58. HIGH INTENSITY DAILY ACTIVITIES: Seizure and Epilepsy Managaement Policy and Procedure

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Purpose

The aim of this procedure policy and procedures is to provide guidance on seizure management, according to established standards and guidelines to ensure participants who require seizure interventions receive care and support relevant to their individual needs.

Scope

It applies to all Australian Quality Care staff providing seizure management support and meets relevant legislation, regulations and Standards as set out in *Schedule 1 Legislative References.*

Definitions

Epilepsy - a common neurological condition characterised by abnormal or excessive brain activity that results in seizures (or fits). Unusual feelings, sensations, and behaviours due to abnormal unprovoked activities in the brain are usually related to an inherited genetic condition, trauma to the head, a brain infection, or developmental disorders of the brain, including unknown causes.

Epilepsy is not a mental disease or illness. It is a long-term brain condition (that can last several years or be lifelong) where the person has repeated and recurrent seizures. There is no known cure, but treatment can help manage the condition.

Anti-epileptic medications and avoiding triggers, to reduce the frequency and intensity of seizures, are the first preferences for treatment of Epilepsy. Prescribed medications for seizure control must be taken in the right doses and not stopped without consulting the treating medical practitioner. Other treatments including brain surgery are recommended when medications fail. Other therapies include vagus nerve stimulation and a ketogenic diet.

Symptoms of Epilepsy vary between individuals, depend on the type of seizure a person has, and can be mild to severe in form. They include:

- euphoria during aura (before the episode)
- temporary confusion
- staring blankly
- uncontrollable jerking movements or twitching of arms and legs (convulsions)
- loss of consciousness (passing out) or awareness
- temporary loss of bladder or bowel control
- fear and

- anxiety.

Midazolam - a short acting sedative drug with muscle relaxant, anti-convulsant, hypnotic, and amnesic properties, used as Epilepsy medication. Long-term use is not recommended, due to its sedative effect and high degree of break-through seizures. Tolerance develops rapidly to the anti-convulsant effect, and the dose may need to be increased several times to maintain anti-convulsant therapeutic effects.

Seizures - although Epilepsy is a seizure disorder, this does not mean that every seizure is a sign of Epilepsy.

> ***Provoked Seizures*** – these seizures can be due to brain trauma, head injury, high or low blood sugars, high fever, infection, stroke, withdrawal from drugs or alcohol, allergic reaction to medicines, and other biochemical imbalances. If seizures are solely due to one of these provoked causes, the person does not have Epilepsy.

To determine the cause of seizures and to make an Epilepsy diagnosis, doctors undertake diagnostic investigations, e.g., EEG tests, blood tests, and brain imaging such as CT or MRI scans.

A person with Epilepsy can experience multiple types of seizures, as follows: -

> ***Absence Seizures*** - previously known as “petit mal” seizures. These are brief seizures often mistaken for daydreaming or inattention. They are characterised by a blank stare, unresponsiveness, blinking, chewing movements of the mouth, and suddenly stopping activity. They usually last a few seconds before the person returns to full awareness. Some people will not be aware they have experienced and an absence seizure.
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> ***Atonic Seizure*** - people with combined-generalised and focal Epilepsy have generalised seizures where both the left and right sides of the brain are affected. These seizures may be either motor or non-motor seizures.
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> - ***Motor Seizures*** - also known as Tonic-clonic Seizures. These are characterised by jerking movements, weakness or limp limbs, tense, rigid muscles, muscle twitching, and full body epileptic spasms.
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> - ***Non-motor Seizures*** - also called Absence Seizure. Symptoms include staring into space, a sudden stop in movement, brief twitches, and fluttering eyelids.
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> ***Focal Seizures*** – these seizures only affect one part of the brain and are typically not convulsive. They may or may not impair consciousness. They can start in one area and move to another. No action is usually necessary unless it becomes convulsive, where first aid response is required. Focus seizures include:
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> - ***Focal Aware Seizures*** – previously called “simple partial” seizures. In these seizures, the person is aware of their surroundings but may not be able to talk or respond normally. They may simply experience sensations such as nausea, déjà vu, numbness, or tingling.
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> - ***Focal Impaired Awareness Seizures*** - previously called “complex partial” seizures. These often involve the person appearing confused and engaging in unusual behaviours, such as fidgeting, mumbling, or chewing. The person is unlikely to be aware of or remember the seizure.
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> - ***Focal to Generalised Tonic-clonic Seizures*** - these start as focal seizures but then evolve into a tonic-clonic seizure (convulsion).
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> ***Myoclonic Seizures*** – these commonly occur in people with generalised or genetic Epilepsy, or

