Neurosciences & the Senses Health Network

WA Epilepsy Services Model of Care

Prepared by the
Epilepsy Review Committee
Neurosciences & the Senses Health Network

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WA Health Networks

Working Together to Create a Healthy WA

Government of **Western Australia**
Department of **Health**

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ACKNOWLEDGEMENTS

This Model of Care summarises the *WA Epilepsy and Clinical Neurophysiology Services* 2007 (**Appendix 1**), developed by the Neurosciences & the Senses Health Network, Epilepsy Review Committee.

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1. BACKGROUND

Epilepsy is the most common serious neurological condition, affecting 1-2% of the population. In Western Australia, at least 20,000 people have active Epilepsy with at least a further 1,400 new patients presenting with a seizure each year. One in 20 children will have a seizure at some time during childhood and adolescence, and Epilepsy is increasingly common after the age of 50 years. The cumulative incidence of epilepsy, the risk of an individual developing epilepsy in his or her lifetime, is between 3 and 5%.

The majority of patients with Epilepsy can be effectively treated, given an accurate diagnosis and appropriate treatment, and are able to lead normal lives.

Ongoing seizures have a major impact on the burden of illness to the patient and the community, including quality of life, mortality and economic costs. The health care costs of Epilepsy increase dramatically in proportion to seizure frequency, whilst the costs of seizure-free Epilepsy patients are similar to the healthcare costs of the general population.

2. VISION AND FUTURE DIRECTIONS

The vision for WA is for integrated Epilepsy services, providing all Western Australians with the opportunity of accessing optimal care and information.

This report and its associated recommendations provide key directions for the delivery of more efficient and equitable Epilepsy care and clinical services in Western Australia. It provides evidence-based recommendations on the diagnosis and treatment of Epilepsy.

The next level of development for the *WA Epilepsy Services Model of Care* will look toward a more detailed plan for the delivery of Care in the Rural & Remote areas of Western Australia.

3. METHODOLOGY

The Epilepsy Review Committee (ERC), a subgroup to the Neurosciences and the Senses Health Network, developed the *WA Epilepsy and Clinical Neurophysiology Services* document in 2006-7. The *WA Epilepsy Services Model of Care* paper draws on the information provided in this document **(Appendix 1)**, as well as international guidelines and pathways.

The *WA Epilepsy and Clinical Neurophysiology Services* document outlines the benefits of integrated Epilepsy Services to deliver improved and cost effective patient outcomes.

WA Comprehensive Epilepsy Service staff from all campuses has contributed to submissions over a long consultative process (since 1990). In addition to monthly service meetings, numerous meetings with patients and their families, clinical staff, voluntary organisations and medical administrations have occurred over these years.

We have referred to the published international guidelines, in particular the Scottish Intercollegiate Guidelines Network (SIGN) and National Institute for Clinical Excellence (NICE) guidelines.

The WA Comprehensive Epilepsy Service and its framework have the full endorsement of the voluntary organisations, the WA Epilepsy Association and the Epilepsy Society of Australia.

The *WA Epilepsy Services Model of Care*, approved by the ERC, was endorsed by the Neurosciences & the Senses Health Network Executive Advisory Group. A broader consultation of the Model was conducted with key stakeholders, including:

- State Health Executive Forum (SHEF)
- Health Reform Implementation Taskforce
- Executive Director, Health Policy & Clinical Reform
- Health Information Division
- Office of the Director General
- Area Chief Executives
- Health Finance
- Clinical Leads of all Health Networks
- Clinical Services Planning
- Directors of Nursing
- Medical Directors
- WA General Practice Network

The number of stakeholders identified for this consultation phase was 76 and feedback received was incorporated into the Model as appropriate.

4. CURRENT SERVICE PROVISION

4.1 WA Comprehensive Epilepsy Service

The WA Comprehensive Epilepsy Service is a state-based service, which aims to provide equitable access and optimal care to patients with Epilepsy. The service commenced in 1990, and involves all teaching hospitals. It continues to lead the organisation of care for Epilepsy patients across the state.

Limited resources have required a focus on people with the most severe Epilepsy, with the establishment of specialist-led Epilepsy clinics and inpatient services at the tertiary sites, and of the single adult (RPH) and paediatric (PMH) Epilepsy Centres.

Funds for the development of service facilities and equipment have been provided by a wide range of sources including donations from community groups (Western Australian Epilepsy Association, Appealathon and the Red Cross), the Health Department, internal funding, the pharmaceutical industry, research funding and private donations.

4.2 Single Adult and Paediatric Epilepsy Centres

Refractory Epilepsy care, both medical and surgical, requires a highly sub specialised and multidisciplinary team and is not a core service for all teaching hospitals, given the population of WA.

Single adult and paediatric centres will continue to:

- Provide a viable state-wide referral service of the highest quality for the population base of WA.
- Build sustainable and adequately resourced adult and paediatric Epilepsy reference centres including clinical service, teaching and research commitments.
- Build the required highly sub-specialised and multidisciplinary team.
- Ensure that adequate medical, technical and nursing skills are maintained and the subspecialty further developed.
- Avoid the cost of duplication of expensive and highly specialised services.
- Allow for economies and efficiencies of scale.

This framework was established in 1996 with the consensus endorsement of the WA Comprehensive Epilepsy Service, involving all teaching hospitals. It has the endorsement of the Health Department of WA, and conforms to international standards of best practice.

The Adult and Paediatric Epilepsy Centres share resources and work very closely together, providing a continuum of care from childhood to adult life.

Patients are referred from all over the metropolitan area and rural Western Australia. Most patients of this service have severe Epilepsy and need complex and ongoing subspecialty care, have been referred for evaluation of a first seizure or for clarification of diagnosis. The proportion of Epilepsy referrals by region reflects the proportion of the Western Australian population by region, with the exception of the Pilbara and other northern areas, which are under-represented. There is a significantly higher incidence of epilepsy in Indigenous Australians.

Clinical and EEG outreach services are provided by the Epilepsy Centres, as are educational programmes for other health professionals and the community.

5. MODEL OF CARE: SERVICES FOR PATIENTS WITH EPILEPSY

Best practice Epilepsy management requires an integrated, multidisciplinary network of primary and specialist care including the GP, general physicians, paediatricians, neurologists, epileptologists, Epilepsy nurses, psychiatrists and psychologists. In addition, close liaison with the education, social work and voluntary sectors is of considerable importance for comprehensive Epilepsy care.

5.1 Essentials of Care

The current management of Epilepsy in Western Australia requires strengthening. Areas of specific concern include accurate initial diagnosis, adequacy of investigation and treatment, management of pregnant women and neonates with Epilepsy, equitable access to care for rural patients, and the ready availability and provision of patient information.

Essentials of care include an accurate diagnosis, optimal investigation and treatment, well-informed patients, co-ordinated long-term care and counselling appropriate to individual needs.

It has been shown that a substantial proportion of Epilepsy diagnoses made by non-specialists are incorrect. Of the patients referred to Western Australian first seizure clinics, 25% have had convulsive syncope rather than an epileptic seizure. Up to a quarter of patients referred for specialist management of apparent drug-resistant Epilepsy on further investigation do not have Epilepsy. Misdiagnosis of Epilepsy has significant implications, such as unnecessary investigations, cost and adverse effects of unnecessary medication, as well as adverse psychosocial and employment consequences [(2)].

Diagnosis and initial treatment is best delivered in a dedicated hospital-based first seizure clinic or by a private neurologist with expertise in Epilepsy. In addition to expert clinical assessment, accurate diagnosis also requires access to a range of diagnostic and investigative tools, including neurophysiology and neuroradiology performed by adequately trained and experienced staff. Dedicated diagnostic facilities for children cater better to their particular needs.

Antiepileptic drug (AED) treatment must take into account the Epilepsy syndrome. AEDs should not routinely be given until the diagnosis of Epilepsy has been confirmed. An Epilepsy specialist should recommend initiation of appropriate treatment and plan continuation of treatment.

Routine monitoring of AED concentrations is generally not indicated. Dose adjustments should be based on seizure control and AED side effects. Discontinuation of AED treatment should be managed by, or be under the guidance of, the Epilepsy specialist.

Failure to respond to AED treatment requires a specialist-led, structured approach to management as provided by the adult and paediatric Epilepsy centres. The choice of drugs singly and in combination should be matched to the patient's seizure type. Adequacy of seizure control must be balanced with the adverse effects of treatment to optimise quality of life. Epilepsy surgery is an effective treatment for some patients with focal Epilepsy resistant to drug treatment.

Close liaison with educational services, social work and the voluntary sector is of considerable importance.

Parents and family members of children with refractory Epilepsy carry a heavy burden. Respite services are required.

Anxiety and depressive disorders are common in people with Epilepsy and the availability of psychological and psychiatric care is a significant issue. When indicated, psychiatric intervention at the earliest opportunity is required to avoid the considerable financial, psychological, social and vocational costs of delayed diagnosis and treatment.

5.2 Primary Care

A shared care management system for Epilepsy should seek to establish the role of the GP and other primary care staff in the following areas:

- Making the provisional diagnosis in new patients and providing appropriate initial information.
- Referring all patients with suspected Epilepsy to an Epilepsy specialist.
- Monitoring progress.
- Disseminating information.
- Assessing and assisting with treatment of co-morbidities.
- Advocacy and support.
- Regular structured reviews.

Implementation of such a shared care model would be facilitated by deployment of specialist Epilepsy nurses, who can liaise between primary care and hospital care and provide people with quick access to medical advice. In rural areas, community nurses would have his role, given adequate training and support.

The primary care needs of patients with Epilepsy should include a structured regular review, as is common with other chronic diseases such as asthma and diabetes.

Interested GPs should be encouraged to be involved as supervised clinical assistants, working for two sessions per month in a hospital-based Epilepsy clinic. This will link primary care to the hospital system and establish real, shared care of patients. Stronger links should be forged with paediatricians and physicians who have a special interest in Epilepsy.

5.3 Emergency Centre and Secondary Care

Assessment of patients with suspected seizures or with Epilepsy are an essential part of the emergency departmental activities of all public hospitals.

These currently comprise initial/emergency assessment of patients with seizures or possible seizures, acute investigations and treatment if necessary and early referral/transfer for tertiary outpatient or inpatient care as required.

For Emergency Centre and Secondary care, an improved and standardised approach to management is required with:

- Common evidence-based protocols for acute seizure assessment and treatment (first seizure, status epilepticus).
- Ready access to patients' medical information.
- CT scanning at presentation or within 24hrs of presentation if required
- Urgent neurological advice on call.
- Ready referral path to specialised services when necessary.
- Evidence-based, uniform information sheets for patients and carers outlining safety issues (e.g. driving, bathing, and diving).

A seizure management plan provided by the treating neurologist for patients who have complicated Epilepsy will assist Emergency Centre Staff.

Emergency Department staff needs 24-hour access to neurological advice – ideally a metropolitan roster should be implemented.

5.4 Tertiary Care

For Tertiary care, specialist-led Epilepsy services and outpatient clinics are an essential part of the core neurology departmental activities of all tertiary teaching hospitals, developed as an integral part of the WA Comprehensive Epilepsy Service. These comprise: initial/emergency neurological assessment, inpatient neurology care when necessary, dedicated hospital-based Epilepsy clinics (first seizure, follow-up and ongoing care), with access to specialised investigations (EEG, imaging) and diagnostic video-EEG monitoring as required.

Refractory Epilepsy care, both medical and surgical, requires a highly sub specialised and multidisciplinary team and is not a core service for all teaching hospitals in WA.

Single adult and paediatric centres were established by the WA Comprehensive Epilepsy Service, and they will continue to provide a viable statewide referral service of the highest quality for the population base of WA, including evaluation for surgery and Epilepsy surgery monitoring. Highly specialised and purpose-built infrastructure is required to allow the Adult and Paediatric Epilepsy Centres to continue to provide optimal patient care, with purpose-built and contiguous facilities that are of crucial importance for optimal patient care.

The Adult and Paediatric Epilepsy Centres have essential links with each other (clinical, dedicated video-EEG) and with related disciplines including neuroimaging, neurosurgery, neuropsychology, neuropsychiatry and neuropathology.

Neurophysiology surgical monitoring also requires an integrated and cross-campus approach to provide a viable statewide service of the highest quality for the population base of WA and to meet the specific needs of patients at the various tertiary campuses.

Specialist-led Epilepsy services should be delivered at the tertiary sites as an integral part of the WA Comprehensive Epilepsy Service seamlessly linked to the single adult and paediatric Epilepsy centres.

Specialist-led clinics are well established in the management of Epilepsy. These clinics provide the expertise of Epilepsy specialists and Epilepsy specialist nurses, and access to further specialised investigations and inpatient facilities. They also have important roles in teaching and research in Epilepsy. Subspecialty Epilepsy clinics should also be available to meet the needs of specific groups of patients (Epilepsy in learning disability, in pregnancy, adolescent transition to the adult service and in potential surgical candidates).

5.5 Equity of Access

A key aim is equity of access to specialised Epilepsy services. Many patients in regional areas have limited or no access to specialist advice and the equitable provision of Epilepsy care is a major challenge.

Well-resourced Telehealth facilities will enable patients in regional areas to be evaluated close to their homes with the assistance of nursing and medical staff who know them and who are responsible for their other medical requirements. These facilities will support country GPs by linking them to specialist services, and will allow triaging of consultations and investigations that need to be done in the Metro area.

In addition, the development of specialised outreach clinics would allow an integrated and statewide approach to care, while potentially building stronger clinical and educational links with local GPs and other health professionals. These outreach clinics could be developed in the major regional centres and would supplement well-resourced Telehealth/Teleconferencing facilities.

Initial diagnostic evaluation with specialised MRI and EEG may require travel to Perth. Travel may be difficult, time consuming and expensive, so coordination of the clinical assessments and investigations is essential.

Patients in remote locations may require additional support, including a seizure management plan and contingency plans for seizure exacerbations.

Private specialists make an important contribution to secondary and tertiary Epilepsy care, particularly outpatient services.

5.6 Information and Education in Epilepsy Care

People with Epilepsy need clear, accurate and appropriate information about their condition.

The ready availability of this information for people with Epilepsy and their families is essential for effective care. This includes information about the cause of Epilepsy, treatment and impact of medications and the implications for safe everyday living.

A checklist could be provided to health workers to give a structure to discussion and ensuring important points such as management of risks are covered. Written information, helpline telephone numbers and contact details of voluntary organisations should be provided to all patients and their families.

Information for schools and the community as well as Epilepsy awareness training should also be available.

The Non-Government and voluntary sector has an extremely important role in providing advice, support, advocacy and education for families affected by Epilepsy.

6. IMPLEMENTATION AND AUDIT

6.1 Implementation

It is acknowledged that not every guideline can be implemented immediately, but mechanisms should be in place to ensure that the care provided is reviewed against the guideline recommendations and the reasons for any differences assessed and, where appropriate, addressed.

Implementation discussion should involve both clinical staff and management. Local arrangements may then be made to implement the guideline in individual hospitals, units and practices, and to monitor adherence. This may be done by a variety of means including patient-specific reminders, continuing education and training and clinical audit.

6.2 Key Points for Audit

6.2.1 Diagnosis

- Proportion of adult first seizure and Epilepsy patients seeing an Epilepsy specialist.
- Proportion of children with Epilepsy seeing an Epilepsy specialist.
- Time to specialist assessment and investigations following first seizure.
- Time to diagnosis of Epilepsy.
- Proportion of patients seeing an Epilepsy nurse specialist when diagnosis is discussed.
- Proportion of patients and carers receiving written information when diagnosis is discussed.
- Accuracy of diagnosis of Epilepsy, seizure classification and Epilepsy syndrome classification.

