CARING FOR SOMEONE WITH BLADDER OR BOWEL PROBLEMS
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Acknowledgements

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Introduction

This book has been written for carers to help them understand and manage the bladder or bowel problems of the person they care for.

People often find bladder or bowel problems, otherwise known as incontinence, difficult to talk about. There are many causes of incontinence. For carers, the clinical details are less important than knowing how to manage episodes of incontinence, including the right equipment and where to get it. Carers also want to know who to contact when they need help.

Who is a carer?

Carers provide care or support to a family member, friend or other person who needs assistance. Carers come from all walks of life, cultures, religions and age groups. A carer might be a spouse, sibling, or a close or distant relative. They may be friends, neighbours or others who are willing to contribute to the care of another person in some way. Carers often provide care and support for another person who, because of illness, disorder or disability, needs care and support to function in life.

Carers may take on the role unexpectedly due to sudden changes in another person’s health, or the role may develop more slowly in response to gradually changing needs. Care might be required for a period of time or continuously, and provided to a person of any age.

What is incontinence?

Incontinence is the accidental or involuntary (i.e. uncontrolled) loss of urine from the bladder or bowel motion from the bowel. Incontinence is not just a problem for older people or people with a disability; however, people from these two groups are at a greater risk of developing incontinence. Poor mobility, memory problems and chronic health problems such as Parkinson’s disease, stroke, dementia and multiple sclerosis, greatly affects bladder and bowel control.

With a good continence assessment, management and treatment program, incontinence can sometimes be cured. If it cannot be cured, it can be improved or better managed.

Caring for a person with incontinence

There are many roles and duties involved in being a carer. Managing incontinence adds to this workload significantly and may in some situations create demands that are so great that they are beyond the capacity of the carer to manage. Incontinence and the stress that it generates for carers is one of the most common factors leading to the decision that a person must move from home into a residential care setting.
Most carers report that they need help and guidance to cope with the person’s incontinence and need practical information to help them deal with the daily realities of incontinence at home and when going out. Some may want to deal with it themselves while others want to know who to call for help.

Balancing the responsibilities of the carer and not overstepping the right of the person being cared for can be difficult and is dependent on the physical and intellectual ability of the person being cared for. Regardless of the situation, it is advisable for carers to communicate as much as possible with the person being cared for and seek agreement where possible. If the person being cared for is able and willing to initiate the steps to seeking help, encourage them in these areas of independence.
Part one: Where to start?

Caring for someone with incontinence can sometimes feel overwhelming. However, there are services available to help you and the person you are caring for to better manage the issue. The following services are a good first step in addressing problems that are experienced. As previously mentioned, it is important both the carer and the person being cared for, where possible, clearly discuss the reasons and need for seeking help.

Step 1: Symptoms requiring immediate attention

- If the problem comes on suddenly, see a doctor to make sure it is not an infection;
- If the person being cared for suddenly CANNOT pass urine, see a doctor IMMEDIATELY as this may be a medical emergency;
- If the person is constipated, see the doctor about treatment options. Constipation can also impact bladder control; and
- See a doctor or a specialist if there is ongoing diarrhoea.

Step 2: Services available

National Continence Helpline 1800 33 00 66

The National Continence Helpline on 1800 33 00 66 is staffed by a team of continence nurse advisors who provide information and advice to people affected by, or caring for someone with a bladder or bowel problem. The Helpline provides free confidential information on continence-related topics, products and financial assistance schemes, and can provide contact details for local continence services. The Helpline is available to Australian residents, and operates 8am to 8pm (AEST) Monday to Friday (except national public holidays).

Interpreter services

To arrange for an interpreter through the Translating and Interpreting Service (TIS), phone 13 14 50 Monday to Friday and ask for the National Continence Foundation Helpline. Information is also available in other languages from continence.org.au/other-languages.

If you are deaf, or have a hearing or speech impairment, contact the National Relay Service:

- TTY users 1800 555 677
- Speak & Listen 1800 555 727

Then give number 1800 33 00 66. For further information visit relayservice.org.au
Other health professionals who can help

Doctor (GP)

The doctor will discuss the incontinence issues and possibly examine the person being cared for. Some treatments will be carried out by the doctor, while others may need referral to a specialist, continence nurse advisor or pelvic floor physiotherapist. Ask the doctor for a referral if needed.

It is important to involve the doctor in the care if possible. If it is a family doctor, they will know the family health history and current medications. Seek advice on all available treatment options. Arrange for a full check-up at the next visit with the person being cared for and discuss all their medicines and their possible effect on incontinence. Discuss the management of any other conditions to reduce their effect on incontinence.

It will help to write down all the issues and the questions you have to ensure you cover all the areas of concern. It is important to let the person being cared for tell their own story where possible. It is helpful to take the following items to the doctor’s appointment:

- a fluid diary;
- a bowel diary;
- a record of what the person eats in a day;
- a list of medicine they are taking, including those you can buy over the counter (or show the doctor the tablet packets); and
- observations of any changes in the person’s behaviour or activities.

Questions to ask the doctor:

- What is causing the incontinence?;
- Could medicine be causing it, or making it worse?;
- Do they need to be examined?;
- How can we prevent it or manage it?;
- Will medicine fix it?;
- Will they need tests?;
- Will they need surgery?;
- Where can I get help to buy the pads and products?;
- Are there any funding schemes to assist with costs?; and
- Should we see someone who specialises in this problem, e.g. a continence nurse advisor or specialist doctor?

A visit to the continence nurse advisor may need referral from the doctor. Phone the National Continence Helpline (1800 33 00 66) to find a continence nurse advisor near you.
Continence nurse advisors
A continence nurse advisor is a nurse with specialised training in continence care who can assess incontinence and advise on treatment and management.

Pelvic floor physiotherapists
A pelvic floor physiotherapist has specialised training in pelvic floor rehabilitation, including continence assessment and management. They work with the person being cared for and assist them to use the pelvic floor muscles correctly.

Step 3: Continence assessment
It is recommended to see a doctor or continence nurse advisor to be assessed for continence problems. This assessment will help you as a carer to manage the incontinence problems with the person you are caring for.

You may be asked to attend an appointment for a continence assessment with the person you care for. You or the person you are caring for will be asked to fill out a chart to show when they pass urine or have a bowel motion. A physical examination is likely as this will let the continence nurse advisor know what kind of continence problem the person you are caring for has.

The sorts of questions that will be asked during a continence assessment include:

- how often they go to the toilet;
- how much urine is passed;
- what their bowel actions look like;
- how often and how much leakage is occurring;
- their fluid intake and diet;
- what current medicine they take;
- other health problems they experience;
- their ability to perform self-care tasks such as toileting, dressing, getting to and from the toilet; and
- any changes in behaviour prior to or during toileting.

It is important to inform the nurse if there are any changes in the symptoms.
Part two: Understanding incontinence

Chapter 1: The bladder and bowel

The bladder and bowel organs sit in the pelvis and are supported by the pelvic floor muscles. The urine, made in the kidneys, passes through the urethra. Bowel motions pass through the anus.

Chapter 2: Bladder problems

It is a common belief that drinking fluid may increase the risk of wetting themselves, so people will refuse to drink to avoid this risk. Fluid is everything a person drinks. Fluid includes milk, juice and soup. The best fluid to drink is water.

While this belief is understandable, it is not the right approach to take. In fact, not drinking enough fluid may cause urinary incontinence, constipation and dehydration. It is important to see a doctor or continence nurse advisor and not wait for the symptoms to get worse in the person you are caring for. The sooner advice is sought the easier it is to understand and manage these problems.

Types of urinary incontinence

Stress incontinence

Stress incontinence is urine leakage usually associated with a physical activity such as coughing, laughing, lifting or physical exertion. The most common cause is weak pelvic floor muscles, which can be aggravated or made worse by another medical condition such as asthma. Management of incontinence may also include treatment for other medical conditions.
Urge incontinence (overactive bladder)

Urge incontinence is urine leakage associated with a sudden and uncontrollable need to pass urine. People with urge incontinence find it difficult to make it to the toilet on time. It can also be related to nocturia (waking at night to pass urine). The cause may be due to the bladder muscle spasming, which makes it hard for the bladder to hold urine. This can happen at any age, but it becomes more common as people get older.

Incontinence associated with chronic retention (i.e. difficulty in emptying the bladder)

Incontinence associated with chronic retention happens when urine leaks out from an already over-full bladder resulting from an obstruction. The bladder does not empty completely and urine continues to fill the bladder, which then overflows with little sensation or warning.

