



Australian Health Ministers' Conference

National Service
Improvement
Framework for
Heart, Stroke and
Vascular Disease

HEART, STROKE AND VASCULAR DISEASE

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PREAMBLE:

National Service Improvement Frameworks

INTRODUCTION

In October 2002, the Australian Health Ministers' Advisory Council agreed to the development of National Service Improvement Frameworks for the national health priority chronic conditions of diabetes, asthma, cardiovascular disease, and arthritis and musculoskeletal conditions, under the auspices of the National Health Priority Action Council (NHPAC). The purpose is to drive health service improvements to achieve better health outcomes for all Australians with these conditions, especially disadvantaged groups.

The National Service Improvement Framework for Heart, Stroke and Vascular Disease complements the National Chronic Disease Strategy and forms part of a national approach for improving health services for chronic disease prevention and care. The National Chronic Disease Strategy is an umbrella strategy supporting a consistent and effective approach for all non-communicable chronic diseases. The frameworks draw upon the expertise of a range of stakeholder groups including leading clinicians, national, state and territory policy makers, consumers and members of non-government and other health organisations.

AIMS OF THE NATIONAL SERVICE IMPROVEMENT FRAMEWORKS

The National Service Improvement Frameworks are intended to encourage the delivery of more person-centred, equitable, timely, effective, affordable and cohesive health care for all Australians. In particular, the frameworks are intended to:

- prevent and limit the progression of these chronic conditions
- slow the onset of the complications that can cause severe disabilities and be life threatening
- reduce preventable hospital admissions
- reduce variations in care that appear
 - across different clinicians and health care services
 - across people from metropolitan, regional, rural and remote areas
 - in the care provided to disadvantaged groups.

IMPLEMENTATION OF THE NATIONAL SERVICE IMPROVEMENT FRAMEWORKS

The National Service Improvement Frameworks will serve as high level guides for health services to inform consumers, clinicians, planners and designers, policy makers, funders and providers; and professionals and managers.

The frameworks recognise that the provision of high quality health services is complex, as health care is a responsibility shared between the Australian, State and Territory Governments, and public, private and non-government organisations. States and territories have their distinctive arrangements and programs to deliver care to their communities, including a range of local service plans, service frameworks and strategies.

The frameworks do not prescribe what health services should look like at the local level, but rather seek to support and complement the broad range of national, state and territory and local initiatives already established or in train to facilitate the delivery of optimal services (including the national tobacco, alcohol, nutrition and physical activity strategies).

The frameworks are not intended to replace existing clinical practice guidelines and pathways, and processes of accreditation, clinical audit and benchmarking approaches. On the contrary, they are provided to further encourage the adoption of activities, practices and processes that will translate evidence into practice. They state what needs to happen to achieve optimal care, but are not implementation plans or guides as to how to achieve this change. Separate implementation plans will need to be developed in consultation with State and Territory Governments and other key stakeholders.

CHAPTER 1. Principles Guiding the Development of The National Service Improvement Framework in Heart, Stroke and Vascular Disease

In identifying the health service needs of the Australian community, the National Service Improvement Frameworks:

- adopt a population health approach
- prioritise health promotion and illness prevention
- achieve person centred care and optimise self-management
- provide the most effective care
- facilitate coordinated and integrated multidisciplinary care across services, settings and sectors
- achieve significant and sustainable change
- ensure that progress is monitored
- locate people, families and communities affected by chronic disease at the centre of care
- span both the continuum of care and the life course for the condition and embrace, where necessary, prevention, diagnosis, treatment, rehabilitation, living with the condition, and palliation
- span different clinical and community settings
- acknowledge that many chronic diseases share risk factors (e.g. nutrition, obesity and physical activity)
- support and encourage the application of evidence-based practice
- focus on the need for disadvantaged, special population groups and Aboriginal and Torres Strait Islander people, in particular, to have access to appropriate health services—these groups include: people with mental disorders; the frail elderly; people with disabilities; people who are socioeconomically disadvantaged; people in regional, rural and remote communities; people from culturally and linguistically diverse communities
- acknowledge carers and families affected by chronic disease as being part of the broader experience of these conditions.

THE PATIENT JOURNEY

The Organising Theme of the Framework

This framework is intended to outline the best practice evidence for integrated heart, stroke and vascular services for people across the patient journey and continuum of care. To do this, it draws on scientific evidence and the unique experiences of people with heart, stroke and vascular disease to identify where critical improvements can be made to health service arrangements at state, territory and national levels.

Each of the five phases of the patient journey—reducing risk, finding disease early, managing acute conditions, long term care, and care in the advanced stages—is addressed. They are not intended to be interpreted as discrete elements. Rather, in an effective health system a person's movement through the system will be seamless, and there will be integration and communication between the services provided at each point in the system.

The framework, depicted in **Figure 1** (page 8), acknowledges that communities comprise people who differ in their level of need for health services—from well people, who want simply to reduce their risk of developing heart, stroke and vascular conditions, to the severely ill, who require care and support to manage these diseases in their advanced stages.

OPTIMAL SERVICES

The optimal health services are for people at different ages and stages of the disease continuum and are proposed by applying empirical evidence and consensus to answer the following questions (the vertical axis):

- 1. *What are appropriate person centred services for people with or at risk of developing heart, stroke and/or vascular disease?***
In particular, what are the needs of people, families and communities affected by this disease?
- 2. *What is happening now? What are the gaps in care?***
Specifically, how effective are current services in meeting these needs? Based on the evidence, what is best practice care?
- 3. *What are the priorities for improving care?***
What are the aspects of care, or critical intervention points, in which Australia might invest most usefully to reduce death and distress from heart, stroke and vascular disease?
- 4. *What is required for the necessary change to occur? How can the gaps be bridged?***
If health services are not meeting the needs of the community, what system level changes are required to improve service provision? Do models of good and innovative practice exist? What is the capacity of the service organisations to make changes so priorities can be acted on? How did they go about improving their services—what needs to be learnt by other services?

The identification of priorities is based on consideration of whether an aspect of care:

- is important in terms of death, suffering or health care costs
- is considered suboptimal, given what is known about optimal services and current care
- can be improved significantly.

Furthermore, what actions could be taken by the Australian and State and Territory Governments, in collaboration with professional colleges, non-government organisations, consumer groups and other key stakeholders, as a basis for establishing many of the optimal services identified in the framework.

HEALTH INEQUALITIES

People living in Australia generally enjoy good health and have access to some of the best health services in the world. However, there is strong evidence that these gains have not been equally shared across the entire population.

A large and growing international literature has documented the association between socioeconomic position and mortality, with disadvantaged groups experiencing higher death rates for most major causes of death. These socioeconomic differences in mortality are evident for both males and females at every stage of the life course and they have been found in different historic periods and in all countries where socioeconomic data are collected.

Socioeconomic differences in smoking, physical activity, hypertension, diabetes, low-density lipoprotein cholesterol, high-density lipoprotein cholesterol, and body-mass index do not wholly account for the observed differences in the incidence of heart, stroke and vascular disease.^{1,2} The extent to which inequalities in health are the result of material or psychosocial factors is also uncertain. The Whitehall study of British civil servants has been of central importance in identifying the ways in which social hierarchies produce increases in risk of heart, stroke and vascular disease.³ These studies have identified psychosocial characteristics, such as low control of daily activities in the workplace and other factors such as heart rate variability and disturbances of the autonomic system as possible mediators of the excess coronary risk associated with low social position.

There is also growing evidence that mortality inequalities have widened over time in some countries. Socioeconomic inequalities in mortality have also been repeatedly observed within the Australian population. These studies have shown that Australia has substantial socioeconomic mortality inequalities, with death rates typically being highest among the disadvantaged.

The magnitude of the inequalities as they impact on mortality is surprisingly large. For example, between 1998 and 2002 there were 13 749 excess deaths in males and 5250 in females in the most disadvantaged groups in Australia (compared to the most advantaged). Deaths from heart, stroke and vascular disease accounted for 34% of these excess deaths in both males and females.⁴

There has been a 70% decline in age-adjusted mortality for heart, stroke and vascular disease in Australia in the past 25 to 30 years. The decline is less evident in rural and remote populations. Differences in the occurrence of heart, stroke and vascular disease between urban and rural areas are likely to be due to differences in the prevalence of major risk factors, less access to coronary artery bypass surgery or coronary angioplasty and lesser numbers of trained health care personnel per head of population.⁵

Redressing these health inequities is an important goal for public health, and an opportunity to develop policies and programs to improve the health of our population. Evidence about the causes of socioeconomic health inequalities points to the need for a 'whole of society' approach to the problem. Health inequalities originate from societal level conditions associated with housing, employment, education, income and transport and reducing inequalities will not be achieved exclusively (or even primarily) by actions taken within the health sector.

A number of frameworks have been developed to tackle health inequalities. They share an acknowledgement that action must simultaneously occur on this broad level—well upstream of the health events in individuals, and at the level of health services and individuals.⁶ NSW Health has recently developed a framework for tackling health inequalities within and outside the health system.⁷

A FOCUS ON HEART, STROKE AND VASCULAR DISEASE IN ABORIGINAL AND TORRES STRAIT ISLANDER PEOPLE

Indigenous Australians have higher rates of death and illness from heart, stroke and vascular diseases. Death rates are 2.6 times and hospitalisation rates 1.4 times those of other Australians. These are likely to be underestimates due to the under identification of Indigenous peoples in hospital and death records. Indigenous Australians have one of the highest rates of acute rheumatic fever and chronic rheumatic heart disease in the world, with death rates from these conditions 19 times those of other Australians. Indigenous people have a high prevalence of many cardiovascular risk factors.⁴ In the 10 years 1990–2000, despite improvements in some conditions, there has been little or no overall progress in the health of the Aboriginal and Torres Strait Islander populations of Australia. This is in stark contrast to the gains made in Indigenous health in New Zealand, Canada and the US.⁸

All health services, whether private or government, or providing primary, secondary or tertiary care, rehabilitation, or counselling, have a responsibility to ensure they provide effective and appropriate services to Aboriginal and Torres Strait Islander people. These services should be provided in accordance with the Australian Health Ministers' Advisory Council's (AHMAC's) Aboriginal and Torres Strait Islander Cultural Respect Framework. In addition, addressing the needs of Aboriginal and Torres Strait Islander people should be incorporated at all levels of health policy development and implementation.

The life expectancy of Aboriginal and Torres Strait Islander people is 17 years less than that of other Australians. Aboriginal and Torres Strait Islander people have higher rates of disease in almost every disease category and in every age group. Factors contributing to continued poor health in Aboriginal and Torres Strait Islander peoples include socioeconomic disadvantage; social, political and environmental factors, specific health risk factors; and lack of access to health care. Aboriginal and Torres Strait Islander people use public hospital services more and private health care services less than other Australians. Barriers to health care access include affordability, distance, access to transport, availability of health professionals, and cultural appropriateness and acceptability of services.

Aboriginal and Torres Strait Islander people access all parts of the health system and all types of services across the continuum of care. It is therefore important that all aspects of these services and all policies affecting these services consider any barriers (e.g. physical, economic, cultural or other) that may limit equitable access for Aboriginal and Torres Strait Islander people. Health service providers should consider the development of effective data systems that enable monitoring and improvement of both accessibility and effectiveness of health care provided to Aboriginal and Torres Strait Islander Australians.

HEALTH LITERACY

The WHO defines health literacy as the possession of cognitive and social skills people need to understand and use information in ways which promote and maintain good health.⁹ Health literacy means more than being able to read pamphlets and successfully make appointments. By improving people's access to health information and their capacity to use it effectively, health literacy is critical to empowerment.

Health literacy is dependent upon levels of fundamental literacy and associated cognitive development. Individuals with undeveloped skills in reading and writing will not only have less exposure to traditional health education, but also less developed skills to act upon the information received.

Health literacy problems have grown as people are asked to assume more responsibility for self-care in a complex health care system. Health literacy, then, can be thought of as the currency needed to negotiate this complex system.

The fundamental premise of this document—that the patient should be at the centre of the management of chronic illness—demands that attention is given to how information vital to self-management is packaged, communicated and understood.

Improving health literacy in a population involves more than the transmission of health information, although that remains a fundamental task. Helping people to develop confidence to act on that knowledge and the ability to work with and support others will best be achieved through more personal forms of communication, and through community based educational outreach.¹⁰

LONG TERM CARE AND SUPPORT OF PEOPLE WITH CHRONIC CONDITIONS

Chronic illness management requires a coordinated and long-term approach to care with a focus on the person with the condition rather than the disease itself.¹¹

The needs for care and support are similar among people with different chronic conditions.¹² These include the need to:

- monitor their physical and emotional status and make appropriate self-management decisions
- manage the impact of the condition on their roles, emotional health and relationships
- interact with health professionals and other care providers and navigate the system
- attend to a medication regimen over the course of their condition
- alter their behaviour to engage in health promoting activities.¹³

The ability to meet the needs of growing numbers of people with chronic conditions will necessitate a paradigm shift in the way in which health services are designed and delivered.^{14,15} High quality care of people with chronic conditions involves empowering people to take responsibility for their care, including optimising their use of evidence-based interventions, and providing information, support and resources to help people engage effectively in self-management tasks.¹³

This document has been designed so that each chapter may be read as a separate unit for easier reference. As a result, some information that is relevant to more than one chapter is duplicated. Every effort has been made to minimise duplication.

FIGURE 1: NATIONAL SERVICE IMPROVEMENT FRAMEWORK
Heart, Stroke and Vascular Disease

Organising matrix for service improvement

Condition of Heart, Stroke and Vascular Disease					
Well Community (including those at increased risk)		People with the condition (and their families and carers)			
Reduce the Risk	Find the condition early	Have the best care and support during the early stages	Have the best care and support for acute episodes	Have the best care and support during long term care	Have the best care and support during the advanced stages
WHAT ARE THE OPTIMAL PERSON OR PATIENT CENTRED SERVICES FOR THE CONDITIONS?					
People's needs		The needs of people who have or are at risk of the condition			
Optimal Services					
WHAT IS HAPPENING NOW?					
Current practice in meeting people's needs and providing optimal services		Gaps in current care			
WHAT ARE THE PRIORITIES FOR IMPROVING CARE?					
Critical intervention points where practical and significant health gains and service improvements can be made		Where do the gaps between the optimal services and current practice matter?			
WHAT ACTIONS ARE NEEDED FOR CHANGE TO OCCUR?					
Actions linked to critical intervention points		Local, jurisdictional and national level			

↑ Making Change from the needs of individuals

↓ To Systems Change

CHAPTER 2. The National Service Improvement Framework in Heart, Stroke and Vascular Disease

OVERVIEW OF THE CONDITIONS*

Heart, stroke and vascular diseases are Australia's largest health problem, accounting for 50 294 deaths in 2002 (37.6% of all deaths) and affecting 3.67 million Australians in 2001. Over 1 million Australians had disabling conditions associated with heart, stroke and vascular diseases in 1998.¹⁶

Heart, stroke and vascular diseases refer to all diseases and conditions of the heart and blood vessels, and include coronary heart disease, stroke, peripheral vascular disease, renovascular and chronic kidney disease, and heart failure. For each of these conditions, the main underlying problem is atherosclerosis, a condition that forms abnormal build-ups of fat, cholesterol and other substances in the inner lining of the arteries (plaque). It is most serious when it affects the blood supply to the heart (causing angina or heart attack) or to the brain (which can lead to a stroke). Acute rheumatic fever and chronic rheumatic heart disease are also major health issues among Aboriginal and Torres Strait Islander peoples.

The process leading to atherosclerosis is slow and complex, often starting in childhood, and it progresses with age. There are a number of well recognised factors which increase the risk of an individual developing atherosclerosis: tobacco smoking, high blood pressure, high blood cholesterol, insufficient physical activity, chronic kidney disease, overweight and obesity, poor nutrition, and diabetes. On a global scale about 62% of cerebrovascular disease and 49% of ischaemic heart disease can be attributed to raised blood pressure and 18% of cerebrovascular disease (mostly nonfatal events) and 56% of global ischaemic heart disease can be attributed to raised cholesterol.¹⁷ The risk of developing heart, stroke and vascular disease increases strongly with age and is higher for men, Aboriginal and Torres Strait Islander peoples, and people from lower socioeconomic groups. Depression and social factors may also play a role. In 2000–02, death rates from heart, stroke and vascular diseases in the most disadvantaged areas were 21.4% higher than in the least disadvantaged and, in the same period, Indigenous Australian death rates from heart, stroke and vascular diseases were 2.6 times as high as for other Australians.

Much of the burden of disease caused by heart, stroke and vascular diseases is preventable, and over the last few decades there have been substantial and continuing falls in death rates. Between 1991 and 2002, death rates from heart, stroke and vascular diseases fell by 36.3% for males and 33.7% for females. These have been driven by improvements in some risk factor levels and major advances in treatment.

1 Much of the information in this section has been drawn directly from Australian Institute of Health and Welfare 2004, Heart, stroke and vascular diseases—Australian facts 2004, AIHW and National Heart Foundation of Australia (Cardiovascular Disease Series No 22).

However, over the last decade, the prevalence of disabling conditions associated with heart, stroke and vascular diseases has risen by an estimated 18.2%. There has been a dramatic increase in the prevalence of diabetes in Australia¹⁸ and this will impact on the subsequent prevalence of vascular disease. The number of people with diabetes is expected to double by 2010, making primary prevention of diabetes a national priority.

Coronary Heart Disease

Coronary heart disease (also known as coronary artery disease or ischaemic heart disease) is the largest single cause of death and the most common cause of sudden death in Australia, claiming 26 063 lives in 2002. This was over half of all deaths from heart, stroke and vascular diseases in that year. Among Australians having an attack, over four in 10 will be dead within a year. Over half of all heart attack deaths occur before the person reaches hospital. In individuals with known coronary heart disease having a second heart attack, the risk of sudden death can increase greatly.

Death rates from coronary heart disease have fallen by around 70% since the late 1960s.

Coronary heart disease occurs when cholesterol plaques block the blood vessels that supply the heart muscle. A heart attack or Acute Myocardial Infarction (AMI) occurs if a plaque suddenly breaks open and a clot forms that completely blocks blood flow to the heart muscle. If the clot cannot be promptly treated some of the heart muscle will die. This is a life threatening emergency. Angina occurs when a plaque or blood clot only narrows the blood vessel, and may occur as a precursor to a heart attack or remain stable for long periods of time. When angina occurs at rest, when there is a new onset of pain with exertion, or when angina is more frequent, longer in duration or lower in threshold than before, this is known as unstable angina. Although all people with angina are more prone to sudden cardiac death or AMI than the general population, those with unstable angina are particularly at risk. The term 'acute coronary syndrome' is used to collectively describe AMI (heart attack) and unstable angina, because both are treated as clinical emergencies.

In 2000–02, death rates from coronary heart disease in the most disadvantaged areas were 28.9% higher than in the least disadvantaged. In 2000–02, coronary heart disease death rates were 2.6 times as high for Indigenous Australians as for other Australians.¹⁹

Heart Failure

Heart failure is a major cause of illness and the third largest cause of death among people with heart, stroke and vascular diseases, claiming 2729 lives in 2002. There were an estimated 22 000 admissions for chronic heart failure, and 100 000 admissions overall related to a diagnosis of CHF, in the same year.²⁰ The burden of hospitalisation is a key feature of CHF.^{21,22} It is estimated that at least 300 000 Australians have chronic heart failure (about 4% of the population aged 45 years or more)²³, with 30 000 new cases diagnosed each year. As the diagnosis is commonly missed in people with mild heart failure, the actual numbers could be twice as high. In 2000–02, death rates from heart failure among Indigenous Australians were almost three times as high as for other Australians.

Heart failure is primarily a condition of the elderly who often have other health problems and declining levels of activity and function.²⁴ It is a major burden on the community, due to the high costs of care and the lower quality of life and premature death of those affected. The number of Australians with heart failure is likely to increase in the future despite the 60% decline in the incidence of disease since the 1980s.²⁵

Reasons for the increase include the ageing of the population, improved survival from heart attack and heart failure, the increased prevalence of diabetes and obesity in the population, and the wider use of sensitive diagnostic technology. The lifetime risk of developing heart failure has been estimated at around 20% for Western countries.

Heart failure occurs when the heart loses the ability to effectively pump blood around the body. It occurs in diseases which impair or overload the heart—heart attack, high blood pressure or a damaged heart valve. It can occur suddenly, although it usually develops over a period of years. People with mild heart failure may have very few symptoms but in more severe cases it can result in chronic tiredness, reduced capacity for physical activity and shortness of breath. Once diagnosed, it is often associated with poor survival.

The most important risk factors for heart failure are coronary heart disease and high blood pressure. Hypertension is the most common risk factor for CHF. The hazard for developing heart failure in people with hypertension increases twofold in men and threefold in women. Hypertension accounts for 39% of cases of heart failure in men and 59% in women.²⁶ Other common causes are diseases of the heart muscle (cardiomyopathy) due to alcohol abuse or infections, diseases of the heart valves (such as with chronic rheumatic heart disease), diabetes and obesity.

Rheumatic Heart Disease

Rheumatic heart disease (RHD) is a chronic consequence of acute rheumatic fever (ARF), which in turn is an auto-immune sequel of infection with the bacterium Group A streptococcus (GAS). In Australia, ARF/RHD is overwhelmingly seen in the Indigenous population, primarily in Northern and Central Australia.²⁷ The high prevalence of RHF and ARF in Indigenous communities is linked to overcrowding and inadequate sanitation.

Acute rheumatic fever is a complication of an infection caused by the GAS organism. The disease can affect the heart and heart valves, with recurrent infections potentially causing chronic heart disease, and eventually heart failure. Recurrent infections can be prevented by four-weekly injections of penicillin. RHD is particularly burdensome for Indigenous Australians, with a prevalence of 13 to 17 cases per 1000 people living in Central and Northern Australia.²⁸⁻³⁰

The incidence of ARF in Indigenous children in Central and Northern Australia is 250 to 350 per 100 000 per year.²⁷ The prevalence of RHD in Indigenous Australians of all ages in the same regions is 13 to 17 per 1000, with the peak occurrence at 29.4 per 1000 in the 25–44 age group in the Top End and 18.6 in those aged 15–24 years in Central Australia.^{28,31,32} The true incidence and prevalence is likely to be higher than this.

ARF still occurs from time to time in other populations, and there are a number of elderly non-Indigenous people with rheumatic heart valve lesions; a legacy of the high rates of ARF that affected all populations in Australia until the mid 1900s.³³ However, the incidence of ARF in non-Indigenous Australians appears to be negligible.²⁷

Peripheral Vascular Disease

Peripheral vascular disease is a disease of the arteries outside the heart and brain. It occurs when fatty deposits build up in the inner walls of these arteries and affect blood circulation, mainly in the arteries leading to the legs and feet. It can be present without symptoms, but often manifests itself as pain on walking (intermittent claudication), pain at rest, or limb threatening reductions in blood supply (acute or chronic limb ischaemia). The latter can lead to amputation. The major preventable risk factors for peripheral vascular disease are diabetes, tobacco smoking, high blood cholesterol, high blood pressure, and overweight and obesity.

Peripheral vascular disease mainly affects older Australians and its prevalence is likely to increase considerably as the population ages. It claimed 2581 lives in 2002 and was responsible for 24 288 hospitalisations in 2001–02. Of the hospitalisations for heart, stroke and vascular diseases, peripheral vascular disease accounted for 5.5%. Atherosclerosis of the peripheral arteries accounted for over half (13 564) and abdominal aortic aneurysm accounted for almost one in five (4577) of the hospitalisations.

Between 1993–94 and 2001–02 there was a 21.4% increase in the hospitalisation rate for peripheral vascular disease, but a marked decline—0.2% among males and 37.1% among females from 1991 to 2002—in the death rate from this condition.

Stroke

Stroke (also known as cerebrovascular disease) occurs when a blood vessel that carries oxygen and nutrients to the brain is either blocked by a clot or bleeds, resulting in part of the brain dying from lack of blood flow. This causes loss of function of the affected part of the brain, leading to death or impaired movement of body parts, vision, planning, communication and swallowing. Another related condition is a transient ischaemic attack (TIA), characterised by temporary stroke like symptoms. They are important predictors of future stroke.

Of those having a first ever stroke, one in five die within the first 28 days, but almost two-thirds are alive one year after their stroke. About one in six people who have survived the first two days of a first ever stroke will have a recurrent stroke over the next five years. Nearly all people are disabled immediately following their stroke. By the end of the first year, about half of stroke survivors remain dependent on others for assistance in the activities of their daily lives.

Risk factors for stroke include TIA, high blood pressure, tobacco smoking, diabetes, high alcohol consumption, low levels of physical activity and poor diet, high blood cholesterol, atrial fibrillation, other heart disease and narrowing of the carotid arteries (carotid stenosis). Older Australians and Aboriginal and Torres Strait Islander peoples are also at a greater risk of stroke than other Australians.

Stroke is Australia's second biggest killer after coronary heart disease, claiming 12 533 lives in 2002. Over 48 000 strokes occur in Australia every year. With the ageing population this number will rise to 74 000 by the year 2017 if current trends continue.

Age-standardised death rates from stroke have fallen dramatically since the late 1960s, by around 68%. These declines appear to have been largely driven by improvements in some risk factor levels, increases in the use of drugs to lower blood pressure and treat and prevent blood clots, and other advances in treatment. The number of people dying from stroke and those surviving with a permanent disability is likely to increase in the future, given the rapid ageing of the Australian population, and a slowing in the decline of stroke death rates in recent years.

Depression and anxiety are common after a stroke and many survivors have difficulty returning to their previous activities.

Stroke can be treated and is preventable.

Chronic Kidney Disease

Chronic kidney disease (CKD) may be caused by any condition that damages the normal structure and function of the kidney. CKD is a common, under recognised, progressive, preventable and highly treatable condition. Approximately 16% of the adult Australian population has at least one indicator of kidney damage.³⁴ Moderate or severe CKD, defined as a glomerular filtration rate (GFR) less than 60 ml/min, is present in 11.2% of the general population (approximately 1.8 million Australian adults).³⁴ The majority of these people are undiagnosed, primarily because kidney disease may remain relatively asymptomatic until kidney function is severely and irreversibly impaired. Glomerulonephritis, diabetes and high blood pressure are the main causes—26%, 26% and 16%, respectively, according to the ANZDATA (Australia and New Zealand Dialysis and Transplant Registry)

There were 13 625 people (69 per 100 000 population) with end-stage renal disease (ESRD) receiving kidney replacement treatment (dialysis or kidney transplantation) at the end

of 2003. In 2003, 1953 people (10 per 100 000 population) with ESRD started kidney replacement treatment in Australia.³⁵

Kidney failure is more common among Aboriginal and Torres Strait Islander peoples than among other Australians. During 2000–02, the age-standardised Indigenous death rate from kidney failure was around five times that of other Australians.

Once CKD is diagnosed, appropriate therapeutic intervention has been demonstrated in large controlled trials to reduce the rate of progressive deterioration in kidney function by up to 50%.³⁶ It is conservatively estimated that kidney failure causes or contributes to one in 10 of all deaths in Australia³⁷, with the risk of death (especially cardiovascular death) directly related to the severity of kidney disease.^{38,39}

This document does not purport to address all of the service improvements needed for people with chronic kidney disease, but has focused on the issues which intersect with those for heart, stroke and vascular disease.

Diabetes

Diabetes (also known as diabetes mellitus) is a condition characterised by high blood glucose levels resulting from defects in secretion of the hormone insulin, the physiological actions of insulin, or both. Insulin is a hormone produced in the pancreas that helps glucose to enter body cells for energy metabolism. Chronic high blood glucose (hyperglycaemia) in poorly controlled diabetes causes long term damage, dysfunction and failure of the eyes, kidneys, nerves, heart and blood vessels.

