

Disability Resource Hub Disclaimer

The material on the Disability Resource Hub is for reference only. No claim or representation is made or warranty given, express or implied, in relation to any of the material. You use the material entirely at your own risk.

The material is provided as point-in-time reference documents. FACS does not maintain the material and does not undertake to ensure that it is accurate, current, suitable or complete.

Where conditions and warranties implied by law cannot be excluded, FACS limits its liability where it is entitled to do so. Otherwise, FACS is not liable for any loss or damage (including consequential loss or damage) to any person, however caused (including for negligence), which may arise directly or indirectly from the material or the use of such material.



Chronic Disease Guidelines

Summary: The Chronic Disease Guidelines provide support workers with information and guidance to understand chronic health conditions that are commonly diagnosed in people with disability. The Guidelines help support workers to recognise when the person they support is unwell, and to know when the person needs to see the GP.





Chronic Disease Guidelines

Document name	Chronic Disease Guidelines
Policy	Health and Wellbeing Policy
Version number	1.0
Approval date	January 2016
Policy manual	Health and Wellbeing Policy and Practice Manual Volume 2
Approved by	Deputy Secretary, ADHC
Summary	The Chronic Disease Guidelines provide support workers with information and guidance to understand chronic health conditions that are commonly diagnosed in people with disability. The Guidelines help support workers to recognise when the person they support is unwell, and to know when the person needs to see the GP.
Replaces document	Health Care Policy and Procedures, 2012 and Attachments 1 - 13
Authoring unit	Contemporary Residential Options Directorate
Applies to	People who are being supported in ADHC operated accommodation support services.
Review date	2017

Version control

The first and final version of a document is version 1.0.

The subsequent final version of the first revision of a document becomes version 1.1

Each subsequent revision of the final document increases by 0.1, for example version 1.2, Version 1.3 etc.

Revision history

Version	Amendment date	Amendment notes
V1.0	January 2016	Chronic Disease Guidelines V1.0

Table of contents

1	Introduction.....	4
1.1	Chronic disease	4
1.2	Examples of chronic disease	4
1.3	Risks associated with chronic disease	5
1.4	Importance of managing chronic disease.....	5
1.5	Self-managed chronic disease.....	5
1.6	Roles and responsibilities in chronic disease support.....	6
2	Specific chronic diseases	10
2.1	Arthritis.....	10
2.2	Asthma.....	11
2.3	Cancer	14
2.4	Cardiovascular disease.....	16
2.5	Chronic Obstructive Pulmonary Disease (COPD).....	18
2.6	Dementia.....	20
2.7	Dental and oral disease	22
2.8	Depression and anxiety	25
2.9	Diabetes	27
2.10	Gastro Oesophageal Reflux Disease (GORD).....	29
2.11	Osteoporosis.....	31
3	Policy and Practice Unit contact details	33

1 Introduction

The ADHC Chronic Disease Guidelines (the Guidelines) embody the principles of legal and human rights found in the New South Wales Disability Service Standards (the Standards), the commitment to deliver culturally responsive services to Aboriginal people under the Aboriginal Policy Statement (the Statement) and the person centred guiding principles of the ADHC Health and Wellbeing Policy.

The Guidelines are provided to support people with disability to exercise their rights and entitlements under the Standards and Statement. The Guidelines describe how ADHC supports people to recognise chronic disease, to know the risks associated with chronic disease and to understand the importance of managing chronic disease under the guidance of their 'usual' general practitioner (GP)¹ and other health specialists.

Chronic disease is associated with symptoms that can cause a person to feel unwell or to be limited in performing daily activities. People with chronic disease require specific health care to lessen the impact of symptoms on their lives.

1.1 Chronic disease

A chronic disease is one that has been (or is likely to be) present for at least six months. It often has more than one cause, is long term, causes some form of disability and is rarely cured completely. People with disability are more likely to have a chronic disease, and to have it occur earlier, than people without disability².

1.2 Examples of chronic disease

Chronic diseases that occur commonly in all people are asthma and other lung diseases, cancer, diabetes, heart disease and diseases of bones and joints. There are many others.

Chronic diseases that frequently affect people with disability are diabetes, heart disease, high blood pressure, gastro-intestinal conditions, mental illness, tooth and gum disease and lung diseases.

¹ Medicare defines the person's 'usual' GP as: *'The GP (or a GP in the same practice) who has provided the majority of services to the patient in the past 12 months, and/or is likely to provide the majority of services in the following 12 months'*.

² Disability and health inequalities in Australia <https://www.vichealth.vic.gov.au/search/disability-and-health-inequalities-in-australia>

1.3 Risks associated with chronic disease

Lifestyle and behaviours that are known to cause and worsen chronic disease are:

- tobacco smoking
- diets high in fat and sugar and; low in fruit and vegetables
- insufficient physical activity and
- excessive alcohol consumption.

People with disability are more often represented in 'at risk' groups for acquiring a chronic disease for example by, being overweight, having unhealthy eating habits, being smokers and engaging less in physical activity.

For guidance on supporting a person to manage these risks refer to the Nutrition and Swallowing Guidelines in the Health and Wellbeing Policy and Practice Manual Volume 1, and the Health Promotion Guidelines in the Health and Wellbeing Policy and Practice Manual Volume 2.

1.4 Importance of managing chronic disease

When chronic disease is not managed, people can experience mental, emotional and physical ill health, pain, unplanned encounters with the health system and hospital admissions, disability and premature death.