Other problems that affect the bladder

There are other problems that can cause or worsen urinary incontinence:

- Urinary tract infections (UTIs) are usually associated with pain or burning when passing urine, although an older person might not have these symptoms. Therefore check for other symptoms such as high temperatures, a sudden need to go to the toilet more frequently or urgently, smelly urine and confusion;
- Not drinking enough fluid makes urine more concentrated. This may irritate the bladder and give a feeling of urgency;
- Drinking too much fluid or too quickly can cause the bladder to fill quickly and often;
- Going to the toilet more often than you need to, or just in case, trains the bladder to hold less urine and increase the number of trips to the toilet;
- Constipation (a rectum full of hard faeces) puts pressure on the bladder and urethra, where it cannot completely empty, or causes frequency;
- Caffeine drinks (such as tea, coffee and cola) can upset or irritate the bladder;
- Alcohol increases production of urine and can also cause frequency;
- Some medicine taken for other health conditions can affect your bladder and bowel. For example, water tablets (diuretics) make the kidneys produce urine more quickly, increasing urgency and frequency to pass urine. Discuss all medicine (both prescription and over the counter) with the doctor or pharmacist, and do not change or stop taking any medication without seeking the doctor’s advice;
- Prostate-related problems (refer to the section on prostate); and
- Chemotherapy or radiotherapy can cause cystitis (inflammation in the bladder).

Urinary incontinence in men with prostate problems

The prostate is a gland found only in men. It is approximately 3cm in diameter - about the size of a walnut. The urethra (the tube that carries urine to the outside) passes through the prostate. In younger men, the size of the prostate changes little. However, as men age, particularly beyond 45–50 years, the prostate enlarges, and may press on the urethra. This can cause an obstruction or blockage to the flow of urine.
Treatment for obstructed urine flow from prostate enlargement can be by medication and/or surgery.

Medication works by relaxing the bladder neck and/or decreasing the size of the prostate to allow improved urine flow. Surgery works by removing the inner part of the prostate that is causing the obstruction or blockage to improve urine flow. All surgery carries risks. Risks such as urinary incontinence and erectile dysfunction (impotence) after this sort of operation should be discussed with the urologist (specialist surgeon).

For prostate problems and surgery-related incontinence, a range (and combination) of treatment approaches are available.

**Chapter 3: Bowel problems**

The best way to keep the bowel healthy is to avoid constipation and have a regular bowel action. Bowel regularity varies depending on the person.

**Types of bowel problems**

Bowel problems can happen for many reasons and can be associated with:
- being unable to hold onto bowel motions;
- being unable to fully empty the bowel; and
- issues relating to toileting process (e.g. sensory, physical or behavioural).

**Constipation**

Constipation is the difficulty of passing a bowel motion that may be very hard. With constipation, bowel motions are often passed less than three times a week. There is often the feeling that the rectum (back passage) has not completely emptied after having passed a bowel motion (bloated sensation). The person you are caring for may have fewer bowel actions than usual and start straining to pass these dry, hard motions.

People who have trouble with constipation may not feel hungry or may become listless, tired, have headaches or stomach cramps. The constant straining may lead to haemorrhoids (or piles) and anal fissures (tears with bleeding in the anus).

Severe constipation or faecal impaction are by far the most common causes of bowel leakage (otherwise known as faecal incontinence), especially in the elderly population. Hard bowel motions are difficult to pass and may cause a partial blockage in the lower bowel, resulting in watery faeces flowing around the bowel motion without warning. This may be mistaken for diarrhoea.

Constipation has many possible causes, including:
- not eating enough fibre (fruit, vegetables, high-fibre bread and cereals, nuts, seeds and legumes);
- not drinking enough – always drink more when you increase the fibre in your diet;
- (more fibre without increased water is even more likely to make the bowel motions harder);
- not exercising enough or reduced general activity level;
- the side effects of some medicines (such as pain-killers or iron tablets);
- not being able to go to the toilet because of poor mobility or problems with standing, walking or sitting;
- some diseases of the nervous system such as Parkinson’s disease and Multiple Sclerosis;
- some bowel problems – haemorrhoids, irritable bowel syndrome, or diverticulitis;
- anorectal pain (pain to the anus and the rectum) caused by haemorrhoids, fissures, surgery or birth trauma;
- a slow transit bowel (this may be due to nerve damage as a result of a stroke, Parkinson’s disease, Multiple Sclerosis, spinal cord injury or trauma);
- refusal to empty the bowels due to behavioural or sensory issues; and
- poor toilet habits —
  — not sitting on the toilet properly
  — ignoring the urge to go to the toilet to pass a bowel motion
  — rushing when on the toilet
  — hovering over the toilet instead of sitting.

**Effects of long-term constipation**

**Faecal impaction**
This may happen when a healthy bowel action has not occurred for a long time. The bowel is unable to pass bowel motion and they become impacted in the bowel.

**Haemorrhoids (piles)**
This condition can happen when constant straining on the toilet to pass a motion causes small blood vessels in the bottom (anus) to get bigger and can sometimes bleed and cause pain.

**Rectal prolapse**
This is an extreme result of long-term straining on the toilet to pass a motion, resulting in part of the bowel to extend beyond the anus.

**Urinary incontinence**
This condition arises when long-term straining weakens the muscles of the pelvic floor, which can make bladder control more difficult.

**Retention of urine**
This condition may happen when a full bowel presses on the bladder. This may obstruct the flow of urine or reduce the amount of urine the bladder can hold.

**Faecal incontinence – diarrhoea**
Losing control of the bowel is called faecal incontinence. This most commonly takes the form of diarrhoea.
Diarrhoea is the passing of frequent, urgent, loose bowel motions. If a toilet cannot be found in time, leakage or faecal incontinence may result. Diarrhoea has many possible causes, including:

- use of laxatives, especially if overused or used incorrectly;
- bowel or stomach infection such as gastroenteritis;
- bowel diseases such as diverticulitis, Crohn’s disease, ulcerative colitis and irritable bowel syndrome;
- some antibiotics;
- a shortened bowel or intestine (following surgery to remove some of the bowel);
- food allergies or intolerances – e.g. wheat, gluten, lactose, dairy, fructose; and
- radiotherapy and chemotherapy.

It is important to find the cause of the diarrhoea. A doctor can help with this.

**Faecal incontinence – other problems**

Faecal incontinence can also be caused by muscle weakness or damage to the anal sphincter muscles that hold the anus closed (from childbirth) or conditions such as Multiple Sclerosis and Parkinson’s. Weakened pelvic floor muscles can contribute to other bowel difficulties such as control of wind, faecal urgency or rushing to the toilet to pass a bowel motion, and soiling (faecal incontinence).

If there is any change in bowel patterns, bleeding from the anus or blood in the bowel motion, always seek the advice of a doctor.
Part three: Practical tips to manage incontinence

Chapter 1: What to do if the person you are caring for has urinary incontinence?

Encourage them to drink sufficient fluids (preferably water). Remind them to drink throughout the day and provide them with more fluids if the weather is hot or when exercising.

Reducing fluid intake may make things worse, not better, as concentrating the urine may irritate their bladder lining and may lead to constipation.

Don’t give them too much to drink from dinner time onwards to minimise frequent trips to the toilet overnight (once a night is considered normal).

Don’t get into the habit of taking the person you are caring for to the toilet just in case. Go only when the need arises.

Cut down on their caffeine drinks (such as coffee and tea) and carbonated beverages as these may dehydrate by increasing urine production. Try decaffeinated drinks instead. Chocolate and some sports drinks also contain caffeine.

Encourage them to maintain an ideal body weight. Being overweight is a high-risk factor for incontinence. Discuss weight management with a doctor or a dietician.

Visit a doctor as soon as you suspect a urinary tract infection (UTI). If UTI is a common event, discuss how to manage this.

Avoid constipation as this can affect the bladder. If the person strains when using the bowels, it can weaken the pelvic floor muscles over time.

Regular exercise helps with general strength and fitness. Exercise can also help to regulate the bowel pattern. If arthritis or other medical problems prevents them from exercising regularly, discuss this with the doctor or physiotherapist to see if there are other forms of exercise that are suitable.

A chronic cough, such as with asthma, can strain and weaken the pelvic floor muscles that control bladder and bowel function. Management for incontinence may also include treatment for other medical conditions.

