ECT Guide

Presenting the booklet designed to give an impartial presentation of the current evidence and advice on ECT.

Aimed at the patient, carer and lay person.
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ACKNOWLEDGEMENTS
The contribution made by patients and other SEAN Network members in the planning and feedback of the project is invaluable. However, this document is not intended to be a combined statement on ECT representing all the views of all individuals and agencies involved.

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WHY THIS BOOKLET HAS BEEN WRITTEN

Electroconvulsive Therapy (ECT) has been used in Scotland for half a century. It is viewed in the medical profession as safe, effective and painless, with a low risk of unacceptable side effects. Furthermore, psychiatrists believe it can save lives.

However, this view has not always been shared by the public; which is perfectly understandable. Much of what people believe about ECT comes from the way it is portrayed in films, television drama and documentary, where the purpose is often to entertain or to be controversial.

The concerns most frequently expressed are that ECT is ineffective, creates unacceptable side effects and is given disproportionately to the elderly, women and the disadvantaged.

Not only is there little or no scientific evidence to back up these concerns, but the results of a national audit carried out from February 1996 to today has shown these fears to be largely without foundation.

The information contained in this booklet is drawn from recent literature and research published on ECT supplemented by findings of the National Audit and subsequent data.

Background

The original audit

The aim of the original audit was to produce improvements in the practices at each site where ECT was delivered. It was intended that these improvements be monitored and maintained in the long term by encouraging local ownership of the audit and its results.

Following a postal survey in 1994 of ECT practice, psychiatrists in Scotland obtained a grant from the Scottish Executive to undertake an audit of ECT to find out as much as possible about facilities, staffing, training, usage and effectiveness.

All 35 ECT consultants in Scotland were recruited as local co-ordinators and the Scottish Electroconvulsive Therapy Audit Network (SEAN) was formed. This group met twice a year for the duration of the project encouraging local ownership of the audit and its results. A pilot study was carried out and the audit itself was undertaken in three phases between 1996 and 1999.
To ensure that all areas of practice were examined all members of the ECT clinical teams took part including psychiatrists, anaesthetists and nurses. During the audit all patients who had ECT in Scotland were included. For example, in phase two, between August 1997 and April 1998, this involved 794 patients.

The last phase of the survey (August 1998 to July 1999) involved unannounced visits to each ECT site, to view treatment sessions and to check if safe and correct procedures were used. Attention was also paid to the atmosphere in the ECT suite.

Some sites were found to have very high standards from the outset, but where this was not the case, appropriate action was taken. For example, the only site considered unacceptable in phase one had been closed by phase three.

Evolution of the audit

From 2000 onwards the audit developed into a National Clinical Network and accreditation project. An electronic integrated care pathway was developed and set up at all ECT clinics in Scotland to collect data and monitor care. In 2008 SEAN became part of the Quality Improvement Programme within Information Services Division (ISD), NHS National Services Scotland (NSS). Membership of SEAN includes clinical staff, service users, carers, representatives from the Scottish Government and Mental Welfare Commission for Scotland.

By involving service users, carers and user-led organisations in the audit, SEAN is striving to deliver the ‘Patient-Centred’ ambition described in the Healthcare Quality Strategy for NHS Scotland.

A key component of the SEAN audit consistent with the ‘Safe’ ambition described in the Healthcare Quality Strategy for NHS Scotland is the accreditation of ECT Services in Scotland against a set of national standards.

The ‘Effective’ ambition described in the Healthcare Quality Strategy for NHS Scotland is evident in SEAN’s efforts to further enhance the knowledge of all staff involved with the delivery of ECT in Scotland. This ongoing education takes many forms: annual national conference, e-learning, peer support and education.

WHAT EXACTLY DID THE MOST RECENT DATA TELL US ABOUT ECT IN SCOTLAND?

Data are collected and analysed for each calendar year and a full report is published on the SEAN website.

