



NSW Consumer Advisory Group – Mental Health Inc  
ABN 82 549 537 349

10<sup>th</sup> February 2010

Mr Carlton Quartly  
A/Manager Clinical Governance  
Mental Health and Drug and Alcohol Office  
NSW Health  
Locked Bag 961  
North Sydney NSW 2059

Email: [carlton.quartly@health.nsw.gov.au](mailto:carlton.quartly@health.nsw.gov.au)

Dear Carlton

**Re: Draft NSW Health Electroconvulsive Therapy (ECT) Standards**

Thank you for providing the NSW Consumer Advisory Group – Mental Health Inc. (NSW CAG) with the opportunity to comment on the Draft NSW Health Electroconvulsive Therapy Standards. NSW CAG is the peak, independent, state-wide organisation representing the views of mental health consumers at a policy level, working to achieve and support systemic change. Our vision is for all mental health consumers to experience fair access to quality services that reflect their needs.

Our main comments below identify issues surrounding informed consent, the provision of information about ECT to consumers, and the credentialing of staff coordinating ECT, in order to ensure consumer safety and the provision of quality efficacious treatment. It should be noted that given the timeframes for the response, NSW CAG has not been able to consult with our network around the Standards and attached documents. Our response is therefore informed by our work with consumers over the past 17 years.

While appreciating the focus on the clinical practice of ECT for the standards, NSW CAG is concerned that consumers were not involved in the development of these standards at an earlier stage. Consumer involvement would particularly have been useful to inform the components around which comment will be made within this letter. It is strongly recommended that earlier consumer involvement in all initiatives, including those around clinical practice, is ensured in the future.

Broadly, the Policy and Guidelines are based on solid evidence surrounding best practice for ECT. The implementation of these documents will ensure a more

consistent approach to the practice of ECT that will also ensure a higher quality of treatment for mental health consumers. Our recommendations for consideration within the Policy and Guidelines are presented in relation to the sections of the Policy and Guidelines.

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It is recommended that this section also includes preparation of the patient through the provision of information about the treatment, including the procedures for the treatment and for the day of treatment, likely benefits, possible side effects and risks, alternative treatment options, why ECT is the recommended treatment, including the risk benefit analysis that has been undertaken by the treating psychiatrist. This information needs to be provided in a timely manner, in easy to understand language, in both a written and verbal format.

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A further component absent from the guidelines pertains to the follow-up care of consumers who have received ECT, particularly after they may have been discharged from a service or having completed a course of ECT. Indeed, such guidelines are also relevant to those undergoing maintenance or continuation ECT. It is recommended that the Policy Guidelines include direction as to the minimum information that must be provided to a consumer's GP and/or care coordinator, and how often or when follow

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Karen Oakley  
Executive Officer

## Appendices

Appendix 1: Information on ECT

Appendix 2: Information for patients going home on the same day of ECT treatment

## APPENDIX 1: INFORMATION ON ECT (Electroconvulsive Therapy)

**Comment [k1]:** Make all information at least size 12 font and in Arial type

This information sheet will try to answer some of the questions you may have about Electroconvulsive Therapy (ECT). Your psychiatrist will discuss with you why ECT has been recommended for you.

### What is ECT and why is it given?



ECT is a modern psychiatric treatment that is effective for a range of mental illnesses, including major depression, mania, some forms of schizophrenia and a small number of other mental and neurological disorders.

It might be used when medications have not worked or other forms of treatment are ineffective. It might also be used for people who have serious side effects from medications or whose medical condition means they can't take medications safely.

A general anaesthetic and muscle relaxant is given. When these have taken full effect, i.e. when you are asleep, a brief, carefully controlled electrical current is passed through the brain, causing a seizure. You will wake up after 5 to 10 minutes, much as you would from minor surgery.

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ECT usually consists of 6 to 12 treatments given 2 to 3 times a week over about a month. The total number of treatments needed to get a person better varies between individuals and your psychiatrist will discuss with you how many treatments you are likely to need. While most people show some improvement after 3 to 4 sessions, it takes on average 9 treatments to achieve recovery and some patients may need more than 12 treatments.

There is evidence that ECT is effective in improving depressive and psychotic symptoms. Approximately 8 out of 10 patients who undergo ECT will experience dramatic improvement.

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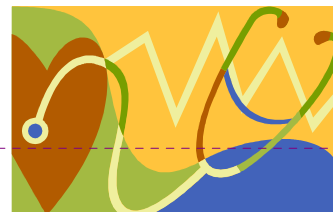
### How Does ECT Work?

A lot of research has been done into the changes that occur within the brain after ECT treatment. It is known that after ECT the activity levels of different parts of the brain are changed, hormones are released, and signalling between brain cells is modified. The latest research studies suggest that ECT may even result in the growth of new brain cells, possibly a process to "repair" impaired brain circuits that may be responsible for depression. There is no one accepted theory about how ECT works, leading some to claim that ECT is unscientific, or to reject it as a treatment. However, it is important to note that we know as much about how ECT works as about some other treatments in medicine, for example, anaesthesia.

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### When will your doctor order ECT treatment?

The decision to administer ECT is based on a thorough physical and psychiatric evaluation of the person, taking into account the type of illness, the degree of suffering, the expected result and the prognosis for the person if the treatment is not given. When the risk of suicide is high or when a seriously ill person is unable to eat or drink, ECT can be life-saving.



**Comment [k3]:** Use a more lay person's term such as expectation of outcomes over a long period

### Prior to your treatment

Before your first ECT treatment, you will be examined to make sure you are fit to have a short general anaesthetic and ECT.

You must not eat or drink anything including water for at least 6 hours before the ECT treatment to make sure your stomach is empty. This is called 'fasting'. If you eat or drink anything within the fasting period, you must tell the nursing or medical staff before the treatment. Some medication might be given early on the morning of ECT treatment, but only with a tiny sip of water.

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### How is ECT given?

In the operating theatre of the hospital the staff will attach the following to you:



- Blood pressure cuff on your arm or leg or both
- Small clip over one of your fingers to check heart rate (pulse) and oxygen levels in your blood
- Small stick-on electrodes on your forehead and behind your ears to record the brain's electrical activity during the treatment
- Face mask over your nose and mouth to give you oxygen. This is to prepare your body and brain for the extra activity that will happen briefly with the treatment.

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**Comment [k4]:** This is a medical term – need to explain in lay person's term

You will have a short general anaesthetic so that you will be asleep and not feel or remember the treatment. The anaesthetic medication will be injected into a vein to make it work quickly and well. An anaesthetist will be present and give the anaesthetic. You will also be given a medicine to relax your muscles. You won't feel the convulsion because of the anaesthetic, and any muscle movement during ECT will be limited because of the medication relaxing the muscles.

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A doctor who has specialised training in ECT will administer the treatment. The doctor puts small electrodes on your scalp and passes a measured amount of electricity to a part of the brain to cause a seizure (fit). Depending on the patient and their condition, one or both sides of the head will be stimulated, known as unilateral or bilateral ECT respectively. The seizure will last up to two minutes.



During the treatment, the anaesthetist will continue to give you oxygen through the face mask and monitor your heart rate and oxygen level. The anaesthetist will give you any medications necessary to adjust your heart rate etc during and after the treatment.

You will not feel or remember any of the actual treatment because you will be asleep due to the anaesthetic medication. Within a few minutes after the treatment, the anaesthetic will have worn off and you will wake up. During this time, you will be moved to the recovery room where you will be looked after until you are awake enough to return to your ward. If you are having day procedure ECT, you might need to wait in the recovery room or a ward for up to several hours to make sure you are ready to go home. After you wake up, the anaesthetic medication and the treatment/seizure will make you groggy for a while.

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### Is it safe? What are the benefits of ECT? What about side-effects?

ECT is regarded as a very safe treatment. Research has shown that ECT doesn't cause brain damage or changes in personality because the amount of electricity used is too small to harm tissue.

Your psychiatrist will discuss with you the expected benefits of ECT. These will vary depending on the nature and seriousness of your illness, but ECT will generally improve your ability to think and return your emotions to a healthier state.

All treatments have risks and side effects—even no treatment has risks.

The risks and side effects of ECT include:

- Side effects from the anaesthetic, such as headache, nausea (feeling sick in the stomach) or queasiness, vomiting. You should tell the staff looking after you and they will be able to give you some medication to help.

- You might get muscle soreness after the ECT as a result of the medication to relax the muscles.
  - The anaesthetic will affect your judgment for the first 24 hours. During this time you must not:



- Drive any type of vehicle
- Operate machinery, including cooking implements
- Make important decisions or sign a legal document
- Drink alcohol, take other mind-altering substances or smoke because they might react with the anaesthetic medication.

- A common and significant side-effect is confusion and memory impairment.

- Many people report difficulty with memory which usually clears up shortly after the end of treatment. For some it may last for a while longer (eg weeks to months) but improves with time.
- Immediately after ECT most people have a short period of confusion and do not remember the actual treatment.
- Over the course of ECT, it might be more difficult to remember newly learned information, eg events that occurred during the weeks you were having ECT.
- Some people also report a patchy loss of memory of events that occurred during the days, weeks and months before the ECT. Memory for recent events, dates, names of friends etc. may not be as good. In most patients the memory problems go away over the days, weeks or months following completion of the course of ECT. Sometimes, but not often, there may be permanent loss of isolated memories from your past.
- Many people will find that their memories are somewhat unclear for the time that they were ill. The same problem is often experienced by people with depression who do not receive ECT.
- Although specific memories from around the time you had ECT might not return, your overall memory should work better in the weeks to months after treatment. Many patients report that their memory improved after a course of ECT.

- Some other side effects are less common and some are extremely rare:

- There is a less common risk of medical complications, such as irregular heart rate and rhythm. There might be a temporary rise in blood pressure and heart rate followed by a slowing of the heart rate.
- As with any general anaesthetic, there is a very small risk of death, but with modern ECT and a short anaesthetic, this risk is now extremely rare. No case of death associated with anaesthesia for ECT has been recorded in New South Wales for more than 25 years.
- Heart attack, stroke or injury related to muscle spasms are also extremely rare.
- Resuscitation equipment and emergency procedures are immediately available if anything should go wrong.

- What are the alternative treatments?

- Talk to your psychiatrist about what other treatments may be offered instead of ECT

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## Giving permission for ECT

Just as with any medical procedure, it is required that informed consent for ECT be obtained in writing. Informed consent is when you agree to have ECT after you have been told what ECT involves, including

- a full explanation of the ECT procedure,
- how it works,
- how it can help your illness,
- possible side effects, discomforts and risks of ECT and
- any beneficial alternative treatments.



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You have the right to discuss your views about ECT with your psychiatrist and ask any questions about it.

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You also have the right to:

- Obtain medical and legal advice
- Obtain a second opinion from a psychiatrist about the ECT. Your psychiatrist can arrange a second opinion from within the mental health service.
- Have a friend, family member, lawyer or an advocate represent you before you consent to ECT

Comment [k7]: May also be useful to provide reference to the ability to do some advanced planning about having ECT or about having an agreement with a person to make decisions for the person while they are having ECT and judgement may be affected

If you agree to have ECT, you will be asked to sign a form to say you have given informed consent. This means if you are able to give informed consent, you have the right to refuse ECT.

If you are incapable of giving informed consent, or if your health professionals consider that ECT treatment is potentially life saving, then your psychiatrist will seek consent on your behalf through the Mental Health Review Tribunal, even if you don't want the treatment.

Comment [k8]: Need to explain how this would be determined

The Mental Health Review Tribunal becomes involved in decisions about ECT when the hospital:

- is uncertain of a voluntary patient's capacity to give consent to treatment with ECT; and
- proposes ECT for an involuntary patient.

Your psychiatrist must do everything reasonably practicable to give notice to your nearest relative, guardian or personal friends about the application for ECT. The Mental Health Review Tribunal will make the decision as to whether or not you are to be treated with ECT.

If you agree to have ECT, but then change your mind, it is your right to withdraw your consent at **any time** and the treatments will be stopped, unless your psychiatrist believes you are unable to give informed consent. If you want to withdraw your consent, you should talk to your psychiatrist. Remember that you can have a friend, a family member, a lawyer or an advocate with you for support or to represent you.

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## Will I need further treatment?

While your illness might be treated with a course of ECT, the illness might come back once the course is finished. Some people need occasional continued ECT treatment, spread-out from around once a week to once a month. To help prevent relapse, your doctor will discuss with you any further treatment you might need after the course of ECT ends, such as medication, maintenance ECT, psychotherapy, counselling and / or rehabilitation.



## References

SANE ECT Information Sheet: <http://www.sane.org/information/factsheets>

Better Health Channel ECT Information Sheet: <http://www.betterhealth.vic.gov.au>

Victorian Government Health Information: <http://www.health.vic.gov.au>

## APPENDIX 2:

### INFORMATION FOR PATIENTS GOING HOME ON THE SAME DAY OF ECT TREATMENT

The following information may assist you in your recovery from your ECT treatment today.

#### **BEFORE LEAVING THE MENTAL HEALTH UNIT**

After your treatment you will be returned to the ward where you must stay for 4 hours to ensure you are well enough to go home following the anaesthetic.

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The nursing staff will ensure you see a doctor before leaving the ward.

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You will be given an appointment card with the date of your next treatment.

#### **WHAT TO EXPECT AFTER ECT TREATMENT**

◆ The anaesthetic will affect your judgment and you may feel a little light headed, slower to react or sleepy for the next 24 hours. During the 24 hours after ECT treatment you **MUST NOT**:

- Drive any type of vehicle (therefore, someone will need to pick you up from hospital)
- Operate machinery, including cooking implements
- Make important decisions or sign a legal document
- Drink alcohol, take other mind-altering substances or smoke because they might react with the anaesthetic medication
- Engage in heavy work or strenuous activities.



◆ Managing side effects from ECT treatment & the anaesthetic

- Side effects from the ECT treatment may include headache. You may take medication such as paracetamol for a headache as directed by your doctor.
- Side effects from the anaesthetic may include nausea, queasiness (feeling sick in the stomach) or vomiting. A light diet is recommended after an anaesthetic. If you are experiencing nausea or vomiting, do not eat solid food and drink clear fluids only. Should nausea, vomiting continue tomorrow, contact your local doctor.

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ECT usually consists of 6 to 12 treatments given 2 to 3 times a week over about a month. The total number of treatments needed to get a person better varies between individuals and your psychiatrist will discuss with you how many treatments you are likely to need. While most people show some improvement after 3 to 4 sessions, it takes on average 9 treatments to achieve recovery and some patients may need more than 12 treatments.

