Help for people who care for someone with bladder or bowel problems
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for someone with bladder
or bowel problems
Incontinence is not generally a topic of social conversation. It is something that people do not like to admit to and become very adept at covering up. But it can affect anyone across the lifespan and for many reasons.

When I was asked to review the contents of this book and have the privilege of rewriting it I was delighted. To me, this is a strong step forward in helping people come to terms with living with incontinence.

I have a passion for engaging with people in the community to help develop management plans that work with their lifestyle and assist in improving their quality of life.

Incontinence is devastating to many and the concept of this booklet means that everyone has a starting place to open the floodgates and start talking about what the problem is and who can provide help.

For those of you in the caring role, help is available. The trick is knowing who to go to and what to ask for. I hope that this book provides you with the inspiration and courage to do so, as the effects of incontinence are underestimated by those that do not live with or experience life with this condition.

I recognise and celebrate the involvement of all those who collaborated with me on this booklet as they share my passion and feel, as do I, that the importance of shining a light in this taboo corner of the world cannot be too undersold.

I hope that this revised edition is as valuable to you as it has been for others over the years and that the journey forward will become a little clearer.

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The carers who participated in the development of the resources are gratefully acknowledged and thanked.
This book has been written for carers to help them to manage the incontinence of the person they care for.

Incontinence is a topic that people often find difficult to talk about. It is a huge topic and there are many causes. For carers, the technical 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 call when they need help.

**What is incontinence?**

Incontinence results from a dysfunction in, or inability to control, the function of the bladder or bowel. Incontinence is not just a problem for older people and should not be considered normal. It is often a sign of health problems.

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

**Language around incontinence**

The language used around the issue of continence and incontinence is influenced by medical terminology, family and cultural language and other factors. While each ethnic group may have its own language for bodily functions, many families develop their own language when they introduce children to body parts and body functions. Because in most cultures bodily functions are private functions, most cultures develop language that is regarded as suitable for use by children and adults. In this book we tend to use the medical language to describe body parts and functions because it enables discussion without the risk of using terms which may be considered vulgar or inappropriate in some groups.

<table>
<thead>
<tr>
<th>Medical or anatomical language</th>
<th>Common, cultural or other words which mean the same thing</th>
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<tbody>
<tr>
<td>Faeces</td>
<td>Poo, Shit, GaGa, Fertiliser, Crap, Number twos, Logs, Bogs, Bigs, Stool</td>
</tr>
<tr>
<td>Urine</td>
<td>Wee, Tinkle, Wiss, Piss, Wizz, Leak, Number ones, Littles</td>
</tr>
<tr>
<td>To defecate</td>
<td>To go to the toilet, to have a crap, to go to the can, to poo</td>
</tr>
<tr>
<td>To urinate</td>
<td>To go to the toilet, to wee, to take a leak, to void, to micturate</td>
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Refer also to the Glossary of terms near the end of this booklet.
Who is a carer?

Carers provide unpaid care or support to a family member, friend or other person who needs assistance. Carers come from all walks of life, all cultures and all religions. Some are children and some may be in their 90s. A carer might be a spouse, sibling, close or distant relative. They may be friends, neighbours or others who are willing to contribute to the care of another person in some great or small 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 suddenly due to sudden changes in another person, or the role may develop more slowly in response to gradually changing needs. Care might be required for a discrete period of time or continuously and might be provided for a person of any age.

What does it mean to be a carer of a person with incontinence?

We have worked closely with carers to find out what would be useful in this book and know that 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 burden 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. Some may want to deal with it themselves. Others want to know what to do in an emergency, while others want to know who to call for help.

National Continence Helpline

The National Continence Helpline is a free telephone advisory service funded by the Australian Government Department of Health and Ageing. This service is available to anyone residing within Australia, and may be accessed from Monday to Friday (except public holidays), between 8.00am and 8.00pm Australian Eastern Standard Time.

Freecall 1800 33 00 66.

The helpline is staffed by a team of continence nurse advisers who provide information, advice and referral to callers with incontinence or who are caring for someone with incontinence. It also provides information and advice to health professionals.

Other sources of help and advice can be found in Part Three.
How to use this book

This book has been written to provide advice and support for people caring for another person with incontinence. In using this book, start by reading the titles and then choose sections that are relevant to you and the person for whom you are caring. Each section can be read alone; however, each will guide you into the next section.

Part One: ‘Where to start?’ is a guide to some immediate solutions that may provide some short-term answers. This section gives practical advice with a view to finding further information and advice. This section advises you about some of the things that can be done immediately at home.

Part Two: ‘Ways to manage incontinence’ offers more information on the problem and wider issues of urinary and faecal incontinence including technical advice on the anatomy of the bladder. This section guides you through the available choices of pads and equipment, while providing you with advice on managing situations often associated with incontinence. It also recommends where you can seek further advice.

Part Three: ‘Help and advice’ is a directory of sources of help. It is important to be informed but it is also important to know where to seek this advice. In this section you will find information on the role of health professionals, including the role of the continence nurse adviser.

This book is a self-directed guide. You can start in any section by selecting the topics that interest you. In any section you will find helpful hints and information about where you can find assistance or advice and information about products and services that can help you manage as a carer.
Continence assessment

It is important to remember that everyone with incontinence problems should be assessed by a general practitioner (GP), general practitioner (GP) practice nurse, continence nurse adviser or continence physiotherapist.

This assessment will help you as a carer to manage the incontinence problems with the person you are caring for. You can make an appointment with any of these professionals – the reference guide at the back of this book will guide you in your choice.

Continence assessments will include both of you visiting a continence professional where you can talk about the person’s problems. You or the person you are caring for will be asked to fill out some charts to show when they pass urine or have a bowel action. A physical examination is likely as this will let the professional know what kind of continence problem the person has.

This book will help guide you through some of the everyday problems of caring for someone with incontinence.

Bladder dysfunction: Little or no control of urine

Step one

- If the problem has come on suddenly, see your doctor. It may be an infection.

Seek professional advice to find out why the incontinence has occurred. The National Continence Helpline on 1800 33 00 66 will be able to provide information about a person in your state or territory that can provide assistance.

If the person suddenly CAN’T pass urine, see a doctor IMMEDIATELY. THIS COULD BECOME A MEDICAL EMERGENCY.

In the first instance, even if you feel uncomfortable with this, consider using an incontinence pad that will keep the person’s clothing or bedding dry. Ask advice from your local chemist or GP practice nurse if you are unsure about the type of pad to use.

Things you might try

- Take the person to the toilet at times close to when they find themselves wetting. In the beginning it may be useful for a day or two to keep a diary of these times.

- Use a commode chair in the same room or beside the bed at night.
Men may find a urinary bottle, jug or a bucket more convenient. These items can be obtained from the local chemist or the National Continence Helpline on 1800 33 00 66 can provide information.

- Use a waterproof sheet under the bed sheet.
- Think about non-slip floors or non-slip mats. Lino and tiles are very slippery when wet, especially at night when people are only half awake. Consider using a towel beside the bed at night to catch any urine.
- Consider using walking frames, grip rails and night lights. Advice on these items can be sought from the local Council.
- Ensure adequate lighting on the way to the toilet.

Step two
Find the section about the bladder in Chapter 1 and read more.