some severe forms of Epilepsy. They are characterised by quick, uncontrollable muscle movements such as muscle spasms, or losing muscle tension, with no change in the person's level of awareness or consciousness. They can happen on their own, but typically occur as a symptom of another medical condition. They aren't usually disabling, and are brief, not painful, and treatable with medication.

Tonic-Clonic Seizures - previously known as "grand mal" seizures. These start with a sudden loss of consciousness, collapsing, and the body becoming rigid, followed by sudden jerking of the muscles, or repetitive stiffening and relaxing of the muscles (convulsions). Turning red or blue, biting the tongue and losing bladder control are common. These seizures usually last a couple of minutes, and the person may experience confusion, fatigue, headache, agitation, and drowsiness upon return to full consciousness.

Unknown – The origins of these seizures are unknown. This type of seizure can have a combination of both motor and non-motor symptoms, and often present as tonic-clonic, characterised by stiffening and loss of consciousness, rapid rhythmic jerking or convulsing, a bluish face from lack of oxygen, and loss of bladder or bowel control. These seizures usually last 1 to 3 minutes. If they last over 5 minutes, call emergency services immediately. Non motor symptoms in unknown Epilepsy can include a sudden stop in movement, vacant staring, and stillness.

Seizure Clusters - periods of increased seizure activity, being 3 or more seizures in 24 hours, 2 or more seizures in 12 hours, and 2 or more seizures in 6 hours.

People with severe and poorly controlled Epilepsy are more likely to experience seizure clusters. Seizure clusters usually require increased health care and can have a negative impact on the person's quality of life, and as well as the quality of life of their caregivers.

Rescue medication, such as use of benzodiazepine (e.g., Midazolam) in the acute management of seizure clusters can help avoid their progression to 'status epilepticus' (see below) and reduce hospital transfer.

Formal action plans and education in the use of rescue medication for seizure clusters can help ameliorate outcomes for this group of Epilepsy sufferers.

Status Epilepticus - a seizure that lasts longer than 5 minutes, or having more than 1 seizure in 5 minutes, without returning to a normal level of consciousness between episodes.

Sudden Unexpected Death in Epilepsy (SUDEP) - death in people with Epilepsy not due to injury, drowning, or other known causes. Most but not all causes of SUDEP happen during or right after a seizure. The main risk factors are uncontrolled or frequent seizures, tonic-clonic seizures, drug resistant Epilepsy, and an increase in nocturnal seizures occurring. Therapies include Epilepsy surgery, devices, or diet therapy.

Policy

Australian Quality Care is committed to ensuring people with high risk of seizure receive safe and appropriate care and support relevant to their individual identified needs, as well as prescribed medication where required, to limit clinical risks.

Risk Analysis

Identified Risks

General Risks

- Lack of experience, knowledge, or understanding of seizure management and monitoring requirements to assess seizure triggers, and how to minimize exposure to seizure risk factors.

- Lack of knowledge, skill, and competency in the methods of emergency management and interventions to undertake during a seizure episode, e.g., application of First Aid, Positioning, and CPR.

- Incorrect interpretation of guidance in the Support Plan to support sound judgement on when to escalate treatment. This can include emergency hospital transfer requirements for safety and wellbeing.

- Insufficient knowledge and experience in documentation relating to the seizure episode, e.g., timing of the seizure duration, frequency, and description of seizure before, during and after, including outcome of any PRN medication administered.

Epilepsy-specific Risks

- Falls: not taking particular care and supervision of people when in the bathroom, kitchen, or any other room with hard surfaces.

- Burn-related injuries: scalding can occur in the kitchen or bathroom during seizures.

- Aggression or agitation: may occur as a seizure is ending when the person is confused.

- Risk of drowning: not ensuring particular care and supervision is given to a person at risk of seizures when showering or bathing, or when swimming.