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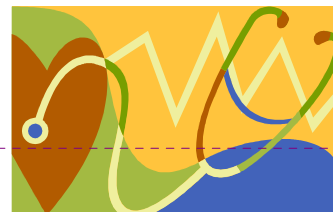
### How Does ECT Work?

A lot of research has been done into the changes that occur within the brain after ECT treatment. It is known that after ECT the activity levels of different parts of the brain are changed, hormones are released, and signalling between brain cells is modified. The latest research studies suggest that ECT may even result in the growth of new brain cells, possibly a process to "repair" impaired brain circuits that may be responsible for depression. There is no one accepted theory about how ECT works, leading some to claim that ECT is unscientific, or to reject it as a treatment. However, it is important to note that we know as much about how ECT works as about some other treatments in medicine, for example, anaesthesia.

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### When will your doctor order ECT treatment?

The decision to administer ECT is based on a thorough physical and psychiatric evaluation of the person, taking into account the type of illness, the degree of suffering, the expected result and the prognosis for the person if the treatment is not given. When the risk of suicide is high or when a seriously ill person is unable to eat or drink, ECT can be life-saving.



**Comment [k3]:** Use a more lay person's term such as expectation of outcomes over a long period

### Prior to your treatment

Before your first ECT treatment, you will be examined to make sure you are fit to have a short general anaesthetic and ECT.

You must not eat or drink anything including water for at least 6 hours before the ECT treatment to make sure your stomach is empty. This is called 'fasting'. If you eat or drink anything within the fasting period, you must tell the nursing or medical staff before the treatment. Some medication might be given early on the morning of ECT treatment, but only with a tiny sip of water.

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### How is ECT given?

In the operating theatre of the hospital the staff will attach the following to you:



- Blood pressure cuff on your arm or leg or both
- Small clip over one of your fingers to check heart rate (pulse) and oxygen levels in your blood
- Small stick-on electrodes on your forehead and behind your ears to record the brain's electrical activity during the treatment
- Face mask over your nose and mouth to give you oxygen. This is to prepare your body and brain for the extra activity that will happen briefly with the treatment.

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**Comment [k4]:** This is a medical term – need to explain in lay person's term

You will have a short general anaesthetic so that you will be asleep and not feel or remember the treatment. The anaesthetic medication will be injected into a vein to make it work quickly and well. An anaesthetist will be present and give the anaesthetic. You will also be given a medicine to relax your muscles. You won't feel the convulsion because of the anaesthetic, and any muscle movement during ECT will be limited because of the medication relaxing the muscles.

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**Comment [k5]:** This is the first time this word is used, need to explain what it is and may be useful to include in explanation of what a seizure is.

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**Comment [k6]:** Need to explain this term

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A doctor who has specialised training in ECT will administer the treatment. The doctor puts small electrodes on your scalp and passes a measured amount of electricity to a part of the brain to cause a seizure (fit). Depending on the patient and their condition, one or both sides of the head will be stimulated, known as unilateral or bilateral ECT respectively. The seizure will last up to two minutes.



During the treatment, the anaesthetist will continue to give you oxygen through the face mask and monitor your heart rate and oxygen level. The anaesthetist will give you any medications necessary to adjust your heart rate etc during and after the treatment.

You will not feel or remember any of the actual treatment because you will be asleep due to the anaesthetic medication. Within a few minutes after the treatment, the anaesthetic will have worn off and you will wake up. During this time, you will be moved to the recovery room where you will be looked after until you are awake enough to return to your ward. If you are having day procedure ECT, you might need to wait in the recovery room or a ward for up to several hours to make sure you are ready to go home. After you wake up, the anaesthetic medication and the treatment/seizure will make you groggy for a while.

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### Is it safe? What are the benefits of ECT? What about side-effects?

ECT is regarded as a very safe treatment. Research has shown that ECT doesn't cause brain damage or changes in personality because the amount of electricity used is too small to harm tissue.

Your psychiatrist will discuss with you the expected benefits of ECT. These will vary depending on the nature and seriousness of your illness, but ECT will generally improve your ability to think and return your emotions to a healthier state.

All treatments have risks and side effects—even no treatment has risks.

The risks and side effects of ECT include:

- Side effects from the anaesthetic, such as headache, nausea (feeling sick in the stomach) or queasiness, vomiting. You should tell the staff looking after you and they will be able to give you some medication to help.

- You might get muscle soreness after the ECT as a result of the medication to relax the muscles.
  - The anaesthetic will affect your judgment for the first 24 hours. During this time you must not:



- Drive any type of vehicle
- Operate machinery, including cooking implements
- Make important decisions or sign a legal document
- Drink alcohol, take other mind-altering substances or smoke because they might react with the anaesthetic medication.

- A common and significant side-effect is confusion and memory impairment.

- Many people report difficulty with memory which usually clears up shortly after the end of treatment. For some it may last for a while longer (eg weeks to months) but improves with time.
- Immediately after ECT most people have a short period of confusion and do not remember the actual treatment.
- Over the course of ECT, it might be more difficult to remember newly learned information, eg events that occurred during the weeks you were having ECT.
- Some people also report a patchy loss of memory of events that occurred during the days, weeks and months before the ECT. Memory for recent events, dates, names of friends etc. may not be as good. In most patients the memory problems go away over the days, weeks or months following completion of the course of ECT. Sometimes, but not often, there may be permanent loss of isolated memories from your past.
- Many people will find that their memories are somewhat unclear for the time that they were ill. The same problem is often experienced by people with depression who do not receive ECT.
- Although specific memories from around the time you had ECT might not return, your overall memory should work better in the weeks to months after treatment. Many patients report that their memory improved after a course of ECT.

- Some other side effects are less common and some are extremely rare:
  - There is a less common risk of medical complications, such as irregular heart rate and rhythm. There might be a temporary rise in blood pressure and heart rate followed by a slowing of the heart rate.
  - As with any general anaesthetic, there is a very small risk of death, but with modern ECT and a short anaesthetic, this risk is now extremely rare. No case of death associated with anaesthesia for ECT has been recorded in New South Wales for more than 25 years.
  - Heart attack, stroke or injury related to muscle spasms are also extremely rare.
  - Resuscitation equipment and emergency procedures are immediately available if anything should go wrong.

- What are the alternative treatments?

- Talk to your psychiatrist about what other treatments may be offered instead of ECT

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## Giving permission for ECT

Just as with any medical procedure, it is required that informed consent for ECT be obtained in writing. Informed consent is when you agree to have ECT after you have been told what ECT involves, including

- a full explanation of the ECT procedure,
- how it works,
- how it can help your illness,
- possible side effects, discomforts and risks of ECT and
- any beneficial alternative treatments.



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You have the right to discuss your views about ECT with your psychiatrist and ask any questions about it.

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You also have the right to:

- Obtain medical and legal advice
- Obtain a second opinion from a psychiatrist about the ECT. Your psychiatrist can arrange a second opinion from within the mental health service.
- Have a friend, family member, lawyer or an advocate represent you before you consent to ECT

Comment [k7]: May also be useful to provide reference to the ability to do some advanced planning about having ECT or about having an agreement with a person to make decisions for the person while they are having ECT and judgement may be affected

If you agree to have ECT, you will be asked to sign a form to say you have given informed consent. This means if you are able to give informed consent, you have the right to refuse ECT.

If you are incapable of giving informed consent, or if your health professionals consider that ECT treatment is potentially life saving, then your psychiatrist will seek consent on your behalf through the Mental Health Review Tribunal, even if you don't want the treatment.

Comment [k8]: Need to explain how this would be determined

The Mental Health Review Tribunal becomes involved in decisions about ECT when the hospital:

- is uncertain of a voluntary patient's capacity to give consent to treatment with ECT; and
- proposes ECT for an involuntary patient.

Your psychiatrist must do everything reasonably practicable to give notice to your nearest relative, guardian or personal friends about the application for ECT. The Mental Health Review Tribunal will make the decision as to whether or not you are to be treated with ECT.

If you agree to have ECT, but then change your mind, it is your right to withdraw your consent at **any time** and the treatments will be stopped, unless your psychiatrist believes you are unable to give informed consent. If you want to withdraw your consent, you should talk to your psychiatrist. Remember that you can have a friend, a family member, a lawyer or an advocate with you for support or to represent you.

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## Will I need further treatment?

While your illness might be treated with a course of ECT, the illness might come back once the course is finished. Some people need occasional continued ECT treatment, spread-out from around once a week to once a month. To help prevent relapse, your doctor will discuss with you any further treatment you might need after the course of ECT ends, such as medication, maintenance ECT, psychotherapy, counselling and / or rehabilitation.



## References

SANE ECT Information Sheet: <http://www.sane.org/information/factsheets>

Better Health Channel ECT Information Sheet: <http://www.betterhealth.vic.gov.au>

Victorian Government Health Information: <http://www.health.vic.gov.au>

## APPENDIX 2:

### INFORMATION FOR PATIENTS GOING HOME ON THE SAME DAY OF ECT TREATMENT

The following information may assist you in your recovery from your ECT treatment today.

#### **BEFORE LEAVING THE MENTAL HEALTH UNIT**

After your treatment you will be returned to the ward where you must stay for 4 hours to ensure you are well enough to go home following the anaesthetic.

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The nursing staff will ensure you see a doctor before leaving the ward.

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You will be given an appointment card with the date of your next treatment.

#### **WHAT TO EXPECT AFTER ECT TREATMENT**

◆ The anaesthetic will affect your judgment and you may feel a little light headed, slower to react or sleepy for the next 24 hours. During the 24 hours after ECT treatment you **MUST NOT**:

- Drive any type of vehicle (therefore, someone will need to pick you up from hospital)
- Operate machinery, including cooking implements
- Make important decisions or sign a legal document
- Drink alcohol, take other mind-altering substances or smoke because they might react with the anaesthetic medication
- Engage in heavy work or strenuous activities.



◆ Managing side effects from ECT treatment & the anaesthetic

- Side effects from the ECT treatment may include headache. You may take medication such as paracetamol for a headache as directed by your doctor.
- Side effects from the anaesthetic may include nausea, queasiness (feeling sick in the stomach) or vomiting. A light diet is recommended after an anaesthetic. If you are experiencing nausea or vomiting, do not eat solid food and drink clear fluids only. Should nausea, vomiting continue tomorrow, contact your local doctor.

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NSW Consumer Advisory Group – Mental Health Inc  
ABN 82 549 537 349

10<sup>th</sup> February 2010

Mr Carlton Quartly  
A/Manager Clinical Governance  
Mental Health and Drug and Alcohol Office  
NSW Health  
Locked Bag 961  
North Sydney NSW 2059

Email: [carlton.quartly@health.nsw.gov.au](mailto:carlton.quartly@health.nsw.gov.au)

Dear Carlton

**Re: Draft NSW Health Electroconvulsive Therapy (ECT) Standards**

Thank you for providing the NSW Consumer Advisory Group – Mental Health Inc. (NSW CAG) with the opportunity to comment on the Draft NSW Health Electroconvulsive Therapy Standards. NSW CAG is the peak, independent, state-wide organisation representing the views of mental health consumers at a policy level, working to achieve and support systemic change. Our vision is for all mental health consumers to experience fair access to quality services that reflect their needs.

Our main comments below identify issues surrounding informed consent, the provision of information about ECT to consumers, and the credentialing of staff coordinating ECT, in order to ensure consumer safety and the provision of quality efficacious treatment. It should be noted that given the timeframes for the response, NSW CAG has not been able to consult with our network around the Standards and attached documents. Our response is therefore informed by our work with consumers over the past 17 years.

While appreciating the focus on the clinical practice of ECT for the standards, NSW CAG is concerned that consumers were not involved in the development of these standards at an earlier stage. Consumer involvement would particularly have been useful to inform the components around which comment will be made within this letter. It is strongly recommended that earlier consumer involvement in all initiatives, including those around clinical practice, is ensured in the future.

Broadly, the Policy and Guidelines are based on solid evidence surrounding best practice for ECT. The implementation of these documents will ensure a more

consistent approach to the practice of ECT that will also ensure a higher quality of treatment for mental health consumers. Our recommendations for consideration within the Policy and Guidelines are presented in relation to the sections of the Policy and Guidelines.

## **Policy Statement**

### **Section 3: Consent and legal issues**

While not required under the Mental Health Act, NSW CAG considers that good practice would be ensuring the consumer's informed consent for each administration of ECT. This may be done verbally.

### **Section 5: Preparing the patient for ECT**

It is recommended that this section also includes preparation of the patient through the provision of information about the treatment, including the procedures for the treatment and for the day of treatment, likely benefits, possible side effects and risks, alternative treatment options, why ECT is the recommended treatment, including the risk benefit analysis that has been undertaken by the treating psychiatrist. This information needs to be provided in a timely manner, in easy to understand language, in both a written and verbal format.

### **Section 9: Continuation, maintenance and outpatient ECT**

While not required under the Mental Health Act, NSW CAG considers that good practice would be ensuring the consumer's informed consent for each administration of ECT. This may be done verbally.

### **Section 11: Nursing and coordination requirements for ECT patients**

Clear direction is required as to how a nurse's competence in ECT will be assessed, including requirements for updating of skills and knowledge. This is important in ensuring quality care for consumers.

## **Policy Guidelines**

A component lacking within the guidelines is how the competence of nursing staff involved in ECT will be assessed. This is important in ensuring safe and quality treatment. It is recommended that minimum standards gauging such competence be included, including requirements for upgrading of skills and knowledge.

A further component absent from the guidelines pertains to the follow-up care of consumers who have received ECT, particularly after they may have been discharged from a service or having completed a course of ECT. Indeed, such guidelines are also relevant to those undergoing maintenance or continuation ECT. It is recommended that the Policy Guidelines include direction as to the minimum information that must be provided to a consumer's GP and/or care coordinator, and how often or when follow

up of cognitive tests should occur, particularly in cases where memory deficits are present.

### **Section 3: Consent and legal issues**

#### **Section 3.2: Informed consent**

Page 22 states

“The MHA [Mental Health Act] specifies that wherever a patient poses questions about ECT, the answers given to the question must “appear to have been understood”. It is not the general information provided which must appear to be understood, but the answer to the questions subsequently asked by the patient.”

NSW CAG is concerned that this statement exemplifies services of ensuring that the general information provided to consumers “appears to have been understood”. If the general information is not understood by consumers, they are unable to give informed consent. It is imperative that all information about any treatment modality, including ECT, is provided in clear language devoid of jargon, in a format appropriate for the individual (for example, written format is not always the most appropriate format for people who may have literacy difficulties, cognitive impairments, or difficulties with reading for other reasons such as medication influences), and in a language that the individual understands. It is also imperative that staff ensure that ALL information “appears to be understood” by the consumer.