There are two main types of diabetes, Type 1 diabetes and Type 2 diabetes. In people with Type 1 diabetes, the pancreas is no longer able to produce insulin because the insulin producing cells (-cells) have been destroyed. Type 1 diabetes develops most frequently in children, young people and young adults.

In people with Type 2 diabetes, the -cells are not able to produce enough insulin for the body's needs. The majority of people with Type 2 diabetes also have some degree of insulin resistance, where the cells in the body are not able to respond to the insulin it produces. Type 2 diabetes is usually part of the 'metabolic syndrome', which is associated with other risk factors from early in the disease process, including abdominal obesity, hypertension, dyslipidaemia, a prothrombotic state and insulin resistance. Type 2 diabetes increases the risk of coronary heart disease two to fourfold and abolishes the protectiveness of female sex observed in the non-diabetic population. The presence of diabetes also worsens the prognosis of coronary heart disease.

Diabetes has a significant impact on the health of Australians, both as a disease in its own right and as a risk factor for heart, stroke and vascular diseases. Diabetes claimed 3329 lives in 2002 (2.5% of all deaths). Based on measured blood glucose levels, about 945 600 Australians aged 25 years and over (7.6% of the population) had diabetes in 1999–2000. About half these people were not aware that they had diabetes.¹⁸

In 2001, the prevalence of self reported diabetes was almost twice as high in the most disadvantaged areas than in the least disadvantaged. Aboriginal and Torres Strait Islander peoples have one of the highest rates of diabetes in the world. In 2001, the age-standardised prevalence of self reported diabetes among Indigenous Australians (11%) was almost four times as high as for other Australians (3%). In 2000–02, death rates from diabetes among Indigenous Australians were almost 15 times as high as for other Australians.

People with diabetes are at increased risk of developing coronary heart disease, chronic kidney disease, stroke and peripheral vascular disease. Diabetes is the sixth leading cause of death in Australia, and contributes to significant illness, disability, poor quality of life and premature death.

CHAPTER 3. A Focus on Prevention

It is estimated that approximately 43 338 people are hospitalised in Australia each year with heart attacks. Around 25% of people who have a heart attack die within an hour of their first ever symptoms, with over half of all heart attack deaths occurring before the person reaches hospital (AIHW 2001). One-fifth of those with stroke die before reaching hospital or in the earliest stages of their condition. These stark facts underscore the importance of disease prevention, and close attention to the identification and management of the risk factors for these conditions.

POPULATION AND HIGH RISK STRATEGIES

Geoffrey Rose characterised two fundamental approaches to disease prevention and treatment—high risk and population based strategies.⁴⁰ These strategies arose from the simple observation that the factors responsible for disease in individuals sometimes differs from the factors responsible for disease in large populations.

The high risk strategy is the traditional and natural medical approach to prevention. If a doctor accepts responsibility for treating individuals who are sick today, then it is a short step to accept some responsibility to advise and assist individuals who may be sick tomorrow. A high risk strategy targets those who are at greater risk of developing heart, stroke or vascular disease, such as people with high blood pressure, lipid abnormalities, diabetes mellitus, heart rhythm disturbances or rheumatic fever.

There are a number of weaknesses in the high risk approach: it can be costly and the effects can often be of a transient or palliative nature. From the perspective of national and state health policy, the high risk strategy has an even more profound manifestation—a large number of people at a small risk may give rise to many more cases of disease than the small number who are at a high risk.

A population strategy attempts to reduce exposure to risk factors in a majority of people. Many of the activities and programs in a population strategy occur outside health systems and away from direct interactions between people and health professionals. Examples include the banning of advertisements for smoking and constraints on the composition of certain foods. If the mean level of cholesterol in the population could be reduced by 0.5 mmol/l, the level of physical inactivity reduced by 25%, and smoking prevalence halved, then 14 000 coronary events per year could be prevented in Australia. This would represent a reduction in mortality from coronary events of 40%. Evidence suggests much of the gain in outcomes would be accrued within five years of achieving changes in risk factor and treatment levels and most of the gain is achievable within 10 years.⁴¹ Unfortunately the population strategy of prevention has also some weighty drawbacks. It offers only a small benefit to each individual. This leads to the *Prevention Paradox*—a preventive measure which brings much benefit to the population but offers little to each participating individual.

In practice, high risk and population based strategies need to be combined and complementary in any comprehensive disease control program.

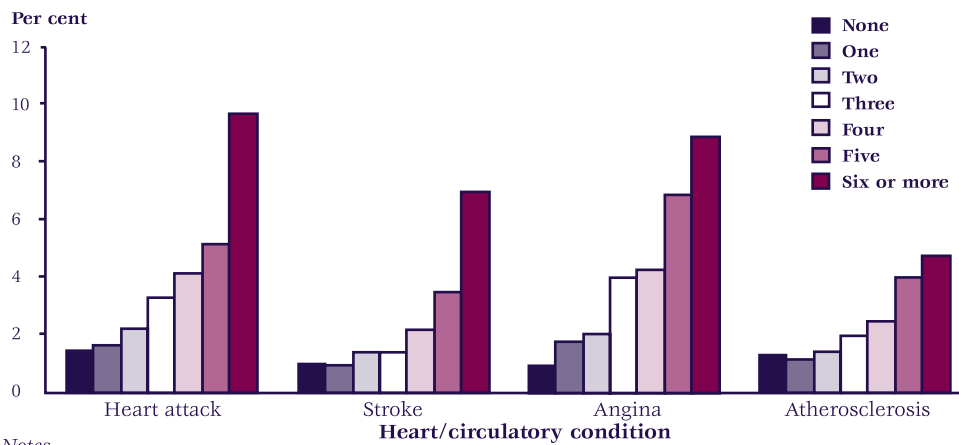
MULTIPLE RISK FACTORS

The major preventable risk factors for cardiovascular diseases are tobacco smoking, insufficient physical activity, poor nutrition, risky alcohol consumption, raised blood pressure, abnormal cholesterol levels, excess body weight, chronic kidney disease and Type 2 diabetes. Some of these risk factors may be interrelated, and there is clear evidence that reducing or eliminating them, where possible, can prevent a significant proportion of strokes and coronary heart disease events. Having more than one risk factor tends to magnify the risk of disease.^{42 43} For example, a person with mildly raised blood pressure (hypertension) and no other risk factors will be at a lower risk of a cardiovascular event than someone with mild hypertension and one or two other risk factors.⁴⁴

Having multiple risk factors has been shown to reduce life expectancy and increase health care costs for an individual. Results from the Chicago Heart Association Study showed that the more risk factors a person had when they were 40–64 years old, the greater were their health care costs later in life.⁴⁵ There is a steady increase in risk of all-cause deaths and cardiovascular disease deaths as the number of risk factors present increases.⁴⁶

It is not just the number of risk factors a person has that is important. Generally, the lower the level of a risk factor the better. For example, starting from quite low levels, blood cholesterol increases raise the risk of death from coronary heart disease.⁴⁷

In Australia people with three or four risk factors were four times more likely to have reported angina and twice as likely to have had heart attack than people with no risk factors. Similarly, people with five or more risk factors were more likely to report ever having had a heart attack, stroke, angina or atherosclerosis than people with less than five risk factors. People with five or more risk factors were six times as likely as people with no risk factors to report having angina; for heart attack and stroke, the likelihood was three times as much, and double for atherosclerosis.⁴⁸ (Figure 2)



Notes

1. Risk factors include obesity, high blood pressure, high blood cholesterol, diabetes, physical inactivity, smoking, risky alcohol consumption, low vegetable consumption and low fruit consumption.
2. Estimates based on self-reported data.

Source: AIHW analysis of the 2001 NHS.

Figure 2. Prevalence of selected heart/circulatory conditions by number of risk factors reported among Australians aged 18 years and over, 2001⁴⁸

Absolute Risk

Absolute risk is the probability of suffering an acute cardiovascular disease event in a given time period. A reliable measure of absolute risk can provide each person with an estimate of the likelihood that they will develop heart, stroke or vascular disease over, for example, the next five years.

The last decade has witnessed a major change in the approaches to the prevention of cardiovascular disease. Interventions that target risk factors in isolation are being replaced by interventions based on absolute risk and integrated cardiovascular risk. Interventions that target a single risk factor for heart, stroke and vascular disease may not be effective if the absolute risk of disease is low. Prediction of overall risk for heart, stroke and vascular disease over five (or 10) years should be the endpoint, as opposed to risk of coronary heart disease alone.

Using an absolute risk approach acknowledges the multifactorial causation of cardiovascular disease, the sex differences in risk, the presence of diabetes and chronic kidney disease, and the steep increase in risk with ageing. Three established risk factors for heart, stroke and vascular disease (high serum total cholesterol, high blood pressure and cigarette smoking) account for at least four-fifths of the attributable risk of heart, stroke and vascular disease during middle age.⁴⁹

Absolute risk is increasingly being reflected in treatment guidelines in the US⁵⁰ and Britain.⁵¹ It is not known to what extent the medical community in Australia has embraced this change. However the New Zealand risk calculator is being widely promulgated in Australia by the National Prescribing Service and the Royal Australian College of General Practitioners. Agreement on and adoption of a standardised approach would facilitate implementing absolute risk prediction in Australia.

Both prevention programs and clinical treatment guidelines should take account of absolute risk estimation in those without manifest cardiovascular disease. In Australia, the National Vascular Disease Prevention Alliance is spearheading a project to develop the tools to implement absolute risk approaches in public health and clinical practice.

The use of standard absolute risk tools can underestimate the risk of heart, stroke and vascular disease in Indigenous people in remote communities, particularly women and younger adults. This is because risk factors have different degrees of impact in these communities, and other factors are contributing to overall cardiovascular risk. Absolute risk tools need to be tailored to this population.⁵²

Secondary Prevention

A Gap in Care

Secondary prevention is the early detection and treatment of people who have begun to develop the disease (see Glossary). The application of secondary prevention guidelines in Australia and in the rest of the developed world is a major gap in care. Important gains might be made sooner through systematic application of proven treatments to patients with clinically evident heart, stroke and vascular disease, especially those over the age of 65 years.⁴¹

Surveys in nine European countries in 1995–1996 found a high prevalence of modifiable risk factors in people with heart, stroke and vascular disease.⁵³ A follow up study⁵⁴ found no change in the prevalence of smoking, an increase in the prevalence of obesity and no improvement in blood pressure management.

To achieve effective prevention of heart, stroke and vascular disease in our community, health care professionals need to consider and implement the recommendations set out in the various available guidelines and reviews.

Monitoring Heart, Stroke and Vascular Disease

Improving the monitoring of the occurrence, causes and consequences of heart stroke and vascular disease is a critical factor in improving service and outcomes for these conditions. The Australian Government has established the National Centre for Monitoring Cardiovascular Disease (<http://www.aihw.gov.au/orgchart/20.cfm>) at the Australian Institute for Health and Welfare, which reports regularly on:

- current trends in cardiovascular disease mortality
- agreed national indicators for cardiovascular health
- the national use of heart surgery and coronary angioplasty
- methods for monitoring the incidence of heart attack, stroke, unstable angina pectoris, and congestive heart failure
- the link between cardiovascular risk factors, socioeconomic and psychosocial factors, and cardiovascular mortality
- strategies to reduce coronary heart disease in Australia.

The Centre is also involved in the monitoring of risk factors for heart, stroke and vascular disease. They are currently developing standard data definitions, methods and procedures for measuring major cardiovascular risk factors for inclusion in the National Health Data Dictionary and there are proposals for a national biomedical risk factor survey, which includes blood sampling.

CHAPTER 4. Critical Intervention and Action Points

The National Service Improvement Frameworks identify 'Critical Intervention Points'. These are points along the continuum of care where significant health gains and service improvements can be made. They have been deduced by examining:

- the needs of the well community for information about a specific chronic disease
- the needs of people with a specific chronic disease
- optimal system(s) or service response(s) to these needs
- gaps between the optimal system(s) or service response(s) and what currently happens
- for each of the gaps, the opportunity for gains in health outcomes and improvement at the system level.

The critical intervention points represent those aspects of care where Australia might most usefully invest to reduce death and distress from heart, stroke and vascular disease. In addition, the identification of critical intervention points is based on consideration of whether the aspect of care:

- is important in terms of death, suffering or health care costs
- is currently suboptimal
- can be improved.

In selecting these points, a review of the evidence about people's needs and the value of the optimal services was undertaken. Patterns of care in Australia were assessed to identify where services are currently different from the optimal services. This analysis was hindered by the lack of data about many aspects of care and about service provision.

Table 1: Critical Intervention Points for Heart, Stroke and Vascular Disease

Critical Intervention Points	Coronary Heart Disease	Heart Failure	Peripheral Vascular Disease	Stroke	Rheumatic Heart Disease	Chronic Kidney Disease
REDUCE RISK						
1. Adopt national, state/territory, and local plans to further reduce rates of smoking using evidence-based public health strategies and government actions.	X	X	X	X		X
2. Adopt national, state/territory, and local plans and school based educative programs to promote awareness of heart, stroke and vascular disease risk factors, healthy eating and active living, including healthy weight, in collaboration with other national health priorities and policies.	X	X	X	X		X
3. Establish and implement national, state/territory, and local plans and incentives to increase opportunities for physical activity through open space and urban planning norms.	X	X	X	X		X
4. Investigate national and state/territory economic and legislative strategies to reduce population exposure to known risk factors for heart, stroke and vascular disease.	X	X	X	X		X
5. Establish and encourage the development of systems and tools to enable absolute risk estimation in people without overt cardiovascular disease (including early detection and management of high blood pressure and dyslipidaemia).	X	X	X	X		X
6. Investigate the feasibility and the benefits of achieving population-wide reductions of saturated fat and dietary salt intake in the Australian context.	X	X	X	X		X

Critical Intervention Points	Coronary Heart Disease	Heart Failure	Peripheral Vascular Disease	Stroke	Rheumatic Heart Disease	Chronic Kidney Disease
EARLY DETECTION, CARE AND SUPPORT OF PEOPLE WITH HEART, STROKE AND VASCULAR DISEASE						
7. Promote awareness of the need for regular monitoring of blood pressure, cholesterol and of the symptoms of diabetes (polyuria and polydipsia).	X	X	X	X		X
8. Promote awareness of the early symptoms of heart, stroke and vascular disease and associated conditions, and emergency response where appropriate.	X	X	X	X	X	X
9. Develop systems that include absolute risk measurements in prescribing and treatment algorithms and help people to understand their individual risk.	X	X	X	X		X
10. Improve detection systems so that all people with transient ischaemic attacks, atrial fibrillation, suspected rheumatic heart disease, and chronic kidney disease are referred appropriately and assessed promptly and effectively.				X	X	X
11. Ensure information about cardiovascular disease symptoms and appropriate responses will be developed and disseminated to general practitioners and primary care providers to be given to people with cardiovascular disease or stroke.	X	X	X	X	X	X
12. Develop effective and integrated programs to increase early detection of asymptomatic chronic kidney disease in people at high risk.						X
13. Ensure that people will have timely and appropriate access to services, including echocardiography, for the diagnosis of heart, stroke and vascular disease.		X			X	

Critical Intervention Points	Coronary Heart Disease	Heart Failure	Peripheral Vascular Disease	Stroke	Rheumatic Heart Disease	Chronic Kidney Disease
14. Provide people with appropriate information about the disease, treatment options and expected outcomes, follow up and support services to facilitate self-management of the physical, psychosocial and economic impacts of their condition.	X	X	X	X	X	X
15. Processes will be in place to assess the extent to which clinical practice guidelines are adopted and to encourage their implementation.	X	X	X	X	X	X
16. Improve access to self-management education programs and support groups to help people develop the knowledge, skills and confidence to self-manage.	X	X	X	X	X	X
17. Establish systems of care to reinforce the importance of risk reduction in people with established heart, stroke and vascular disease.	X	X	X	X	X	X
BEST CARE AND SUPPORT FOR ACUTE EPISODES						
18. Develop systems to improve the coordinated, multidisciplinary care for people with heart, stroke and vascular disease, including appropriate care plans, defined referral pathways, and designated coordinators of care.	X	X	X	X	X	X
19. All people with stroke will receive stroke unit care or in rural or remote areas alternate models of organised stroke care.				X		
20. People attending hospital with suspected or confirmed coronary heart disease will receive timely and appropriate treatment to relieve their symptoms and reduce their risk of subsequent coronary events.	X					

Critical Intervention Points	Coronary Heart Disease	Heart Failure	Peripheral Vascular Disease	Stroke	Rheumatic Heart Disease	Chronic Kidney Disease
21. People who develop symptoms of stroke will have timely access to CT scanners for accurate diagnosis.				X		
22. Improve access to treatment services for all Australians, particularly those living in regional, rural and remote areas, and Aboriginal and Torres Strait Islander people.	X	X	X	X	X	X
23. Develop approaches to monitoring all aspects of heart, stroke and vascular disease control, including safety and quality, and ensure that the agreed indicators are aligned with heart, stroke and vascular disease plans at national, state/territory, and local levels.	X	X	X	X	X	X
BEST LONG-TERM CARE AND SUPPORT						
24. Develop and implement strategies to support a multidisciplinary team approach which promotes continuity of care.	X	X	X	X	X	X
25. People with chronic kidney disease will have access to appropriate specialist care.						X
26. Current barriers to organ donation in Australian hospitals should be addressed.						X
27. Implement policies to encourage the safe and quality use of medicines.	X	X	X	X	X	X
28. Access to rehabilitation services for people with heart, stroke and vascular disease.	X	X		X	X	
29. Ensure that psychosocial needs of people with heart, stroke and vascular disease are met across the patient journey.	X	X	X	X	X	X

Critical Intervention Points	Coronary Heart Disease	Heart Failure	Peripheral Vascular Disease	Stroke	Rheumatic Heart Disease	Chronic Kidney Disease
30. Improve access to culturally appropriate care and support for all Australians with the conditions, and in particular Aboriginal and Torres Strait Islander people, people with diverse language and literacy needs, and people in rural and remote areas.	X	X	X	X	X	X
BEST CARE IN THE ADVANCED STAGES						
31. Services will adequately inform people and caregivers for the future course of the illness and the pathways of care.	X	X		X		
32. People will be informed about advance directives and receive appropriate support.	X	X	X	X		
33. Programs will be in place to provide information and support to caregivers and reduce caregiver and patient health problems.	X	X	X	X	X	X
34. Improve timely and appropriate access to adequate palliative care services which are integrated with treatment services.	X	X	X	X	X	X

CHAPTER 5. Reduce the Risk of Heart, Stroke and Vascular Disease

Notwithstanding the huge gains that have been made in reducing death and disability rates from heart, stroke and vascular diseases, the number of people in the community with modifiable risk factors for these conditions appears to be increasing.¹⁹ Over seven million Australians (60%) are overweight, 54% are not participating in enough regular physical activity, 30% have high blood pressure, 20% smoke daily and 8% have diabetes. The prevalence of obesity and diabetes has doubled over the past 20 years and average levels of physical activity are on the decline. Blood cholesterol concentrations do not appear to have changed over the past 10 years, and at least 80% of the adult population has at least one of the major cardiovascular risk factors.

By addressing these underlying causes of heart, stroke and vascular disease, and improving systems to detect and manage risk factors for these conditions, significant reductions in disability and premature mortality could be achieved. For example, effective combined lifestyle measures and medical treatments could decrease coronary heart disease events by 37% and 47%, respectively.^{55,56}

Many individuals have multiple risk factors for heart, stroke and vascular disease. Risk factor ‘clustering’ is more common in those at higher risk of these conditions: Aboriginal people and Torres Strait Islanders, the elderly, those with diabetes, and those in the lower socioeconomic groups. In turn, many of the important risk factors—tobacco, nutrition, physical inactivity—are implicated as causes of a range of other chronic conditions. The value of prevention of heart, stroke and vascular disease by reducing risk factors is amplified because of the impact on other conditions. This ‘common agenda’ underpins the development of the National Chronic Disease Strategy.

PEOPLE’S NEEDS

To reduce their risk of heart, stroke and vascular disease, people need:

- access to high quality, culturally appropriate information about the prevention of heart, stroke and vascular disease disseminated in a manner that encourages, facilitates and supports lifestyle modification
- tools that allow people and their medical practitioners to individualise risk assessment and management
- to know how to reduce their risk of developing heart, stroke or vascular disease
- access to interventions and care to help them adopt and maintain healthy lifestyles and behaviours
- to live in an environment that encourages and supports healthy lifestyle choices.

CRITICAL INTERVENTION POINTS

1. Adopt national, state, territory and local plans to further reduce rates of smoking using evidence-based public health strategies and government actions.
2. Adopt national, state, territory and local plans, and school-based educative programs to promote awareness of heart, stroke and vascular disease risk factors, healthy eating and active living, including healthy weight, in collaboration with other national health priorities and policies.
3. Establish and implement national, state, territory and local plans and incentives to increase opportunities for physical activity through open space and urban planning guidelines.
4. Investigate national, state and territory economic strategies to reduce population exposure to known risk factors for heart, stroke and vascular disease.
5. Establish and encourage the development of systems and tools to enable absolute risk estimation in people without overt cardiovascular disease (including early detection and management of high blood pressure and dyslipidaemia).
6. Investigate the feasibility and the benefits of achieving population wide reductions of saturated fat and dietary salt in the Australian context.

Optimal Services and Rationale for Critical Intervention Points

Information will be available to enable identification of risk factors for heart, stroke and vascular disease, absolute risk assessments and opportunities for reducing risk

Optimal Services: People in the community will have access to consistent and culturally appropriate information to increase their awareness of heart, stroke and vascular disease and associated conditions.

Information developed by a partnership between key stakeholder groups will be available through a range of sources including health professionals and other care providers, the mass media, websites of peak organisations, and the Internet.

Building information capacity through partnership

There is a need to improve awareness of heart, stroke and vascular disease among the well population, and to provide information to alter risk perception and facilitate behavioural change. Developing and disseminating messages that are consistent and evidence-based requires the involvement of a range of key groups, including peak consumer and professional organisations, community groups and other stakeholders, together with government organisations at the national, regional and local levels.⁵⁷

The involvement of a number of stakeholder groups pools the skills and resources needed for a sustainable approach to information provision, and builds capacity to respond to advances in knowledge and changes in the information needs of the community.⁵⁸ The involvement of all key groups, including those who are specialised in the translation and presentation of scientific evidence, improves the quality and credibility of the information. Broad representation can help ensure that messages tailored for different groups and delivered by different organisations contain consistent information, and are widely distributed through a number of communication channels.

People will be aware of opportunities to reduce risk of heart, stroke and vascular disease

Optimal Services: There will be broad strategies in place to ensure that health professionals, the media and the wider community are aware of and are educated about opportunities for reducing the risk of heart, stroke and vascular disease through the adoption of healthy lifestyle behaviours.

Individuals and communities at greatest risk of developing heart, stroke and vascular disease will be targeted by culturally appropriate strategies aimed at promoting lifestyle change and initiation of appropriate medical treatment, when necessary.

Risk Factors

Tobacco

Tobacco smoking is responsible for approximately 13% of all cardiovascular deaths. Recent data suggest that approximately 17.4% of Australians aged 14 years and over smoke on a daily basis. Although smoking rates, in general, have declined over the last decade (by 21% and 16% for males and females, respectively), smoking rates in Aboriginal and Torres Strait Islander (43%), disadvantaged (24%) and rural and remote (22%) communities, remain high.¹⁹ Tobacco use is the single largest preventable cause of disease and premature death in Australia.⁵⁹

- The majority of deaths from tobacco could be prevented by reducing the uptake of smoking in children and adolescents and increasing smoking cessation in adults.
- Well funded and implemented tobacco control mass media campaigns targeted at the general population and run in conjunction with tobacco control programs are associated with reductions in smoking rates in adults and youth.⁶⁰ Australia's National Tobacco Campaigns have been shown to be associated with reductions in the understanding of risk behaviours and smoking rates.⁵⁹
- Sustained efforts in this area are required to provide continued reductions in smoking prevalence.⁵⁹
- Promotion of smoke free policies combined with educational strategies directed towards smoking cessation are associated with successful behaviour change.^{61,62} School-based and workplace programs are favourable settings for primary prevention programs.⁶³⁻⁶⁵
- Self help resources and counselling interventions provided at the community level and through general practices are effective for enhancing smoking behaviour change.^{61,66,67}

Alcohol misuse

The impact of alcohol use on cardiovascular disease risk varies with levels of consumption. Low to moderate consumption is potentially protective, however, alcohol misuse (in particular binge drinking) is associated with increased blood pressure and death from stroke. In 2001, it was estimated that 9.9% of people aged 14 years and over were consuming alcohol at levels risky, or highly risky, to their health. The National Health and Medical Research Council have published guidelines for the treatment of alcohol problems.⁶⁸

Although Aboriginal and Torres Strait Islander peoples are less likely to drink alcohol than the rest of the population, those that do are more likely to consume at highly risky levels (9.3% compared to 2.7%).¹⁶

Physical inactivity

People who are physically inactive are almost twice as likely to die from coronary heart disease as those who are active. It has been estimated that 18% of coronary heart disease events, and 16% of stroke events, are attributable to physical inactivity.⁶⁹⁻⁷²

In 2000, 54% of Australians aged between 18 and 75 years did not undertake physical activity at recommended levels. There is a dearth of information about physical activity levels in specific sub-groups of the population, including Aboriginal and Torres Strait Islander peoples, and people from culturally and linguistically diverse and rural or regional communities. There is some evidence to suggest that people who complete high school engage more in appropriate levels of physical activity.

There is strong epidemiological evidence to support the role of physical activity in the prevention of cardiovascular disease:

- It is recognised that moderate intensity exercise of 30 minutes duration undertaken at least five days per week can reduce the risk of cardiovascular events.^{72,73}
- Informational, behavioural and social interventions (school-based physical education, social support in community settings, and individually adapted health behaviour change) have been shown to be effective in increasing physical activity. Policies and programs that create and enhance access to places for physical activity have also been shown to be effective.
- Evidence is insufficient to assess a number of other interventions, including; classroom based health education focused on information provision, family based social support, mass media campaigns and school-based health education and physical education; and classroom-based health education focused on reducing television viewing and video game playing (because of insufficient evidence of an increase in physical activity).

The National Public Health Partnership and Strategic Intergovernmental Forum for Physical Activity have developed a framework for action by the health sector for improving physical activity in the community.

Overweight and obesity

Excess body weight and obesity is an independent risk factor for cardiovascular disease, cancer and other risk factors such as hypertension, dyslipidaemia and Type 2 diabetes.⁷⁴ The percentage of Australians who are overweight or obese has increased rapidly over the past 20 years.¹⁹ Recently, the Aus-Diab study found that in a randomly selected population of 11 000 men and women from around Australia, 48% men and 30% women were overweight and 19% men and 22% women were obese.⁷⁵ Appropriate monitoring of the size and trends of this epidemic of obesity have begun⁷⁶, but awareness of what is undoubtedly one of the biggest health threats facing Australian children remains low.⁷⁷

- Exercise and/or behaviour therapy appear to improve weight loss when added to diet. Low fat diets with exercise, or with exercise and behaviour therapy, are associated with the prevention of Type 2 diabetes and hypertension. In epidemiological studies, long term weight loss was associated with reduced risk of Type 2 diabetes and may be beneficial for cardiovascular disease.⁷⁸⁻⁸¹
- Low fat diets and exercise interventions in individuals at risk of obesity related illness are of comparable cost to drug treatments.⁷⁸
- A recent systematic review of interventions for preventing obesity in children concluded that there are 'limited high quality data on the effectiveness of prevention programs'.⁸² This may well reflect the methodological and ethical challenges of conducting such studies, often in a sociopolitical environment not conducive to change. However, the review did highlight the potential effects of reducing sedentary behaviours and increasing physical activity.
- The current individual-based approaches to obesity have only a modest long term success, and relatively few population-based strategies have been attempted or evaluated.⁷⁷

The National Health and Medical Research Council have published clinical practice guidelines for the management of obesity in children and adolescents.⁸³ The National Obesity Taskforce has developed a comprehensive strategy to address the obesity epidemic—*Healthy Weight 2008*.⁸⁴ This strategy recommends better protection for young people against the promotion of high energy, poor nutritional value foods and drinks and/or sedentary lifestyles through advertising⁸⁴ and media that encourage unhealthy eating, inactivity and overweight.

