Lifting the Rating: Stroke Management in Western Australia

Report No. 6
August 2001
PERFORMANCE EXAMINATION: Lifting the Rating - Stroke Management in Western Australia

This report has been prepared consequent to an examination conducted under section 80 of the Financial Administration and Audit Act 1985 for submission to Parliament under the provisions of section 95 of the Act.

Performance examinations are an integral part of my overall Performance Auditing Program and seek to provide Parliament with assessments of the effectiveness and efficiency of public sector programs and activities thereby identifying opportunities for improved performance.

The information provided through this approach will, I am sure, assist Parliament in better evaluating agency performance and enhance Parliamentary decision-making to the benefit of all Western Australians.

D D R PEARSON
AUDITOR GENERAL
August 22, 2001
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Background

**What is a stroke?** – A stroke occurs when part of the brain is damaged by a clot or haemorrhage. The effects may be minor, disabling, devastating or fatal. Stroke survivors commonly have one-sided paralysis, problems with swallowing and difficulty in understanding or speaking. Most people who survive stroke cannot live at home without support. Many need to be placed in hostels or nursing homes for the rest of their lives.

**Who does stroke affect?** – Stroke can occur at any age but its prevalence increases rapidly in older persons. In Western Australia, stroke is the third most common cause of death and the single biggest cause of adult disability. Nearly 1 000 people die each year from strokes. More than 10 000 stroke survivors, with varying disabilities, are alive at any time.

**How can the effects of stroke be reduced?** – The hardship to stroke victims and their carers, and the total costs to State and Commonwealth governments, can potentially be reduced in four areas: prevention, acute care, rehabilitation and community support. Many of the issues concerning stroke management are also relevant to other areas of health care.

Overall findings and conclusions

**Stroke management and outcomes have improved in recent years...**

The view that stroke is largely unpreventable and untreatable is no longer held. Medical understanding and treatment of the condition has advanced. In 1992 Royal Perth Hospital opened the first purpose-built stroke unit in Australia and rehabilitation has become better organised at some hospitals. Incidence and death rates for stroke have fallen within all age groups. Community support schemes have been enhanced with the aim of allowing more stroke survivors to return home.

...but there is currently no consistent policy or practice for the management of stroke in WA...

Facilities and practices for managing stroke at public hospitals within WA vary. Best practice can be found at a number of acute care and rehabilitation units where medical, nursing and allied health staff all have special expertise in treating stroke. However, the care received can depend on when and where the patient is when the stroke occurs...
and what beds are available. Some patients, particularly in country areas, have limited immediate access to diagnostic equipment, medical specialists and allied health services, but can be transferred to other hospitals when this is clinically appropriate.

...suggesting that some deaths and disabilities could be avoided.

International research strongly indicates that patients treated in special stroke units have lower death and disability rates than comparable patients managed in general wards. However, only a minority of WA stroke patients are managed in special acute units, and the tertiary neuro-rehabilitation facility at Shenton Park Campus does not have the capacity to treat all eligible cases.

Change in stroke management in WA is taking place...

The Department in line with national health priorities, launched a stroke strategy in May 2001. This was largely based on the WA Stroke Strategy, produced by the National Stroke Foundation with financial assistance from the Department. Working parties have been set up to address developments in prevention, acute care, rehabilitation, community care, rural issues, and research and education.

...in a number of key areas (most of which also apply to other aspects of health care).

- **Planning for a growing and ageing population** – The WA population of persons aged 65 and over is forecast to grow by about 30 per cent in the next ten years. Extra beds, specialists, nurses and allied health services will be needed at some stage to maintain and raise care standards for stroke.

- **Prevention** – The most effective protection against stroke, and many other diseases, is a healthy lifestyle. Changing personal attitudes and habits concerning matters such as diet, smoking, alcohol and exercise is a deep social issue. Health screening programs can identify people with modifiable risk factors, such as high blood pressure, and offer medical treatment that will prevent or defer strokes.

- **Acute care** – Patients need to be more aware of stroke symptoms and react to them as a life-threatening emergency. Ideally, acute care would always include a brain scan and assessment by a stroke specialist. Many stroke victims do not receive optimal care because of delays in presenting at hospitals and the absence of specialists and diagnostic equipment.

- **Rehabilitation** – Nearly all stroke survivors require some rehabilitation. Coordinated expert care from a multi-disciplinary team is the key to achieving better outcomes after the initial phase of acute treatment. The range and organisation of allied health services vary widely between hospitals. Access to rehabilitation is a major problem in the country.

- **Community support** – Post-discharge support, apart from services provided at outpatient clinics or day hospitals, is largely a Commonwealth responsibility. There are concerns about the sudden scaling down of services and lack of follow-up that often occur after a patient is discharged from hospital.
Evidence-based medicine – Acute care and rehabilitation methods for stroke vary within WA, Australia and other countries. As with other medical conditions, clinical opinions on best practice are divided. WA hospitals can continue to contribute to and learn from international research concerning the effectiveness of different medical, surgical and allied health approaches.

Service delivery – Admission to a tertiary unit is not necessary or desirable for all stroke patients. Many will be better served by treatment closer to their homes. A realistic compromise is to have a tertiary unit that treats the most complex cases, and is the focus of development, research, training and advice to local providers. An important aspect of stroke management is the way in which patients are assessed and transferred to a tertiary unit when this is in their best overall interests.

Outcomes and funding – As with many medical conditions, there is no consistent measurement of outcomes for stroke patients in WA. Little information about trends in the effectiveness of care is available to clinicians or patients. Hospital funding for stroke has yet to take account of the outcomes achieved by different treatment regimes.