6.2.2 Treatment

- Proportion of treatment recommended by an Epilepsy specialist.
- Proportion of patients that are seizure free.
- Number on monotherapy, two, three and four drugs.
- Drug levels only done for appropriate indications.
- Percentage of schools offered Epilepsy awareness training and written Epilepsy information.
- Existence and use of local protocol for management of status epilepticus.

6.2.3 Contraception, pregnancy and Hormone Replacement Therapy

Documentation of:

- Contraceptive advice.
- Preconception counselling.

- Risks of Epilepsy and antiepileptic drugs in pregnancy.
- Information given about the Australian Pregnancy Register for Epilepsy.
- Advice about care of the baby and breastfeeding.
- Proportion of pregnant women taking folic acid appropriately.

6.2.4 Models of care

The extent to which data on the measures outlined above are routinely shared between primary and specialist care is a consideration for audit. It should include:

- Proportion of patients in primary care:
    - Receiving structured annual review (at least six monthly in children).
    - With documentation within past year of:
        - Seizure frequency.
        - Last seizure.
        - Drug adverse effects.
        - Review of medication.
- Access to Epilepsy nurse specialist.

6.2.5 Tertiary care

- Availability and speed of access to specialist first seizure clinics.
- Availability and speed of access to specialist Epilepsy clinics.
- Availability and speed of access to subspecialty joint clinics (teenage, pregnancy).
- Availability and speed of access to specialist investigations.

7. RESOURCE IMPLICATIONS

Implementation of these recommendations will require the identification and recruitment of additional staff with expertise in Epilepsy and clinical neurophysiology, including training and ongoing administrative support for these posts. This group may have immediate and ongoing professional development needs.

Telehealth facilities and resources will require significant enhancements, including additional staff, in order to provide adequate support for rural and country patients and their health carers.

MRI facilities are increasingly available within district general hospitals. Availability of specialists to interpret the MRI is more limited. There are resource implications in terms of training and sharing of specialist skills across WA, and with the provision of high field MRI systems.

8. RECOMMENDATIONS

Recommendation 1:

The development of evidence-based **guidelines and pathways** for the appropriate management of Epilepsy, including:

- Diagnosis and treatment decisions that should be guided by an Epilepsy specialist;
- Standardised approach to emergency and secondary care, including acute seizure assessment and treatment in Emergency Departments;
- Ongoing management of Epilepsy with a clearly defined management plan, regular structured reviews and appropriate referral pathways

Recommendation 2:

The development of **appropriate outpatient services**, including:

- A shared care system for Epilepsy between primary care and specialist Epilepsy services facilitated and enhanced by the deployment of specialist Epilepsy nurses.
- Ready access to a range of investigations, particularly EEG and MRI, when clinically indicated, provided by staff with subspecialty training and experience.
- Specialist-led Outreach services in secondary hospitals, metropolitan and regional, as an integral part of the WA Comprehensive Epilepsy Service.
- Well-resourced telehealth facilities and specialised outreach clinics in regional areas to provide equity of access for country patients and adequate support for their health carers.
- Specialised Epilepsy services at the tertiary sites to meet the needs of specific groups of patients (e.g. First Seizure, Epilepsy in learning disability, in pregnancy, adolescent transition to the adult service and in potential surgical candidates).

Recommendation 3:

The further development of **specialised Epilepsy services at the tertiary sites:**

- As an integral part of the WA Comprehensive Epilepsy Service.
- With single adult and paediatric Epilepsy reference centres caring for patients who require more detailed evaluation and management, including presurgical treatment and Epilepsy surgery.
- With the adult and paediatric Epilepsy centres having purpose-built facilities and ready access to the spectrum of advanced imaging techniques provided by neuroimaging specialists.
- With the adult and paediatric Epilepsy centres having integral neuropsychiatry and neuropsychology staff.

- With the tertiary sites having a dedicated intramural and cross-campus video-EEG network.
- With the interrelated intraoperative neural monitoring continuing to be provided and further developed as a cross-campus and statewide service.

Recommendation 4:

The development of **information and education materials**, including:

- Information for patients, families, carers, schools and the community.
- A checklist to help healthcare professionals deliver appropriate information.
- Involvement of and a partnership with the voluntary sector.

Recommendation 5:

The development of **Information and Communication Technology** for the electronic patient records system that will provide access to patient medical information across campuses.

Recommendation 6:

The development of a **detailed implementation plan** that incorporates:

- Consideration of staffing levels required to develop and support the W.A. Comprehensive Epilepsy Service, including the adult and paediatric Epilepsy centres.
- Strategies for recruitment and retention of staff for ongoing viability of services. This may include ongoing subspecialty training.
- Provision of ongoing administrative support, including database and audit for evaluating needs and outcomes.

GLOSSARY

ALOS

Average length of stay. It refers to the number of days patients stay in medical institutions such as hospitals.

DRG

Diagnosis Related Group. A system to classify hospital cases into one of approximately 500 groups.

EEG

Electroencephalogram. A diagnostic test, which measures the electrical activity of the brain using highly sensitive recording equipment, attached to the scalp by fine electrodes.

Epilepsy

An ongoing predisposition to recurrent unprovoked seizures

Intraoperative monitoring

The constant checking on the state or condition of a patient during the course of a surgical operation (e.g., checking of vital signs).

MRI

Magnetic Resonance Imaging. A specialised imaging technique used to image internal structures of the body, particularly the soft tissues. An MRI image is often superior to a normal X-ray image.

Neurophysiology

Physiology of the Nervous System.

Refractory Epilepsy

Consistent, recurrent seizures despite appropriate treatment

Seizure

A sudden disturbance of electrical activity in the brain that can result in a wide variety of clinical manifestations such as: muscle twitches, staring, tongue biting, urination, loss of consciousness and total body shaking.

Status epilepticus

A life threatening condition in which the brain is in a state of ongoing or recurrent seizures without fully recovering between seizures for more than 30 minutes.

Syncope

Transient global reduction in brain blood flow leading to loss of consciousness.

Telehealth

The use of electronic information and telecommunications technologies to support long-distance clinical health care, professional health-related education, public health, and health administration. (Dorland's Medical Dictionary).

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APPENDICES

Appendix 1: WA Epilepsy and Clinical Neurophysiology Services

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Appendix 2: Epilepsy DRG data

****Table 1:** Public hospital separations by DRG for Western Australia Metro/Country, year and sameday/overnight stay (Epilepsy as principal diagnosis).

	DRG	Description	Total Separations			
			2002	2003	2004	2005
Metro WA						
SAME DAY	B76B	Seizure W/O Catastrophic or Severe CC	122	161	166	175
	B76A	Seizure W Catastrophic or Severe CC	5	15	6	11
Total			**127**	**176**	**172**	**186**
OVERNIGHT	B76B	Seizure W/O Catastrophic or Severe CC	529	529	529	584
	B76A	Seizure W Catastrophic or Severe CC	180	148	126	143
Total			**709**	**677**	**655**	**727**
Country WA						
SAME DAY	B76B	Seizure W/O Catastrophic or Severe CC	112	117	120	114
	B76A	Seizure W Catastrophic or Severe CC	18	13	5	9
Total			**130**	**130**	**125**	**123**
OVERNIGHT	B76B	Seizure W/O Catastrophic or Severe CC	536	576	487	519
	B76A	Seizure W Catastrophic or Severe CC	92	67	72	68
Total			**628**	**643**	**559**	**587**

Source: Epidemiology Branch, Analysis and Performance Reporting, DOH, WA Dec 2006

Table 2: Public hospital ALOS for DRG by Western Australia Metro/Country and year (Epilepsy as principal diagnosis) over total separations.

	DRG	Description	ALOS			
			2002	2003	2004	2005
Metro WA						
ALOS	B76B	Seizure W/O Catastrophic or Severe CC	2.2	2.5	2.2	2.3
	B76A	Seizure W Catastrophic or Severe CC	6.8	10.3	9.4	7.1
Country WA						
ALOS	B76B	Seizure W/O Catastrophic or Severe CC	4.4	2.7	2.2	2.0
	B76A	Seizure W Catastrophic or Severe CC	3.4	3.3	4.7	4.1

Source: Epidemiology Branch, Analysis and Performance Reporting, DOH, WA Dec 2006

Table 3: National Public Hospital cost per separation by DRG (Epilepsy as principal diagnosis).

	DRG	Description	ALOS			Cost per Seps ($)
			Metro WA	Country WA	National	
National						
	B76B	Seizure W/O Catastrophic or Severe CC	2.3	2.8	2.1	1,845
	B76A	Seizure W Catastrophic or Severe CC	8.4	3.9	7.0	5,489

Source: Australian Hospital Statistics 2004-05, Australian Institute of Health and Welfare (AIHW).

Note:

When reviewing the above data, it is important to note that Epilepsy does not have a Diagnosis Related Group (DRG). In the most straightforward cases, when Epilepsy is the primary reason for admission, the DRG will be B76A or B76B. However these DRGs also contain admission for fit, seizure and convulsion not specified as Epilepsy. The ICD-10-AM codes for Epilepsy principal diagnoses are G40.xx or G41.xx.

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EXECUTIVE SUMMARY

Epilepsy is the most common serious neurological condition, affecting more than 1% of the population. In Western Australia at least 20,100 people have active epilepsy with a further 1400 new patients presenting each year.

The majority of people with epilepsy can be effectively treated, enabling them to lead normal lives. However ongoing seizures have a major impact on the burden of illness to the patient and the community, including quality of life, mortality and economic costs.

The current management of epilepsy in Western Australia is sub-optimal. Areas of specific concern include accurate initial diagnosis, adequacy of investigation and treatment, management of pregnant women and neonates with epilepsy, equitable care of rural patients, and the ready availability and provision of patient information.

Best practice epilepsy management requires an integrated, multidisciplinary network of primary and specialist care including the GP, paediatricians, neurologists, epilepsy nurses, psychiatrists and psychologists. In addition, close liaison with the education, social work and voluntary sectors is of considerable importance for comprehensive epilepsy care.

It has been shown that a substantial proportion of epilepsy diagnoses made by non-specialists are incorrect. Detailed knowledge of epilepsy and its treatment cannot be reasonably expected of GPs. Misdiagnosis of epilepsy has significant implications, such as unnecessary investigations, cost and adverse effects of unnecessary medication and adverse psychosocial and employment consequences. Diagnosis and initial treatment is ideally delivered in a dedicated hospital-based first seizure clinic or by a private neurologist with expertise in epilepsy. In addition to expert clinical assessment, accurate diagnosis also requires access to a range of diagnostic and investigative tools including neurophysiology and neuroradiology. Dedicated diagnostic facilities for children cater better to their particular needs.

Clinical neurophysiology services have an essential role in diagnosis, monitoring and treatment of epilepsy and other neurological conditions. Diagnostic neurophysiology services form a part of the core services of all tertiary hospitals, and are also provided in the private sector. More specialised neurophysiology assessments and treatments, including intra-operative neural monitoring, are confined to tertiary teaching hospitals. An integrated and adequately resourced state public hospital service is required to meet specific patient needs.

Anxiety and depressive disorders are quite common in people with epilepsy and the availability of psychological and psychiatric care is a significant issue. When indicated, psychiatric intervention at the earliest opportunity is required to avoid the considerable financial, psychological, social and vocational costs of delayed diagnosis and treatment.

Many patients in regional areas have limited or no access to specialist advice and the equitable provision of epilepsy care is a major challenge. The development of specialised outreach clinics would allow an integrated and statewide approach to care as well as build stronger clinical and educational links with local GPs and other health professionals. These outreach clinics could be developed in the major regional centres and include well-resourced Telehealth/Teleconferencing facilities.

The ready availability and provision of clear, accurate and appropriate information for people with epilepsy and their families is essential for effective care. This includes information about the cause of epilepsy, treatment and impact of medications and the implications for safe everyday living. Written information, helpline telephone numbers and contact details of voluntary organisations, should be given to all patients and their families. Information for schools and the community as well as epilepsy awareness training should also be available.

The role of the Non-Government and voluntary sector in the provision of advice, support, advocacy and education of families affected by epilepsy is crucial.

This report and its associated recommendations will provide key directions for the delivery of more efficient and equitable epilepsy care and clinical neurophysiology services in Western Australia.

1. SUMMARY OF RECOMMENDATIONS

1.1 The Diagnosis Of Epilepsy

1. A diagnosis of epilepsy should be made by an epilepsy specialist.
2. All individuals with a recent onset suspected seizure should be seen by an epilepsy specialist, either hospital-based or in private practice, preferably within two weeks.

1.2 The Investigation Of Epilepsy

3. A clear history from the patient and an eyewitness to the attack give the most important diagnostic information, and should be the mainstay of diagnosis.
4. People who have had a suspected epileptic seizure require ready access to a range of investigations, particularly EEG and MRI, when clinically indicated. For most children with febrile seizures, investigations are not indicated.
5. EEG should be performed by a trained clinical neurophysiology technician and reported by a neurologist with subspecialty training and skills in EEG.
6. Where the clinical diagnosis of epilepsy is uncertain and if events are sufficiently frequent, video-EEG monitoring should be used to assist in the diagnosis of an epileptic or non-epileptic seizure.
7. Individuals with epilepsy who require imaging should have an elective MRI brain scan. CT has a role in the urgent assessment of seizures, or when MRI is contraindicated.
8. A spectrum of advanced imaging techniques, including ictal SPECT, PET and high field MRI systems (at least 3 tesla) provided by Neuro-imaging specialists (neuroradiologists, nuclear physicians) are necessary to support the adult and paediatric epilepsy centres.
9. Electrocardiography (ECG) should be considered in the assessment of all patients with altered consciousness, since disorders of cardiac rhythm may simulate epilepsy.

1.3 The Treatment Of Epilepsy

10. The decision to start antiepileptic drugs (AEDs) should be made by the patient and an epilepsy specialist.
11. Antiepileptic drug treatment should not be commenced routinely after a first, unprovoked tonic-clonic seizure, but may be offered to patients with a high risk of recurrence.
12. Following an acute brain insult or neurosurgery, prophylactic AED treatment is not usually indicated.
13. Following an acute brain insult, AEDs used to treat the provoked seizures should be withdrawn after 2 weeks (unless seizures continue).

14. Routine monitoring of antiepileptic drug concentrations is not indicated. Measurements can sometimes be useful in specific circumstances.
15. Withdrawal of antiepileptic drug treatment should be considered in patients who have been seizure free for two or more years, and in some children who have been seizure free for shorter periods.
16. Discontinuation of AED treatment should be managed by, or be under the guidance of, the epilepsy specialist.
17. Assessment for suitability for epilepsy surgery should be performed at the adult or paediatric epilepsy centre.
18. People with epilepsy should have access to services for the assessment of the common neuropsychiatric and psychological complications of epilepsy.

1.4 Epilepsy Models Of Care

19. A shared care system for epilepsy should be established between primary care and specialist epilepsy services, facilitated and enhanced by the deployment of specialist epilepsy nurses.
20. Each patient should have an individual and clearly defined management plan, agreed to by the patient and the shared care team.
21. An epilepsy specialist should recommend initiation of appropriate treatment, plan continuation of treatment and, when appropriate guide discontinuation of treatment.
22. All individuals with epilepsy should have a regular structured review at least yearly (in children twice yearly), even for patients with well-controlled epilepsy.