- Prolonged seizures: prolonged or repetitive seizures without medical intervention may lead to status epilepticus and risk of suffocation.

- SUDEP: there is an estimated 20-fold increased risk of unexpected death among people with Epilepsy, compared to the general population.

Factors that may contribute to risks include inadequate Epilepsy medication, poor recording of Epilepsy management, inadequate seizure monitoring, support staff not being aware or confident of best practice in responding to seizures, and lack of access to timely medical reviews or specialist consultations.

Risk Management Strategies

General Risk Management Strategies

- Provide staff and health professionals with the relevant training and education in seizure recognition and First Aid to increase their knowledge, skills, and confidence to recognise seizures and safely administer seizure First Aid (including CPR and placing the person in a recovery position).

- Seizure documentation training provided to staff relating to the key points that need to be reported and documented for effective ongoing seizure management.

- Patient-specific training completed by staff, delivered by qualified health professionals.

- Medication management to be only undertaken by a person specifically trained in post-seizure medication (PRN) - correct administration and outcome monitoring is crucial and critical.

- Monitoring of staff competency by the Registered Nurse to ensure safe and effective care.

- Timely reporting to attending medical practitioner and the Registered Nurse if staff are at any time uncertain of what actions to take.

- Use of seizure detection alarms that can detect movement, falls, or heart rate deviations for people who are at risk.

Epilepsy-specific Risk Management Strategies

- Ensure Epilepsy medication is taken as prescribed.
- Recognise and address seizure triggers and risk factors that may reduce the likelihood of a seizure occurring.
- Implement strategies to reduce or eliminate the risk of injuries during seizures.
- Watch for changes in behaviour that may indicate a seizure, such as falling, unresponsiveness, confusion, or purposeless or uncharacteristic movements or behaviours.
- Maintain a detailed record of seizures, including the time and duration, triggers that may have preceded them, and behaviours before, during and after.
- Consult with a neurologist, specialist doctor or Epilepsy nurse to develop an individualised *Epilepsy Management Support Plan*, and *Medication Plan* (where prescribed).
- Develop, implement, and review protocols that guide decision-making when administering emergency (PRN) medication, and when an ambulance is required.
- Identify and discuss individual SUDEP risk factors through completing the *SUDEP and Seizure Safety Checklist* with a specialist Epilepsy nurse or treating doctor.

Roles and Responsibilities

To ensure Australian Quality Care's standards and commitments are met and delivered, the following actions are taken, and responsibilities assigned for seizure management support:

1. A *Seizure Management Support Plan* has been developed for each person and is overseen by a relevant health practitioner, and each person is involved in the assessment and development of their *Seizure Management Support Plan*.
2. *Seizure Management Support Plans* are up-to-date, readily available, clear, and concise, and clearly identify and describe people's support needs and preferences. They also identify how risks, incidents and emergencies will be managed, including required actions and escalation to ensure wellbeing.
3. People at risk of seizure are supported to seek regular and timely reviews of their health status by an appropriately qualified health practitioner. This includes support people with Epilepsy to arrange a review by their Neurologist or specialist doctor at least annually, or more often if seizures are not well controlled.
4. Each *Seizure Management Support Plan* is communicated, where appropriate and with the person's consent, to their support network, other providers, and relevant government agencies. Copies of the *Seizure Management Support Plans* are provided to the person at risk of seizure and readily available where care is provided.
5. Staff understand the support needs outlined in *Seizure Management Support Plans* such as:
    - what risks to look for and
    - action required to respond to risks, incidents, and emergencies.

6. Staff are provided with access to appropriate policies and procedures, timely supervision, support, equipment, and consumables required to provide seizure management support.

7. People who require seizure management support, and who also have Epilepsy, have an *Epilepsy Management Support Plan*, and a *Medication Plan* where Epilepsy medications are to be administered.

8. Policies, procedures, and plans are in place and easily accessible to staff, including a training plan for staff, that relate to the specific support provided to each person who requires seizure management support, including those who have Epilepsy.

9. A holistic approach to seizure management and Epilepsy support is taken, consistent with current contemporary practice, and is aligned with the *Infection Control Policy and Procedure*.

10. Skilled, trained, and experienced staff are allocated to manage people who have a high risk of seizure, as support provided is high risk and complex and can be life threatening if not effectively managed.