Step three
Choose the sections throughout the book that you feel are relevant to you and read more.

Bowel dysfunction: Little or no control of the bowel

Step one
- If the problem has come on suddenly, see your doctor.
- Look for causes such as food poisoning, or eating different foods from usual. Where possible, to prevent this happening again, try to remove or avoid these foods.
- Stress can bring on diarrhoea. Is the person you care for unduly anxious or worried?
- If you have recently started new medication, speak to your doctor about any side effects. Some medicines cause problems. For example, antibiotics may cause diarrhoea. Pain killers may cause constipation.
- In the first instance, even if you feel uncomfortable with this, consider using an incontinence pad for protection. Your local chemist or GP practice nurse can provide advice if you are unsure about the type of pad to use.
- Use a barrier cream to protect the person’s skin. (Bowel motions make skin red and sore very quickly.) Your local chemist or supermarket can supply these.
- Wear disposable gloves (from the supermarket or chemist) to protect yourself.
- Wash your hands carefully and thoroughly, even after wearing gloves.
• Have a commode chair handy for the person you are caring for.
• Use air freshener or neutraliser to clear the odours from the air.

In Step one of the section below, see how to dispose of the used continence pads.

Step two
Find the section about the bowel in Chapter 1 and read more.

Step three
Choose the sections throughout the book that you feel are relevant to you and read more.

Cleaning and washing clothing, linen and your home

Step one
• Check that you have domestic cleaning products from the supermarket – most are OK to use.
• Wear disposable gloves (purchased from the supermarket or chemist) to protect yourself.
• Dispose of used pads by wrapping in a plastic bag and placing in your garbage bin for disposal.
• If you are using washable continence products, rinse off the bowel motion in the toilet before soaking and washing.
• For clothing and linen, set up a soaker bucket with water and soaking solution; for example, a nappy soaker or pre-soaker. It is important to think about safety, so once you have soaked the clothing or bedding overnight the bucket can be emptied into the washing machine. A full bucket is heavy and you may seek advice from a physiotherapist on how to lift properly.
• Consider wash-and-wear and easy-to-change clothing and bedding.
• Consider the easiest way to clean your floors and chairs. Plastic-backed towels can be used around the chairs and beds to protect carpet and rugs.
Step two

Chapter 2 and 6 (Part Two) contain more helpful hints for home care.

Step three

Choose the sections throughout the book that are relevant to you and read more.

Food and fluids

Some foods, such as fruit and vegetables, can be pureed or vitamised. This helps to soften the stools and improve bowel health. They also add fluid to the body. Foods such as porridge, weetbix and wholemeal bread also provide good sources of fibre for the bowel.

If the person you are caring for has constipation or diarrhoea it may be helpful to look at the amount of fibre in their diet. Too little fibre can make the stools hard and dry, too much can make the stools soft and runny. Speak to the GP, GP practice nurse or your continence nurse adviser about the best way to manage these problems. Having constipation can cause urinary incontinence as well.

It is important for people with incontinence to remain well hydrated, so unless you have been advised differently you need to provide the person you are caring for with between 1.5 and 2 litres of fluid every day, including:

- water
- fruit juice
- tea and coffee – in moderation.

These fluids should be spread across the day. Remember that unless you have been advised by your doctor. DO NOT RESTRICT FLUIDS.

Remember: Jellies, custards and ice cream can also add fluid.

Take care with caffeinated and alcoholic drinks, such as coffee, tea or cola as these make the bladder irritable and cause people to go to the toilet more often.

Alcoholic drinks and some medicines make the body produce more urine, so the bladder fills faster than normal, which means that it may need to pass urine more often. It may also mean there is less control over the bladder or bowel.
Mobility

People who live with incontinence may be unable to get to the toilet in time because they have difficulty in walking or moving. It is important to think about the best way to manage this; it may be that if the person can reach the toilet in time they are no longer incontinent.

Set up the house to make access to the toilet as easy as possible.

For men, try a urinary bottle. Alternatively, for either men or women, a commode chair or portable chemical toilet (from camping stores) brings the toilet to the person.

Also available are walking frames, rails, hand grips, bed poles (to help get in and out of bed), wheelchairs and commode chairs with wheels. An occupational therapist or physiotherapist can assist you with a suitable choice. You can find either of these professionals through the resource page at the end of this book.

Make safety your first concern: ensure floors are made ‘non-slip’ by using washable grip-backed rugs and try ‘stick-on’ or ‘paint-on’ etching, tiles or non-slip compounds over lino, floor tiles, concrete and terrazzo.

Extra assistance

If you need extra help:

- ask your doctor about options for caring for someone with incontinence
- contact the Carers Advisory Service on freecall 1800 242 636
- contact the National Continence Helpline on freecall 1800 33 00 66
- ask your doctor about how to contact a continence nurse adviser
- ask your doctor or local hospital about how to find a social worker.

If money a problem:

- ask your doctor or local hospital about how to find a social worker
- ask the Carers Advisory Service on freecall 1800 242 636
- talk to your local continence nurse adviser about options for cheaper continence products
- look at Chapter 8 of this book, which has options and information on subsidy schemes that the person you care for may be eligible for
- ask a local product wholesaler about trying free samples.
If you want to understand the problem better:

- look at Part Two for further information.
- call the National Continence Helpline on freecall 1800 33 00 66
- talk through the problem with a continence nurse adviser
- ask your doctor for a referral to a specialist
- read about sources of help and advice either from your local library, the internet (refer to ‘Contact details for support organisations’ in Part Three of this book) or the helpline listed above.

**Whose problem is it?**

Sometimes incontinence does not bother the person being cared for. They may not be aware of their incontinence or may deny it. It can be more of a problem for the carer who must manage it. The carer needs to work out how much, if any, warning time the person has and if the person they care for is aware of the problem. This will help the carer know when to attend to the person’s toileting needs before the problem arises.
Chapter 1: Understanding incontinence

Bladder and bowel anatomy

It may be easier to understand incontinence with a view of the anatomy.
The bladder

Many people believe that drinking water may increase the risk of wetting themselves, so they refuse to drink to avoid this risk.

While this belief is understandable, it is not the whole picture. In fact, not drinking enough water will cause urinary incontinence, constipation and dehydration.

The normal, healthy bladder can comfortably hold 300–500mls and is able to completely empty itself when we go to the toilet. A healthy adult will only pass urine up to six times in the day and up to twice overnight. More than twice overnight might suggest a problem.

Bladder dysfunction: Types of incontinence

With any of these types of incontinence mentioned below, it is important to see your GP, GP practice nurse or continence nurse adviser and not wait for the symptoms to get worse. The sooner advice is sought the easier it is to manage these problems.

Stress incontinence

Stress incontinence is a leak of urine usually associated with a physical activity such as coughing, laughing 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 for the incontinence may also include treatment for other medical conditions.

Urge incontinence (overactive bladder)

Urge incontinence is a leak of urine associated with an uncontrollable strong need to pass urine. People with urge incontinence find it difficult to make it to the toilet on time. The cause may be that the bladder muscle is spasming which makes it hard for the bladder to hold onto urine.