The way forward

The Department of Health, hospitals and health services should work together to finalise detailed plans to implement a statewide stroke strategy. The aims will be to prevent disease, provide optimal acute and rehabilitation services, and support chronically affected survivors in the community.

Action plans, within a broader planning framework for stroke and other conditions, should be prepared for each action area and include:

- statements of principles and objectives;
- developments (in facilities, organisation, clinical methods, evaluation and research) needed to give practical effect to the principles;
- estimation and allocation of the resources needed to effect change;
- setting of timelines;
- assignment of responsibilities and accountabilities, particularly in matters requiring cooperation beyond existing management boundaries; and
- specification of evaluation criteria and preparation of systems to capture the required measurements.
What is a stroke?

A stroke occurs when the brain’s blood supply is interrupted by a blood clot or haemorrhage. The effects can be transient, disabling or fatal. One year after a stroke, roughly equal numbers of victims have recovered well, survived with a disability or died.

Common problems for survivors include paralysis or weakness on one side of the body, loss of speech, blindness, impaired cognition and difficulty with swallowing. Strokes are sudden and can be devastating for victims and their families. Physical disabilities are generally compounded by frustration, anger or depression.

Most strokes occur in older persons because of ‘wear and tear’ to the vascular system, often aggravated by unhealthy lifestyles. Old people are more likely to have other problems, such as frailty or dementia. These problems preclude some of the more intensive treatment options available during the acute and rehabilitation phases of care. However, stroke can occur at any age. Among younger people, most cases are haemorrhagic, caused by congenital weakness of the brain’s blood vessels.

Stroke is not a simple condition to manage. The effects of a stroke depend on its type, location and severity. Medical opinion remains divided on some aspects of best practice. Many patients do not reach hospital within the short ‘window of opportunity’ for limiting the cascade of irreversible damage to the brain. Significant numbers of strokes in WA occur in regions where there is poor access to diagnostic equipment, specialist doctors and rehabilitation.

Recovery prospects are difficult to predict. For some patients, rapid early improvement soon reaches a plateau. For others, slow and steady improvement may continue over several years. The fate of survivors can be heavily influenced by their personal attitudes and resources. More than half of survivors with disabilities need assistance with self-care, mobility or communication, either at home or in residential accommodation.

What are the key issues in stroke management?

Government health services aim to prevent illness, restore health and maximise the quality of life for chronically ill people. Management of stroke, like any other medical condition, applies to this whole ‘continuum of care’. 

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Prevention – The risk factors for stroke, such as high blood pressure, are now much better understood than 20 years ago. Stroke prevalence and mortality have reduced dramatically since the late 1960s. However, stroke is still considered to be largely a preventable health problem. Lowering the level of risk factors in the entire population remains the most important lever for reducing the burden of stroke.

Restoration – There have been useful developments in acute care and rehabilitation. Compelling evidence has accumulated around the world that coordinated multi-disciplinary care in specialist units significantly reduces death and dependency from stroke. For most stroke survivors, the major component of care is given by the allied health services of physiotherapy, occupational therapy, speech pathology and others.

Support – The transition from hospital to the community is difficult for many stroke patients. Those with moderate or severe disabilities have to adjust to new ways of living and may have lost much of their independence. Quality of life is vitally dependent on the provision of continuing medical, domestic and social support to survivors and their carers.

Examination aims, scope and methods

The aims of this report are to:

■ provide a background to stroke and its importance as a health issue;
■ identify opportunities for reducing death and disability from stroke; and
■ use stroke as an example to illustrate a number of broader health issues.

The report draws extensively on published research, reviews and plans. These information sources were supplemented by visits, interviews and analysis of hospital activity records.

The final chapter summarises the principles on which the development of stroke care in WA should be based, the main areas where action is needed, and how success could be measured.
3 The Importance of Stroke as a Health Issue

- Stroke is the third most common cause of death and the main cause of long-term adult disability.
- Stroke mainly affects older persons but can occur at any age.
- The burden of acute stroke care falls mainly on public hospitals.
- In addition to public health service costs, stroke imposes enormous hardships on survivors and their carers.
- Prevalence and death rates for stroke have declined but the number of strokes may increase as the population of WA grows and ages.

Hospital separations and deaths for stroke in WA

Stroke accounts for about nine per cent of all deaths in WA, claiming around 1 000 lives each year. There are at least 10 000 survivors of stroke alive at any time. More than half need assistance to live at home or are placed in hostels or nursing homes.

The number of recorded hospital separations (discharges from hospital) for stroke remained steady in the 1990s at about 2 300 per year. Death rates during hospital stays varied only slightly, averaging about 19 per cent, apart from an unexplained jump in 1993-95.

![Figure 1: Stroke separations and death rates in WA hospitals.](image)

The number of stroke separations and death rates remained fairly steady in the 1990s.

Source: OAG analysis of Hospital Morbidity Database

1 The Department of Health uses a narrower definition of stroke than the Australian Institute of Health and Welfare. On the broader definition there are about 3 500 to 4 000 stroke separations a year. A separation is when a record of a hospital stay is formally closed.

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Stroke and age

Most strokes occur as a result of ‘wear and tear’ of the body’s vascular system. Prevalence (the number of cases in a given population) approximately doubles with every ten years of age. Persons aged 75 and over made up only five per cent of the population but accounted for about half of all stroke admissions to WA hospitals in 1999-2000.

Figure 2: Population, strokes and stroke prevalence by age group.
The likelihood of stroke rises rapidly with age.
Source: ABS Australian Demographic Statistics and OAG analysis of Hospital Morbidity Database

Many older stroke victims have multiple medical problems. They may lack the understanding, motivation or strength to benefit from rehabilitation regimes suitable for other survivors. The discharge destinations of older stroke survivors are often dependent on their domestic circumstances, especially the availability of family carers.