For consumers who will be having involuntary ECT, it is also imperative that all information be provided to consumers prior to the administration of ECT, and that any questions they have are answered. The same stipulation that staff need to ensure that the information and answers to the questions “appear to have been understood” also needs to apply.

NSW CAG considers that best practice for ECT is the provision of information to the consumer upon each administration of ECT, and where the individual has been assessed as capable of giving informed consent, that this be sought for each administration. This may occur verbally.

#### **Section 3.3: ECT and the MHRT (Mental Health Review Tribunal)**

The document reads that a determination that a course of ECT will be administered to a consumer involuntarily must be made by the Mental Health Review Tribunal in situations when “the patient... is capable of giving informed consent to ECT but has refused...” (page 23).

While this is reflective of the Mental Health Act, NSW CAG is concerned that for someone who has been assessed as **capable** of giving informed consent, their decisions can be overturned. This is a violation of rights and poses concerns regarding the human rights of mental health consumers who may be on an

involuntary treatment order. Further exploration regarding this provision is required.

### **Section 5: Preparing the patient for ECT; Section 5.1: Pre-ECT work up**

It is recommended guidance be provided on how often throughout a single course of ECT the history, physical examination, baseline cognitive testing, relevant investigations, and consultations with other specialties should occur. This may be particularly relevant for maintenance and continuation ECT that may occur at periods of one month apart. It is also recommended that it be stipulated that such pre-ECT work up be conducted prior to each course of ECT.

NSW CAG further recommends that an additional sub-section be included regarding discussions with consumers, and where requested, family and carers, about the treatment. The information provided should cover all aspects, including the procedures for the treatment and for the day of treatment, likely benefits, possible side effects, alternative treatment options, why ECT is the recommended treatment. This information needs to be provided in a timely manner, in language that can be understood by the consumer, and in a suitable format.

### **Section 6: Administration of ECT; Section 6.8: Information for patients**

It is recommended that the information contained in appendices 1 and 2 be stated as the minimum information to be provided to consumers.

It is further recommended that the guidelines stipulate that all information be provided in a timely manner, in language that can be understood by the consumer, and in a suitable format.

### **Section 8: ECT in children and adolescents**

Given that there is minimal research regarding the effects, particularly long term effects of administering ECT to children and adolescents, it is recommended that the guidelines include minimum standards for ongoing follow up of children and adolescents administered ECT and the recording of this information.

### **Section 11: Nursing and coordinator requirements for ECT**

#### **Section 11.1: Provide emotional and educational support to the patient and family/carer**

It is recommended that the provision of honest information about all aspects of ECT be provided to consumers and their family or carer.

#### **Section 11.6: Role of the ECT coordinator**

The inclusion of the following within the table of possible activities and responsibilities of an ECT Coordinator is recommended:

- Informing consumers and their family or carer about all aspects of ECT
- Education of staff around informing consumers and their family or carer about all aspects of ECT
- Education of staff around ensuring informed consent

## **Appendices 1 and 2**

NSW CAG recommends some changes to the language used in the information documents suggested for use. We also recommend that the font be a minimum of 12 points to enable ease of reading. These recommendations are highlighted as tracked changes on the original appendices and are attached.

Please do not hesitate to contact me should you wish to discuss the recommendations presented.

Yours sincerely,

A handwritten signature in black ink, appearing to read 'K Oakley', with a large, sweeping flourish at the end.

Karen Oakley  
Executive Officer

## Appendices

Appendix 1: Information on ECT

Appendix 2: Information for patients going home on the same day of ECT treatment

## APPENDIX 1: INFORMATION ON ECT (Electroconvulsive Therapy)

**Comment [k1]:** Make all information at least size 12 font and in Arial type

This information sheet will try to answer some of the questions you may have about Electroconvulsive Therapy (ECT). Your psychiatrist will discuss with you why ECT has been recommended for you.

### What is ECT and why is it given?



ECT is a modern psychiatric treatment that is effective for a range of mental illnesses, including major depression, mania, some forms of schizophrenia and a small number of other mental and neurological disorders.

It might be used when medications have not worked or other forms of treatment are ineffective. It might also be used for people who have serious side effects from medications or whose medical condition means they can't take medications safely.

A general anaesthetic and muscle relaxant is given. When these have taken full effect, i.e. when you are asleep, a brief, carefully controlled electrical current is passed through the brain, causing a seizure. You will wake up after 5 to 10 minutes, much as you would from minor surgery.

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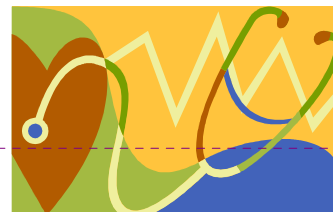
### How Does ECT Work?

A lot of research has been done into the changes that occur within the brain after ECT treatment. It is known that after ECT the activity levels of different parts of the brain are changed, hormones are released, and signalling between brain cells is modified. The latest research studies suggest that ECT may even result in the growth of new brain cells, possibly a process to "repair" impaired brain circuits that may be responsible for depression. There is no one accepted theory about how ECT works, leading some to claim that ECT is unscientific, or to reject it as a treatment. However, it is important to note that we know as much about how ECT works as about some other treatments in medicine, for example, anaesthesia.

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### When will your doctor order ECT treatment?

The decision to administer ECT is based on a thorough physical and psychiatric evaluation of the person, taking into account the type of illness, the degree of suffering, the expected result and the prognosis for the person if the treatment is not given. When the risk of suicide is high or when a seriously ill person is unable to eat or drink, ECT can be life-saving.



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### Prior to your treatment

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You must not eat or drink anything including water for at least 6 hours before the ECT treatment to make sure your stomach is empty. This is called 'fasting'. If you eat or drink anything within the fasting period, you must tell the nursing or medical staff before the treatment. Some medication might be given early on the morning of ECT treatment, but only with a tiny sip of water.

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### How is ECT given?

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- There is a less common risk of medical complications, such as irregular heart rate and rhythm. There might be a temporary rise in blood pressure and heart rate followed by a slowing of the heart rate.
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If you agree to have ECT, you will be asked to sign a form to say you have given informed consent. This means if you are able to give informed consent, you have the right to refuse ECT.

If you are incapable of giving informed consent, or if your health professionals consider that ECT treatment is potentially life saving, then your psychiatrist will seek consent on your behalf through the Mental Health Review Tribunal, even if you don't want the treatment.

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NSW Consumer Advisory Group – Mental Health Inc  
ABN 82 549 537 349

10<sup>th</sup> February 2010

Mr Carlton Quartly  
A/Manager Clinical Governance  
Mental Health and Drug and Alcohol Office  
NSW Health  
Locked Bag 961  
North Sydney NSW 2059

Email: [carlton.quartly@health.nsw.gov.au](mailto:carlton.quartly@health.nsw.gov.au)

Dear Carlton

**Re: Draft NSW Health Electroconvulsive Therapy (ECT) Standards**

Thank you for providing the NSW Consumer Advisory Group – Mental Health Inc. (NSW CAG) with the opportunity to comment on the Draft NSW Health Electroconvulsive Therapy Standards. NSW CAG is the peak, independent, state-wide organisation representing the views of mental health consumers at a policy level, working to achieve and support systemic change. Our vision is for all mental health consumers to experience fair access to quality services that reflect their needs.

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It is recommended that this section also includes preparation of the patient through the provision of information about the treatment, including the procedures for the treatment and for the day of treatment, likely benefits, possible side effects and risks, alternative treatment options, why ECT is the recommended treatment, including the risk benefit analysis that has been undertaken by the treating psychiatrist. This information needs to be provided in a timely manner, in easy to understand language, in both a written and verbal format.

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A further component absent from the guidelines pertains to the follow-up care of consumers who have received ECT, particularly after they may have been discharged from a service or having completed a course of ECT. Indeed, such guidelines are also relevant to those undergoing maintenance or continuation ECT. It is recommended that the Policy Guidelines include direction as to the minimum information that must be provided to a consumer's GP and/or care coordinator, and how often or when follow

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The document reads that a determination that a course of ECT will be administered to a consumer involuntarily must be made by the Mental Health Review Tribunal in situations when “the patient... is capable of giving informed consent to ECT but has refused...” (page 23).

While this is reflective of the Mental Health Act, NSW CAG is concerned that for someone who has been assessed as **capable** of giving informed consent, their decisions can be overturned. This is a violation of rights and poses concerns regarding the human rights of mental health consumers who may be on an

involuntary treatment order. Further exploration regarding this provision is required.

### **Section 5: Preparing the patient for ECT; Section 5.1: Pre-ECT work up**

It is recommended guidance be provided on how often throughout a single course of ECT the history, physical examination, baseline cognitive testing, relevant investigations, and consultations with other specialties should occur. This may be particularly relevant for maintenance and continuation ECT that may occur at periods of one month apart. It is also recommended that it be stipulated that such pre-ECT work up be conducted prior to each course of ECT.

NSW CAG further recommends that an additional sub-section be included regarding discussions with consumers, and where requested, family and carers, about the treatment. The information provided should cover all aspects, including the procedures for the treatment and for the day of treatment, likely benefits, possible side effects, alternative treatment options, why ECT is the recommended treatment. This information needs to be provided in a timely manner, in language that can be understood by the consumer, and in a suitable format.

### **Section 6: Administration of ECT; Section 6.8: Information for patients**

It is recommended that the information contained in appendices 1 and 2 be stated as the minimum information to be provided to consumers.

It is further recommended that the guidelines stipulate that all information be provided in a timely manner, in language that can be understood by the consumer, and in a suitable format.

### **Section 8: ECT in children and adolescents**

Given that there is minimal research regarding the effects, particularly long term effects of administering ECT to children and adolescents, it is recommended that the guidelines include minimum standards for ongoing follow up of children and adolescents administered ECT and the recording of this information.

### **Section 11: Nursing and coordinator requirements for ECT**

#### **Section 11.1: Provide emotional and educational support to the patient and family/carer**

It is recommended that the provision of honest information about all aspects of ECT be provided to consumers and their family or carer.

#### **Section 11.6: Role of the ECT coordinator**

The inclusion of the following within the table of possible activities and responsibilities of an ECT Coordinator is recommended:

- Informing consumers and their family or carer about all aspects of ECT
- Education of staff around informing consumers and their family or carer about all aspects of ECT
- Education of staff around ensuring informed consent

## **Appendices 1 and 2**

NSW CAG recommends some changes to the language used in the information documents suggested for use. We also recommend that the font be a minimum of 12 points to enable ease of reading. These recommendations are highlighted as tracked changes on the original appendices and are attached.

Please do not hesitate to contact me should you wish to discuss the recommendations presented.

Yours sincerely,

A handwritten signature in black ink, appearing to read 'K Oakley', with a large, sweeping flourish at the end.

Karen Oakley  
Executive Officer

## Appendices

Appendix 1: Information on ECT

Appendix 2: Information for patients going home on the same day of ECT treatment

## APPENDIX 1: INFORMATION ON ECT (Electroconvulsive Therapy)

**Comment [k1]:** Make all information at least size 12 font and in Arial type

This information sheet will try to answer some of the questions you may have about Electroconvulsive Therapy (ECT). Your psychiatrist will discuss with you why ECT has been recommended for you.

### What is ECT and why is it given?



ECT is a modern psychiatric treatment that is effective for a range of mental illnesses, including major depression, mania, some forms of schizophrenia and a small number of other mental and neurological disorders.

It might be used when medications have not worked or other forms of treatment are ineffective. It might also be used for people who have serious side effects from medications or whose medical condition means they can't take medications safely.

A general anaesthetic and muscle relaxant is given. When these have taken full effect, i.e. when you are asleep, a brief, carefully controlled electrical current is passed through the brain, causing a seizure. You will wake up after 5 to 10 minutes, much as you would from minor surgery.

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ECT usually consists of 6 to 12 treatments given 2 to 3 times a week over about a month. The total number of treatments needed to get a person better varies between individuals and your psychiatrist will discuss with you how many treatments you are likely to need. While most people show some improvement after 3 to 4 sessions, it takes on average 9 treatments to achieve recovery and some patients may need more than 12 treatments.

There is evidence that ECT is effective in improving depressive and psychotic symptoms. Approximately 8 out of 10 patients who undergo ECT will experience dramatic improvement.

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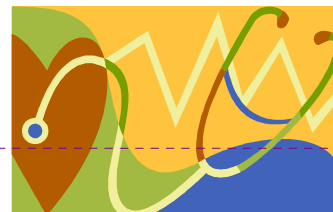
### How Does ECT Work?

A lot of research has been done into the changes that occur within the brain after ECT treatment. It is known that after ECT the activity levels of different parts of the brain are changed, hormones are released, and signalling between brain cells is modified. The latest research studies suggest that ECT may even result in the growth of new brain cells, possibly a process to "repair" impaired brain circuits that may be responsible for depression. There is no one accepted theory about how ECT works, leading some to claim that ECT is unscientific, or to reject it as a treatment. However, it is important to note that we know as much about how ECT works as about some other treatments in medicine, for example, anaesthesia.

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### When will your doctor order ECT treatment?

The decision to administer ECT is based on a thorough physical and psychiatric evaluation of the person, taking into account the type of illness, the degree of suffering, the expected result and the prognosis for the person if the treatment is not given. When the risk of suicide is high or when a seriously ill person is unable to eat or drink, ECT can be life-saving.



**Comment [k3]:** Use a more lay person's term such as expectation of outcomes over a long period

### Prior to your treatment

Before your first ECT treatment, you will be examined to make sure you are fit to have a short general anaesthetic and ECT.

You must not eat or drink anything including water for at least 6 hours before the ECT treatment to make sure your stomach is empty. This is called 'fasting'. If you eat or drink anything within the fasting period, you must tell the nursing or medical staff before the treatment. Some medication might be given early on the morning of ECT treatment, but only with a tiny sip of water.

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### How is ECT given?

In the operating theatre of the hospital the staff will attach the following to you:



- Blood pressure cuff on your arm or leg or both
- Small clip over one of your fingers to check heart rate (pulse) and oxygen levels in your blood
- Small stick-on electrodes on your forehead and behind your ears to record the brain's electrical activity during the treatment
- Face mask over your nose and mouth to give you oxygen. This is to prepare your body and brain for the extra activity that will happen briefly with the treatment.

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**Comment [k4]:** This is a medical term – need to explain in lay person's term

You will have a short general anaesthetic so that you will be asleep and not feel or remember the treatment. The anaesthetic medication will be injected into a vein to make it work quickly and well. An anaesthetist will be present and give the anaesthetic. You will also be given a medicine to relax your muscles. You won't feel the convulsion because of the anaesthetic, and any muscle movement during ECT will be limited because of the medication relaxing the muscles.