Overflow incontinence

Overflow incontinence is a leak of urine associated with a bladder that cannot empty properly. Symptoms include uncontrollable urinary dribbling, passing small amounts of urine many times in the day and overnight with a slow urinary stream and difficulty in starting that flow. The cause is an obstruction to the outlet of the bladder, for example, an enlarged prostate.

Reflex incontinence

Reflex incontinence is usually due to a spinal cord or brain injury. It is usually a complete leak of all the urine in the bladder. The leak happens without a feeling of needing to go to the toilet and the person has no control.
Other problems that affect the bladder

Dehydration

Dehydration means there is not enough fluid in the body. Some people, especially the frail-aged and children, can dehydrate very quickly if they do not drink enough fluid.

Signs of dehydration may include:

- having little or no energy
- having a loss of balance or feeling unsteady on their feet
- becoming confused and not being able to think clearly
- having a dry mouth
- having a fever with hot dry skin and faster-than-usual pulse
- having darker or more smelly urine
- being constipated.

Because many of these symptoms can be associated with other health problems, it is important to also seek medical advice.

Adults need about 1.5 to 2 litres of fluid each day and usually more in hot weather. It is important to recognise that some fluids will cause dehydration by increasing urine production, such as:

- caffeinated drinks like Milo, chocolate or coffee
- carbonated drinks like lemonade and cola
- alcoholic drinks.

Avoid these fluids in hot weather, during exercise and before going to bed.

*Generally, water is the best fluid to drink.*

As the carer, it is important that you help the person you are caring for to have enough fluid to drink every day. The challenges of this are known, so there are many ways you can help manage this including:

- using special cups or drink bottles
- changing the person’s position; for example, assisting the person to an upright position if they are bedridden
- using different types of drink, for example milk, fruit juice, soda water
- offering small amounts of fluid more often.
**Preventing dehydration**

The ways in which you prevent dehydration will depend on the person you are caring for. This person may have either memory or physical difficulties (or both) so the ways in which you would care for each person will differ. Some things you can do for the person you are caring for are to:

- place a jug of water and glass on the table next to the person
- write a note and place it on the fridge to remind the person to ‘have another drink’
- remind them to drink with meals
- use a straw to encourage the sucking reflex, if necessary
- offer appetising fluids, such as soups, jelly, favourite drinks, ice blocks and ice cream
- offer a variety of fluids in small, frequent amounts.

See also ‘Food and fluids’, in the Introduction (Part One) for more information.

*Remember to keep up a correct fluid intake for the person for whom you are caring. Talk to your GP or continence nurse adviser about what is a correct amount.*

**Swallowing problems**

Due to medical or physical conditions, people can sometimes choke or cough when swallowing. If this happens when drinking, this may mean that the fluid is ‘going down the wrong way’ which may cause problems such as chest infections. This choking may make people reluctant to drink resulting in bladder and bowel problems including dehydration.

Your GP can make a referral to a speech pathologist. It is possible that following an assessment by a speech pathologist, thickened fluids will overcome this problem.

*Swallowing problems need to be investigated – see your GP.*

**Urinary tract infections**

Urinary tract infections (UTIs) are very common for many people and they may develop symptoms including:

- high temperature
- stinging or burning when they pass urine
- a need to go to the toilet more frequently
- smelly urine
- acute confusion.

It is important to remember that not all elderly people will have all of these signs. Instead, they may just have a sudden onset of incontinence, or a worsening of existing incontinence. In addition, they may also be tired with less energy than usual and may not be able to tell you how they feel.
As the carer, if you detect these signs, treatment is needed. See your local doctor for treatment and advice.

The doctor will advise you that often the symptoms may stop after a couple of days; however, it is important to complete all the antibiotics unless the person you are caring for has a reaction. If this happens, go back to your GP for advice and a new prescription. If the antibiotics are stopped before the whole course is completed the infection may return.

When a person is taking antibiotics to help them recover from a UTI, it is important to remember they need to drink more fluids than usual which may help flush germs from the bladder. The bladder finds it hard to hold urine that is smelly and infected.

To help prevent more infections from developing, try the following:

- Encourage the person to drink more water-based fluids (e.g. fruit juice, mineral water). About 1.5 to 2 litres each day is recommended; however, some people find it very hard to drink that much fluid so you can try jellies, diet cordial or soda water instead.

- Make sure the person is not rushed and they sit on the toilet comfortably with their feet on the ground. This will help the bladder to empty fully.

- In women, always wipe between the legs with toilet paper from the front of the body towards the back.

- Use the toilet paper once and then dispose of it in the toilet bowl.

- After using the toilet, ensure the person you are caring for washes their hands thoroughly.

- If you assist the person, ensure you wash your hands thoroughly.

The bowel

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

Fluids and fibre

To keep the bowel healthy it needs sufficient fluids, good fibre and some exercise daily. The following will help develop a regular bowel action:

- Encourage the person to drink more water-based fluids (e.g. fruit juice, mineral water). About 1.5 to 2 litres each day is recommended; however, some people find it very hard to drink that much fluid so you can try jellies, diet cordial or soda water instead.

- Encourage a minimum of three serves of vegetables and two serves of fruit daily. Fruit can be fresh, preserved or stewed. It is important to mix different fibres from fruit, vegetables, whole grain cereals, breads and products such as kidney beans, lentils and butter beans.

- Encourage a hot drink before or during breakfast.
• Have regular meal times.
• Train the bowel to pass a motion about 30 minutes after breakfast or lunch.
• Encourage the person you care for to walk whenever they can even if it is for a short distance. If they cannot walk, sitting exercises are helpful. A physiotherapist will be able to help you with some of these exercises.
• Avoid bowel medications (laxatives, aperients) where possible. Talk to your GP, GP practice nurse or pharmacist before taking these medications. Chapter 5 has more information about medications.

Bowel dysfunction

Bowel regularity and bowel control are a part of everyday life. People who have trouble with either of these need help to prevent further problems developing. The chart at the end of this section will assist you with recording bowel motions to determine bowel patterns. You can talk to your GP, GP practice nurse or continence nurse about the chart.

Constipation

Constipation is the most common bowel problem and affects people of all ages, especially those with another medical, physical or mental health problem. Constipation happens when the stools become dry and hard.

This can make the bowel action slow and difficult to pass. The person for whom you are caring 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 also lead to the start of a condition called piles or haemorrhoids.

Causes of constipation

The most common causes of constipation are:

• low fibre intake
• dehydration or low fluid intake
• too little exercise
• not going to the toilet when you feel the urge or not ‘going’ when the urge arises
• some medications
• long-term use of laxatives/aperients, which reduce the strength of the bowel
• not emptying the bowel fully
• long-term illness.
Effects of long-term constipation

Faecal impaction
This may happen when the person you are caring for has been unable to have a healthy bowel action for some time. The bowel finds it very hard to push out any stools and they become impacted in the bowel.

Piles (haemorrhoids)
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.

Rectal prolapse
This is an extreme result of long-term straining on the toilet to pass a motion where it is possible for part of the bowel to come 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. (See the diagrams — Bladder and Bowel anatomy.)

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
Losing control of the bowels is called faecal incontinence or diarrhoea.

Diarrhoea is when bowel motions are loose and watery. The bowel motions feel urgent, are difficult to control and are more frequent. If it is difficult to get the person you are caring for to the toilet or you have difficulty undoing their clothes, this can be a sign they are incontinent.

