

Neurosciences & the Senses Health Network

WA Epilepsy Services Model of Care

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

February 2008

WA Health Networks

Working Together to Create a Healthy WA



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



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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
OVERNIG HT	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
OVERNIG HT	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	Natio nal	
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.

A large, stylized logo consisting of the number '2020' formed by a grid of squares. The top row of the '2020' is in a dark red color, while the rest of the logo is in a light grey color. The logo is positioned in the upper right and center of the page.

Delivering a **Healthy WA**

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