Nutrition

Current recommendations to reduce cardiovascular risk include maintaining a healthy body weight, eating five or more portions of fruit and vegetables each day, reducing intake of fat (particularly saturated fatty acids), increasing the intake of omega 3 fatty acids, reducing salt intake and eating one portion of oily fish per week.⁸⁵ Although some improvements have been made in recent years (e.g. a reduction in total fat intake), national studies suggest that more effective campaigns are required to increase awareness of the benefits of these dietary changes.

There is good evidence for replacing saturated fatty acids with n-6 polyunsaturated fatty acids (found primarily in vegetable oils and spreads made from seeds such as sunflower and soybean) to reduce the risk of coronary events and death, and to lower total cholesterol, LDL cholesterol and triglycerides. In 1995, the average Australian intake was 5% of total energy intake which is below the NHMRC's recommended range of 6-8%. Similarly the current intake of n-3 polyunsaturated fatty acids (found in oily fish, leafy plants, and canola and flaxseed oil) among Australian adults is low (about 0.2 g).¹⁹

There is good evidence that increased consumption of fruit and vegetables reduces the risk of heart, stroke and vascular diseases. Protection may arise from reduced risk of developing atherosclerosis, a reduction in blood cholesterol levels, a reduction in levels of homocysteine (which is a possible risk factor for coronary heart disease) and reduced blood pressure. The Australian dietary guidelines for adults recommend consuming at least two serves of fruit and at least five serves of vegetables per day. Consumption of fruit and vegetables is below recommended levels for a significant proportion of the population, especially among men aged 19–34 years, people residing in cities, and socioeconomically disadvantaged groups.⁸⁶

The Dietary Approach to Stop Hypertension (DASH) Diet, which is high in fruits, vegetables, and low fat dairy products and low in fat, has been shown in large, randomised, controlled trials to reduce blood pressure significantly.⁸⁷ Behavioural interventions to alter dietary intake have resulted in meaningful improvements in dietary behaviours associated with the prevention of chronic disease, particularly among individuals at elevated disease risk.

There is evidence that a high dietary intake of salt is contributing to the increased blood pressure in an ageing population, and that modest salt reduction can reduce blood pressure⁸⁸⁻⁹¹. The estimated average consumption by Australian adults is 20 grams per day (g/d), which is 2–3 times the current recommended intake of 2.3 g/d.⁹² A reduction of 3 grams of salt g/d predicts a fall in blood pressure of 3.6 to 5.6/1.9 to 3.2 mm Hg (systolic/diastolic) in people with hypertension and 1.8 to 3.5/0.8 to 1.8 mm Hg in people with normal blood pressure. The effect would be doubled with a 6 g/d reduction and tripled with a 9 g/d reduction.

A reduction of 3 g/d could reduce strokes by 13% and ischaemic heart disease by 10%. Reducing salt intake by 9 g/d (e.g. from 12 to 3 g/d) would reduce strokes by approximately one third and ischaemic heart disease by one quarter. The current recommendations to reduce salt intake from 9 to 12 g/d to 5 to 6 g/d will have a major effect on blood pressure and cardiovascular disease.

The largest source of dietary salt is processed foods (e.g. certain breads and processed meats), and achieving population wide reductions in salt intake will require changes to food manufacturing practice.⁹³

Conditions that put people at high risk of heart, stroke and vascular disease

High blood pressure and dyslipidaemia

Approximately one in four Australians are hypertensive, with the prevalence increasing with advancing age.¹⁹ Approximately 50% of the population has elevated lipid levels. Modest reductions in blood pressure can reduce people's risk of coronary heart disease and stroke events by between 14% and 42%.⁹³

There needs to be greater emphasis on recognising the importance of a multifactorial approach to risk factor detection in preference to the current isolated risk factor approach.^{74,94} An isolated risk factor approach may be a barrier to the implementation of population-based primary prevention strategies.⁹⁵

- The awareness and treatment of hypertension and dyslipidaemia is sub-optimal, with an estimated 30% of those screened being unaware of the condition.⁹⁴
- Of those being treated with anti-hypertensive and anti-hyperlipidaemic medicines, approximately 30% are not being adequately controlled.^{94,96}
- Several guidelines have been published by the National Heart Foundation of Australia and others for the management of hypertension and dyslipidaemia.^{47,97}
- General practice provides a major opportunity for active detection programs for the prevention of cardiovascular disease.¹⁹
- A large proportion of hypertension and dyslipidaemia could be prevented through dietary and lifestyle approaches to treatment including reduced salt consumption⁹⁸, moderate alcohol intake, increased physical activity⁹⁹, reduce dietary fat intake and maintenance of an ideal body weight.¹⁸
- There are no national data on the prevalence of hypertension or dyslipidaemia in Indigenous Australians. Improving access to health care services in rural and remote areas may improve opportunities for the identification of people at high risk.
- Increasing the number of Indigenous health care workers available for active detection and health promotional activities will help to ensure appropriateness for specific populations.
- Nurse provided or nurse coordinated care management programs using an integrated or multifactorial approach have been highly effective in reducing morbidity and mortality of people at high risk of heart, stroke and vascular disease.⁵⁵ Further evaluation of this strategy in the wider Australian community as well as in special populations is warranted.

Diabetes mellitus

Diabetes is a major risk factor for the development of cardiovascular disease. In 1999–2000¹⁸, approximately 7.6% of Australians aged 25 years or older had the disease. Of these, half were not aware that they had diabetes.

Aboriginal and Torres Strait Islander groups are almost four times more likely than their non-Indigenous counterparts to have diabetes, with prevalence estimates rising to 16% for Indigenous Australians residing in remote as opposed to non-remote areas.¹⁸ They also tend to develop diabetes at a younger age than other Australians. Pacific Islanders, people of Chinese descent and those from the Indian Subcontinent are also more likely than other Australians to have diabetes, in particular Type 2 (or non-insulin dependent) diabetes.

Chronic kidney disease

People with chronic kidney disease are at high risk of heart, stroke and vascular diseases. Cardiovascular disease is the leading cause of death in people with kidney failure. Among people treated by dialysis, the risk ranges from 500-fold higher in individuals aged 25–35 years to 5-fold higher in individuals aged >85 years.^{39,100}

Modifiable risks for CKD include smoking, high blood pressure, diabetes, poor diet and, in Indigenous populations, recurrent skin infections and overcrowded living conditions.^{34,101,102} National surveys show that almost half of all people were not aware they could reduce their risk of developing kidney disease, and had little or no knowledge of how to keep their kidneys healthy.¹⁰³ A recent survey revealed that less than 15% of respondents were aware that risks such as drinking¹⁰⁴, poor diet, insufficient physical activity, and high blood pressure could impact on the health of kidneys.¹⁰¹

Lifestyle changes and treatments to reduce the risk of heart, stroke and vascular events are especially important in this group.

There is limited public awareness of chronic kidney disease, and this lack of awareness contributes to the development and progression of the disease.¹⁰⁴ People from non-English speaking backgrounds experience difficulties receiving messages regarding the prevention of kidney disease due to poor communication with health professionals, inferior access to health services, and problems accepting messages about self-help and lifestyle modification.¹⁰⁵ This is particularly so in Aboriginal and Torres Strait Islander peoples, where community development, social change, and education are required to improve the uptake of preventive health behaviours for kidney disease.^{35,106,107}

A widely publicised, centralised repository for information from credible organisations and sources about the detection and treatment of CKD could improve access to CKD knowledge. The provision of such an information service would provide an opportunity to reduce the incidence of CKD in Australia.

Information for specific population groups

Aboriginal and Torres Strait Islander Peoples

There are a number of difficulties faced by Aboriginal and Torres Strait Islander groups negotiating the health system, including the cultural appropriateness of some information and services, geographic isolation and the affordability of these services. There is a need to improve the development and delivery of culturally appropriate services for Aboriginal and Torres Strait Islander peoples to reduce the prevalence of modifiable risk factors.

It is critical to involve Aboriginal and Torres Strait Islander peoples in the development of information in order to ensure that appropriate language and imagery are used. Indigenous media outlets should be used, where possible, to disseminate information.¹⁰⁸ Lack of time, and cultural and language issues have been identified as barriers to communicating with Aboriginal and Torres Strait Islander women on health matters.¹⁰⁹ A website has been created to support improved communication between health staff and their Indigenous clients (www.sharingtruestories.com/index) to make relevant information on intercultural communication accessible and to promote cultural awareness.¹¹⁰

The National Strategic Framework for Aboriginal and Torres Strait Islander Health¹¹¹ outlines nationally agreed strategies to address specific health problems and identifies the need to address the predeterminants of chronic diseases as an immediate priority. The framework supports mainstream national strategies addressing nutrition, physical activity, smoking, and alcohol use.

Specific population groups

Certain population groups may be predisposed to heart, stroke and vascular diseases for a number of reasons, including current and past diet. It is important that this ethno-specific data be gathered and interpreted and that preventative campaigns be tailored for those specific communities.

Lower socioeconomic status is associated with the presence of multiple risk factors for heart, stroke and vascular diseases, and a higher risk of all diseases.¹¹² In Australia, the total burden of all diseases is 37% higher among men and 27% higher among women

in those classified as the most disadvantaged in relation to income, education, housing, employment and other attributes. Lower socioeconomic status is associated with higher rates of smoking, lower rates of physical activity, higher rates of obesity¹¹⁰, and lower intake of foods in all food groups.¹¹³

People will have access to information and services which enable them to adopt and maintain a healthy lifestyle

Optimal services: People will have access to primary health care that provides lifestyle and pharmacological treatment to prevent heart, stroke and vascular disease based on an assessment of an individual's level of risk.

Models of care that are tailored specifically to meet the needs of high risk groups will be designed and implemented, especially in Aboriginal and Torres Strait Islander populations.

Community education

Information and guidelines about risk factors for heart, stroke and vascular disease and ways to reduce risk are currently made available by a range of government and non-government organisations: the NHMRC, the National Heart Foundation of Australia, the National Stroke Foundation, Heart Support Australia, Diabetes Australia, Nutrition Australia, Dietitians Association of Australia and Food Standards Australia and New Zealand. Information and guidelines on improving physical activity are available from the Australian Council for Health, Physical Education and Recreation, and the Australian Sports Commission.

At present, the extent to which the general population accesses these resources remains unclear. Systematic evaluation of the uptake of this information by the general population is necessary, and should aim to:

- establish whether improved knowledge translates into behavioural change
- identify barriers to access for the population generally, and high risk groups in particular
- determine the most effective marketing/distribution processes and educational campaigns for elderly people and those from Indigenous, culturally and linguistically diverse, and disadvantaged socioeconomic backgrounds.

National health promotion initiatives using mixed media models (e.g. television, radio and print) and, in some cases, supported by legislative change, have also aimed at broad dissemination of information to reduce risk through the adoption of healthy lifestyle choices, for example, the *Life. Be in it* (1977) and National Tobacco campaigns.⁵⁹ Other strategies such as effective policy and change in environments are needed to complement these social marketing messages.

Primary care

The primary health care setting and in particular general practice has significant potential as the locus for activities which encourage healthy lifestyle choices, with 80% of Australians visiting a general practitioner at least once a year.⁶⁶

General practitioner attempts to modify the smoking, physical activity and dietary behaviours of their patients are generally most effective when:

- strategies are tailored to reflect the unique needs of the person
- single rather than multiple risk factors are targeted
- preventive attempts reflect an understanding of behaviour theory.

Guidelines produced by the Royal Australian College of General Practitioners for the provision and implementation of preventive activities in general practice are key documents for progressing the role of general practitioners in prevention of heart, stroke and vascular disease.^{114,115} This role will be further enhanced when strategies addressing the barriers to implementing preventive practice, such as time constraints and patient beliefs, are determined.

The SNAP Framework¹¹⁶ has been developed to guide the implementation of integrated approaches to modification of a limited set of behavioural risk factors in general practice focusing on smoking, nutrition, alcohol and physical activity (SNAP). The SNAP risk factors have been identified as significant contributors to the burden of disease in Australia.

The SNAP Framework aims to improve health outcomes in the community by supporting and enhancing the role that general practice plays in increasing levels of good nutrition and physical activity and decreasing smoking prevalence and alcohol misuse. The SNAP Framework represents a system-wide approach to behavioural risk factor identification and management and it acknowledges the importance of socioeconomic factors in behavioural risk factor modification. The initiative targets consumer awareness of the links between behavioural risk factors and chronic disease and highlights the role of the general practitioner as an agent for supporting behavioural change.

The Lifestyle Prescription Initiative was introduced as part of the Focus on Prevention package in the 2003–04 Australian Government Budget. The Initiative is built upon and consistent with the SNAP Framework. It aims to make it easier for general practitioners and their practices to encourage patients to make healthier lifestyle choices, by providing a framework for:

- discussion of lifestyle health issues
- advice in the form of a written script
- referral to other providers to support healthy lifestyle choices.

The Initiative will support general practitioners incorporating lifestyle risk reduction into their usual processes for treating their patients. Lifestyle prescriptions are tools for general practitioners to use when giving patients healthy lifestyle advice—about quitting smoking, eating a healthier diet, reducing alcohol use, increasing physical activity, managing bodyweight, or a combination of these.

People's environments will support and encourage healthy lifestyle choices

Optimal Services: The environments in which people live will support and encourage optimal health and wellbeing by limiting exposure to the risk factors for heart, stroke and vascular disease and advocating healthy lifestyle choices. This may occur through the application of legislation, financial incentives and disincentives, and policies that target the social, physical and economic factors impacting on people's health related behaviour, especially in individuals and groups at high risk.

Tobacco

Regulatory Strategies

Smoke free environments

Comprehensive strategies for smoke free environments effectively reduce smoking in public places.¹¹⁷ Policies, regulations and laws banning smoking in workplaces and other public venues have been successful in reducing exposure to environmental tobacco smoke¹¹⁸ and smoke free workplaces encourage smokers to quit or reduce their tobacco consumption.¹¹⁹ In Australia, there is state and territory legislation and/or regulations relating to smoking in enclosed public areas.¹¹⁹ There are variations to legislation in each

jurisdiction, with some banning smoking in all enclosed public places with few exceptions, and others only prohibiting smoking in specified venues.

Tobacco advertising

Comprehensive bans on tobacco advertising can reduce tobacco consumption.¹²⁰ However, more limited partial advertising bans will have little or no effect.¹²¹ In Australia, there is a complete ban on all forms of tobacco advertising in print, television, radio and in cinemas.¹²⁰ The *Tobacco Advertising Prohibition Act 1992* is currently being reviewed to ensure it remains an effective tobacco control measure.

Labelling of tobacco products

Health warnings on cigarette packets have been shown to be effective in reducing cigarette consumption.¹²² In Australia there has been labelling of tar and nicotine levels on cigarette packages since 1982, with stronger warnings implemented in 1994.¹²⁰ New graphic health warnings for cigarette packs will be introduced in March 2006.

Sales to minors

Interventions with retailers can lead to large decreases in the number of outlets selling tobacco to youths.¹²⁰ In Australia, efforts to reduce the access of minors to tobacco products include a minimum age of purchase of 18 years in all jurisdictions, with penalties imposed on those selling to minors or, in some cases, supplying to minors.¹²³ Restrictions on the locations of vending machines in most jurisdictions also apply.¹²⁴ Despite this policy, the sale of cigarettes to minors is still prevalent. In 2001, 82.6% of underage smokers most commonly obtained tobacco from a shop or retail outlet.¹²⁵

Economic Strategies

Higher tobacco prices significantly reduce tobacco use.¹²⁶ In Australia, large price increases for cigarettes occurred in the 1990s¹²⁷, in particular in 1999, when the method for calculating excise was changed.

Health promotion programs

School based programs

There is some evidence to support school-based programs for discouraging smoking.¹²⁶

Promoting cessation of tobacco use

Smoking cessation is a major means of reducing smoking related mortality as it prevents the occurrence of disease and reduces the risk of further disease in those who quit. Strategies such as mass media campaigns, medical practitioner interventions, offers of support to smokers and effective Quit Line services all play critically important roles in reducing the proportion of people in the population who smoke on a regular basis.

Physical inactivity

Interventions to alter environments by removing barriers and providing more opportunities for physical activity can be effective in increasing population levels of physical activity.¹²⁷

Assigning priority to the development of an environment conducive to physical activity will be increasingly important in the planning of new, and the regeneration of old, urban areas. Evidence is emerging that people living in walkable neighbourhoods who spend less time each day in cars report higher levels of physical activity. Walkable neighbourhoods are those with increased residential density, land use mix, street connectivity, aesthetics and safety. People living in walkable neighbourhoods in US cities had 70 minutes more physical activity per week and lower levels of obesity than residents in low walkability neighborhoods.^{128,129} It is recognised that more could be done to improve access to public spaces for physical activity in Australia.¹³⁰

Nutrition, overweight and obesity

There is some evidence that school-based programs can improve diet among school children¹³¹ and good evidence that worksite interventions are effective in increasing fruit and vegetable consumption by workers.^{132,133}

Eat Well Australia: an agenda for action for public health nutrition¹³⁴ provides direction for improvements in diet in Australia. This document outlines the need to equip educators such as teachers and health professionals with the knowledge, skills, framework and tools to encourage healthy changes in diet.

Price reductions are an effective strategy to increase the purchase of healthy foods in community based settings such as work sites and schools.¹³⁵ In Australia, lower income adults are more likely than their higher income counterparts to report that price is a barrier to increasing their fruit and vegetable consumption.¹³⁶ Socioeconomic differences in fruit and vegetable consumption are apparent in Australian adults.¹³⁶

CHAPTER 6. Early Detection, Care and Support of People with Heart, Stroke and Vascular Disease

Around 25% of people who have a heart attack die within an hour of their first ever symptoms, with over half of all heart attack deaths occurring before the person reaches hospital.¹⁹ A person who suffers a heart attack has double the chance of surviving if they get to hospital within an hour of feeling the symptoms. Clearly people need to know the early symptoms of heart, stroke and vascular disease and to seek appropriate medical assistance should they occur.

With a diagnosis made, people need in the early stages of their illness good quality information about their condition. They need to know what opportunities are available for self-management education and participation in decision making about the management of their illness, to have timely access to evidence-based care. They should have a mutually agreed, written, individualised management plan that outlines how they can participate in their care and slow the progression of their disease, and should be supported to manage the physical, social, emotional, and economic impact of the condition.

An estimated 3.2 million Australians reported having a cardiovascular condition in 2001.¹³⁷ People with known coronary heart disease (CHD) have a higher rate of cardiovascular events than the healthy population. In the absence of treatment they have a 10% risk of a further event in the first year after their first myocardial infarction (MI), particularly in the first two months after the event, and 5% risk per subsequent year.¹³⁸ Secondary prevention in CHD encompasses medical therapies and lifestyle changes with the aim of reducing recurrent cardiac events and procedures and improving the quality of life.

Those with established CHD for whom secondary prevention is a priority include people with a history of chronic/stable angina or an acute coronary syndrome (ACS). ACS refers to a spectrum of clinical syndromes which include unstable angina and MI.

PEOPLE'S NEEDS

People need:

- to know how to recognise and respond to the symptoms of heart attack and stroke
- to be aware of their risk profile and know the symptoms associated with the conditions, and know the value of detecting the conditions early
- an accurate diagnosis at the earliest opportunity
- to be fully informed about their diagnosis, and provided with information and support to participate in decisions about their care

- timely access to high quality care to optimise their health outcomes
- education on how to self-manage their day-to-day health care needs, and to modify their lifestyle to slow the progression of their condition
- a written, individualised management plan that includes arrangements for planned, periodic review.

CRITICAL INTERVENTION POINTS

1. Promote awareness among people of the need for regular monitoring of blood pressure, cholesterol and of the symptoms of diabetes (polyuria and polydipsia).
2. Promote awareness of the early symptoms of heart, stroke and vascular disease and associated conditions, and emergency response where appropriate.
3. Develop systems that include measuring absolute risk in prescribing and treatment algorithms and which help people to understand their individual risk.
4. Improve detection systems so that all people with transient ischaemic attacks, atrial fibrillation, suspected rheumatic heart disease, and chronic kidney disease are referred appropriately and assessed promptly and effectively.
5. Information about cardiovascular disease symptoms and appropriate responses will be developed and disseminated to general practitioners and primary care providers to be given to people with cardiovascular disease or stroke.
6. Develop effective and integrated programs to increase early detection of asymptomatic chronic kidney disease in people at high risk.
7. People will have timely and appropriate access to services, including echocardiography, for the diagnosis of heart, stroke and vascular disease.
8. Provide appropriate information to people about the disease, treatment options and expected outcomes, follow up and support services to facilitate self-management of the physical, psychosocial and economic impacts of their condition.
9. Processes will be in place to assess the extent to which clinical practice guidelines are adopted and to encourage their implementation.
10. Improve access to self-management education programs and support groups to help people develop the knowledge, skills and confidence to self-manage their condition.
11. Establish systems of care to reinforce the importance of risk reduction in people with established heart, stroke and vascular disease.

OPTIMAL SERVICES AND RATIONALE FOR CRITICAL INTERVENTION POINTS

People will know how to recognise and respond to the early symptoms of heart attack, stroke and rheumatic heart disease

Optimal Services: People will have access to information about the factors which increase their risk and the early signs and symptoms of heart, stroke and vascular disease. Information will stress the importance of early diagnosis of these health problems and symptoms.

People will receive information about the process of diagnostic testing and the implications of test results to enable them to participate in decisions about testing. Information will be evidence-based, consistent, and available through a range of channels. It will be tailored for Aboriginal and Torres Strait Islander peoples, and will meet the different cultural, language and literacy needs of diverse communities.

Acute myocardial infarction

The delay between the time of onset of symptoms and the time at which a patient comes under medical attention is a major determinant of prognosis in AMI; the largest single component of the delay is the time taken by the patient deciding to summon help.¹³⁹ In the UK heart attack study, lives saved per thousand people treated were 107 for people coming under care within one hour of onset, compared with 31 for those coming under care at 4–12 hours, and 21 if the delay was 12 hours or greater.¹⁴⁰ Reducing delay optimises the benefit of thrombolytic treatment and is also crucially important for improving outcome in people who develop ventricular fibrillation. Currently only about 25% of all infarct patients receive thrombolytic treatment and this number would increase significantly if delays were shortened. Delaying the administration of thrombolysis by 30 minutes, particularly in the early hours of AMI, reduces life expectancy by an average of one year.¹⁴¹

The general perception of AMI is of crushing chest pain accompanied by collapse and unconsciousness, which in fact may happen in only a minority of cases.^{142,143} The onset may be gradual, the symptoms intermittent, and the location of pain variable. A Scottish study found that one-third of cases with a history of previous AMI and half of those with a history of angina attributed their symptoms either to indigestion or to another non-cardiac cause. Denial is thought to be a common response to coronary symptoms, and while it is probably present to some degree in all people experiencing an AMI, it may be more pronounced in those with a previous cardiac history and other high risk groups. The relation between denial and delay is difficult to evaluate and has not been investigated thoroughly.¹⁴⁴ People and family members should be told to expect denial and understand that it is a usual but inappropriate response to coronary symptoms.

A history of previous myocardial infarction or angina does not reduce patient delay times¹⁴⁵, on the contrary some studies report a positive association between angina and increased delay.¹⁴⁶

In any heart health education program, it is important to emphasise the serious nature of coronary symptoms and that they always warrant a call to the emergency ambulance service. Effort is required on the part of the ambulance service to promote the expertise of their crews in dealing with coronary events. This may increase public confidence in the acceptability of bypassing their general practitioners and phoning an ambulance directly.

While those with a previous cardiac history should be targeted, education campaigns must be aimed at all sectors of the population. To date, the effect of media campaigns, which are usually of limited duration, on patient delay times is mixed. While some succeeded in reducing the delay to call for help, they report no success in increasing the proportion of people who call the ambulance service in the first instance.¹⁴⁷ Long term low intensity strategies aimed at raising the awareness of the general public, particularly in rural or remote areas where delays in treatment may be longer, about the benefits that can be achieved by early coronary care may be more effective in changing attitudes.¹⁴⁸

Stroke

Stroke is an emergency. Depending on the cause of the stroke, severe disability and death can be prevented if diagnosis and appropriate treatment are commenced within three or fewer hours of onset. Strategies aimed at promoting broad awareness of stroke symptoms, combined with widespread dissemination of information about what to do when symptoms occur, will be the key to reducing morbidity and mortality from stroke.

Although there is limited Australian data on awareness of stroke risk factors and warning signs, a number of surveys have been conducted indicating very limited appreciation of the cardinal clinical features of stroke and the major risk factors for stroke. Community surveys conducted by the National Stroke Foundation have indicated low levels of awareness of risk factors and warnings signs. A community-based survey conducted in the Hunter region of NSW confirmed low levels of community knowledge, with approximately

20% of individuals surveyed not aware that stroke was actually a condition affecting the brain. A significant proportion of people were not aware of the cardinal clinical features of weakness and speech disturbance.

Safe (Stroke Awareness For Everyone) is an international non-profit organisation which seeks to promote awareness of stroke and stroke symptoms.¹⁴⁹ Strokesafe is a 10 year program launched in 2004 by the National Stroke Foundation. One of its aims is to improve awareness of stroke symptoms. At the end of the six week launch period the proportion of people aged over 40 able to correctly name a stroke symptom increased from 68% to 73%. Evaluation of this program will be ongoing.

Rheumatic heart disease

Improving awareness in the general community of the symptoms of Acute Rheumatic Fever (ARF) and the need to seek medical attention, particularly in Indigenous communities, may reduce the incidence of the condition.¹⁵⁰ People with classical ARF are generally quite unwell (with severe joint symptoms or '*chorea*', a condition characterised by abnormal voluntary movements) and are likely to seek medical attention. On the other hand, people with only mild choreiform movements, or for whom carditis (i.e. inflammation of the heart) is the major manifestation, may not visit a clinic.^{151,152}

There have been attempts to improve awareness in the general community of the symptoms of ARF and the need to seek medical attention. Often these campaigns have focused on schools, by including ARF in the health curriculum, educating teachers about the signs that may be apparent in their students, and/or by teacher initiated screening of students^{153,154} These campaigns have not been evaluated. Other comprehensive programs have included larger scale education campaigns, sometimes using posters, radio and television. Although a comprehensive program in the French Caribbean was associated with a dramatic reduction in ARF incidence, it was not possible to determine which aspects of the program were effective.¹⁵⁰

There will be systems in place to support early identification and treatment of people with important risk factors for heart, stroke and vascular disease.

Optimal Services: Health and community service providers will understand the importance of early detection and management of health problems that increase people's risk of heart, stroke and vascular disease.

People will understand the benefits of a healthier lifestyle, and how to access services to support this healthier lifestyle.

Decisions regarding lifestyle intervention and/or pharmacological management of these conditions will be based on consideration of an individual's absolute risk of developing heart, stroke and vascular disease, with maximal therapy provided to people at moderate to high risk and very high risk of disease.

Risk factors

High blood pressure

High blood pressure is one of the most readily preventable causes of stroke and other complications of cardiovascular disease. High blood pressure is easily detected and there are very effective, evidence-based ways of treating the condition.⁹³ Nevertheless, hypertension is still under diagnosed and under treated, and losses to follow up are high and are responsible for avoidable vascular deaths.¹⁵⁵

Strategies and supportive infrastructure to promote regular monitoring of blood pressure within a broader risk assessment context are needed. When hypertension is diagnosed, care

and referral pathways to ensure appropriate investigation, treatment and ongoing review, consistent with the best available evidence, need to be in place.