There are relatively few young stroke victims, but they present exceptional challenges in treatment and reintegration in the community. Successful rehabilitation can avoid the cost and loss of quality of life of decades in residential accommodation.

Public and private health care for stroke

The burden of acute stroke care falls mainly on the public health system. In 1999-2000, 85 per cent of the overnight stays for inpatients with a principal diagnosis of stroke were in public hospitals. Much of the post-acute restorative care was also provided at public hospitals.
There are several reasons why the private health sector has a limited involvement in stroke.

- The onset of stroke is sudden and normally requires an emergency admission, but few private hospitals have emergency departments.
- Rehabilitation after a stroke may take weeks or months and require amounts of allied health services well beyond what is covered by private health insurance.
- No private hospitals have the high level of tertiary neuro-rehabilitation facilities provided at the Shenton Park Campus.

**Cost and other impacts of stroke**

Precise statements of the financial cost of stroke to the public purse cannot be made because older stroke survivors commonly have multiple medical problems. There are no accounting systems for apportioning costs to individual conditions. Despite this difficulty, the total cost of hospital and community care for stroke in WA, shared by State and Commonwealth, has been estimated\(^2\) to be in the order of $100 million per annum.

A large proportion of stroke survivors are left with chronic disabilities. These often cause severe financial and other hardships to victims and their carers. Working age survivors may find it impossible to return to the jobs they held, or any job at all, profoundly affecting themselves and their families. Much of the post-hospital care of stroke cases is voluntarily shouldered by spouses or other family members, often continuing for many years.

The impacts, in terms of cost and human misery, of failing to prevent stroke or not providing optimal treatment are great. Any shortcomings in prevention or hospital care will result in enormous additional demands on community support services and carers.

**Future trends in stroke**

The Australian Institute of Health and Welfare (AIHW) notes that “the epidemic of heart attack, stroke and other forms of vascular disease has been a prominent and constant challenge to the health of Australians and remains so as we begin the new century.”

The future burden of stroke will depend upon the trends in prevalence, the ageing and growing population and advances in treatment. Between 1950 and 1970 the age-standardised annual death rate from stroke across Australia remained steady at about 1600 per million. By the end of the 1990s there had been impressive gains, and the rate in WA had fallen by two thirds to about 500 per million.

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\(^2\) The WA Stroke Strategy found: “The total prevalence cost [in WA in 2000 for all strokes] is estimated at $88 million...will increase to $155 million in 2017.”
Figure 3: Stroke death rates per million population.

Stroke death rates, standardised for age, have decreased significantly in WA.

Source: AIHW National Cardiovascular Disease Database

If stroke prevalence stabilises at current levels, there will be a large increase in cases because of the changes in population size and age profile. One recent estimate projected a 25 per cent increase in strokes over the next 15 years.

However, if the prevalence of stroke continues to fall and more effective outcomes are achieved from improved treatment, the effects of population change may continue to be offset.
Cardiovascular health, including stroke, is now one of six national health priority areas.

A rehabilitation review noted the absence of consistent policy or practice for stroke management in WA, and the lack of access to rehabilitation for some patients.

A new stroke strategy for WA was launched in May 2001.

Stroke prevention and treatment is improving

Up to 20 years ago, stroke care was largely passive. Preventive measures were uncommon because the risk factors for the condition were poorly understood. Medical and surgical interventions were rare. Strokes were generally allowed to run their course with little more than nursing care for the survivors.

Knowledge about stroke has advanced. Better patient management in the acute and rehabilitation stages of care can produce better outcomes for patients. Cardiovascular health, including stroke, is now one of six national health priority areas.

Three recent reports have given significant attention to stroke, how it is managed and the opportunities for improved prevention, treatment and post-discharge support.

Rehabilitation: A Plan for Selected Services in WA

This 1999 Health Department report included stroke as one of five main conditions requiring rehabilitation. The report forecast large increases in the numbers of strokes. It recommended a statewide tertiary neuro-rehabilitation service for complex cases, offering equal access to all patients, supported by rehabilitation closer to home for others.

Findings of the report included:

- stroke is the major neurological disorder requiring rehabilitation;
- there is no consistent policy or practice for the management of stroke in WA; and
- some patients who would benefit from rehabilitation do not have access to appropriate services.
Western Australian Stroke Strategy

The strategy described in this report, produced by the National Stroke Foundation with financial assistance from the Health Department, was launched by the State Government on May 25, 2001. The report stated key principles and made recommendations for prevention, acute care, rehabilitation, continuing care, aboriginal and other special groups, remote and rural issues, and research and education.

The basic principles of the National Stroke Strategy were repeated:

■ stroke should always be regarded as a life-threatening emergency;
■ the best outcomes are achieved by multi-disciplinary teams working in specialist units; and
■ acute care, rehabilitation and community services need to be carefully coordinated.

Matters for attention noted in the WA Stroke Strategy included:

■ poor access to specialised care for some stroke patients;
■ limited long-term follow up after discharge from hospital;
■ little specific training for stroke in medical and allied health undergraduate courses; and
■ relatively poor funding for stroke research in Australia.

Heart, stroke and vascular diseases: Australian facts 2001

This Australian Institute of Health and Welfare 2001 report provides descriptive and statistical information about cardiovascular disease, risk factors and care. The report notes:

■ “There is a continuing need to inform the public, health professionals and policy makers about the considerable scope for prevention, progress in treatment and care, and the areas and groups of people that may need more attention.”