Diarrhoea can be caused by many things including:

- food poisoning
- infection
- too much fibre
- too many laxatives
- some medications (e.g. antibiotics)
- some illnesses (e.g. ulcerative colitis)
- some mental health conditions.

*It is important to find the cause of the diarrhoea — your GP will be able to help with this.*
How to avoid further problems

When someone you are caring for has diarrhoea, other problems may occur. You can help prevent these problems in the following ways:

Protect the skin

Wash the person’s buttocks and between their legs after each bowel motion with warm soap and water. Make sure the skin is kept as dry as possible. Loose motions can make the skin red and sore. Use a barrier cream sparingly to waterproof the skin.

Settle the stomach

Certain food and drinks can make the diarrhoea worse. Avoid milk-based drinks, spicy foods, caffeinated drinks and alcohol, which can irritate the bowel further.

Prevent the spread of infection

It is important to remember that if the person you are caring for has an infection that is causing the diarrhoea, you need to avoid infecting yourself and others (cross infection). Wash your hands after assisting with toileting or handling soiled garments. Wash the person’s hands including between the fingers and scrub their fingernails after using the toilet.

Prevent dehydration

Remember the advice from earlier in the book and avoid dehydration by giving sufficient fluid every day.

Medications

Ask your GP or pharmacist to review the person’s medications to see if there are any that may be causing the problem.

It is important to remember that most bowel medications can be purchased over the counter at the chemist or supermarket; however, your GP may also prescribe medication. Tell your GP about all the bowel medications that the person you are caring for is taking as it will help when making decisions about the person’s bowel needs.

If the person you care for has a problem with constipation or faecal incontinence, see the GP, GP practice nurse or continence nurse adviser.

Laxatives (aperients)

This is a group of medications that make the bowel empty itself. Long-term use of these medications may cause your bowel to become weak and lazy. Long-term problems with constipation and/or faecal incontinence need to be managed or treated by the person’s GP or continence nurse adviser.
Laxatives or aperients work in different ways. Some can:

- add bulk to the bowel action
- soften the bowel action
- stimulate the bowel to move along
- do one or more of these things.

**Bulking agents**

Products such as bran, psyllium and sterculia will add bulk to the bowel motion and help stimulate the bowel to push. When using these medications, it is important to follow the manufacturer’s instructions about extra fluids.

**Stool softeners**

Products such as liquid paraffin soften the stool but also help to make the bowel push the motion out. When using these medications, it is important to follow the manufacturer’s instructions about extra fluids.

**Stimulants**

Products such as senna stimulate the bowel to push. These may be effective for a short time but can cause problems in the long term.

*Always talk to your doctor about the medications being taken by the person you are caring for – let them know about any changes or side-effects.*

If it has been decided by the person’s GP or continence nurse adviser that laxatives (aperients) may be useful for a short time, then a pharmacist can advise on the selection. It is important to manage these wisely.

**Bowel diary**

A bowel diary can be useful for a short time to help you know when the person you are caring for has a bowel motion. You may copy this chart to use at home and if needed it can be shown to the GP for advice. More charts and diaries are in the toileting section.
Name:

Date commenced:

<table>
<thead>
<tr>
<th>Date</th>
<th>Time</th>
<th>Size of motion (small/medium/large)</th>
<th>Formed/loose</th>
<th>Hard/soft/watery</th>
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To fill in the chart follow the words at the top and complete each section when the person has a bowel motion.

The prostate

Men can have continence problems because of enlargement of the prostate gland (see the figure of the male anatomy that shows where the prostate gland is located).

Prostate enlargement is part of the normal ageing process. This may not necessarily be cancerous or cause problems. The following signs may mean a problem has developed:

- disturbed sleep because the person needs to pass urine more often at night
- increased risk of falling because of poor mobility or unsteady balance
- passing small frequent amounts of urine often less than two hourly
- feeling like the bladder is not fully emptying; needing to ‘go again’
- a slow start; having to wait a long time for the urine flow to begin
- a weak stream; a slow flow of urine taking a long time to finish
- after dribble; drops of urine in the underwear after finishing
- urinary incontinence; unable to hold on until the person gets to the toilet
- strong odour to the urine
- blood in the urine.

See a doctor if any of these signs happen to a man you care for and take a specimen of urine with you.

It may not be a prostate problem but it needs to be investigated.
Chapter 2: Products and equipment

Disposable pads

There are many different kinds, brands, sizes and absorbencies of disposable pads.

It is important to read this whole section before choosing pads to make sure that you have all the information that you require to make an informed choice of pad, that you do not spend more money than you need to and that the product suits the person that you are caring for.

When choosing a disposable pad, consider the following:

• Does the person need a pad to protect the underwear from becoming damp from drips when they cough or sneeze?

• Do they need a pad to hold more urine because the amount of leakage is larger?

• Does the person have trouble with their hands or eyes that make it difficult to remove the sticky protector strip and place the pad the right side up in the underwear?

• If the person is confused, will they flush the pad down the toilet and block the drains?

• Will they let you help them in the toilet?

• Wearing two pads together is not ideal. It is better to think about either a booster (a special secondary pad) or wear a single, bigger pad.

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

• wash the skin each time you change the pad

• use barrier creams and moisturisers sparingly as they may ‘waterproof’ the surface of the pad and reduce absorbency of urine.

If the continence pad leaks, try to find a pad that better suits the person’s level of incontinence. To ensure that the person stays healthy, a urinary tract infection should be ruled out before a larger capacity pad is used.
Types of disposable pads

**Smaller pads**

Smaller stick-on pads are best for small to moderate urinary incontinence (when underpants become damp or wet). There is a range of sizes from thin, flat panty liners to larger, thicker pads with gathered elastic sides.

Choice will depend on:

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

**Shaped pads**

Shaped pads are larger disposable pads designed for larger urine loss (when underpants would have become wet or soaked).

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 net pants. Loose underwear will cause these pads to leak.

Choice will depend on:

- the amount of urine lost
- whether the person minds tighter fitted underwear
- whether the person can manage tighter net underwear.

**Net pants**

Net pants are stretchy elastic briefs 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.
Pads with elastic side straps (or undergarments)

There are a number of pads available that have elastic side straps that hug the hips and are gathered along the sides to fit firmly into the groin. These pads are also known as undergarments and may be worn with the person’s own underpants over them if they prefer.

Undergarments hold a medium amount of urine (when the underpants would have become damp to wet).

Choice will depend on:

- the amount of urine lost
- how mobile or independent is the person
- whether the person is confused
- how much assistance the person needs with the elastic straps or to prepare the pads.

All-in-one pads

All-in-one pads are a full sized ‘brief’ designed to wrap around the body and seal with re-useable adhesive tapes. They hold large amounts of urine (when underpants would have become soaked), many up to 2 litres. With these products, advice from a company sales representative or your continence nurse adviser 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
- whether the person has any skin reactions to a full-brief pad.

Remember to:

- wash the skin each time you change the all-in-one
- use barrier creams and moisturisers sparingly as they may ‘waterproof’ the surface of the pad and reduce absorbency.
Disposable pants (adult pull-ups)

Adult disposable ‘pull-ups’ 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 confused people, because they feel like underwear, and for people who would not tolerate another type of pad.