- In 2013 there were 372 patients who received ECT, relating to 454 episodes of treatment.
- The most prevalent primary diagnosis of patients receiving ECT was depression in the context of both major depressive disorder and its various manifestations (most prevalent depression without psychosis (45%).
- The most common indication remains resistance to antidepressant medication (55%). In a total of 7% of patients ECT was administered as an emergency life saving treatment. The majority of treatments involved patients deemed to have capacity (i.e. capable of giving informed consent) (67%).
- Overall 92% of patients who completed an episode of ECT showed some improvement in their MADRS score. Significant improvement was demonstrated in 67% of patients as evidenced by 50% or greater reduction in MADRS score over the course of treatment. The percentage of patients without capacity who showed this magnitude of improvement was greater than those with capacity (72% v 65%) reflecting the more severe nature of the illness in this group at the outset.
• ECT was given to adults from all age groups. The average age for men and women is similar at 60 and 61 respectively. The percentage of women to men receiving ECT (70% to 30%) reflects the percentage relating to gender of patients being treated for depression.

• The most frequently recorded side effects remains headache (27%).

• The majority of patients (70%) have received just one course of treatment since the current SEAN audit began in 2005, whilst a small number (4%) have received treatment on 5 or more occasions since 2005. This would appear to be indicative of the relapsing nature of the illness.

• There were no significant regional variations in treatment or provision across Scotland.

• Prescription rates varied throughout the country but no significant trend could be seen for example, between hospitals serving rural, urban or mixed areas.

All annual reports can be viewed on the following link

http://www.sean.org.uk/AuditReport/Main.html

For those without access to the internet SEAN are happy to provide hard copies via the post. Requests should be addressed to Linda Cullen at the address on page 3 of this guide.
HISTORY OF ECT

In the 1930s it was noticed that people who had both epilepsy and mental health problems often became brighter or indeed, happier, after an epileptic seizure. ECT was introduced as a result of this.

In the past, ECT was used for a wide variety of problems, without anaesthetic and very long courses were given. THIS IS NO LONGER THE CASE. However, ECT remains controversial. Some people want it banned; others have claimed it saved their lives.

A great deal is known about how it works. We know more about how ECT and drug treatments work than we do about how psychotherapy works.

WHEN IS ECT USED?

A consultant may recommend ECT if:

- There has been severe depressive illness for some time and drug treatments have either not worked or only partly worked.
- Illness is causing serious distress and making it impossible for the patient to function.
- Anti-depressants have been tried but stopped because of side effects and no other treatment has worked.
- A patient’s life may be in danger because of not eating or drinking and refusal to accept measures to support life.

WHAT SAFEGUARDS ARE THERE?

- Usually ECT does not have to be given urgently. There should be plenty of time to discuss the treatment.
- It’s always important to talk to someone, a doctor, your GP, a nurse, close friend or trusted family member.
- Try to talk to other patients who have had ECT.
- If there is no one close to you that you can confide in ask the ward staff for advice, or contact the local independent advocacy service in your hospital.
- If you are unsure don’t be afraid to ask your doctor to arrange a second opinion.
- Make sure that the alternatives to ECT have been explained to you. Make sure you know what will happen if you don’t have ECT.
- ECT treatment has been endorsed by the National Institute for Clinical Excellence (NICE) (https://www.nice.org.uk/guidance/ta59)
CAN ECT BE REFUSED?

Normally, the treatment can be refused. The patient will be asked to sign a consent form before treatment starts and can withdraw consent at any time. Anyone who is capable of making a decision about whether or not to have ECT can refuse or withdraw consent at any point throughout the treatment. Capable people cannot be given ECT against their will.

People who are not capable of making their own decisions (most likely due to severity of illness) about ECT can be given the treatment. There are very clear safeguards for this under the law.

NO ONE SHOULD BE PUT UNDER UNDUE PRESSURE TO HAVE ECT. IF THERE ARE DOUBTS INDEPENDENT ADVICE SHOULD BE SOUGHT. SOMEONE IS ALWAYS AVAILABLE. SEE THE RELEVANT ADDRESSES AT THE END OF THIS BOOKLET.

Remember however, in the latest report published 67% of patients were able to give informed consent.