Blood pressure measurement has traditionally been the responsibility of health professionals. The Royal Australian College of General Practitioners recommends regular blood pressure testing every two years from the age of 18 years.¹⁵⁶ Blood pressure monitoring at home is now feasible, and more importantly, blood pressure monitoring by people at home is typically associated with better blood pressure values and improved control of hypertension. An approach to care that acknowledges and supports home blood pressure monitoring as a useful adjunct to clinical care may help people to more effectively manage hypertension.¹⁵⁷

Serum lipid levels

Assessment of serum lipids should form part of any broad approach to risk factor monitoring and measurement. For people with abnormal lipid profiles, treatment should take absolute risk status into account and be consistent with currently available guidelines.⁴⁷ As any lowering of low density lipoprotein (LDL-C) or triglycerides (TG) and/or raising of high density lipoprotein (HDL-C) is considered beneficial to heart, stroke and vascular health¹⁵⁸, interventions aimed at encouraging healthy lifestyles (i.e. improved diet, weight loss and physical activity) and commencement of appropriate drug therapy (statin therapy)¹⁵⁹, should be available for all people with heart, stroke and vascular disease. The Royal Australian College of General Practitioners recommends cholesterol testing for both men and women from the age of 45, earlier in high risk groups.¹⁵⁶

Atrial fibrillation

Atrial fibrillation (AF) is one of the most common irregular heart rhythms. People with atrial fibrillation are five to seven times more likely to have a stroke than the general population.

Antithrombotic therapy can significantly reduce the risk of thromboembolic events in people with atrial fibrillation and anticoagulation with Warfarin is the most effective option.¹⁶⁰ Rational and safe use of Warfarin requires the identification of people at particularly high risk who are most likely to benefit from Warfarin therapy. For people over 80 years there is uncertainty as to the relative merits of antiplatelet therapy or anticoagulation therapy alone. At present there is a well recognised under utilisation of Warfarin in atrial fibrillation.

Others risk factors: homocysteine and C-reactive protein

Homocysteine is an amino acid (a building block of protein) that is produced in the human body. Raised homocysteine levels may irritate blood vessels, leading to blockages in the arteries (atherosclerosis), increasing the risk of heart, stroke and vascular disease.¹⁶¹⁻¹⁶³ This risk is increased substantially when raised homocysteine levels are combined with smoking, hypertension and dyslipidaemia.^{164,165} Folic acid reliably reduces plasma total homocysteine, but whether this reduces heart, stroke and vascular disease risk is unknown.¹⁶³

C-reactive protein is a protein that increases in the blood during periods of systemic inflammation. Although it has been suggested that testing serum CRP levels in the blood may be a new way to assess cardiovascular disease risk, the role of CRP in monitoring the progression of heart, stroke and vascular disease is still uncertain.

Absolute risk

Many who are at high or even very high risk for heart, stroke and vascular disease will not experience any symptoms until they have an acute and potentially life threatening event. The Framingham Heart Study data indicate that the lifetime risk of a person aged 40 developing cardiovascular symptoms is 1:2 for males and 1:3 for females. By age 70, these risks remain daunting: a risk of 1:3 for males and 1:4 for females.¹⁶⁶

When treatment decisions are based on elevated levels of a single risk factor for heart, stroke and vascular disease, interventions may be inappropriately prescribed for individuals with little chance of improvement because their absolute risk of experiencing a cardiovascular event is low. Absolute risk of future cardiovascular events is defined as the probability of suffering an acute disease related event within a finite period of time. It is determined by equations incorporating risk variables when all significant risk factors are considered, including age, sex, and high serum total cholesterol, the presence of diabetes or chronic kidney disease, high blood pressure and cigarette smoking.

Absolute risk assessment has the potential to optimise the impact of lifestyle interventions and pharmacological treatments: people with a low absolute risk (e.g. < 10% likelihood of CHD events over 10 years) are unlikely to benefit from intensive pharmacological treatment, while people with a moderate to high risk and very high risk should receive more intensive therapy. Absolute risk assessment is likely to be implemented most effectively using electronic tools which can link to other national initiatives and with prescribing. Absolute risk assessment will not only optimise health gains, but will result in more cost effective treatment and prevention.¹⁶⁷

There will be systems in place to support early diagnosis and optimal care for people with heart, stroke and vascular disease

Optimal Services: There will be systems in place to support early and accurate diagnosis and, when necessary, pharmacological management of symptoms of heart, stroke and vascular disease.

Diagnostic care will be provided in a timely manner, by appropriately qualified and experienced health professionals or other care providers, and will be supported by evidence-based diagnostic pathways and established referral pathways.

Strategies to ensure appropriate access to diagnostic and specialist services for Aboriginal and Torres Strait Islander peoples and people living in rural and remote communities will be developed and implemented.

Active case detection and management

Atrial Fibrillation

Presently there are no coordinated opportunistic screening programs for atrial fibrillation. Using an absolute risk approach and stratifying risk using recognised clinical and echocardiographic risk factors, individuals with atrial fibrillation can carry a stroke risk varying from around 3–5% up to 15–20% p.a. People in moderate and high risk groups have a clear and pronounced benefit if treated with Warfarin.

Systems for opportunistic screening, particularly in the population groups with highest prevalence—those over the age of 75—are not well developed, nor are means of readily stratifying risk and hence guiding appropriate use of anticoagulation. Systems need to be developed to achieve these ends and could involve clinical support systems, algorithms and structured programs for opportunistic screening in primary care and hospital care.

Rheumatic heart disease

Acute rheumatic fever (ARF) is a complication of an infection caused by the GAS organism. The disease can affect the heart and heart valves (RHD), with recurrent infections potentially causing chronic heart disease, and eventually heart failure.

Acute rheumatic fever

The main risk factor for developing ARF is the frequency with which individuals come into contact with different GAS strains.^{168,169} Circumstantial evidence suggests that factors

contributing to high exposure relate predominantly to lower socioeconomic status, and include poverty, poor living conditions and overcrowded housing.

Early detection and antibiotic treatment of GAS pharyngitis and skin infection can prevent most subsequent cases of ARF.¹⁷⁰⁻¹⁷² In populations where ARF is rare, the symptomatic benefits of antibiotics may be insufficient to justify their use,¹⁷³ although this matter is still unresolved.¹⁷⁴

While there is no argument about the importance of prevention in high risk populations presenting with symptomatic GAS pharyngitis, such as Indigenous Australians, there are significant impediments to the implementation of prevention programs which are not triggered by clinical presentations. This is because:

- the success of programs depends on people routinely presenting for medical care when they have a sore throat
- in high risk populations, the cost and accessibility of care¹⁷⁵ are barriers to prevention
- effective prevention programs rely on clinicians making a diagnosis of GAS pharyngitis, yet clinical diagnostic algorithms are notoriously imperfect, and microbiological diagnosis is expensive and not available in many populations at high risk^{174,176}
- programs which aim to reduce risk of ARF have questionable efficacy and poor cost effectiveness as preventative tools.¹⁷⁷⁻¹⁷⁹

There is circumstantial evidence to support a possible role for GAS skin infections in ARF pathogenesis in some populations, including Indigenous Australians.¹⁸⁰ At present, skin sore treatment and prevention cannot be considered a proven method of primary prevention of ARF/RHD. However, there is good evidence that community-based 'Healthy Skin' programs have many other health benefits, and should be promoted in Indigenous communities with high rates of impetigo (a contagious skin infection caused by bacteria) and underlying scabies.

Rheumatic heart disease

Screening of Indigenous Australians to detect RHD is currently restricted to school age children in some regions. In the Northern Territory it is recommended that children have heart auscultation (listening with the ear or stethoscope) performed as part of school screening twice between the ages of five and 10 years. Ideally, screening would include adults because the prevalence of RHD peaks in Indigenous adults aged 20 to 40 years.¹⁸¹

A recent survey in Tonga concluded that screening of all school children is logistically feasible and reveals a very high prevalence of previously undiagnosed RHD (over 3% overall, increasing to over 4% in children aged 10–14 years).¹⁸² This survey also suggested that one-stage auscultation to detect any cardiac murmur, and follow up echocardiographic examination, was a preferred protocol.

Many centres have developed their own guidelines for assessment of RHD, and the Central Australian Rural Practitioners Association manual is widely used in remote settings.¹⁸³

The National Heart Foundation of Australia and the Cardiac Society of Australia and New Zealand are currently sponsoring the development of National Best Practice Guidelines for Management and Secondary Prevention of Rheumatic Fever and Rheumatic Heart Disease.

Chronic kidney disease

In the absence of evidence to support mass screening of the general population by urine or blood testing, current professional guidelines recommend a targeted approach to the detection of individuals at high risk of developing kidney disease¹⁸⁴, including people with Type 2 diabetes and Indigenous groups.

Recent survey results indicate that only half of people with Type 2 diabetes are having the right tests performed to detect early kidney damage¹⁸⁵, and only one-quarter of people with significant complications known to accelerate kidney disease progression (e.g. hypertension) are treated effectively.¹⁸⁶ Further, up to 40% of Indigenous people in end-stage kidney disease programs are not known to have been diagnosed with kidney disease prior to presenting with kidney failure.¹⁸⁷ The results of a community-based detection and treatment programs undertaken in the Tiwi Islands demonstrated a substantial decrease in the incidence of kidney failure and cardiovascular disease, and resulted in a 50% reduction in the rate of natural deaths.¹⁸⁸

Despite the apparent benefits of active detection programs for kidney disease, there is a reluctance to participate in these programs. A recent Tasmanian study showed that the majority of people approached refused kidney disease tests and, of those who accepted free testing kits, only 15% actually assessed their urine.¹⁸⁴ Findings from the United States Kidney Early Evaluation Program have indicated that even when people are willing to undergo testing for kidney disease, they do not necessarily consult their general practitioner regarding follow up for abnormal test results.¹⁸⁵

Active case detection programs for kidney disease need to be delivered in conjunction with educational initiatives aimed at both the public and health professionals.¹⁸⁶ To succeed in Indigenous communities, kidney disease detection programs will need a strong sense of community ownership, a non-judgemental and non-authoritarian style, and respect for competing personal and community perspectives and priorities.¹⁸⁸

Early diagnosis and optimal care

Coronary heart disease and unstable angina

People with myocardial ischaemia or infarction can present with chest pain or pressure, syncope, palpitations, dyspnoea, or sudden death. Many people deny a history of pain, but instead complain of pressure, tightness, or constriction, or place a fist over the central chest. Prolonged pain or discomfort occurring at rest or after physical exertion is mostly characteristic of unstable angina or myocardial infarction. The severity of this discomfort is not strongly correlated with the degree of ischaemia, with about a quarter of myocardial infarcts being painless.^{189,190}

Almost two-thirds of people with chest pain presenting to emergency departments are admitted, many to coronary care units, with only about 15% proven to have myocardial infarction.¹⁹¹ Of the third of people discharged from the emergency department, 1–5% have a myocardial infarction^{192,193} and these ‘missed’ infarcts carry a high mortality—up to 16% in one study.^{194,195} A non-structured approach to the diagnosis of chest pain leads to a rate of missed myocardial infarction of 1–5%^{192,193}, and the unnecessary hospital admission of more than 50% of people.¹⁹¹ The aims of management should be to reduce the incidence of death and myocardial infarction, reduce the incidence of recurrent angina and readmission to hospital and improve long term functional health outcomes and unnecessary hospitalisation.

One approach to this problem has been the development of an accelerated chest pain assessment strategy for people with intermediate risk unstable angina. Depending on the hospital, the chest pain assessment service might be located in the coronary care unit, emergency department, or a monitored bed in a country hospital. Irrespective of the location, people with chest pain should be observed by staff specifically trained in coronary care practice, and should undergo accelerated diagnostic evaluation and risk stratification. Patient care is facilitated by integration of care between the emergency medical services, emergency medicine department, coronary care unit and cardiac diagnostic laboratories.

A structured period of observation and investigation is likely to reduce the number of people discharged with a ‘missed infarct’. There are also clear opportunities to more rapidly identify and apply a reperfusion strategy to people who develop ST elevation after being admitted to hospital, and to enhance the treatment of those who develop other high risk

features. Effective and rapid risk stratification should also reduce length of stay for people with low risk. A structured chest pain assessment service has demonstrated a reduction in missed myocardial infarctions (from 4.5 down to 0.4%)^{196,197} while also reducing total hospital admissions (from 57 to 47%) and costs.

Transient ischaemic attack

A TIA is the sudden onset of stroke like symptoms—a localised neurological or visual deficit that recovers within 24 hours. The majority of episodes last less than 30 minutes^{198,199} and are caused by blood clots originating most commonly from the carotid arteries, the heart (particularly in people with atrial fibrillation, a heart rhythm disturbance), the aorta, or the vertebrobasilar arteries.

People who experience these TIAs are at high risk of subsequent stroke or other vascular disease. The risk of stroke in the first week after a TIA is 5–10%, 10% in the next year and 7% per annum thereafter. This is seven times the risk of the normal population.^{198,200,201} The annual risk of heart attack after a TIA is about 2–3%, and 35% of people who have had a TIA will eventually die of cardiac disease. The combined risk of stroke, heart attack or vascular death is about 9% per year.^{198,199}

People with a suspected TIA require urgent assessment and aggressive treatment.²⁰² Modifiable risk factors such as smoking, hypertension, atrial fibrillation, hyperlipidaemia, diabetes mellitus, excessive alcohol consumption, and physical inactivity must be managed.^{203,204} Hypertension is the single most important modifiable risk factor, with 26% of subsequent strokes attributable to raised blood pressure.²⁰⁵ Hyperlipidaemia should be managed in line with secondary prevention recommendations. There is evidence that lipid lowering therapy reduces the risk of stroke, but the data is derived from trials of primary and secondary prevention of coronary heart disease.²⁰³⁻²⁰⁵

Anti-platelet treatment and, if indicated, surgical treatment of obstructed carotid arteries (endarterectomy) can improve outcomes for people with TIAs. Aspirin, the mainstay of anti-platelet treatment, reduces the three year risk of subsequent stroke, heart attack or vascular death in people with TIA by 22%.

Acute stroke

Evidence supports the use of three key interventions in acute stroke. All three are supported by level one evidence.²⁰⁶⁻²⁰⁸ These interventions are organised stroke care, intravenous tissue plasminogen activator in selected people with acute ischaemic stroke, and aspirin in ischaemic stroke more generally. The implementation of all these therapies requires training and understanding in stroke pathophysiology and an understanding of the neurobiology of brain ischaemia.

The essential requirement, in addition to a skilled workforce, is an organised service termed a stroke unit or stroke team. It is a platform from which acute and rehabilitation care can be delivered to the stroke sufferer. Beyond organised care the use of aspirin in ischaemic stroke produces a modest but broadly applicable benefit. In selected people who are able to be treated in a three hour time frame from stroke onset the use of intravenous tissue plasminogen activator (tPA) can result in a significant improvement, with up to 15% of people treated showing dramatic recovery to full independence. The use of intravenous tPA requires coordination of care across the continuum between the community, ambulance services, emergency departments and stroke units. The narrow time frame in which this treatment is effective means that support structures, such as brain imaging, must be available for its safe use.

Blood pressure and stroke

The single most important modifiable risk factor for stroke is blood pressure. Over a surprisingly large range of usual blood pressures (diastolic greater than 70mmHg), a higher blood pressure is associated with a higher risk of stroke.^{194,195} The association between higher blood pressure and a greater risk of stroke has also been seen in people who have

survived an ischaemic stroke or TIA.²⁰⁹ In the frailer stroke population the use of multiple medication needs to be balanced by the side effects of polypharmacy and major problems such as falls, postural hypotension and renal dysfunction.

Atrial fibrillation and stroke

Atrial fibrillation is a major risk factor for stroke, and antithrombotic treatment reduces the risk of stroke. Warfarin is substantially better than aspirin but not as practicable. The utility and safety of warfarin in older people (especially those older than 80 years) is not established.²¹⁰ Warfarin is still the preferred drug of choice for the secondary prevention of stroke for people with AF and TIA or ischaemic stroke.²¹¹ For those to whom warfarin can be safely given, and with appropriate caution in the very elderly, warfarin should be used to prevent stroke due to atrial fibrillation. Safer anticoagulant medication and more trials including elderly people are required.

Carotid stenosis and stroke

Carotid stenosis, or narrowing of the carotid artery, is a risk factor for stroke. The risk is greater if the stenosis is in the same arterial distribution as the TIA. Successful stroke prevention depends on urgent multidisciplinary assessment of potential carotid territory TIA's and AFx.

Access to safe surgery

Local vascular surgery results must be continuously monitored.²¹²⁻²¹⁵ Two large international randomised controlled trials have demonstrated that people with asymptomatic carotid disease also benefit from surgery provided they have a reasonable life expectancy and access to safe surgery.^{216,217} There is no evidence to support a policy of population screening for asymptomatic carotid disease. It is also unknown whether surgery for asymptomatic disease would remain better than best medical care if appropriate maximal medical therapy (cholesterol reduction, antithrombotic treatment and blood pressure lowering) was universally applied.

Heart failure

The diagnosis of heart failure is often not made until the person presents with overt symptoms. This is because symptoms of fatigue and dyspnoea (shortness of breath) can easily be confused with other clinical conditions and are often attributed to ageing.²¹⁸

The National Heart Foundation of Australia and the Cardiac Society of Australia and New Zealand (NHFA/CSANZ) guidelines determine that the role of clinical investigations in CHF is to:

- confirm the clinical diagnosis
- identify a cause
- distinguish exacerbating factors and reversible causes
- guide therapy
- determine prognosis.²¹⁹

Key investigations in CHF management include electrocardiography, echocardiography, chest x-ray and assessment of biochemical and haematological parameters.^{220,221}

As in many chronic conditions, the quality and extent of diagnosis and referral in the early stages of illness is dependent upon general practitioner diagnosis and referral. The research identified several barriers in heart failure treatment²²², including the need for more information on the benefits of new tests or medicines (both for general practitioners themselves and for educating their patients), and for practical information on initiating and optimising complex therapies. External factors, both real and perceived, such as access to echocardiography services, as well as patient issues, such as age, mobility, cost and perceived willingness to comply, also affected implementation of best practice. These data

highlight the need for strategies aimed at bridging the gap between what the evidence suggests and best practice in CHF management.

Peripheral vascular disease

Abdominal aortic aneurysm

Abdominal aortic aneurysm (AAA) is an enlargement of the abdominal aorta, which if not repaired, can rupture. The overall mortality rate for ruptured AAA is estimated to exceed 80%. Mortality rates can be reduced to 1–5% if the aorta can be repaired before rupture occurs.

The incidence of AAA in screening programs ranges from 5–10% in males aged between 65 and 80 years of age.^{223,224} There is now good evidence of the benefits of AAA ultrasound screening in high risk groups²²⁵⁻²²⁸ and all males at age 65 years.^{224,229-233} High risk groups include siblings and offspring of people with AAA, people with aneurysms at other sites, smoking, hypertension, narrowing of the carotid artery, peripheral or coronary artery disease, and some other disorders of connective tissue.

Studies have demonstrated the cost effectiveness²³⁴⁻²³⁹ of such a screening strategy and the benefits in terms of reduction in mortality from ruptured AAA.^{229,239-243} Recently in the USA, the US Preventive Service Task Force (USPSTF) has recommended screening at age 65 years for all males.²⁴⁴ Screening women for AAA is neither clinically indicated nor economically viable^{245,246} except for those with first degree relatives suffering from AAA.

Ultrasound screening of the abdominal aorta to detect AAA in high risk groups and a one off screening of all males at age 65 years is now appropriate and justified by the available evidence.

Rheumatic heart disease

Acute rheumatic fever

Although there are occasional cases of ARF that are very mild or even subclinical, almost all people with RHD will have had an earlier episode of symptomatic ARF. Many of these episodes, however, remain undiagnosed. In the Top End of the Northern Territory, for example, 43% of Indigenous people with RHD in 1995 did not have a prior diagnosis of ARF.²⁴⁷

ARF diagnosis is currently guided by the updated Jones Criteria²⁴⁸, requiring the presence of either two major or one major and two minor manifestations of the disease, plus evidence of a recent GAS infection for a diagnosis of ARF. A WHO Technical Advisory Group has made recommendations about how the Jones Criteria should be applied to people with potential recurrent episodes of ARF.²⁴⁹ The NHFA/CSANZ Best Practice Guidelines Writing Group is developing separate diagnostic guidelines for high risk and low risk populations.

People with ARF require long term follow up to detect the presence of chronic valve lesions.²⁵⁰ As diagnosis of ARF improves, and with the introduction of coordinated, register-based control programs, it is hoped that most cases of RHD will be detected in this way.

Rheumatic heart disease

Most cases of RHD are currently detected in people who either have no documented history of ARF, or in whom ARF episodes did not lead to long term follow up.²⁴⁷ The 64% increase in RHD prevalence in Top End Indigenous people between 1998 and 2003 occurred predominantly in previously undiagnosed ARF.^{28,251} This situation may be improved by routine auscultation of Indigenous Australians whenever they present for medical care and raising awareness among health staff of the clinical features of RHD and high risk subgroups.

The NHFA/CSANZ are currently sponsoring the development of National Best Practice Guidelines for Management and Secondary Prevention of Rheumatic Fever and RHD, which will facilitate uniformity of management recommendations around the country.

Chronic kidney disease

As an individual can lose up to 90% of kidney function before symptoms of CKD appear, it is important that the public and health professionals do not wait for signs and symptoms before testing for kidney disease. Early diagnosis of CKD, combined with appropriate evidence-based therapeutic intervention, provides the greatest opportunity for the preservation of kidney function.

Many of the known complications of CKD, such as hypertension, osteodystrophy, anaemia, sleep apnoea, cardiovascular disease, hyperparathyroidism and malnutrition, are often already evident at mild levels of CKD.²⁵² A recent review of available level I and level II evidence confirmed that the progression of CKD can be slowed by adequate blood pressure control, administration of statins, cessation of smoking, correction of uraemic anaemia with erythropoietin, glycaemic control, and early referral to a renal unit providing multidisciplinary patient education.²⁵² It is imperative, therefore, that health professionals be aware of the evidence and of treatment guidelines and services available to ensure the provision of optimal care.

Kidney Check Australia Taskforce (KCAT) is a national program of Kidney Health Australia that focuses on up skilling general practitioners in the early detection and management of kidney disease. In Australia, 15% of general practitioners have attended a KCAT workshop, and evaluations have indicated a significant increase in knowledge of kidney disease immediately following the workshop.²⁵³

Diabetes

People with heart, stroke and vascular disease have a high prevalence of previously undiagnosed diabetes mellitus (DM) or impaired glucose tolerance (IGT)²⁵⁴, both of which are risk factors for future cardiovascular events.²⁵⁵

People with heart, stroke and vascular disease should have their blood sugar levels assessed using procedures commensurate with currently available best practice guidelines for the diagnosis of DM and IGT. Subsequent management of these conditions should also concur with appropriate management guidelines.

Diagnostic Tools

Imaging

Central to well organised stroke unit care is access to neuroimaging support, particularly CT scanning, to allow early definition of stroke pathophysiology and vascular imaging with various modalities including ultrasound, CT scanning and MR imaging. Vascular imaging allows further definition of stroke mechanisms and guides rational secondary prevention. Additional cardiac imaging and the capacity to investigate rare potential causes of stroke such as blood dyscrasias, and genetic conditions, are also required.

Echocardiography

Echocardiography, or cardiac ultrasonography, is a valuable non-invasive tool for imaging the heart and surrounding structures. It supports the clinical examination to identify many cardiac anomalies and guide appropriate further diagnostics and interventions. Technical expertise in performing and interpreting the echocardiographic examination are prerequisites to the valid use of this clinical tool.

Echocardiography has become the gold standard for diagnosis of RHD, and has the advantage of being able to detect subclinical rheumatic carditis.²⁵⁶ The procedure can confirm the type and severity of valve lesions, the presence and severity of associated

cardiac abnormalities and the presence of rheumatic heart valve disease. Echocardiography also has a critical role in the clinical follow up of Indigenous Australians with RHD, and is an essential tool for the ongoing management of ARF/RHD in Australia.

The cost of and access to echocardiography services, particularly in rural and remote Australia²⁰, often preclude active detection of high risk individuals. Services are often confined to specialist cardiology practices, and even if these services are accessed, there is often a need for expert consultation to aid in interpretation and planning of ongoing care. This underscores the need for telemedicine consultation, peer support for clinicians and the development of designated clinical networks to support clinical investigation using echocardiography.

The availability of portable echocardiography and the increasing focus on provision of medical specialist services to remote communities means that all Australians with RHD should have access to echocardiographic examination for diagnosis and at the recommended intervals for ongoing management.²⁵⁰

People will receive the information and support they need during initial diagnosis and referral

Optimal Services: People will be provided with information about the short and long term implications of their diagnosis and about the next steps, including options available for managing their condition.

Culturally appropriate information and support will be available.

There will be established care and referral pathways to support timely access to appropriate services and ensure people receive the best care and support during the early stages of their condition.

Information and support

After receiving their diagnosis, people need evidence-based information about the condition, including its prognosis and the options for management. As people may have difficulty understanding or absorbing this information, it is preferable to provide written material as an adjunct to verbal information.²⁵⁷

Clearly, health care services and health professionals have a responsibility to provide appropriate and evidence-based information and support at the time of diagnosis. In addition, there are numerous national non-government organisations which provide people newly diagnosed with heart, stroke and vascular disease and chronic kidney disease, their carers and health professionals with information and support. The peak organisations are:

- The National Heart Foundation of Australia
- Diabetes Australia
- Heart Support Australia
- Kidney Health Australia
- National Stroke Foundation.

The Australian and State and Territory Government health websites and publications are a rich source of information about disease prevention and support services.

People will have access to information that enables them to participate in care decisions

Optimal Services: People will receive consistent, evidence-based information about their condition, options for treatment, and opportunities to slow disease progression and disability.

People will have the opportunity to participate in decisions about their care, and access to decision aids to help them make informed decisions.

Information will be tailored to suit different language and literacy needs, and will be culturally appropriate.

Shared decision making

Treatment of chronic conditions involves complex and long term partnerships between affected individuals, health professionals, and other people and organisations that assist with providing ongoing care and support. A key element in effective service provision for people with heart, stroke and vascular disease is the involvement of people with the conditions and carers in decisions about care.²⁵⁸

Shared decision making involves health professionals and people with heart, stroke and vascular disease working together to consider treatment options within the context of people's unique values, goals and capabilities.^{259,260} The ability, desire and confidence to participate in decision making varies between individuals.²⁶¹ Whereas some people wish to take sole responsibility for decision making, others want little to no involvement in decisions about their care.²⁶²

People with these conditions may have different thresholds for treatment than their health advisers. A Canadian study²⁶³ found that people were significantly less likely to want antihypertensive treatment than were their physicians, particularly when the baseline risk was low. A similar investigation in the UK²⁵⁷ showed that doctors were willing to accept treatment at lower absolute risk levels than their patients when attempting to reach joint decisions on initiating antihypertensive therapy.

People who participate actively in decision making, by providing more information, asking more questions and expressing their opinions, are more likely to feel in control over their health, understand and adhere to the agreed plan of care, attend appointments, and experience better health outcomes than people who delegate responsibility for decision making to others.^{259,264}

A participative approach to communicating with people to identify their care needs is promoted in the guidelines developed by the Royal Australian College of General Practitioners to support the Sharing Health Care initiative.²⁶⁵

Some of the elements of participatory decision making have been suggested by von Korff²⁵⁸—collaborative problem definition, goal setting and planning, self-management support and active, sustained follow up.

Information and communication

There is growing demand from consumers for information to help them participate effectively in their own care, as well as a growing awareness among health professionals of the need to provide information in a format that best meets individual needs.