Choice will depend on:

- how much urine is lost
- whether the person use the toilet themselves and how often
- whether they are confused
- whether they are able to manage these pants by themselves.

Disposal of pads

It is important to think about how you are going to dispose of the used pads.

In practical terms, and to ensure you meet health standards, 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.

What about the environment?

Manufacturers of disposable pads tell us that the materials are biodegradable; however, plastics do account for 10% of council land fill.

Some people say that the amount of water and detergents used in washing garments is also harmful to the environment. The case can be discussed for both sides. You and the person you are caring for will make the choice about which is the best product and method of disposal that suits your lifestyle.

Samples

There is a vast range of pads available and this may present a problem when choosing a product. Some help may be required to make sure they don’t become too expensive. Samples are useful to try before you buy. Most product companies will provide free samples if you ring or write to them and ask.

A continence nurse adviser can help you choose the pad or product that will suit the person you care for.
What are pads made of?

Disposable pads contain absorbent fibres made from wood pulp with a waterproof backing to protect the wearer’s clothing.

Most pads contain a super absorbent substance that looks like sand and turns to gel when wet. This ‘locks’ the urine into the pad and prevents leakage. Good-quality pads have a ‘stay-dry’ surface to keep moisture away from the skin and prevent skin problems.

Hygiene and skin care

It is important to remember the following when caring for someone with incontinence:

• Wear disposable gloves to protect your hands when changing pads or washing the person’s bottom or between their legs.
• Wash your hands after handling soiled pads and garments, even if wearing gloves.
• Wash the person’s buttocks and between their legs when changing used pads.
• Keep the skin clean to remove the smell of stale urine/faeces and to prevent red, sore skin problems.
• Use a barrier cream sparingly to protect the skin. Avoid perfumed moisturisers, especially if the person has allergies or sensitive skin or if there is redness or broken skin.
• Do not use solutions with alcohol or disinfectant directly onto the person’s skin as this can be very drying, cause soreness and cause skin breakdown or allergic rashes.

Re-usable products

A range of re-usable, washable products are available for personal use, bedding and furniture protection.

Re-usable products are available in a large range of sizes and absorbencies from a number of manufacturers and will differ in quality and price.

Choice will depend on the:

• type of incontinence
• amount of urine lost (whether the underwear would have become damp, wet or soaked)
• person's or carer's physical capabilities
• personal preferences (e.g. colour, comfort, size)
• cost.

Things you need to know
• To prolong the life of these items, care must be taken to ensure that they are washed according to the manufacturer’s instructions.
• Before you put these garments on the person for the first time they usually need to be washed, following the manufacturer's instructions.

Personal use

Washable padded briefs/all-in-ones

Washable 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
• with faecal incontinence
• who are confused and may flush pads down the toilet
• who are immobile
• who cannot wear disposable pads.

Choice will depend on:
• cost
• the type of stay-dry surface available
• personal choice
• odour control
- toileting routine
- skin care.

A continence nurse adviser can guide your choice of product. An informed decision will help you save money.

**Purchasing pads**

Pads are expensive. Choosing the right product for the person’s incontinence will help to save money. For example, sanitary pads are not made for urine and are not cost effective.

When choosing a pad you might like to consider the following:

- The price of the pad increases with size. The larger the volume of urine, the bigger the pad required and the more it will cost.
- Often more expensive pads, if changed less often, will work out cheaper as fewer are used.
- If the person wants to change their pad every time they go to the toilet, use a smaller pad. This is cheaper than using a larger pad each time.
- Think about trying the pad before ordering a full packet. Most manufacturers or medical wholesalers supply sample packs. You can look at pads at Continence Resource Centres (VIC, NSW, WA) or at an Independent Living Centre located in each state and territory (except for the Northern Territory). Or ask a continence nurse adviser to help you. The ‘Other sources of help and advice’ and ‘Contact details for support organisations’ sections in Part Three provide more information.
- If the person’s incontinence is ongoing, then consider washable, reusable products. These may work out cheaper over time. Washable pads/pants, if cared for properly, can last for six months.

Depending on the needs of the person for whom you care, you may need different pads for different circumstances, for example:

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

Using different pads will work out to be more cost effective than buying one pad to meet the needs of all situations. A continence nurse adviser can help you decide.

In general, the following points will help when you are buying pads:

- 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; at the very least, 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 larger up-front cost or a storage problem. Local medical wholesalers will have more information on bulk purchase. See ‘Other sources of help and advice’, in Part Three, for more information.

• Some pharmacies have discounts for customers who are members.

• Some medical wholesalers have their own discount schemes for ‘valued customers’.

• Some manufacturers have a ‘factory direct’ service. You may need to buy a carton at a time and it will be delivered to your home.

The ‘Other sources of help and advice’ and ‘Contact details for support organisations’ sections in Part Three provide more information.

Catheters

Catheters are flexible tubes that are inserted into the bladder to drain the urine out. Depending on the type of incontinence, some people may need an intermittent or indwelling urinary catheter. Both these types of catheters are used in special circumstances and under medical supervision. They are not suitable for everyone.

Intermittent catheters

Intermittent catheters are where a soft flexible tube is inserted into the bladder and removed several times every day.

This technique needs to be taught correctly by a registered nurse or continence nurse adviser to avoid problems.

Indwelling catheters

A long-term indwelling catheter is inserted into the bladder once and left there for an extended period of time (up to 12 weeks). If the person you care 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 nurse or continence nurse adviser.

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 and keep the bladder healthy. Usually the amount of fluid will depend on the person you are caring for and their circumstances.

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 then careful attention must also be paid to washing after each bowel action. Do not use talcum powder if there is a catheter.
For people living with an intermittent or indwelling urinary catheter, attention must be given to keeping the bladder and bowel healthy and avoiding constipation.

See the section on bowels in Chapter 1, or see your GP, continence nurse adviser or GP practice nurse if there is a problem.

Cost of supplies needs to be considered. See Chapter 8, 'Getting financial help'.

**Purchasing urinary catheters and sheaths**

Catheters and sheaths are specialised products that require teaching to understand and use correctly. A continence nurse adviser can help you with this. Urinary catheters and sheaths can be purchased from medical wholesalers. The ‘Other sources of help and advice’ section in Part Three will help you locate a supplier.

**Protecting the home**

Depending on your lifestyle and the person you are caring for, there is a large choice in products designed to protect furniture and bedding.

**Chair pads**

Washable chair pads are designed to protect furnishings. They only have a small absorbency but do have a waterproof backing. They are not designed to be used alone; the person still needs to wear a pad. Washable chair pads come in various qualities, colours and designs.

**Absorbent bed sheets**

Absorbent bed sheets have a stay-dry surface and a thick absorbent underlayer. They must be used over a waterproof undersheet (unless there is one already on the back) to protect the mattress.

Advantages of absorbent bed sheets are that they:

- are highly absorbent
- have a stay-dry surface that helps protect the skin
- require less need to change the bed during the night
- may be laundered at home.
Disadvantages of absorbent bed sheets are that:

- they are heavy when wet
- they require a strong washing machine with a spin dry cycle
- some brands cannot be put in a tumble drier.