WHAT HAPPENS IF A PERSON MIGHT NEED ECT BUT DOESN’T CONSENT?

ECT can only be given under certain circumstances if the person lacks capacity to consent. There are two laws that provide for this:

The Mental Health (Care and Treatment) (Scotland) Act 2003 allows for ECT to be given if an independent doctor appointed by the Mental Welfare Commission approves it. If the person lacks capacity and resists or objects, the Act only allows ECT to be given if the person is at serious risk or is seriously suffering.

The Adults with Incapacity (Scotland) Act 2000 allows for ECT to be given to people who lack capacity but are not treated under the Mental Health Act. It can only be used for people who do not resist or object.

In both cases, people should be allowed to make their own decisions about treatment when they regain capacity.

CAN PATIENTS MAKE ADVANCE DECISIONS ABOUT ECT?

Yes. A capable person can make an “Advance Statement” stating whether he/she would want to have ECT. If the person loses capacity, anyone providing treatment must pay attention to this statement. If ECT is given despite a capable advance refusal, the person authorising treatment must give reasons in writing. The Mental Welfare Commission will get a copy of this and will take a close interest if this happens.

CAN ECT BE GIVEN AS AN EMERGENCY?

In very urgent situations this can happen. If a consultant believes that a patient’s life is in danger because of severe depression then ECT can be given as an emergency. This usually only applies to the first one or two treatments. The Mental Welfare Commission must be contacted as soon as possible.
SHOULD ECT BE BANNED FOR PATIENTS WHO CAN’T CONSENT?

• If this happens about 33% of patients who now get ECT would not receive it.
• These patients would be those with the most severe depression.
• Such patients would be disadvantaged and deprived of an effective treatment.
• It is these patients who are among the most depressed and most in need of ECT.
• It is this group of patients who respond best to ECT.
• In some cases these patients’ lives would be at risk.

WHAT ACTUALLY HAPPENS DURING AN ECT TREATMENT?

A general anaesthetic is given by a senior anaesthetist and this puts the patient to sleep. At the same time a muscle relaxant is administered. Then a carefully calculated electric current is passed across the brain via electrodes, for approximately 3 - 4 seconds. The effect is to trigger an epileptic seizure. Because of the muscle relaxant, there will be little movement of the body. It is not a surgical operation, no incision is made.

The patient will be unaware of the treatment because of the anaesthetic. Routine monitoring of heart function and brain wave patterns (EEG) should take place. The photographs and plan of the ECT suite show a typical layout and examples of equipment used.

HOW OFTEN IS ECT GIVEN?

Normally a course of treatments is needed but the prescription should be reviewed after each one. ECT is usually given twice a week until the patient has had between six and twelve treatments. Some people may only need two or three. For the years from 2009-13, the average number of treatments per course has been 8.

WHAT ARE THE IMMEDIATE AFTER EFFECTS?

When the patient wakes up they will be back in a recovery room. Once wide-awake, they will be offered a light breakfast either in the clinic or back in the ward.

A patient may have no side effects at all, but they may have a headache or feel confused for a while.
WHAT ARE THE RISKS?

The risks are small.

- The most commonly quoted low death rate for ECT does not adequately account for all the risks of treatment.
- Patients with a pre-existing medical condition are at increased risk of experiencing cardiac or respiratory problems following treatment.
- All ECT centres in Scotland follow guidelines and standards, which stress the importance of pre-treatment medical assessments to identify and minimise any risk.
- The risk of a swing into manic mood is the same as for treatment with antidepressant drugs.
- Not having ECT also has risks. Studies have shown that depressive illness increases mortality rate and the suicide rate is higher in depressed patients not treated with ECT.

RISKS OF ANAESTHESIA

ECT is always carried out under general anaesthesia

Nothing to eat or drink - fasting (‘Nil by mouth’)

There should be clear instructions given about fasting. It is important to follow these. Usually clear fluids are allowed up to 2 hours and food up to 6 hours prior to anaesthesia.