1.5 Management of Epilepsy in Emergency and Secondary Care

23. An improved and standardised approach to Emergency Centre and Secondary care is required.
24. Common evidence-based protocols for acute seizure assessment and treatment (first seizure, status epilepticus)
25. Ready access to:
    - Patients' medical information
    - CT scanning at presentation or within 24hrs of presentation if required.
    - Urgent neurological advice on call
    - Specialised services when necessary, enabling probable recent-onset seizures to be seen in specialist epilepsy clinics within two weeks of onset.
26. Evidence-based, uniform information sheets for patients and carers

1.6 Tertiary Care for Epilepsy - WA Comprehensive Epilepsy Service

27. Specialist-led epilepsy services should be delivered at the tertiary sites as an integral part of the WA Comprehensive Epilepsy Service, seamlessly linked to the single adult and paediatric epilepsy centres.

28. Dedicated epilepsy clinics and related outpatient diagnostic EEG services could eventually be developed in secondary metropolitan hospitals as outreach services from the adult and paediatric epilepsy centres dependent on the provision of adequate resources (see below).

29. Specialised epilepsy outreach and Telehealth clinics would provide better access to people in peripheral metropolitan and especially regional areas, encouraging interested GPs to be involved as supervised clinical assistants and strengthening links with paediatricians. For such a service to be viable it has to be well resourced.

1.7 Single Adult and Paediatric Epilepsy Centres

30. Single adult and paediatric epilepsy reference centres should care for patients who require more detailed evaluation and management, including presurgical assessment and epilepsy surgery.

31. Single adult and paediatric epilepsy reference centres require functional and geographic integrity, with purpose-built and contiguous facilities and a dedicated intramural and cross-campus video-EEG network.

32. A spectrum of advanced imaging techniques, including ictal SPECT, PET and high field MRI systems (at least 3 Tesla) provided by Neuro-imaging specialists (neuroradiologists, nuclear medicine physicians) are necessary to support the adult and paediatric epilepsy centres.

33. Like paediatric epilepsy surgery, a single epilepsy surgical team should continue to perform all adult epilepsy surgery and intra-operative monitoring, and the medical and surgical components of the service should be in the same hospital.

34. Subspecialty epilepsy clinics should also be available to meet the needs of specific groups of patients (epilepsy in learning disability, in pregnancy, adolescent transition to the adult service and in potential surgical candidates).

35. Neuropsychiatry and neuropsychology staff should be an integral part of the adult and paediatric epilepsy centres.

1.8 Information and Education in Epilepsy Care

36. People with epilepsy have a right to clear, accurate and appropriate information about their condition.

37. A checklist should be provided to help healthcare professionals deliver appropriate information to patients, families and carers.

38. Epilepsy awareness training and written information should be offered to schools and the community.

39. People with epilepsy and healthcare professionals, should be aware of the valuable contribution that can be made by the voluntary sector. Services provided and requiring support include: Advisory and Counselling Services, Public Awareness and Education programmes, and Support Groups for both metropolitan and rural and remote Areas.

40. Epilepsy education is best provided by the public health and community sectors working together.

1.9 Clinical Neurophysiology Models of Care

41. Clinical neurophysiology services have an essential role in neurological diagnosis, monitoring and treatment. Diagnostic neurophysiology services form a part of the core services of the neurology departments of all tertiary hospitals, and are also provided in the private sector.

42. More specialised neurophysiology assessments and treatments, including intra-operative neural monitoring, are confined to tertiary teaching hospitals.

43. An integrated and adequately resourced statewide and cross-campus public hospital service is required to meet specific patient needs.

44. Intraoperative neural monitoring should continue to be provided and further developed as a cross-campus and statewide service.

45. Staffs with subspecialty training in clinical neurophysiology are required to deliver these services. Training of further medical and technical staff is essential for the ongoing viability of these services.

1.10 Epilepsy and Clinical Neurophysiology Resource Implications

Full implementation of these recommendations will require additional staff with expertise in epilepsy, including training and ongoing administrative support for these posts.

2. INTRODUCTION

Epilepsy is the most common serious neurological condition, affecting 1-2% of the population and with an incidence of 70 per 100,000 per annum. In Western Australia, at least 20,100 people have active epilepsy with a further 1,400 new patients presenting each year (Sander J W & Shorvon S D, 1996). One in 20 children will have a seizure at some time during childhood and adolescence, and epilepsy is increasingly common after the age of 50 years.

Whilst epilepsy is common, the majority of patients with epilepsy can be effectively treated, given an accurate diagnosis and appropriate treatment, and are able to lead normal lives.

Ongoing seizures have a major impact on the burden of illness to the patient and the community, including quality of life, mortality and economic costs. In Western Australia, people with refractory epilepsy who would benefit from comprehensive assessment number at least 3,000 (15% of people with epilepsy), with a further 211 new cases per year. These patients require complex medical management and in some cases epilepsy surgery is needed.

More than most neurological conditions, epilepsy requires an integrated network of primary and specialist care, given the psychological, social, and vocational implications, together with the potential complexity of management.

3. COST OF EPILEPSY/BURDEN OF ILLNESS

The health care costs of epilepsy increase dramatically in proportion to seizure frequency, whilst the costs of seizure-free epilepsy patients are similar to the general population.

Patients with epilepsy suffer:

Sudden death

The incidence of sudden unexpected death in epilepsy increases dramatically with the severity of the epilepsy and the frequency of the seizures: 1 in 2,500 person/year with well-controlled epilepsy and up to 1 in 100 persons/year with severe epilepsy (Nashef & Sander 1997; Sillanpaa et al. 1998).

Injuries

Up to 35% of patients/year report seizure-related injury, 5% per year visit emergency centres for seizure-related accidents, including seizures behind the wheel (Buck et al. 1997; Hauser, Annegers & Elveback 1980).

Anti-epileptic drug side-effects (Gilliam et al. 2004).

Impaired quality of life

Health related quality of life is progressively reduced in proportion to seizure frequency. Seizure-free patients experience quality of life similar to the general population. Epilepsy often affects the whole family and can have an impact on the quality of life and activities of the other family members (Devinsky et al. 1995; Leidy et al. 1999).

Loss of Employment

Over two thirds of patients with severe epilepsy are unemployed or are difficult to employ (Gilliam et al. 1997; van Hout et al. 1997).

Educational and Social Costs

Epilepsy in childhood is of special significance because it occurs at a time of rapid brain development and can influence the child's development, personality, achievement, as well as long-term intellectual outcome, physical and mental wellbeing.

People with epilepsy have a higher incidence of learning difficulties, special education needs, mental health consultations, unemployment and long term social isolation.

An increased incidence of learning difficulties, under achievement, self esteem issues and difficulties with peer relationships have been identified in children with epilepsy who have normal intellect. Sensible restrictions and precautions, that may be necessary at times, may also have an impact on peer interactions.

Economic Costs

The economic costs to the community for a patient with regular seizures is four times that of a seizure free patient, and this figure doubles again for patients having >1 seizure/month.

Those with refractory epilepsy account for 74% of the direct costs and 79% of the indirect costs of epilepsy.

The greatest direct medical costs are hospital admissions. For patients having >1 seizure per month, 1 in 10 requires admission at least once a year because of seizures (Begley et al. 1994; Begley et al. 2000; Cockerell, Hart & Shorvon 1994; Frost et al. 2000; Griffiths et al. 1999; Jacoby et al. 1998; Langfitt 1997).

3.1 Local Data: Total Costs/All Direct Costs/Indirect Costs

No published Australian data is available, nor do we have the resources to ascertain all costs locally, save for the following:

Number of emergency centre attendances

ROYAL PERTH HOSPITAL (2003/2004)	= 907/year
PRINCESS MARGARET HOSPITAL	~ 600/year

Costs of hospitalisation

ROYAL PERTH HOSPITAL Real cost (1999/2000)	= $AUS 3,163,630/year *Excluding video-EEG monitoring, epilepsy surgery and emergency centre observation patients*
Number of admissions (1999/2000) Average length of stay	424 /year 4.4 days (1835 bed days)

3.2 Published data

(van Hout B, 1997, Begley C E, 1994, Jacoby A, 1998, Langfitt J T, 2000, Begley C E, 2000, Griffiths R I, 1999, Frost FJ, 2000, Cockerell O C, 1994)

Total costs

TOTAL COMBINED COSTS OF ILLNESS	= $AUS 12,000-36,000/person/year

Direct medical costs (~1997)

United Kingdom	
Seizure free	£443/year
Mild <1 seizure/month	£1,705/year
Moderate >1 seizure/month	£3,508/year
Severe	£6,078/year
United States of America	
Mild	$US 8,419/year
Moderate	$US 16,000/year

Direct non-medical costs

- Patient time, travel costs, institutional care, childcare, unpaid caregiver time, social security services/disability and carer support.
- Indirect (largely productivity related), influencing the patients, their family and carers costs.
- Days off work, inefficiency at work, unemployment, loss of education.
- Financial costs of delayed diagnosis of undiagnosed non-epileptic seizures (pseudo seizures) patients in 199816: mean estimate of $15,000 per patient.

4. GOALS AND HURDLES

Essentials of care include an accurate diagnosis, optimal investigation and treatment, well-informed patients, co-ordinated long-term care and counselling appropriate to individual needs.

Management in Western Australia is sub-optimal in some areas. Areas of specific concern include initial diagnosis, adequacy of investigation and treatment, management of pregnant women and neonates with epilepsy, care of rural patients, and the provision of patient information.

Many audits, patient satisfaction surveys and national reports express concern about standards of epilepsy care in adults and children. People with epilepsy often report inadequate provision of information and advice. Previous audits have demonstrated:

- Inappropriate use of investigations.
- Inadequate classification of epilepsy and sub-optimal therapy.
- Lack of systematic follow up.
- Unnecessarily poor seizure control or anti-epileptic drug toxicity.
- Widespread poor compliance.
- Injudicious withdrawal of treatment.
- Poor communication between primary and specialist care.
- Inadequate information and time for discussion.
- Poor patient knowledge.

Within the prevalent population there is a group of patients with refractory (poorly controlled) epilepsy who have never been adequately assessed, and their management represents an enormous challenge. Numerous single- and multi-practice audits reveal that a minority of these patients have formal review arrangements (Chappell & Smithson 1998; Jacoby et al. 1998; Poole et al. 2000).

This submission provides evidence-based recommendations on the diagnosis and treatment of epilepsy, referring heavily to the published SIGN and NICE guidelines (Scottish Intercollegiate Guidelines Network 2003, 2005; (National Institute for Health and Clinical Excellence, 2004).

5. DIAGNOSIS

The diagnosis of epilepsy has important physical, psychosocial and economic implications for the patient. It is therefore essential that the diagnosis is correct.

The accurate diagnosis of epilepsy and its type can be difficult, as there is a wide differential diagnosis. It has been shown that a significant proportion of epilepsy diagnoses made by non-specialists are incorrect (Scottish Intercollegiate Guidelines Network 2003, 2005; Stokes et al. 2004).

Of the patients referred to Western Australian first seizure clinics, 25% have had convulsive syncope rather than an epileptic seizure (Kho et al. 2006). Up to a quarter of patients referred for specialist management of apparent drug-resistant epilepsy on further investigation do not have epilepsy.

The misdiagnosis of epilepsy has significant implications, including:

- Adverse psychosocial and employment impact.
- Iatrogenic adverse effects of unnecessary medication, including inappropriate treatment of young women with risks of teratogenicity to an unborn child.
- Misdiagnosis of cardiogenic syncope as epilepsy may result in an otherwise preventable death.

Given these concerns regarding misdiagnosis, the breadth of epilepsy syndromes and the range of differential diagnoses, the diagnosis of epilepsy should be made by an epilepsy specialist.

Accurate epilepsy syndrome diagnosis is very important at all ages. Some children with benign epilepsy syndromes may not need treatment, whereas others with the more severe epilepsy syndromes need aggressive management. Many conditions may mimic epilepsy, including syncope, cardiogenic syncope, parasomnias, migraine, non-epileptic psychogenic seizures and episodic events such as daydreaming.

The diagnosis is most appropriately made in the setting of a dedicated hospital-based first seizure clinic or by a neurologist with expertise in epilepsy in private practice.

An **epilepsy specialist** has been defined by the Royal College of Physicians (Edinburgh) as a consultant with expertise in epilepsy as demonstrated by training and continuing education in epilepsy, peer review of practice and regular audit of diagnosis. Epilepsy must be a significant part of their clinical workload (equivalent to at least one session a week).

5.1 Recommendations

1. A diagnosis of epilepsy should be made by an epilepsy specialist.

2. All individuals with a recent onset suspected seizure should be seen by an epilepsy specialist, either hospital-based or in private practice, preferably within two weeks.

6. THE INVESTIGATION OF EPILEPSY

Classification of seizure types and epilepsy syndromes should always be attempted, as both have a significant impact on treatment, investigation, prognosis and counselling.

Clinical Factors

A clear history from the patient and an eyewitness to the attack give the most important diagnostic information, and should be the mainstay of diagnosis. The history taking skills needed to ascertain comprehensive witness accounts of events are built upon thorough training, continuing education and experience. They can be acquired only with an understanding of the range and complexity of the differential diagnosis that exists.

EEG

Electroencephalography (EEG) should be performed as soon as possible after a first seizure. It is often helpful in supporting a clinical diagnosis of epilepsy and in classification of seizure type. An EEG can also determine differentiation between generalised-onset and partial (focal)-onset seizures. However, it is essential to understand the scope and limitations of the technique when requesting an EEG and subsequently evaluating an expert report on the recording.

Non-specific EEG abnormalities are relatively common, especially in neuro-developmental disorders, the elderly, patients with migraine, psychiatric illness and on psychotropic medication. Non-specific EEG abnormalities and numerous artefacts are commonly misinterpreted as supporting a diagnosis of epilepsy. EEG is not indicated for children with febrile seizures.

EEG should not be performed to exclude a diagnosis of epilepsy. The sensitivity of interictal EEG recordings is too low to be a reliable diagnostic test for epilepsy. A single routine EEG recording will show definite epileptiform abnormalities in 29-56% of adults who have epilepsy. With repeat recordings this rises to 69-77% (Marsan C A, 1970, Salinsky M, 1987, Doppelbauer A, 1993). Sleep has an activating effect on the EEG and repeated recordings, which include a period of sleep, often achieved after sleep deprivation, further increases the yield of epileptiform activity.

Time-locked video recording during a standard EEG will contribute further to classification and diagnosis by identifying movement artefacts. It is also effective if a clinical event occur spontaneously or following induction.

Flexible outpatient, same day ambulatory care and inpatient services should be available. Most EEG is performed as an outpatient procedure.

EEG performance and interpretation requires adequately trained and experienced neurophysiology technicians and reporting neurologists. The EEG and Clinical Neurophysiology Committee of the Australian and New Zealand Association of

Neurologists recommends that neurologists who wish to perform clinical neurophysiology on a regular basis require a minimum additional training of six months full-time, or its equivalent, provided by a supervisor specifically trained in clinical neurophysiology and in an accredited laboratory. A one-year clinical neurophysiology fellowship in EMG or EEG/epilepsy is required to gain the knowledge and experience necessary to establish and supervise a laboratory service in an academic institution (EEG and Clinical Neurophysiology Committee, 2006).

Video-EEG

Where episodes occur most days, referral for simultaneous video and EEG recording of attacks may be helpful. This may require only a few hours as an outpatient if events are very frequent or are inducible. Where episodes occur at least once a week, long-term inpatient video EEG monitoring will often allow a confident diagnosis to be made.

ECG

Cardiogenic syncope is an important part of the differential diagnosis of an episode of loss of consciousness. A routine 12-lead ECG may detect prolonged QT interval or other findings that lead to an accurate diagnosis. Ambulatory 24 hour ECG and other cardiovascular tests may also be helpful in selected patients.