Talk about it. A doctor, continence nurse advisor, pelvic floor physiotherapist or other health professionals can help improve and better manage incontinence issues of the person being cared for. Discussing bladder or bowel problems, especially for the first time, can be confronting. Continence professionals have specialised knowledge around this area of health and they are also aware it is a sensitive and emotional issue.
**Swallowing**

Due to medical or physical conditions, people can sometimes choke or cough when swallowing. If this happens when the person you are caring for is drinking, this may mean the fluid is going down the wrong way which can cause problems such as chest infections. They may be reluctant to drink as a result. The doctor can make a referral to a speech pathologist, who may recommend thickened fluids to overcome this problem.

**Managing stress incontinence**

If the person you are caring for leaks urine or faeces when they cough or sneeze, doing pelvic floor muscle exercises may help improve this problem. Strengthening these muscles through exercise helps to hold the bladder and bowel in place. This improves bladder control and can reduce or stop leakage of urine and faeces. Like other muscles, the pelvic floor muscles will become stronger with a regular exercise program.

Pelvic floor muscle exercises (if appropriate) are most effective when individually tailored and monitored by a continence physiotherapist or continence nurse advisor.

Managing urge incontinence

Managing urge incontinence may improve bladder control by:

- reducing the degree of urgency and accidental leakage of urine;
- gradually increasing the storage capacity, or size, of the bladder; and
- increasing the period of time between visits to the toilet.

Seek professional help for assistance and treatment. Contact the National Continence Helpline on 1800 33 00 66 or the Continence Foundation of Australia (continence.org.au) for referral to a local continence nurse advisor or continence physiotherapist for advice about bladder training.

**Managing incontinence associated with chronic retention (i.e. bladder not emptying properly)**

Incontinence associated with chronic retention occurs when the bladder doesn’t empty completely, resulting in uncontrolled urine loss.

When diagnosed, this problem should always be treated and monitored by a continence nurse advisor. If ongoing incontinence is not managed by emptying the bladder regularly (e.g. with a catheter), damage to the kidneys may occur due to backflow of urine to the kidneys.

If the person being cared for is experiencing symptoms of incontinence associated with chronic retention, it is important to immediately bring this to the attention of a doctor who can organise tests to diagnose the problem.

Some of the causes, such as constipation (when very hard bowel motions fill the rectum) or enlarged prostate, are treatable. Conditions that may impact on the bladder and the nervous system (such as diabetes) need to be closely monitored to prevent damage to the kidneys.
Chapter 2: What to do if the person you are caring for has bowel problems and faecal incontinence?

Diet and nutrition

In many cases incontinence is linked to other major health conditions or disabilities such as diabetes, obesity, heart problems, stroke, cancer, prostate and kidney problems, and neurological conditions such as spina bifida autism, spinal cord injuries and Parkinson’s disease. To prevent or better manage incontinence, the Continence Foundation of Australia promotes a healthy diet and lifestyle along with good bladder and bowel habits.

Encourage the person you are caring for to drink normally and to drink fluid every day. Fluid includes water, milk, juice, tea, coffee, soup, jelly and ice cream. The best fluid to drink is water. Fibre and fluid work together to keep bowel motions regular. Without enough fluid, bowel motions may become dry and difficult to pass. Minimise the consumption of alcohol and caffeine as they can irritate the bowel.

Provide regular meals. Skipping meals often results in a larger meal later in the day, which is not good for their digestion. Include a variety of foods from each of the key food groups, with an emphasis on high-fibre foods to prevent constipation.

Fibre is found in plant foods. These foods include wholegrain breads, grains, cereals and cereal products such as porridge, fruit, vegetables, legumes, nuts and seeds. It is important to mix these different fibres. Avoid or reduce the intake of low-fibre products made from white flour, refined breakfast cereals, cakes, biscuits and pastries, fruit and vegetable juices and most fast foods, which tend to be high in fat and sugar.

Increase the fibre intake slowly by making one change a week to avoid gas, bloating, cramps and diarrhoea, which may result when building up fibre intake too quickly. Increase their fluid as they increase their fibre. Foods such as fruit and vegetables can be pureed or vitamised preserved or stewed. This will help soften the bowel motions as well as adding fluid to the body.

Activity and exercise

Being overweight has been found to have a big impact on bladder and bowel health. Daily exercise and dietary habits are very important in reducing any bowel problems. Exercise stimulates or triggers the bowel to move. Even gentle exercise such as walking is useful. If possible, exercise daily.

Managing constipation

As well as increasing dietary fibre and exercising regularly you can reduce their likelihood of constipation by:

- Maintaining a regular bowel pattern. They are more likely to use their bowels after a meal. A hot drink often promotes bowel movement. The strongest urge is usually about 30 minutes after breakfast but this can be different for everyone;

- Encourage them to use their bowels when there is the urge to do so. Delays in going to the toilet will result in the urge disappearing and increasing the risk of constipation;
Look for signs if the person is non-verbal such as flushed face and strained expression or noises, tugging at clothes and different rituals; and

When using the toilet, recommend the person you are caring for:
- Sit on the toilet properly (don’t hover over it);
- Lean forward, keeping the back straight. A small footstool may be required to firmly position their feet;
- Relax and push out their tummy to widen their waist;
- If the person is tense, relax them by providing music or other distractions; and
- Firmly pull up the muscles around their anus (back passage) as this helps to fully relax the pelvic floor and anal sphincter muscles.

Knees higher than hips. Lean forward and put elbows on your knees. Push out your stomach. Straighten your spine.

**Medicine for constipation**

It is best to seek professional advice on laxatives, as there are several types available, including bulk-forming agents, softeners, osmotics and stimulants. The correct choice for the needs of the person you are caring for is very important and a continence nurse advisor or doctor can help select the best one. Ask the health professional for assistance with dosages: what to take, how much, how often and for how long.

Sometimes a suppository or enema is needed at the start to clear the rectum of hard bowel motions, particularly if they have been constipated for two to three days or more. Always consult the doctor if constipation persists and ask for a long-term management plan if the person you are caring for is regularly constipated.
Managing diarrhoea

See the doctor or a specialist if there is ongoing diarrhoea. Bowel diseases (such as Crohn’s disease) can cause diarrhoea and require close medical management to stabilise the condition and overall health. Diarrhoea or loose bowel actions can be more difficult to control than formed motions. There are foods that trigger diarrhoea and others that help to settle the bowel, so changing the diet may help. For example, some of the coarse, insoluble fibre foods such as wholegrain, skins and seeds and certain vegetables can trigger diarrhoea, while the soluble fibre foods such as smooth wholemeal breads and cereals like porridge can help to form bowel motions.

Sometimes a specific type of fibre supplement can help. See the doctor or a dietician for more advice about these. It may be necessary to increase their fluid intake to replace fluids lost in bowel motions.

Chapter 3: Medication

Some medicine can interfere with bladder and bowel function. Medicine can be anything prescribed by the doctor and/or specialist, purchased over the pharmacy counter, at the health food store or at the supermarket.

It is important to let the doctor know all the medicine the person you are caring for is taking. Never give one person’s medicine to another person.

If you think any medicine prescribed by the doctor may be causing a problem, get advice from the doctor.

Medicine that may affect the bladder includes:
- fluid tablets (diuretics);
- antihistamines (for hay fever);
- blood pressure tablets (antihypertensives);
- strong pain killers (analgesia);
- antidepressants;
- medicine for Parkinson’s disease;
- sleeping tablets;
- medicine for constipation; and
- antipsychotic and other tranquilising medications.

Medicine that may affect the bowel includes:
- antidepressants;
- sleeping tablets;
- medicine for Parkinson’s disease;
- anti-inflammatory tablets;
- strong pain killers;
- medicine for constipation;
- fluid tablets;
medicine used for bladder control;
calcium or magnesium products (for strong bones or indigestion);
antipsychotic and antidepressant medications; and
antibiotics.

Chapter 4: Products and equipment

For some people, it is necessary to use continence products such as pads, pants, catheters, condom drainage, or bed protection to manage urinary and/or faecal incontinence. The use of continence products should manage any leakage and maintain the person’s dignity.

There are a wide range of products on the market. Assessment by a continence nurse advisor is encouraged to make sure the best product is chosen. They teach how to use and care for these products. The National Continence Helpline can also provide product information and the details of local and national continence product suppliers.

Getting financial assistance

Many people find the cost of continence products very expensive. Their cost varies greatly depending on the degree and type of incontinence, and the type and quantity of product needed. Because of the cost, it is important to get the most suitable product at the best price. This information can be provided by a continence nurse advisor to best meet individual needs.