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A doctor who has specialised training in ECT will administer the treatment. The doctor puts small electrodes on your scalp and passes a measured amount of electricity to a part of the brain to cause a seizure (fit). Depending on the patient and their condition, one or both sides of the head will be stimulated, known as unilateral or bilateral ECT respectively. The seizure will last up to two minutes.



During the treatment, the anaesthetist will continue to give you oxygen through the face mask and monitor your heart rate and oxygen level. The anaesthetist will give you any medications necessary to adjust your heart rate etc during and after the treatment.

You will not feel or remember any of the actual treatment because you will be asleep due to the anaesthetic medication. Within a few minutes after the treatment, the anaesthetic will have worn off and you will wake up. During this time, you will be moved to the recovery room where you will be looked after until you are awake enough to return to your ward. If you are having day procedure ECT, you might need to wait in the recovery room or a ward for up to several hours to make sure you are ready to go home. After you wake up, the anaesthetic medication and the treatment/seizure will make you groggy for a while.

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### Is it safe? What are the benefits of ECT? What about side-effects?

ECT is regarded as a very safe treatment. Research has shown that ECT doesn't cause brain damage or changes in personality because the amount of electricity used is too small to harm tissue.

Your psychiatrist will discuss with you the expected benefits of ECT. These will vary depending on the nature and seriousness of your illness, but ECT will generally improve your ability to think and return your emotions to a healthier state.

All treatments have risks and side effects—even no treatment has risks.

The risks and side effects of ECT include:

- Side effects from the anaesthetic, such as headache, nausea (feeling sick in the stomach) or queasiness, vomiting. You should tell the staff looking after you and they will be able to give you some medication to help.

- You might get muscle soreness after the ECT as a result of the medication to relax the muscles.
  - The anaesthetic will affect your judgment for the first 24 hours. During this time you must not:



- Drive any type of vehicle
- Operate machinery, including cooking implements
- Make important decisions or sign a legal document
- Drink alcohol, take other mind-altering substances or smoke because they might react with the anaesthetic medication.

- A common and significant side-effect is confusion and memory impairment.

- Many people report difficulty with memory which usually clears up shortly after the end of treatment. For some it may last for a while longer (eg weeks to months) but improves with time.
- Immediately after ECT most people have a short period of confusion and do not remember the actual treatment.
- Over the course of ECT, it might be more difficult to remember newly learned information, eg events that occurred during the weeks you were having ECT.
- Some people also report a patchy loss of memory of events that occurred during the days, weeks and months before the ECT. Memory for recent events, dates, names of friends etc. may not be as good. In most patients the memory problems go away over the days, weeks or months following completion of the course of ECT. Sometimes, but not often, there may be permanent loss of isolated memories from your past.
- Many people will find that their memories are somewhat unclear for the time that they were ill. The same problem is often experienced by people with depression who do not receive ECT.
- Although specific memories from around the time you had ECT might not return, your overall memory should work better in the weeks to months after treatment. Many patients report that their memory improved after a course of ECT.

- Some other side effects are less common and some are extremely rare:

- There is a less common risk of medical complications, such as irregular heart rate and rhythm. There might be a temporary rise in blood pressure and heart rate followed by a slowing of the heart rate.
- As with any general anaesthetic, there is a very small risk of death, but with modern ECT and a short anaesthetic, this risk is now extremely rare. No case of death associated with anaesthesia for ECT has been recorded in New South Wales for more than 25 years.
- Heart attack, stroke or injury related to muscle spasms are also extremely rare.
- Resuscitation equipment and emergency procedures are immediately available if anything should go wrong.

- What are the alternative treatments?

- Talk to your psychiatrist about what other treatments may be offered instead of ECT

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## Giving permission for ECT

Just as with any medical procedure, it is required that informed consent for ECT be obtained in writing. Informed consent is when you agree to have ECT after you have been told what ECT involves, including

- a full explanation of the ECT procedure,
- how it works,
- how it can help your illness,
- possible side effects, discomforts and risks of ECT and
- any beneficial alternative treatments.



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You have the right to discuss your views about ECT with your psychiatrist and ask any questions about it.

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You also have the right to:

- Obtain medical and legal advice
- Obtain a second opinion from a psychiatrist about the ECT. Your psychiatrist can arrange a second opinion from within the mental health service.
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ABN 82 549 537 349

10<sup>th</sup> February 2010

Mr Carlton Quartly  
A/Manager Clinical Governance  
Mental Health and Drug and Alcohol Office  
NSW Health  
Locked Bag 961  
North Sydney NSW 2059

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It is recommended that the information contained in appendices 1 and 2 be stated as the minimum information to be provided to consumers.

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The inclusion of the following within the table of possible activities and responsibilities of an ECT Coordinator is recommended:

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- Education of staff around informing consumers and their family or carer about all aspects of ECT
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## **Appendices 1 and 2**

NSW CAG recommends some changes to the language used in the information documents suggested for use. We also recommend that the font be a minimum of 12 points to enable ease of reading. These recommendations are highlighted as tracked changes on the original appendices and are attached.

Please do not hesitate to contact me should you wish to discuss the recommendations presented.

Yours sincerely,



Karen Oakley  
Executive Officer

## Appendices

Appendix 1: Information on ECT

Appendix 2: Information for patients going home on the same day of ECT treatment

## APPENDIX 1: INFORMATION ON ECT (Electroconvulsive Therapy)

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This information sheet will try to answer some of the questions you may have about Electroconvulsive Therapy (ECT). Your psychiatrist will discuss with you why ECT has been recommended for you.

### What is ECT and why is it given?



ECT is a modern psychiatric treatment that is effective for a range of mental illnesses, including major depression, mania, some forms of schizophrenia and a small number of other mental and neurological disorders.

It might be used when medications have not worked or other forms of treatment are ineffective. It might also be used for people who have serious side effects from medications or whose medical condition means they can't take medications safely.

A general anaesthetic and muscle relaxant is given. When these have taken full effect, i.e. when you are asleep, a brief, carefully controlled electrical current is passed through the brain, causing a seizure. You will wake up after 5 to 10 minutes, much as you would from minor surgery.

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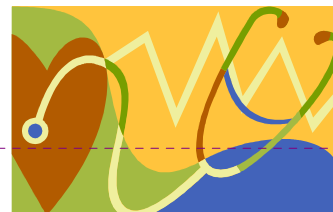
### How Does ECT Work?

A lot of research has been done into the changes that occur within the brain after ECT treatment. It is known that after ECT the activity levels of different parts of the brain are changed, hormones are released, and signalling between brain cells is modified. The latest research studies suggest that ECT may even result in the growth of new brain cells, possibly a process to "repair" impaired brain circuits that may be responsible for depression. There is no one accepted theory about how ECT works, leading some to claim that ECT is unscientific, or to reject it as a treatment. However, it is important to note that we know as much about how ECT works as about some other treatments in medicine, for example, anaesthesia.

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### When will your doctor order ECT treatment?

The decision to administer ECT is based on a thorough physical and psychiatric evaluation of the person, taking into account the type of illness, the degree of suffering, the expected result and the prognosis for the person if the treatment is not given. When the risk of suicide is high or when a seriously ill person is unable to eat or drink, ECT can be life-saving.



**Comment [k3]:** Use a more lay person's term such as expectation of outcomes over a long period

### Prior to your treatment

Before your first ECT treatment, you will be examined to make sure you are fit to have a short general anaesthetic and ECT.

You must not eat or drink anything including water for at least 6 hours before the ECT treatment to make sure your stomach is empty. This is called 'fasting'. If you eat or drink anything within the fasting period, you must tell the nursing or medical staff before the treatment. Some medication might be given early on the morning of ECT treatment, but only with a tiny sip of water.

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### How is ECT given?

In the operating theatre of the hospital the staff will attach the following to you:



- Blood pressure cuff on your arm or leg or both
- Small clip over one of your fingers to check heart rate (pulse) and oxygen levels in your blood
- Small stick-on electrodes on your forehead and behind your ears to record the brain's electrical activity during the treatment
- Face mask over your nose and mouth to give you oxygen. This is to prepare your body and brain for the extra activity that will happen briefly with the treatment.

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You will have a short general anaesthetic so that you will be asleep and not feel or remember the treatment. The anaesthetic medication will be injected into a vein to make it work quickly and well. An anaesthetist will be present and give the anaesthetic. You will also be given a medicine to relax your muscles. You won't feel the convulsion because of the anaesthetic, and any muscle movement during ECT will be limited because of the medication relaxing the muscles.

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A doctor who has specialised training in ECT will administer the treatment. The doctor puts small electrodes on your scalp and passes a measured amount of electricity to a part of the brain to cause a seizure (fit). Depending on the patient and their condition, one or both sides of the head will be stimulated, known as unilateral or bilateral ECT respectively. The seizure will last up to two minutes.



During the treatment, the anaesthetist will continue to give you oxygen through the face mask and monitor your heart rate and oxygen level. The anaesthetist will give you any medications necessary to adjust your heart rate etc during and after the treatment.

You will not feel or remember any of the actual treatment because you will be asleep due to the anaesthetic medication. Within a few minutes after the treatment, the anaesthetic will have worn off and you will wake up. During this time, you will be moved to the recovery room where you will be looked after until you are awake enough to return to your ward. If you are having day procedure ECT, you might need to wait in the recovery room or a ward for up to several hours to make sure you are ready to go home. After you wake up, the anaesthetic medication and the treatment/seizure will make you groggy for a while.

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### Is it safe? What are the benefits of ECT? What about side-effects?

ECT is regarded as a very safe treatment. Research has shown that ECT doesn't cause brain damage or changes in personality because the amount of electricity used is too small to harm tissue.

Your psychiatrist will discuss with you the expected benefits of ECT. These will vary depending on the nature and seriousness of your illness, but ECT will generally improve your ability to think and return your emotions to a healthier state.

All treatments have risks and side effects—even no treatment has risks.

The risks and side effects of ECT include:

- Side effects from the anaesthetic, such as headache, nausea (feeling sick in the stomach) or queasiness, vomiting. You should tell the staff looking after you and they will be able to give you some medication to help.

- You might get muscle soreness after the ECT as a result of the medication to relax the muscles.
  - The anaesthetic will affect your judgment for the first 24 hours. During this time you must not:



- Drive any type of vehicle
- Operate machinery, including cooking implements
- Make important decisions or sign a legal document
- Drink alcohol, take other mind-altering substances or smoke because they might react with the anaesthetic medication.

- A common and significant side-effect is confusion and memory impairment.

- Many people report difficulty with memory which usually clears up shortly after the end of treatment. For some it may last for a while longer (eg weeks to months) but improves with time.
- Immediately after ECT most people have a short period of confusion and do not remember the actual treatment.
- Over the course of ECT, it might be more difficult to remember newly learned information, eg events that occurred during the weeks you were having ECT.
- Some people also report a patchy loss of memory of events that occurred during the days, weeks and months before the ECT. Memory for recent events, dates, names of friends etc. may not be as good. In most patients the memory problems go away over the days, weeks or months following completion of the course of ECT. Sometimes, but not often, there may be permanent loss of isolated memories from your past.
- Many people will find that their memories are somewhat unclear for the time that they were ill. The same problem is often experienced by people with depression who do not receive ECT.
- Although specific memories from around the time you had ECT might not return, your overall memory should work better in the weeks to months after treatment. Many patients report that their memory improved after a course of ECT.

- Some other side effects are less common and some are extremely rare:

- There is a less common risk of medical complications, such as irregular heart rate and rhythm. There might be a temporary rise in blood pressure and heart rate followed by a slowing of the heart rate.
- As with any general anaesthetic, there is a very small risk of death, but with modern ECT and a short anaesthetic, this risk is now extremely rare. No case of death associated with anaesthesia for ECT has been recorded in New South Wales for more than 25 years.
- Heart attack, stroke or injury related to muscle spasms are also extremely rare.
- Resuscitation equipment and emergency procedures are immediately available if anything should go wrong.

- What are the alternative treatments?

- Talk to your psychiatrist about what other treatments may be offered instead of ECT

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## Giving permission for ECT

Just as with any medical procedure, it is required that informed consent for ECT be obtained in writing. Informed consent is when you agree to have ECT after you have been told what ECT involves, including

- a full explanation of the ECT procedure,
- how it works,
- how it can help your illness,
- possible side effects, discomforts and risks of ECT and
- any beneficial alternative treatments.



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You have the right to discuss your views about ECT with your psychiatrist and ask any questions about it.

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You also have the right to:

- Obtain medical and legal advice
- Obtain a second opinion from a psychiatrist about the ECT. Your psychiatrist can arrange a second opinion from within the mental health service.
- Have a friend, family member, lawyer or an advocate represent you before you consent to ECT

Comment [k7]: May also be useful to provide reference to the ability to do some advanced planning about having ECT or about having an agreement with a person to make decisions for the person while they are having ECT and judgement may be affected

If you agree to have ECT, you will be asked to sign a form to say you have given informed consent. This means if you are able to give informed consent, you have the right to refuse ECT.

If you are incapable of giving informed consent, or if your health professionals consider that ECT treatment is potentially life saving, then your psychiatrist will seek consent on your behalf through the Mental Health Review Tribunal, even if you don't want the treatment.

Comment [k8]: Need to explain how this would be determined

The Mental Health Review Tribunal becomes involved in decisions about ECT when the hospital:

- is uncertain of a voluntary patient's capacity to give consent to treatment with ECT; and
- proposes ECT for an involuntary patient.

Your psychiatrist must do everything reasonably practicable to give notice to your nearest relative, guardian or personal friends about the application for ECT. The Mental Health Review Tribunal will make the decision as to whether or not you are to be treated with ECT.

If you agree to have ECT, but then change your mind, it is your right to withdraw your consent at **any time** and the treatments will be stopped, unless your psychiatrist believes you are unable to give informed consent. If you want to withdraw your consent, you should talk to your psychiatrist. Remember that you can have a friend, a family member, a lawyer or an advocate with you for support or to represent you.

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## Will I need further treatment?

While your illness might be treated with a course of ECT, the illness might come back once the course is finished. Some people need occasional continued ECT treatment, spread-out from around once a week to once a month. To help prevent relapse, your doctor will discuss with you any further treatment you might need after the course of ECT ends, such as medication, maintenance ECT, psychotherapy, counselling and / or rehabilitation.



## References

SANE ECT Information Sheet: <http://www.sane.org/information/factsheets>

Better Health Channel ECT Information Sheet: <http://www.betterhealth.vic.gov.au>

Victorian Government Health Information: <http://www.health.vic.gov.au>

## APPENDIX 2:

### INFORMATION FOR PATIENTS GOING HOME ON THE SAME DAY OF ECT TREATMENT

The following information may assist you in your recovery from your ECT treatment today.