11. Where supports are delivered by a competent worker who is not a qualified or allied health practitioner, the Registered Nurse ensures:
    - the worker is suitably trained and equipped with the skills and knowledge required for safe service delivery and maintains currency of skills and knowledge
    - competency of workers' skills and knowledge is assessed annually
    - refreshers are completed when people's needs change, best practice requirements change, or when the worker has not provided the required support in the last three (3) months
    - supports are not provided until workers have successfully completed competency assessments and refresher training and
    - competency assessments are documented and regularly audited, with audit records and a *Training and Development Register* maintained.

12. Staff deployed to provide seizure management support have the pre-requisite knowledge and have completed training delivered by an appropriately qualified health practitioner. They receive regular supervision, support, equipment, and consumables required to provide support.

    <u>Seizure management support training must include:</u>
    - basic anatomy of the nervous system
    - types of seizures and underlying causes
    - seizure triggers, such as missed or changed medications, lack of sleep, fever, stress (physical or emotional), dehydration, constipation, photo sensitivity (flashing lights), and environmental factors, e.g., change in home environment, temperature, or noise
    - how to identify and minimise exposure to seizure risk factors
    - the difference between a seizure and a heart attack, stroke or syncope (fainting)
    - monitoring and recording seizure information, including the type, duration, frequency, and common patterns or clusters
    - what to check for before, during and after seizures, and required documentation
    - the distinction between Epilepsy (when there are recurring seizures) and a single event seizure due to an acute cause, e.g., brain trauma, high fever, etc.
    - the impact of Epilepsy, including risks of related health and other complications, e.g., loss of sense of independence, memory and learning problems, sleep disorders, and heart disease
    - appropriate seizure recognition, seizure management, and control procedures
    - factors that increase risk and appropriate methods of control
    - emergency response including Epilepsy First Aid and CPR and
    - interpreting advice in *Seizure Management* and *Epilepsy Management Support Plans* and exercising sound judgement on when to escalate treatment.

    Where required, additional training must be provided on the parameters to guide decisions in administering Epilepsy medication such as Midazolam, and medication-specific emergency procedures.

In addition, where relevant intensive training must be provided in the correct administration of emergency medication, and positioning required to administer those medications safely and correctly.

13. In addition to the above, staff must also keep their first aid knowledge and CPR training up-to-date and be trained on the specific needs of each person, including the appropriate use of equipment.

14. The *Seizure Management Support Plan* and/or *Epilepsy Management Support Plan* is signed by the person at risk of seizure, their health practitioner, and the Registered Nurse, agreeing to the Plan and providing informed consent.

15. *Seizure Management Support Plans* and *Epilepsy Management Support Plans* are reviewed, evaluated, and updated regularly, and when changes occur.

16. Referrals are facilitated by the Registered Nurse to other relevant health professionals, where required, in consultation with the person at risk of seizure and their health practitioner.

17. Australian Quality Care accesses appropriate equipment for people who require seizure or Epilepsy support and provides staff with the required training on equipment use and maintenance.

18. Staff communicate with people using their preferred communication method e.g., use of devices, aides, or language resources as needed, e.g., picture cards.

19. The Registered Nurse monitors compliance with support requirements via an internal audit process and stakeholder feedback surveys, to ensure service provision is appropriate and effective.

20. The Registered Nurse:
    - ensures all support workers undertake the necessary training
    - maintains training records and appropriate registrations and
    - monitors staff compliance.

21. All health professionals and consulting Health Practitioners are accountable for their own practice and are aware of their own legal and professional responsibilities of work within the Code of Practice of their professional body.

Precautions/Considerations

Seizure can be a result of a medical condition (that is, provoked) or of Epilepsy or Traumatic Brain Injury (unprovoked). There are many other types of seizures and the majority end in a few minutes. It is important to keep the person safe until the seizure episode stops and know when to call for an ambulance for more acute care.

Epilepsy is not a mental condition. Not everyone who has a seizure has Epilepsy - knowing how to help during a seizure episode can make a difference and save the person's life.

Epilepsy is more common among people with disabilities such as Autism and intellectual disability. They are also more likely to have severe and uncontrollable seizures, and an increased risk of associated death. In addition, they may be less likely to receive adequate treatment for their Epilepsy compared to the general population.