Even with good management, a person may die from a chronic disease or from complications relating to the disease. A diagnosis of chronic disease can act as a 'clinical trigger' for a person or carer to think about planning for future support (end of life care planning). Planning allows the person and others to explore how they want to live with the disease, as it progresses, and as the person approaches the end stage of the illness.

For more information refer to the End of Life Care Planning Guidelines in the Health and Wellbeing Policy and Practice Manual, Volume 2.

1.5 Self-managed chronic disease³

Self management of chronic disease is an approach used in the mainstream health system. It has been shown that people who are supported to actively participate in managing their chronic disease have better health outcomes. Symptoms of their disease are reduced, progress of the disease is slowed, fewer emergency hospital visits and shorter stays in hospital are required, and visits to GP and other health professionals are less frequent. Where possible, people are encouraged to follow this approach to achieve an improved health outcome.

³ The Flinders Program TM <https://www.flinders.edu.au/medicine/sites/fhbhru/programs/self-management.cfm>

1.6 Roles and responsibilities in chronic disease support

It is important to understand the roles of those who are involved in supporting a person with chronic disease. The three main participants are the person, the carer and the GP.

1.6.1 The person

As much as possible, carers support the person to 'self manage' all areas of health and wellbeing, and particularly chronic disease.

The person can be supported to self manage chronic disease by being helped to understand as much as possible about the disease. This can be done in various ways:

- explain the symptoms of the disease and how the GP plans to manage them
- recruit a nurse or other health professional to talk to the person about the disease if carers are not able to do it
- arrange with the person to attend a support group for the disease
- support the person to avoid the 'risks' associated with the disease, for example, discuss and prepare healthy meals with someone whose disease is made worse by being overweight
- explain the negative effects on the person's life of continuing to take risks that make the disease worse
- support the person during health checks and assist the health professional to communicate using a method the person understands
- if the GP has provided a management plan, help the person to understand and follow it.

Aboriginal people have significantly poorer health outcomes than other Australians, and late diagnosis of disease means that many Aboriginal people enter the chronic phase of a disease before it is diagnosed.

In addition to the health support described above, the Aboriginal person can be well supported if culturally sensitive and person centred approaches are employed. The person can be supported to engage with the disability and health service systems in the following ways:

- use the person's communication profile to learn the best way of communicating information about the disease and its management
- understand the person's history and experiences, and difficult relationships, especially with hospitals
- ask how the whole of life view (life-death-life) affects health care management and the person's acceptance of a chronic disease

- ask how and where the Aboriginal person would prefer to receive services
- record the name of the proper contact person to discuss health issues and provide consent
- determine which health issues or practices are sensitive or taboo and who to refer to if they are
- confirm whether the person or family would prefer to work with the health system through an Aboriginal Liaison Officer
- ensure that the person and family understand the health service options and how they can access them.

1.6.2 The carer

In the context of these Guidelines the carer is the 'primary carer' and is often a support worker or nurse, but it may also be a family member or other support person.

As well as supporting the person to understand the disease, the carer can learn about its progress and symptoms and be able to recognise when the person is unwell.

Most common diseases have a national or state-based association, for example the Heart Foundation. The association's website contains basic information about the disease and its management, and the person's GP can provide more if it is needed.

Information about staying well and preventing certain diseases is provided in the Health Promotion Guidelines and Nutrition and Swallowing Guidelines of the Health and Wellbeing Policy and Practice Manual, Volume 1 that is located in each accommodation support unit.

A carer who is familiar with, and understands the person's health, should accompany the person to the GP appointment.

If the GP has provided a management plan for the person's disease, carers should understand and be able to explain and support the person to follow the plan. If the person does not agree to any part of the plan, the carer supports the person to understand the consequences of this decision, and how to achieve the best possible health outcomes.

A carer is not required to diagnose the person's condition. However, in the course of monitoring the person's overall health, and recording health related events in the **Health Learning Log**, the carer should be aware of changes that indicate the person is unwell, and be able to communicate them to the GP.

1.6.3 The GP

The doctor who manages the person's chronic disease from day-to-day is the person's 'usual' GP. Medicare recognises the 'usual' GP as the doctor who

has provided the majority of care over the last 12 months or will be providing it over the next 12 months.

Medicare supports chronic disease management with a range of Medicare items that the GP can use to identify, treat and manage chronic disease.

The GP conducts the person's annual health assessment and provides other medical support during the year, as the person requires it. At any time the GP may decide that the person needs a management plan for chronic disease.

The GP can develop a GP Management Plan (the Plan) for chronic disease under Medicare (item 721) once a year. The GP assesses the person, agrees on management goals with the person and carer, identifies actions to be taken by the person, prescribes treatments and services, and enters the information in the Plan. A date for reviewing the Plan is recorded at the same time, and the GP can claim a review of the Plan under Medicare every three months.

Under the terms of Medicare, the GP is required to explain to the person and carer how the Plan is developed, and to record the person's agreement to having the Plan. The GP must also offer the person and carer a copy of the Plan.

If the GP decides that the chronic disease requires treatment from other health professionals, a Medicare Team Care Arrangement (item 723) is used to coordinate services from a multidisciplinary team. The team must consist of at least three health or care providers, one of whom is the GP. The GP also has access to a range of Medicare item numbers for referring a person to individual allied health services (items 10950-10970).

The GP coordinates the Team Care Arrangement by collaborating with the other providers, developing a plan of treatment and service goals for all the providers, getting agreement from the person for actions contained in the treatment plan, and securing dates to review the Team Care Arrangement.