The availability of good quality information is pivotal to the decision making process.²⁶⁶ While the simple provision of information is not enough to enable participatory decision making, people want to receive accurate information about their condition, their prognosis, and the options for treatment from a credible source, irrespective of how they choose to use it.^{267,268}

The type of information needed will vary between individuals depending on their circumstances, the nature of the intervention required, and the risks associated with intervening or not intervening.²⁶⁹ Disclosure of information about a health condition and options for its treatment, coupled with exploration of the values, experiences and expectations of the patient, is a key element of patient-centred care, and the basis for shared decision making.^{11,262}

The quality of professional-patient communication during clinical assessment and discussion of treatment and prognosis impacts on people's health and quality of life outcomes. For example, when specific communication skills are used effectively, doctors identify their patients' problems more accurately; and people are more satisfied with their care, better understand their condition and treatment options, report greater adherence with treatment and other self-management behaviours, and experience less psychological distress. These communication skills include: active listening techniques, avoiding information overload, validating interpretation, the use of plain English, reinforcement of verbal explanations with other material, and avoiding discussion if the person receiving care is unreceptive or distressed.^{267,269}

To help meet their needs for information, many people search for health information via the Internet. The difficulty in distinguishing reliable information on the Internet has been recognised, and resources are available to guide Internet surfing. They include *How to access health information online*, developed by the Australian Government Department of Health and Ageing.²⁷⁰

Rural Australians have difficulty gaining access to health information, and prefer to receive information in a range of formats through a range of sources, particularly local, independent, convenient, and inexpensive services, such as Freecall telephone numbers.²⁷¹

Tailored information

Cultural and social diversity have an impact on communication. It is important for health professionals to be sensitive to the potential for communication problems that may arise from differences in the language or culture of their patients, and to attempt to tailor information and their communication with patients accordingly.²⁷⁰

There is currently a paucity of culturally appropriate written information that meets the broad range of language and literacy needs of people with heart, stroke and vascular disease, although some useful information resources are currently available on the Internet (<http://www.mhcs.health.nsw.gov.au/>). The majority of health information is produced in English, and direct translations are often inaccurate or not relevant to people from different cultural and language backgrounds.

A website has been created to support improved communication between health staff and their Indigenous clients (www.sharingtruestories.com/index), with funding from the Australian Council for Safety and Quality in Health Care. The site content is based on a Cooperative Research Centre for Tropical and Aboriginal Health research project *Sharing the True Stories: Improving Communication between health staff and their Aboriginal patients*. The Web site aims to promote cultural awareness by making relevant information available.

Systems will be in place to support timely access to high quality care

Optimal Services: There will be capacity among health and other care providers and community services to respond in a timely manner to the care needs of people with newly diagnosed heart, stroke and vascular disease. This response will reflect the best available evidence and be consistent with established care and referral pathways.

Provision of high quality care

Coronary Heart Disease

Secondary prevention in people with coronary heart disease, stroke and vascular disease should begin at the moment of diagnosis and certainly at discharge from hospital. Cardiac rehabilitation programs are available after discharge as one component of secondary prevention. The NHFA/CSANZ have published guidelines for preventing cardiovascular events in people with coronary heart disease.¹⁵⁸ These guidelines focus on caring for

patients through lifestyle management, medication and continuing prevention advice after the patient leaves hospital—based on the assessment of the patient's individual needs and circumstances. This care can best be provided through hospital or community-based cardiac rehabilitation programs, together with ongoing partnership with the patient's general practitioner and/or other health professionals.

In particular they emphasise smoking cessation, healthy eating, alcohol intake, physical activity; and weight, blood pressure, blood lipids and diabetes management, as well as addressing psychosocial issues. Other points made include:

- Any improvement in risk factors and movement towards the ideal risk factor 'goals' and 'targets' will be beneficial. Risk factor modification should be considered as a total package so that, for example, attention is not diverted from addressing smoking cessation while treating dyslipidaemia, hypertension and diabetes.
- Diabetes, renal impairment, and non-coronary heart disease manifestations of atherosclerosis such as cerebrovascular disease or peripheral vascular disease indicate higher risk for coronary events. People with coronary heart disease should be screened for these conditions and managed appropriately.
- It is important to monitor and support adherence to lifestyle advice and medications on an ongoing basis and, where appropriate, to consider using ancillary measures, such as special clinics or telephone support services.

Heart failure

For people with heart failure, medication and treatment issues are paramount in the early stages. People with heart failure often have problems adhering to their medication and other treatment requirements. Poor compliance and physician error with medication plans frequently leads to re-hospitalisation. Twenty five percent of the estimated 90 000 heart failure related admissions in 1998 were drug related hospitalisation events.²⁷²

Specialist heart failure treatment programs have been shown repeatedly to optimise health outcomes and quality of life for people with heart failure. Key features of these programs are implementation of evidence-based therapies, promotion of self-care and improved coordination of care. The application of multidisciplinary programs of care to older people after they leave hospital has been shown to significantly reduce subsequent morbidity and mortality.²⁷³⁻²⁷⁶ Substantial cost savings, mainly through avoidance of hospitalisation, have also been documented for these programs.²⁷⁶

Stroke

Following stroke or TIA, the highest risk period for recurrent events is within the first few weeks following the initial event. Up to 10% of people will suffer a recurrent event within the first month. For people who suffer their first stroke, and survive at least two days, the proportion having another event in the first six months is 9%, and in the subsequent five years is 15%.²⁷⁷

This indicates that early admission to a stroke unit, investigation on stroke pathophysiology and early use of appropriate secondary prevention is crucial in maximising risk reduction. In most health care settings nationally there is limited understanding of the time urgency of stroke secondary prevention, and health systems are not organised to provide prompt access to appropriate imaging, other investigations and clinical consultations. Identification of modifiable risk factors during the early stages is, therefore, critical to ensuring the initiation of appropriate evidence-based secondary prevention measures, and the provision of appropriate educational advice and support.

A number of models are described^{278,279} and have been published indicating that access can be improved with the establishment of rapid response outpatient clinics or enhanced support for primary care practitioners to implement early stroke prevention.

Peripheral vascular disease

People with intermittent claudication (calf pain on walking) are at two to four times greater risk of dying from the complications of generalized atherosclerosis than similar people without claudication. Studies of people presenting with claudication show that within 10 years, 43% will develop CHD, 24% will have heart failure and 21% will suffer a stroke. The aggressive treatment of risk factors for heart, stroke and vascular disease can slow this progression.²⁸⁰

There is convincing data indicating that physical activity programs can produce clinically significant improvements in exercise performance and community-based walking ability. However, physical activity can range from the physician recommending unsupervised walking in the community to a formal supervised exercise program on a treadmill. Several studies suggest that some level of supervision is necessary to achieve optimal results.²⁸¹ In prospective studies of supervised exercise conducted for three months or longer there are clear increases in treadmill exercise performance, and a lessening of claudication pain severity during exercise.^{282,283}

Exercise rehabilitation also has the potential to favourably modify other cardiovascular risk factors.²⁸⁰ Numerous trials provide evidence that the walking capacity and overall functional status are increased by physical activity training in patients with disabling claudication. The most effective programs are supervised, employ walking exercises, and last three to six months. Maintenance of regular physical activity, whether supervised or not, needs to be continued indefinitely or the benefit will eventually be lost.

The TransAtlantic Inter-society Task Group has published a comprehensive guideline for the management of peripheral vascular disease.²⁸⁰

People will have access to education, information and support to help them improve their health

Optimal Services: People will have access to self-management education programs that can help them develop the knowledge, skills and confidence to attend to their daily care and support needs.

Services will be provided in a way that facilitates and supports long-term management.

Programs and services will be available in the community to help people adopt and maintain a healthy lifestyle. Health professionals and other care providers will be aware of the services available in their community.

Self-management

People with heart, stroke and vascular disease play a central role in the ongoing management of their conditions, and there is a need to encourage them to take control of and assume responsibility for their health^{258,284}—including daily symptom management, behaviour and role adaptation, and management of the psychosocial aspects of living with a chronic illness.²⁸⁵ People with these conditions may need education and support to help them optimise their ability and effectiveness to self-manage.

The WHO promotes health self-management as a key element in the global chronic disease strategy.²⁸⁶ Self-management can be supported through education programs; the development of written, individualised management plans to guide self-management at home; and planned, periodic review.

In the UK, the Expert Patient Program, developed to improve the treatment of people with chronic conditions, provides accredited, local, self-management education programs.²⁸⁷ Preliminary results of this approach show a need to raise awareness of the program among health professionals and the public, and a need to target local programs to population sub-groups, particularly marginalised groups.²⁸⁸

Self-management is a major focus of the Australian Government's Sharing Health Care Initiative, which aims to improve the quality of life of people with chronic conditions. The initiative comprises demonstration projects testing a range of chronic condition self-management models, including Indigenous specific projects, and education and training of health professionals and people with chronic conditions. To support the demonstration projects, guidelines on self-management have been developed for general practitioners and other health professionals. Education and training support are being provided in the form of a post graduate education module and training programs on chronic conditions for health professionals and other care providers.²⁸⁹ As part of the initiative, work is underway to develop self-management education programs that are culturally appropriate and designed for delivery in Indigenous communities. The national evaluation of the Sharing Health Care Initiative has been completed and will feed into future strategies and programs.

Over the past eight years, Battersby and colleagues have developed The Flinders Model, which is an approach to self-management that can be applied to a wide range of chronic health conditions. It provides a structured, patient-centred framework for collaborative problem definition, goal setting, care planning and review between an individual and their health professional. A semi-structured, self-initiated assessment is a core element of the chronic care model. (www.som.flinders.edu.au/FUSA/CCTU/home.html).

The National Stroke Foundation is developing and piloting a self-management program to meet the specific needs of stroke survivors.

People who benefited most from this approach were those not previously linked with services, lacked knowledge of their condition, were depressed, lacked motivation to change behaviour, and had lifestyle risk factors or poorly controlled conditions.²⁹⁰

Reducing the Risk of Subsequent illness

People who have previously had a heart attack, stroke, angina or atherosclerosis are at increased risk of subsequent cardiovascular events. The risk for these people is increased even further by having multiple risk factors and they should, therefore, be particular targets for secondary prevention.

Nutrition

People with heart, stroke and vascular disease should establish and maintain a diet which includes fruits, vegetables and legumes (dried peas, beans and lentils) and grain based foods, especially wholegrain, such as bread, pasta, noodles and rice. An example of an appropriate diet, the Mediterranean diet, also includes moderate amounts of lean meats, poultry and fish as well as reduced fat dairy products.^{291,292} The benefits of this diet include improved lipid profile, weight reduction, lowering of blood pressure and reduced insulin resistance.

Overweight and obesity

It is recommended that individuals with heart, stroke and vascular disease establish and maintain a BMI (body mass index, weight/height²) between 18.5 and 24.9, and a waist circumference of <94cm in males and <80 cm females.^{293,294} General practitioners should regularly monitor these two parameters and, when necessary, recommend an intervention that is consistent with guidelines and/or the best available evidence. This may consist of dietary recommendations (to restrict energy intake), modification of physical activity levels, and referral to a dietitian to facilitate weight loss.

Physical activity

Regular physical activity plays an important role in reducing the subsequent risk of early or premature death from all causes, as well as the incidence of and mortality from heart, stroke and vascular disease.^{70,295} It is recommended that people with heart, stroke and vascular disease participate in 30 minutes of moderate physical activity at least five days a week, where moderate is defined as activity that results in a slight increase in heart and respiratory rate and some light perspiration, but where the patient is not panting and can still maintain a conversation. More frequent activity is preferable, as there is evidence of a greater benefit with greater duration of activity.^{70,295}

Tobacco smoking

Cessation of smoking is one of the most powerful secondary prevention strategies²⁹⁶⁻²⁹⁸, and individuals with heart, stroke and vascular disease and their families should be strongly encouraged to cease smoking. The risk of subsequent MI is 50% higher for those who continue to smoke after an episode of MI.²⁹⁹⁻³⁰¹ Cessation of smoking has been linked with a 50% reduction in re-infarction rate and mortality at one year.^{302,303} Recommendations in respect of cessation of smoking need to be consistent with guidelines and currently available best practice evidence.

Alcohol

There is good epidemiological evidence that the voluntary intake of a moderate quantity of alcohol is beneficial in terms of cardiovascular morbidity and mortality.³⁰⁴ However, it is not recommended that abstainers take up alcohol consumption, nor that moderate drinkers be advised to increase their intake to prevent the progression of CHD.¹⁵⁸

Alcohol increases systolic blood pressure and diastolic blood pressure in both men and women, and the increase in blood pressure is dose dependent.³⁰⁵ People with hypertension who drink alcohol should limit their intake to two standard drinks for men and one standard drink for women.¹⁵⁸

Psychological and social factors

Depression, social isolation and lack of social support are independent risk factors for heart, stroke and vascular disease.³⁰⁶⁻³¹⁰ The increased risk posed by these factors is comparable to that conferred by conventional risk factors such as smoking, dyslipidaemia and hypertension.³¹¹

The prevalence of depression among people with heart, stroke and vascular disease has been estimated to be 35%.^{158,312} Consequently, people with heart, stroke and vascular disease should be screened for depression and, if indicated, treated according to currently available guidelines or best practice evidence. Physical activity can reduce risk for subsequent cardiovascular disease and depression.

Cardiac rehabilitation does assist in ameliorating the impact of social isolation and lack of social support on the progression of heart, stroke and vascular disease.^{311,313,314} There are opportunities to improve outcomes for people with heart, stroke and vascular disease by close attention to lifestyle and behavioural factors.

Written, individualised management plans to promote optimal, shared management

Optimal Services: Written, individualised management plans will promote shared involvement in the early and ongoing treatment of people with the conditions. Plans can include an outline of the agreed treatment goals and evidence-based interventions, and self-management strategies including measures to prevent avoidable declines in health status, and lifestyle changes to improve health outcomes.

Individualised management plans will outline arrangements for planned contact with health professionals and other care providers as a means of supporting self-management, and to promote proactive care of people with the conditions.

The written plan will be available to people with the conditions and their carers, and reviewed and revised as needed in collaboration with health professionals and other care providers in response to changing health needs.

Written, individualised management plans

Written, individualised management plans, developed collaboratively by people in the early stages of their condition, their health professionals and other care providers, can outline a plan of care, together with strategies for the day-to-day self-management of a specific condition. Written, individualised management plans are based on self-management principles, and may include an action plan for acute episodes, an agreed plan of management, and arrangements for planned review. The aim is to provide written information for use by patients and their carers to guide optimal treatment of the condition at home. A written plan is one of the key elements of effective chronic illness care, as it involves the patient and promotes optimal, evidence-based care.³¹⁵

Written, individualised management plans should be developed early in the course of heart, stroke and vascular disease, to promote a proactive, long term approach to care. They should be patient centred, and should consider individual attitudes, beliefs and coping mechanisms. Management plans that include individual preferences are more likely to result in satisfied patients who agree with and adhere to the agreed plan.²⁵⁸

Care and Referral Pathways

Stroke

Clinical support systems, such as clinical pathways and referral systems for stroke care, are not widely used in Australian health care. A number of studies have examined reorganisation of stroke care guided by clinical pathways. They have demonstrated improved efficiencies and improvements in surrogate clinical outcomes for stroke care. The *Towards a Safer Culture* clinical support system project by the Royal Australasian College of Physicians and the NSW and Australian Governments focused on access to acute stroke care and acute stroke therapies. Care pathways for stroke commencing in the emergency departments have been implemented. They are still under evaluation but have demonstrated improvements in access to organised stroke care in hospitals, improvements in efficiencies, improvements in appropriate utilisation of CT scanning, and reduction in stroke complication rates in the inpatient setting.³¹⁶

The National Stroke Foundation has developed an evidence-based care pathway that encompasses all stages of stroke care.

Chronic kidney disease

Current Australian guidelines indicate that adequate preparation for dialysis or transplantation (or both) requires at least 12 months of frequent contact with a renal care team.³¹⁷ Early referral of people with CKD to a renal unit is associated with a reduced rate of decline in kidney function, a decreased need for and duration of hospitalisation, reduced initial costs of care following the commencement of dialysis, and decreased patient morbidity and mortality.³¹⁰ Data from the Australian and New Zealand Dialysis and Transplant Registry indicate that 26% of all people receiving dialysis or kidney transplantation do not see a nephrologist until less than 90 days before dialysis starts.³¹⁸

Key issues in the provision of high quality care for people with CKD relate to the availability of diagnostic and treatment services. In rural and remote Australia, in particular, there is evidence to suggest a lack of specialist (nephrologists and renal nurses),

local general practitioner and ancillary services. For example, Western Australia has one of the lowest proportions of nephrologists in Australia and the second highest incidence rate for end-stage kidney disease.³¹⁹

Findings from a chronic disease public consultation process in rural and regional Victoria also indicated high levels of dissatisfaction with the availability of diagnostic and treatment services outside the metropolitan area.³²⁰

CHAPTER 7. Care and Support During Acute Episodes

In 2002, an estimated 96 000 coronary heart disease and stroke events claimed the lives of almost 40 000 Australians. The burden of heart, stroke and vascular disease is especially significant for Indigenous Australians, for whom the stroke rate is twice as high and the coronary heart disease rate is 2.6 times as high as for non-Indigenous Australians.¹⁹

People with acute coronary syndromes and stroke require both an emergency response and appropriate risk assessment with suitable ongoing acute and multidisciplinary care.³²¹⁻³²³ Most people present with less severe disease. The cornerstones of optimal acute care include: rapid clinical presentation to a health care facility able to initiate care; prompt and accurate diagnosis and risk assessment, early brain scanning for people with stroke, timely delivery of life sustaining therapies, early invasive treatment, and appropriate medicines.

PEOPLE'S NEEDS

People with heart, stroke and vascular disease experiencing an acute event need:

- timely access to effective acute care services regardless of where they live or their cultural and linguistic background
- seamless, high quality care that is consistent with the best available evidence
- access to health care that is acceptable, accountable and appropriate
- information about their treatment options and expected outcomes, including risks and implications of acute treatment
- the opportunity and encouragement to discuss their concerns and feelings and receive support, if necessary, for themselves and their families
- coordinated discharge or care planing to minimise potential complications related to moving from the acute sector back to the community.

CRITICAL INTERVENTION POINTS

1. Develop systems to improve the coordinated, multidisciplinary care for people with heart, stroke and vascular disease, including appropriate care plans, defined referral pathways and designated coordinators of care.
2. All people with stroke will receive stroke unit care or, in rural or remote areas, alternate models of organised stroke care.
3. People attending hospital with suspected or confirmed coronary heart disease will receive timely and appropriate treatment to relieve their symptoms and reduce their risk of subsequent coronary events. People at high risk will be managed in a coronary care facility.
4. People who develop symptoms of stroke will have timely access to CT scanners for accurate diagnosis.

5. Improve access to treatment services for all Australians, particularly those living in regional, rural and remote areas and Aboriginal and Torres Strait Islander people.
6. Data will be collected, analysed and disseminated on a national basis to ensure the safety and quality of evidence-based treatments is optimised and to create a continual quality improvement loop.

OPTIMAL SERVICES AND RATIONALE FOR CRITICAL INTERVENTION POINTS

Timely and effective acute care services will be available, regardless of where people live

Optimal Services: People with acute heart, stroke and vascular disease will have access to relevant acute care expertise and facilities regardless of where they live. People with MI will have access to emergency services with the capacity to stratify risk, implement effective out-of-hospital care, and transfer to the most suitable centre for ongoing treatment.

Facilities for high quality intervention therapy will be available.

People with stroke will have access to hospitals with stroke units or other appropriate models of organised stroke care and brain imaging facilities.

Models of service provision will ensure that people with acute heart, stroke and vascular disease in regional, rural and remote areas and Aboriginal and Torres Strait Island communities can access high quality care through links (such as telehealth) established between smaller centres and large specialist centres. This could be achieved by using fixed-care protocols and a 24 hour–7 day a week on-call cardiology service or direct links to the nearest stroke unit.

People will receive timely transfer to the most appropriate facility to manage their ongoing care. Adequate support for travel and accommodation will be provided for individuals and families who need to travel for treatment.

Coronary heart disease

Sudden Cardiac Death

Sudden death from cardiac causes is estimated to account for approximately 50% of all deaths from cardiovascular causes.³²⁴⁻³²⁶ The majority of such sudden deaths are caused by disturbances of heart rhythm, often triggered by acute coronary events, which may occur in persons without known cardiac disease or in association with structural heart disease.³²⁵⁻³²⁷

Epidemiologic data indicates that structural coronary arterial abnormalities and their consequences are the cause of 80% of fatal arrhythmias.³²⁵⁻³²⁸ Common cardiovascular risk factors, such as cigarette smoking, hypertension, and hyperlipidemia are easily identifiable markers of an elevated risk of sudden death from cardiac causes.³²⁵⁻³²⁷ Their limitation is that they primarily identify the risk of the underlying disease that may be responsible for sudden death, rather than the risk of the event immediately responsible for death. The usefulness of conventional risk factors in identifying high risk subgroups in epidemiologic terms is unquestionable, and it is likely that active interventions aimed at prevention will influence some of these risk factors and reduce the number of fatal arrhythmic events.

Clinical trials have shown that antiarrhythmic drug therapy is not effective in reducing mortality among patients who are assumed to be at risk for such death³²⁹⁻³³¹, but some trials have demonstrated a survival benefit in high risk patients of therapy with an implantable cardioverter-defibrillator, as compared with conventional drug therapy.³³²⁻³³⁴ However, the majority of sudden deaths occur among patients who do not have the characteristics that would have led to their inclusion in trials of implantable defibrillators.

A large randomised trial of Public Access Defibrillation (PAD) in the United States and Canada showed that surviving to hospital discharge after experiencing an out-of-hospital cardiac arrest was doubled if people received cardiopulmonary resuscitation (CPR) plus an automated external defibrillator (AED), rather than receiving CPR alone.³³⁵ In 24 centres across the United States and Canada, 993 community units, composed of 1260 individual facilities, trained more than 19 000 layperson responders in CPR only or CPR + AED. Intense focus on facility infrastructure, including responder recruitment and training, communication, evaluation, and oversight, was necessary for implementing the emergency response systems for the trial. Use of an AED within this structured response system can increase the number of survivors to hospital discharge after an out-of-hospital cardiac arrest. Trained nonmedical responders can use AEDs safely and effectively.

A review commissioned by the Australian Government concluded that PAD has potential to improve the survival following cardiac arrest occurring out of hospital.³³⁶ However, there remain several issues which would require further investigation in the Australian context. Experience in the UK suggests that this would involve:

- adopting a national approach, with appropriate clinical advice, to this issue
- achieving government and financial support for the scheme
- involvement of the community
- integration with emergency medical services
- training
- data collection and program evaluation.

Pre-hospital care

The acute coronary syndromes (ACS) represent a range of clinical presentations, from first onset of chest pain (angina), chest pain at minimal exertion, to heart attack and its consequences.

The key opportunity to prevent deaths from ACS is to reduce the time taken for people to present to a health care facility.³³⁷⁻³³⁹ It is estimated that over 70% of coronary deaths in males and 55% of coronary deaths in females occur before the person reaches hospital³⁴⁰, and that 50% of heart attack patients delay seeking treatment by more than six hours.³⁴⁰ Cardiac causes account for over 60% of ambulance attendances for chest pain, and 1.5% of these people will experience an out-of-hospital cardiopulmonary arrest.³⁴¹

Patient recognition and response time

In the case of myocardial infarction, delays in response time in calling for help have been considered the 'weakest link' in the chain of survival. Delays in response time are most likely among elderly people, females, people for whom English is not the first language, and people who fail to use emergency services as their point of first contact when symptoms present.^{143,342-345} Overseas data suggest that delays are most likely due to a misinterpretation of symptoms, the underestimation of personal risk, particularly in women, 'blunting' or dulling of symptoms in the elderly, and minority groups feeling uncomfortable about accessing emergency services.³⁴⁶

There is only limited evidence on strategies to improve patient response times. Public health programs designed to increase awareness of symptoms do increase the use of emergency ambulance services, but have not been shown to reduce the time from symptom onset to hospital presentation, or to result in more rapid administration of effective intervention therapy.^{339,347-350}

Emergency services and transfer destination

With the Australian population distributed over metropolitan, rural and remote locations, substantial amounts of time may be taken to transfer people to the nearest suitable facility. The delay between ambulance service assessment and presentation to a suitable facility

represents a critical point where treatment may be improved. For example, ambulance services can potentially direct high risk patients to centres where suitable facilities are known to be available. En-route notification of these centres has been shown to reduce the time taken between arrival at hospital and initiation of effective intervention therapy.^{351,352}

Paramedic support: Electrocardiograph (ECG) and Pre-hospital Fibrinolysis

The time between initial assessment and transfer to a suitable facility will still be prolonged for some people, particularly those residing in rural or remote communities. These people may benefit from administration of pre-hospital intervention (for example, fibrinolysis, intravenous therapy designed to 'break up' clots), a strategy that will require the availability of suitable ECG recording and transmission capabilities within all ambulance vehicles, and on-call medical support for interpretation of a patient's clinical state and ECG (level 3).

Although significant improvements in mortality as a consequence of pre-hospital intervention have not yet been identified (level 1)^{350,353,354}, the intervention will improve time to treatment and assist decisions regarding the transport of people to appropriate institutions.

Hospital care

Current national and international benchmarks³⁵⁵ for the management of acute coronary syndromes including myocardial infarction emphasize three core principles:

- high risk patients require intensive medical management
- high risk patients should be managed with an early invasive strategy that seeks to undertake early coronary angiography and revascularisation where possible
- rural centres and other community centres that do not have the facility to offer such an invasive service should consider the early transfer of patients to centres that can offer this therapy.

There is a need to establish and foster specialized acute care centres that are capable of providing high level interventional services, such as cardiac catheter laboratories, on a regional basis.³⁵⁶ The challenge facing hospitals and catheter laboratories is managing the increasing demand, both metropolitan and rural/remote. Increased demand from regional public hospitals to transfer at risk patients to tertiary centres has occurred as clinical management has evolved to reflect the evidence base available as summarised in the national guidelines.

Hospital Access

In 2001, 34% of the total population and 70% of the total Indigenous population lived outside a major city, with 3% of the total population and 27% of the total Indigenous population living in a remote or very remote location. For these groups, distance to the nearest hospital will significantly delay access to suitable therapy.³⁴⁰ Further, tertiary care centres that perform only a limited number of invasive procedures are not able to provide a service of the same quality as urban centres with an ongoing case load.³⁵⁷⁻³⁶¹

Supportive networks have been instituted in the care of remote and rural people in South Eastern South Australia (*iCARnet*). Using fixed-care protocols, and supported by a round-the-clock on-call cardiology service facilitating delivery of intervention therapy, the expertise of tertiary referral cardiology services can be extended into the rural environment. This is supported by observational data indicating improved mortality associated with cardiological care of ACS.³⁶²

Hub and Spokes Systems of Care

A hub and spokes system of managing all severe cardiac problems, and in particular acute coronary syndrome patients, requires sufficient infrastructure and workforce at the hub hospitals to accommodate all urgent referrals, while not jeopardizing the elective waiting lists. Hub hospitals must operate at high volume, including high volumes of primary

angioplasties. People undergoing these procedures have better outcomes in hospitals doing high numbers of procedures³⁶³ and in this setting people have better outcomes than with thrombolytic or clot dissolving therapy. The time from arrival at hospital until removal of the obstruction in the coronary artery should be lower than two hours³⁶⁴, and institutions should be performing at least three of these procedures per month. Hub hospitals should not be restrained in their ability to treat urgent cases and bed access to urgent patients is essential.

People with a final diagnosis of myocardial infarction have better outcomes if cared for by cardiologists³⁶⁵, and these better outcomes are at least partly due to better adherence to professional clinical practice guidelines.