#### **BEFORE LEAVING THE MENTAL HEALTH UNIT**

After your treatment you will be returned to the ward where you must stay for 4 hours to ensure you are well enough to go home following the anaesthetic.

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The nursing staff will ensure you see a doctor before leaving the ward.

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You will be given an appointment card with the date of your next treatment.

#### **WHAT TO EXPECT AFTER ECT TREATMENT**

◆ The anaesthetic will affect your judgment and you may feel a little light headed, slower to react or sleepy for the next 24 hours. During the 24 hours after ECT treatment you **MUST NOT**:

- Drive any type of vehicle (therefore, someone will need to pick you up from hospital)
- Operate machinery, including cooking implements
- Make important decisions or sign a legal document
- Drink alcohol, take other mind-altering substances or smoke because they might react with the anaesthetic medication
- Engage in heavy work or strenuous activities.



◆ Managing side effects from ECT treatment & the anaesthetic

- Side effects from the ECT treatment may include headache. You may take medication such as paracetamol for a headache as directed by your doctor.
- Side effects from the anaesthetic may include nausea, queasiness (feeling sick in the stomach) or vomiting. A light diet is recommended after an anaesthetic. If you are experiencing nausea or vomiting, do not eat solid food and drink clear fluids only. Should nausea, vomiting continue tomorrow, contact your local doctor.

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NSW Consumer Advisory Group – Mental Health Inc  
ABN 82 549 537 349

10<sup>th</sup> February 2010

Mr Carlton Quartly  
A/Manager Clinical Governance  
Mental Health and Drug and Alcohol Office  
NSW Health  
Locked Bag 961  
North Sydney NSW 2059

Email: [carlton.quartly@health.nsw.gov.au](mailto:carlton.quartly@health.nsw.gov.au)

Dear Carlton

**Re: Draft NSW Health Electroconvulsive Therapy (ECT) Standards**

Thank you for providing the NSW Consumer Advisory Group – Mental Health Inc. (NSW CAG) with the opportunity to comment on the Draft NSW Health Electroconvulsive Therapy Standards. NSW CAG is the peak, independent, state-wide organisation representing the views of mental health consumers at a policy level, working to achieve and support systemic change. Our vision is for all mental health consumers to experience fair access to quality services that reflect their needs.

Our main comments below identify issues surrounding informed consent, the provision of information about ECT to consumers, and the credentialing of staff coordinating ECT, in order to ensure consumer safety and the provision of quality efficacious treatment. It should be noted that given the timeframes for the response, NSW CAG has not been able to consult with our network around the Standards and attached documents. Our response is therefore informed by our work with consumers over the past 17 years.

While appreciating the focus on the clinical practice of ECT for the standards, NSW CAG is concerned that consumers were not involved in the development of these standards at an earlier stage. Consumer involvement would particularly have been useful to inform the components around which comment will be made within this letter. It is strongly recommended that earlier consumer involvement in all initiatives, including those around clinical practice, is ensured in the future.

Broadly, the Policy and Guidelines are based on solid evidence surrounding best practice for ECT. The implementation of these documents will ensure a more

consistent approach to the practice of ECT that will also ensure a higher quality of treatment for mental health consumers. Our recommendations for consideration within the Policy and Guidelines are presented in relation to the sections of the Policy and Guidelines.

## **Policy Statement**

### **Section 3: Consent and legal issues**

While not required under the Mental Health Act, NSW CAG considers that good practice would be ensuring the consumer's informed consent for each administration of ECT. This may be done verbally.

### **Section 5: Preparing the patient for ECT**

It is recommended that this section also includes preparation of the patient through the provision of information about the treatment, including the procedures for the treatment and for the day of treatment, likely benefits, possible side effects and risks, alternative treatment options, why ECT is the recommended treatment, including the risk benefit analysis that has been undertaken by the treating psychiatrist. This information needs to be provided in a timely manner, in easy to understand language, in both a written and verbal format.

### **Section 9: Continuation, maintenance and outpatient ECT**

While not required under the Mental Health Act, NSW CAG considers that good practice would be ensuring the consumer's informed consent for each administration of ECT. This may be done verbally.

### **Section 11: Nursing and coordination requirements for ECT patients**

Clear direction is required as to how a nurse's competence in ECT will be assessed, including requirements for updating of skills and knowledge. This is important in ensuring quality care for consumers.

## **Policy Guidelines**

A component lacking within the guidelines is how the competence of nursing staff involved in ECT will be assessed. This is important in ensuring safe and quality treatment. It is recommended that minimum standards gauging such competence be included, including requirements for upgrading of skills and knowledge.

A further component absent from the guidelines pertains to the follow-up care of consumers who have received ECT, particularly after they may have been discharged from a service or having completed a course of ECT. Indeed, such guidelines are also relevant to those undergoing maintenance or continuation ECT. It is recommended that the Policy Guidelines include direction as to the minimum information that must be provided to a consumer's GP and/or care coordinator, and how often or when follow

up of cognitive tests should occur, particularly in cases where memory deficits are present.

### **Section 3: Consent and legal issues**

#### **Section 3.2: Informed consent**

Page 22 states

“The MHA [Mental Health Act] specifies that wherever a patient poses questions about ECT, the answers given to the question must “appear to have been understood”. It is not the general information provided which must appear to be understood, but the answer to the questions subsequently asked by the patient.”

NSW CAG is concerned that this statement exemplifies services of ensuring that the general information provided to consumers “appears to have been understood”. If the general information is not understood by consumers, they are unable to give informed consent. It is imperative that all information about any treatment modality, including ECT, is provided in clear language devoid of jargon, in a format appropriate for the individual (for example, written format is not always the most appropriate format for people who may have literacy difficulties, cognitive impairments, or difficulties with reading for other reasons such as medication influences), and in a language that the individual understands. It is also imperative that staff ensure that ALL information “appears to be understood” by the consumer.

For consumers who will be having involuntary ECT, it is also imperative that all information be provided to consumers prior to the administration of ECT, and that any questions they have are answered. The same stipulation that staff need to ensure that the information and answers to the questions “appear to have been understood” also needs to apply.

NSW CAG considers that best practice for ECT is the provision of information to the consumer upon each administration of ECT, and where the individual has been assessed as capable of giving informed consent, that this be sought for each administration. This may occur verbally.

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The document reads that a determination that a course of ECT will be administered to a consumer involuntarily must be made by the Mental Health Review Tribunal in situations when “the patient... is capable of giving informed consent to ECT but has refused...” (page 23).

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Yours sincerely,

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Karen Oakley  
Executive Officer

## Appendices

Appendix 1: Information on ECT

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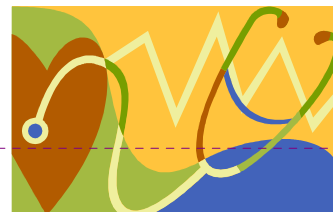
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During the treatment, the anaesthetist will continue to give you oxygen through the face mask and monitor your heart rate and oxygen level. The anaesthetist will give you any medications necessary to adjust your heart rate etc during and after the treatment.

You will not feel or remember any of the actual treatment because you will be asleep due to the anaesthetic medication. Within a few minutes after the treatment, the anaesthetic will have worn off and you will wake up. During this time, you will be moved to the recovery room where you will be looked after until you are awake enough to return to your ward. If you are having day procedure ECT, you might need to wait in the recovery room or a ward for up to several hours to make sure you are ready to go home. After you wake up, the anaesthetic medication and the treatment/seizure will make you groggy for a while.

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ECT is regarded as a very safe treatment. Research has shown that ECT doesn't cause brain damage or changes in personality because the amount of electricity used is too small to harm tissue.

Your psychiatrist will discuss with you the expected benefits of ECT. These will vary depending on the nature and seriousness of your illness, but ECT will generally improve your ability to think and return your emotions to a healthier state.

All treatments have risks and side effects—even no treatment has risks.

The risks and side effects of ECT include:

- Side effects from the anaesthetic, such as headache, nausea (feeling sick in the stomach) or queasiness, vomiting. You should tell the staff looking after you and they will be able to give you some medication to help.

- You might get muscle soreness after the ECT as a result of the medication to relax the muscles.
  - The anaesthetic will affect your judgment for the first 24 hours. During this time you must not:



- Drive any type of vehicle
- Operate machinery, including cooking implements
- Make important decisions or sign a legal document
- Drink alcohol, take other mind-altering substances or smoke because they might react with the anaesthetic medication.

- A common and significant side-effect is confusion and memory impairment.

- Many people report difficulty with memory which usually clears up shortly after the end of treatment. For some it may last for a while longer (eg weeks to months) but improves with time.
- Immediately after ECT most people have a short period of confusion and do not remember the actual treatment.
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- Some people also report a patchy loss of memory of events that occurred during the days, weeks and months before the ECT. Memory for recent events, dates, names of friends etc. may not be as good. In most patients the memory problems go away over the days, weeks or months following completion of the course of ECT. Sometimes, but not often, there may be permanent loss of isolated memories from your past.
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If you are incapable of giving informed consent, or if your health professionals consider that ECT treatment is potentially life saving, then your psychiatrist will seek consent on your behalf through the Mental Health Review Tribunal, even if you don't want the treatment.

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While your illness might be treated with a course of ECT, the illness might come back once the course is finished. Some people need occasional continued ECT treatment, spread-out from around once a week to once a month. To help prevent relapse, your doctor will discuss with you any further treatment you might need after the course of ECT ends, such as medication, maintenance ECT, psychotherapy, counselling and / or rehabilitation.



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NSW Consumer Advisory Group – Mental Health Inc  
ABN 82 549 537 349

10<sup>th</sup> February 2010

Mr Carlton Quartly  
A/Manager Clinical Governance  
Mental Health and Drug and Alcohol Office  
NSW Health  
Locked Bag 961  
North Sydney NSW 2059

Email: [carlton.quartly@health.nsw.gov.au](mailto:carlton.quartly@health.nsw.gov.au)

Dear Carlton

**Re: Draft NSW Health Electroconvulsive Therapy (ECT) Standards**

Thank you for providing the NSW Consumer Advisory Group – Mental Health Inc. (NSW CAG) with the opportunity to comment on the Draft NSW Health Electroconvulsive Therapy Standards. NSW CAG is the peak, independent, state-wide organisation representing the views of mental health consumers at a policy level, working to achieve and support systemic change. Our vision is for all mental health consumers to experience fair access to quality services that reflect their needs.

Our main comments below identify issues surrounding informed consent, the provision of information about ECT to consumers, and the credentialing of staff coordinating ECT, in order to ensure consumer safety and the provision of quality efficacious treatment. It should be noted that given the timeframes for the response, NSW CAG has not been able to consult with our network around the Standards and attached documents. Our response is therefore informed by our work with consumers over the past 17 years.

While appreciating the focus on the clinical practice of ECT for the standards, NSW CAG is concerned that consumers were not involved in the development of these standards at an earlier stage. Consumer involvement would particularly have been useful to inform the components around which comment will be made within this letter. It is strongly recommended that earlier consumer involvement in all initiatives, including those around clinical practice, is ensured in the future.

Broadly, the Policy and Guidelines are based on solid evidence surrounding best practice for ECT. The implementation of these documents will ensure a more

consistent approach to the practice of ECT that will also ensure a higher quality of treatment for mental health consumers. Our recommendations for consideration within the Policy and Guidelines are presented in relation to the sections of the Policy and Guidelines.

## **Policy Statement**

### **Section 3: Consent and legal issues**

While not required under the Mental Health Act, NSW CAG considers that good practice would be ensuring the consumer's informed consent for each administration of ECT. This may be done verbally.

### **Section 5: Preparing the patient for ECT**

It is recommended that this section also includes preparation of the patient through the provision of information about the treatment, including the procedures for the treatment and for the day of treatment, likely benefits, possible side effects and risks, alternative treatment options, why ECT is the recommended treatment, including the risk benefit analysis that has been undertaken by the treating psychiatrist. This information needs to be provided in a timely manner, in easy to understand language, in both a written and verbal format.

### **Section 9: Continuation, maintenance and outpatient ECT**

While not required under the Mental Health Act, NSW CAG considers that good practice would be ensuring the consumer's informed consent for each administration of ECT. This may be done verbally.

### **Section 11: Nursing and coordination requirements for ECT patients**

Clear direction is required as to how a nurse's competence in ECT will be assessed, including requirements for updating of skills and knowledge. This is important in ensuring quality care for consumers.

## **Policy Guidelines**

A component lacking within the guidelines is how the competence of nursing staff involved in ECT will be assessed. This is important in ensuring safe and quality treatment. It is recommended that minimum standards gauging such competence be included, including requirements for upgrading of skills and knowledge.

A further component absent from the guidelines pertains to the follow-up care of consumers who have received ECT, particularly after they may have been discharged from a service or having completed a course of ECT. Indeed, such guidelines are also relevant to those undergoing maintenance or continuation ECT. It is recommended that the Policy Guidelines include direction as to the minimum information that must be provided to a consumer's GP and/or care coordinator, and how often or when follow

up of cognitive tests should occur, particularly in cases where memory deficits are present.

### **Section 3: Consent and legal issues**

#### **Section 3.2: Informed consent**

Page 22 states

“The MHA [Mental Health Act] specifies that wherever a patient poses questions about ECT, the answers given to the question must “appear to have been understood”. It is not the general information provided which must appear to be understood, but the answer to the questions subsequently asked by the patient.”

NSW CAG is concerned that this statement exemplifies services of ensuring that the general information provided to consumers “appears to have been understood”. If the general information is not understood by consumers, they are unable to give informed consent. It is imperative that all information about any treatment modality, including ECT, is provided in clear language devoid of jargon, in a format appropriate for the individual (for example, written format is not always the most appropriate format for people who may have literacy difficulties, cognitive impairments, or difficulties with reading for other reasons such as medication influences), and in a language that the individual understands. It is also imperative that staff ensure that ALL information “appears to be understood” by the consumer.

For consumers who will be having involuntary ECT, it is also imperative that all information be provided to consumers prior to the administration of ECT, and that any questions they have are answered. The same stipulation that staff need to ensure that the information and answers to the questions “appear to have been understood” also needs to apply.

NSW CAG considers that best practice for ECT is the provision of information to the consumer upon each administration of ECT, and where the individual has been assessed as capable of giving informed consent, that this be sought for each administration. This may occur verbally.

#### **Section 3.3: ECT and the MHRT (Mental Health Review Tribunal)**

The document reads that a determination that a course of ECT will be administered to a consumer involuntarily must be made by the Mental Health Review Tribunal in situations when “the patient... is capable of giving informed consent to ECT but has refused...” (page 23).