■ “Most people who have suffered a stroke have the potential to benefit from rehabilitation...It is not known how many people in Australia currently participate in a rehabilitation program following stroke.”

■ “Carers [of stroke survivors] face considerable psychological strain in their caring role and require both emotional and practical support.”
Prevention remains the most promising way to reduce the burden of stroke.

The levels of some risk factors, such as high blood pressure, are reducing while others, such as obesity, are increasing.

Stroke remains a major preventable health problem

Improved understanding of risk factors suggests that many strokes could be prevented or deferred. There are three approaches to prevention:

- **Primary** – This covers all the general ‘healthy living’ factors such as diet, physical activity, tobacco smoking and alcohol consumption. Any behaviour that maintains the circulatory system in good order helps to protect against stroke and cardiovascular disease.

- **Secondary** – There are specific factors for stroke (and other cardiovascular disease) such as transient ischaemic attack, atrial fibrillation, elevated blood pressure and high cholesterol. Medication can help to control these conditions.

- **Tertiary** – After a previous stroke there are some treatments that reduce the likelihood of recurrence. These include anticoagulant drugs and operations to relieve obstructed blood vessels, together with adopting a healthy lifestyle.

Campaigns promoting healthy living have had variable success. The proportion of adult males with high blood pressure has halved since 1980 and smoking rates for males have declined from about 45 to 30 per cent over the last 25 years. On the other hand, the prevalence of overweight and obesity has increased steadily during the last two decades.

Primary care by GPs is Commonwealth funded. Apart from the Enhanced Primary Care scheme for persons aged 75 and over, there are few incentives for GPs to screen for and advise about risk factors that may cause disease many years ahead.
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Figure 4: High blood pressure and overweight rates in Australia.
Fewer people have hypertension but more are overweight than 20 years ago.
Source: AIHW National Cardiovascular Disease Database

The WA Stroke Strategy estimated the costs of preventing one stroke by a number of prevention strategies. Quitting smoking has a zero cost if achieved by will-power alone. Cholesterol lowering drugs cost about $40 000 to avoid a stroke. Carotid endarterectomy (an operation that removes plaque from obstructed arteries supplying the brain) costs about $180 000 for each stroke prevented.
Many patients do not access the best possible acute care

Treatment for stroke normally involves a combination of acute care and rehabilitation. The acute phase includes diagnosis and care to stabilise the patient, limit the progress of the stroke where possible and reduce the risk of complications.

Many WA stroke patients are not able to take advantage of the best possible acute care.

- **Delays in seeking help** – Public awareness about the symptoms of stroke is poor. It is estimated that over 40 per cent of stroke cases in Australia take at least 24 hours to reach hospital, by which time any opportunity to limit the progress of the stroke is over. Stroke symptoms (such as the sudden onset of numbness or paralysis, violent headache, disturbed vision, difficulty in understanding or speaking) should always be regarded as an urgent, potentially life-threatening emergency.

- **Unavailability of expert care** – If advantage is to be taken of the brief ‘window of opportunity’ for limiting the progress of a stroke, prompt arrival at a hospital must be supported by access to diagnostic equipment and medical expertise. The ‘gold standard’ of acute care includes a brain scan to determine the type and site of the stroke and early assessment by a neurologist or other stroke specialist. This standard is not met by the majority of WA’s public hospitals.

- **Limited access to stroke units** - Strong evidence has accumulated from around the world that stroke patients have lower death and dependency rates when treated in specialist units\(^3\). Only Royal Perth Hospital has a purpose-built stroke unit, opened in 1992 and the first facility of its type in Australia. Other hospitals have a variety of special facilities and practices for stroke patients. Even where special care is available, stroke cases are often placed on general medical wards because of admission practices or bed shortages.

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\(^3\) The benefits of care in a stroke unit depend on the alternative placement. For older patients in WA, assignment to a geriatrician who has access to other specialists and restorative facilities is often the preferred model of care.
Where stroke patients are treated

In 1999-2000 nearly 60 per cent of all WA inpatients with a principal diagnosis of stroke were treated at Royal Perth, Sir Charles Gairdner or Fremantle hospitals. It is common for metropolitan stroke patients to be transferred from the emergency department of a secondary hospital. Country hospitals retain a higher proportion of local stroke victims, but difficult cases are likely to be evacuated to Perth.

Twelve public hospitals admitted 25 or more strokes during the year. The separation mode profiles (died in hospital, returned home, transferred to an acute hospital, transferred to a nursing home, other) show some large differences. These do not directly indicate the effectiveness of patient care. For example, the low death rates and high return home rates for Armadale/Kelmscott and Rockingham/Kwinana hospitals reflect their practice of redirecting severe cases on to a teaching hospital.

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<th>% Nursing</th>
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Figure 5: Stroke separations from the WA public hospitals treating most cases in 1999-2000.

Almost 60 per cent of stroke hospitalisations in WA are at the three general teaching hospitals. Separation destinations vary widely between hospitals.

Source: OAG analysis of Hospital Morbidity Database

Care practices have changed and vary between hospitals

All the major WA hospitals have developed different facilities and care practices for stroke. There are currently no statewide protocols for assessment and treatment, although some hospitals have produced their own and statewide guidelines are being developed.

In many respects, the care received by a stroke victim is largely determined by chance. Factors include the destination chosen by the ambulance, the availability of special equipment and facilities, the arrangements for placing medical emergencies, the treatment regimes favoured by individual doctors and the subsequent access to rehabilitation services.