The CSANZ currently recommends that the minimum number of procedures for maintenance of competence of angioplasty operators is 75 cases per year, and for centres is 200 per year. The CSANZ also recommends ongoing audit of the centres and operators, including regular morbidity and mortality review.

Appropriate Treatment

Initial assessment and classification of a patient with suspected ACS into non-cardiac, chronic stable angina, possible ACS or definite ACS is the key to appropriate treatment. A consistently applied strategy to identify MI and to screen for unstable angina and underlying coronary artery disease is required. Current guidelines and relevant literature describe a suitable strategy^{355,366-368}, which consists of a resting electrocardiogram, biomarkers, short term observation, cardiac imaging and provocative testing.

Immediate treatment of the patient will depend on electrocardiograph diagnosis³⁵⁵ and should be consistent with currently available guidelines and/or the best available evidence. Consequently, general practitioners, other clinicians, the ambulance service, and country hospitals without appropriate cardiological expertise should ideally be able to communicate with a central facility with appropriate expertise to interpret the electrocardiogram and advise on treatment.

Discharge care

Cardiac rehabilitation programs are an essential component of the ongoing care of people presenting with ACS, with attendance linked with improved survival, compliance with medications³⁶⁹ and reduction in risk factors.^{321,370-372} The impact of these programs is limited, however, by poor attendance, especially among elderly and female patients, and people from lower socioeconomic backgrounds.^{370,372}

Strategies for increasing the reach of cardiac rehabilitation services include: home follow up programs, home self help packages, and the use of specialised cardiac liaison nurses.³⁷³⁻³⁷⁶ The efficacy of specialised cardiac liaison nurses has been validated.³⁷⁷

Stroke

Acute stroke treatment

Rational stroke treatment depends on early diagnosis and classification of the stroke syndrome. Ischaemic stroke, caused by a blockage of a cerebral artery, is the commonest type, accounting for 80–85% of all stroke events. Access to CT scanning or magnetic resonance imaging is necessary to make this diagnosis correctly. Subsequent to diagnosis, treatment should be consistent with currently available best practice guidelines and/or evidence.

Stroke units

The vast majority of people with stroke will be admitted to hospital for assessment and treatment. There is now impressive RCT and meta-analytic data to support a policy of stroke unit care for all people hospitalised with stroke.³⁷⁸ The benefits are substantial and have greater public health benefit than any other acute stroke intervention—for every 100

people treated in a stroke unit, there will be five to six extra independent survivors, and people benefit whether young or old, and whether with mild, moderate or severe stroke.

The types of stroke units that have demonstrated the greatest benefit include comprehensive stroke units, which provide an acute assessment and rehabilitation function from admission to discharge, and rehabilitation units, which provide care once the patient has been medically assessed and stabilized. There are currently few data to support the use of high dependency or acute stroke units.

The benefits associated with stroke unit care have been acknowledged in Australia in recent times with a growth in the number of specialist stroke units. The key features of these units are:

- the presence of a coordinated multidisciplinary team, usually comprising a stroke physician, nursing staff, occupational therapist, physiotherapist, speech pathologist, dietitian, social worker and, where possible, a psychologist
- staff with special interest in the treatment of stroke and who have access to ongoing professional education and training
- clear communication, including regular team meetings to discuss treatment and discharge planning
- active encouragement of those with stroke, their carer/family members to be involved in the rehabilitation process.³⁷⁹

The National Stroke Foundation has developed the Stroke Services in Australia Model to facilitate equal access to organised stroke services across Australia. Stroke Units are recommended in Category A and B hospitals. Currently only 23% of public hospitals have organised stroke services. Less than 85% of Category A and around 30% of Category B hospitals have stroke units.

There is an under provision of stroke unit care in Australia, with few units outside metropolitan areas. In some rural and remote areas, the incidence of stroke is not high enough to warrant a dedicated stroke unit and to enable staff to maintain expertise. In these circumstances, other models of care should be considered. The potential risks and benefits of a transfer to the nearest stroke unit need to be balanced against the risks and benefits of less specialised care closer to home. Many aspects of good stroke unit care could be introduced to hospitals too small to support a stroke unit. These could include the formation of a rapid multidisciplinary team and initiation of rehabilitation from the day of admission. This level of service should be routine for geriatric medicine, rehabilitation and good general medical admission units.

The National Stroke Foundation now has acute³⁸⁰ and post-acute (rehabilitation) guidelines³⁶⁹, together with a Care Pathway³⁸¹ and these can be used to guide local processes.

Discharge planning

Discharge planning is crucial for effective and efficient hospital use and successful reintegration into the community.³⁸² Successful discharge planning:

- is the culmination of a good rehabilitation program
- ensures that social isolation and the risk of depression post discharge is minimised and that independence is maximized
- relies on effective communication between team members, the person with stroke, family members, and community service providers including general practitioners
- emphasises the role of self-management in ongoing care and incorporates a self-management care plan
- occurs within the context of availability of support services and the desires of the stroke survivor and carer.

Although the transfer of responsibility for treatment from inpatient to the community is known to be difficult, insufficient attention and resources are provided to facilitate this process.³⁸³⁻³⁸⁵

Care plans

Collaborative care planning ensures that people with stroke and their families are actively engaged in the rehabilitation process. An emphasis on self-management is an important part of this process, as it encourages people to focus on their personal goals as well as medical issues and lifestyle changes. All members of the health care team, including the general practitioner, should be involved in developing and documenting the agreed care plan. As care plans are often one component of a more complex service delivery package (that may also include early supported discharge or inpatient integrated pathways), it is difficult to determine the efficacy of this specific component of care from a large number of trials.

Heart Failure

Key features of CHF are the high rates of hospitalisation^{386,387} and rehospitalisation for people with the condition. In order to improve health outcomes and quality of life for people with CHF, a key focus of CHF treatment should be avoidance of crisis admissions to hospital through the implementation of systems that support early identification of clinical deterioration, attention to psychological and social issues, and optimisation of pharmacological and non-pharmacological interventions.

Acute care for people with chronic conditions is often delivered in settings configured for care of temporary or transient health problems. It is important that services be implemented to facilitate discharge planning, and transition to the community³⁸⁸, including ongoing monitoring and review of a person's care plan. This would ensure that when crisis situations do occur, hospitalisation provides the opportunity to reflect on a person's treatment plan, review prognostic information, negotiate treatment goals, and incorporate the person with CHF into an integrated disease management program in consultation with their general practitioner and family members.

There have been almost 30 randomised studies (involving almost 5 500 participants) and many more non-randomised studies of interventions using the key principles of optimising evidence-based therapies, promotion of self-care and coordination of care. A series of meta-analyses provide high level evidence that the application of multidisciplinary programs of care to typically older patients post acute hospitalisation significantly reduce subsequent morbidity and mortality.^{273,276,386} These studies have also demonstrated improvements in health related quality of life and have also produced cost savings, mainly through avoidance of hospitalisation.²⁷⁶

Peripheral vascular disease

Acute limb ischaemia (ALI) is caused by a sudden decrease in blood supply to a limb. Symptoms usually worsen and limb viability is threatened. The treatment of ALI is an emergency situation. Minimizing any delay in relieving the occlusion is essential, because risk of limb loss increases with the duration of the acute ischaemia. In one study, the amputation rates were found to be proportional to the interval between onset of acute limb ischaemia and exploration (6% if within 12 hours, 12% within 13 to 24 hours, and 20% after 24 hours).²⁸⁰

Although review of people with ALI in a non-specialised primary care setting is inappropriate, prompt referral to a vascular specialist centre with expertise in treating people with chronic leg ischaemia is required to optimise health outcomes. Specialist centres should have access to all services required for the complete characterization and subsequent treatment according to clinical guidelines or the best available evidence.

People with chronic limb ischaemia are likely to have overt or subclinical multisystem disease. Consequently, a multidisciplinary team approach is preferable for the diagnosis, assessment, and treatment of these people.

People will receive high quality care that is consistent with the best available evidence

Optimal Services: People with acute heart, stroke and vascular disease will be confident that they are being treated according to the best available evidence and agreed national clinical practice guidelines.

Services will have systems for collecting information about an individual's care which enable an evaluation of the extent to which care is consistent with the evidence and relevant protocols.

People with acute heart, stroke and vascular disease will have access to information about the guidelines and/or the protocols used by their service providers.

Clinical practice guidelines

Clinical practice guidelines, which are systematically developed reviews of evidence to assist health professionals and people in making decisions in specific circumstances, play an important role in ensuring a consistent and evidence-based approach to clinical practice. In Australia, a range of clinical practice guidelines are available for acute care of people with heart, stroke and vascular disease.

Overseas data suggest that between 30 and 40% of people do not receive care that is based on scientific evidence.³⁸⁹ Implementation strategies are required to ensure the widespread adoption of clinical practice guidelines. Specific strategies will vary according to the particular barriers to implementation, clinical practice environments and patient groups, and may include changes in health systems, funding and policies, the knowledge, attitude or skills of health professionals; and consumer knowledge.³⁹⁰ In Australia, insufficient time, limited research skills and limited access to evidence have been cited as reasons for less than optimal use of evidence in practice.³⁹¹

Keeping abreast of advances in scientific research and incorporating such research into clinical practice is especially problematic for practitioners working in rural and remote communities. Difficulties include: obtaining evidence-based information, isolation from peers and information resources, mobility, lack of time, and limited and unreliable information technology infrastructure.

Decision support tools, including evidence-based guidelines and care pathways, standard orders and computerised access to valid and relevant evidence, have been advocated as a means for incorporating evidence into day-to-day clinical practice.³⁹² Computerised decision support provided by handheld computers has been shown to improve learning in evidence-based medicine, increase current and future use of evidence, and boost confidence in clinical decision making in medical students.³⁹³ On the contrary, complex decision support systems required for the treatment of chronic conditions have been reported to have little to no effect on either the process or outcomes of care for people with asthma and angina, and were viewed negatively by general practitioners and practice nurses.³⁹² Considerable challenges still exist to computerising guidelines in a way that supports the management of complex disease.

Integrating quality assurance and patient care

Routine evaluation of the process of care can lead to the improvement of clinical outcomes. Audit activity and quality improvement strategies in the key areas of emergency services response time, time to reperfusion therapy, safe delivery of coronary revascularization,

prescription of proven prognostic therapies and attendance at rehabilitation are essential for the optimisation of clinical care delivery to people with heart, stroke and vascular disease.

To reduce the burden and improve the accuracy of audit activity, data collection should occur simultaneously with clinical care processes, and be supported by appropriate time, technologies and staff education. Potential advantages of such audit activity are the implementation of care plans, real time risk stratification and decision support^{394,395} and, in the US and locally, improved physician compliance with clinical guideline advocated therapies and rehabilitation attendance.³⁹⁶ Similar initiatives are underway in Australia, and evidence of improved clinical outcomes is awaited.

The responsibility for assessing the care process and the burden of data abstraction resides with the clinical provider. Where possible, the activities of clinical care data collection should be merged (e.g. electronic prescribing) to reduce the burden of data collection while improving the accuracy of the data. Of potential value is the collection of outcome data including clinical events, hospitalisation and quality of life indicators, patient satisfaction and cost. If these data are sought, key clinical variables necessary for risk adjustment are also of value.

People will receive care that is acceptable, appropriate and accountable

Optimal Services: People with acute heart, stroke and vascular disease will receive services that are responsive to and reflect their unique care needs.

They will have the opportunity to provide feedback and comment about the care provided and be confident that it will be attended to, and will have access to information about the extent to which their care is consistent with agreed national benchmarks.

Aboriginal and Torres Strait Islander people and people from culturally and linguistically diverse backgrounds will receive care that is culturally appropriate.

Person-centred Care

The provision of person-centred care requires that health care services are perceived as acceptable, accountable and appropriate by the people who use them. Care is person-centred when:

- Care reflects an understanding of the unique care needs of people with chronic and complex health problems—these include people's need to receive the best treatment regimens to control disease and alleviate symptoms, and for ongoing information and support to self-manage their health.²⁶⁴
- People are supported and encouraged to provide feedback about their care and are confident that their feedback will be attended to in a timely manner—feedback may be provided informally with care providers or formally through hospitals, practice managers, state based medical ombudsmen, Medical Boards, the police, or civil litigation through the courts.³⁹⁷ Any changes implemented as a consequence of feedback should be monitored and evaluated.
- Systems are in place to enable people and their families to find out about the quality of care provided by health care services and professionals—for example, accreditation of services and credentialing of health professionals.

After hospitalisation, people with heart, stroke and vascular disease will be supported and provided with advice about the prevention of subsequent adverse events

Optimal Services: After hospitalisation, people with acute heart, stroke and vascular disease will be confident that their general practitioner will be aware of recent events and that they will be provided with the best advice to prevent subsequent adverse health events.

Aboriginal and Torres Strait Islander people and people from culturally and linguistically diverse backgrounds will receive care that is culturally appropriate.

Secondary Prevention in Practice

Several nationally consistent guidelines exist to assist general practitioners and other health professionals to provide effective, consistent treatment of the risk factors for heart, stroke and vascular disease, including high blood pressure, abnormal lipid profiles, diabetes mellitus, heart rhythm disturbances and rheumatic fever. There is limited information on how well existing guidelines are implemented in general practice. The available evidence suggests that the extent of guideline implementation is modest—30% of people being reviewed for high blood pressure and lipid abnormalities are unaware that they have the condition⁹⁴, and 30% of people on medicines to treat high blood pressure or abnormal lipids are not being adequately controlled.^{94,96}

'Disease management' approaches are being increasingly advocated for the ongoing care and prevention needs of people with heart, stroke and vascular disease, to help address the current inadequacies in their risk factor management. The key elements of these programs are:

- coordinated, ongoing and systematic care based on evidence-based guidelines
- patient education component
- specialist 'nurse led' secondary prevention clinics.

A systematic review of secondary prevention programs in heart, stroke and vascular disease found that such programs improved processes of care, reduced admissions to hospital and enhanced quality of life.³⁹⁸ A four year follow up study of nurse led secondary prevention clinics in Scotland³⁹⁹ concluded that nurse led secondary prevention clinics improved medical and lifestyle components of secondary prevention and this seemed to lead to significantly fewer total deaths and probably fewer coronary events.

General practice is ideally placed to coordinate the ongoing preventive care needs of people with heart, stroke and vascular disease, including involvement with, referral to and/or information sharing with other services and programs. Practice nurse initiatives in Australian general practice could be extended to include a role with secondary prevention programs or 'clinics' which could be piloted as part of the proposal presented here.

The strengthening of information management and information technology support systems in general practice, as with the National Integrated Diabetes Program, together with the appropriate provision of structural support and incentives, could assist the implementation of this proposal.

Currently there are no national data to describe and monitor the care and health outcomes of people after they are diagnosed with heart, stroke and vascular disease, as they make contact with various health providers. The potential establishment of a National Cardiac Procedures Register could be a powerful tool to help address this deficiency, which could inform the information and data needs of this proposal.

Increasing the use of practice-based nurses to coordinate management programs may further assist in reducing poor cardiovascular outcomes for high risk individuals. Further, programs to increase the use of Aboriginal Health Workers in appropriate settings may support the uptake of preventive and sustainable healthy behaviours by Indigenous peoples.

The Australian Primary Care Collaboratives Program aims to improve clinical outcomes and reduce lifestyle risk factors for people with chronic and complex conditions by promoting a culture of quality improvement in general practice and primary health care.

It will involve 600 individual general practices in sustained improvements to their prevention activities, management, and clinical and business systems. The collaborative methodology, designed by the Institute for Healthcare Improvement in the USA, provides a generic quality improvement model that can be applied to achieve small, rapid and locally relevant improvements across a broad range of clinical and practice business issues. It has successfully delivered improvements in care for people with asthma, diabetes, coronary heart disease and cancer in the primary health care setting in the US, UK and Europe. The focus areas for the Australian program are diabetes, coronary heart disease and access to general practice.

The Coordinated Vascular Risk Assessment and Management Program was a program initiated by NSW Health which was developed to implement secondary prevention initiatives for vascular disease in people discharged from a Western Sydney hospital with both an acute coronary syndrome and diabetes.

People will receive information to assist participation in decision making

Optimal Services: People with heart, stroke and vascular disease and their families will receive sufficient information about prognosis; treatment options; benefits risks and possible complications of treatment; pain management; and supportive care to facilitate their participation in decision making.

Information will be available in a number of formats, and will be tailored to reflect the educational, cultural and linguistic backgrounds of different individuals.

Systems will be in place to support and encourage people to openly discuss their needs and concerns with the treatment team as required.

A good understanding of the risks and implications of invasive treatment improves people's satisfaction with care, psychosocial wellbeing and compliance with treatment.⁴⁰⁰ Nevertheless, people with acute heart, stroke and vascular disease generally have limited understanding of the treatment choices available to them and what might happen to them as a consequence of each of these.

Written information

Consumer guides describing various aspects of acute heart, stroke and vascular disease care are available. The best written information is that which includes evidence-based statements about the benefits and harms associated with treatment options and the quality and consistency of the empirical studies underlying these statements. Information should also be presented in a balanced way using concise, jargon free language.⁴⁰¹

When medicines are considered necessary, relevant and high quality information should be made available. Consumer Medicine Information (CMI) is designed to inform consumers about prescription and pharmacist-only medicines, and is produced by the pharmaceutical company that makes the particular medicine. CMI are available from a number of sources, and can be requested by a consumer through their pharmacist or doctor.

Patient held records and treatment plans

Patient held medical records can be valuable. The utility of these records in terms of their impact on quality of life or the outcomes of care seems to vary with the condition and circumstances of the person being treated. Some benefits may be obtained by encouraging people to use a notebook to write down their thoughts, worries or questions, and to keep

their own record of medications and appointments, offering them the choice of a more structured patient held record if they so desire.⁴⁰² The recall of information by people increases when they are provided with individualised information.⁴⁰³

Communication with the treatment team

There is evidence that doctors elicit only half of the complaints and concerns people have about the physical, emotional and social impact of their problems. Training in key communication skills can be beneficial.⁴⁰⁴ Effective communication skills can include using active listening, summarising information, and inquiring about the social and psychological impact of important issues on the patient and family. Applying these skills will require sensitivity and cultural appropriateness. Making eye contact, for example, can be an inappropriate technique in some Aboriginal and Torres Strait Islander and culturally and linguistically diverse peoples.⁴⁰⁵

The significance of doctor-patient communication is reflected in the inclusion of communication skills in overseas medical curricula.²⁶⁴ In Australia, the National Health and Medical Research Council has developed a guide for medical practitioners to help them provide information to people.

Communication with Aboriginal and Torres Strait Islander peoples

Indigenous and non-Indigenous cultures have different assumptions about appropriate ways of obtaining and communicating information. For example, direct questions aimed at eliciting detailed personal information can be unsuccessful in communicating with Aboriginal and Torres Strait Islander peoples. An indirect approach, establishing a two-way exchange, volunteering information and hinting at the information required is customarily more effective.⁴⁰⁵ The Queensland Ministry for Justice has produced an informative booklet which provides advice about communication issues, including linguistic, pragmatic and non-verbal, involving Aboriginal and Torres Strait Islander peoples.⁴⁰⁵

People and their families will receive appropriate support

Optimal services: People with acute heart, stroke and vascular disease and their families will receive appropriate psychosocial support.

They will receive detailed information about the supportive care services available in their respective communities and be provided opportunities to discuss their support needs with members of their treatment teams and community health providers on a regular basis.

Information about entitlements to financial assistance for costs associated with treatment, including travel and accommodation, will be available.

Supportive care is not stage-of-disease dependent, neither is it a distinct speciality. Rather, supportive care for people with acute heart, stroke and vascular disease and their carers starts with diagnosis, continues throughout treatment, and is the responsibility of all providers of health and community care.

It is underpinned by open and sensitive communication and by organisations and teams who work in a coordinated way to ensure the smooth progression of people with acute heart, stroke and vascular disease from one service to another.

CHAPTER 8. Treatment and Support During Long Term Care

The decline in mortality from heart, stroke and vascular disease has meant that an increasing number of people require long term and complex care for these conditions. The provision of this care is and will be a significant challenge to current health care services which have been designed around the provision of acute services, often by a single health professional.

People with chronic health conditions have some needs in common. They need to manage the social and emotional impacts of symptoms, disabilities and possible approaching death and take medicines and interact with a broad range of health professionals over time. Improving health outcomes and quality of life for people with chronic diseases will involve a shared approach to care involving the patient, carers and health professionals and other care providers working as a team. It will involve self-management education and ongoing support; an agreed, written action plan to guide self-management; aligning the tasks and work of health professionals with the needs of people with chronic conditions; clinical information systems to support the provision of evidence-based care; and partnerships between health care services and community resources to bridge the gap between hospital and community.^{13,406}

Despite broad acceptance of the optimal model of care for people with chronic conditions, the available evidence suggests that current health service delivery systems do not always meet the care and support needs of this group.⁴⁰⁷

PEOPLE'S NEEDS

People need:

- timely access to high quality care for their condition and other health needs
- integration and coordination of services in the community, general practice and hospital setting
- to be fully informed about their condition, their treatment and how to reduce the risk of side effects; this includes education and support to self-manage their health needs, modify their lifestyle risk factors, and preserve their quality of life
- to be supported in their recovery and rehabilitation from heart disease and stroke
- encouragement and support to participate in decisions about their care
- a culturally appropriate, individualised care plan that is tailored to their personal needs and resources
- help with managing the physical, social, emotional and financial impacts of the condition.

CRITICAL INTERVENTION POINTS

1. Develop and implement strategies to support a multidisciplinary team approach which promotes continuity of care.
2. People with chronic kidney disease will have access to appropriate specialist care.
3. Current barriers to organ donation in Australian hospitals should be addressed.
4. Develop and implement evidence-based guidelines.
5. Implement policies to encourage the safe and quality use of medicines.
6. Access to rehabilitation services for people with heart, stroke and vascular disease.
7. Ensure that psychosocial needs of people with heart, stroke and vascular disease are met across the patient journey.
8. Improve access to culturally appropriate care and support for all Australians with the conditions, and particularly Aboriginal and Torres Strait Islander peoples, people with diverse language and literacy needs and people in rural and remote areas.

OPTIMAL SERVICES AND RATIONALE FOR CRITICAL INTERVENTION POINTS.

People will have access to high quality health care

Optimal Services: People with heart, stroke and vascular disease and their families will have access to coordinated and multidisciplinary long term care that is evidence-based and consistent with agreed national clinical practice guidelines.

People will be encouraged and supported to contribute to the development of individualised long term multidisciplinary care plans that outline the actions to be followed in the event of deterioration of their condition, agreed goals of care, self-management strategies, and arrangements for ongoing review.

People with heart, stroke and vascular disease will be invited to participate in clinical trials and will receive as much information as is necessary for them to make informed decisions about participation.

Multidisciplinary care

The combined knowledge, expertise and skills of a coordinated multidisciplinary care team have been embraced widely as essential for high quality care of people with chronic conditions.

A disease management approach to care, defined as multidisciplinary care for chronic diseases, that coordinates comprehensive care along the disease continuum and across healthcare delivery systems⁴⁰⁸, has been shown to improve the quality of patient care. In New Zealand, a chronic disease management program for people with chronic heart failure—comprising information systems to identify population groups, clinical review by a general practitioner, educational material and education sessions with a practice nurse, written patient held action plans, and monthly follow up by telephone to offer support and encouragement—was rated as helpful or very helpful by a majority of people (94%), especially in relation to their understanding of their disease, and their medication and lifestyle changes. Perceived obstacles to the program included: lack of time for practice staff to provide the services and review notes prior to visits; problems remunerating practice nurses for their services; and too many projects.⁴⁰⁹

In heart failure treatment, nurse-led, multidisciplinary interventions that optimise evidence-based therapies, and promote self-care and coordination of care, have been shown to be beneficial in terms of reducing readmission to hospital and improving quality of life.^{273,275,276,386,410,411} Programs that have key coordinating roles for a heart failure nurse and specialised multidisciplinary teams, and which support the role of general practitioners and other key personnel through outreach interventions or outpatient visits, have the potential to improve the management of people with heart, stroke and vascular disease, and enhance integration of care.⁴¹² However, uptake of these programs is variable and subject to funding constraints.⁴¹³

The benefits of a dedicated multidisciplinary team and stroke unit care for meeting the heterogeneous needs of people hospitalised after a stroke are well recognised. Particularly beneficial is the capacity of the team to coordinate the care of the person with stroke into the most appropriate, multidisciplinary rehabilitation service. There is, however, evidence of poor communication between staff, between staff and people with stroke and their families³⁸⁴, and between community services and carers of people with stroke.^{384,414} This highlights a need for those with stroke, their carers and their general practitioners to be involved with the multidisciplinary team in the development of a written care plan that outlines appropriate post-discharge care.

Coronary Heart Disease

Several lines of evidence support the increased use of early invasive risk stratification and management among patients presenting with acute coronary syndromes.^{415,416} This represents a shift away from the previous practice of waiting for clinical or functional evidence of persistent ischaemia before coronary angiography and revascularisation are undertaken.

A major improvement in the management of these patients would be the availability of exercise testing, both in and out of working hours. People are keen to have a diagnosis and, if they do not have acute coronary syndromes, to be appropriately triaged and discharged home. Chest pain centres represent cost savings compared with an inpatient evaluation to rule out MI.^{417,418}

There is mounting evidence that people with ECG evidence of ischaemia or elevations in cardiac biomarkers should undergo angiography and revascularisation within 48–72 hours, and that any delay is associated with worse outcomes.⁴¹⁹

Revascularisation, both bypass surgery and angioplasty, require appropriate and timely access to cardiac catheterisation laboratories. Evidence supporting routine invasive management of patients with high risk acute coronary syndromes is likely to increase the number of patients requiring rapid access to angiography, angioplasty and surgical services. This evolving treatment paradigm has implications for service planning and delivery.

Cardiac rehabilitation programs are an essential component of treatment for patients presenting with acute coronary syndromes. Studies demonstrate attendance to cardiac rehabilitation is associated with an improvement in survival, compliance with medications, and improvements in risk factor status.⁴¹⁸

Chronic kidney disease

Pre-dialysis

People are classified as being at the pre-dialysis stage when they satisfy criteria for severe CKD, and are expected to require dialysis or transplantation (renal replacement therapy RRT) in the next six to 18 months. Each year in Australia about 1900 people commence RRT³¹⁸, with the number of people with severe CKD estimated to be about 40 000.³⁴ The annual mortality of this pre-dialysis group is not well documented in Australia but is high.³⁸ The major cause of death is cardiovascular disease.

The choice of treatment modality for renal replacement treatment at the pre-dialysis stage is complex, and there is a need to ensure the application of clinical guidelines in this process. Whereas it is currently recommended that people and families receive comprehensive explanations of their options from experienced medical, nursing and other personnel, and have adequate time to consider the issues, there is currently no evidence regarding the extent to which this occurs in Australia.

Referral to specialist care

Late referral to specialist care is defined as referral to a nephrologist less than 90 days prior to the initiation of dialysis. In Australia, late referral has been estimated at between 25–30%³¹⁸, and is the most frequently reported factor affecting the timing of initiation of dialysis.

Many of the issues affecting late referral to a nephrologist appear resolvable with improved education of primary care physicians, widespread implementation of Caring for Australians with Renal Impairment (CARI) guidelines, and improved communication between hospitals and general practice through a shared health care record or computer-based record system.

Counselling

The key issues regarding the provision of counselling, education and rehabilitation for people on haemodialysis have been reviewed.^{417,420} Improving knowledge of people in the pre-dialysis phase of their illness may enable them to adopt the productive confrontational coping style used by dialysis-experienced patients.⁴²¹

Multidisciplinary care

Recent trials have reported that attendance at a multidisciplinary clinic is associated with reduced mortality and less frequent hospitalisation after starting dialysis, compared to those who received standard care.⁴²² The CARI guidelines recommend access to multidisciplinary pre-dialysis training programs and staff²⁰, but these services are not currently widely available in Australia.