As with the GP Management Plan, the GP explains to the person and carer how the Team Care Arrangement is developed, identifies the contributing providers and their services, and gets agreement from the person to have the Team Care Arrangement. The GP must also offer the person and carer a copy of the Team Care Arrangement.

Summary of roles and responsibilities

<p>Person</p>	<ul style="list-style-type: none"> • report illness, pain and discomfort to carer • attend GP's appointments with carer • agrees to management goals and actions in the GP Management Plan (the Plan)
<p>Carer</p>	<ul style="list-style-type: none"> • observe changes in the person's health and wellbeing • record and report changes in health and wellbeing • make appointments with the GP or other health professionals • accompany the person to the GP's appointment • support the GP to understand the person's communication style • understand the actions required by the person in the Plan • support the person to follow the Plan
<p>GP</p>	<ul style="list-style-type: none"> • identify and diagnose symptoms • develop a management Plan or other disease management strategy • OR • refer the person to a specialist • explain and document the Plan, and the actions required, to the person and carer • provide a copy of the Plan to the person and carer • book in a review of the Plan for a future date

2 Specific chronic diseases

2.1 Arthritis⁴

What is it? Arthritis is the term used for more than 100 medical conditions that affect muscles, bones and joints (the musculoskeletal system). Common arthritic conditions are osteoarthritis, rheumatoid arthritis and gout.

Signs and symptoms Common symptoms of arthritis are pain, swelling, redness, deformation, weakness and loss of dexterity, often affecting joints.

Causes and risks The causes depend on the type of arthritis and can be wear and tear, related to lifestyle (inactivity and diet), the result of injury or auto-immune disease.

Treatment and management Most types of arthritis cannot be cured, but treatments can manage the symptoms. Early diagnosis is important for effective treatment, and can prevent damage to the joints.

Symptoms of arthritis are managed by following the GP Management Plan if the GP has provided one. The Plan could include prescription of medication to manage the inflammation and pain, an exercise program and other methods of maintaining mobility and managing symptoms.

If the person is following the Plan and any of the symptoms reappear or worsen, the person should consult the GP for a review of the Plan and to receive a general health check.

If the person does not have a GP Management Plan, and has pain or weakness in the joints and muscles, the GP should be consulted for an assessment of the symptoms.

Health professionals The person's GP is the first contact for arthritis and other health concerns. The GP will provide treatment and information.

If the person does not have a clear diagnosis of arthritis the GP may make a referral to a rheumatology specialist. The specialist diagnoses and treats the condition. The person may need further referral to an orthopaedic specialist for diagnosis and surgical treatment, or for other management options.

A range of allied health professionals are available to provide support for people with arthritis. If the GP decides to use a Team Care Arrangement to manage the person's arthritis, the person may be eligible to claim five allied health services per year from Medicare.

More information: Arthritis Australia www.arthritisaustralia.com.au

⁴ Sourced from Arthritis Australia www.arthritisaustralia.com.au

2.2 Asthma⁵

What is it? Asthma is a disease of the tubes that carry air in and out of the lungs. Many people with asthma have allergies such as hay fever.

Asthma can be made worse by smoking tobacco or being overweight.

When a person is diagnosed with asthma it is important to have regular check-ups with the GP. The person and the GP can then manage the condition together.

Signs and symptoms Asthma causes wheezing, breathlessness and chest tightness due to widespread narrowing of the airways⁶. A person with asthma does not always have all the symptoms. The symptoms are often worse at night, in the early morning or during exercise.

Causes and risks While the underlying causes of asthma are not clear, people have different triggers for an asthma attack. The most common triggers are:

- respiratory infections (such as the common cold)
- exercise
- cold weather and changes in weather
- breathing cigarette smoke and other irritants
- house dust mites, pollen, moulds and animal fur
- work-related triggers (such as wood dust, chemicals, metal salts)
- some food additives
- some medicines (such as aspirin, some blood pressure drugs).

Treatment and management An asthma attack can come on gradually (with a cold) or quickly (from inhaling a trigger such as pollen). If symptoms are getting worse refer to the person's Asthma Management Plan or consult the GP. An asthma attack can become life-threatening if not treated properly, even in someone whose asthma is usually mild or well controlled.

If symptoms get worse, quickly call an ambulance.

⁵ Sourced from the National Asthma Council Australia www.nationalasthma.org.au

⁶ Australian Institute of Health and Welfare <http://www.aihw.gov.au/what-is-asthma/>

The person with asthma is **well** when:

- there is no night-time wheezing, coughing or chest tightness
- there is occasional wheezing, coughing or chest tightness during the day
- the person needs reliever medication only occasionally or before exercise
- the person can do usual activities without getting asthma symptoms.

Maintain the current management regime.

The person with asthma is **not well** when:

- there is night-time wheezing, coughing or chest tightness
- there are morning asthma symptoms when the person wakes up
- the person needs to take reliever medication more than usual e.g. more than 3 times per week
- asthma is interfering with the person's usual activities.

Refer to the person's Management Plan or see the doctor for a review of asthma management.

The person with asthma is **having an asthma attack** when:

- there is increasing wheezing, cough, chest tightness or shortness of breath
- the person is waking often at night with asthma symptoms
- the person needs to use the reliever medication again within 3 hours.

Refer to the person's Management Plan for instructions.

The person with asthma is an **emergency** when:

- the symptoms get worse very quickly
- there is severe shortness of breath
- the person can't speak comfortably or lips look blue
- reliever medication gives little or no relief.