Normal medicines

Patients should continue to take their normal medicines up to and including the day of ECT, unless the anaesthetist advises otherwise. However, there are exceptions. For example, drugs for diabetes or drugs similar to diazepam should be omitted on the morning of treatment.

If the patient feels physically unwell

If the patient becomes physically unwell before treatment the anaesthetist will need to know and ECT may need to be postponed.

Meeting your anaesthetist

The patient will normally meet the anaesthetist immediately before ECT. The anaesthetist must be informed about every patient in advance and every effort will be made to assess the patient earlier if the patient’s general health is poor. The anaesthetist will discuss the anaesthetic and the risks prior to ECT with the patient. During ECT the patient will be fully monitored:

- Electrocardiogram or ECG to monitor heart rate
- Sphygmomanometry to measure blood pressure
- Pulse oximeter to monitor the oxygen level in the blood
- Capnography to monitor the carbon dioxide in exhaled breath
- Electroencephalograph or EEG to monitor the activity in the brain

Intravenous cannula

The anaesthetist will place a cannula using a needle into a vein in the back of the patient’s hand or arm. Sometimes, it can take more than one attempt to insert the cannula.
Risks of Anaesthesia
People vary in how they interpret words and numbers. This scale is provided to help.

<table>
<thead>
<tr>
<th>Very common</th>
<th>Common</th>
<th>Uncommon</th>
<th>Rare</th>
<th>Very rare</th>
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<tr>
<td>1 in 10</td>
<td>1 in 100</td>
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<td>1 in 10,000</td>
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Possible side effects

**Headache**
The headache usually gets better in a few hours and can be treated with pain relievers.

**Aches, pains and backache**
During your treatment you may strain the muscles in your arms, legs, neck or back. Great care is taken to avoid this, but some people still feel uncomfortable afterwards. Muscle ache sometimes happen if you have received a drug called suxamethonium. This is a muscle relaxant given to modify the convulsion. If you suffer from muscle pains after ECT tell your anaesthetist and a drug may be given to try and prevent it.

**Confusion or memory loss**
This is common because of the effects of ECT. It may last from just the day of treatment to a few days or weeks.

**Feeling sick and vomiting**
Sickness can be treated with anti-vomiting drugs (anti-emetics), but it may last for a few hours after ECT.

**Damage to teeth, lips or tongue**
Damage can be caused to your teeth, lips or tongue during ECT. It is important to inform the anaesthetist about dentures, crowns and any loose teeth. A careful assessment of dentition will be carried out prior to treatment and a foam guard put in to protect the teeth.

Uncommon side effects

**An existing medical condition getting worse**
Your anaesthetist will always make sure that you are as fit as possible before ECT. However, if you have had a heart attack or stroke, it is possible that it may happen again - as it might even without ECT. Other conditions such as diabetes or high blood pressure will also need to be closely monitored and treated.

Rare side effects

**Serious allergy to drugs**
Allergic reactions will be noticed and treated very quickly. Very rarely, these reactions lead to death even in healthy people. Your anaesthetist will want to know about any allergies in yourself or your family.

Very rare side effects

**Death**
Deaths caused by anaesthesia are very rare, and are usually caused by a combination of predisposing medical conditions and four or five complications arising together. There are probably about five deaths for every million anaesthetics given in the UK

REASONS FOR DISCONTINUING ECT

During the audit in Scotland a record was kept of the reasons why a course of treatment was not completed as planned.

- In 2013, of approximately 300 courses, or episodes, of ECT, 58 (19%) were discontinued for various reasons.
- 7% were due to a medical decision unrelated to ECT and 3% were a decision related to the ECT.
- Less than 1% of patients overall were unwilling to continue with treatment due to side effects.
• In discontinued episodes in 2013, headache was the most common side effect reported, affecting around a third of these patients and anaesthetic side effects were reported in 1 episode (2%).

• In discontinued episodes in 2013, acute confusion was recorded as a side effect in 1 episode (2%)

MEMORY IMPAIRMENT AT ECT

• Memory impairment following ECT is common.

• Memory impairment can be associated with severe depression and can be marked even when patients have not had ECT.