Staff should consult with the person on how they would like to be best supported during seizures, and identify any seizure risk factors, e.g., falls, to remove or minimize exposure.

People with high risk of seizures must have a baseline seizure assessment completed, which includes seizure type, triggers, patterns, and duration, and their relevant medical history.

Staff deployed to support people at risk of seizure must:

- have access to a charged, fully functional phone at all times for emergency contact
- be sufficiently skilled, competent, and confident to support the person safely
- be encouraged to contact the Registered Nurse and medical practitioner if they are uncertain or not confident on any aspect of a person's seizure management
- be alert to any psychological problems the person may experience e.g., fear, anxiety, depression, bipolar disorders, and suicidal tendencies, and alert the medical practitioner and Registered Nurse for appropriate action and supportive treatment
- be aware of other factors that can cause seizures e.g., alcohol or drug withdrawal. Seizures during alcohol or drug withdrawal are generally self-limited, although they can also be very serious and require seizure management interventions
- administer and check the person has taken their anti-Epileptic drugs as prescribed to prevent the occurrence of seizures and
- facilitate referrals and promote access to timely medical reviews and specialist consultation.

Procedures

As seizure management and Epilepsy support are highly personal in nature and high risk, staff need to maintain communication and work closely with people at risk of seizure to understand their specific needs, and when and how to best deliver supports that meet the person's preferences and daily routines.

General

1. Check and confirm consent is current for seizure management and Epilepsy support, including medication management where required.

2. Read and understand the *Seizure Management Support Plan*, as well as any *Epilepsy Management Support Plan* and *Medication Plan*, and perform duties only within scope of practice.

3. Ensure the person's privacy and dignity, as well as a safe environment, prior to commencing support.

4. Communicate with the person as per their preferred communication method e.g., use of devices, aides, or language resources as needed, e.g., picture cards.

5. Follow strict personal hygiene handwashing and infection control procedures before, during, and after providing care.

6. Consult with the person on how they would like to be supported during a seizure episode and identify and minimize any risk factors that could cause potential harm.

7. Check and be familiar with the person's seizure triggers, signs and symptoms, types of seizures experienced, and frequency, patterns, and duration, to understand and undertake appropriate early interventions.

8. Ensure the person takes any anti-Epileptic medication as prescribed in the correct doses and time intervals. Medications must not be stopped unless consultation has occurred first with the person's medical practitioner. Specific drug therapy depends on seizure type, with some people requiring multiple medications, or frequent medication adjustments. The goal is optimal seizure suppression with the lowest possible dose of a drug and fewest side effects.

9. People should be supported to seek a neurologist or specialist doctor as soon as possible if:
    - they are not responding to anti-seizure medication
    - their seizures are not controlled
    - they are experiencing unwanted side effects from their medication or
    - they have any concerns about their Epilepsy treatment.

Support in the Event of a Seizure

1. People may experience seizures while receiving supports. While there are different types of seizures, individuals can have many symptoms, meaning that one person's seizure frequently appears very different from another person's seizure. Therefore, the type of seizure, how to support the person during a seizure, and specific emergency procedures will be unique for each person.

2. Support the person during a seizure with the specific emergency procedures detailed in their *Seizure Management* and/or *Epilepsy Management Plan*.

3. Stay with the person until they are awake and alert after the seizure episode.

4. Time the seizure (frequency and duration), monitor the person's breathing, and keep their airway clear.

5. Remain calm and talk to the person to reassure them until they regain consciousness.

6. Do **not** restrain or hold the person down to stop jerking movements.

7. Do **not** put any objects in the person's mouth.

8. Keep the person free from harm.

9. Turn the person onto their side if they are not awake and aware (recovery position). This is particularly important if the person has vomited or has food or fluid in their mouth, as it is a potential aspiration and choking hazard.

10. Loosen any tight clothing around the person's neck, chest, and abdominal areas.

11. Put something small and soft under the person's head.

12. When the seizure stops, put the person in the recovery position.

13. If the person falls asleep after the seizure episode, don't disturb them. Let them sleep but keep monitoring their breathing.

14. Do not give the person any food or drink until the seizure episode is completely resolved and they are fully conscious and awake.