Call the ambulance on 000 and say:

THIS IS AN ASTHMA EMERGENCY

Health professionals The GP plays a central role in asthma management by assessing and reviewing the person's condition, prescribing medication, providing education and managing acute attacks. The GP Management Plan contains comprehensive information about the person's asthma and its management. It includes actions to help the person and carer to understand when symptoms of asthma are worsening and how they should respond.

More information:

National Asthma Council Australia: www.nationalasthma.org.au

Australian Institute of Health and Welfare: <http://www.aihw.gov.au/what-is-asthma/>

2.3 Cancer⁷

What is it? Cancer refers to around 100 different diseases caused by uncontrolled growth of the body's cells. Cancer can be benign (generally not dangerous although it can be) or malignant.

Signs and symptoms Detection of cancer relies partly on observation of changes in the look and feel of a person's body, and of changes in regular body functions. Support workers have a role in supporting people to recognise when any of these changes occur, and in referring the person to the GP for further investigation.

Changes that could indicate the presence of cancer are:

- changes in the shape or colour of breasts or nipples
- a lump in the neck, armpit or anywhere else in the body
- sores or ulcers that don't heal
- cough or hoarseness that won't go away or coughing up blood
- blood in a bowel motion
- new moles or skin spots, or ones that have changed
- unusual vaginal discharge or bleeding
- unexplained weight loss.

Causes and risks Some cancers share common risks, for example, being older, female (e.g. breast cancer) or male (e.g. prostate cancer), overweight or a smoker, but the cause of many cancers is unknown.

Carers can support people to avoid some of the risks by helping protect their skin from excessive exposure to the sun, and encouraging them to eat healthy foods and including vegetables and fruit in their diets, not smoke, and have regular cancer screening checks.

Treatment and management Treatments vary depending on the type of cancer, as well as the benefits and risks of treatments. Treatments include surgery, radiotherapy, chemotherapy, hormone therapy, and complementary and alternative therapies.

The most common cancers in Australia are skin, prostate, bowel, breast, melanoma and lung cancer. Treatment of cancer can be more effective if it is found early (early detection). Screening a person for cancer is one way of detecting the disease early.

⁷ Sourced from the Cancer Council Australia <http://www.cancer.org.au/about-cancer/early-detection/general-advice.html>

Australia has population screening programs for cancer of the breast, cervix, bowel and prostate, that are available free of charge to eligible individuals. These cancers were chosen for screening programs because they are more common in the population than other cancers (bowel, breast and prostate cancer), and can be easily detected at an early stage (all four). A person who has a screening test may not have any symptoms at the time of screening.

As people with disability access screening services less frequently than the rest of the population, it is the carer's role to remind the person and the GP when a regular screening test is due. Difficulty accessing screening facilities and poor understanding of health issues are among the reasons for the less frequent use of screening services by people with disability.

For more information on the detection and prevention of cancers that occur in particular parts of the body **refer to the Health Promotion Guidelines** contained in the Health and Wellbeing Policy and Practice Manual.

Health professionals The GP is likely to be the first contact for a person who has symptoms that could indicate the presence of cancer. Initially, the GP's role is early diagnosis and referral to specialist services. The GP has a continuing role in follow-up after diagnosis and treatment, detection of a recurrence, and support for patients to survive cancer. The GP may develop a GP Management Plan if it is the best way of managing the person's illness following diagnosis and treatment of cancer.

2.4 Cardiovascular disease⁸

What is it? Cardiovascular disease is a common term for all conditions and diseases that affect the heart and blood vessels. Common cardiovascular diseases are:

- coronary heart disease
- deep vein thrombosis
- high blood pressure
- heart failure
- stroke
- angina.

Signs and symptoms Pain is associated with angina, deep vein thrombosis and heart attack. Other cardiovascular conditions e.g. high blood pressure, are often only detected during a health check.

Heart attack is a common cause of death from heart disease and it is important to recognise when a person is showing any of the following symptoms of heart attack:

- pain, pressure, heaviness or tightness in the chest, shoulder/s, neck, arm/s, jaw or back
- nausea
- dizziness
- cold sweat
- shortness of breath.

If a person experiences any or all of these symptoms **call 000 (or 112 on a mobile if 000 does not work)** for an ambulance. The sooner the ambulance attends, the less long term damage is done to the heart muscle.

Causes and risks People who are most at risk of heart disease are:

- older
- overweight
- inactive
- smokers
- socially isolated, depressed and lack social support

⁸ From Heart Foundation <http://heartfoundation.org.au/your-heart/heart-conditions>

or have

- heart defects from birth
- a family history of heart disease
- high blood pressure
- high cholesterol
- diabetes.

Treatment and management Following emergency treatment, the person's GP and carers can support a person to recover, and to achieve a good long term health outcome. Diabetics can be supported to manage blood glucose, keep within the normal range, and follow the doctor's advice. A person, who has a heart disease, can be supported and encouraged to make practical lifestyle changes that reduce the chance of another heart attack. For example, attendance at a cardiac rehabilitation program is known to help the person resume a productive life and function more efficiently following a heart attack.

For more information on how a person with cardiovascular disease can be supported to stay well through physical activity and healthy eating, refer to the Health Promotion Guidelines and Nutrition and Swallowing Guidelines contained in the Health and Wellbeing Policy and Practice Manual.

Health professionals The GP measures the person's blood pressure and performs general checks of heart function at the annual health assessment. If any abnormalities are detected, the GP prescribes treatments and, depending on the severity of the condition, may draw up a GP Management Plan or refer the person to a heart or vascular specialist.