**Bed pads**

Bed pads are absorbent mats with a waterproof backing.

Advantages of bed pads are that:

- they do not have tuck-in edges
- no plastic sheet is needed.

Disadvantages of bed pads are that:

- they have lower absorbencies
- they take longer to dry
- they are heavy when wet
- they require a strong washing machine with a spin dry cycle
- some brands cannot be put in a tumble drier
- not all brands have a stay-dry surface and skin problems may occur
- they can shift or bunch up when the person moves around in bed.

Examples of pads and furniture protection can be viewed at the Victorian Continence Resource Centre and the Continence Foundation of Australia in NSW and WA and Independent Living Centres, located in all states and territories other than the Northern Territory.

The National Continence Helpline on 1800 33 00 66 can provide information on aids and appliances and where they can be purchased. The Continence Foundation of Australia website [www.continence.org.au](http://www.continence.org.au) also has a product directory to assist you in locating a supplier in your area.

Further information is available in Part Three of this book.
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 aid the person you are caring for. See the reference list at the end of this book to assist you and the person you care for in your choices. 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. You may need extra help with this.

Slipper pan

Useful for people who cannot lift their hips too high or move too easily in bed. These need to be placed under the person and removed. You may need extra help with this.

Urinary bottle (urinal)

Useful for men who are able to ‘aim well’ but 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 that is used like a regular urinal.

Female bottle/urinal

Useful for women with poor mobility or who are in a wheelchair. You and the person you care for may require help to use and hold in place.

Disposable bottle

Can be used for men or women. It is non-spill and is useful when going out if disposal of the bottle is preferred.
Travel bottle

Can be used for men or women. This is a collapsible plastic container with a lid. It is compact to carry and can be washed and reused.

Toilet surround

A frame that fits around the toilet with armrests and adjustable legs for height. Assists people 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.
Sheath and leg bag drainage system

This is an alternative to pads for men but does not suit all men. Sheaths are also known as ‘external catheters’ and ‘condom catheters’.

The sheath fits over the penis like a condom but has a drainable outlet. It is connected to a small disposable bag, which can be strapped to the leg during the day, or to a larger drainage bag at night. The sheath works by sticking onto the shaft of the penis, so care must be taken when applying and removing to prevent skin damage. Sheaths need to be removed daily, and the skin washed and dried carefully before being reapplied.

Sheaths need to be fitted correctly to prevent leakage. A continence nurse adviser can help with fitting these. If the wearer has problems with their hands, they will need help to apply and remove the sheath and drainage bag.

Men who have difficulty getting out of bed or walking to the toilet find them useful; however, the wearer needs to be mentally alert to be able to use this appliance.

Read the manufacturer’s instructions on the package to apply and remove the sheath correctly.

Choosing suitable equipment

As there are many pieces of equipment available, it is wise to seek advice before purchasing to be sure the selection will be suitable and to avoid unnecessary expense.

A continence nurse adviser will be able to help you decide on personal equipment and pads or other products.

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

You may be able to purchase or view equipment at:

- local community health services
- local council offices
- medical equipment hire stores, to find out about the supply and rental of equipment
- the Independent Living Centre in your state or territory (except for the Northern Territory)
- Technical Aid for the Disabled.

Contact the National Continence Helpline on 1800 33 00 66 for information in your local area.
Chapter 3: Common reactions and responses

If incontinence is not managed and treated 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 the carer to feel overwhelmed with the stress arising from changes in your life and in the relationship, from the cost burden of continence care and aids and from the increasing time and cost spent on cleaning clothes and bedding.

Everyone’s reaction to incontinence is different.

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 try to hide it, may deny it and may not want to talk about it.

People react to incontinence in many ways. 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, 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 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. This is the dynamic that occurs when a cigarette smoker won’t give up cigarettes, even though they understand that it is likely to be giving them cancer or another form of lung disease.

Magic thinking

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 and dearest 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 increasing age, giving birth to children or of having had prostate surgery and so may not feel that there is any point to 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 adviser or doctor that they 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 attempt to avoid the situation that 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 that person being cared for has never talked about this problem before, and so may be anxious about their response to the problem. Will they be able to find the words to explain the problem? What is the problem? Can it be fixed? Or, if I tell the doctor, where will it lead?

- being referred on for tests — anxiety might be raised in some by the prospect of having to tell even more people about the problem or about the fear of being incontinent on the way to the office or in the waiting room. There may be anxieties for some in the thought of a physical examination or in having to undergo tests. Having had a test might lead some to then become anxious about the result of the test. Many of these anxieties are very common in carers and in those experiencing continence problems.

**Frustration and anger**

Frustration is a normal human reaction when a person feels that they are unable to achieve something that they want, value, believe that 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, side effects, etc may lead to anger in carers or those experiencing incontinence.

In most people, anger arises from frustration, and 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 leave the person and carer exhausted. Irritability, impatience and reduced tolerance can result and place severe strain on the health and relationships of both parties.

Sometimes, people experiencing continence problems feel that they are treated like children. A frustrated, irritable and angry carer might vent their feelings in nonhelpful 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 finding that expressed anger and frustration are becoming a problem should seek advice from their GP or continence nurse adviser on how to access support in managing these emotions. Your GP may be able to make a referral for cognitive behaviour therapy, one useful form of psychological help for stress, anxiety and anger-related problems.

Grief

Grief is a very normal response to any change in a person’s life. It represents their response to actual or perceived loss that they experience as a result of that change. Grief responses occur as a person feels the loss and adjusts to the loss. For that reason, grief is usually a transient state; it lessens and passes with time. Grief may look and 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.

Grief, however, is always an individual experience.

Depression

Depression refers to a serious common condition that affects about one in five Australian women and about one in eight Australian men. People who are carers and people who experience incontinence are more likely than others to experience depression. If you think that you or the person you care for could be depressed, it is important to raise your concern with your doctor. Because depression tends to rob people of hope and can lead some people to suicide, it is very important to obtain help.

There are many easily-accessible resources available through libraries, your health professional and on the internet.

The following checklist might help you establish whether depression is present in you or the person you care for. If you tick five or more of the items then it is likely that depression exists and this should be discussed with your health professional.
### Depression checklist

<table>
<thead>
<tr>
<th>For more than two weeks have you:</th>
<th>Tick if YES</th>
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<tbody>
<tr>
<td>1. Felt sad, down or miserable for most of the time?</td>
<td>☐</td>
</tr>
<tr>
<td>2. Lost interest or pleasure in most of your usual activities?</td>
<td>☐</td>
</tr>
<tr>
<td>If you answered 'YES' to either of these questions, complete the symptom checklist that follows. If you did not answer 'Yes' to either of these questions it is unlikely that you have a depressive illness.</td>
<td>☐</td>
</tr>
<tr>
<td>3. Lost or gained a lot of weight? Or had a decrease or increase in appetite?</td>
<td>☐</td>
</tr>
<tr>
<td>4. Had sleep disturbance?</td>
<td>☐</td>
</tr>
<tr>
<td>5. Felt slowed down, restless or excessively busy?</td>
<td>☐</td>
</tr>
<tr>
<td>6. Felt tired or had no energy?</td>
<td>☐</td>
</tr>
<tr>
<td>7. Felt worthless? OR, Felt guilty? OR Felt guilt about things you should not have been feeling guilty about?</td>
<td>☐</td>
</tr>
<tr>
<td>8. Had poor concentration? OR Had difficulties with thinking? OR Had trouble making decisions?</td>
<td>☐</td>
</tr>
<tr>
<td>9. Had recurring thoughts about death, about suicide or about not being alive anymore?</td>
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</table>

**ADD UP THE NUMBER OF TICKS FOR YOUR SCORE**

Assuming that you answered 'YES' to Q1 and/or Q2, a score of 5 or more suggests that you are likely to have depression to such a degree that is identifiable as an illness requiring medical intervention. This checklist provides a guide only. It is worthwhile discussing your test result with your doctor or health professional.