Co-morbid conditions

Treatment of co-morbid conditions forms an integral component of the care of all people with progressive CKD, and needs to be consistent with currently available guidelines and/or the best available evidence. Such conditions include anaemia, hypertension, bone disease and dyslipidaemia.

Dialysis and transplantation

The ANZDATA Registry has documented the numbers of people receiving dialysis or maintaining life with a kidney transplant for almost 40 years, and is believed to have 100% reporting of these conditions. At the end of March 2004, 14 408 RRT people were being followed, 54% of these were on dialysis and 46% on a functioning kidney transplant. In Australia:

- the annual growth rate of the dialysis pool over the last decade has averaged 6%, meaning that the numbers have doubled in that time period
- the acceptance rate to RRT is 94 new cases per million population per annum (pmp/yr), lagging well behind most countries in Europe and less than one-third of the new case rate in the US
- the renal transplant rate (30 transplants/pmp/yr) is about average by international standards, with a high live donor rate (40% of total) compensating for a low deceased donor rate
- home haemodialysis only accounts for 11% of the total on dialysis and is reducing each year.

Key issues in Australia pertaining to optimal RRT services are:

- ensuring that the health system plans for, and resources adequately, the 6% annual growth in the number of people dependent on dialysis
- ensuring that the full range of types of dialysis is available through each major renal treatment centre so that individuals can fairly and equitably choose and access the best treatment
- addressing the barriers that currently restrict the use of home haemodialysis, the most cost effective and flexible form of haemodialysis
- reducing the social and financial impact of transport to dialysis facilities
- increasing the number of donors by addressing the barriers to deceased donation that exist in most major hospitals, and by removing financial disincentives for live donation.

A patient-centred program providing full information and education, participation of patient and family in the free choice of the best pathway, and the adequate provision of high quality services in all areas of RRT underpin the UK framework and should be replicated in the Australian context.

Treatment of CKD in Aboriginal and Torres Strait Islander Populations

The predicted doubling of End-Stage Renal Disease (ESRD) incidence among Indigenous people will add an enormous burden to limited resources. These alarming figures are probably underestimates, because some Indigenous people, especially older people and those from very remote communities, decline treatment for ESRD or are medically unsuited. The persistently high rate of withdrawal of Indigenous people from ESRD treatment reflects difficulties with chronic disability, the complex treatment regimen, and loss of social and family support and 'land identity' associated with relocation from their communities. Initiatives to move treatment closer to home include attempts to promote chronic ambulatory peritoneal dialysis, which has low rates of technical failure and peritonitis, but major problems with exit-site infections and a renewed focus on transplantation.³⁵

Stroke

Stroke is a chronic and complex condition which leaves half of the survivors with a disability that makes them dependent on others for activities of daily living. Many require high level care. A significant proportion of stroke patients are malnourished on admission.⁴²³ Depression is common. Stroke survivors should have access to regular review and may benefit from peer support, information, education and self-management.

Every person with stroke should be assessed and informed of their risk factors for a further stroke, and evidence-based interventions aimed at modifying identified risk factors should be implemented and monitored.

Key issues in the provision of on-going care for people with stroke include:

- ensuring that classification of stroke and subsequent intervention therapies are consistent with existing guidelines and/or the best available evidence
- there is appropriate access and referral to health and other personnel to ensure consistency with guidelines and evidence and to provide ongoing support.

Heart Failure

The nature of CHF is such that people diagnosed with the condition will require ongoing monitoring and support. Care for people with CHF will also be compounded by issues related to ageing and high rates of co-morbid conditions. Management plans for people

with CHF need to acknowledge this complexity, and seek to ensure appropriate provision and access to ongoing support and infrastructure to assist people's management of their condition.

Given the structure of the Australian health care system, general practitioners are critical to coordinating care for people with CHF. At the same time, it is becoming increasingly evident that general practitioners require further education and support from expert heart failure clinicians to help them manage people with heart failure.^{222,424,425} The increasing number of people in residential aged care facilities with heart failure⁴²⁶ means that health care workers in this sector also require information and support.

Peripheral vascular disease

Chronic critical limb ischaemia (CLI) is the term used to include patients with ischaemic pain at rest and ulcers or gangrene. People with this condition often require hospitalisation and intensive treatment for long periods. They are at high risk of other cardiovascular events and limb amputation.²⁸⁰

People with CLI must pay particular attention to proper foot care and avoid trauma to their extremities. They should be evaluated by a podiatrist and evaluated for proper foot care. Extremes of heat and cold should be avoided. Even mild physical trauma can convert a patient from having intact skin to an ischaemic ulcer.

Clinical trials

People in clinical trials usually have lower than anticipated morbidity and mortality rates than people seen by clinicians in real life. Many factors acknowledged as important in delivering effective care are addressed in the 'usual care' arms of clinical trials, with the concomitant provision of increased monitoring and individualised follow up. Given that volunteers for trials generally have better health outcomes than non-volunteers, and tend to be more homogenous as a group, there is a need for trials that include a wider variety of enrollees.

Women, the elderly and minority groups are under represented in clinical trials in heart failure.^{427,428} Consequently, there is a lack of data to guide clinicians in the optimum management of these groups. The increased prevalence of diabetes and hypertension in specific cultural groups underscores the importance of community engagement and targeting of high risk groups.⁴²¹ The participation of these groups in clinical trials should be sought not only to ensure access to novel therapies, but also to establish a knowledge base on the physiological, psychological and sociocultural responses to care provision.

Systems will be in place to support continuity of care between services provided in community, general practice and hospital settings

Optimal Services: Systems will be in place to facilitate the seamless transition between services provided in community, general practice and hospital settings for people with heart, stroke and vascular disease and their families.

These systems will support and encourage more effective communication and sharing of information between service providers in the different health settings and sectors, comprehensive and shared care planning, and continuity in the use of medicines, and may involve the identification of a 'health systems navigator' or 'care coordinator' for each person with heart, stroke and vascular disease to facilitate access to appropriate services.

Continuity of care

Continuity of care is the degree to which a series of discrete healthcare events involving an individual are experienced as coherent and connected and consistent with their medical needs and personal context.⁴²⁹ In the context of chronic disease, continuity of care has several aspects.

Continuity of Information

Information is the common thread linking care from one provider to another, and from one episode of care to another. Existing paper-based or provider-based information systems do not support effective information transfer between care providers in different settings. A report released by the Institute of Medicine recommended the use of clinical information systems, including electronic health records, as a means of improving communication. Electronic health records—which involve the collection, storage and exchange of patient information within a secure network with strict privacy safeguards—are one component of a national approach to information management and information and communications technology. The program, HealthConnect, is currently being trialled in several Australian states.

Continuity of Treatment

People need a consistent and coherent approach to the management of a health condition that is responsive to changing needs. Shared management plans or care protocols provide a sense of predictability and security in future care. They outline agreed strategies to manage a person's condition, including evidence-based interventions and self-management strategies, steps to take in the event of a decline in health status, activities that will slow the progression of the conditions and/or reduce symptoms, and plans for ongoing monitoring and review.

Continuity of the Therapeutic relationship

A health systems 'navigator' or care coordinator is an individual responsible for ensuring effective access to and integration of health and community care for a person with a chronic disease. They may assist in providing individuals with a sense of predictability and coherence, as mentioned above. The system navigator might be a general practitioner, practice nurse or other health professional.

Quality Use of Medicines

Many people maintain their health without using medicines while, for others, medicines play an important role in maintaining health, preventing illness and curing disease. The National Strategy for the Quality Use of Medicines⁴³⁰ aims to make the best possible use of medicines for consumers and health practitioners by:

- asking for and utilising objective information, resources and services to make decisions and take actions that enable medicines, when they are required, to be chosen and used wisely
- becoming more aware of the risks and benefits of medicines, the possibility of non-drug options and the importance of a healthy lifestyle
- developing the skills and confidence to use medicines appropriately and seeking help to solve problems when they arise
- becoming more aware of the place of medicines in the broader context of health services and society
- assisting people to make informed decisions and learn more about health issues and health care through information, education and discussion.

Continuity in the use of medicines

Poor compliance with management plans, and errors with medication plans, are major contributors to re-hospitalisation rates in people with long term heart disease.^{218,272} Further, poor continuity in the use of medicines between episodes of care has been linked with excess morbidity for people with chronic disease.⁴³¹⁻⁴⁴¹ As people with heart, stroke and vascular disease may require up to 10 medications, improving understanding of their treatments and ensuring continuity in the flow of information about their medication requirements between providers are key requirements to reducing the burden of re-hospitalisation.

Medication Action Plans

The Australian Pharmaceutical Advisory Council released national guidelines on achieving continuity in the quality use of medicines in 1998.⁴⁴² The guidelines are currently being revised. In addition to providing a set of principles to guide the collection of information on patients' medication regimens, the guidelines also stress the importance of developing individualised Medication Action Plans as part of an overall care plan with the person's treatment team. The development of culturally specific Medication Action Plans will support access to quality health information, and assist in raising the confidence of people from culturally and linguistically diverse backgrounds to deal effectively with their condition.²⁶⁸

Home Medicines Review is a service to patients living at home in the community. The goal is to maximise an individual patient's benefit from their medication regimen. The reviews involve a team approach, including the general practitioner, the patient's preferred community pharmacy and an accredited pharmacist, with the patient as the focus. A Home Medicines Review might also involve other relevant members of the health care team, such as nurses in the community or carers. The review allows the patient the opportunity to have a pharmacist, in collaboration with their general practitioner, comprehensively review their medication regimen in a home visit and to be central in the development and implementation of an agreed medication management plan.

Provision of medicines information

People are often not aware of what medicines they are taking⁴³¹, and general practitioners are not consistently made aware of changes to treatment plans.⁴³³⁻⁴³⁵ A lack of medication information provided to out-of-hospital professionals is associated with an increased likelihood of the person suffering an adverse event related to their medication.^{438,439}

There are various methods to inform people about their medications. The use of both oral and written information has been recommended²⁶⁹, as has the use of medication records. One review⁴⁴³ has concluded that information provided in an educational context is more effective than information provided through leaflets or booklets. Several trials have assessed the provision of information as part of a multifactorial intervention, and the successes of these trials support the notion that information is best provided as part of an overarching multidisciplinary care plan. This plan will include the input of community-based health professionals, especially pharmacists, in caring for the person with heart, stroke and vascular disease, and will reduce the likelihood of errors in the transfer of medication information between service providers. Two recent trials of the use of medication liaison services as part of a multidisciplinary care model have been effective in reducing problems associated with medications.^{438,439}

The National Prescribing Service Medicines Line⁴⁴⁴ is a national information service, providing Australians with access to independent, accurate and up-to-date information about medicines, including prescription medicines, over-the-counter medicines, complementary medicines and herbal and natural therapies.

The Consumer Medicine Information (CMI) guide is published by the Australian Government Department of Health and Ageing to inform consumers about prescription

and pharmacist-only medicines.⁴⁴⁵ CMI leaflets are produced by the pharmaceutical company that makes the particular medicine. The CMI Guide provides information about how CMI can be used by consumers and health professionals to build better relationships to achieve quality use of medicines.

Supportive Infrastructure: The Enhanced Primary Care (EPC) items

The provision of seamless and continuous care for people with ongoing health problems, including people with heart, stroke and vascular disease, will require existing health care systems to foster a partnership approach and to make a commitment to multidisciplinary care.¹¹ Acknowledging this, the Australian Government introduced Enhanced Primary Care (EPC) items to the Medicare Benefits Schedule in 1999. These items provide Medicare rebates for annual health assessments for older Australians, and care planning and case conferencing services for patients of any age with chronic conditions and multidisciplinary care needs. These items and, in particular, the care planning items (with their emphasis on improved coordination of care) are highly relevant to people with heart, stroke and vascular disease.

Since July 2004 patients who have received an EPC multidisciplinary care planning service from their general practitioner (or whose general practitioner has contributed to a multidisciplinary care plan prepared for the patient by an aged care facility) have also been able to access up to five rebates a year for allied health services. Health professionals whose fees may be subject to a rebate under the allied health and dental items (and whose services are of potential benefit to patients with heart, stroke and vascular disease) include, for example, physiotherapists, dieticians, Aboriginal and Torres Strait Islander health workers and psychologists.

Medicare Item 710 (a health check for Aboriginal and Torres Strait Islander people aged 15–54 years inclusive) was added to the EPC suite of items in May 2004 and is designed to improve the early detection and diagnosis of common and preventable conditions. A mandatory element of the examination included in this service is measurement of a patient's blood pressure, pulse rate and rhythm. The development of a simple strategy for good health (including treatment and services) is a mandatory part of item 710.

EPC Care Planning items are being replaced by new Chronic Disease Management (CDM) items which will widen eligibility for Medicare care planning services to people with chronic or terminal conditions (whether or not they have multidisciplinary care needs). More information on the CDM items can be found at <http://www.health.gov.au/internet/ministers/publishing.nsf/Content/health-mediarel-yr2005-ta-abb074.htm?OpenDocument&yr=2005&mth=6>.

The EPC Medicare Benefits Schedule (MBS) items provide a framework to encourage and support a multidisciplinary approach to health care. The EPC MBS items cover:

- health assessments for people aged 75 and over (55 and over for Aboriginal and Torres Strait Islander people in recognition of their particular health needs)
- multidisciplinary care planning
- multidisciplinary case conferencing
- multidisciplinary discharge care planning and case conferencing.

Collaborative medication review items also support pharmacists and general practitioners working together to manage the medication management needs of those at risk of medication misadventure. While these items are important incentives for general practitioners they do not obviate the need to improve communication and referral pathways between hospital and primary care settings.

People will have access to appropriate rehabilitation services

Optimal Services: When necessary, people with heart, stroke and vascular disease will have timely access to evidence-based, multidisciplinary rehabilitation services.

Cardiac rehabilitation

Cardiac rehabilitation is the comprehensive care required to minimise functional, psychological and social disability in cardiac patients, thereby restoring them to an enjoyable, productive life.⁴⁴⁶ These programs incorporate secondary prevention strategies that are designed to maximise healthy lifestyle changes and to improve adherence to medication regimens that are known to reduce subsequent cardiovascular morbidity and mortality.

Programs vary in content, but essential components appear to be reassurance, advice, education, physical activity, and tight secondary prevention regimens. Group programs are generally used because of cost savings, camaraderie, and also the benefit of people being able to model those who are further advanced in their recovery.

The WHO considers that cardiac rehabilitation is ‘an essential part of the care that should be available to *all* cardiac patients’.⁴⁴⁷ There is no age limit to rehabilitation, although the standard programs are not generally suitable for those with dementia or in nursing homes. In Australia, programs are now generally available for people after specific cardiac events such as AMI and cardiac surgery, and often after percutaneous coronary intervention (PCI). People with chronic stable angina or unstable angina without PCI are rarely included. There are also programs at larger centres for people with chronic heart failure. Most states have a centre that provides a program for children after surgery for congenital heart disease.

However, the programs offered currently in the majority of centres in Australia are limited in their scope. They generally do not include the specific components, intensity, or duration of the programs that have been shown to improve clinical outcomes in the published randomised clinical trials (RCTs). The approach in Australia has been based on the presumption that, in the absence of adequate funding, a low cost program is more likely to be implemented and thus will be better than no program at all. However, there is little RCT data to support this presumption. While it is true that lower intensity group exercise programs (twice weekly over 11 weeks) deliver the same benefits as high intensity training programs⁴⁴⁸⁻⁴⁵⁰, most Australian cardiac rehabilitation programs only allow attendance once weekly for six weeks.

There is a substantial body of RCT evidence published over 30 years which demonstrates that both comprehensive, multifactorial cardiac rehabilitation programs and also individual components of rehabilitation programs provide significant benefits over and above usual medical care alone. These studies examine a range of different interventions and include people of varying risk levels at varying periods in the historical development of new cardiac therapies.

Rehabilitation is a proactive and goal oriented process that begins the first day after stroke. Its aim is to improve function and/or prevent deterioration of function, and to bring about the highest possible level of independence—physically, psychologically, socially and financially. Rehabilitation is concerned not only with physical recovery but also with reintegration of the person into the community, although these two facets are part of the one process.

Cardiac Rehabilitation for Aboriginal and Torres Strait Islander peoples

Aboriginal and Torres Strait Islander people are known to die from heart, stroke and vascular disease at twice the rate of other population groups. It is also well known that Indigenous peoples are under represented in cardiac rehabilitation clinics and thus there is a strong need to provide flexible methods of delivery to this group.

Aboriginal Health Services employ general practitioners, Indigenous Health Workers and Community Support Workers who should all be supported to deliver cardiac rehabilitation.⁴⁵¹⁻⁴⁵³ Consideration of the Indigenous patient and their family should be expanded to include the community. This is an important factor in the Indigenous view of health—a holistic view that includes the spiritual, the body and the past dreaming. Staff working with Aboriginal and Torres Strait Islander communities should be supported to access appropriate training. The National Heart Foundation is developing a guidance document on cardiac rehabilitation in Indigenous communities.

Recovery and Rehabilitation from Stroke

People with disabilities have the same basic human rights as others, including; the right to live in and be part of the community; realise individual capacity and potential; access services that will support attaining a reasonable quality of life; choose lifestyle and participate in decisions affecting themselves as individuals; and pursue grievances in relation to services without fear of recrimination or service withdrawal. Rehabilitation from stroke should commence as early as possible.

The following principles are basic to the planning and delivery of rehabilitation services:

- respect for the individual needs of each person with stroke, with care tailored specifically to those needs
- equity of access across geographic, cultural, linguistic and socioeconomic groups to the full range of rehabilitation services
- an interdisciplinary approach, involving a team of professionals from different disciplines working together towards a common clinical goal, with recognition of the unique contribution of each member of the team
- involvement of the person with stroke and, where relevant, the family in the interdisciplinary team and, in particular, in setting realistic and achievable rehabilitation goals
- recognition that the person with stroke is part of a family and a community, with all the demands, needs and strengths that this entails
- respect for cultural and other differences and the different service delivery needs that these may entail
- continuity of care across acute, rehabilitation and community services, to enable each person with stroke to move smoothly from one to another.

Rehabilitation is the provision of a coordinated program by a specialist, interdisciplinary team of health professionals. It involves a combined and coordinated use of medical, nursing and allied health skills, along with social, educational and vocational services, to provide individual assessment, treatment, regular review, discharge planning, and follow up.

The National Stroke Foundation has produced Clinical Guidelines for Stroke Rehabilitation and Recovery.³⁶⁹ They should be used in conjunction with the Clinical Guidelines for Acute Stroke Management³⁸⁰ to underpin high quality, integrated stroke care across the continuum of care. Consumer versions of these documents are also available through the National Stroke Foundation. While there has been no formal evaluation of their implementation, a CD-ROM has recently been developed in conjunction with the Acute Stroke Guidelines for dissemination of case-based learning. The evaluation of this program will be completed in 2005.

Quality information about the treatment and prognosis of heart, stroke and vascular disease will be available

Optimal Services: People with heart, stroke and vascular disease and their families will be updated consistently about their prognosis; treatment options; benefits, risks and possible complications of treatment; pain management; and supportive care.

Particular attention will be paid to the ongoing provision of information designed to promote effective self-management and optimal quality of life for people with heart, stroke and vascular disease.

The potential for people with chronic disease to positively influence their own health outcomes when they are provided with good information and appropriate self-management tools has received recent consideration.²⁶⁸ The reported benefits include more efficient and effective service delivery, reduced depression and anxiety, a greater perception of control, and greater emotional wellbeing. In addition, a good understanding of treatment choices and what may happen with the progression of disease improves people's satisfaction with care, psychosocial wellbeing and compliance with treatment.

Although evidence exists to support the positive benefits of disease-specific knowledge on health behaviour, compliance with medical treatment and health outcomes, information alone may be insufficient to motivate all people to engage actively in their health care. For example, people who perceive themselves as incapable of performing their treatment requirements, or not at risk to the development of complications of their condition, are less compliant with their treatment than people who perceive themselves as capable and at high risk. These data suggest that information and education programs may need a psychosocial component targeting people's beliefs about their illness.

There is recent data to suggest that health professionals tend to underestimate the needs of people for information^{262,267}, and that the decision making preferences are not met consistently in private practice and other settings. Strategies are needed to bridge the gap between expectations and what actually occurs, and may include improving the interpersonal skills of practitioners and eliciting people's information and decision making preferences.²⁶² A collaborative approach to care planning and development of individualised self-management plans may also prove effective.

People will receive appropriate psychosocial and practical support

Optimal services: There will be systems in place to address the psychological, social, emotional and financial needs of people with heart, stroke and vascular disease and their carers.

People with the conditions and their carers will be provided with the opportunities and encouragement they need to discuss issues and concerns about their family, carer and/or work roles, and the impact of their respective condition on these roles.

Information about relevant community support services will be available, and people will have access to knowledgeable and skilled health professionals and other care providers capable of identifying people's needs for information and support, and referring appropriately.

Co-existing Psychosocial Risk Factors and Heart, Stroke and Vascular Disease

Optimal care for people with heart, stroke and vascular disease is achieved when all of their needs, and those of their families and carers, are met. For many people, this means addressing psychosocial factors in addition to health care needs.

Mood disorders such as anxiety and depression are relatively common in people with heart disease, and in those who have had a stroke. The prevalence of depression is reported to range from 10–60% and panic disorder from 10–50% in people with heart disease. The prevalence of depression was in the range 6–34% in people who have had a stroke. The peak prevalence of depression in people who have had a stroke is at three to six months

post-stroke, but the risk remains high even after one to three years. Phobias also increase the risk of sudden cardiac death.³¹³

In addition to these emotional disorders, chronic stressors and inadequate structural and functional support have been consistently linked to the occurrence of cardiac death and all-cause mortality.³⁰⁹ Living alone⁴⁵⁴, lacking in confidence⁴⁵⁵, social isolation⁴⁵⁶, lack of perceived social support⁴⁵⁷, marital discord⁴⁵⁸, work stress^{459,460}, low socioeconomic status⁴⁶⁰, and caring for an ill or disabled spouse⁴⁶¹ are similarly linked to increased risks of cardiac events.

Emotional factors and stressors often co-exist in an individual. The strong overlap between chronic stress and emotional factors suggests that any life situation that has the capacity to evoke chronic negative emotional responses may promote heart disease. These psychosocial risk factors are highly prevalent within cardiac populations⁴⁶², and can also adversely affect treatment adherence.⁴⁶³ Several systematic reviews have shown an association between the presence of depression in people with heart disease and stroke and poor outcomes.⁴⁶⁴ These outcomes ranged from a decrease in quality of life measures, increased mortality, increased dependence, poorer physical outcomes and reduced social activity. Two reviews have also shown an association between low social support and poorer prognosis for people with coronary heart disease.^{455,465} The risks of heart, stroke and vascular disease in people with depressive symptoms is of a similar magnitude to the traditional risk factors for these conditions.^{466,467}

There is limited information available on the use of active case detection for early diagnosis of depression in people with heart disease. The Scottish Intercollegiate Guidelines Network recommend that people with coronary disease be evaluated for signs of anxiety and depression, but more information needs to be collected on the appropriate instruments to test for mood disorders in these people. There have been contradictory findings on the validity of instruments for diagnosing depression in people following a stroke. The current recommendation is that a diagnosis of depression should ideally be made following a structured interview.⁴⁶⁸⁻⁴⁷⁰

There is some evidence to suggest that psychosocial interventions are effective in reducing anxiety and depression in heart disease. Although there is limited evidence relating to the role played by psychosocial interventions in stroke, it does appear that during the 'returning home' phase, people benefit from high levels of emotional support combined with moderate levels of instrumental support.⁴⁶⁹

Exercise may modify psychosocial risk factors, including depression. Cross sectional studies of both medical populations and healthy cohorts have consistently demonstrated lower depression scores among those who are most active. A meta-analysis⁴⁷¹ was undertaken of 23 randomised controlled trials that evaluated the impact associated with adding psychosocial interventions to cardiac rehabilitation programs. During the first two years of follow up, lack of psychosocial intervention was associated with greater rates for mortality and recurrent heart attack. There is increasing evidence that exercise training and secondary prevention programs incorporating psychosocial interventions, with antidepressant medication, may be effective in treating psychologic distress and improving outcomes among people with cardiac disease.

Carer support

The strain of looking after someone with heart, stroke and vascular disease results in higher anxiety and depression, and lower perceived quality of life in 30–50% of carers.⁴⁷² It is important for people with heart, stroke or vascular disease to know that their families and carers are able to receive appropriate support, which may include informational, financial and psychosocial support.

Interventions to support stroke care givers by using information packages, specialist nurses, or family support workers have been shown to have little impact on people and modest

psychological or social benefits for care givers. On the contrary, recent data suggests that training carers of people with stroke in basic nursing and facilitation of personal care techniques reduced costs and caregiver burden while improving psychosocial outcomes. Interventions may, therefore, need to take into account the physical demands of caring for disabled people.⁴⁷³

To improve the psychosocial wellbeing of people and carers, strategies should be in place to detect and treat depression and anxiety, mobilise social support (when necessary) and provide effective patient/carer education on the routine treatment of heart, stroke and vascular conditions.

Access to care for special populations

Rural and remote communities

Professional, geographic and social isolation, difficulties finding appropriate accommodation and transport, and insufficient employment opportunities for spouses have contributed to a poorly distributed health workforce in rural and remote Australia. In addition, there is increasing evidence that disadvantage is associated with reduced access to general practitioner services and other health practitioners in rural areas. These are major barriers to the provision of effective multidisciplinary care to rural and remote Australians with heart, stroke and vascular disease.

General practitioners in rural and remote communities can be supported in their key coordinating role by:

- improving educational links with and providing additional support from expert clinicians^{222,424,425}
- developing formal links with larger centres, through regular specialist visits, or video or teleconferencing
- by ensuring that suitable infrastructure and community supports are in place.

Even with optimal treatment, some people with heart, stroke and vascular disease will suffer from exacerbations in their condition. There will, therefore, need to be adequate plans and links in place to facilitate the transfer of people in rural and remote communities to centres better able to provide the necessary care when care cannot be provided locally.

Aboriginal and Torres Strait Islander peoples

While Aboriginal and Torres Strait Islander peoples are overly burdened with disability due to heart, stroke and vascular disease, access to health care among these groups remains poor. It is estimated that Aboriginal and Torres Strait Islander peoples' access primary health services at only one-third of the rate of the rest of the Australian population.⁴⁷⁴

Models of care that emphasise the key coordinating role of general practitioners, and self-management of chronic disease are probably not appropriate for Aboriginal and Torres Strait Islander peoples. Improved access to appropriate models of care may be facilitated by implementing strategies to encourage community participation and development of collaborative solutions. Funding for Aboriginal Community Controlled Health Services that allow communities to be involved in service delivery has been one way to achieve this. Additional strategies are required and may include: moving the professional-patient relationship to one of mutual negotiation; building a shared cultural understanding between health professionals and communities; and increasing Aboriginal and Torres Strait Islander participation in the health workforce.^{475,476}

People from Culturally and Linguistically Diverse Backgrounds

Current models of health care have been developed predominantly to meet the needs, values and beliefs of people of Anglo-Celtic origin.⁴⁷⁷ These models may prove inadequate when dealing with people of Afro-Asian origin.

Culture provides an important context within which to interpret health and illness related behaviour.⁴⁷⁸ Community engagement with people from culturally and linguistically diverse backgrounds^{478,479} and the use of bilingual health workers may be promising strategies for improving the quality of services delivered to these groups. At this stage, there remains only limited information about access to services for people born overseas, and the potential role of bilingual health workers.