4 Many patients who remain in hospital or are transferred to another for rehabilitation after a stroke are recorded as having a separate episode with stroke no longer recorded as the principal diagnosis.
Across WA, the average length of stay for patients with a principal diagnosis of stroke almost halved from 29.2 days in 1988-89 to 15.2 days in 1999-00. The number of patients discharged within a week has increased while the number retained for two months or longer has greatly decreased.

![Figure 6: Average length of stay for stroke at teaching hospitals.](image)

*Teaching hospitals show very different trends in lengths of stay for stroke patients in recent years.*

Source: OAG analysis of Hospital Morbidity Database

The differences over time and between teaching hospitals are not reliable indicators of efficiency. For disabled stroke victims, the component of stay for rehabilitation is likely to be longer than for acute care. At Fremantle Hospital the length of stay generally reflects the full time in hospital. At Royal Perth Hospital and Sir Charles Gairdner Hospital, many patients are transferred to other units for rehabilitation that is no longer coded as stroke. Royal Perth Hospital and Sir Charles Gairdner Hospital reduce the length of stay for some patients by providing some ‘hospital at home’ services.

**Information about patient outcomes is limited**

It is impossible to draw clear conclusions about overall trends in WA of the outcomes for stroke patients. Like many areas in health, there is no systematic statewide measurement of the condition of stroke patients when they are admitted and discharged from hospital. Various assessments of mobility, independence and other factors are often used to design care plans and monitor the progress of individual patients. However, these instruments are not universally and consistently applied, and are not summarised to produce an overall picture of outcomes.
The only stroke-related performance indicator used by the Department and the (former) Metropolitan Health Service Board is the survival rate of patients admitted to hospital with a principal diagnosis of stroke. This indicator (reported for different age groups and hospital types) can only measure inpatient activity. It is of limited use in measuring the overall success in achieving health objectives for stroke because:

- it reveals nothing about prevalence, hence the success of preventive measures;
- deaths caused by stroke before a hospital admission or after discharge are excluded;
- the reported survival rates are inflated because patients who are transferred are counted as survivors although some die at the receiving hospital;
- it gives no indication of the condition of the patient or the degree of improvement following hospital treatment; and
- it does not measure any aspect of the subsequent quality of life of survivors in the community.
Coordinated, expert, multi-disciplinary rehabilitation gives stroke survivors the best prospects of overcoming disability.

Hospitals face several obstacles in achieving optimal rehabilitation outcomes.

The neuro-rehabilitation unit at Shenton Park Campus does not have the capacity to treat all patients who would benefit from its services.

Well-organised rehabilitation improves outcomes for stroke

Since the early 1980s there has been compelling evidence from all over the world about the benefits of rehabilitation for stroke and other conditions. Rehabilitation is now recognised as a medical speciality and an essential extension of traditional medical and surgical care.

For the majority of people who are disabled by a stroke, rehabilitation is the main component of their treatment. The period of acute care is often complete after a few days while rehabilitation may continue for weeks or months. Early rehabilitation is given in hospital. After discharge, services may be continued at outpatient clinics, day therapy centres or in the home.

The aims of rehabilitation are to prevent medical complications and deteriorations (such as pneumonia and contractures), restore damaged functions and compensate for disabilities that cannot be corrected. Key features of rehabilitation to optimise outcomes include:

- **Early assessment** – All stroke patients should have their conditions assessed and rehabilitation needs identified by a multi-disciplinary team, ideally within 24 hours and preferably within 48 hours. This is standard practice in stroke units but may not happen in general wards.

- **Mix and level** – Rehabilitation patients are likely to need the allied health services of physiotherapists, occupational therapists, speech pathologists, dieticians, clinical psychologists and social workers. Some patients will benefit from therapy of several hours a day. Others, particularly the frail and elderly, cannot tolerate such intensity and require much lower levels of attention.
Teamwork – Stroke survivors often have multiple and interacting disabilities, compounded by depression or emotional problems. Rehabilitation needs to be carefully planned and monitored for individual patients in a holistic way by a coordinated team of medical, nursing and allied health staff. Such teams cover all specialty areas as well as general medical and surgical units in teaching hospitals. They also exist in other metropolitan hospitals and in the larger country centres.

Expertise – The needs of stroke patients are many and varied, and often subtle. A patient may, for example, say ‘yes’ when he or she means ‘no’. Paralysis increases the risk of choking or accidentally damaging parts of the body where feeling has been lost. Specialist stroke teams are confident that they provide more effective care, including the prevention of mishaps, than non-specialists.

There are several obstacles to providing optimal rehabilitation

There are no statewide standards defining the allied health services that should be delivered to stroke (and other) patients according to their age, disabilities and other factors. Hospitals and health services decide their own allied health resources and how to deploy them. The unreleased 1999 Rehabilitation Plan noted: “It has been difficult to identify statistics that provide a comprehensive and accurate picture of the level and mix of rehabilitation services across all public hospitals.”

Allied health professionals normally cover a range of wards and units, and serve many types of patients. Within a hospital, allied health staff apportion their time between patients and implement treatment regimes determined by the multi-disciplinary teams. Patients are likely to receive different treatment according to where they are admitted.

Obstacles faced by hospitals in achieving the optimal rehabilitation of stroke (and other) patients include:

Lack of knowledge of best practice – Little research has been undertaken to identify the most effective rehabilitation regimes for patients with vastly differing disabilities, potential for improvement, motivation and support. The research that has been done does not promote any one model of rehabilitation over another, other than the need for customised individual care delivered by a multi-disciplinary team.