### Vulnerable life stages and understanding

Incontinence often occurs during times when people are already at greater risk of depression. Some life stages that hold a greater risk for incontinence AND depression include:

- moving into old age
- experiencing problems with the prostate and prostate cancer
- being pregnant
- having recently given birth
• experiencing menopause
• developing midlife health problems such as diabetes
• experiencing side effects of medications used to treat other new health problems.

Recognising and addressing these vulnerable life stages will help build a relationship where you and the person you are caring for can express how they feel. Discussing and recognising that these problems are common and that treatment and support are available will assist in the understanding and appropriate acknowledgement of these life stages.

Patience and understanding are needed. Incontinence is not a sign of being lazy, but an indicator of health problems. Equally, feeling frustrated, angry or depressed does not mean that there is something ‘wrong’ with you, but understanding and seeking help and support for these is important for everyone’s health and wellbeing.

What can you do?

General recommendations for what you can do to help are listed below:
• Ask your doctor and/or health professional for help.
• Ask a continence nurse adviser for support and guidance.
• Explore access to cognitive behaviour therapy or interpersonal therapy.
• Discuss the merits and consequences of medication.
• Explore local and internet sources of advice and help (see ‘Other sources of help and advice’ and ‘Contact details for support organisations’ in Part Three of this book).
• Make regular appointments for review with your GP.
• Engage in 30 minutes of physical exercise daily.
• Eat good healthy and fresh food and drink at least 1.5 to 2 litres of fluid daily.
• Achieve and maintain a healthy body weight. Being overweight is associated with many physical and psychological health problems.
• Don’t smoke cigarettes and minimise alcohol and caffeine intake (alcohol can interfere with medications and make feelings worse).
• Practice healthy sleep habits.
• For more information, see Part Three of this booklet.
Chapter 4:  
Mental health and incontinence

There is a clear relationship between continence and mental illness.

People with mental illness are more likely than those without to develop problems associated with continence. Equally, people with incontinence are also more likely to have some form of mental illness.

Incontinence in a person with mental illness might reflect the symptoms of their illness, such as the confusion or lack of motivation often experienced by a person with severe depression. Equally, a person with schizophrenia might become so distracted by hallucinations that they fail to recognise the normal signals alerting us to a full bladder or bowel. Some people with serious mental illness, such as schizophrenia, may develop strange and frightening ideas that might prove to be barriers to entering a toilet when they need to. Medications used to treat people with mental illness are often tranquillisers or antidepressants. Many drugs of this type can interfere with bowel and bladder functions in a number of ways and may contribute to incontinence.

Some people with serious and enduring mental illness become prone to addictions around smoking cigarettes and drinking high quantities of coffee, cola, etc. These behaviours can contribute to incontinence because of their specific effect on the body and brain. For example, caffeine has a diuretic effect.

Generally, encouraging activities that improve overall health and reduce body weight such as eating and drinking well, avoiding smoking and exercising regularly will reduce continence problems.

Caring for someone with dementia

Dementia results from damage to the brain. It occurs most commonly 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 have increasing difficulties with the everyday activities (communicating, bathing, cooking, etc). Alzheimer’s disease (pronounced ‘Olz-hy-merz’) is the most common form of dementia and affects mainly older adults. It often causes people to feel lost, anxious and confused.

Because dementias such as Alzheimer’s disease cause confusion and anxiety, they may cause withdrawal, resistance and aggressive behaviours that add to the burden of the carer. Because dementias most commonly occur in the later third of life, it often occurs with age-related health changes such as heart disease, cancers, diabetes, gynaecological changes, prostate enlargement, obesity and arthritis.

As you may already know, incontinence is associated with many of these health changes. Thus, the picture of a person with dementia and incontinence is likely to be a complex and challenging one for the carer and the medical professionals involved. Incontinence
in 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 become more of a problem as the person:

- forgets where to find the toilet
- forgets how to unfasten their clothes
- forgets what to do when they get to the toilet
- becomes more susceptible to urinary infections because of prostate or gynaecological changes
- becomes more prone to bowel changes such as diarrhoea or constipation in response to medication side effects.

The burden for the carer may increase if confusion and memory loss lead to the person resisting assistance with post-toileting or incontinence hygiene.

A professional 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.

(See ‘Seeking help from a GP’ in Part Three)

For professional help, see a doctor or a continence nurse adviser. Contact the National Dementia Helpline on freecall 1800 100 500 or the 24 hour Dementia Behaviour Management Advisory Service on freecall 1800 699 799.

Sometimes, assessment reveals that the incontinence is the result of brain damage that has occurred due to an irreversible dementia such as Alzheimer’s.

In this circumstance, the most practical management measures will always include:

- the best fluid, food and fibre intake that the person will accept
- as regular and routine toileting as the person will permit.

**Managing difficult behaviours**

People with dementia can become very distressed and resistive when toileting because of the confusion and memory loss that they commonly experience.

‘Imagine how it might feel for you 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!’

Carers of people with dementia require enormous support in order to be able to remain calm, gentle, firm, patient and accepting and to maintain their sense of humour.

All of these, including a broad smile, may be required in successful attempts to get the confused person to the toilet in time.
In some instances, in response to confusion, the person with dementia may be passing urine (voids) in the wrong place. 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 that the person is about to void in the wrong place or for those who become very anxious around toileting
- placing a commode or receptacle in the ‘trouble’ area
- creating a barrier to accessing the ‘trouble’ area
- joining a carer’s group and exploring how others address this problem.

*Toileting is very stressful for people with dementia.*

Knowing the person’s previous lifestyle may help to plan strategies.

The person’s previous work, interests, standards of living, where they lived, where their toilet used to be (for example, outside in the garden) all help to plan management of behaviours.

Remember to:

- not hurry a person with dementia
- use short step-by-step instructions, such as ‘sit down’
- 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 my (or other’s) unrealistic expectations of my ability to manage (‘I’m failing as a carer/husband/wife’).

In some circumstances, the worst that happens as a result of the person voiding in the wrong spot is that you have to mop it 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**

Often the person being cared for may not be able to tell you clearly about how they are feeling, what they are feeling and where they are feeling it. Feelings associated with hunger, thirst, cold, anxiety, a full bladder, a full rectum, a headache or stomach-ache might all present as agitation, irritability or tears in the person with dementia. No longer able to express themselves with language, feelings may be demonstrated in behaviours.
Urinary and bowel incontinence may be distressing the person you care for, making them more anxious than usual. Look for changes in behaviour and patterns associated with toileting. While the following emotions and behaviours may be connected to more complex issues, they are commonly associated with continence problems.