While this is reflective of the Mental Health Act, NSW CAG is concerned that for someone who has been assessed as **capable** of giving informed consent, their decisions can be overturned. This is a violation of rights and poses concerns regarding the human rights of mental health consumers who may be on an

involuntary treatment order. Further exploration regarding this provision is required.

### **Section 5: Preparing the patient for ECT; Section 5.1: Pre-ECT work up**

It is recommended guidance be provided on how often throughout a single course of ECT the history, physical examination, baseline cognitive testing, relevant investigations, and consultations with other specialties should occur. This may be particularly relevant for maintenance and continuation ECT that may occur at periods of one month apart. It is also recommended that it be stipulated that such pre-ECT work up be conducted prior to each course of ECT.

NSW CAG further recommends that an additional sub-section be included regarding discussions with consumers, and where requested, family and carers, about the treatment. The information provided should cover all aspects, including the procedures for the treatment and for the day of treatment, likely benefits, possible side effects, alternative treatment options, why ECT is the recommended treatment. This information needs to be provided in a timely manner, in language that can be understood by the consumer, and in a suitable format.

### **Section 6: Administration of ECT; Section 6.8: Information for patients**

It is recommended that the information contained in appendices 1 and 2 be stated as the minimum information to be provided to consumers.

It is further recommended that the guidelines stipulate that all information be provided in a timely manner, in language that can be understood by the consumer, and in a suitable format.

### **Section 8: ECT in children and adolescents**

Given that there is minimal research regarding the effects, particularly long term effects of administering ECT to children and adolescents, it is recommended that the guidelines include minimum standards for ongoing follow up of children and adolescents administered ECT and the recording of this information.

### **Section 11: Nursing and coordinator requirements for ECT**

#### **Section 11.1: Provide emotional and educational support to the patient and family/carer**

It is recommended that the provision of honest information about all aspects of ECT be provided to consumers and their family or carer.

#### **Section 11.6: Role of the ECT coordinator**

The inclusion of the following within the table of possible activities and responsibilities of an ECT Coordinator is recommended:

- Informing consumers and their family or carer about all aspects of ECT
- Education of staff around informing consumers and their family or carer about all aspects of ECT
- Education of staff around ensuring informed consent

## **Appendices 1 and 2**

NSW CAG recommends some changes to the language used in the information documents suggested for use. We also recommend that the font be a minimum of 12 points to enable ease of reading. These recommendations are highlighted as tracked changes on the original appendices and are attached.

Please do not hesitate to contact me should you wish to discuss the recommendations presented.

Yours sincerely,



Karen Oakley  
Executive Officer

## Appendices

Appendix 1: Information on ECT

Appendix 2: Information for patients going home on the same day of ECT treatment

## APPENDIX 1: INFORMATION ON ECT (Electroconvulsive Therapy)

**Comment [k1]:** Make all information at least size 12 font and in Arial type

This information sheet will try to answer some of the questions you may have about Electroconvulsive Therapy (ECT). Your psychiatrist will discuss with you why ECT has been recommended for you.

### What is ECT and why is it given?



ECT is a modern psychiatric treatment that is effective for a range of mental illnesses, including major depression, mania, some forms of schizophrenia and a small number of other mental and neurological disorders.

It might be used when medications have not worked or other forms of treatment are ineffective. It might also be used for people who have serious side effects from medications or whose medical condition means they can't take medications safely.

A general anaesthetic and muscle relaxant is given. When these have taken full effect, i.e. when you are asleep, a brief, carefully controlled electrical current is passed through the brain, causing a seizure. You will wake up after 5 to 10 minutes, much as you would from minor surgery.

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ECT usually consists of 6 to 12 treatments given 2 to 3 times a week over about a month. The total number of treatments needed to get a person better varies between individuals and your psychiatrist will discuss with you how many treatments you are likely to need. While most people show some improvement after 3 to 4 sessions, it takes on average 9 treatments to achieve recovery and some patients may need more than 12 treatments.

There is evidence that ECT is effective in improving depressive and psychotic symptoms. Approximately 8 out of 10 patients who undergo ECT will experience dramatic improvement.

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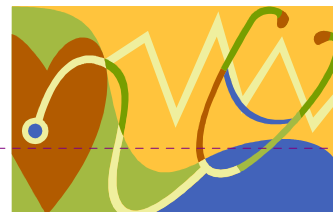
### How Does ECT Work?

A lot of research has been done into the changes that occur within the brain after ECT treatment. It is known that after ECT the activity levels of different parts of the brain are changed, hormones are released, and signalling between brain cells is modified. The latest research studies suggest that ECT may even result in the growth of new brain cells, possibly a process to "repair" impaired brain circuits that may be responsible for depression. There is no one accepted theory about how ECT works, leading some to claim that ECT is unscientific, or to reject it as a treatment. However, it is important to note that we know as much about how ECT works as about some other treatments in medicine, for example, anaesthesia.

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### When will your doctor order ECT treatment?

The decision to administer ECT is based on a thorough physical and psychiatric evaluation of the person, taking into account the type of illness, the degree of suffering, the expected result and the prognosis for the person if the treatment is not given. When the risk of suicide is high or when a seriously ill person is unable to eat or drink, ECT can be life-saving.



**Comment [k3]:** Use a more lay person's term such as expectation of outcomes over a long period

### Prior to your treatment

Before your first ECT treatment, you will be examined to make sure you are fit to have a short general anaesthetic and ECT.

You must not eat or drink anything including water for at least 6 hours before the ECT treatment to make sure your stomach is empty. This is called 'fasting'. If you eat or drink anything within the fasting period, you must tell the nursing or medical staff before the treatment. Some medication might be given early on the morning of ECT treatment, but only with a tiny sip of water.

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### How is ECT given?

In the operating theatre of the hospital the staff will attach the following to you:



- Blood pressure cuff on your arm or leg or both
- Small clip over one of your fingers to check heart rate (pulse) and oxygen levels in your blood
- Small stick-on electrodes on your forehead and behind your ears to record the brain's electrical activity during the treatment
- Face mask over your nose and mouth to give you oxygen. This is to prepare your body and brain for the extra activity that will happen briefly with the treatment.

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You will have a short general anaesthetic so that you will be asleep and not feel or remember the treatment. The anaesthetic medication will be injected into a vein to make it work quickly and well. An anaesthetist will be present and give the anaesthetic. You will also be given a medicine to relax your muscles. You won't feel the convulsion because of the anaesthetic, and any muscle movement during ECT will be limited because of the medication relaxing the muscles.

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A doctor who has specialised training in ECT will administer the treatment. The doctor puts small electrodes on your scalp and passes a measured amount of electricity to a part of the brain to cause a seizure (fit). Depending on the patient and their condition, one or both sides of the head will be stimulated, known as unilateral or bilateral ECT respectively. The seizure will last up to two minutes.



During the treatment, the anaesthetist will continue to give you oxygen through the face mask and monitor your heart rate and oxygen level. The anaesthetist will give you any medications necessary to adjust your heart rate etc during and after the treatment.

You will not feel or remember any of the actual treatment because you will be asleep due to the anaesthetic medication. Within a few minutes after the treatment, the anaesthetic will have worn off and you will wake up. During this time, you will be moved to the recovery room where you will be looked after until you are awake enough to return to your ward. If you are having day procedure ECT, you might need to wait in the recovery room or a ward for up to several hours to make sure you are ready to go home. After you wake up, the anaesthetic medication and the treatment/seizure will make you groggy for a while.

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ABN 82 549 537 349

10<sup>th</sup> February 2010

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A/Manager Clinical Governance  
Mental Health and Drug and Alcohol Office  
NSW Health  
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North Sydney NSW 2059

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## Appendices

Appendix 1: Information on ECT

Appendix 2: Information for patients going home on the same day of ECT treatment

## APPENDIX 1: INFORMATION ON ECT (Electroconvulsive Therapy)

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This information sheet will try to answer some of the questions you may have about Electroconvulsive Therapy (ECT). Your psychiatrist will discuss with you why ECT has been recommended for you.

### What is ECT and why is it given?



ECT is a modern psychiatric treatment that is effective for a range of mental illnesses, including major depression, mania, some forms of schizophrenia and a small number of other mental and neurological disorders.

It might be used when medications have not worked or other forms of treatment are ineffective. It might also be used for people who have serious side effects from medications or whose medical condition means they can't take medications safely.

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There is evidence that ECT is effective in improving depressive and psychotic symptoms. Approximately 8 out of 10 patients who undergo ECT will experience dramatic improvement.

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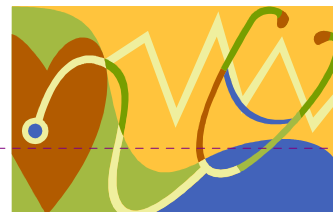
### How Does ECT Work?

A lot of research has been done into the changes that occur within the brain after ECT treatment. It is known that after ECT the activity levels of different parts of the brain are changed, hormones are released, and signalling between brain cells is modified. The latest research studies suggest that ECT may even result in the growth of new brain cells, possibly a process to "repair" impaired brain circuits that may be responsible for depression. There is no one accepted theory about how ECT works, leading some to claim that ECT is unscientific, or to reject it as a treatment. However, it is important to note that we know as much about how ECT works as about some other treatments in medicine, for example, anaesthesia.

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### When will your doctor order ECT treatment?

The decision to administer ECT is based on a thorough physical and psychiatric evaluation of the person, taking into account the type of illness, the degree of suffering, the expected result and the prognosis for the person if the treatment is not given. When the risk of suicide is high or when a seriously ill person is unable to eat or drink, ECT can be life-saving.



**Comment [k3]:** Use a more lay person's term such as expectation of outcomes over a long period

### Prior to your treatment

Before your first ECT treatment, you will be examined to make sure you are fit to have a short general anaesthetic and ECT.

You must not eat or drink anything including water for at least 6 hours before the ECT treatment to make sure your stomach is empty. This is called 'fasting'. If you eat or drink anything within the fasting period, you must tell the nursing or medical staff before the treatment. Some medication might be given early on the morning of ECT treatment, but only with a tiny sip of water.

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### How is ECT given?

In the operating theatre of the hospital the staff will attach the following to you:



- Blood pressure cuff on your arm or leg or both
- Small clip over one of your fingers to check heart rate (pulse) and oxygen levels in your blood
- Small stick-on electrodes on your forehead and behind your ears to record the brain's electrical activity during the treatment
- Face mask over your nose and mouth to give you oxygen. This is to prepare your body and brain for the extra activity that will happen briefly with the treatment.

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**Comment [k4]:** This is a medical term – need to explain in lay person's term

You will have a short general anaesthetic so that you will be asleep and not feel or remember the treatment. The anaesthetic medication will be injected into a vein to make it work quickly and well. An anaesthetist will be present and give the anaesthetic. You will also be given a medicine to relax your muscles. You won't feel the convulsion because of the anaesthetic, and any muscle movement during ECT will be limited because of the medication relaxing the muscles.

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A doctor who has specialised training in ECT will administer the treatment. The doctor puts small electrodes on your scalp and passes a measured amount of electricity to a part of the brain to cause a seizure (fit). Depending on the patient and their condition, one or both sides of the head will be stimulated, known as unilateral or bilateral ECT respectively. The seizure will last up to two minutes.



During the treatment, the anaesthetist will continue to give you oxygen through the face mask and monitor your heart rate and oxygen level. The anaesthetist will give you any medications necessary to adjust your heart rate etc during and after the treatment.

You will not feel or remember any of the actual treatment because you will be asleep due to the anaesthetic medication. Within a few minutes after the treatment, the anaesthetic will have worn off and you will wake up. During this time, you will be moved to the recovery room where you will be looked after until you are awake enough to return to your ward. If you are having day procedure ECT, you might need to wait in the recovery room or a ward for up to several hours to make sure you are ready to go home. After you wake up, the anaesthetic medication and the treatment/seizure will make you groggy for a while.

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### Is it safe? What are the benefits of ECT? What about side-effects?

ECT is regarded as a very safe treatment. Research has shown that ECT doesn't cause brain damage or changes in personality because the amount of electricity used is too small to harm tissue.

Your psychiatrist will discuss with you the expected benefits of ECT. These will vary depending on the nature and seriousness of your illness, but ECT will generally improve your ability to think and return your emotions to a healthier state.

All treatments have risks and side effects—even no treatment has risks.

The risks and side effects of ECT include:

- Side effects from the anaesthetic, such as headache, nausea (feeling sick in the stomach) or queasiness, vomiting. You should tell the staff looking after you and they will be able to give you some medication to help.

- You might get muscle soreness after the ECT as a result of the medication to relax the muscles.
  - The anaesthetic will affect your judgment for the first 24 hours. During this time you must not:



- Drive any type of vehicle
- Operate machinery, including cooking implements
- Make important decisions or sign a legal document
- Drink alcohol, take other mind-altering substances or smoke because they might react with the anaesthetic medication.

- A common and significant side-effect is confusion and memory impairment.

- Many people report difficulty with memory which usually clears up shortly after the end of treatment. For some it may last for a while longer (eg weeks to months) but improves with time.
- Immediately after ECT most people have a short period of confusion and do not remember the actual treatment.
- Over the course of ECT, it might be more difficult to remember newly learned information, eg events that occurred during the weeks you were having ECT.
- Some people also report a patchy loss of memory of events that occurred during the days, weeks and months before the ECT. Memory for recent events, dates, names of friends etc. may not be as good. In most patients the memory problems go away over the days, weeks or months following completion of the course of ECT. Sometimes, but not often, there may be permanent loss of isolated memories from your past.
- Many people will find that their memories are somewhat unclear for the time that they were ill. The same problem is often experienced by people with depression who do not receive ECT.
- Although specific memories from around the time you had ECT might not return, your overall memory should work better in the weeks to months after treatment. Many patients report that their memory improved after a course of ECT.

- Some other side effects are less common and some are extremely rare:

- There is a less common risk of medical complications, such as irregular heart rate and rhythm. There might be a temporary rise in blood pressure and heart rate followed by a slowing of the heart rate.
- As with any general anaesthetic, there is a very small risk of death, but with modern ECT and a short anaesthetic, this risk is now extremely rare. No case of death associated with anaesthesia for ECT has been recorded in New South Wales for more than 25 years.
- Heart attack, stroke or injury related to muscle spasms are also extremely rare.
- Resuscitation equipment and emergency procedures are immediately available if anything should go wrong.

- What are the alternative treatments?

- Talk to your psychiatrist about what other treatments may be offered instead of ECT

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## Giving permission for ECT

Just as with any medical procedure, it is required that informed consent for ECT be obtained in writing. Informed consent is when you agree to have ECT after you have been told what ECT involves, including

- a full explanation of the ECT procedure,
- how it works,
- how it can help your illness,
- possible side effects, discomforts and risks of ECT and
- any beneficial alternative treatments.