Allied health staff shortages and lack of experience – Few hospitals outside the metropolitan area or larger country centres are in a position to provide intensive, daily physiotherapy and other rehabilitation services. Regional hospitals usually provide physiotherapy, occupational therapy and speech pathology. However, at the smaller country hospitals allied health visits are often weekly or less, with some services available erratically or not at all. In country areas, allied health staff are difficult to recruit and retain, and are likely to be relatively inexperienced or less well-supervised practitioners.
Inadequate equipment – Smaller hospitals are less likely to have the same rehabilitation facilities and equipment as larger ones. Even larger hospitals may use unsuitable equipment, such as wheelchairs with no special back support for stroke patients who find it difficult to sit upright.

Lack of home visits – Although most metropolitan hospitals have functional training units where patients are prepared for discharge home, help relating to daily living activities may not adequately prepare a patient for the very different conditions to be coped with at home.

Accelerated discharge – Care teams who would have preferred to retain rehabilitation patients in the hope of further improvement often find it necessary to discharge patients as early as possible to make room for newer and sicker arrivals. Increased access to slow stream rehabilitation would extend the treatment options for some patients.

Bed blocking – Delays in transfer or discharge, along with other factors, cause many hospital beds to be inappropriately occupied. Between August and November 2000, a daily average of over 150 patients in metropolitan acute hospitals were awaiting residential placements. Bed blockages deny or delay acute or rehabilitation beds to patients with greater clinical need, interfere with other hospital activity (such as elective surgery) and leave elderly patients in beds where they do not receive the attention and diversional activities they would in aged care facilities.

Special neuro-rehabilitation is provided at Shenton Park

The 27 bed Neuro-rehabilitation Unit at the Shenton Park Campus of Royal Perth Hospital is WA’s leading restorative facility for stroke and other neurological patients. When the Unit opened in 1959 it was the first of its type in Australia. There has been no increase in beds since the early 1970s and one small decrease when space was taken for an additional bathroom.

Admission to the Unit is selective. The main criteria are that a patient has no significant additional medical problems, good awareness and understanding, strong motivation and reasonable prospects of not needing a nursing home place. These criteria result in an average age for Shenton Park Campus stroke rehabilitation admissions of below 60 years compared with over 70 years for all strokes.

The Unit provides specialised services that should, ideally, be available to a larger number of stroke patients, either at Shenton Park or duplicated at other sites. Features of the care include a written admissions policy, comprehensive patient assessment, individual rehabilitation plans with clear goals, regular and documented multi-disciplinary team review of patient progress, high intensity treatment and careful discharge planning.
Royal Perth controls 21 beds in the Unit and Sir Charles Gairdner the remaining six. Patients can be transferred to the Unit from elsewhere by negotiation with the consultants who manage the beds, but this is not common. In 1999-2000 all but one of 116 stroke rehabilitation transfers to the Unit were from Royal Perth or Sir Charles Gairdner hospitals.

The more difficult access to the Unit in 1999-2000 for Sir Charles Gairdner stroke rehabilitation patients compared to those at Royal Perth is illustrated by their lower average age (54 years compared with 58) and longer delays before transfer (37 days compared to 24). As a further example of inequitable access, only two of 220 Fremantle residents admitted to hospital in 1999-2000 for stroke were later transferred to Shenton Park Campus.

It is recognised by the Unit that neuro-rehabilitation is being denied to some stroke survivors who meet the admissions criteria. In the view of a senior clinician: “The needs of the disabled are great and the services are limited...Equity of access is desirable but not practicable at this time...We really should work towards expanding the neurological rehabilitation opportunity to take all eligible candidates.” The number of stroke patients treated elsewhere who meet the Unit’s admission criteria is unknown.

Geriatric restorative units

Many stroke patients needing rehabilitation receive the greater part of their treatment in geriatric restorative units. There are about 240 geriatric rehabilitation beds in the metropolitan area serving a wide range of medical conditions, including stroke. From Royal Perth Hospital, about equal numbers of stroke patients are transferred to Shenton Park Campus or among the four geriatric restorative units in the eastern metropolitan area.

Most stroke survivors less than 65 years old are likely to benefit from neuro-rehabilitation while the majority of over 80s will be better suited to geriatric care. The most effective setting for rehabilitating stroke patients aged between 65 and 80 is uncertain. There is no clear evidence in the literature to show whether care under a neuro-rehabilitationalist or a geriatrician produces better outcomes for this age group.

In practice, it would be easier to expand geriatric rehabilitation beds in the appropriate areas than to increase the size of Shenton Park Campus (or its replacement). The tertiary neuro-rehabilitation ‘hub’ would serve the more complex strokes, leaving the remainder to be treated in the geographically more convenient ‘spokes’.

Whatever balance is struck between neuro-rehabilitation and geriatric restorative units for stroke and how they are operated, geriatric rehabilitation will continue to play a large and important part in the management of stroke, particularly for older patients.
Disabled stroke survivors face challenging social adjustments and may need extensive support to continue living at home.

Few hospitals provide long-term support after discharge and there is no overall coordination of care for stroke survivors in the community.

Stroke survivors may continue to have problems after leaving hospital

Most stroke victims prefer to return home, if possible. The need for hostel or nursing home places depends on the severity of the stroke, the outcomes of rehabilitation and the availability of community services such as home help, transport, meals-on-wheels and nursing. Many survivors, including people living alone and with limited mobility, can be maintained in their homes with suitable support. With dedicated carers, visiting nurses and special equipment, even severely disabled people may be able to go home.

The funding and administration of community services is shared between State and Commonwealth governments. State auditor generals have no mandate to examine the performance of Commonwealth services. However, it must be noted that the quality of community support, such as is provided by the Commonwealth’s Staying at Home program, and the links to State-provided health services have important impacts on the lives of stroke survivors.