2.5 Chronic Obstructive Pulmonary Disease (COPD)⁹

What is it? COPD describes long term lung conditions that cause shortness of breath, including chronic bronchitis and emphysema. Many people with COPD have a combination of emphysema, chronic bronchitis and asthma.

Signs and symptoms COPD gets worse over time with increased shortness of breath, coughing and lung secretions.

Causes and risks People at risk of COPD are smokers or ex-smokers, those experiencing long term exposure to irritants in their environment including second hand smoke, those with genetic predisposition and females.

People with cerebral palsy can develop COPD due to aspiration of food and fluids, repeated lung infections or gastro-oesophageal reflux disease (see section 2.5.1 below).

Treatment and management Supporting the person to manage the disease is the best way to improve lung function and relieve some of the symptoms.

People can be supported to manage COPD in various ways:

- stop smoking or avoid inhaling second hand smoke and other irritants
- seek help from health professionals
- understand and take GP prescribed medications
- join a COPD exercise program
- vaccinate against flu, pneumococcal and other infectious diseases
- seek treatment for a chest infection quickly
- join a support group.

Health professionals The GP may decide that the best way to manage the person's COPD is with a GP Management Plan or Team Care Arrangement. The person and carer follow the actions recommended in the plans to work with the doctor and other health professionals in keeping track of the person's health, and progress of the disease.

Carers can help the person to understand the management plan and support the person to follow the recommended actions. The doctor is consulted if the person is:

- having trouble following the management plan
- coughing more than usual
- more breathless or tired than usual
- otherwise obviously unwell.

⁹ The Australian Lung Foundation <http://lungfoundation.com.au/patient-support/copd/>

2.5.1 Cerebral palsy and respiratory problems¹⁰

What is it? Cerebral palsy is the term for a number of disorders that affect a person's ability to move. It is a permanent life-long condition, but generally does not worsen over time. It is caused by damage to the developing brain either during pregnancy or shortly after birth.¹¹

It is common for people with cerebral palsy, especially severe forms, to experience respiratory complications. People with cerebral palsy are often less able to cough properly and clear material from their breathing passages.

Signs and symptoms People with cerebral palsy, especially those who are not able to communicate, can have trouble expressing their discomfort, and respiratory problems can go undetected for a long time.

Some common signs of respiratory problems in people with cerebral palsy include:

- recurrent chest infections
- persistent cough
- noisy breathing
- breathing faster than normal, or difficulty breathing
- bluish or greyish colour of lips or fingernails

Causes and risks Lower mobility, reduced muscle function and structural deformity can all contribute to the risk of respiratory complications. They can cause:

- frequent aspiration of food and fluids
- dysphagia
- gastro – oesophageal reflux
- poor cough and airway clearance
- respiratory muscle weakness
- obstructive sleep apnoea.

Treatment and management Follow the treatment and management for COPD and pay additional attention to 24 hour positioning, mealtime management, oral hygiene, saliva and bowel management.

Health professionals Consult with occupational therapists, speech pathologists, physiotherapists, dentists, dental hygienists and dietitians for management of the specific needs of people with cerebral palsy.

¹⁰ MyChild <http://cerebralpalsy.org/about-cerebral-palsy/conditions/respiratory/>

¹¹ Cerebral palsy alliance <https://www.cerebralpalsy.org.au/what-is-cerebral-palsy/>

2.6 Dementia¹²

What is it? Dementia is a general term for loss of memory and other mental abilities that is severe enough to interfere with daily life. It is caused by physical changes in the brain and is often associated with ageing. There are a number of different types of dementia and the two most common forms are Alzheimer's Disease and Vascular Dementia.

Symptoms of dementia are also found in people with Parkinson's Disease, Huntington's Disease, Creutzfeldt-Jakob Disease (mad cow disease) and Wernicke-Korsakoff Syndrome (a thiamine deficiency mostly caused by alcohol misuse).

Early onset of dementia is seen in some syndromes associated with intellectual disability, for example, Down Syndrome.

Signs and symptoms People with dementia may have problems with:

- short-term memory
- keeping track of everyday items (purse or keys)
- paying bills
- planning and preparing meals
- remembering appointments
- travelling in unfamiliar areas.

Or show signs of:

- apathy and depression
- impaired judgement
- disorientation and confusion
- behaviour changes
- difficulty speaking and swallowing
- difficulty with mobility.

Changes in the brain that cause these symptoms are mostly permanent and get worse over time. Some conditions or lifestyle factors can cause thinking and memory problems, for example depression, medication, alcohol, thyroid, and vitamin deficiency. Thinking and memory problems can often be improved if the condition is treated.

Causes and risks Dementia is caused by damage to brain cells which prevents the cells having normal communication with each other. The body

¹² Alzheimer's Association <http://www.alz.org/dementia/types-of-dementia.asp>

functions that are affected by dementia will depend on the part of the brain that contains damaged cells.

Treatment and management Treatment depends on the cause and many types of dementia have no cure or treatment, for example, Alzheimer's Disease. However, there are drug treatments that can temporarily improve symptoms.

A medical assessment will identify symptoms that are caused by medications or other health conditions (for example, infection or pain, hearing or vision problems) and adjustments may be made to reduce the symptoms.

Other treatments can help reduce the behavioural responses that often accompany dementia. They include minimising the amount of change that occurs in the person's life, for example, changes in the familiar environment or changes of familiar care givers.

Other non-medical approaches include:

- monitor personal comfort
- avoid arguing about facts
- redirect the person's attention
- allow adequate rest between activities
- explore a range of solutions
- not taking the person's behaviour personally.