Brain Imaging

Neurological imaging is pivotal in the management of patients with focal or symptomatic generalised epilepsies. Brain imaging detects abnormalities in 20-30% of adult patients presenting with epilepsy (King M A, 1998, Roberts R C, 1988, Ramirez-Lassepas M, 1984, International League Against Epilepsy, 1997). The detection of such lesions allows for better selection of medical treatments and also has implications for planning surgical treatment in the small group of patients in whom epilepsy becomes intractable.

Abnormalities that may be encountered include mesial temporal sclerosis, developmental malformations, neoplasms, vascular malformations and brain damage from a variety of previous insults. Each of these lesions has their own characteristics, and requires dedicated and appropriate imaging strategies for accurate evaluation and interpretation.

Neuro-imaging is not necessary in all people with epilepsy. Most children with febrile seizures, benign partial epilepsies of childhood, and patients with primary generalised epilepsy do not need imaging. The idiopathic generalised epilepsies are not associated with an increased prevalence of brain lesions.

<u>Computed Tomography (CT)</u>

CT scanning is readily available in hospitals and the community. This imaging modality has a role in the urgent assessment of seizures, when MRI is contraindicated (e.g. when patients have pacemakers or metallic implants), in the evaluation of calcified lesions,

and in some cases with pre-surgical planning and invasive monitoring. However, it is otherwise of limited value in epilepsy evaluation.

Magnetic Resonance Imaging (MRI)

Magnetic resonance imaging (MRI) scanning is the current standard of reference in the investigation of patients with epilepsy. These scans account for approximately 10% of hospital neurological imaging. MRI scanning is superior to CT scanning in elective imaging, identifying abnormalities with greater sensitivity (95% v 32%). The advantages include excellent soft tissue contrast resolution, multi-planar capabilities and no exposure to ionising radiation. Given that many patients requiring repeated imaging are children and young adults, avoiding exposure to radiation is of significant importance.

Many epileptogenic lesions are subtle, so contemporary machinery and software is required to optimise lesion detection and evaluation. Imaging protocol optimisation and standardisation are required, distinguishing temporal lobe and extra-temporal epilepsy syndromes. Both public and private imaging facilities should be encouraged to provide standardised and appropriate primary examinations.

A subspecialty neuroradiologist is essential to provide the required systematic analysis, review and reporting.

Neuroradiological representation at the WA Comprehensive Epilepsy Service multidisciplinary patient review is essential for optimal patient care and should be provided for.

Advanced Neuro-Imaging

Qualitative and quantitative imaging techniques are sometimes required in the tertiary evaluation of the medically refractory epileptic and should be provided to the adult and paediatric epilepsy centres.

These include:

- Focused high-resolution studies.
- Co-registration techniques.
- Volumetric studies.
- MR spectroscopy.
- Functional MRI.
- Diffusion tensor imaging.

The availability of local high field MRI systems (at least 3 tesla (3T)) is essential for tertiary epilepsy centres. Supportive physics and medical imaging technologist personnel are also required to effectively provide these services.

Additional Imaging

Neuroradiology provides facets of preoperative assessment with:

- Intra-carotid Amytal tests (IAT, WADA; Neurological Interventional Radiology Unit).
- Functional MRI (sensorimotor, language lateralization/location).
- Intracranial grid localisation.
- "Stealth" neurosurgical guidance system scans.

Radiology services are required and utilised in many additional settings e.g. the evaluation of patient's injuries sustained during seizures, such as recurrent posterior shoulder dislocations.

Nuclear Medicine

Radionuclide scintigraphy is often required to assist in the pre-surgical localisation of the epileptogenic region when radiologically occult and when several abnormalities are present.

Modalities include ictal-interictal Single Photon Emission CT (SPECT) and Positron Emission Tomography (PET). Molecular imaging, in the form of novel ligands, and co-registration capabilities should be supported.

The facility for an ictal SPECT is a necessity for the adult and paediatric epilepsy centres.

Nuclear medicine physicians familiar with neuro-radiological applications are needed to support and correlate with conventional and advanced imaging techniques. These physicians should form a part of the WA Comprehensive Epilepsy Service team.

Paediatric Patients

The imaging of paediatric patients has a similar demand for focussed appropriate imaging strategies and evaluation. Neuroimaging is required in children:

- With focal seizures.
- With abnormal neurological examination.
- When clinical examination and profile suggests the need for imaging.
- When seizures are refractory.
- With certain focal abnormalities on EEG.

Availability of sedation and general anaesthesia to ensure diagnostic examinations is an important consideration in this setting, as well as the availability of advanced imaging techniques. Radiation exposure should be considered when repeated imaging is required.

On-site paediatric neuroimaging facilities providing tertiary level epilepsy neuro-imaging services are better able to cater for the needs of children rather than adult services that attempt to cater for children.

Accessibility to Imaging Services

In the light of the geography of Western Australia, the provision of imaging evaluation should be timed appropriately with non-imaging assessment.

Accessibility to imaging services should be equitable. All patients have the right to have their imaging evaluation in a public or private setting, depending on the level of imaging required.

Studies for Aetiological Diagnosis

Epilepsy may be due to many different disorders including congenital, traumatic, inherited, vascular and infectious aetiologies. Investigations need to be individualised and may include metabolic studies (urine, blood and CSF), chromosomal and genetic studies, with the assistance of the neurogenetics service.

6.1 Recommendations

1. A clear history from the patient and an eyewitness to the attack give the most important diagnostic information, and should be the mainstay of diagnosis.

2. People who have had a suspected epileptic seizure require ready access to a range of investigations, particularly EEG and MRI, when clinically indicated. For children with febrile seizures, investigations are not indicated.

3. EEG should be performed by a trained clinical neurophysiology technician and reported by a neurologist with subspecialty training and skills in EEG.

4. Where the clinical diagnosis of epilepsy is uncertain and if events are sufficiently frequent, video-EEG monitoring should be used to assist in the diagnosis of an epileptic or non-epileptic seizure.

5. Individuals with epilepsy who require imaging should have an elective MRI brain scan, the imaging modality of choice, in a timely fashion. CT has a role in the urgent assessment of seizures, or when MRI is contraindicated

6. A spectrum of advanced imaging techniques, including ictal SPECT, PET and high field MRI systems (at least 3 tesla) provided by Neuroimaging specialists (neuroradiologists, nuclear physicians) are necessary to support the adult and paediatric epilepsy centres.

7. Electrocardiography (ECG) should be considered in the assessment of all patients with altered consciousness, since disorders of cardiac rhythm may simulate epilepsy.

7. THE TREATMENT OF EPILEPSY

The crucial decision on whether or not to start antiepileptic drug (AED) treatment must take into account the epilepsy syndrome. The decision is influenced by the risks of recurrent seizures (including the small risk of SUDEP) and the commitment to long-term medication with potential side effects. AEDs should not routinely be given until the diagnosis of epilepsy has been confirmed (Scottish Intercollegiate Guidelines Network, 2003, Scottish Intercollegiate Guidelines Network, 2005).

AEDs are not always chosen and used appropriately by clinicians. It is possible that the incidence of SUDEP could be reduced if antiepileptic treatment was always optimised. The national UK audit of epilepsy-related deaths discovered that only 33% of adults under GP care had been reviewed in the year before death.

7.1 Should Antiepileptic Drug Treatment be Started?

An epilepsy specialist should recommend initiation of appropriate treatment and plan continuation of treatment.

Single Seizures

When considering treatment, the clinician and the patient must take into account both what may be an isolated event and the risks of adverse effects of AED treatment. Whether to treat a single seizure or not is largely determined by the risk of further seizures, which is influenced by the clinical syndrome.

Estimates of risk of seizure recurrence vary. Highest recurrence rates (up to 90%) are seen in patients with epileptic discharges on EEG or in those with congenital neurological deficits. Lowest rates (13- 40%) are associated with acute symptomatic seizures (provoked) or patients with a normal EEG and no identifiable cause for seizures. Overall the risk is 40-50%; this is greatest in the first six months and falls to <10% after two years (Kho L K, 2006).

Early treatment with AEDs, while reducing the risk of seizure recurrence within two years of the first event, does not appear to alter the long-term prognosis of epilepsy.

Acutely provoked seizures

Seizures can be provoked by acute metabolic disturbances, the use or withdrawal of certain drugs, alcohol and with acute brain insults (including traumatic head injury). When metabolic disturbances or drugs provoke seizures, attention should be directed to correction or withdrawal of the provocative factor.

There is evidence that treatment can reduce the acute risk of recurrence of such provoked seizures. For example, short-term benzodiazepine treatment may be given to

reduce the risk of seizures in the context of acute alcohol withdrawal and delirium tremens.

There is no evidence however, that prophylactic treatment and prevention of provoked seizures influences the subsequent development of epilepsy. For acute traumatic brain injury, there is also no evidence that the prevention of early provoked seizures by AED treatment influences other outcomes such as death and neurological disability. Therefore is no justification for the routine prophylactic use of AED treatment to prevent provoked seizures in the context of acute brain insults, other than in the first 1-3 weeks after the event.

If AED treatment is started following the occurrence of provoked seizures, it should be used only in the short term, unless unprovoked seizures occur later.

Recurrent Seizures (unprovoked)

The choice of first AED should be determined where possible by syndromic diagnosis and potential adverse effects. The majority of patients with newly diagnosed epilepsy respond well to AEDs.

7.2 Anti-epileptic drug levels

Routine monitoring of AED concentrations is generally not indicated. The upper and lower borders of the target ranges are imprecise and are not applicable to all patients. Dose adjustments should be based on seizure control and AED side effects. Measurement can sometimes be useful in the dose adjustment of some AEDs and in assessment of adherence or toxicity.

7.3 Anti-epileptic drug withdrawal

The question of continued treatment or AED withdrawal should be discussed with adults with epilepsy who have been seizure free for at least two years, so that they can make an informed choice. Studies suggest that in selected children one year of seizure freedom (even 6 months in some situations) is adequate.

The risk of seizure recurrence after AED withdrawal varies, but overall for children it is ~ 20-35% and for adults it is at least 40%. Factors that influence risk of seizure recurrence include the duration of seizure freedom on AEDs, epilepsy syndrome and seizure type and whether one or more AEDs are being taken.

Factors to be discussed should include driving, employment, fear and risks of further seizures and concerns about prolonged AED treatment. Decisions need to be individualised, and any withdrawal must be gradual. One drug should be withdrawn at a time.

7.4 Outcome measures

The assessment of seizure severity, adverse effects and the impact of epilepsy on the quality of life should be considered in assessing individuals in clinical practice. Care should be taken to use appropriate outcome measures (Gilliam FG, 2004, Baker G A, 2000, Baker G A, 1998, Cramer J A, 2002).

7.5 Drug Resistant Epilepsy

Failure to respond to AED treatment may be due to:

- An incorrect diagnosis of epilepsy.
- An inappropriate choice of AED for the epilepsy syndrome.
- Failure to take the prescribed AED.
- The underlying cause.
- Failure to address provoking factors such as alcohol, drugs and sleep deprivation.

This problem demands a specialist-led, structured approach to management as provided by the adult and paediatric epilepsy centres. It should prompt a review of the diagnosis of epilepsy and careful adherence to medication. Up to 25% of these patients will not have epilepsy and 10-30% of those who do have epilepsy will not have received optimal therapy. The adult and paediatric epilepsy centres provide a subspecialty referral service for other Neurologists managing these patients.

Combination therapy should be considered when treatment with two first-line AEDs has failed or when the first well-tolerated drug substantially improves seizure control but fails to produce seizure-freedom at maximal dosage.

The choice of drugs in combination should be matched to the patient's seizure type and usually should be limited to two or at most three AEDs. Once the decision has been made to use combination therapy, AEDs appropriate to the epilepsy syndrome should be added as necessary, increasing the dose of each slowly to obtain the maximum response with minimal toxicity. The aim should be seizure-freedom. If an encouraging but sub-optimal effect is obtained with a particular combination, it may be worthwhile trying the addition of a small dose of a third AED.

The law of diminishing returns may require patient and doctor to accept the persistence of some seizures once a range of treatment options has been tried. Adequacy of seizure control must be balanced with the adverse effects of treatment to optimise quality of life. Producing less intrusive episodes, abolishing tonic-clonic seizures, preventing falls and decreasing seizure-related automatisms can be acceptable end points for some patients.

Epilepsy surgery

Epilepsy surgery is an effective treatment for some patients with epilepsy resistance to drug treatment. Referral for presurgical evaluation should be considered if epilepsy is drug resistant and is focal in onset.

Patients undergoing evaluation for surgery require complex and highly sub specialised evaluation, which is very time-intensive. These patients should be referred to the adult or paediatric epilepsy centre.

Some neurosurgical procedures involve cortical resection of part of the brain in patients with focal epilepsy, and the aim is to attain complete seizure freedom. Temporal lobe epilepsy surgery, the most commonly performed procedure, can result in about 70% of patients becoming seizure free.

Other procedures such as corpus callosotomy and vagus nerve stimulation are essentially palliative, but can provide important benefits to selected patients.

For each individual the potential benefits of improved seizure control, quality of life and possible reduction in antiepileptic medication need to be balanced against the risks of the surgical procedure.

Vagal Nerve stimulation

Vagus nerve stimulation is a well-established therapeutic option for epilepsy. It is reserved for patients with severe epilepsy who have failed to respond to AEDs and resective surgery where possible. Rates of implantation of vagus nerve stimulation systems are approximately 10 per million of the population per annum in the USA and some Northern European countries. In Western Australia, this translates to 5-10 patients per year, representing only 0.004% of the refractory epilepsy population.

While a seizure free state is rarely achieved by vagus stimulation, approximately 45% of patients will benefit significantly, particularly children.

PMH is acknowledged as a national leader in the development of vagus stimulation as a treatment modality, and has implanted 24 devices, including insertion of the first vagal nerve stimulator for epilepsy in an adolescent in Australia (Nagarajan L, 2002).

These devices have been shown to be safe, cost-effective and have long-term benefits. Currently funding is provided ad-hoc, utilising limited internal funding when available. Private Medical funds will provide funding for this, but vagus nerve stimulation is not yet available through the Pharmaceutical Benefits Scheme.

Ketogenic diet

The ketogenic diet is used in selected children for treatment of intractable epilepsy, and can be of benefit. It is a time intensive and difficult diet, requiring extensive time commitments from the dietician and family, with the need for careful and regular follow-

up. The Atkins diet (high protein, low carbohydrate) may be another diet that in the future will be used for patients with epilepsy.

Social support and respite for carers

Parents and family members of children with refractory epilepsy carry a heavy burden. Respite services are inadequate and carers are often worried about being responsible for children with seizures while parents can be worried about leaving children in the care of someone who is not experienced in the management of seizures.

7.7 Psychological and Psychiatric Care

Psychological problems in epilepsy are common

Prevalence rates of psychiatric disorders in epilepsy vary widely from 6% to 74% (Jones et al, 2005; Matsuura et al 2003,).

Rates of up to 70% are found in patients with intractable complex partial seizures.

Anxiety and Depressive Disorders are most frequent. Other psychiatric disorders also represented include Psychotic disorders and Personality Disorders. Mood Disorders in Epilepsy are poorly recognised and are under-treated (Gilliam & Kanner 2002). Mood Disorders may present differently in epilepsy as compared to non-epilepsy populations (Blumer 2000).

Co-morbidity of psychiatric disorders is common (especially co-morbid Anxiety and Depressive Disorders (Jones et al 2005). Patients with Depression are higher medical utilisers (Simon et al 1995). Completed suicide is between 5 to 25 times as common in epilepsy as in the general population (Barraclough, 1987; Matthews, 1981).