• Some studies have shown that ECT does not increase the memory impairment already caused by severe depression.

• Despite this there is no doubt that short term memory impairment around the course of ECT and the few weeks afterwards is very common during the course of ECT. Memory impairment was reported during 17% of episodes in 2013.

• Past memories can also be affected. It is difficult to know how much of this is caused by ECT and how much by severe depression.

• Memory impairment due to ECT recovers gradually over the six months following treatment though some patients only very slowly recover past memories and some have permanent gaps in their memory for some past events.

DOES ECT CAUSE BRAIN DAMAGE?

The straightforward answer is ‘NO’.

Brain damage can be of two types:

1. Shrinkage of the brain or loss of particular groups of cells.
   o There are many studies using modern brain scans, which have shown that ECT does not cause such damage.

2. Impairment of function
   o This might not show up on brain scans.
   o It might be detected by tests of memory, concentration or ability to plan.
   o Most studies show that these abilities improve in patients who have had ECT. This is because ECT reverses depression not because of a direct positive effect on brain function.
   o This emphasises that depression itself has profound effects on memory, concentration and other mental tasks.

Could there be a small number of people who do have permanent memory changes after ECT?

• Yes, there are certainly patients who have lost memories from their past which have not returned even after many years.

• Detecting these gaps in individual memories has proved very difficult in large research studies.
Even in this very small number of patients the ability to learn new facts remains intact.

**WHY IS ECT CONTROVERSIAL?**

- There is a lot of misinformation about ECT.
- ECT has become an important target for anti-psychiatry groups. Several such groups want ECT to be banned.
- Claims are made that ECT always causes brain damage, irreversibly changes personality or even causes breast cancer.
- The majority of ECT web sites on the internet are strongly anti-ECT. The most extreme ones state that ECT never does any good, if patients appear to get better it is because they are stunned, shocked or brain damaged.
- A common claim is that ECT works because it impairs memory, in other words it makes you forget why you were depressed. This is **NOT TRUE**; getting better with ECT does not depend on memory impairment.
- Another often stated view is that ECT works because it is a punishment. This is because some severely depressed patients feel they are responsible for things going wrong. They may even feel they deserve to be punished and believe this is the purpose of the treatment.
- However most patients who have ECT do not feel so guilty and they still get better.

**HOW TO COPE WITH MISINFORMATION**

- Remember the internet has free access, anyone can say anything, and you need to be selective about what you read.
- If you feel overwhelmed by negative views, speak to other patients, to staff or ask to speak to an advocate.
- Don’t be embarrassed. Discuss any information you have with members of the team treating you. If you are not happy ask for a second opinion.
- Our website has information on it and links to other relevant sites.

[www.sean.org.uk/](http://www.sean.org.uk/)
WHAT IS THE STANDARD OF ECT IN SCOTLAND?

In Scotland, ECT is always delivered in an acceptable setting and to the standards required by the Royal College of Psychiatrists. Following the last round of accreditations all ECT clinics in Scotland achieved accreditation and 84% achieved accreditation with excellence.

This map shows ECT units currently treating in Scotland. Some units have amalgamated but ECT remains available to psychiatric services in all parts of the country.
IS THERE ROOM FOR IMPROVEMENT?

There is always room for improvement.

For example, the original audit found that while all junior staff received training and were supervised for their first ECT session, problems remained with continuing supervision. Since then this has improved greatly because ongoing supervision is a Level 1 (Mandatory) SEAN Standard. The Royal College of Psychiatrists has produced competencies for all medical staff at ECT and consultants have secured protected time in their contracts for ECT supervision.

Through the audit the pivotal role of nursing staff in the delivery of ECT was highlighted and SEAN has developed a specialist ECT nurse sub group, the Committee of Nurses at ECT in Scotland (CONECTS) which has produced a web based training programme for nurses. There is now a lead ECT nurse at every clinic.

ARE THERE ANY QUESTIONS STILL TO BE ANSWERED?

The audit made recommendations about documentation and legal procedures around consent. It could not consider in detail the validity of informed consent in every case.