Health professionals The GP is likely to be the health professional to first diagnose dementia based on the person's medical history, physical examination, laboratory tests, and the characteristic changes in memory and day-to-day function associated with each type of dementia.

GPs can usually make a firm diagnosis of dementia from the range of tests they perform. But it is harder to be sure of the exact type of dementia because the symptoms and brain changes of different dementias can overlap. In some cases the GP may diagnose dementia but not the type. If this occurs the person may need to see a specialist such as a neurologist or psychiatrist.

2.7 Dental and oral disease

What is it? Dental and oral disease affects any part of the mouth, teeth and gums. The two main forms are tooth decay¹³ and gum disease¹⁴. Oral cancer¹⁵ can occur on the lips, tongue, gums, mouth and throat.

Tooth decay is a result of plaque build-up on teeth that allows bacteria to collect and convert sugars into acids and cause cavities to develop.

Gum disease is a result of plaque that builds up on teeth near the gum line. If left untreated teeth and bone are affected and teeth can be lost.

Signs and symptoms Tooth decay is usually detected during dental examination or by pain when chewing food.

Signs of gum disease are bleeding, redness and swelling of the gums. At a more advanced stage, bad breath, bad taste in the mouth and loose teeth are additional signs of gum disease.

Symptoms of oral cancer vary and include:

- a visible mass or lump that may or may not be painful
- an ulcer that won't heal
- a persistent blood blister
- bleeding from the mass or ulcer
- loss of sensation anywhere in the mouth
- trouble swallowing
- impaired tongue mobility
- difficulty moving the jaw
- speech changes, such as slurring or lack of clarity
- loose teeth and/or sore gums
- altered taste
- swollen lymph glands.

Causes and risks Tooth decay and gum disease are caused by a build up of plaque on teeth as a result of poor tooth brushing routines and frequent snacking on sugary foods.

¹³ <https://www.betterhealth.vic.gov.au/health/conditionsandtreatments/teeth>

¹⁴ <https://www.betterhealth.vic.gov.au/health/conditionsandtreatments/gum-disease>

¹⁵ <https://www.betterhealth.vic.gov.au/health/conditionsandtreatments/mouth-cancer>

The exact cause of oral cancer is unknown although tobacco use is thought to be a significant factor in most cases. Risks associated with oral cancer include:

- tobacco use
- regular and heavy alcohol consumption
- advancing age
- sun exposure
- poor diet
- poor oral hygiene and gum disease
- habitual chewing of the lips or cheeks
- irritants, such as breathing in smoky, or constantly polluted, atmospheres
- leukoplakia (light-coloured patches of atypical cells inside the mouth)
- herpes simplex infection (cold sores)
- human papilloma virus infection (warts)
- family history of cancer (genetic makeup).

Treatment and management Following treatment for cavities and plaque removal, ongoing oral and dental care is often performed by the person or carer. The dentist or oral hygienist can provide instruction on a tooth and gum cleaning routine that maintains good oral health.

General tips for good oral and dental health are to:

- have regular dental checks
- clean teeth at least twice a day after meals
- use fluoride toothpaste
- have a wide variety of nutritious foods
- limit intake of sugary foods and snacks – especially between meals
- drink plenty of tap water – especially if fluoridated.

Treatment of oral cancer depends on the size, type and location and whether it has spread and includes surgery, radiotherapy and chemotherapy. Ongoing monitoring is maintained to check for recurrence of oral cancer. Speech therapy or dietary advice may be required in addition to regular medical follow-up. Clinical psychologists, social workers and counsellors can also help people come to terms with the post-operative changes to their lives and appearance.

Tooth decay and gum disease are common problems for people with disability. Good oral hygiene requires constant monitoring and is aided by

using an Oral Health Plan. Refer to the Nutrition and Swallowing Guidelines and Health Planning Procedures for best practice in oral health and hygiene.

Health professionals The GP may be the first to detect the presence of tooth decay or gum disease during an annual health assessment and should refer the person to a dentist or oral health professional for diagnosis and treatment.

The GP is also likely to detect symptoms of oral cancer during a routine examination and would refer the person to a specialist for tests to determine the cause. Specialists provide treatment and management of oral cancer.

The GP has a continuing role in follow-up after diagnosis and treatment for detection of a recurrence and support for patients to survive cancer. The GP may develop a GP Management Plan if it is the best way of managing the person's illness following diagnosis and treatment of oral cancer.

2.8 Depression and anxiety^{16 17}

What is it? Depression is a serious and common illness. It refers to a feeling of being 'down' that can arise when things in life don't seem to be going well, or sometimes, for no reason at all.

A generalised anxiety disorder can develop over time and is associated with excessive worrying following a stressful event, or sometimes, for no reason at all. Other forms of anxiety disorder include:

- panic disorder
- post traumatic stress disorder
- obsessive compulsive disorder
- phobia.

Websites provide specific information about different forms of anxiety disorder.

Signs and symptoms Depression is associated with certain behaviours:

- moodiness that is out of character
- increased irritability and frustration
- finding it hard to take minor personal criticisms
- spending less time with friends and family
- loss of interest in food, sex, exercise or other pleasurable activities
- being awake throughout the night
- increased alcohol and drug use
- staying home from work or school
- increased physical health complaints like fatigue or pain
- being reckless or taking unnecessary risks (e.g. driving fast or dangerously)
- slowing down of thoughts and actions.