Non-Epileptic Seizures (NES)

Psychiatric Disorders may present as seizures (variously called NES, Dissociative Seizures, Conversion Seizures, Pseudo Seizures) and may mimic or co-exist with epilepsy.

NES have been diagnosed in 8% to 25% of outpatients referred for intractable seizures (Tsopelas et al. 2001). NES have a poor prognosis and contribute significantly to morbidity, mortality and health costs. Accurate diagnosis and psychiatric intervention at the earliest opportunity are essential to avoid the considerable financial, psychological, social and vocational costs of delayed diagnosis and intervention.

Quality of Life (QOL)

The presence of Depressive Disorder is associated with poorer QOL in patients with epilepsy (Hermann et al. 2000).

Treatments

Antiepileptic Drugs may be associated with psychiatric adverse effects (Scheepers & Kerr, 2004).

Epilepsy Surgery

Evidence suggests that there can be an increase in mood disturbance and adjustment disorder in the early post-operative period after epilepsy surgery especially after temporal resections (Wrench et al, 2004). Without psychiatric involvement as required there is the potential for significant morbidity resulting in increased health costs.

People with epilepsy should have ready access to:

- General Practitioner advice
- General Psychiatric Services (public and private) when required
- Hospital Consultation Liaison (CL) Services
- Dedicated Neuropsychiatrist and Neuropsychologist staff with all available psychiatric management modalities (which includes access to psychologists and social workers) as core requirements at the adult and paediatric epilepsy centres.

Due to the current shortages of the psychiatric workforce and lack of availability of mental health services to various parts of Western Australia, patients with medically intractable/poorly-controlled epilepsy should have a priority (amongst epilepsy patients) to access mental health services.

7.8 Recommendations

1. The decision to start antiepileptic drugs (AEDs) should be made by the patient and an epilepsy specialist.

2. Antiepileptic drug treatment should not be commenced routinely after a first, unprovoked tonic-clonic seizure, but may be offered to patients with a high risk of recurrence.

3. Following an acute brain insult or neurosurgery, prophylactic AED treatment is usually not indicated.

4. Following an acute brain insult, AEDs used to treat the provoked seizures should be withdrawn after 2 weeks (unless seizures continue).

5. Routine monitoring of antiepileptic drug concentrations is not indicated. Measurements can sometimes be useful in specific circumstances.

6. Withdrawal of antiepileptic drug treatment should be considered in patients who have been seizure free for two or more years, and in some children who have been seizure free for shorter periods.

7. Discontinuation of AED treatment should be managed by, or be under the guidance of, the epilepsy specialist.

8. Assessment for suitability for epilepsy surgery should be performed at the adult or paediatric epilepsy centre.

9. People with epilepsy should have access to services for the assessment of the common neuropsychiatric and psychological complications of epilepsy.

8. MODELS OF CARE: SERVICES FOR PATIENTS WITH EPILEPSY

People with epilepsy require a multidisciplinary approach to their care. This may include a range of professionals, for example the GP, paediatrician, neurologist, epilepsy nurse, psychiatrist and psychologist.

Access is required to a range of diagnostic and investigative tools, including clinical neurophysiology and neuroradiology.

Close liaison with educational services, social work and the voluntary sector is of considerable importance.

8.1 Primary Care

Current Hurdles

Care planning and follow-up

In the UK, only 37% of epileptic patients have consulted their GP about their illness within the last year, with little evidence of any regular review being undertaken. Counselling about safety and lifestyle issues seems inadequate (Jacoby A, 1996).

Such shortfalls are reflected in descriptive studies of patients' views. Only around a fifth of patients felt that their care is being effectively shared between hospital and general practice, and provision of information about epilepsy is perceived to be poor at all levels.

However, most people with epilepsy (68%) would prefer their care to be community based, especially older patients and patients with mild epilepsy, and most would prefer their care to be shared between primary and specialised services.

Knowledge about epilepsy

Detailed knowledge of epilepsy and its treatment cannot reasonably be expected of GPs.

In a survey of epilepsy management in Perth General Practice (Thom G A, 2002):

- Only 42% regarded their knowledge of epilepsy as adequate for their practice
- Only 50% advised their patients of the existence of the Epilepsy Association, the local voluntary organisation that provides information and support to patients with epilepsy and their families.
- Plasma AED measurements were overvalued, with 69% performing levels without regard to symptoms and 20% would alter doses solely on the basis of plasma levels.
- 40% would wait for weekly or daily complex partial seizures before considering referral to a specialist epilepsy service.

- GPs have not been adequately informed of the existence of the WA Comprehensive Epilepsy Service, with only 18% of GPs being aware of the service.

General practice care for epilepsy is still reactive rather than proactive.

Hospital discharge planning

The care of patients at the time of hospital discharge is often neglected. GPs are insufficiently included in hospital discharge processes, in particular for patients with severe epilepsy.

Discharge planning can produce better health outcomes, facilitate the patient's and the GP's involvements with discharge care, and improve communication between hospital and general practice services. In a recent Western Australian study investigating enhanced primary discharge care planning for chronically ill patients, 90% of GPs in the intervention arm of the study willingly contributed to discharge care planning for their patients. This finding indicates both the importance of this issue to GPs and the belief that GPs are not sufficiently involved in discharge processes.

Solutions

Promoting a shared care model involving the GP and specialist epilepsy services

A shared care management system for epilepsy should seek to establish the role of the GP and other primary care staff in:

- Making the provisional diagnosis in new patients, providing appropriate initial information and ensuring rapid access to an epilepsy specialist, either hospital-based or in private practice.
- Referring all patients with suspected epilepsy to an epilepsy specialist, either hospital-based or in private practice, for accurate diagnosis and management advice.
- Monitoring seizures, aiming to improve control by adjustment of medication or re-referral to specialist epilepsy services.
- Enhanced primary discharge care planning in patients with severe epilepsy.
- Minimising side effects of medications and their interactions.
- Disseminating information to help improve quality of life for patients with epilepsy.
- Addressing specific women's issues and needs of patients with learning disabilities.
- Assessing and assisting with co-morbidities, including depression.
- Advocacy and support.

Structured annual review

The primary care needs of patients with epilepsy should include a structured annual review, as is common with other chronic diseases such as asthma and diabetes. An annual review is recommended as a minimum, even for patients with well-controlled epilepsy, to identify potential problems, ensure discussion on issues such as withdrawal of treatment, and minimise the possibility of becoming lost to follow up. In children,

review at least twice a year is recommended to monitor treatment, growth and development.

Implementation of such a shared care model would be facilitated by:

- Deployment of specialist epilepsy nurses, who can liaise between primary care and hospital care providing people with quick access to medical advice. Good communication with the specialist epilepsy clinic is essential.
- Identification of lead GPs for epilepsy services.
- Identification of lead Paediatricians for epilepsy services. Paediatricians are important providers of care in children with epilepsy, especially those with multiple disabilities.

8.2 Recommendations

1. A shared care system for epilepsy should be established between primary care and specialist epilepsy services, facilitated and enhanced by the deployment of specialist epilepsy nurses.

2. Each patient should have an individual and clearly defined management plan, agreed to by the patient and the shared care team.

3. An epilepsy specialist should recommend initiation of appropriate treatment, plan continuation of treatment and, when appropriate guide discontinuation of treatment.

4. All individuals with epilepsy should have a regular structured review at least yearly (in children twice yearly), even for patients with well-controlled epilepsy.

9. MANAGEMENT OF EPILEPSY IN EMERGENCY AND SECONDARY CARE

Assessment of patients with suspected seizures or with epilepsy are an essential part of the emergency departmental activities of all public hospitals.

These currently comprise initial/emergency assessment of patients with seizures or possible seizures, acute investigations and treatment if necessary, and early referral/transfer for tertiary outpatient or inpatient care as required.

First Seizures

- All patients presenting to an emergency centre with a first-ever seizure, excepting children with febrile seizures, should have:
  - Baseline blood investigations appropriate to the clinical situation
  - Blood sugar level
  - 12-lead ECG
- Access to CT scanning within 24 hours of presentation, if required
- Provision of Emergency Centre Education regarding management of first possible seizure, emphasizing the importance of considering other possibilities (e.g. syncope, psychological)
- Provision of Emergency Centres with Evidence based Guidelines to ensure that all patients have a uniform and high standard of initial care.
- Patients should be advised not to drive or partake in other potentially dangerous activities until reviewed by a neurologist.
- Patients should have rapid and ready access to a neurologist-led first seizure clinic – ideally appointment times should be available at the time of ED presentation as this is likely to improve compliance with follow-up.
- Appointments - clerical staff should co-ordinate imaging, EEG and neurological consultation, with adequate resources to optimise compliance with follow up.

Recurrent Epilepsy

- ED should have ready access to a patient's full medical history, including current and past AEDs.
- Patients may present to hospital EDs other than their main hospital, so a linked electronic record system between hospitals in Western Australia is required.
- Ideally, patients who have complicated epilepsy should be provided with a seizure management plan from their neurologist, and the treating neurologist should be informed when they present with problems.
- Patients should be reminded about driving and other potentially dangerous activities.

- Evidence based guidelines for the management of status epilepticus should be available in all ED's.

General

- Evidence-based, uniform information sheets should be available for patients outlining safety issues (e.g. driving, bathing, diving). Similar sheets already exist for other common conditions (e.g. head injury, febrile children, and gastro-enteritis).
- ED staff needs 24-hour access to neurological advice – ideally a metropolitan roster should be implemented.
- ED staff needs access to the CITRIX Neurology database, developed by the adult epilepsy centre at Royal Perth Hospital, until a uniform electronic record is implemented. This database contains the neurology correspondence and investigations of all RPH patients, and will be deployed for use across hospital campuses.

9.1 Recommendations

1. An improved and standardised approach to Emergency Centre and Secondary care is required.

2. Common evidence-based protocols for acute seizure assessment and treatment (first seizure, status epilepticus)

3. Ready access to:
   - Patients' medical information
   - CT scanning at presentation or within 24hrs of presentation if required.
   - Urgent neurological advice on call
   - Specialised services when necessary, enabling probable recent-onset seizures to be seen in specialist epilepsy clinics within two weeks of onset
4. Evidence-based, uniform information sheets for patients and carers

10. TERTIARY CARE FOR EPILEPSY - WA COMPREHENSIVE EPILEPSY SERVICE

The WA Comprehensive Epilepsy Service

This is a state-based service, which aims to provide equitable access and optimal care to patients with epilepsy. The service commenced in 1990, and involves all teaching hospitals.

Limited resources have required a focus on people with the most severe epilepsy, with the establishment of specialist-led epilepsy clinics and inpatient services at the tertiary sites, and of the single adult (RPH) and paediatric (PMH) Epilepsy Centres.

Funds for the development of service facilities and equipment have been provided by a wide range of sources including donations from community groups (Western Australian Epilepsy Association, Appealathon and the Red Cross), the Health Department, internal funding, the pharmaceutical industry, research funding and private donations.

Specialist-led Epilepsy Services and Outpatient Clinics

Patients require equitable access to specialised services. Epilepsy services are an important and essential part of the core neurology departmental activities of all tertiary teaching hospitals, developed in conjunction with the WA Comprehensive Epilepsy Service.

These comprise:

- Initial/emergency neurological assessment.
- Inpatient neurology care when necessary.
- Dedicated hospital-based epilepsy clinics with access to specialised investigations (EEG, imaging)
  - Fast-track assessment of patients with suspected first seizures.
  - Follow-up clinics and ongoing care of patients with drug-resistant epilepsy.
  - Diagnostic video-EEG monitoring: ambulatory daytime, inpatient and intensive care.

Specialist clinics are well established in the management of other chronic diseases such as diabetes, and a similar model is required for people with epilepsy. These clinics provide the expertise of epilepsy specialists, epilepsy specialist nurses, and access to further specialised investigations and to inpatient facilities. They also have important roles in teaching and research in epilepsy.

A key aim is equity of access to specialised epilepsy services. Specialised outreach clinics would provide better access to people in peripheral metropolitan and especially

regional areas. This will also allow an integrated and statewide approach to care and build stronger clinical and educational links with local medical staff.

In regional areas, where locally based specialist neurology services are not available, Health Networks may be a suitable model. Services developed within the network could include joint consultations with visiting neurologists and via teleconferencing facilities, shared protocols, access to appropriate investigations, continued medical education, audit, and peer review.

Interested GPs should be encouraged to be involved as supervised clinical assistants, working for two sessions per month in a hospital-based epilepsy clinic. This will link primary care to the hospital system and establish real, shared care of patients. Stronger links should be forged with paediatricians who have a special interest in epilepsy.

Dedicated epilepsy clinics (first seizure and follow-up) with related outpatient diagnostic EEG services could be developed in secondary metropolitan hospitals (Rockingham, Armadale/Kelmscott, Swan Districts, Joondalup). These can operate as outreach services from the adult and paediatric epilepsy centres dependent on the provision of adequate resources. Similarly regional outreach clinics and Telehealth clinics could be developed in Broome, Port Hedland, Geraldton, Kalgoorlie, Bunbury and Albany.

In regional areas, patients have limited or no access to specialist advice, to information and education, and to advances in investigation and treatment. Patients in remote locations may require additional support, including contingency plans for seizure exacerbations.

Initial diagnostic evaluation with specialised MRI imaging and EEG may require travel to Perth. Travel may be difficult, time consuming and expensive, so coordination of the clinical assessments and investigations is essential. Telehealth optimally provides follow-up. Telehealth may also allow triaging of consultations and investigations that need to be done in Perth (e.g. MRI, EEG and consultation).

Regional outreach clinics are yet to be developed, and Telehealth has limited availability and resourcing. For such a clinical network to be viable it has to be well resourced including local patient support and secretarial support for Telehealth.

10.1 Recommendations

1. Specialist-led epilepsy services should be delivered at the tertiary sites as an integral part of the WA Comprehensive Epilepsy Service, seamlessly linked to the single adult and paediatric epilepsy centres.

2. Dedicated epilepsy clinics and related outpatient diagnostic EEG services could eventually be developed in secondary metropolitan hospitals as outreach services from the adult and paediatric epilepsy centres dependent on the provision of adequate resources (see below).

3. Specialised epilepsy outreach clinics and Telehealth clinics would provide better access to people in peripheral metropolitan and especially regional areas, encouraging interested GPs to be involved as supervised clinical assistants and strengthening links with paediatricians. For such a service to be viable it has to be well resourced

11. SINGLE ADULT AND PAEDIATRIC EPILEPSY CENTRES

11.1 Framework and Justification

Refractory epilepsy care, both medical and surgical, requires a highly sub specialised and multidisciplinary team and is not a core service for all teaching hospitals, given the population of W.A.

Single adult and paediatric centres were established and will continue to:

- Provide a viable statewide referral service of the highest quality for the population base of WA.
- Build sustainable and adequately resourced adult and paediatric epilepsy reference centres including clinical service, teaching and research commitments.
- Build the required highly sub-specialised and multidisciplinary team.
- Ensure that adequate medical, technical and nursing skills are maintained and the subspecialty further developed.
- Avoid the cost of duplication of expensive and highly specialised services.
- Allow for economies and efficiencies of scale.

This framework was established in 1996 with the consensus endorsement of the WA Comprehensive Epilepsy Service, involving all teaching hospitals. It has the endorsement of the Health Department of WA, and conforms to international standards of best practice (International League Against Epilepsy, 1997, Clinical Standards Advisory Group, 2000).