The Scottish ECT Accreditation Network (SEAN) continues to work on quality assurance, person centeredness and outcomes. Clinics and prescribing units will be inspected on a regular basis against a set of national clinical standards and data will be published on an annual basis to answer some of the questions still being posed.

IN SUMMARY

In Scotland the standard of premises, ECT equipment and procedures for treatment with ECT meet The Royal College of Psychiatrists standard.

ECT is very effective in a routine clinical setting. The degree and rate of improvement is better than would be expected for either drug or talking treatments.

It is true that ECT is not effective for everyone, but the number of patients who do not improve is small.

Many of the public perceptions about ECT are not corroborated by audit of current practice. For example, the notion that ECT is used disproportionately on the elderly, women or minorities is not borne out by the evidence.

The quality of ECT in Scotland is high and it is the aim of SEAN that it continues to improve.
## APPENDIX

### Advice and Support

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<th>Organization</th>
<th>Address</th>
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<th>Email</th>
<th>Website</th>
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<tbody>
<tr>
<td>Citizens Advice Scotland</td>
<td></td>
<td>0808 800 9060 (direct Advice)</td>
<td><a href="http://www.cas.org.uk/">http://www.cas.org.uk/</a></td>
<td></td>
</tr>
<tr>
<td>Bipolar Fellowship Scotland</td>
<td>Studio 1015 Mile End Mill, Abbeymill Business Centre, Seedhill Road, Paisley, PA1 1TJ</td>
<td>+44(0)141 560 2050,</td>
<td><a href="mailto:info@bipolarscotland.co.uk">info@bipolarscotland.co.uk</a>,</td>
<td><a href="http://www.bipolarscotland.org.uk/">http://www.bipolarscotland.org.uk/</a></td>
</tr>
<tr>
<td>Support in Mind Scotland (no longer called schizophrenia fellowship)</td>
<td>1 Rutland Court Edinburgh, EH3 8EY</td>
<td>+44 (0)131 662 4359</td>
<td><a href="mailto:info@supportinmindscotland.org.uk">info@supportinmindscotland.org.uk</a></td>
<td><a href="http://www.supportinmindscotland.org.uk/">http://www.supportinmindscotland.org.uk/</a></td>
</tr>
<tr>
<td>Samaritans</td>
<td>Telephone number below is on the inside front cover of all phone books, UK wide. The number routes caller to nearest Samaritans office which has an available line at time of calling.</td>
<td>08457 90 90 90 - (charged at local rate)</td>
<td><a href="mailto:jo@samaritans.org">jo@samaritans.org</a></td>
<td><a href="http://www.samaritans.org/">http://www.samaritans.org/</a></td>
</tr>
<tr>
<td>Scottish Association for Mental Health</td>
<td>Brunswick House 51 Wilson Street Glasgow G1 1UZ</td>
<td>+44(0) 141 530 1000</td>
<td><a href="mailto:enquire@samh.org.uk">enquire@samh.org.uk</a></td>
<td><a href="http://www.samh.org.uk/">http://www.samh.org.uk/</a></td>
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### Official Bodies

<table>
<thead>
<tr>
<th>Mental Welfare Commission for Scotland</th>
<th>Haymarket Terrace Edinburgh EH12 5HE</th>
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<tbody>
<tr>
<td>Tel: 0300 244 4000</td>
<td>Website: <a href="http://www.mwcscot.org.uk/">http://www.mwcscot.org.uk/</a></td>
</tr>
<tr>
<td>Freephone 0800 389 6809 (for service users and carers)</td>
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<table>
<thead>
<tr>
<th>The Scottish Government</th>
<th>St Andrew's House Regent Road Edinburgh EH1 3DG</th>
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<tr>
<td>Tel: +44(0) 131 313 8777</td>
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| National Institute for Clinical Excellence (NICE) | Website: [www.nice.org.uk](http://www.nice.org.uk) |
Further Information and Updates

References, comments, links and further information are available via this web site www.sean.org.uk/ or on request from:

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LAYOUT OF AN ECT SUITE

![Layout of an ECT Suite]