They can also advise about continence product funding schemes administered by the Australian Government and state/territory government departments. These have differing requirements for eligibility and varying amounts and types of continence products that are funded.

The National Continence Helpline (1800 33 00 66) can provide information about local funding schemes and provide the contact details for local agencies.

More often than not incontinence is linked with other chronic health conditions or disabilities. As a carer for someone who is likely to have one of these health conditions or disabilities, you may be eligible for financial assistance from the government.

To find out more and assess your eligibility, contact:
- Carer Advisory Service on 1800 242 636;
- Centrelink on 132 717 or humanservices.gov.au;
- Department of Veterans’ Affairs on 133 254 (metro) or 1800 555 254 (regional) or dva.gov.au; and
- other health professionals associated with the care, including the doctor.
**Pads and pants**

Pads come in many shapes and sizes and can be disposable or washable (reusable). The choice will depend on the:

- type of incontinence;
- amount of urine or bowel motion lost;
- your physical capabilities and that of the person you are caring for;
- personal preferences (e.g. comfort, size, colour); and
- cost.

When you are caring for anyone wearing a disposable pad, remember to:

- always wear disposable gloves (available from supermarkets and chemists) when in contact with urine or faeces to protect yourself;
- wash and carefully pat dry the skin each time you change the pad;
- use barrier creams and moisturisers to protect the skin from perspiration, urine or faeces but check with the pharmacist about whether the cream chosen will affect the absorbency of the pad;
- find a pad that better suits the person’s level of incontinence if the continence pad leaks; and
- immediately see a doctor if the skin becomes red and is sore.

**Disposable pads**

Some disposable pads are available at supermarkets, pharmacies and medical suppliers. Some companies and suppliers will offer free samples for trial upon request. Disposable pads are available in many shapes, sizes and absorbencies.

Disposable pads are convenient, but cost can be an issue. Disposable pads contain absorbent material that hold varying amounts of urine and are designed to be worn with firm fitting underwear or stretch pants. Some people need different or more absorbent continence products overnight for a good night’s sleep. Some pads are specifically designed for faecal incontinence. It is important to use a pad that fits snugly because a pad that is too big or too small or does not fit closely can leak and also cause skin rashes and skin irritation. This is why an assessment by a continence nurse advisor is helpful in determining which products are appropriate for the person you are caring for.

**Small pads**

Small stick-on pads are best for small to moderate urinary incontinence. There is a range of sizes, from thin, flat panty liners to larger, thicker pads with gathered elastic sides. There are disposable pads and pouches specifically for men with urinary incontinence. These pouches are mainly available for light leakage.
Choice will depend on:

- amount of urine lost;
- how often they use the toilet;
- ability of the person to manage the sticky strip on the back of the pad; and
- ability of the person to pull down their underwear.

**Shaped pads**

Shaped pads are larger disposable pads designed for larger urine loss.

They are shaped like an hourglass to fit between the legs and around the body.

Some have elastic gathers along the sides to ensure a closer fit to the body and prevent leakage.

Shaped pads need to be worn close to the body by using stretch pants. Stretch pants are an elastic fitting stretch pant that hold pads firmly against the body to prevent leakage. They can be bought in various shapes and sizes for comfort.

Manufacturers recommend they be worn with the side seams on the outside to avoid pressure areas on the skin.

Choice will depend on:

- amount of urine lost; and
- whether the person can wear and manage tighter fitted underwear.

**All-in-one pads**

All-in-one pads are a full-sized brief that wraps around the body and seals with reusable adhesive tape. They hold large amounts of urine (many up to two litres) and are suitable for people who cannot walk or stand, or require a carer to change the pad. You will be able to change the pad while the person is lying down. Advice from a continence nurse advisor is important to ensure the person has the correct fit and type.

Choice will depend on:

- the amount of urine lost;
- the size and weight of the person;
- whether the person has any difficulty getting to the toilet;
- whether the person is confused or has any mental health problems; and
- whether the person has any skin reactions to a full-brief pad.

Remember to:

- wash and carefully pat dry the skin each time you change the all-in-one; and
- use barrier creams and moisturisers to protect the skin, first checking with the pharmacist about whether the cream will affect the absorbency of the pad.
Disposable pants (adult pull-ups)

Adult disposable pull-up pants are designed to hold larger amounts of urine. They fit like regular underwear but have a shaped section between the legs to absorb and contain the urine. They are useful for people with dementia or confusion because they feel like underwear.

Choice will depend on:

- how much urine is lost; and
- whether they are able to manage these pants by themselves.

Disposal of pads

It is important to think about how the used pads will be disposed of.

In practical terms, and to ensure the health standards are met, bowel motions must be flushed down the toilet. This means emptying the faeces into the toilet before discarding the pad.

Once this has been done, used pads can be placed in a plastic bag or wrapped in newspaper and sealed before placing into garbage/rubbish bins.

Reusable products

Reusable items are more expensive to buy but less costly over time. They require washing and drying between use. They include pads and pants with built-in pads. Some reusable pads need attaching to special reusable underpants. Pants with built-in pads are designed to be worn like underpants.

Reusable items need to be replaced every 6 to 12 months.

To prolong the life of reusable products, care must be taken to ensure they are washed according to the manufacturer’s instructions. Wash reusable garments before putting on the person for the first time.

Reusable padded briefs/all-in-ones

Reusable briefs come in a variety of sizes, colours and designs for both men and women. They can be either pull-ups or have studs down each side.

These will suit people:

- with small-to-medium urine loss;
- who are confused and may flush pads down the toilet;
- who are immobile; and
- who cannot wear disposable pads.

Alternatively, a reusable and washable body stocking can be used to hold an all-in-one in place for someone who removes the pads all the time.
**Tips when buying pads**

Depending on the needs of the person being cared for, different pads may be needed for different circumstances, for example:

- a larger all-in-one pad for overnight;
- a small, cheaper pad when at home during the day; and
- a better, more secure pad for going out and about.

A continence nurse advisor can help in the decision.

The supermarket has pads readily available, but only in a limited range.

If you have to change to a different pad, try to get a sample first or buy a packet before buying a carton.

It is cheaper to buy a whole carton of one product, however, this may not be an option due to the more expensive up-front cost or a storage problem. Local medical suppliers will have more information on bulk purchase.

Some pharmacies have discounts for customers who are members.

Some medical wholesalers also have discount schemes.

**Sheath drainage for men**

Some men prefer to use a sheath (condom) drainage system instead of a pad. A specialised device similar to a condom fits closely over the penis and is connected to a drainage leg bag, which collects the urine. A larger drainage bag can be used overnight. Some sheaths are self-adhesive, while others require a separate strip of adhesive on the penis before the sheath is applied. Sheaths need to be fitted correctly to prevent leakage. A continence nurse advisor can teach how to fit a sheath. Sheaths need to be removed daily and the skin washed and dried carefully before being reapplied. Men will need to be mentally alert to use this appliance and need help to apply and remove the sheath and drainage bag if they have problems with their hands.

As many men prefer a sheath to a pad, particularly those who have difficulty getting out of bed or walking to the toilet, it is usually worth a trial. Once again, it is important to get professional advice.

**Bed pads, bed sheets and chair pads**

Pads for beds and chairs, including wheelchairs and car seats, can be used alone or as a back-up to pads and pants, and may assist when travelling. Bed pads and chair pads have a waterproof backing. These can also be disposable or reusable. Absorbent bed sheets are reusable only, though they are more absorbent than bed pads and can be tucked under the sides of the mattress. They draw the urine away from the body and are often used at night to allow a good night’s sleep and prevent sheets and mattresses getting wet. Reusable bed pads are not designed for faecal incontinence, however, disposable bed pads are.

**Protecting bedding**

Fitted waterproof covers are available for mattresses, pillows and doonas. These are available in many waterproof fabrics, styles and sizes.
Examples of pads and furniture protection can be viewed at continence resource centres and independent living centres or larger medical suppliers, located in most states.

The National Continence Helpline (1800 33 00 66) can provide information on aids and appliances and where they can be purchased. The Continence Foundation of Australia website (continence.org.au) also has a product directory listing local suppliers.

**Catheters**

A catheter is a hollow tube that drains urine directly from the bladder into a drainage bag or is connected to a valve. Drainage bags may be secured onto the leg under clothing during the day or to a larger night bag hung beside the bed. Night bags hold larger volumes of urine so there is no need to get up overnight to empty the drainage bag. A catheter is used only if absolutely necessary and is prescribed by a doctor or specialist. Depending on the type of incontinence, some people may need an intermittent or indwelling urinary catheter.