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You have the right to discuss your views about ECT with your psychiatrist and ask any questions about it.

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You also have the right to:

- Obtain medical and legal advice
- Obtain a second opinion from a psychiatrist about the ECT. Your psychiatrist can arrange a second opinion from within the mental health service.
- Have a friend, family member, lawyer or an advocate represent you before you consent to ECT

**Comment [k7]:** May also be useful to provide reference to the ability to do some advanced planning about having ECT or about having an agreement with a person to make decisions for the person while they are having ECT and judgement may be affected

If you agree to have ECT, you will be asked to sign a form to say you have given informed consent. This means if you are able to give informed consent, you have the right to refuse ECT.

If you are incapable of giving informed consent, or if your health professionals consider that ECT treatment is potentially life saving, then your psychiatrist will seek consent on your behalf through the Mental Health Review Tribunal, even if you don't want the treatment.

**Comment [k8]:** Need to explain how this would be determined

The *Mental Health Review Tribunal* becomes involved in decisions about ECT when the hospital:

- is uncertain of a voluntary patient's capacity to give consent to treatment with ECT; and
- proposes ECT for an involuntary patient.

Your psychiatrist must do everything reasonably practicable to give notice to your nearest relative, guardian or personal friends about the application for ECT. The Mental Health Review Tribunal will make the decision as to whether or not you are to be treated with ECT.

If you agree to have ECT, but then change your mind, it is your right to withdraw your consent at **any time** and the treatments will be stopped, unless your psychiatrist believes you are unable to give informed consent. If you want to withdraw your consent, you should talk to your psychiatrist. Remember that you can have a friend, a family member, a lawyer or an advocate with you for support or to represent you.

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## Will I need further treatment?

While your illness might be treated with a course of ECT, the illness might come back once the course is finished. Some people need occasional continued ECT treatment, spread-out from around once a week to once a month. To help prevent relapse, your doctor will discuss with you any further treatment you might need after the course of ECT ends, such as medication, maintenance ECT, psychotherapy, counselling and / or rehabilitation.



## References

SANE ECT Information Sheet: <http://www.sane.org/information/factsheets>

Better Health Channel ECT Information Sheet: <http://www.betterhealth.vic.gov.au>

Victorian Government Health Information: <http://www.health.vic.gov.au>

## APPENDIX 2:

### INFORMATION FOR PATIENTS GOING HOME ON THE SAME DAY OF ECT TREATMENT

The following information may assist you in your recovery from your ECT treatment today.

#### **BEFORE LEAVING THE MENTAL HEALTH UNIT**

After your treatment you will be returned to the ward where you must stay for 4 hours to ensure you are well enough to go home following the anaesthetic.

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The nursing staff will ensure you see a doctor before leaving the ward.

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You will be given an appointment card with the date of your next treatment.

#### **WHAT TO EXPECT AFTER ECT TREATMENT**

◆ The anaesthetic will affect your judgment and you may feel a little light headed, slower to react or sleepy for the next 24 hours. During the 24 hours after ECT treatment you **MUST NOT**:

- Drive any type of vehicle (therefore, someone will need to pick you up from hospital)
- Operate machinery, including cooking implements
- Make important decisions or sign a legal document
- Drink alcohol, take other mind-altering substances or smoke because they might react with the anaesthetic medication
- Engage in heavy work or strenuous activities.



◆ Managing side effects from ECT treatment & the anaesthetic

- Side effects from the ECT treatment may include headache. You may take medication such as paracetamol for a headache as directed by your doctor.
- Side effects from the anaesthetic may include nausea, queasiness (feeling sick in the stomach) or vomiting. A light diet is recommended after an anaesthetic. If you are experiencing nausea or vomiting, do not eat solid food and drink clear fluids only. Should nausea, vomiting continue tomorrow, contact your local doctor.

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NSW Consumer Advisory Group – Mental Health Inc  
ABN 82 549 537 349

10<sup>th</sup> February 2010

Mr Carlton Quartly  
A/Manager Clinical Governance  
Mental Health and Drug and Alcohol Office  
NSW Health  
Locked Bag 961  
North Sydney NSW 2059

Email: [carlton.quartly@health.nsw.gov.au](mailto:carlton.quartly@health.nsw.gov.au)

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There is evidence that ECT is effective in improving depressive and psychotic symptoms. Approximately 8 out of 10 patients who undergo ECT will experience dramatic improvement.

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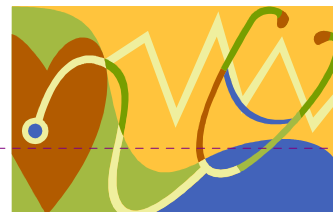
### How Does ECT Work?

A lot of research has been done into the changes that occur within the brain after ECT treatment. It is known that after ECT the activity levels of different parts of the brain are changed, hormones are released, and signalling between brain cells is modified. The latest research studies suggest that ECT may even result in the growth of new brain cells, possibly a process to "repair" impaired brain circuits that may be responsible for depression. There is no one accepted theory about how ECT works, leading some to claim that ECT is unscientific, or to reject it as a treatment. However, it is important to note that we know as much about how ECT works as about some other treatments in medicine, for example, anaesthesia.

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### When will your doctor order ECT treatment?

The decision to administer ECT is based on a thorough physical and psychiatric evaluation of the person, taking into account the type of illness, the degree of suffering, the expected result and the prognosis for the person if the treatment is not given. When the risk of suicide is high or when a seriously ill person is unable to eat or drink, ECT can be life-saving.



**Comment [k3]:** Use a more lay person's term such as expectation of outcomes over a long period

### Prior to your treatment

Before your first ECT treatment, you will be examined to make sure you are fit to have a short general anaesthetic and ECT.

You must not eat or drink anything including water for at least 6 hours before the ECT treatment to make sure your stomach is empty. This is called 'fasting'. If you eat or drink anything within the fasting period, you must tell the nursing or medical staff before the treatment. Some medication might be given early on the morning of ECT treatment, but only with a tiny sip of water.

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### How is ECT given?

In the operating theatre of the hospital the staff will attach the following to you:



- Blood pressure cuff on your arm or leg or both
- Small clip over one of your fingers to check heart rate (pulse) and oxygen levels in your blood
- Small stick-on electrodes on your forehead and behind your ears to record the brain's electrical activity during the treatment
- Face mask over your nose and mouth to give you oxygen. This is to prepare your body and brain for the extra activity that will happen briefly with the treatment.

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**Comment [k4]:** This is a medical term – need to explain in lay person's term

You will have a short general anaesthetic so that you will be asleep and not feel or remember the treatment. The anaesthetic medication will be injected into a vein to make it work quickly and well. An anaesthetist will be present and give the anaesthetic. You will also be given a medicine to relax your muscles. You won't feel the convulsion because of the anaesthetic, and any muscle movement during ECT will be limited because of the medication relaxing the muscles.

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**Comment [k5]:** This is the first time this word is used, need to explain what it is and may be useful to include in explanation of what a seizure is.

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**Comment [k6]:** Need to explain this term

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A doctor who has specialised training in ECT will administer the treatment. The doctor puts small electrodes on your scalp and passes a measured amount of electricity to a part of the brain to cause a seizure (fit). Depending on the patient and their condition, one or both sides of the head will be stimulated, known as unilateral or bilateral ECT respectively. The seizure will last up to two minutes.



During the treatment, the anaesthetist will continue to give you oxygen through the face mask and monitor your heart rate and oxygen level. The anaesthetist will give you any medications necessary to adjust your heart rate etc during and after the treatment.

You will not feel or remember any of the actual treatment because you will be asleep due to the anaesthetic medication. Within a few minutes after the treatment, the anaesthetic will have worn off and you will wake up. During this time, you will be moved to the recovery room where you will be looked after until you are awake enough to return to your ward. If you are having day procedure ECT, you might need to wait in the recovery room or a ward for up to several hours to make sure you are ready to go home. After you wake up, the anaesthetic medication and the treatment/seizure will make you groggy for a while.

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### Is it safe? What are the benefits of ECT? What about side-effects?

ECT is regarded as a very safe treatment. Research has shown that ECT doesn't cause brain damage or changes in personality because the amount of electricity used is too small to harm tissue.

Your psychiatrist will discuss with you the expected benefits of ECT. These will vary depending on the nature and seriousness of your illness, but ECT will generally improve your ability to think and return your emotions to a healthier state.

All treatments have risks and side effects—even no treatment has risks.

The risks and side effects of ECT include:

- Side effects from the anaesthetic, such as headache, nausea (feeling sick in the stomach) or queasiness, vomiting. You should tell the staff looking after you and they will be able to give you some medication to help.

- You might get muscle soreness after the ECT as a result of the medication to relax the muscles.
  - The anaesthetic will affect your judgment for the first 24 hours. During this time you must not:



- Drive any type of vehicle
- Operate machinery, including cooking implements
- Make important decisions or sign a legal document
- Drink alcohol, take other mind-altering substances or smoke because they might react with the anaesthetic medication.

- A common and significant side-effect is confusion and memory impairment.

- Many people report difficulty with memory which usually clears up shortly after the end of treatment. For some it may last for a while longer (eg weeks to months) but improves with time.
- Immediately after ECT most people have a short period of confusion and do not remember the actual treatment.
- Over the course of ECT, it might be more difficult to remember newly learned information, eg events that occurred during the weeks you were having ECT.
- Some people also report a patchy loss of memory of events that occurred during the days, weeks and months before the ECT. Memory for recent events, dates, names of friends etc. may not be as good. In most patients the memory problems go away over the days, weeks or months following completion of the course of ECT. Sometimes, but not often, there may be permanent loss of isolated memories from your past.
- Many people will find that their memories are somewhat unclear for the time that they were ill. The same problem is often experienced by people with depression who do not receive ECT.
- Although specific memories from around the time you had ECT might not return, your overall memory should work better in the weeks to months after treatment. Many patients report that their memory improved after a course of ECT.

- Some other side effects are less common and some are extremely rare:

- There is a less common risk of medical complications, such as irregular heart rate and rhythm. There might be a temporary rise in blood pressure and heart rate followed by a slowing of the heart rate.
- As with any general anaesthetic, there is a very small risk of death, but with modern ECT and a short anaesthetic, this risk is now extremely rare. No case of death associated with anaesthesia for ECT has been recorded in New South Wales for more than 25 years.
- Heart attack, stroke or injury related to muscle spasms are also extremely rare.
- Resuscitation equipment and emergency procedures are immediately available if anything should go wrong.

- What are the alternative treatments?

- Talk to your psychiatrist about what other treatments may be offered instead of ECT

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## Giving permission for ECT

Just as with any medical procedure, it is required that informed consent for ECT be obtained in writing. Informed consent is when you agree to have ECT after you have been told what ECT involves, including

- a full explanation of the ECT procedure,
- how it works,
- how it can help your illness,
- possible side effects, discomforts and risks of ECT and
- any beneficial alternative treatments.



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You have the right to discuss your views about ECT with your psychiatrist and ask any questions about it.

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You also have the right to:

- Obtain medical and legal advice
- Obtain a second opinion from a psychiatrist about the ECT. Your psychiatrist can arrange a second opinion from within the mental health service.
- Have a friend, family member, lawyer or an advocate represent you before you consent to ECT

Comment [k7]: May also be useful to provide reference to the ability to do some advanced planning about having ECT or about having an agreement with a person to make decisions for the person while they are having ECT and judgement may be affected

If you agree to have ECT, you will be asked to sign a form to say you have given informed consent. This means if you are able to give informed consent, you have the right to refuse ECT.

If you are incapable of giving informed consent, or if your health professionals consider that ECT treatment is potentially life saving, then your psychiatrist will seek consent on your behalf through the Mental Health Review Tribunal, even if you don't want the treatment.

Comment [k8]: Need to explain how this would be determined

The Mental Health Review Tribunal becomes involved in decisions about ECT when the hospital:

- is uncertain of a voluntary patient's capacity to give consent to treatment with ECT; and
- proposes ECT for an involuntary patient.

Your psychiatrist must do everything reasonably practicable to give notice to your nearest relative, guardian or personal friends about the application for ECT. The Mental Health Review Tribunal will make the decision as to whether or not you are to be treated with ECT.

If you agree to have ECT, but then change your mind, it is your right to withdraw your consent at **any time** and the treatments will be stopped, unless your psychiatrist believes you are unable to give informed consent. If you want to withdraw your consent, you should talk to your psychiatrist. Remember that you can have a friend, a family member, a lawyer or an advocate with you for support or to represent you.

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## Will I need further treatment?

While your illness might be treated with a course of ECT, the illness might come back once the course is finished. Some people need occasional continued ECT treatment, spread-out from around once a week to once a month. To help prevent relapse, your doctor will discuss with you any further treatment you might need after the course of ECT ends, such as medication, maintenance ECT, psychotherapy, counselling and / or rehabilitation.



## References

SANE ECT Information Sheet: <http://www.sane.org/information/factsheets>

Better Health Channel ECT Information Sheet: <http://www.betterhealth.vic.gov.au>

Victorian Government Health Information: <http://www.health.vic.gov.au>

## APPENDIX 2:

### INFORMATION FOR PATIENTS GOING HOME ON THE SAME DAY OF ECT TREATMENT

The following information may assist you in your recovery from your ECT treatment today.

#### **BEFORE LEAVING THE MENTAL HEALTH UNIT**

After your treatment you will be returned to the ward where you must stay for 4 hours to ensure you are well enough to go home following the anaesthetic.

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The nursing staff will ensure you see a doctor before leaving the ward.

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You will be given an appointment card with the date of your next treatment.

#### **WHAT TO EXPECT AFTER ECT TREATMENT**

◆ The anaesthetic will affect your judgment and you may feel a little light headed, slower to react or sleepy for the next 24 hours. During the 24 hours after ECT treatment you **MUST NOT**:

- Drive any type of vehicle (therefore, someone will need to pick you up from hospital)
- Operate machinery, including cooking implements
- Make important decisions or sign a legal document
- Drink alcohol, take other mind-altering substances or smoke because they might react with the anaesthetic medication
- Engage in heavy work or strenuous activities.



◆ Managing side effects from ECT treatment & the anaesthetic

- Side effects from the ECT treatment may include headache. You may take medication such as paracetamol for a headache as directed by your doctor.
- Side effects from the anaesthetic may include nausea, queasiness (feeling sick in the stomach) or vomiting. A light diet is recommended after an anaesthetic. If you are experiencing nausea or vomiting, do not eat solid food and drink clear fluids only. Should nausea, vomiting continue tomorrow, contact your local doctor.