Comments made about problems after discharge from hospital include:

Delayed or incomplete discharge summaries – Some stroke patients are discharged with gaps in the information provided for GPs, nursing homes and others who need to understand a survivor’s condition.

Poorly coordinated handover – Organisations or individuals who will be involved in supporting a survivor, such as Silver Chain, are often not closely involved in discharge planning or fully informed about the disability and management of a patient.

Lack of follow-up – State-provided health services normally end on discharge, or after a program of outpatient or day hospital attendances. Few rehabilitation services provide long-term follow-up or support in the community.
Availability of special equipment – Stroke victims often need special equipment, such as wheelchairs and hoists, after discharge. In some cases discharge is prevented or made more difficult by lack of equipment.

Psychological and social adjustment – Many survivors face profound changes in their lives. Relatively little attention is given to preparing patients for the frustration, depression and loss of confidence that are almost always felt after a stroke.

Concern was expressed in many quarters that limitations in continuing health and community support cause some stroke survivors problems that could be avoided. There is no overall coordination of care for stroke survivors in the community. It is reported that many feel isolated and poorly informed about the services and support groups that are available.

Increasingly the burden of stroke is borne by spouses and families. Many carers of elderly stroke victims are of a similar age and have health problems of their own. The added stress caused by earlier discharge and the discharge of more survivors to their homes may precipitate a decline in the health of carers.
The management of stroke in WA illustrates several wider health issues:

- planning for a growing and ageing population;
- improving health by more effective prevention;
- using evidence-based medicine findings as the basis for care;
- determining the best balance between centrally and locally delivered health services;
- improving the monitoring of health outcomes;
- providing better coordination across the continuum of care; and
- funding hospitals by activity rather than results.

The management of stroke presents many unique problems, but several of the challenges and opportunities have wider currency within health.

Planning for a growing and ageing population

The Health Administrative Review Committee report of June 2001 noted: “The WA health system, like other health systems round the world, has developed not as a single, elegantly planned entity, but rather through a mix of some deliberate direction, some historical accident, many changes in focus, a wide range of external and internal pressures…”

One of the key challenges for the future is the disproportionate increase in the older age groups as WA’s population grows and ages. The population of over 65s is expected to grow from 185,000 in 1996 (10.5 per cent of 1.77 million) to 406,000 in 2021 (16 per cent of 2.52 million). Between 1996 and 2041 there is likely to be a sixfold increase in the number of over 85s.

Unless there are considerable advances in prevention and medical treatment, there will be significant and continuing increases in the numbers of people with physical and intellectual disabilities.

In 1999-2000, patients aged 65 and over accounted for 48 per cent of the overnight stays at Royal Perth, and 55 per cent at both Sir Charles Gairdner and Fremantle. The changing age and condition mix of patients will at some point stop or reverse the trend...
towards shorter length of stay. Acute hospitals will progressively become places occupied mainly by older patients. It is unrealistic to expect that hospital bed numbers, staffing requirements and health costs can be contained while making available more advanced care to an older and sicker population.

Stroke (in common with other medical conditions) is a sufficiently important health issue, needing special medical, nursing and allied health expertise, to merit separate planning. To date there has been little work or agreement on the future numbers of strokes, how they should be managed, and the resource and cost implications.

Prevention

The State funding of health is heavily directed towards hospitals. The Auditor General’s 1999 ‘A Stitch in Time’ report included the observation by a hospital manager that “the funding system rewards providing treatment to patients and discriminates against treatments that prevent illnesses or promote health. We have a culture amongst patients, hospitals and doctors that encourages intervention and hospitalisation.”

Much illness and injury is, in principle, avoidable. Despite warnings and publicity campaigns, substantial numbers of WA’s population continue to smoke, abuse alcohol and other substances, have unbalanced diets, take insufficient exercise and become overweight or obese.

For stroke, and many other medical conditions, health services can promote awareness of causes and symptoms, facilitate screening and provide treatment to assist individuals at risk. However, it is beyond the capacity and role of any health department to manage the broader socio-economic conditions that are the fundamental cause of most self-damaging behaviour.

Evidence-based medicine

Medicine, despite its numerous and impressive advances in many areas, remains an inexact science in others. The causes of disease and the effectiveness of treatment options are often unknown or poorly understood.

Stroke is one of a large number of conditions where definitive best practice has not been established because of divergent research results. Consequently, the treatment regimes for identical patients may differ according to the hospital they attend or the doctor and other staff who treat them. However, there is now very strong evidence that some care strategies, such as the use of aspirin and specialist stroke units, produce significantly better outcomes.

In a State with the small population of WA, it is important that the constantly accumulating ‘evidence-based medicine’ findings from around the world are used to inform clinical practice. Where treatment varies, it should be for defensible reasons, such as in controlled trials to advance clinical knowledge.
The Department and the teaching hospitals should conduct more local research, continue to monitor international evidence on the effectiveness of clinical methods, and disseminate more current best practice protocols and guidelines throughout the State.

**Service delivery options**

Many health services can be delivered in a number of ways. For instance, a physiotherapy session could be provided at a tertiary centre, a small country hospital, an outpatient clinic or a home visit.

Rehabilitation (for stroke and other conditions) involves a range of services where the advantages of local treatment need to be weighed against difficulties of providing the service locally and any cost or quality implications.

A ‘hub and spoke’ arrangement will often be appropriate. A tertiary centre can provide services directly to the most complex cases, be responsible for education and research and give advice to satellite services. For any condition, the optimal configuration of central and dispersed services will depend on the critical masses of patients and health professionals needed to provide effective and efficient care.