**Intermittent catheters**

Intermittent catheters are a soft, flexible tube inserted into the bladder and removed several times every day. This technique needs to be taught correctly by a registered nurse or continence nurse advisor.

**Indwelling catheters**

A long-term indwelling catheter is inserted into the bladder once and left there for a period of time as recommended by the manufacturer. If the person being cared for needs a permanent catheter and drainage bag, certain precautions must be taken to care for the catheter to prevent problems. Correct management of catheters needs to be taught by a registered nurse or continence nurse advisor.

**Advice about catheters**

Generally, people who use catheters need to drink more fluid each day, unless advised otherwise by a doctor, as this will help flush the catheter, keep the bladder healthy and avoid constipation.

Careful attention must be given to personal hygiene between the legs. This is best done with daily washing around the catheter. If the person has faecal incontinence, careful attention must also be paid to washing after each bowel motion. Do not use talcum powder if using a catheter.

Urinary catheters and sheaths can be purchased from medical suppliers. Contact the National Continence Helpline (1800 33 00 66) for information on suppliers.
Equipment and toilet alternatives

Continence equipment can be used as an alternative to the toilet or to assist with using the toilet. There are many types of toileting equipment to assist you and the person you are caring for. Assistance with installation may be needed for some equipment. Professional advice will help prevent unnecessary expense.

Commode
A portable toilet chair for people who have difficulty getting to the toilet on time or if the toilet is too far from the living/sleeping area.

Bed pan
Useful for people who cannot get out of bed to use the toilet. A bed pan can be used under a shower chair or commode. These need to be placed under the person and removed. Carers may need help with lifting to do this.

Slipper pan
Useful for people who cannot lift their hips high or move easily in bed. These need to be placed under the person and removed. Carers may need help with lifting to do this.

Urinary bottle (urinal)
Useful for men who have difficulty in getting up or down from a chair or bed. Men with eyesight or hand problems may need help holding the urinal in place. A jug or bucket may be easier to use. A urinal can also come as a non-spill bottle, which is used like a regular urinal.

Female bottle/urinal
Useful for women with poor mobility or who are in a wheelchair. Help may be required to use and hold in place.

Disposable bottle
Can be used for both men and women. It is non-spill and is useful when going out.

Travel bottle
Can be used for both men and women. This is a collapsible plastic container with a lid. It is compact to carry and can be washed and reused.
Choosing suitable equipment

A continence nurse advisor or an occupational therapist can help you decide on suitable continence aids and products.

An occupational therapist will be able to assess the needs in the home. They can help select equipment and suggest modifications to the home to make moving, handling and personal hygiene easier.

Equipment may be purchased or viewed at:

- medical equipment hire stores;
- an Independent Living Centre in each state or territory (except for the Northern Territory); and
- contact the National Continence Helpline on 1800 33 00 66 for local services.

Toilet surround

A frame that fits around the toilet with armrests and adjustable legs for height. Assists people to get on and off the toilet without raising the seat.

Grab rails

These can be fitted to the toilet wall to help people get on and off the toilet

Toilet seat raiser with rails

A raised toilet seat with armrests and adjustable legs for height, to help people get on and off the toilet.

Shower chair with commode seat

This is a commode chair on wheels. It can be used in the shower or to transport the person to the toilet and backed in over the toilet bowl. Some designs can take a bedpan beneath the seat.
Chapter 5: Managing incontinence at home

Functional incontinence: mobility or memory/learning issues

Functional incontinence relates to physical, intellectual or environmental issues that can be a contributing cause of incontinence.

For example:
- not being able to get up and walk to the toilet easily;
- when the toilet is hard to get to or use;
- clothing that is hard to remove in the toilet;
- not having handrails when needed;
- not being able to find the toilet without help; and
- finding the toilet in the dark.

Some of the causes of functional incontinence include problems with walking (arthritis or cerebral palsy) and problems with memory or learning (dementia and intellectual disability).

Improving access to the toilet

Make sure that:
- the toilet is easy to find and easy to get to, even during the night;
- tripping hazards are removed such as floor rugs or bath mats;
- there is enough room for a second person to assist; if not, have the door adjusted to open outwards or sliding;
- the toilet is at the correct height; use a raised toilet seat and install grab rails to make sitting and getting up easier; an occupational therapist can help with this;
- the person being care for is in a supported, seated position; use a foot stool if it can be done safely and if their feet do not reach the floor comfortably;
- the toilet floor is non-slip;
- the toilet environment is comfortable and clean with good lighting and warmth; and
- if possible store products and equipment such as pads and catheters near the toilet for easier access.

Alternatives to a toilet

For people unable to access a toilet, consider options listed under Equipment and toilet alternatives, page 27.
**Lighting**

People can become confused or lose their way in the dark, so consider either a small night-light, sensor light, or leaving on the toilet light. If the path from the bedroom to the toilet is long or hard to get to, consider a hand-held urinal or commode.

**Clothing and shoes**

Both day and night-time clothing should be easy to undo or remove, especially if it is young children still learning to operate zippers and buttons, or people with a disability, or with poor coordination, sight, flexibility or strength. It can be difficult and frustrating to remove garments in time for a toilet visit, so consider front-opening Velcro fastenings or elasticised waists rather than buttons or zips.

Simple sewing jobs like extending a fly down to the crotch seam or replacing zips and buttons with Velcro are useful. Modify nightwear to open down the back. Choose dark or patterned fabric for clothing to disguise any leakage.

Shoes made of leather or vinyl are easier to clean than material shoes and slippers. Shoes should be well fitted but easy to put on and remove. Look for shoes with Velcro straps.

**Furniture**

There is a clear link between falls and incontinence. Finding a way through a house filled with furniture, ornaments, clutter, or with a long hallway, can become an obstacle course and cause a delay in getting to the toilet. Tripping, especially in the dark, can also be dangerous, so clear the path and provide some light along the way.

Ensure all floors are non-slip and avoid the use of floor coverings such as mats and rugs. The person being cared for might not be able to reach the toilet fast enough, so a stick or walking frame left within reach might help. An occupational therapist may help with improving access to the toilet.

Protect chair seats with a waterproof chair pad. Keep a bucket or bottle nearby in case of emergencies. Make sure this gets washed and disinfected regularly to prevent odours.
In the bedroom

- protect the bed with an absorbent bed sheet or bed pad – see the section Products and Equipment for more information;
- wipe over waterproof fitted mattress protectors to keep odours to a minimum;
- try placing a commode by the bed;
- give men the option of using a bottle if they can hold it in place. Some men may also find a jug or bucket easier to hold and aim into;
- protect or, if possible, remove carpeting. Place a rubber-backed absorbent mat on the floor by the bed. This can be hosed down outside or machine washed and hung out to dry;
- install a sensor device on the bed or on the floor beside the bed, which buzzes when the person gets up. (The Independent Living Centre or Alzheimer’s Australia have more details); and
- if possible, move the person to a bedroom nearer to the toilet.

Other issues in managing incontinence

Skin care

Skin irritation is common with urinary and faecal incontinence so:

- keep the skin clean and dry; wash the person’s buttocks and between their legs with warm water and soap-free cleanser designed to maintain normal pH when changing used pads;
- do not use solutions with alcohol or disinfectant directly onto the person’s skin as this can be very drying and cause soreness, skin breakdown or allergic rashes;
- avoid perfumed moisturisers, especially if the person has allergies or sensitive skin or if there is redness or broken skin;
- change the pad frequently enough to keep the skin dry;
- wash skin at least twice daily, preferably with a soap-free cleanser or a soap alternative;
- pat dry carefully – do not rub;
- avoid talcum powder, use barrier creams to protect the skin from perspiration, urine or faeces but check with your pharmacist about whether the cream chosen will affect the absorbency of the pad;
- make sure the continence product is put on and removed correctly (read the instructions carefully); and
- if the skin becomes red and sore, seek help from a continence nurse advisor or doctor.
Odours
Fresh urine does not usually smell bad. If it does, it may be infected and a urine sample should be tested by the doctor. Urine will begin to smell if it is left exposed to the air, so it is advisable to:

- wear a pad that is fitted firmly to the skin to reduce the urine exposure to the air;
- replace continence products according to manufacturer’s instructions so they don’t leak onto clothes, furniture and bedding;
- dispose of continence products into a container with a fitted lid, or place in a sealed bag and put into a rubbish bin;
- wash wet bed linen and clothing regularly;
- open the windows and doors to encourage air flow; and
- use room deodorants and odour neutralisers, if necessary.