International League Against Epilepsy Recommendation

> "A single reference centre is required for a catchment population of 2-4 million, with the need for all patient investigations to be carried at the centre rather than having a two-tier system. The minimum throughput is 20-40 patients undergoing surgery [presurgical assessment] per year to maintain adequate medical, technical and nursing skills." (Binnie C D, 2000)

Clinical Standards Advisory Group Recommendations (United Kingdom)

CSAG was established in 1991 as an independent source of expert advice to UK Health Ministers and to the NHS. Ministers asked CSAG to advise on standards of NHS epilepsy services.

"We consider that there will not be the requisite experience at a (epilepsy surgery) unit unless at least 50 patients are assessed annually." (Clinical Standards Advisory Group, 2000)

The Adult (RPH) and Paediatric (PMH) Epilepsy Centres share resources and work very closely together, providing a continuum of care from childhood to adult life. RPH was designated by consensus as the adult epilepsy centre because of its performance, personnel, purpose-built infrastructure with geographic integrity, and its highly developed complementary services.

Patients are referred from all over the metropolitan area and rural Western Australia. The proportion of epilepsy referrals by region reflects the proportion of the Western Australian population by region, with the exception of the Pilbara and other northern areas, which are under-represented.

Clinical and EEG outreach services are provided, as are educational programmes for other health professionals and the community. Most patients have severe epilepsy and need complex and ongoing subspecialty care. Some patients are referred for clarification of diagnosis.

Epilepsy Surgery

The WA Comprehensive Epilepsy Service is first and foremost a medical service, with epilepsy surgery playing an essential but much smaller role. Patients undergoing evaluation for surgery require complex and highly sub-specialised neurological evaluation, which is very time intensive. This continues in the medium term after surgery for a minimum of 1-2 years given the need to alter medications and manage other issues such as eligibility to drive.

A single epilepsy surgical team that performs all adult epilepsy surgery and intra-operative monitoring in Western Australia performs epilepsy surgery. This team approach is of key importance in ensuring a uniform and high standard of pre-operative evaluation and surgery with electrocorticography. Most epilepsy surgery patients are now seizure free or rarely have seizures.

All paediatric epilepsy surgery is performed on-site at PMH. All adult epilepsy surgery was performed at RPH, until recently, and all intracranial monitoring continues on-site. For optimal patient care and safety, the medical and surgical components of the Adult Epilepsy Centre should be together in the same hospital.

Continuity

The eventual proposed relocation of the Adult Epilepsy Centre requires preservation of the functional and geographic integrity of the Centre. This includes the essential links with the Paediatric Epilepsy Centre and with related disciplines including neuroimaging, neurosurgery, neuropsychology, neuropsychiatry and neuropathology.

Specific infrastructural and network requirements

Highly specialised and purpose-built infrastructure is required to allow the Adult and Paediatric Epilepsy Centres to continue to provide optimal patient care. Functional and geographic integrity is required.

Accommodation

Purpose-built and contiguous facilities are of crucial importance for optimal patient care. These included the neurophysiology laboratory, radioisotope handling area, outpatient clinics, consultant and technician rooms, offices, meeting and staff rooms and the inpatient ward. A devoted seizure alarm system links these areas.

The neurophysiology laboratory is purpose built for epilepsy monitoring with radio frequency shielding, an isolated and filtered power supply and radioisotope storage facilities for ictal SPECT studies.

Currently at RPH two single wardrooms are equipped for and dedicated to patient video-EEG monitoring, with a-nominal 5 epilepsy beds added to the neurology bed allocation. Currently at PMH a single wardroom is equipped for and dedicated to patient video-EEG monitoring.

Dedicated video-EEG network

Intramural: Real-time video-EEG fibre optic links and alarm network linking the whole neurophysiology laboratory and staff rooms to the ward, clinics, ICU, operating theatres, technical services and neuroimaging. Dedicated local area network. Logical separation from the hospital is installed providing streaming video & EEG communication between all linked areas.

Inter hospital: linking the elements of the WA Comprehensive Epilepsy Service (adult and paediatric), deployed across the tertiary sites, is required.

Remote-access: to allow epilepsy specialists rapid and ready access to patients undergoing video-EEG monitoring, whether in the epilepsy unit or in intensive care.

Integrated cross-campus service and links

The adult and paediatric epilepsy centres share resources and work closely together, providing a continuum of care from childhood to adult life. However, there is a need to improve transitional care arrangements with specific shared clinics, an adolescent clinic for example. The epilepsy centres provide inpatient consultative and outpatient specialised epilepsy and neurophysiology services to other hospitals.

Educational programs for other health professionals and the community are provided, albeit limited by current inadequate resources. The Adult and Paediatric Epilepsy Centres are also regularly involved in undergraduate and postgraduate medical, nursing and allied health training programs.

Current cross campus links – Adult and Paediatric Epilepsy Centres

The adult and paediatric epilepsy centres share resources and work closely together, providing a continuum of care from childhood to adult life.

Fremantle Hospital

Is provided with inpatient consultative and outpatient specialised epilepsy services outreach.

Sir Charles Gairdner Hospital (SCGH)

Inpatient consultative and outpatient specialised epilepsy clinics are provided as part of the WA Comprehensive Epilepsy Service. Most adults requiring presurgical monitoring, including all complex and invasive monitoring, are referred from the northern region and SCGH to the Adult Epilepsy Centre. For patients having elective epilepsy surgery at SCGH, the Adult Epilepsy Centre team visits SCGH to provide electrocorticography and to provide continuity of clinical care.

Bentley Hospital	Provision of EEG services at RPH since 1995 & PMH
Swan Districts Health Service	Provision of EEG services at RPH & PMH
Armadale Hospital	Provision of EEG services at RPH & PMH
Mercy Hospital	Provision of EEG services at RPH & PMH
Kalamunda Hospital	Provision of EEG services at RPH & PMH
Joondalup Health Campus	Provision of EEG services at RPH & PMH

Educational programs for other health professionals and the community are provided. The Adult and Paediatric Epilepsy Centres are also regularly involved in undergraduate and postgraduate medical, nursing and allied health training programs.

Further requirements

Subspecialty epilepsy clinics should also be available to meet the needs of specific groups of patients (epilepsy in learning disability, in pregnancy, adolescent transition to the adult service and in potential surgical candidates).

Improved communications between primary, secondary and tertiary care are necessary.

11.2 Recommendations

1. Single adult and paediatric epilepsy reference centres should continue to care for patients who require more detailed evaluation and management, including presurgical assessment and epilepsy surgery.

2. Single adult and paediatric epilepsy reference centres require functional and geographic integrity, with purpose-built and contiguous facilities and a dedicated intramural and cross-campus video-EEG network.

3. A spectrum of advanced imaging techniques, including ictal SPECT, PET and high field MRI systems (at least 3 Tesla) provided by Neuroimaging specialists (neuroradiologists, nuclear medicine physicians) are necessary to support the adult and paediatric epilepsy centres.

4. Like paediatric epilepsy surgery, a single epilepsy surgical team should continue to perform all adult epilepsy surgery and intra-operative monitoring, and the medical and surgical components of the service should be in the same hospital.

5. Subspecialty epilepsy clinics should also be available to meet the needs of specific groups of patients (epilepsy in learning disability, in pregnancy, adolescent transition to the adult service and in potential surgical candidates).

6. Neuropsychiatry and neuropsychology staff should be an integral part of the adult and paediatric epilepsy centres.

12. PRIVATE SPECIALISTS

Private specialists, particularly neurologists and paediatricians make an important contribution to secondary and tertiary epilepsy care, particularly outpatient services. Private specialists see a large number of patients, providing initial assessments, follow-up and referral to the public epilepsy sector when required.

Patients seen in private practice tend to have less severe epilepsy, less co-morbidities, better social supports and greater resources when compared to those seen within the public sector.

Perceived advantages of private sector management include continuity and availability of care. Potential problems with the private providers may include:

- Absence of credentialing of neurologists as specialising in epilepsy.
- Variable continuing medical education if not linked to a public epilepsy service.
- Limited emergency and inpatient services.
- Lack of specialised investigations and support services e.g. Epilepsy nurses, EEG, video-EEG.
- Financial cost:
  - The patients requiring more care can least afford it.
  - Some medications are expensive in the private sector.

The Public Epilepsy Sector provides an expert resource for clinical assessment and management and for neurophysiological evaluations.

Public sector referral is required for:

- Complex management issues e.g. diagnosis, medical therapy, driving.
- Complex investigation issues e.g. Diagnostic and pre-surgical evaluations.
- Support issues e.g. Epilepsy nurse input.
- Financial issues.
- Country patients requiring Telehealth.

With the increasing complexity of epilepsy management, the number of patients referred from the private sector to the WA Comprehensive Epilepsy Service is progressively increasing.

Epilepsy specialists in private practice can participate in the WA Comprehensive Epilepsy Service, refer patients for more detailed assessment as required (including presurgical evaluation and ongoing care) and participate in clinical research.

They should be invited to further contribute, including participation in shared protocols and database, audit and peer review, and with the ability to refer their patients to the epilepsy nurse specialists based at the tertiary sites.

Most inpatient epilepsy services will remain in the public hospitals. The private arena lacks equivalent services given:

- The highly specialised and multidisciplinary epilepsy team required.
- The limited availability of private emergency services.
- Limited Medicare benefits for complex epilepsy services.
- Most patients with severe epilepsy are not privately insured.

Private specialists make an important contribution to secondary and tertiary epilepsy care, particularly outpatient services.

13. INFORMATION AND EDUCATION IN EPILEPSY CARE

People with epilepsy and their families have a right to clear, accurate and appropriate information about their condition including the specific epilepsy syndrome, its treatment and the implications for everyday living. Surveys of people affected by epilepsy have reported that up to 90% wanted more information about the cause of epilepsy, effects and interactions of drugs and the avoidance of potentially dangerous situations. Many people prefer talking to an epilepsy nurse specialist or someone from a voluntary organisation with whom they feel more at ease.

As people forget or fail to take in much of what they are told during clinic visits, written information, helpline telephone numbers and contact details of voluntary organisations should be available to all families. A checklist could be provided to give a structure to discussion and ensuring important points are covered. This can be kept in the patient's records, ensuring other professionals are aware of what information has already been given.

The checklist can include information on:

- General epilepsy.
- Seizure triggers.
- Antiepileptic drugs and drug interactions.
- Safety Issues, including Sudden Unexpected Death in Epilepsy (SUDEP).
- First Aid.
- Issues for women (contraception, pregnancy).
- Lifestyle, education and employment.
- Epilepsy and driving.
- Possible psychosocial consequences.
- Support organisations.

13.1 Women with Epilepsy

Women with epilepsy, who are of childbearing age, need additional advice about issues such as contraception and pregnancy. Women should be fully informed about treatment choices and their options during pregnancy and the postnatal period to minimise risk to the child and mother.

The choice of epilepsy medication for women may be influenced by the potential efficacy, the potential teratogenicity of the different anti-epileptic drugs (AED), interactions with oral contraceptives, cosmetic and other side effects.

Information about the Australian Pregnancy Register, a voluntary national register exploring the effects of AEDs in pregnancy, should be provided to all pregnant women with epilepsy.

13.2 Information For Schools and the Community

Families are concerned about their child having a seizure at school and the possible associated stigma. School staff is keen to provide a safe environment for the child but this can lead to the child not being allowed to participate fully in some activities. Schools should be given written information and staff should be offered further discussion on epilepsy and its management, ideally involving the parent(s). Leaflets on epilepsy safety specifically written for teachers should be available.

Children with epilepsy, like other children, spend a significant proportion of their awake period at school. Management of seizures at school is an issue that often requires individualised plans. Awareness and knowledge of epilepsy by the teachers and the extended school community helps with acceptance of children with epilepsy. Peer interactions, innovative methods of minimising restrictions and using sensible precautions, all have an impact on the psychosocial as well as the physical well being of the child with epilepsy.

Discussions about any possible restrictions on activities within the school should always involve the parents, the child, school staff and a health professional that is knowledgeable about epilepsy. There may be additional risk of minor injuries for some children, who have epilepsy, but inclusion and independence should be prioritised and joint decisions made about risk and safety. It is important that restrictions be as minimal as possible, so that the child's quality of life at school is maximised.

Many children feel that more open discussion about epilepsy and education of their peers is the best way of reducing stigma and dispelling myths leading to greater acceptance of them and their seizures. The child and family should make the decision about what information is given to classmates. When children have a history of prolonged seizures, training on administration of emergency medication may be given to school staff that is willing to do this. A care plan should be agreed on with the school and family and with involvement of the general practitioner. Training of school staff (usually by the school nurse with the assistance of an epilepsy nurse specialist) in the administration of emergency medication should be updated regularly. PMH provides an annual Epilepsy Seminar directed at school staff. More seminars with tele-linking to Regional and Rural WA are needed.

Adolescence can be a challenging stage in life. Education and counselling is particularly important in order to ensure compliance, adoption of sensible lifestyles, make appropriate career choices and enjoy good physical and mental health.

13.3 Management of Risk

Safety

When a diagnosis of epilepsy is made, safety may be a major concern. Safety in some common situations should be covered as outlined in the checklist and information sheets. People may be inappropriately restricted from participating in some sports, social and other activities. Advice and supervision requirements should be individualised taking into account the type of activity and the seizure history.

Epilepsy and Driving

The consequences of having a seizure while driving a vehicle are potentially devastating. National guidelines for assessing fitness to drive have been proposed by the National Road Transport Commission and are currently undergoing revision. They are yet to have the required legislative support in Western Australia.

In Western Australia, the Department of Planning and Infrastructure (DPI) has the legal obligation for certifying a person medically fit to drive. The treating doctor's role is to provide medical information sufficient for the Department to make a determination. A clear delineation of these roles is required.

Unlike in other states, applicants/drivers are not yet required by law to advise the DPI of any conditions that may affect their ability to drive, and medical practitioners are not indemnified for providing medical information to the DPI. Legislative reform is required to correct these deficiencies. The DPI should establish an expert panel, constituted and indemnified by the DPI, for making determinations in difficult or uncertain situations, and judging appeals.

Death in Epilepsy

People with epilepsy have an increased risk of premature death compared to the general population. Most of these deaths can be explained by the condition underlying the epilepsy, seizure-related accidents, or status epilepticus.

In some situations, the death of someone with epilepsy cannot be adequately explained, and is defined as sudden unexpected death in epilepsy (SUDEP). Although SUDEP may occur in any patient with epilepsy, factors that influence the incidence include early age of onset of epilepsy, number of seizures, severe learning difficulty and seizure type.

13.4 Role of The Voluntary Sector, Non-Government Organisations

There are agencies, which offer information, advice, support, advocacy and training for families affected by epilepsy. The Epilepsy Association of WA (Epilepsy Australia), and Epilepsy Action are key providers of this support. Both organisations work together in Western Australia, and are members of the Joint Epilepsy Council of Australia (JECA), representing the International Bureau for Epilepsy in Australia. Many people request information about all aspects of epilepsy from their help lines and websites. They also

provide leaflets and training to people with epilepsy, families and carers as well as health, educational and other professionals.

The Epilepsy Society of Australia is the peak medical body, representing the International League Against Epilepsy, and provides a website with links to information. The Epilepsy Association of WA, JECA and Epilepsy Society of Australia have a longstanding and cooperative relationship with the WA Comprehensive Epilepsy Service. Key benefits to people with epilepsy are best provided when the medical/hospital and community sectors work together.

Roles served by the non-government organisations include:

Advisory and Counselling Services and a link with Epilepsy Nurse Specialists

- Epilepsy Nurse Specialists are much needed to provide education on seizures and advice on support services and to liaise with medical staff as required. This facility is best suited to the Perth Metropolitan Region.
- Regular updates to advisory and counselling facilities to alleviate pressures on acute care nursing staff.