CHAPTER 9. Care and Support During Advanced Stages

Despite important advances in evidence-based treatments, age adjusted survival rates for chronic heart failure remain worse than for many cancers⁴⁷², with the median length of survival following a diagnosis of heart failure being only 18 months. One-third of stroke sufferers will die within six months.⁴⁸⁰

The WHO⁴⁸¹ has emphasised the need for timely involvement of palliative services in patient care, including a smooth transition from active treatment to palliative and supportive care. In Australia the goals of the National Palliative Care Strategy⁴⁸² are to improve awareness and understanding of palliative care, support quality and effectiveness in service delivery and promote partnerships in care delivery. These strategies incorporate promoting an awareness of the need to adopt a palliative approach in the care and management of all people who are dying, including those with chronic illnesses such as heart, stroke and vascular diseases, and promoting support to those in rural and remote areas.

Specialised palliative care services have been found to improve a range of outcomes for people at the end of life, including patient and carer satisfaction, symptom control, provision of information to families, and shorter hospital stays.⁴⁸³ Thirty percent of people with end-stage organ failure, such as heart failure, require ongoing input from a specialised palliative care service.⁴⁷⁴

Current consensus among professionals and people with heart, stroke and vascular disease is that few people with end-stage disease are referred for assessment and advice.^{474,484} There is some evidence to suggest that people are being referred earlier to palliative care services.⁴⁸¹

PEOPLE'S NEEDS

People need:

- services that are responsive to their needs and preferences, and that help them maintain personal control, autonomy and dignity
- timely access to specialist palliative care services
- to be informed of their prognosis and be included in decisions about their care
- to know that their family is receiving/will receive the psychosocial, financial and bereavement support they require.

Families and carers need:

- to know that their family member is receiving the best care
- information and support to assist them to provide appropriate care
- access to financial, physical, psychological support and respite care when necessary
- to be able to maintain their own quality of life while providing care
- support in bereavement.

CRITICAL INTERVENTION POINTS

1. Services will adequately inform people and caregivers for the future course of the illness and the pathways of care.
2. People will be informed about values-based advance directives and receive appropriate support.
3. Programs will be in place to provide information and support to caregivers and reduce caregiver and patient health problems.
4. Improve timely and appropriate access to adequate palliative care services which are integrated with treatment services.

OPTIMAL SERVICES AND RATIONALE FOR CRITICAL INTERVENTION POINTS

People will receive the information they need to participate in and make decisions about their care

Optimal services: People with heart, stroke and vascular disease and their families and carers will have access to consistent, evidence-based information about their care options, medicines and strategies for optimising their quality of life in the advanced stages of their condition.

People will be supported and encouraged to use this information to participate in decision making in respect of their condition, and to set out their care preferences in the event that they are unable to participate in decision making.

Information will be tailored to meet the cultural, language and literacy needs of people with heart, stroke and vascular disease and their families and carers and will be available in a number of formats.

Provision of information

People, carers and their families need to be informed about and understand their illness, its prognosis, and their treatment options. The right of people to be fully informed about their condition and its prognosis is one of the basic principles of palliative care espoused by Palliative Care Australia⁴⁸⁴ and the WHO.⁴⁸¹ A realistic understanding of their condition allows people to make informed decisions in respect of their current and future care.

People with cardiac failure rarely recall being given any written information; generally have a poor understanding of their condition; in the absence of chest pain, do not connect symptoms such as breathlessness and oedema to their heart; do not acknowledge that end-stage cardiac failure is a terminal illness; and do not feel involved in decision making or empowered to work in partnership with health professionals.⁴⁸⁵

There is evidence that proper discussion and appropriate recording of people's wishes in the event of life threatening deterioration of their health does not occur routinely. There is data to suggest that an overwhelming majority of people prefer as much information as possible about their condition, whether good or bad, with a lack of information causing unnecessary anxiety, fear and confusion.⁴⁸⁶

Advance directives

Advance directives provide a means for people to state treatment preferences in advance, should they later become unable to participate in decisions about their care. The legal

status of advance directives, living wills or medical powers of attorney vary in each Australian state and territory.

Data from the US suggest that the rate of uptake of advance directives in general is low, with approximately one-third of people aged 65 years and over reporting having filed an advance directive.⁴⁸⁷ No Australian data are available.

Health professionals can play an important role in making advance directives a more effective part of patient care.⁴⁸⁷ People are three times as likely to establish an advance directive if they have been asked about their wishes.⁴⁸⁷

Advance directives should detail what actions should and should not be undertaken, and specify who is responsible for decision making if the person who creates the directive is unable to speak for themselves.⁴⁸⁸ This information is likely to flow easily from a discussion of goals, quality of function and level of comfort. Advance directives may include statements about several matters.

Nutrition and Hydration

Hydration and feeding difficulties after stroke are commonly encountered. The challenge is to decide when adequate nutrition and hydration is simply prolonging the dying process as opposed to improving the level of function or comfort of the patient.⁴⁸⁹

The response of courts to requests to withdraw nutrition from people incompetent to make the decision themselves has been variable, especially in the US.⁴⁹⁰ In the UK and Australia, artificial nutrition and parenteral or enteral fluid support have consistently been defined by the courts as 'extraordinary' measures to sustain life.

Cardiopulmonary resuscitation

The other major challenge in providing care at the end of life to people with cardiac dysfunction is the role of CPR. CPR is primarily for people with unexpected cardiac or respiratory problems. Its role is crucial and is responsible for saving thousands of lives. At the same time, its role in end-stage disease, where death is expected, is quite different.

Eliciting patient wishes in respect of CPR, and interventions at the end-of-life, generally continues to challenge health service providers. One suggestion is to focus on the acceptability of potential treatment outcomes to the patient, as people seem more concerned with functional outcomes than the medical procedures implemented to achieve these outcomes.⁴⁸⁷

Palliative care services will provide high quality, coordinated and multidisciplinary care at the end of life

Optimal Services: People with heart, stroke and vascular disease and their families will receive high quality, coordinated and multidisciplinary care at the end of life.

Services will adopt an holistic approach to assist in meeting the broad range of needs of people who are dying, including physical, psychological, social, sexual and spiritual needs, and will be mindful of the particular needs of people from culturally and linguistically diverse and Aboriginal and Torres Strait Islander groups.

Condition specific issues in palliative care

Heart Failure

Heart failure is diagnosed, by definition, when other treatable causes for the failure have been addressed.⁴⁹¹ Improving the level of function and level of comfort in people with heart failure can be achieved with many of the clinical and procedural interventions now available. Given the progressive nature of many cardiovascular clinical presentations,

however, even when prognoses can be influenced, the overall intent of care is palliative and at least a palliative approach should be taken.

Although a large percentage of the people with heart failure have prognoses that are worse than many people living with advanced cancer⁴⁷⁴, palliation of heart failure is poorly done around the world⁴⁹¹⁻⁴⁹³, and few people with non-cancer diagnoses are actually accessing palliative services.^{494,495} In the UK, an estimated 4% of people with end-stage cardiac failure accessed palliative services.⁴⁹⁶

The burden of heart failure is shared unequally amongst the population, with a far higher proportion of people affected coming from lower socioeconomic groups.^{497,498} Conversely, people in the more affluent and educated strata tend to access services, including palliative care, most frequently.⁴⁹⁷ Seeing a general practitioner has been shown to be far less likely in lower socioeconomic populations with heart failure.⁴⁹⁸ Further, rates of hospital admission are higher, case fatality rates are higher and survival after the time of diagnosis shorter, for socioeconomically disadvantaged groups.⁴⁹⁸

The number of people with heart failure who should be referred for specialised palliative support is not clear. Nationally, it would be expected that 30% of people with end-stage organ failure, such as heart failure, would need to have ongoing input from a specialised palliative care service.⁴⁷⁴

Stroke

Stroke rates behind coronary heart disease and cancer as the leading cause of death in developed countries. It is a major cause of mortality world wide, and leads to significant levels of long term disability.^{212,480} The palliative nature of stroke treatment is emphasised by the fact that one in three people who have a stroke are dead within six months.⁴⁸⁰

The nature of ongoing care, including palliative care, for people with stroke is influenced by a number of factors, including:

- the extent of residual deficit and concomitant disability
- a person's likelihood of survival
- the presence or absence of a formal care-giver
- a person's age.

Adequate care planning for people with stroke is crucial. In the Australian context, a one year study that developed and evaluated the impact of a distinct stroke pathway for a regional hospital noted several benefits including: decreased length of stay overall (in acute and rehabilitation wards), decreased unplanned readmission and increased referral to palliative services for people who were likely to die as a result of their stroke. This was done through early multidisciplinary assessment by an identified stroke team. The result of referral to palliative care appears to indicate an increase in the number of people who were discharged to the community to die.⁴⁹⁹

For the vast majority of people with heart, stroke and vascular disease, the physical symptoms can be improved substantially, while reversible causes are defined and treated. Dyspnoea, when all reversible causes have been treated, can be improved with non-pharmacological interventions such as breath control, functional pacing, relaxation and visualisation techniques and improved breathing habits. Low dose opioids are useful in helping with dyspnoea in opioid naive people.

Multidisciplinary care

Palliative care is optimal when a range of service providers work together as a team to address the complexity of needs for people dying of heart, stroke and vascular disease. *Palliative Care Service Provision in Australia: A Planning Guide*, developed by Palliative Care Australia, specifies the disciplines required and the quantum of input required for quality

palliative care across all care settings.^{484,494} In addition to professional clinical services, volunteer services are acknowledged as a vital component of many palliative care services, helping meet people's social, emotional and practical needs (e.g. activities of daily living, finance, legal issues). Lay volunteers also play important roles in bridging the language and cultural gaps between health professionals and people from culturally and linguistically diverse backgrounds.⁵⁰⁰

Funding models for Australian palliative care services enable multidisciplinary care and adequate use of allied health care services.⁵⁰¹ Relationships between Australian palliative and cardiology services are not well established. Barriers to implementation include professional, organisational and financial issues.

Diagnosing dying

Both in hospital inpatient unit and community settings, it is imperative that carers recognise death as it approaches in order to allow people and their families to prepare for death. Naturally, this diagnosis requires knowledge of the key signs and symptoms of imminent death.

However, the predictability of the dying phase is not always clear, particularly in heart failure. Some of the characteristics of people with a poor prognosis in heart failure include ⁵⁰⁰:

- previous admissions with worsening heart failure
- no identifiable reversible precipitant
- receiving optimum tolerated conventional medicines
- deteriorating renal function
- failure to respond within two or three days to appropriate changes in diuretic or vasodilator medicines.

Providing care to groups with special needs

Aboriginal and Torres Strait Islander peoples

Indigenous peoples see health as 'not just the physical well-being of the individual but the social, emotional and cultural well-being of the whole community. This is a whole-of-life view and it also includes the cyclical concept of life-death-life'.⁵⁰² This view sees health span the whole of life from before birth to after death, with cultural duties associated with maintaining the life-death-life cycle.

Care of a person prior to their death is not separated by Indigenous peoples from the whole of the dying process, which includes the care of the body after death. For palliative care to be a valuable service option for Indigenous peoples, it will need to encompass this broader view of the dying process and its cultural significance. It must also be recognised that cultural beliefs and practices associated with death and dying differ between the many Indigenous clan groups.^{502,503}

The Menzies School of Health Research has published a practice guideline for health professionals dealing with the death of a Northern Territory Aboriginal Person.⁵⁰³

People from culturally and linguistically diverse backgrounds

While the opportunity to die with dignity is accepted by health professionals the world over as one of the most fundamental of all human rights, notions of a 'good death' vary considerably between cultures, raising the risk of misunderstanding and cultural insensitivity. Given the broad cultural diversity of the Australian population, understanding the needs of people from culturally and linguistically diverse, and Aboriginal and Torres Strait Islander backgrounds is crucial to ensuring effective provision of palliative care for these groups.

To date there has been little attempt to develop systematically appropriate services for people from culturally and linguistically diverse backgrounds. In addition, little is known about the extent to which current models of service delivery meet the needs of these groups, although there is evidence suggesting that they are less likely to access palliative care services than the rest of the community.⁵⁰⁴

Evidence from overseas and Australia suggests that palliative care workers could benefit from cultural competency training with respect to information regarding terminal illness, death and dying, the handling of a body and the notification of families. The extent to which provisions are in place for training of health care professionals in cross-cultural medicine are unclear. One possibility would be to incorporate cross-cultural medicine into medical and nursing curriculum.

In reference to Aboriginal and Torres Strait Islander groups, another possibility is for health professionals to work collaboratively with specific communities to examine the care that members expect at the end of life, and how that community can best be supported to provide this care.⁵⁰⁵

Elderly people with complex care needs

For many elderly people, palliative care needs will include treatment of other significant co-morbidities requiring specialist attention (e.g. other chronic health condition, Alzheimers disease or other types of dementia). This presents a challenge for palliative care of people in, for example, residential aged care setting, where resources for staff development and deployment and adequate time pose significant challenges.⁵⁰⁶

Continuity of care

Currently in Australia there is considerable variation in the extent to which people with end-stage heart, stroke and vascular disease experience care that is seamless and continuous, especially as they move from hospital to community-based settings.

The appointment of care coordinators or health systems 'navigators' for people with heart, stroke and vascular disease may assist further in improving continuity of care. General practitioners usually play a key coordinating role for people with chronic conditions, yet the extent and nature of their participation in the provision of palliative care services in Australia is unknown. Further, the interface between general practice (and consequently community nursing) and specialised palliative care services is currently considered to be less than optimal.⁵⁰⁷

People will receive appropriate psychosocial, spiritual and bereavement support

Optimal Services

Services will be available to provide people with heart, stroke and vascular disease, their families and carers with the information and support they need during the end-of-life period.

Service will be available 24 hours daily, seven days per week, and provide information, education, financial assistance and bereavement support. There will be an attempt to more clearly articulate the needs of people dying with heart, stroke and vascular disease.

There is little information relating to the needs of people with heart, stroke and vascular disease at the end of life. However, the needs and concerns at the end of life have been well articulated for people with cancer⁵⁰⁸, and include: control of physical symptoms; the need for social, existential and financial support; not wanting to be a burden; and wanting to maintain a sense of humour. Importantly, people's perceived needs do not coincide necessarily with the perceptions of professionals and carers of the needs of people who are dying.

Ensuring that people's psychosocial needs are met is likely to be a challenge for palliative care services. There is currently a paucity of Australian data on access to psychological services during palliation. Similarly, little is known about the extent to which current care meets the social support, sexual and spiritual needs of people receiving palliative care.

People who experience psychological and spiritual distress and social isolation are more likely to express a desire for death, have higher mortality rates, and their family members are more likely to have a lengthy and complicated bereavement process and are at greater risk of illness and death.⁵⁰⁹

The carers of people with chronic and complex health care needs are often ill trained for their role⁴⁸⁵, and have to contend with the economic cost of care⁵¹⁰, social isolation⁴⁸⁵, progressive losses of autonomy and self esteem, and lack of appropriate respite care.

For those at high risk of chronic grief, there is some evidence to support interventions provided by health care providers with specialised expertise.

CHAPTER 10.

National Priority Actions for Change

Significant improvements in heart, stroke and vascular disease control as outlined in the National Service Improvement Framework will require change at the local, state/territory and national level.

A number of strategies may facilitate improvements in heart, stroke and vascular disease control in Australia, including: the establishment of state/territory heart, stroke and vascular disease plans; improvements in primary care management of heart, stroke and vascular disease; improved access to services; the improvement of care for regional, rural and remote communities; the establishment of accreditation systems; strengthening training and professional development; targeted funding systems; the improvement of data and monitoring systems; strengthened approaches to research; and planning strategies for the future.

The adoption of the National Service Improvement Framework for Heart, Stroke and Vascular Disease will require a systematic implementation plan developed in consultation with states and territories, professional colleges, non-government organisations, consumer groups and other key stakeholders.

Based on the consultations under taken so far to develop the National Service Improvement Framework, nine initial priority actions are recommended. These national actions underpin the critical intervention points and would provide the basis for many of the changes identified in the Framework.

PRIORITY ACTIONS

1. Implement and evaluate culturally appropriate programs to improve heart, stroke and vascular disease control with special emphasis on the needs of disadvantaged groups, particularly Aboriginal and Torres Strait Islander people.
2. Enhanced and integrated health promotion efforts, targeting healthy behaviours in individuals and fostering environments which facilitate healthy choices.
3. Ensure that people with heart, stroke and vascular disease receive coordinated, multidisciplinary care that is guided by an agreed care plan and provides continuity across all levels of service.
4. Investigate arrangements that provide improved support for multidisciplinary care in hospitals and the community.
5. Develop approaches to monitoring all aspects of heart, stroke and vascular disease control and ensure that the agreed indicators are aligned with heart, stroke and vascular disease plans at national, state/territory and local levels.
6. Make stroke unit care available to all Australians who suffer a stroke.

7. Provide evidence-based consumer information in a form which encourages and facilitates shared decision making and self-management about:
 - prevention and individual risk
 - early detection and warning signs that indicate the need for further care
 - diagnosis and treatment
 - quality use of medicines
 - rehabilitation and supportive services
 - the environmental, behavioural and genetic risks of heart, stroke and vascular disease.
8. Review the evidence, gaps in research and opportunities for action within a specific timeframe, at least every three years.
9. Strengthen supports for primary health care and general practitioners to provide high quality and appropriate assessment of risk, detection of heart, stroke and vascular disease, referral to treatment, coordination of treatment and supportive care and rehabilitation from diagnosis to palliative care.

NEXT STEPS

As a national policy document, the National Service Improvement Framework for Heart, Stroke and Vascular Disease is intended to guide the implementation process which will be steered by each of the jurisdictions. It is expected that the implementation of the Framework will be a collaborative effort between the Australian and State/Territory Governments as well as public, private and non-government organisations.

Acronyms and Abbreviations

AAA	Abdominal Aortic Aneurysm
ABS	Australian Bureau of Statistics
ACS	Acute coronary syndrome
ACE	Angiotensin-converting enzyme
AIHW	Australian Institute of Health and Welfare
AF	Atrial fibrillation
ANZDATA	Australia and New Zealand Dialysis and Transplant Registry
ARF	Acute rheumatic fever
AMI	Acute myocardial infarction
CHF	Chronic heart failure
CHD	Coronary heart disease
CKD	Chronic kidney disease
CVD	Cardiovascular disease
CT	Computerised tomographic
GAS	Group A streptococcus
GFR	Glomerular filtration rate
DM	Diabetes mellitus
ECG	Electrocardiograph
EPC	Enhance Primary Care
ESRD	End-stage renal disease
HDL-C	High-density lipoprotein – cholesterol
HSVD	Heart, stroke and vascular disease
LDL-C	Low -density lipoprotein – cholesterol
IGT	Impaired glucose tolerance
IHD	Ischaemic heart disease
MAP	Medication Action Plan
MBS	Medical Benefits Schedule
MI	Myocardial infarct
NHFA/CSANZ	National Heart Foundation of Australia/Cardiac Society of Australia and New Zealand
NHMRC	National Health and Medical Research Council
PCI	Percutaneous coronary intervention

PHR	Patient held record
RCT	Randomised Control Trial
RHD	Rheumatic heart disease
RRT	Renal replacement therapy
SEP	Socioeconomic position
SLA	Statistical Local Area
SNAP	Smoking, Nutrition, Alcohol, Physical Activity
TIA	Transient ischaemic attack
TG	Triglyceride
UA	Unstable angina
WHO	World Health Organization

Glossary

Term	Definition
Absolute risk	One way of expressing the likelihood that a particular event (e.g. disease) will occur for individuals or groups. It is used to estimate the total number of events to be expected by a specific group or the actual odds for an individual to have an event.
Acute	Coming on sharply and often brief, intense and severe.
Acute coronary syndrome	Describes acute myocardial infarction (heart attack) or unstable angina when they first present as a clinical emergency with chest pain or other features.
Atherosclerosis	A process in which fatty and fibre-like deposits build up on the inner walls of arteries, often forming plaques. It is the main underlying condition in heart attack, angina, stroke and peripheral vascular disease.
Asymptomatic	Without symptoms or producing no symptoms.
Atrial fibrillation	When the atrium (the upper, low pressure chamber of the heart) does not squeeze or contract at one uniform, coordinated time but contracts irregularly with one portion contracting well before or after another, the result is what is called atrial fibrillation. When this happens the atrium cannot push blood into the ventricles in the normal manner.
Audit	A methodical examination or review of clinical practice.
Burden of disease	Refers to the loss of health and premature mortality at the population level. By definition burden of disease is to be found in any population that presents variation in health outcomes.
Cardiac rehabilitation	This is a comprehensive exercise, education, and behavioural modification program designed to improve the physical and emotional condition of people with heart disease.
Cardiovascular disease	Any disease of the heart (cardio) or blood vessels (vascular). Includes heart attack, angina, stroke and peripheral vascular disease. Also known as circulatory disease.
Carotid stenosis	Also known as carotid artery atherosclerosis. The condition occurs as a consequence of a narrowing of the carotid artery.
Case detection	Case detection strategies aim to identify asymptomatic individuals at high risk for the development of a particular condition.
Cholesterol	Fatty substance produced by the liver and carried by the blood to supply the rest of the body. Its natural function is to supply material for cell walls and for steroid hormones, but if levels in the blood become too high this can lead to atherosclerosis and heart disease.

Chronic disease	A disease, such as heart disease and kidney disease, that tends to be long-lasting and persistent in its symptoms or development.
Clinical practice guidelines	Systematically developed reviews of evidence to assist health professionals and people with specific conditions to make decisions in respect of their care.
Consumer	A person who has in the past used, uses or is a potential user of health services, including their family and carers.
Coordinated care	Care is coordinated when people experience the care they receive in the primary, community and secondary care sectors as being provided by the one organised service. Coordinated care relies on effective communication, liaison and integration between services provided in the different sectors.
Coronary Heart Disease	Heart attack and angina. Also known as ischaemic heart disease.
Diabetes	The name given to a group of medical conditions that are characterised by relative or absolute deficiencies in the secretion and/or action of the hormone insulin and other metabolic problems.
Dialysis	A process used to treat kidney failure. A machine is connected to the patient's bloodstream so it can take on the role of the kidneys by removing excess substances and waste from the blood.
Discharge planning	This is a process that facilitates each patient's continuity of care after leaving hospital or a day surgery. It involves a multidisciplinary approach to assessing a patient's needs, in consultation with the patient, his or her carers, the hospital/day surgery and community based service providers.
Dyslipidaemia	A lipid abnormality characterised by raised levels of both triglycerides and low-density lipoprotein (LDL) cholesterol, and a low level of high-density lipoprotein (HDL) cholesterol.
Glomerular Filtration Rate	This is a measure of kidney function. It is the rate at which water is filtered out of blood plasma.
Glomerulo-nephritis	Glomerulonephritis is a type of kidney disease caused by inflammation of the internal kidney structures (glomeruli) which filter impurities from the blood.
Heart attack	Life threatening emergency that occurs when a vessel supplying blood to the heart muscle is suddenly blocked completely by a blood clot. The medical term commonly used for a heart attack is myocardial infarction. See also cardiovascular disease.
Heart failure	When the heart cannot pump strongly enough to keep the blood circulating around the body at an adequate rate.

HDL cholesterol	HDL is one of the classes of lipoproteins that carry cholesterol in the blood. HDL is considered to be beneficial because it removes excess cholesterol and disposes of it. Hence HDL cholesterol is often termed 'good' cholesterol.
LDL cholesterol	Low-density lipoprotein is the major cholesterol carrier in the blood. If too much LDL cholesterol circulates in the blood, it can slowly build up in the walls of the arteries feeding the heart and brain. Also referred to as 'bad' cholesterol.
Hypertension	A condition that occurs when blood pressure is sustained above the normal range.
Impaired glucose tolerance (IGT)	People with IGT have blood sugar levels higher than normal, although not high enough for them to be diagnosed with diabetes.
Indigenous	A person of Aboriginal and/or Torres Strait Islander descent who identifies as an Aboriginal and/or Torres Strait Islander and is accepted as such by the community with which he or she is associated.
Ischaemia	Local anaemia due to obstruction of the blood supply
Ischaemic heart disease	Heart attack and angina (chest pain). Also known as coronary heart disease.
Level I evidence	Evidence that is based on randomised clinical trials (or meta-analysis of such trials) of adequate size to ensure a low risk of incorporating false-positive or false-negative results.
Level II evidence	Evidence that is based on randomised clinical trials that are too small to provide Level I evidence. These may show either positive trends that are not statistically significant or no trends and are associated with a high risk of false negative results.
Medication Action Plan (MAP)	A continuing plan for the use of medicines, developed by the health care professional in collaboration with the consumer, to identify and document actual and potential medication management issues, medication management goals and actions or strategies needed to address the treatment goals. The MAP is to be used by the consumer and all members of the health care team.
Patient held record (PHR)	Patient held records exist in a number of formats. All PHRs are designed to ensure that people have ready access to individualised information about their medical condition, and an ongoing record of their care.
Patient-centred care	Patient-centred care is an approach to care in which people share management of their illness with their health professionals. The three elements defining patient-centred care are communication; partnerships; and a focus beyond the specific condition to health promotion, healthy lifestyles and quality of life.

Primary prevention	Promoting health in people who have not yet begun to develop disease to help them avoid that disease. An example is counselling young people on dietary practices to help them reduce the risk of subsequently developing heart disease or diabetes.
Quality Use of Medicines	Selecting management options wisely, choosing suitable medicines if a medicine is considered necessary, and using medicines safely and effectively.
Randomised Control Trial (RCT)	The RCT is one of the most commonly reported methods for evaluating the effectiveness of treatments. The essential features of an RCT are: the comparison between a treatment and placebo group; participants are allocated randomly to one of the two groups; and there is at least a single and more likely a double blind procedure used to collect the data. If sufficient rigour is used to conduct these processes, then it should be possible to conclude that the observed outcome, if statistically significant, has indeed been caused by the treatment, i.e. there is a high probability that the treatment works.
Relative Risk	The ratio of the probability of developing, in a specified period of time, an outcome among those receiving a treatment of interest or exposed to a risk factor, compared with the probability of developing the outcome if the risk factor or intervention is not present.
Rheumatic fever	An acute, serious disease that affects mainly children and young adults and can damage the heart valves, the heart muscle and its lining, the joints and the brain. Is brought on by a reaction to a throat infection by a particular bacterium. Now very rare in the non-Indigenous population, it is still at unacceptably high levels among Indigenous Australians living in remote areas.
Rheumatic heart disease	Chronic disease from damaged heart valves caused by earlier attack(s) of rheumatic fever.
Risk factor	An attribute or exposure that is associated with an increased probability of a specified outcome, such as the occurrence of a disease. Risk factors are not necessarily causes of disease.
Secondary prevention	Early detection and treatment of people who have begun to develop the disease (possibly with silent symptoms). An example is screening to detect high blood pressure so that people with preclinical symptoms can be treated with appropriate medications or lifestyle change.
Statins	Drugs that inhibit the manufacture of cholesterol by the liver; used to treat high cholesterol.
Stroke	Stroke (also known as cerebrovascular disease) occurs when the supply of blood to the brain is suddenly disrupted. Blood is carried to the brain by blood vessels called arteries. Blood may stop moving through an artery because the artery is blocked by a blood clot or plaque, or because the artery breaks or bursts.

Transient Ischaemic Attack (TIA)	Sudden onset of brain dysfunction (eg. paralysis, slurred speech, loss of consciousness, visual disturbance) which recovers completely within 24 hours. Usually an indication of underlying vascular disease.
Torres Strait Islander	A person of Torres Strait Islander descent who identifies as a Torres Strait Islander and is accepted as such by the community in which he or she lives.
Triglycerides	The scientific name for the common form of fat, found in both the body and in foods. Most body fat is stored in the form of triglycerides.
Vascular disease	Vascular disease refers to all conditions of the heart and blood vessels and includes coronary heart disease, stroke and vascular complications relating to diabetes.

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