Hygiene
- As a carer, wear disposable gloves to protect your hands when changing pads or washing the person’s buttocks or between their legs. Also wash your hands after handling soiled pads and garments, even if wearing gloves;
- Dispose of used pads by wrapping in a plastic bag and placing in the garbage bin;
- If reusable continence products are being used, rinse off the bowel motion in the toilet before soaking and washing; and
- Consider the easiest way to clean the floors and chairs. Water proof, nonslip mattress protectors, chair pads and floor mats may be used to protect beds, chairs, carpet and rugs.

Chapter 6: Managing incontinence out and about
Caring for a person who is incontinent does not mean either of you has to stay at home.

At home, the toilet can be set up for comfort and convenience. When you take the person you are caring for out and about it can be more difficult using an unfamiliar toilet. So planning ahead is advisable.

Planning ahead
Before going out, consider the following:

- Where you are going?;
- How long will you be out?;
- When will the person most likely need to go to the toilet next?;
- The person usually wears a pad or uses equipment when going to the toilet?;
- How often does the pad need changing? When was it last changed?;
- What equipment is normally used? Can this be taken with you or are there other alternatives that can be used?;
- When is the best time to go? Is the person more alert earlier or later in the day? Increased tiredness may result in incontinence;
- Urine is produced from food eaten as well as drinks. Would it be better to go out before a meal, rather than afterwards?; and
- If the person is taking medicine (i.e. fluid tablets), consider the timing of the outing. Talk to the doctor if it would be possible to delay the medicine until after the outing.

Items you might think about taking are:
- a change of clothes;
- a plastic bag or airtight container if you are going somewhere where you cannot immediately dispose of or wash the pad or equipment;
- baby wet wipes, cloths, towels to wash and dry, odour remover;
- spare pads or equipment; and
- a container, in case the person needs to pass urine during the car trip.

**Public toilets**

Where possible, try to find out where the toilets are located at your destination.

The National Public Toilet Map website shows the location of more than 14,000 public and private toilets across Australia. The website provides useful information about each toilet such as location, opening hours, availability of baby changing rooms, accessibility for people with a disability and the details of other nearby toilets.

If you are planning a trip, the Trip Planner function enables you to locate toilets along the major travel routes and for shorter journeys as well. The National Public Toilet Map can be accessed on the internet, mobile phone web browser or a free iPhone app.

For more information, go to toiletmap.gov.au or phone the National Continence Helpline on 1800 33 00 66.

Public toilets with full sized changing tables and hoists are also available in some public spaces across Australia to meet the needs of people with severe and profound disability.

Go to changingplaces.org.au for more information.

**The Master Locksmiths Access Key (MLAK)**

This key enables people with disability to gain 24/7 access to a network of public toilets across Australia. People with disability are able to purchase an MLAK master key to open the special locks.

For information about where to get keys within your area, contact the Master Locksmiths Association of Australasia on 1800 810 698 or visit masterlocksmiths.com.au/mlak.php
Chapter 7: Psychological impact of incontinence

If incontinence is not managed well, the person with incontinence may experience feelings of rejection, social isolation, dependency, loss of control and may also develop problems with their body image. Equally, if not managed well, incontinence may lead you, as their carer to, feel overwhelmed with the stress arising from changes in your life and in the relationship, the cost burden of continence care and aids, and the increasing time and cost spent on cleaning clothes and bedding.

Research tells us that many people with incontinence do not seek help. Depending on the individual’s personal beliefs and feelings about incontinence, the person you are caring for may not be bothered by it, may try to hide it, may deny it and may not want to talk about it. You may find these behaviours difficult to understand and accept, making it harder for you to help the person achieve the best outcomes for you both. As a carer, work out how much warning time there is, if any, and if the person you are caring for is aware of the problem. This will help you know when to attend to the person’s toileting needs before the problem arises.

As a carer, it is especially important to recognise your own changing emotions and feelings. These may be in response to the situation you are facing. Although this section is mainly written about the person you are caring for, some of it may also apply to you.

Denial

Sometimes when a person is challenged by a change in their life circumstance, a part of them may want to deny that there is a problem, even when there is overwhelming evidence that a problem exists. It may be embarrassment or it may be fear that’s behind the denial. Equally, denial might simply reflect that the person doesn’t fully or accurately understand what the problem is.

When the problem is slight and can be managed independently and without too much fuss, some people may tell themselves that the incontinence only happens occasionally and hope it will magically go away. People often think that no one will know, even those nearest to them.

Some people admit there is a problem but for various reasons will not seek help. Incontinence in some people leaves them feeling bad, dirty, ashamed, helpless and hopeless. Some may recall an aged parent having the same problem and believe incorrectly that nothing can be done to manage it effectively. Others believe that it is simply a result of ageing, having children or prostate surgery and therefore see no point in seeking help. When a person comes to believe that things are hopeless and that they are helpless to do anything about it, they are very prone to becoming depressed.

Even when people do seek help, they may not admit how serious the problem is. It is only as they become comfortable with their continence nurse advisor or doctor that they may be willing to reveal the full extent of the problem and be open to hearing about current continence management options.

Anxiety

Because passing urine or faeces is regarded as a very private and personal activity in most societies, many people are prone to feeling embarrassed about any accidental
leaks and smell associated with incontinence. As a result, it is understandable that many people with incontinence and their carers might become very anxious when thinking about or planning social activities.

It is common for people experiencing anxiety to try to avoid the situation they most fear. When a person experiences incontinence they may try to reduce their anxiety by avoiding social activities such as shopping, going out or having friends over. It is also common for people experiencing incontinence to try to manage their problem by reducing the amount or type of food they eat or fluid they drink.

Situations that commonly cause anxiety include:

- visiting the doctor; the doctor may be someone who has known the person for years or may be a relative stranger; either way, it is likely the person being cared for has never talked about this problem, and so may be anxious about the response; and
- being referred for tests. The prospect of having to tell even more people about the problem or the fear of leaking on the way to the consulting room or in the waiting room can heighten anxiety. The thought of a physical examination or having to undergo tests and wait for the test results can also be stressful.

Frustration and anger

Frustration is a normal human reaction when a person feels they are unable to achieve something that they want, value, believe they have a right to, or believe that they should be able to do. A person who is incontinent may show their frustration when they are unable to master their incontinence or some aspect of their care or treatment. Because anger is closely related to frustration, even the smallest problem with leakage, smells or side effects can lead to anger in those experiencing incontinence.

In most people, anger arises from frustration from unmet needs. A key to helping someone who is angry is to listen while you explore the needs that are unmet. Lack of sleep due to frequent toileting at night or from some other reason such as stress, pain or depression is likely to exhaust the person and you as their carer. Irritability, impatience and reduced tolerance can result and place severe strain on the health and relationship of both parties.

Sometimes, people experiencing continence problems feel as if they are treated like children. A frustrated, irritable and angry carer might vent their feelings in non-helpful ways at the person with incontinence for having an accident. If feelings become overwhelming, the carer may become angry and shout at the person, telling them not to be so lazy. This may cause the incontinent person to become angry or withdrawn, depending on their personality, and further increase the stress already felt. Because soiling and wetting are common in childhood, some carers might incorrectly see the person with incontinence as being childish.

Carers and those with continence problems who are experiencing anger and frustration should seek advice from their doctor or continence nurse advisor on how to access support in managing these emotions.
Grief

Grief is a very normal response to any change in a person's life. It represents their response to actual or perceived loss they experience as a result of that change. For that reason, grief is usually a transient state that lessens and passes with time as we adjust to a loss. Grief may feel like depression but tends to be different in the time it lasts, its intensity of feelings and the way that it affects a person’s beliefs. However, grief is always an individual experience.

Depression

If you think that you or the person you care for could be depressed, it is important to raise your concern with the doctor, as depression and incontinence are common conditions.

For more information on symptoms of depression, phone BeyondBlue (1300 22 4636) or go to beyondblue.org.au

What can you do to help?

Ask the doctor and/or health professional for help, and keep regular appointments for review.