15. Re-orientate the person following the seizure episode to alleviate their anxiety - they may be confused, anxious, or disorientated.

16. Allow for “automatic behaviours” without interfering, while keeping the person safe, as attempts to control or prevent activity may result in the person becoming aggressive or combative.

17. Investigate any reports of pain, which may be due to repetitive muscle contractions or symptoms of an injury incurred, that require further evaluation or intervention..

18. **Call “000” for an ambulance if:**
    a. **the seizure lasts 5 minutes or more, or as specified in the person’s *Support Plan***
    b. **status epilepticus occurs**
    c. **the person does not return to their usual self after the seizure episode**
    d. **this is a first seizure event for the person**
    e. **difficulty breathing is observed and the person is unconscious or**
    f. **the person has an injury that requires further medical attention.**

19. If the person is admitted to hospital, ensure that a copy of their *Seizure Management Support Plan*, as well as any *Epilepsy Management Support Plan* and *Medication Plan* goes with them, and that hospital staff are aware of any Epilepsy medication that has been prescribed.

20. On discharge from hospital, support the person to follow up on recommendations, including neurologist or specialist doctor review where indicated.

21. Ensure any emergency post-seizure medication (PRN) is administered only by highly trained staff, as correct administration is critical and requires the person to have basic first aid skills, CPR skills, and positioning skills.

22. Undertake and document a neurological/vital signs check after the seizure, e.g., level of consciousness, orientation, ability to comply with simple commands, ability to speak, memory of incident, weakness or motor deficits, blood pressure (BP), pulse, and respiratory rate.

23. Time completeness of recovery to a normal state (this may identify additional concerns to be addressed).

24. Advise the person’s medical practitioner and Registered Nurse of the seizure episode, actions taken, and outcomes.

25. Maintain a seizure log of what happened before, during, and after the seizure episode in the person’s records. Ensure documentation includes their pre-seizure activity, e.g., presence of aura or unusual behaviour, including whether they fell, called out, drooled, or had automatisms (e.g., lip smacking, chewing, picking at clothes). Also record the type of seizure activity (e.g., location, duration, loss of consciousness, incontinence, eye activity, respiratory impairment, cyanosis, etc.).

26. Keep the *Seizure Management Support Plan*, as well as any *Epilepsy Management Support Plan*

and *Medication Plan*, updated.

27. Actively involve the person to the extent they choose, check any changes needed to support they are receiving, and any other aeras where the *Seizure Management Support Plan*, *Epilepsy Management Support Plan* or *Medication Plan* are not meeting their needs.

28. Encourage feedback from the person and request changes from attending health professionals to their *Support* or *Medication Plans* as required.

29. Identify, document, and report information where *Support* or *Medication Plans* are not meeting the person's needs.

30. Undertake ongoing training and education and maintain up to date First Aid knowledge and participate in regular competency assessments to ensure practices are safe and up to date with current best-practice guidelines for supporting people at high risk of seizure.

Supporting documents

Procedural guidelines for high risk of seizure management are covered in the following documents for staff and can be used for reference where seizure management is provided.

Documents relevant to this policy and procedure include:

- *Management of Medication Policy and Procedure*
- *Infection Prevention and Control Policy and Procedure*
- *Reportable Incident, Accident and Emergency Policy and Procedure*
- *Seizure Management Support Plans*
- *Epilepsy Management Support Plans*
- *Medication Plans*
- *Staff Training Plan*
- *Staff Training and Development Register*
- *Staff Performance Reviews*
- *Incident Forms*
- *Continuous Improvement Plan*
- *Epilepsy Action Australia - SUDEP and Seizure Safety Checklist*

References

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Monitoring and review

This Policy and Procedure will be reviewed by the Board annually, or sooner if changes in legislation occur or new best practice evidence becomes available. Reviews will incorporate staff, the participant, and other stakeholder feedback, and identified continuous improvements as relevant.

Review of procedures will assess if their implementation is efficient, effective, and able to be actioned.

Australian Quality Care's *Continuous Improvement Plan* will be used to record improvements identified and monitor the progress of their implementation. Where relevant, this information will be considered as part of Australian Quality Care's future service planning and delivery processes.

Document Control

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