment (was) that it was severe, an electric shock was administered and that it would 'jolt' the mind back into action. I remember my sister (two years older than me) who had visited my brother following one of his treatments coming home very upset - don't know really what her experience was - but I was really upset for her then. What a dreadful time! It have been so helpful if someone had discussed ECT with the whole family.”*

Family Member: *“In 1971 following a bout of depression which failed to respond to medication, the possibility of my husband having ECT treatment was suggested by his doctor. Having little knowledge of this treatment and being aware of the negative connotations associated with it, we*

were naturally apprehensive. However, having unsuccessfully explored other treatments, we were left with no other option and agreed.

The length of the episode and the severity of the symptoms had necessitated Derek being hospitalised. On the evening of the first treatment when I visited, I saw my husband walking down a corridor away from me. I was immediately struck by the change in his demeanour. He was no longer the slow moving person imprisoned by depression; rather he was walking with purpose and confidence. I couldn't wait to reach him and see if there really was an improvement - I was not disappointed. Further sessions progressed his recovery to the extent that he was able to complete the course of treatments as an out-patient. My husband recovered and enjoyed, with the help of medication, the support of family and self-help groups and an increased awareness of coping strategies for his illness, many years of wellness. On a couple of occasions when my husband's condition failed to respond to medication, he himself requested further ECT treatments. Although, these subsequent sessions did not have the same dramatic and immediate effect, they nevertheless assisted in his recovery."