- Ask a continence nurse advisor for support and guidance;
- Discuss the merits and consequences of medication;
- Engage them in 30 minutes of physical exercise daily;
- Encourage them to eat fresh, healthy food and drink fluid every day;
- Encourage them to achieve and maintain a healthy body weight. Being overweight is associated with many physical and psychological health problems;
- Discourage smoking and minimise alcohol and caffeine intake (alcohol can interfere with medications and make feelings worse);
- Practise healthy sleep habits; and
- Contact Carers Australia or Alzheimer’s Australia for counselling and support.
Part four: Disability and incontinence

Disability is defined as an impairment that has existed for 6 months or more and restricts a person’s activities on a daily basis. Most people with disability report a physical condition as their main condition, for example, back problems or arthritis and related problems. However, almost 1 in 5 people with disability report a mental or behavioural impairment as their main condition, including intellectual disability, developmental delay, depression and anxiety, and dementia. This highlights how disability can affect a person in many different ways, and is not limited to more obvious physical or mobility issues requiring the use of walking aids or wheelchairs.

People with disability are more likely to develop bladder or bowel problems. There are many reasons why people with disability develop incontinence. Problems can develop over time, be there from birth, or acquired due to medicine they are taking.

Managing incontinence resulting from disability requires careful planning, regular clinical assessments and learning new strategies as needed. This is dealt with in more detail in the next two chapters.

Incontinence in children with physical and/or intellectual disability is a common issue. Learning to go to the toilet independently is complex and requires development of appropriate toileting skills. There are resources to assist parents teach children with special needs on how to use the toilet independently. Contact the National Continence Helpline (1800 33 00 66) for assistance.

The Continence Foundation has fact sheets on chronic conditions available at continence.org.au

Chapter 1: Mental health and incontinence

People with a mental illness may experience problems associated with bladder and bowel control. The cause may not be related to the mental illness itself. However, mental illness does increase the risk of incontinence due to poor physical health, or for the following reasons:

- Mental illness may interfere with the person’s ability to get to the toilet on time where there is disorganised thinking, confusion or inattention;
- Medicine used to treat mental illness can directly affect the bladder and bowel or make the person less aware of the need to go to the toilet; and
- Lifestyle factors such as poor diet, not drinking enough fluid or drinking large amounts of caffeine – coffee, tea, chocolate drinks and cola drinks.

Generally, encouraging activities that improve overall health and reduce body weight, such as eating and drinking well, regular exercise and not smoking, will reduce continence problems.
Managing behaviours in a person with a mental illness

- Try to time toileting when the person is in a calm state;
- Keep calm and make toileting as relaxed as possible;
- Be aware of and address fears and sensory issues;
- Display visual aids such as picture cards and schedules of step-by-step processes of toileting like pulling down pants, sitting on toilet, wiping, flushing and washing hands;
- Use minimal word commands;
- Use a reward chart – rewarding positive behaviours and ignoring negative behaviours; and
- Provide stress relief aids to hold onto during toileting to reduce anxiety and calm the person, such as stress balls, water tubes and foot massager.

Chapter 2: Caring for someone with dementia

Dementia is progressive brain damage which may result in changes in personality, mood and behaviour. It occurs in some people as they reach old age but can occur in younger people as the result of head injury, brain disease and substance misuse. People with dementia typically have memory problems and increasing difficulties with everyday activities (communicating, bathing, cooking, etc). Alzheimer’s disease is the most common form of dementia and affects mainly older adults. It often causes people to feel lost, anxious and confused.

Because dementia such as Alzheimer’s disease causes confusion and anxiety, it also may cause withdrawal, resistance and aggressive behaviours that add to the pressure of the person caring for them. Dementia most commonly occurs in the later third of life, and often occurs with age-related health changes such as heart disease, cancers, diabetes, gynaecological changes, prostate enlargement, obesity and arthritis.

Incontinence is associated with many of these health changes. Therefore, a person with dementia and incontinence is likely to be complex and challenging for you as their carer and the medical professionals involved. Incontinence caused by dementia is primarily related to functional impairments (recognising the toilet, coordinating the toileting actions/post-toilet hygiene).

In an older person with dementia, incontinence may occur or become more of a problem as the person:

- fails to recognise the urge to go to the toilet;
- forgets where to find the toilet;
- forgets how to unfasten their clothes;
- forgets what to do when they get to the toilet (including post toilet hygiene);
- becomes more susceptible to urinary infections due to poor hygiene practices; and
- becomes more prone to continence issues due to forgetting to eat and drink properly.
A continence assessment will help determine the cause of the incontinence and is the foundation for planning appropriate management of co-existing health problems and behaviour factors.

However, you can help the person to use the toilet by:

- placing a notice or picture of a toilet on the toilet door;
- keeping the light on in the toilet to assist the person to find the bathroom at night;
- ensuring contrast in colours (e.g. a black toilet seat with a white toilet bowl, or coloured water in the toilet bowl);
- ensuring they wear loose fitting clothes with simple or no fasteners to assist with dressing and undressing;
- use language that is simple and familiar to the individual (e.g. ‘wee’ or ‘poo’);
- keeping a daily routine for meals, exercise and using the toilet;
- keeping a diary of when the person uses the toilet or is incontinent, then taking them at these times or prior to them being incontinent (but don’t take them to the toilet too often as this can irritate them). See the bladder and bowel chart in Appendix A as examples; and
- watching for signs that the person needs to use the toilet (e.g. fidgeting and wandering) and taking them to the toilet when they show these signs.

See a doctor or a continence nurse advisor for help. Contact the National Dementia Helpline on 1800 100 500 or the 24 hour Dementia Behaviour Management Advisory Service on 1800 699 799.

**Managing difficult behaviours**

People with dementia can become very distressed and resistive when offers of assistance for going to the toilet are made because of the loss of insight, confusion and memory loss they commonly experience.

Imagine how it might feel and how you would behave if a person who you may no longer recognise began to undress you or insist that you go to the toilet when you don’t even recall what a toilet is.

You will need to remain calm, gentle, firm, patient and accepting and maintain a sense of humour to successfully get a confused person to the toilet in time.

In some instances, in response to confusion, the person with dementia may not be passing urine in the toilet. Strategies that may help in these instances include:

- watching and recording where and when the person voids in the wrong place;
- toileting more frequently;
- using distraction methods when it is evident the person is about to void in the wrong place or for those who become very anxious around toileting;
- making the toilet area more obvious (i.e. familiar) and inviting;
- placing a commode or receptacle in the area where they commonly go to pass urine;
- reorganising the pathway to the toilet to be inviting to use; and
- joining a carer’s group and find how others address the same issues.

Remember to:
- not hurry a person with dementia;
- avoid over-reaction that can include shame or humiliation – their behaviour is not intentional;
- use short, step-by-step instructions, such as “sit down”;
- use a combination of visual, physical and verbal cues to prompt; and
- watch for body language — agitation, pulling at clothing, wandering, opening doors or always trying to go outside.

Be clear about whether the biggest problem is the person’s behaviour (for example, “I feel embarrassed for them and me when I have visitors over”), the effect of the person’s behaviour (“It’s ruining the carpet and leaving a smell I can’t get out”), or your (or others’) unrealistic expectations of your ability to manage (“I’m failing as a carer/husband/wife”). Do not ignore your feelings or concerns. Talk about it and seek help or advice. For example, in some circumstances, the worst that happens as a result of the person voiding in the wrong spot is that you have to mop up. This might be easier than the perpetual struggle to stop them from voiding in the wrong spot, especially if the person is prone to resistance or aggression.

**Understanding difficult behaviours in the person with dementia**

People with dementia are often unable to express themselves with language and instead communicate their feelings through behaviours. As such, feelings associated with hunger, thirst, cold, anxiety, a full bladder, a full rectum, a headache or stomach ache might present in behaviours such as agitation, irritability or tears.

Urinary and bowel incontinence may be distressing the person you are caring for, making them more anxious than usual. Look for changes in behaviour and patterns associated with toileting. While emotions and behaviours may be connected to more complex issues, they can also be associated with toileting needs such as:
- an inability to find or recognise the toilet;
- the need to pass urine or use their bowels urgently;
- an inability to pass urine or use their bowels;
- severe constipation;
- dehydration; and
- a urinary tract infection.
An inability to communicate these problems might be expressed through the following behaviours:

- the person getting angry, agitated, yelling and hitting or being disruptive with constant repetitive questions because they may be in pain or discomfort;
- disturbed sleep;
- the person showing signs of paranoia (feeling that someone is against them) or hallucinating (seeing things that aren’t really there);
- feeling lethargic (tired, fatigued) or more confused than usual; and
- wandering and restlessness.

If they are displaying any unusual behaviour or any of the above behaviours, see the doctor or continence nurse advisor for a full assessment.