Anxiety disorders are associated with:

- persistent, excessive or unrealistic worries (generalised anxiety disorder)
- compulsions and obsessions which can't be controlled (obsessive compulsive disorder)
- intense excessive worry about social situations (social anxiety disorder)

¹⁶ The Black Dog Institute <http://www.blackdoginstitute.org.au/public/depression/depressionexplained/index.cfm>

¹⁷ beyondblue http://www.beyondblue.org.au/index.aspx?link_id=89

- panic attacks (panic disorder)
- an intense, irrational fear of everyday objects and situations (phobia).

Causes and risks Depression can be caused by a mix of personal factors and recent events.

Personal factors include:

- past bad experiences
- personality (worrier, perfectionist, shy, low self-esteem)
- high anxiety
- changes in the brain (brain injury, stroke)
- inherited tendency
- illness or medical treatment (thyroid, cancer, infection, chronic pain).

Recent events include:

- family or interpersonal conflict
- recent losses and disappointments
- poor working conditions
- drugs and alcohol
- medical illness or treatment (thyroid, cancer, infection, chronic pain).

Treatment and management The person's GP can treat depression or anxiety if the condition is at an early stage and not severe, or may choose to refer the person to a specialist. Other treatment options include hospitalisation, and a range of therapies that can help the person to recover from an acute episode and prevent it recurring.

Health professionals The GP has access to a number of Medicare items to treat a person with a mental illness. The GP assesses the person and develops a GP Mental Health Treatment Plan (items 2700, 2701, 2715, 2717) which includes access to psychologists. The GP provides ongoing management at an extended consultation under Medicare (item 2713).

The GP refers the person to a psychiatrist if the person's depression is severe, is complicated by medical problems, the person is likely to self-harm or requires intensive treatments or monitoring.

Similarly a person with anxiety may require referral to a psychiatrist if:

- the anxiety is severe
- it lasts a long time or comes back
- the person is likely to self-harm
- the person has failed to respond to treatment, or
- the GP doesn't feel sufficiently skilled to treat the person effectively.

2.9 Diabetes¹⁸

What is it? Diabetes occurs when the body produces insufficient insulin to undertake the normal body process of converting the glucose we eat in food into energy. There are various forms of diabetes, and Types 1 and 2 are the most common. In Type 1 the pancreas stops making insulin altogether, and in Type 2 it makes insufficient amounts.

Signs and symptoms Type 1 and 2 diabetes have many of the same symptoms:

- excessive thirst
- increased urine output
- tiredness and lethargy
- always hungry
- slow healing cuts
- itching, skin infections
- blurred vision
- unexplained weight loss (Type 1)
- gradual weight gain (Type 2)
- mood swings
- headaches
- dizziness
- leg cramps.

Causes and risks Type 1 diabetes is an auto-immune disease. Its cause is unknown but it does have a strong family link.

Type 2 diabetes has no single cause but risks are well known:

- family history
- age
- being overweight
- high blood pressure
- Aboriginal or Torres Strait Islander background

¹⁸ Diabetes Australia <http://www.diabetesaustralia.com.au/>

- having given birth to a child over 4.5 kg (9 lbs), or gestational diabetes during pregnancy
- some medications
- some auto-immune diseases.

Type 2 diabetes is a result of environmental and genetic factors and is more common than Type 1. The chance of developing Type 2 is greatly increased by association with any of the risks above.

Treatment and management Treatment of Type 1 diabetes requires insulin by injection up to four times a day. It is life threatening if not treated.

Type 2 diabetes is managed initially by healthy eating and regular physical activity. Eventually medication is needed in the form of tablets or insulin.

Type 1 diabetes is not curable or preventable. Type 2 diabetes may be prevented in many cases by following a healthy lifestyle of:

- maintaining a healthy weight
- regular physical activity
- making healthy food choices
- managing blood pressure
- managing cholesterol levels
- not smoking.

For more information on managing diabetes with healthy eating refer to the Nutrition and Swallowing Guidelines.

Health professionals People with Type 1 diabetes are generally referred to a specialist by the GP or hospital.

People with Type 2 diabetes may have a GP Management Plan and Team Care Arrangement. The Plan is developed by the GP to manage acute symptoms, blood sugar levels and other risk areas e.g. vision and wound healing, existing complications of diabetes and prevention activities.

Under a Team Care Arrangement the person with diabetes may access a diabetes educator, dietitian, endocrinologist, ophthalmologist, physiotherapist or podiatrist for ongoing support to maintain a healthy lifestyle and prevent or manage complications of diabetes.

2.10 Gastro Oesophageal Reflux Disease (GORD)¹⁹

What is it? GORD is described as frequent heartburn and occurs when the stomach contents wash back up into the oesophagus (reflux) and damage the lining.

Signs and symptoms GORD causes a range of mild to extreme symptoms, the most common and well known being heartburn. This is a burning sensation in the stomach or lower chest that rises into the throat. Other symptoms include:

- regurgitation causing a sour acid taste in the mouth
- difficult or painful swallowing
- nausea
- excessive burping
- chest pain
- bad breath
- chronic cough.

A person who is unable to verbally communicate symptoms of GORD may display the following symptoms:

- distress after eating
- apparent discomfort when eating
- stops eating or refuses food
- gags while eating
- excessive saliva and dribbling
- hiccups that won't stop
- night cough.

Causes and risks Symptoms of GORD usually appear after eating, and can be brought on by lying down or bending over. People who receive enteral feeding are prone to GORD and some medications can aggravate it.

Being overweight, smoking and drinking alcohol, are also among the risks for experiencing GORD.

Acid refluxing to the throat can cause pain in the throat or changes in the person's voice, and if acid regularly reaches the mouth, it can dissolve tooth enamel.