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NSW Consumer Advisory Group – Mental Health Inc  
ABN 82 549 537 349

10<sup>th</sup> February 2010

Mr Carlton Quartly  
A/Manager Clinical Governance  
Mental Health and Drug and Alcohol Office  
NSW Health  
Locked Bag 961  
North Sydney NSW 2059

Email: [carlton.quartly@health.nsw.gov.au](mailto:carlton.quartly@health.nsw.gov.au)

Dear Carlton

**Re: Draft NSW Health Electroconvulsive Therapy (ECT) Standards**

Thank you for providing the NSW Consumer Advisory Group – Mental Health Inc. (NSW CAG) with the opportunity to comment on the Draft NSW Health Electroconvulsive Therapy Standards. NSW CAG is the peak, independent, state-wide organisation representing the views of mental health consumers at a policy level, working to achieve and support systemic change. Our vision is for all mental health consumers to experience fair access to quality services that reflect their needs.

Our main comments below identify issues surrounding informed consent, the provision of information about ECT to consumers, and the credentialing of staff coordinating ECT, in order to ensure consumer safety and the provision of quality efficacious treatment. It should be noted that given the timeframes for the response, NSW CAG has not been able to consult with our network around the Standards and attached documents. Our response is therefore informed by our work with consumers over the past 17 years.

While appreciating the focus on the clinical practice of ECT for the standards, NSW CAG is concerned that consumers were not involved in the development of these standards at an earlier stage. Consumer involvement would particularly have been useful to inform the components around which comment will be made within this letter. It is strongly recommended that earlier consumer involvement in all initiatives, including those around clinical practice, is ensured in the future.

Broadly, the Policy and Guidelines are based on solid evidence surrounding best practice for ECT. The implementation of these documents will ensure a more

consistent approach to the practice of ECT that will also ensure a higher quality of treatment for mental health consumers. Our recommendations for consideration within the Policy and Guidelines are presented in relation to the sections of the Policy and Guidelines.

## **Policy Statement**

### **Section 3: Consent and legal issues**

While not required under the Mental Health Act, NSW CAG considers that good practice would be ensuring the consumer's informed consent for each administration of ECT. This may be done verbally.

### **Section 5: Preparing the patient for ECT**

It is recommended that this section also includes preparation of the patient through the provision of information about the treatment, including the procedures for the treatment and for the day of treatment, likely benefits, possible side effects and risks, alternative treatment options, why ECT is the recommended treatment, including the risk benefit analysis that has been undertaken by the treating psychiatrist. This information needs to be provided in a timely manner, in easy to understand language, in both a written and verbal format.

### **Section 9: Continuation, maintenance and outpatient ECT**

While not required under the Mental Health Act, NSW CAG considers that good practice would be ensuring the consumer's informed consent for each administration of ECT. This may be done verbally.

### **Section 11: Nursing and coordination requirements for ECT patients**

Clear direction is required as to how a nurse's competence in ECT will be assessed, including requirements for updating of skills and knowledge. This is important in ensuring quality care for consumers.

## **Policy Guidelines**

A component lacking within the guidelines is how the competence of nursing staff involved in ECT will be assessed. This is important in ensuring safe and quality treatment. It is recommended that minimum standards gauging such competence be included, including requirements for upgrading of skills and knowledge.

A further component absent from the guidelines pertains to the follow-up care of consumers who have received ECT, particularly after they may have been discharged from a service or having completed a course of ECT. Indeed, such guidelines are also relevant to those undergoing maintenance or continuation ECT. It is recommended that the Policy Guidelines include direction as to the minimum information that must be provided to a consumer's GP and/or care coordinator, and how often or when follow

up of cognitive tests should occur, particularly in cases where memory deficits are present.

### **Section 3: Consent and legal issues**

#### **Section 3.2: Informed consent**

Page 22 states

“The MHA [Mental Health Act] specifies that wherever a patient poses questions about ECT, the answers given to the question must “appear to have been understood”. It is not the general information provided which must appear to be understood, but the answer to the questions subsequently asked by the patient.”

NSW CAG is concerned that this statement exemplifies services of ensuring that the general information provided to consumers “appears to have been understood”. If the general information is not understood by consumers, they are unable to give informed consent. It is imperative that all information about any treatment modality, including ECT, is provided in clear language devoid of jargon, in a format appropriate for the individual (for example, written format is not always the most appropriate format for people who may have literacy difficulties, cognitive impairments, or difficulties with reading for other reasons such as medication influences), and in a language that the individual understands. It is also imperative that staff ensure that ALL information “appears to be understood” by the consumer.

For consumers who will be having involuntary ECT, it is also imperative that all information be provided to consumers prior to the administration of ECT, and that any questions they have are answered. The same stipulation that staff need to ensure that the information and answers to the questions “appear to have been understood” also needs to apply.

NSW CAG considers that best practice for ECT is the provision of information to the consumer upon each administration of ECT, and where the individual has been assessed as capable of giving informed consent, that this be sought for each administration. This may occur verbally.

#### **Section 3.3: ECT and the MHRT (Mental Health Review Tribunal)**

The document reads that a determination that a course of ECT will be administered to a consumer involuntarily must be made by the Mental Health Review Tribunal in situations when “the patient... is capable of giving informed consent to ECT but has refused...” (page 23).

While this is reflective of the Mental Health Act, NSW CAG is concerned that for someone who has been assessed as **capable** of giving informed consent, their decisions can be overturned. This is a violation of rights and poses concerns regarding the human rights of mental health consumers who may be on an

involuntary treatment order. Further exploration regarding this provision is required.

### **Section 5: Preparing the patient for ECT; Section 5.1: Pre-ECT work up**

It is recommended guidance be provided on how often throughout a single course of ECT the history, physical examination, baseline cognitive testing, relevant investigations, and consultations with other specialties should occur. This may be particularly relevant for maintenance and continuation ECT that may occur at periods of one month apart. It is also recommended that it be stipulated that such pre-ECT work up be conducted prior to each course of ECT.

NSW CAG further recommends that an additional sub-section be included regarding discussions with consumers, and where requested, family and carers, about the treatment. The information provided should cover all aspects, including the procedures for the treatment and for the day of treatment, likely benefits, possible side effects, alternative treatment options, why ECT is the recommended treatment. This information needs to be provided in a timely manner, in language that can be understood by the consumer, and in a suitable format.

### **Section 6: Administration of ECT; Section 6.8: Information for patients**

It is recommended that the information contained in appendices 1 and 2 be stated as the minimum information to be provided to consumers.

It is further recommended that the guidelines stipulate that all information be provided in a timely manner, in language that can be understood by the consumer, and in a suitable format.

### **Section 8: ECT in children and adolescents**

Given that there is minimal research regarding the effects, particularly long term effects of administering ECT to children and adolescents, it is recommended that the guidelines include minimum standards for ongoing follow up of children and adolescents administered ECT and the recording of this information.

### **Section 11: Nursing and coordinator requirements for ECT**

#### **Section 11.1: Provide emotional and educational support to the patient and family/carer**

It is recommended that the provision of honest information about all aspects of ECT be provided to consumers and their family or carer.

#### **Section 11.6: Role of the ECT coordinator**

The inclusion of the following within the table of possible activities and responsibilities of an ECT Coordinator is recommended:

- Informing consumers and their family or carer about all aspects of ECT
- Education of staff around informing consumers and their family or carer about all aspects of ECT
- Education of staff around ensuring informed consent

## **Appendices 1 and 2**

NSW CAG recommends some changes to the language used in the information documents suggested for use. We also recommend that the font be a minimum of 12 points to enable ease of reading. These recommendations are highlighted as tracked changes on the original appendices and are attached.

Please do not hesitate to contact me should you wish to discuss the recommendations presented.

Yours sincerely,

A handwritten signature in black ink, appearing to read 'K Oakley', with a large, sweeping flourish at the end.

Karen Oakley  
Executive Officer

## Appendices

Appendix 1: Information on ECT

Appendix 2: Information for patients going home on the same day of ECT treatment

## APPENDIX 1: INFORMATION ON ECT (Electroconvulsive Therapy)

**Comment [k1]:** Make all information at least size 12 font and in Arial type

This information sheet will try to answer some of the questions you may have about Electroconvulsive Therapy (ECT). Your psychiatrist will discuss with you why ECT has been recommended for you.

### What is ECT and why is it given?



ECT is a modern psychiatric treatment that is effective for a range of mental illnesses, including major depression, mania, some forms of schizophrenia and a small number of other mental and neurological disorders.

It might be used when medications have not worked or other forms of treatment are ineffective. It might also be used for people who have serious side effects from medications or whose medical condition means they can't take medications safely.

A general anaesthetic and muscle relaxant is given. When these have taken full effect, i.e. when you are asleep, a brief, carefully controlled electrical current is passed through the brain, causing a seizure. You will wake up after 5 to 10 minutes, much as you would from minor surgery.

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ECT usually consists of 6 to 12 treatments given 2 to 3 times a week over about a month. The total number of treatments needed to get a person better varies between individuals and your psychiatrist will discuss with you how many treatments you are likely to need. While most people show some improvement after 3 to 4 sessions, it takes on average 9 treatments to achieve recovery and some patients may need more than 12 treatments.

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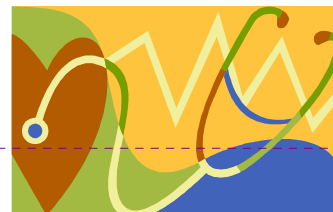
### How Does ECT Work?

A lot of research has been done into the changes that occur within the brain after ECT treatment. It is known that after ECT the activity levels of different parts of the brain are changed, hormones are released, and signalling between brain cells is modified. The latest research studies suggest that ECT may even result in the growth of new brain cells, possibly a process to "repair" impaired brain circuits that may be responsible for depression. There is no one accepted theory about how ECT works, leading some to claim that ECT is unscientific, or to reject it as a treatment. However, it is important to note that we know as much about how ECT works as about some other treatments in medicine, for example, anaesthesia.

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### When will your doctor order ECT treatment?

The decision to administer ECT is based on a thorough physical and psychiatric evaluation of the person, taking into account the type of illness, the degree of suffering, the expected result and the prognosis for the person if the treatment is not given. When the risk of suicide is high or when a seriously ill person is unable to eat or drink, ECT can be life-saving.



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### Prior to your treatment

Before your first ECT treatment, you will be examined to make sure you are fit to have a short general anaesthetic and ECT.

You must not eat or drink anything including water for at least 6 hours before the ECT treatment to make sure your stomach is empty. This is called 'fasting'. If you eat or drink anything within the fasting period, you must tell the nursing or medical staff before the treatment. Some medication might be given early on the morning of ECT treatment, but only with a tiny sip of water.

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### How is ECT given?

In the operating theatre of the hospital the staff will attach the following to you:



- Blood pressure cuff on your arm or leg or both
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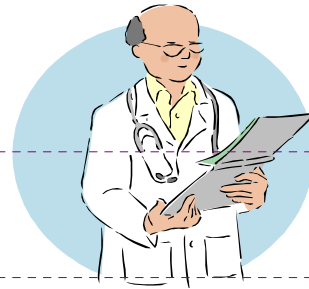
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- Heart attack, stroke or injury related to muscle spasms are also extremely rare.
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- Obtain medical and legal advice
- Obtain a second opinion from a psychiatrist about the ECT. Your psychiatrist can arrange a second opinion from within the mental health service.
- Have a friend, family member, lawyer or an advocate represent you before you consent to ECT

Comment [k7]: May also be useful to provide reference to the ability to do some advanced planning about having ECT or about having an agreement with a person to make decisions for the person while they are having ECT and judgement may be affected

If you agree to have ECT, you will be asked to sign a form to say you have given informed consent. This means if you are able to give informed consent, you have the right to refuse ECT.

If you are incapable of giving informed consent, or if your health professionals consider that ECT treatment is potentially life saving, then your psychiatrist will seek consent on your behalf through the Mental Health Review Tribunal, even if you don't want the treatment.

Comment [k8]: Need to explain how this would be determined

The Mental Health Review Tribunal becomes involved in decisions about ECT when the hospital:

- is uncertain of a voluntary patient's capacity to give consent to treatment with ECT; and
- proposes ECT for an involuntary patient.

Your psychiatrist must do everything reasonably practicable to give notice to your nearest relative, guardian or personal friends about the application for ECT. The Mental Health Review Tribunal will make the decision as to whether or not you are to be treated with ECT.

If you agree to have ECT, but then change your mind, it is your right to withdraw your consent at **any time** and the treatments will be stopped, unless your psychiatrist believes you are unable to give informed consent. If you want to withdraw your consent, you should talk to your psychiatrist. Remember that you can have a friend, a family member, a lawyer or an advocate with you for support or to represent you.

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## Will I need further treatment?

While your illness might be treated with a course of ECT, the illness might come back once the course is finished. Some people need occasional continued ECT treatment, spread-out from around once a week to once a month. To help prevent relapse, your doctor will discuss with you any further treatment you might need after the course of ECT ends, such as medication, maintenance ECT, psychotherapy, counselling and / or rehabilitation.



## References

SANE ECT Information Sheet: <http://www.sane.org/information/factsheets>

Better Health Channel ECT Information Sheet: <http://www.betterhealth.vic.gov.au>

Victorian Government Health Information: <http://www.health.vic.gov.au>

## APPENDIX 2:

### INFORMATION FOR PATIENTS GOING HOME ON THE SAME DAY OF ECT TREATMENT

The following information may assist you in your recovery from your ECT treatment today.

#### **BEFORE LEAVING THE MENTAL HEALTH UNIT**

After your treatment you will be returned to the ward where you must stay for 4 hours to ensure you are well enough to go home following the anaesthetic.

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The nursing staff will ensure you see a doctor before leaving the ward.

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You will be given an appointment card with the date of your next treatment.

#### **WHAT TO EXPECT AFTER ECT TREATMENT**

◆ The anaesthetic will affect your judgment and you may feel a little light headed, slower to react or sleepy for the next 24 hours. During the 24 hours after ECT treatment you **MUST NOT**:

- Drive any type of vehicle (therefore, someone will need to pick you up from hospital)
- Operate machinery, including cooking implements
- Make important decisions or sign a legal document
- Drink alcohol, take other mind-altering substances or smoke because they might react with the anaesthetic medication
- Engage in heavy work or strenuous activities.



◆ Managing side effects from ECT treatment & the anaesthetic

- Side effects from the ECT treatment may include headache. You may take medication such as paracetamol for a headache as directed by your doctor.
- Side effects from the anaesthetic may include nausea, queasiness (feeling sick in the stomach) or vomiting. A light diet is recommended after an anaesthetic. If you are experiencing nausea or vomiting, do not eat solid food and drink clear fluids only. Should nausea, vomiting continue tomorrow, contact your local doctor.

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