For assistance with changed behaviours in dementia, phone the Dementia Behaviour Management Advisory Service on 1800 699 799.
Part five: Further advice and support

The Continence Foundation of Australia

The Continence Foundation of Australia is the peak national organisation working to improve the quality of life of all Australians affected by incontinence.

The Continence Foundation manages the National Continence Helpline (1800 33 00 66) on behalf of the Australian Government under the National Continence Program.

The Continence Foundation offers a wide range of free information resources for individuals, carers and professionals. These resources can be ordered from the National Continence Helpline on 1800 33 00 66 or by visiting the carer section of the website (continence.org.au). It covers topics relating to incontinence care and provides detailed information on financial assistance, products and aids, product suppliers, other services and organisations, and online access to a continence nurse advisor.

Continence resource centres

There are continence resource centres in Victoria, New South Wales, South Australia and Western Australia, which undertake a range of activities in their states and are integral in promoting better continence care and prevention.

The resource centres provide:

- continence health promotion, education and training programs;
- information, counselling and support services;
- continence literature and resources; and
- unbiased product information.

Phone the National Continence Helpline (1800 33 00 66) or go to continence.org.au for locations.

Carers Australia

Carers Australia and its state carer associations can provide carers with information, advice and referral to services that can assist them in their caring role.

Phone the Carer Advisory Service (1800 242 636) for further information on available services. Information is available on a range of topics, including home help, carer support groups, financial entitlements, support services, respite and general assistance.

Respite

Respite can provide carers with a break from care. Carer respite centres can organise either short-term or emergency respite for carers. This respite can take place in the person’s home or in a registered facility. Contact the local Commonwealth Respite and Carelink Centre on 1800 052 222 during business hours. For emergency respite outside standard business hours, phone 1800 059 059.
Alzheimer’s Australia

Alzheimer’s Australia provides a range of services to support people with a memory disorder, their carers, families and friends. The services offered include counselling, education courses, community seminars, multicultural services, support groups, professional training and advocacy.

The association provides a range of resources, including brochures, help sheets and a library. Alzheimer’s Australia can be contacted through the National Dementia Helpline on 1800 100 500.

Dementia Behaviour Management Advisory Service

The Dementia Behaviour Management Advisory Service (DBMAS) provides assistance in managing the behavioural and psychological symptoms of dementia to family carers, care workers, health professionals, and aged care service providers who are supporting people with dementia.

DBMAS services include assessment, information and advice, care planning and education and training. The helpline can be accessed 24 hours a day on 1800 699 799.

My Aged Care

My Aged Care has been established by the Australian Government to help people navigate the aged care system. Information is also available in a number of languages.

For further information, go to myagedcare.gov.au or phone on 1800 200 422 between 8.00am and 8.00pm on weekdays and between 10.00am and 2.00pm on Saturdays.

National Disability Insurance Scheme

The National Disability Insurance Scheme (NDIS) was launched in July 2013 and is being rolled out across Australia. The NDIS supports people with a permanent disability that affects their ability to take part in everyday activities. The NDIS gives an eligible participant more choice and control over how, when and where ‘reasonable and necessary’ supports are provided. ‘Reasonable and necessary’ supports are supports that help participants reach their goals, objectives and aspirations, and to undertake activities to enable their social and economic participation.

For further information, phone NDIS Helpline (1800 800 110) or go to ndis.gov.au
## Contact details for support organisations and services

<table>
<thead>
<tr>
<th>Organisation</th>
<th>contact phone number</th>
<th>website</th>
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<tbody>
<tr>
<td>National Dementia Helpline (Alzheimer’s Australia)</td>
<td>1800 100 500</td>
<td>alzheimers.org.au</td>
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<tr>
<td>Dementia Behaviour Management Advisory Service</td>
<td>1800 699 799 (24 hours)</td>
<td>dbmas.org.au</td>
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<tr>
<td>BeyondBlue</td>
<td>1300 224 636</td>
<td>beyondblue.org.au</td>
</tr>
<tr>
<td>Carer Advisory Service (Carers Australia)</td>
<td>1800 242 636</td>
<td>carersaustralia.com.au</td>
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<tr>
<td>Young carers (Carers Australia)</td>
<td>1800 242 636</td>
<td>youngcarer.net.au</td>
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<tr>
<td>Centrelink</td>
<td>13 27 17</td>
<td>humanservices.gov.au</td>
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<tr>
<td>Children with Disability Australia</td>
<td>03 9417 1025 or 1800 222 660</td>
<td>cda.org.au</td>
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<tr>
<td>Commonwealth Respite and Carelink Centre</td>
<td>1800 052 222 or 1800 059 059</td>
<td>myagedcare.gov.au</td>
</tr>
<tr>
<td>National Continence Helpline (Continence Foundation of Australia)</td>
<td>1800 33 00 66</td>
<td>continence.org.au/carers</td>
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<tr>
<td>Bladder and bowel website (Department of Health)</td>
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<td>bladderbowel.gov.au</td>
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<tr>
<td>National Public Toilet Map (Department of Health)</td>
<td>1800 33 00 66</td>
<td>toiletmap.gov.au</td>
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<tr>
<td>Department of Veterans’ Affairs</td>
<td>13 32 54 or 1800 555 254</td>
<td>dva.gov.au</td>
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<td>Dietitians Association of Australia</td>
<td>1800 812 942</td>
<td>daa.asn.au</td>
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<tr>
<td>Independent Living Centres Australia</td>
<td>1300 885 886</td>
<td>ilcaustralia.org.au</td>
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</table>
References


**Appendix A**

A bladder and bowel diary can be useful for a short time to help you know when the person you are caring for passes urine or a bowel motion. You may copy this chart to use at home and it can be shown to the doctor for advice.

Bladder and bowel diary can be useful for a short time to help you know when the person you are caring for passes urine or a bowel motion. You may copy this chart to use at home and it can be shown to the doctor for advice.

<table>
<thead>
<tr>
<th>Bladder diary</th>
<th>Name</th>
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<tbody>
<tr>
<td>Keep this diary accurately each day, for at least 3 days (if you can, make these 3 consecutive days). If you have not already spoken to your doctor or continence nurse about a bladder control problem, it could be helpful to take this diary with you to an appointment.</td>
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</tbody>
</table>

**Bladder diary**

<table>
<thead>
<tr>
<th>Day and times passed urine, or times of any leakage episodes</th>
<th>Amount of urine passed</th>
<th>Did you feel the urge to go?</th>
<th>Urgency 1-10 (10 is a desperate urge)</th>
<th>Leakage episodes Small, Medium or Large and record times in left hand column</th>
<th>Fluid intake Note types of drinks and amounts (record total of drinks over 24 hours)</th>
<th>Bowel function check Record day/times when bowel motions passed</th>
<th>Notes about when you urinate or leakage happened (e.g., &quot;when I arrived home and put the key in the door...&quot;, &quot;when I was out walking...&quot;, &quot;didn’t feel like I had emptied&quot;, &quot;or leaked before I got to the toilet...&quot;, and similar. You could also list any drinks or foods you suspect might be irritating the bladder and include comments about your diet or digestion etc.</th>
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**NATIONAL CONTINENCE HELPLINE 1800 33 00 66**

In the toilet, we into a large plastic container, then tip into a measuring jug. Record the amount before flushing urine.
### Bowel diary

Keep this diary accurately each day, for about 7 days
Use with Bristol Stool Form Chart
(available on the Continence Foundation website
www.continence.org.au)

<table>
<thead>
<tr>
<th>Name</th>
<th>Day and times of every bowel movement</th>
<th>Stool description (refer to Bristol Stool Chart Type)</th>
<th>Did you feel the urge to go? Yes/No</th>
<th>Accident/soiling? Record time in left hand column and note description of leakage in this column</th>
<th>Fluid intake (all drinks taken during the 24 hours - type and quantity)</th>
<th>Laxatives, aperients, fibre supplements etc (what taken and when)</th>
<th>Comments (include when bowel movement or leakage happened, eg “half hour after breakfast”, “11 am, soiling when I was out walking”)</th>
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If you have not already spoken to your doctor or continence nurse about a bowel problem, it could be helpful to take this diary with you to an appointment.
NATIONAL CONTINENCE MANAGEMENT STRATEGY

Call the National Continence Helpline on FREECALL™ 1800 33 00 66

The helpline has a team of clinical advisors providing free, confidential advice, resources, details for local continence services, products and subsidies.

For more information, you can also visit:
www.continence.org.au
www.toiletmap.gov.au
www.bladderbowel.gov.au

All information in this publication is correct as of May 2017.