¹⁹ <http://www.mydr.com.au/gastrointestinal-health/gastro-oesophageal-reflux-disease>

Some people with GORD regurgitate acid into the lungs (aspiration) causing them to wheeze or cough. This can lead to aspiration pneumonia and cause serious health issues. It is a common condition in people with disability who have swallowing and other gut problems.

Treatment and management Avoiding foods or drink that make the symptoms of GORD worse, for example, alcohol, coffee, spicy or fatty foods, large meals and cigarettes, is a good start.

Aspirin and non-steroidal anti-inflammatory drugs may increase symptoms of GORD and should be discussed with the doctor who prescribed the medications, or where not prescribed, before using aspirin.

Milder symptoms can be managed with over-the-counter medications like antacids, but it is preferable to seek advice from the GP who is best placed to diagnose and treat GORD.

Treatment may start with medication, and be followed by tests if there is no relief from symptoms. Tests include an endoscopy, which allows the doctor to view the lining of the oesophagus and stomach for damage.

Oesophageal pH monitoring can be applied to test the gut's acidity, and is useful for diagnosing a cough that could be caused by GORD. Surgery may be considered if medication does not provide relief from symptoms.

Health professionals The GP and a gastroenterologist are responsible for treating the symptoms of GORD.

A team of allied health professionals may be required to support the management of symptoms:

- an occupational therapist for advice on correct positioning during and after meals to avoid reflux
- a speech pathologist to develop a **Mealtime Management Plan** for a person with eating and swallowing problems
- a dietitian to provide advice on foods that are suitable for a person with GORD and/or to develop an **Enteral Nutrition Plan**.

2.11 Osteoporosis²⁰

What is it? Osteoporosis refers to bones that have become weak because of calcium loss. It is not normally associated with pain and illness but, because bones become fragile and less dense, they break easily. Most commonly, breaks are in the spine, hip and wrist, and occur after a minor fall or knock.

Women are three times more likely to have osteoporosis than men.

Signs and symptoms There are usually no signs or symptoms of osteoporosis until a bone breaks.

In older people a loss of height can be a sign of osteoporosis, resulting in compression of the bones of the spine which can be painful and cause stooping²¹. This can increase the risk of falling and lead to difficulty with digestion and breathing.

Hip fractures require hospitalisation and surgery, and recovery can be painful and prolonged. They may also result in permanent loss of mobility.

Causes and risks There are a number of factors that can put a person at risk of osteoporosis:

- family history of osteoporosis (mother, sister or grandmother) or fractures at older age
- insufficient calcium in the diet
- low vitamin D levels
- cigarette smoking
- alcohol intake of more than two standard drinks per day
- caffeine intake of more than three cups of tea, coffee or equivalent per day
- lack of physical activity
- entering menopause before the age of 45
- loss of menstrual period (and reduced oestrogen) e.g. following excessive dieting and exercise
- long-term use of medications such as corticosteroids for rheumatoid arthritis and asthma.

Some health conditions can increase the risk of osteoporosis, for example:

- thyroid disease or an overactive thyroid gland

²⁰ <http://www.betterhealth.vic.gov.au/bhcv2/bhcarticles.nsf/pages/Osteoporosis>

²¹ <http://www.bonehealthforlife.org.au/about-osteoporosis/implications>

- rheumatoid arthritis
- chronic liver and kidney disease
- conditions that affect the body's ability to absorb nutrients, such as Crohn's disease, Coeliac disease and other inflammatory bowel conditions.

Treatment and management Men and women can take steps to develop and maintain bone density and prevent osteoporosis by:

- having a healthy and varied diet with plenty of fresh fruit, vegetables and whole grains
- eating calcium rich foods e.g. dairy food, canned sardines, white or kidney beans, sweet potato, green leafy vegetable, almonds, brazil nuts, pistachio nuts and hard tofu
- getting enough Vitamin D (10 – 20 minutes of sun exposure each day, before 11am and after 3pm)
- avoiding or stopping smoking
- drinking less alcohol (no more than 2 drinks per day)
- drinking less tea and coffee (no more than 2 cups per day)
- doing regular weight-bearing and muscle strengthening activities e.g. walking, dancing, using weights.

People who are diagnosed with osteoporosis can be treated to reduce bone loss and reduce the risk of fractures with medication. While minor falls or even coughing can result in a fracture at any age, older people are at particular risk of falling, and could benefit from having a falls prevention assessment.

The best management of osteoporosis is to develop strong bones early in life, eat well, be active and avoid the known risks where possible.

For more information on managing osteoporosis with healthy eating refer to the Nutrition and Swallowing Guidelines.

Health professionals People may be diagnosed with osteoporosis in a variety of ways:

- the GP orders a bone density scan for women entering menopause
- scanning a person on long term corticosteroids
- during treatment for a fracture following a minor fall or knock.

The GP or a specialist (endocrinologist or rheumatologist) will diagnose osteoporosis, and recommend treatments to reduce its progression and to prevent bone fractures.

3 Policy and Practice Unit contact details

You can get advice and support about this Policy from the Policy and Practice Unit, Contemporary Residential Options Directorate.

Policy and Practice, Service Improvement
Contemporary Residential Options Directorate
ADHC
policyandpracticefeedback@facs.nsw.gov.au

If you are reviewing a printed version of this document, please refer to the Intranet to confirm that you are reviewing the most recent version. Following any subsequent reviews and approval this document will be uploaded to the internet and/or intranet and all previous versions removed.