Public Awareness / Education and Research

- Delivering epilepsy and seizure awareness training to a variety of audiences.
- Improved public awareness to help eliminate the existing social stigma and improve the quality of life of persons with epilepsy.
- Education alleviates unnecessary Government costs on medical staff, hospital beds and emergency departments.
- School education removes the existing stigma in future generations and assists in achieving better education for those with epilepsy.
- Social awareness/education will help bring epilepsy out of the shadows.

Support Groups

- The establishment and maintenance of individual and social support groups.
- Individual support groups for face to face meetings to establish confidence and diminish the sense of loneliness and separation.
- Social Support Groups to enhance self-confidence and social interaction with all members of the community.
- These groups are very important in remote and regional areas with physical isolation, limited medical availability and facilities.

Rural and Remote Areas / Aboriginal Health

- An area currently largely overlooked and needing the implementation of new initiatives.
- Indigenous health and the distribution of educational data in a suitable format.
- Indigenous support groups will need to be community orientated with unified forums.

- The incidence of epilepsy is higher among Aboriginal people than other Australians and needs a collaborative approach with other parties.

13.5 Recommendations

1.	People with epilepsy have a right to clear, accurate and appropriate information about their condition.
2.	A checklist should be provided to help healthcare professionals deliver appropriate information to patients, families and carers.
3.	Epilepsy awareness training and written information should be offered to schools and the community.
4.	People with epilepsy and healthcare professionals, at all levels, should be aware of the valuable contribution, which can be made by the voluntary sector. Services provided and requiring support include: Advisory and Counselling Services, Public Awareness and Education programmes, and Support Groups for both metropolitan and rural and remote Areas.
5.	Epilepsy education is best provided by the public health and community sectors work together.

14. WESTERN AUSTRALIAN CLINICAL NEUROPHYSIOLOGY SERVICES: DIAGNOSTIC AND INTRAOPERATIVE

14.1 Western Australian Clinical Neurophysiology Services (adult)

Clinical neurophysiology services required and provided in Western Australia

Clinical neurophysiology services have an essential role in neurological diagnosis, monitoring and treatment. They are required for clinical neurosciences (neurology, neurosurgery, spinal care) and related disciplines such as orthopaedics, rehabilitation, the medical specialties, intensive care, plastic surgery and the burns unit. They comprise:

Diagnostic neurophysiology studies

Diagnostic EMG, EEG, video-EEG and evoked potentials are provided as a part of the core services of the neurology departments of all tertiary hospitals. Similarly assessment and treatment of movement disorders, including botulinum toxin injections, are provided at all tertiary teaching hospitals. Some diagnostic neurophysiology services and botulinum toxin injections are also available in private practice.

Specialised neurophysiology assessments

These include the neurophysiological assessment and treatment of particular movement disorders (e.g. severe Parkinson's disease, laryngeal dystonia, cricopharyngeal dystonia, neurorehabilitation) and are confined to specialised tertiary public hospitals. For example SCGH staff provides a statewide service for the deep brain stimulation treatment of complex movement disorders, and RPH-SPC is the state neurorehabilitation centre.

Intraoperative monitoring

This highly sub specialised and time intensive service is provided statewide by RPH staff:

Spinal Monitoring	State service
Interventional neuroradiology monitoring	State and national service
Epilepsy Surgery Monitoring	State service
Cortical Functional mapping for tumour surgery	State service
Complex Posterior fossa monitoring	State service
Carotid endarterectomy	Regional service
Spinal injured & brachial plexus programmes	State services

The medico legal implications of not performing intraoperative monitoring are not adequately recognised at present**.**

Staff and Equipment

These services are provided by technical and medical staff that have had specific and comprehensive subspecialty training in all aspects of intraoperative and diagnostic neurophysiology. All these services are interrelated and are highly sub-specialised, requiring multidisciplinary teams, including manufacturing our own electrodes (one patented) and cabling.

The EEG and Clinical Neurophysiology Committee of the Australian and New Zealand Association of Neurologists (ANZAN) recommends that neurologists who wish to perform clinical neurophysiology on a regular basis require a minimum additional training of six months full-time or its equivalent provided by a supervisor specifically trained in clinical neurophysiology and in an accredited laboratory. A one-year clinical neurophysiology fellowship in EMG or EEG/epilepsy is required to gain the knowledge and experience necessary to establish and supervise a laboratory service in an academic institution (EEG and Clinical Neurophysiology Committee, 2006).

14.2 Adult Service Model

Hurdles and Local Resources

For neurophysiology technicians, ongoing training and educational support is required to maintain and enhance standards of care. Appropriate training opportunities, career path progression, and salary levels are urgently required in order to attract and retain clinical neurophysiology technical staff.

There is also a shortage of trained clinical neurophysiologists in Australia. There is also a need to establish and improve standards of training and clinical neurophysiology practice in Australia. These problems are recognised by the ANZAN and the Epilepsy Society of Australia (ESA), who are working to change the current situation. Dr John Dunne, as Chairman of the EEG and Clinical Neurophysiology Committee of the AAN and the immediate past-president of the ESA, is directly involved in planning for the future.

Only a few neurologists in Australia have the training and expertise in intraoperative neural monitoring. In WA, the only technical and medical staff, with the sub-specialised skills and experience required form part of the RPH neurology team. Drs Peter Silbert, Nicholas Lawn and John Dunne have had comprehensive training in aspects of intraoperative and diagnostic neurophysiology during fellowships at the Mayo Clinic. The neurophysiology technical staff has had comprehensive training and experience built up over 17 years.

Intraoperative monitoring and sub-specialised clinical neurophysiology are extremely time intensive. A further investment in developing intraoperative services in some areas currently performed by only one member of the team is required (e.g. microvascular decompression for hemifacial spasm).

Service framework

Integrated and adequately resourced cross-campus services are required to meet the specific needs of patients at the various campuses.

For neurophysiology surgical monitoring it is essential to have an integrated and cross-campus approach to:

- Provide a viable statewide service of the highest quality for the population base of WA.
- Maintain the required highly sub-specialised medical and technical team.
- Optimal utilisation of the limited availability of staff with the skills for this highly intensive but low-volume work.
- Avoid the cost of duplication of expensive and highly specialised services.
- Meet the requirements at each campus, including:
  - Spinal surgery weekly at RPH.
  - Posterior fossa and spinal monitoring for complex spine at SCGH.
  - Eventually the Southern campus will need to be served.

These clinical neurophysiology services and the WA adult epilepsy centre are the fabric of the same entity - functionally and geographically- with the same staff and equipment performing these duties. The monitoring team at RPH should continue to provide and further develop a cross-campus and statewide service.

Implementation and Resource Implications

Monitoring services require a minimum of 8 channel monitoring machines capable of multimodality monitoring, plus electrical and magnetic stimulators. Standard modern equipment is required across campuses to allow the team to seamlessly move to different sites according to need. The possibility and implications of equipment (monitoring machine) failure requires modern well-maintained equipment and some equipment at each site.

Additional equipment will be provided at SCGH equivalent to that being used at RPH in order to avoid the risks and costs of transporting delicate equipment between campuses. Clinical neurophysiologists require an office and computer facilities within the theatre suite at SCGH.

1. The appointment of 2 FTE Neurologists/Neurophysiologists to work between RPH and SCGH.
2. The appointment of a further neurophysiology technician to RPH.
3. The development of a similar cross-campus framework to encompass the proposed Southern Tertiary Campus.

14.3 Western Australian Clinical Neurophysiology Services (Paediatric)

Clinical neurophysiology services have an essential role in neurological diagnosis, monitoring and treatment for children. Diagnostic neurophysiology services form an essential part of the core services of Princess Margaret Hospital.

Intraoperative neural monitoring is highly sub-specialised and time intensive, and is provided as a co-operative statewide service by PMH and sometimes RPH staff. This monitoring team should continue to provide and further develop as a cross-campus and statewide service.

Neurophysiology Services for Neonates, Children and Adolescents in WA

The Department of Neurology at Princess Margaret Hospital provides:

1. EEG and Video EEG services.
2. Intracranial EEG Monitoring, Stimulation Mapping.
3. Evoked Potential Studies – Somato Sensory Evoked Potentials, Visual Evoked Potentials, Brain Stem Evoked Potentials.
4. Nerve Conduction Studies – Motor and Sensory.
5. EMG.
6. Intraoperative Spinal Monitoring – for spinal lipomas, tumours, tethered cord, Chiari-malformation.
7. Neurophysiological investigations for many neurological disorders such as brachial plexus injuries, other nerve injuries and Guillain-Barre syndrome.

14.4 Recommendations

1. Clinical neurophysiology services have an essential role in neurological diagnosis, monitoring and treatment. Diagnostic neurophysiology services form a part of the core services of the neurology departments of all tertiary hospitals, and are also provided in the private sector.

2. More specialised neurophysiology assessments and treatments, including intra-operative neural monitoring, are confined to tertiary teaching hospitals.

3. An integrated and adequately resourced statewide and cross-campus public hospital service is required to meet specific patient needs.

4. Intraoperative neural monitoring should continue to be provided and further developed as a cross-campus and statewide service.

5. Staff with subspecialty training in clinical neurophysiology is required to deliver these services. Training of further medical and technical staff is essential for the ongoing viability of these services.

15. IMPLEMENTATION AND AUDIT

15.1 Implementation

It is acknowledged that not every guideline can be implemented immediately, but mechanisms should be in place to ensure that the care provided is reviewed against the guideline recommendations and the reasons for any differences assessed and, where appropriate, addressed.

These discussions should involve both clinical staff and management. Local arrangements may then be made to implement the guideline in individual hospitals, units and practices, and to monitor adherence. This may be done by a variety of means including patient-specific reminders, continuing education and training, and clinical audit.

Key Points for Audit

Diagnosis

- Proportion of adult first seizure and epilepsy patients seeing an epilepsy specialist.
- Proportion of children with epilepsy seeing an epilepsy specialist.
- Time to specialist assessment and investigations following first seizure.
- Time to diagnosis of epilepsy.
- Proportion of patients seeing an epilepsy nurse specialist when diagnosis is discussed.
- Proportion of patients and carers receiving written information when diagnosis is discussed.
- Accuracy of diagnosis of epilepsy, seizure classification and epilepsy syndrome classification.

Treatment

- Proportion of treatment recommended by an epilepsy specialist.
- Proportion of patients that are seizure free.
- Number on monotherapy, two, three and four drugs.
- Drugs levels only done for appropriate indications.
- Percentage of schools offered epilepsy awareness training and written epilepsy information.
- Existence and use of local protocol for management of status epilepticus.

Contraception, pregnancy and HRT

Documentation of:

- Contraceptive advice.
- Preconception counselling.
- Risks of epilepsy and antiepileptic drugs in pregnancy.
- Information given about the Australian Pregnancy Register for Epilepsy.
- Advice about care of the baby and breastfeeding.
- Proportion of pregnant women taking folic acid appropriately.

Models of care

Extent to which data on measures above routinely shared between primary and specialist care.

- Proportion of patients in primary care:
  - Receiving structured annual review (at least six monthly in children).
  - With documentation within past year of:
    - Seizure frequency.
    - Last seizure.
    - Drug adverse effects.
    - Review of medication.
- Access to epilepsy nurse specialist.

Tertiary care

- Availability and speed of access to specialist first seizure clinics.
- Availability and speed of access to specialist epilepsy clinics.
- Availability and speed of access to subspecialty joint clinics (teenage, pregnancy).
- Availability and speed of access to specialist investigations.

16. RESOURCE IMPLICATIONS

Full implementation of these recommendations will require the identification and recruitment of additional staff with expertise in epilepsy, including training and ongoing administrative support for these posts. This group may have immediate and ongoing professional development needs.

MRI facilities are increasingly available within district general hospitals. Availability of specialists to interpret the MRI is more limited. There are resource implications in terms of training and sharing of specialist skills across WA, and with the provision of high field MRI systems.

17. RESOURCING BENCHMARKS – ADULT AND PAEDIATRIC EPILEPSY CENTRES

International Guidelines for Specialised Epilepsy Centres indicate that the WA Comprehensive Epilepsy Service and Adult and Paediatric Epilepsy Centre are understaffed.

17.1 Epileptologists

Recommended personnel include a minimum of 3 FTE adult epileptologists.

The National Association of Epilepsy Centres (USA)

Regional referral facilities such as the epilepsy centre, termed fourth-level medical centres, require:

> *"1. Physicians* (Epileptologist)
>
> *(i) Medical Director with…special training in epilepsy and intensive neurodiagnostic monitoring techniques*
>
> *(ii) Neurologist with…special training in the pharmacology of antiepileptic drugs*
>
> *Both of these individuals should have specific training in prolonged EEG recording*
>
> *with video monitoring capability...*
>
> *(iii) Other long-term monitoring electroencephalographers…"*
>
> (Other medical staff)
>
> *(iv) Neurosurgeon…with special interests in epilepsy*
>
> *(v) Psychiatrist…with special interest in treatment of epileptic patients with psychiatric disorders*
>
> *(vi) Pharmacologist or Pharm.D. with special interest in training in epilepsy*
>
> (The National Association of Epilepsy Centers, 1990)

Clinical Standards Advisory Group: Services for Patients with Epilepsy (UK)

The Clinical Standards Advisory Group (CSAG) was established in 1991 as an independent source of expert advice to UK Health Ministers and to the NHS. Ministers asked CSAG to advise on standards of NHS epilepsy services and access to them.

"The pre-surgical assessment of patients requires skill and experience, as well as a range of facilities, despite the fact that the assessment has been simplified by the introduction of high-resolution MRI…However, we recommend that all candidates for potential surgery be referred to a specialised epilepsy surgery unit, which should have as a minimum, the following facilities:

- high-resolution MRI;
- neuroradiological facilities for sodium Amytal testing;
- EEG video telemetry;
- a fully equipped neurosurgical unit with ITU facilities;
- a multidisciplinary team that includes as a minimum an experience neurosurgeon, neurophysiologist, neurologist, neuropsychiatrist and neuropsychologist.

In addition, we consider that there will not be the requisite experience at a unit unless at least 50 patients are assessed annually." (Clinical Standards Advisory Group, 2000)

International League Against Epilepsy Commission Report: Recommended Standards.

Criteria for Basic Epilepsy Surgery Centers

1. "Context: situated within a comprehensive neurosciences center, as part of a comprehensive epilepsy program, and able to provide proper presurgical assessment and surgical treatment for a significant range of patients.
2. Core team of specialists: neurophysiologist, neurologist, and neurosurgeon.
3. Reasonable access to other specialists: neuroanesthesiologist, neuropsychologist, neuropsychiatrist, and neuroradiologist.
4. Throughput: 20-40 patients undergoing surgery per year.
5. Catchment population: approximately 2 million.
6. Equipment: standard neuroimaging facilities, including MRI and standard neurophysiological facilities, with availability of machines and technicians for intracarotid amobarbital test (Wada), intraoperative recording, and video-EEG monitoring." (International League Against Epilepsy, 1997)

17.2 Epilepsy nurse specialists

Recommended personnel for adults includes a minimum of 2-3 FTE

"For a catchment population of 200,000 a service comprising…. a full-time specialist nurse (four clinics per week) and 0.3 GP with a special interest (two clinics) could provide rapid access for all patients with suspected epilepsy, annual follow-up of patients with epilepsy in remission, as needed support for women with epilepsy and regular review for all patients with drug-resistant conditions." (Reid J J A, 1969, Scottish Intercollegiate Guidelines Network, 2003, National Institute for Health and Clinical Excellence, 2004)

Staffing requirements - Adult Epilepsy Centre

Additional staff is required to sustain the care of the increasing number of patients (see multiple WA Comprehensive Epilepsy Service submissions to HDWA), to support dedicated epilepsy clinics for the greater metropolitan region and links with regional state centres, and to support educational programmes and research.