**Outcome measurement**

Health services in WA, and elsewhere in the world, find it easier to measure activity rather than outcomes. Hospital performance is largely measured in terms of waiting times, length of stay, patient satisfaction and other process matters that give no information about the correctness of diagnosis, the appropriateness of treatment or the quality of outcomes.

It is hard to assess whether optimum results have been achieved for a stroke patient. Detailed cause and effect relationships between health service inputs and outcomes are hard to establish for some types of patients. This can make it difficult to construct a compelling business case to support, for example, the appointment of additional allied health services staff. The keys to obtaining the best results are often teamwork and attention to many small details rather than any easily identified single factors.

In general, there is a need to produce more information about health outcomes, to help the development of medical care and demonstrate the increasing effectiveness of health services.

**Integrated care**

For chronically disabled people who have lost some capacity for independent living, their quality of life and protection against future medical problems depends largely on support available in the community.
The Department’s ‘Health 2020: A Plan for Metropolitan Perth’ introduced the idea of Integrated Clinical Services. Key principles included the needs to “span the continuum of care to coordinate health services throughout the health system” and “link together services that share the same model of care, similar requirements, infrastructure or technology needs and have common objectives.”

An integrated clinical service for rehabilitation and aged care was set up in 2000 but its resources and powers are limited. There is widespread agreement that the coordination of continuing health and other services needed by groups such as stroke survivors leaves much to be desired.

Funding by activity rather than outcomes

Public hospitals in WA are now funded on ‘casemix’ principles. Each episode of care is classified into one of several hundred diagnostic related groups and attracts a notional payment based on estimates of current treatment costs at benchmark hospitals. The 2000-01 arrangements allow health providers to receive separate funds for an average episode and additional funds for extra nights of stay.

For some conditions, standard care practices have evolved, outcomes are highly predictable and costs can be accurately estimated, although these are not used in funding. However, for stroke and other conditions there are no agreed clinical pathways to provide a basis for estimates of resources and costs. As with all other health conditions, the funding earned by a stroke episode places no obligations on a hospital to provide any specific treatment and is unrelated to the outcome achieved.

Care for the elderly, including the rehabilitation of stroke survivors, was commonly described as “unglamorous medicine” and one of the easiest areas where cuts could be made to ease funding problems.
This final chapter summarises the principles on which stroke management should be based, the developments needed across the continuum of care, and examples of indicators that would measure whether improvements are being achieved.

Principles

Any failure to minimise death and disability from stroke adds to the burden of cost and human misery. Key principles underpinning the future management of stroke are:

- **Prevention** – stroke is a major preventable health problem.
- **Acute care** – acute care should be in accordance with evidence-based best practice.
- **Rehabilitation** – rehabilitation should start at the earliest opportunity and be managed by a specialist multi-disciplinary team.
- **Community support** – stroke survivors benefit from follow-up and support in the community.
- **Access** – patients of all types and in all places should have access to high quality care.
- **Planning** – forecasts and plans are essential to ensure that future needs are met.
- **Evaluation** – indicators are needed to verify that improvements in care are occurring and patient outcomes are improving.

Possible developments

The WA Stroke Strategy presented 12 high level recommendations for improving stroke management. Action was proposed in the following areas:

- Develop and evaluate health promotion programs.
- Develop a network of stroke units throughout WA.
- Develop evidence-based protocols for acute stroke care.
- Develop a network of specialist stroke rehabilitation teams throughout WA.
- Develop standardised measures of impairments, disabilities, handicaps and outcomes.
- Develop, implement and evaluate the role of the coordinators of stroke care.
■ Develop a network of stroke support groups.
■ Include stroke as a specialist area in the education of health professionals.
■ Increase the amount and quality of research into stroke in WA.
■ Research stroke in aboriginal and culturally and linguistically diverse populations.
■ Develop regionally appropriate protocols across the continuum of care.

The immediate need is for a detailed action plan to be agreed and implemented for each area. The plans should be set within a planning framework that estimates the number of expected cases of stroke and other conditions with competing and overlapping care needs.

The overall plan and its components should include:
■ statements of principles and objectives;
■ estimation and allocation of the resources needed to bring about change;
■ setting of timelines;
■ assignment of responsibilities and accountabilities, particularly in matters requiring cooperation and coordination beyond existing management boundaries; and
■ preparation of evaluation criteria and systems to capture the required measurements.

**Measurement**

There is presently a shortage of information to make comparisons and identify favourable or adverse trends in most aspects of stroke management. Examples of indicators (not intended as an exhaustive list) that might be measured as part of the evaluation plans include:
■ Numbers of stroke deaths before arrival at hospital, in hospital and after discharge.
■ Prevalence of first and recurrent strokes.
■ Levels of principal risk factors in the general population.
■ Time between onset of symptoms and arrival at hospital.
■ Proportion of admissions receiving a brain scan and assessment by a stroke specialist within target times.
■ Proportions of admissions placed under the care of a stroke specialist in a unit with special stroke expertise.

■ Changes in the levels of impairments from time of arrival to time of discharge.

■ Numbers of acute and rehabilitation beds blocked by patients awaiting placements.

■ Quantities of allied health services provided to stroke patients.

■ Length of stay in acute and rehabilitation beds.

■ Number of stroke survivors receiving rehabilitation at outpatient clinics, day therapy centres or in the home.

■ Number of follow-up contacts with stroke survivors after discharge.

■ Discharge destinations of stroke patients.

In summary, the growing and ageing population of WA presents considerable challenges to the management of stroke and many other conditions. Concerted effort is now needed to build on the initiatives to date so that the future impacts on stroke victims and their carers, and on health service costs, can be minimised.
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