Staff position*	**Current (± allocated funding)**	**Total Required**
Epileptologists	1.3 FTE (funded)	3.5 FTE
Epilepsy Nurse Specialist	1.0 FTE (funded)	2.0 FTE
Neurophysiology Technicians	5.0 FTE (funded)	6.0 FTE
Neuropsychologist	0.2 FTE (funded)	0.5 (or 1.0) FTE
Neuropsychiatrist	0.2 FTE (unfunded)	1.0 FTE
Epilepsy/neurophysiology registrar (PMH/RPH)	Nil	1.0 FTE
Neurogenetics consultant	0.1 FTE (funded)	0.1 FTE
Technical services support	0.5 FTE (unfunded)	0.5 FTE
Secretarial	Nil	1.5 FTE
Social Worker	Nil	1.0 FTE
Extra nurse on the ward	3.0 FTE (funded neurology ward dependencies)	3.0 FTE

*See appendix 1

Staffing requirements -Paediatric Epilepsy Centre

The Neurology Department at PMH is under resourced. PMH neurology staff at present comprises one paediatric epileptologist with neurology & epileptology duties (1 FTE) and three paediatric neurologists with epilepsy expertise ~1.5 FTE) at PMH. No funded training position for Paediatric Neurology is available.

PMH is the single designated Paediatric Epilepsy Centre for the state of WA, and additional staff are required to manage the workload, including:

Accident & Emergency presentations for seizures:	~600/year
Outpatient neurology clinic attendances:	~3000/year (80% epilepsy)
EEGs	~2000/year
Video EEG monitoring	~25/year

The provision of neonatal video-EEG monitoring across campuses (PMH-KEMH) should be part of the outreach from the paediatric epilepsy centre. Currently babies from King

Edward Memorial Hospital and other neonatal units in Perth and greater WA, have to be transported to PMH for an EEG.

Staff Position*	Current	Total Required
Paediatric Neurologist/Epileptologist	1.0 FTE	2.0 FTE
Neurophysiology Technician –for epilepsy	1.0 FTE	2.0 FTE
Epilepsy Nurse Specialist	0.5 FTE	1.0 FTE
Epilepsy Education and Research Assistant	Nil	1.0 FTE
Neuropsychologist	Nil	0.5 FTE
Clinical Psychologist	Nil	1.0 FTE
Psychiatrist	Nil	0.5 FTE
Speech Pathologist	Nil	0.5 FTE
Occupational Therapist	Nil	0.5 FTE
Physiotherapist	Nil	0.2 FTE
Biotechnologist	Nil	0.5 FTE
Information Systems Officer	Nil	0.2 FTE
Administrative Assistant	Nil	1.0 FTE
Dietician	Nil	0.5 FTE
Social Worker		0.5 FTE
School Liaison Teacher	Through Neurology, 0.3 FTE	0.5 FTE
Play Therapist		0.5 FTE

*See appendix 1

Full implementation of the recommendations will require the identification and recruitment of additional staff with expertise in epilepsy, including training and ongoing administrative support for these posts.

18. DEVELOPMENT OF THE GUIDELINES

WA Comprehensive Epilepsy Service staff from all campuses has contributed to our submissions over a long consultative process (since 1990). In addition to monthly Service meetings, numerous meetings with clinical staff, voluntary organisations and medical administrations have occurred over these years.

The WA Comprehensive Epilepsy Service and its framework have the full endorsement of the voluntary organisations, the WA Epilepsy Association and the Epilepsy Society of Australia.

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APPENDICES

Appendix 1: W.A Comprehensive Epilepsy Service Staff: Essential

Epilepsy Specialist Nurses

Epilepsy specialist nurses are a fundamental element of the multidisciplinary epilepsy team.

A Cochrane review concluded that there was a perceived higher quality of care, less time spent on travel, reduction of the waiting times, and better continuity of care noted by the patients who had contact with an epilepsy nurse specialist (Bradley P, 2001).

Studies have shown that epilepsy nurse specialists are cost effective, and can improve AED adherence, reduce the length of stay in hospital for people with epilepsy and increase patient satisfaction.

Patients expressed the belief that they would have benefited most by seeing a special nurse at the time when epilepsy was first diagnosed. A recurring theme from interview data was that patients perceived the doctors' time as too limited to explain the condition and how to manage it, whilst the nurse had the time and expertise to do so. Overall the nurse trained in epilepsy care was valued highly for providing advice and support, especially in explaining the social aspects of epilepsy.

The role of epilepsy nurses generally follows the wider role of the specialist nurse and includes:

- Support and information for the patient, carer and family.
- Provision of advocacy and advice.
- Improving continuity of care, coordinating outpatient and inpatient investigations.
- Liaising with schools/employers/general practitioners.
- Education for statutory and voluntary organisations.
- Source of expert knowledge.

More specific roles include monitoring patient progress, adjusting medication, arranging relevant tests and patient review, and liaison between the family, school and the multidisciplinary team involved in the person’s care.

Clinical Neurophysiology Technicians

Clinical neurophysiology technicians are a core part of Epilepsy and related services. The Epilepsy Centre technicians perform diagnostic EEG and evoked potential studies, play a key role in the interpretation of video-EEG monitoring, handle and administer intravenous radio-isotopes for injection during seizures, and are largely responsible for patient care during epileptic seizures. Epilepsy centre technicians are trained and

certified in the handling of unsealed radioisotopes. They have important direct responsibilities in patient care.

They are also a part of the surgical monitoring team for carotid endarterectomy, spinal, neurointerventional, posterior fossa and epilepsy surgery.

Ongoing training and educational support is required to maintain and enhance standards of care. Appropriate training opportunities, career path progression, and salary levels are urgently required in order to attract and retain clinical neurophysiology technical staff.

Epileptologists

It is essential to have a clinicians who are epilepsy specialists leading Epilepsy Services. Whilst neurologists may have a long experience in epilepsy, it is acknowledged that subspecialty expertise is required for many aspects of epilepsy care, especially the management of refractory epilepsy, including presurgical evaluation. Patient evaluation (clinical, video-EEG) and treatment are highly specialised and time-intensive, as is ongoing follow-up.

Neuropsychologists

Patients undergoing presurgical and post-surgical evaluations require neuropsychological testing, by specifically trained neuropsychologists, This testing of various aspects of brain function establishes baseline function and sometimes gives clues as to the location of an epileptogenic focus, and its effects.

Neuropsychiatrists

People with epilepsy have an increased incidence of anxiety, depression and psychosis, particularly patients with severe epilepsy. Designated psychiatry and psychology staff is an essential part of the team.

Epilepsy surgeons

Epilepsy surgery has become an acknowledged subspecialty of neurosurgery, requiring specific training and skills. A single epilepsy surgery team evaluates and treats patients with severe epilepsy, and for optimal patient care and safety the medical and surgical members of the team should be together.

Neurogenetics liaison

Neurogenetics liaison is required for an increasingly recognised group of patients with the inherited epilepsies.

Specialised neurology nurses

Provision of an additional nurse per shift is required to meet the intensive needs of monitored patients. They are at high risk, being vulnerable to multiple seizures and status epilepticus. Unlike children, adults often do not have family available to stay with them to assist in seizure recognition and patient care. The neurology ward already has heavy nursing responsibilities caring for the neurologically and cognitively disabled, in addition to trying to meet the needs of patients with epilepsy. Furthermore, all patients having invasive monitoring require continuous nursing observation, as at other epilepsy centres nationally and internationally.

Home School Services

School liaison teachers are very important to communicate with the school and provide the interface between the school and the epileptic team in the management of children with epilepsy.

Medical Physics-Technical/Biomedical Services

Medical Physics provides a high standard of maintenance for the electronic equipment, and manufacture tailor-made electrodes when needed. A daily input into the smooth running of the Epilepsy Centre is required, often many hours per day. We rely heavily on the services of Medical Physics. Failure of the recording systems can result in the loss of essential clinical information, and Medical Physics provides us with guaranteed 24-hour/seven day service.

Epilepsy imaging services

An expert team who attend all epilepsy meetings provides functional and structural neuroimaging services, including MRI, ictal SPECT and neuroangiography.

Social work

Social workers familiar with epilepsy and its effects on individuals and families assist with patient and family counselling, liaison with financial and community services, accommodation advice, and resource information.

Diagnostic laboratories

Biochemistry, haematology and neuropathology services.

Secretarial support

The investigation and management of refractory epilepsy requires complex communications and documentation, including input from multiple disciplines. Submissions, protocol development, database, audit and support for administrative and research activities are also required. Adequate resources are essential to allow timely delivery of information.

Appendix 2: Outcomes and Cost Effectiveness: Adult Epilepsy Centre Case Study

The WA Comprehensive Epilepsy Service is very cost-effective. The cost of epilepsy increase dramatically in proportion to seizure frequency. Ongoing subspecialty care benefits epilepsy patients and the community by reducing the burden of illness, including reducing attendances at emergency centres and hospital admissions related to seizures, injuries and the side effects of medications.

At the Adult Epilepsy Centre, almost half the patients with uncontrolled epilepsy have become seizure free or have rare/infrequent seizures, usually with medication adjustments (83%) and with frequent follow-up (review appointments and by telephone). Most patients require ongoing care and follow-up in order to provide adequate treatment.

Patients with good seizure outcomes experience improved health-related quality of life (QOL) after treatment, whether via medical or surgical intervention. Patients report increased independence, income and employment. Medical resource use is dramatically reduced.

The following are minimum estimates of cost savings, based on a conservative direct medical cost saving of $8,000/patient/year and with a 25% reduction in admissions alone, *excluding* prevention of injuries and other morbidity and mortality.

Adult Epilepsy Centre (1999-2000)

Patient numbers	Minimum direct medical cost savings
Outpatient	
Refractory epilepsy outpatients:	
Medically treatable/ or not suitable for surgery	47% of patients become seizure free/rare seizures.
470 patients (1996 to 1999)	$3,760,000 per year ongoing
134 of 285 new patients in 1999/2000	$1,071,600 per year
Inpatient	
(i) Inpatient admission savings:	$790,907 per year
(ii) RPH epilepsy surgery patients:	87% of patients seizure free or rare seizures
78 of 90 patients (1996 to 1999)	$624,000 per year ongoing
20 of 23 patients in 1999/2000	$160,000 per year
MINIMUM DIRECT MEDICAL COST SAVINGS (1999-2000)	**$6,406,507* annually**

**If indirect medical and other costs included, the figure would be at least $17,641,920*

Updated details for children and adults will be obtained if required and if resources provided.

Quality of life data of a survey of temporal lobe epilepsy surgery patients treated at the Adult Epilepsy Centre found a major improvement with:

- Seizure outcome.
- Reduced medications.
- Eligibility to drive a motor vehicle (71%).

Quality of Life in Epilepsy-10 (QOLIE-10) and Subjective Handicap in Epilepsy (SHE) survey data – Adult Epilepsy Centre, Royal Perth Hospital

N=36	PRE-SURGERY	POST SURGERY
QOLIE-10		
Downhearted (some/most/all)	75%	25%
Memory difficulties	55.5%	44.4%
Work limitations	66.7%	33.3%
Social limitations	61.1%	25.1%
Physical side effects AEDs	55.6%	22.2%
Mental side effects AEDs	55.5%	27.8%
Good quality of life	22.2%	80.6%
SHE ASSESSMENT		
Improvements since surgery	control of epilepsy	97.1%
	life better/much better	91.2%
	work better/much better	70.6%
	enjoy life much more	70.6%

International data similarly indicates the cost-effectiveness and savings produced by Comprehensive Epilepsy Service care with Medical treatments (van Hout B, 1997, Jacoby A, 1998, Langfitt J T, 2000, Begley C E, 2000, Griffiths R I, 1999, Frost FJ, 2000), Surgery (Vickrey B G, 1995, Langfitt J T, 1997, McLachlan R S, 1997, Byrne P O, 1999, Gilliam FG, 2004, Wiebe S, 2001) and Vagus nerve stimulation.

Appendix 3: Activities And Outcomes - Intraoperative Neural Monitoring Services (adults)

Spinal surgery/ interventional angiography

Patients referred	Scoliosis and complex spinal surgery Spinal vascular malformations Aortic arch surgery (including interstate and overseas referrals)
Activity	One or two days per week
Locations	RPH, outreach to SCGH and PMH
Methods	Somatosensory and motor evoked potential monitoring of spinal cord function.

Staff and Equipment

The same neurophysiology technicians, medical staff (Drs John Dunne and Peter Silbert) and equipment perform this monitoring, epilepsy and other intraoperative monitoring.

Outcomes

An average of 30 patients/year are monitored, predominantly scoliosis and complex spinal surgery. These patients have had detailed preoperative and operative clinical/neurophysiological evaluation. Through the RPH programme, 14 of the first 336 monitored patients undergoing posterior spinal fusion or interventional angiography have avoided post-operative paraplegia as a direct result of the monitoring; without false negative or positive abnormalities.

Epilepsy Surgery Monitoring And Cortical Functional Mapping For Tumour Surgery

Provided as a part of Adult Epilepsy Centre activities, discussed in detail above, and provided by Drs Nicholas Lawn and John Dunne.

Intraoperative Monitoring of Cranial Nerve Function During Posterior Fossa Surgery.

Patients referred	Posterior fossa tumours Microvascular decompression
Activity	≥4 patients per year

The main aims of neural monitoring during posterior fossa surgery are to preserve cranial nerve and brainstem function. Whilst facial nerve preservation during acoustic

neuroma removal is the most common reason for monitoring, the techniques described are applicable to a wide range of procedures for extrinsic and intrinsic tumours, hemifacial spasm, trigeminal neuralgia and vascular brainstem lesions.

The monitoring methods are:

1. Nerve conduction studies to allow nerve localisation, mapping of its course prior to dissection, assessment of nerve function during and at the end of surgery. In addition, nerve action potentials can be recorded directly (eg. acoustic nerve), and the adequacy of microvascular decompression for hemifacial spasm can be assessed.
2. Electromyography with intramuscular wires to allow continuous cranial nerve monitoring to warn the surgeon when he/she is near the nerve and may not realise it.
3. Evoked potentials to monitor brainstem or acoustic nerve function.

Previous Results

Thirteen patients have been monitored over 4 years, ten with large posterior fossa tumours, and three undergoing microvascular decompression surgery. The monitoring has allowed facial nerve anatomical preservation in the ten tumour patients (average diameter 3 cm) and functional preservation in nine (no or mild weakness in seven). The three decompression surgeries have been successful.

Intraoperative Monitoring Service For Carotid Endarterectomy.

EEG is used as sensitive and reliable cerebral monitoring technique during carotid endarterectomy under local and general anaesthesia. Continuous information is provided, and EEG abnormalities usually precede clinical changes.

We have provided EEG monitoring for 45-55 patients/year undergoing carotid endarterectomy, mainly performed by the vascular surgeons, but also balloon occlusions for the neuroradiologists.

A shortage in trained technical staff and the demands of the epilepsy and other programs require rationing the service to those patients where clinical monitoring is difficult or impossible, including the sporadic cases performed under general anaesthesia, currently 3 patients per year.

Spinal injured & brachial plexus programmes

We have only a peripheral involvement in these programmes, which are based at the Shenton Park campus of RPH. We provide clinical and neurophysiological diagnostic studies as needed. We have been asked to provide intra-operative monitoring during brachial plexus surgery, both at RPH and FH, but our resources do not permit this.

In the future we hope to assist with the routine assessment and intraoperative monitoring of patients with brachial plexus injuries (pre- and intra-operative).

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