If they are displaying any unusual behaviour or any of the behaviours outlined on the next page, see your doctor or continence nurse adviser for a full assessment.

For further information contact the National Dementia Helpline on freecall 1800 100 500 or the National Continence Helpline on freecall 1800 33 00 66.

**Challenging behaviours seen in the person with dementia and some possible causes associated with incontinence**

- If the person is angry, agitated, yelling and hitting or being disruptive with constant repetitive questions, they may be in pain or discomfort because of:
  - constipation
  - feeling the need to pass urine and not being able to
  - being distressed by their incontinence.

- If the person is restless and wandering, this may be because they:
  - feel hungry
  - feel thirsty
  - feel the need to pass urine or have bowels open urgently
  - are unable to recognise the toilet.

- If the person has disturbed sleep, this may be because they:
  - have a urinary tract infection
  - are constipated
  - feel the need to pass urine or have bowels open urgently
  - may have problems with their prostate, if male
  - may have a delirium brought on by urinary tract infection, dehydration or constipation.
• If the person is paranoid (feeling that someone is against them) or hallucinating (seeing things that aren’t really there), this may be because they:
  • have a urinary tract infection
  • are severely constipated.

• If the person is lethargic (tired, fatigued) or more confused than usual, this may be because they:
  • are constipated
  • are dehydrated
  • have a urinary tract infection.
Chapter 5: Medication

Some medications can interfere with bladder and bowel functions. Medications can be anything prescribed by the GP and/or specialist, or purchased over the pharmacy counter, at the health food store or at the supermarket.

Medications prescribed by your doctor to treat a condition should not be withheld without speaking to your doctor, even if you think they may be causing a problem.

It is important to let the GP know all the medications the person you are caring for is taking and never to give one person’s medication to another, no matter how well meaning you are.

Medications that may lead to incontinence

Medications that may affect the bladder include:

- fluid tablets (diuretics)
- antihistamines (for hay fever)
- blood pressure tablets (antihypertensives)
- strong pain killers (analgesia)
- antidepressants
- Parkinson’s tablets
- sleeping tablets
- constipation medicine
- antipsychotic and other tranquilising medications.

Medications that may affect the bowel

- antidepressants
- sleeping tablets
- Parkinson’s tablets
- anti-inflammatory tablets
- strong pain killers
• laxatives/aperients
• fluid tablets
• medications used for bladder control
• calcium or magnesium products (for strong bones or heartburn (indigestion))
• antipsychotic and antidepressant medications
• antibiotics.

If you are having problems, ask your GP or pharmacist to check any medication the person may be taking.
Chapter 6: Helpful hints at home

Helping people go to the toilet may require some adjustments to the home. Adjustments will depend on the person’s abilities.

It is important to know where to get help. An occupational therapist is trained in assessing the needs of the person and advising on the right equipment for the person’s situation. This advice could save money in the long run.

Read about ‘Equipment and toilet alternatives’ in Chapter 2.

In the toilet

- If there is limited room in the toilet for a second person to assist, have the door adjusted to open outwards.

- To make sure the way to the toilet is clear, remove all clutter and loose mats from the bedrooms, hallways and bathrooms.

- Make sure there is adequate lighting to and from the toilet.

- Small ‘night lights’ that plug into the power point or sensor lights are useful for directing the way.

- Place a strip of ‘flexi lights’ (an electric strip of lights in a plastic tube) along the floor to direct the way to the toilet. You can purchase these at electronic or large hardware stores and lighting outlets.

- For someone with dementia, place a picture of a toilet on the door. This will help the person to remember the toilet and find their way there. It is important to keep the sign within their line of vision, so place it at chest height. Alternatively, attach a toilet sign to the wall, to protrude out like a flag to catch their attention.

- Make the surface on the toilet floor non-slip. For more information, see the Section ‘Mobility’ in Part One.

- Grab rails mounted on the toilet wall or a toilet surround or toilet seat will help getting on and off the toilet.

- Try to make the toilet comfortable. For example, install a heat light and use air fresheners.

- Wipe up any spills to prevent anybody from slipping or falling. Keep a mop, bucket and disinfectant (if you want) handy.
In the bedroom

• Protect the bed with an absorbent bed sheet. The section ‘Protecting the home’ in Chapter 2 has more information about bedding protection.

• 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.)

• Use a ‘bed pole’ (self-help pole) to help the person turn over in bed and to get up more easily.

• If possible, move the person to a bedroom nearer to the toilet.

In the living room

• If the person you care for urinates into pot plants, remove the pot plants and allow safe access to the garden. Some men with mental health problems prefer to urinate outside.

• Give free access to the toilet by making sure you remove all clutter from doorways and along the passageway to the toilet.

• Arrange the living room furniture to allow free access from a favourite chair to the doorway.

• Keep a bucket or bottle nearby in case of emergencies. Make sure this gets washed and disinfected regularly to prevent odours.

• Protect chair seats with a waterproof chair pad. Chapter 2 has more information about protecting the furniture, in ‘Protecting the home’.

• Make sure the person you care for can get out of their chair without difficulty. Their favourite chair may need some modifications. An occupational therapist can advise you on this.
Clothing

- Clothes such as track pants are simple, but not everybody likes wearing them. Simplify all trousers for men and women by sewing velcro in to replace buttons, zips or side seams. A seamstress would be able to help you.
- Purchase slacks and skirts with elastic waistbands.
- To reduce workloads, buy non-iron clothes that wash and wear.
- Modify nightdresses to open down the back.
- Women may wear wrap-around skirts with the opening turned to the back.
- Where possible, and if the person agrees, a man could wear just a pyjama top to bed and women could just wear a short night dress.

The section ‘Equipment and toilet alternatives’ (in Chapter 2) has more information on equipment. For help in choosing equipment and for making adjustments to the home, ask:

- an occupational therapist
- the Independent Living Centre
- a continence nurse adviser
- Alzheimer’s Australia
- your local Carer Information Service.
Chapter 7:  
Going out and about

At home, the toilet can be set up for comfort and ease. When you take the person you are caring for out and about it can be much more difficult both finding and using a strange toilet. Caring for a person who is incontinent does not mean either of you has to stay at home.

Planning ahead

Before you go out, ask yourself the following questions:

• Where are we going?
• How long will we be out?
• When will the person most likely need to go to the toilet next?
• Does the person usually wear a pad or use equipment when going to the toilet?

Consider the following:

• How often does the pad need changing? When it was last changed?
• What equipment do you normally use? Can you take this with you?
• Are there other alternatives you can use?
• When is the best time to go, for example, 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?

What to take with you

What you take with you will depend on:

• how often the person for whom you are caring is incontinent
• how long you are going to be out
• where you are going—shopping centre, friend’s house.
Some things 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 appliance
- baby wet wipes, cloths, towels to wash and dry, odour remover
- spare pads, appliances or equipment
- a container, in case the person needs to pass urine during the car trip.

Knowing where the toilets are

Do you know where the toilets are located at your destination?

- The National Public Toilet Map (www.toiletmap.gov.au) can be accessed via the internet, mobile phone web browsers or a free iPhone app.
- At the shopping centre or place you are visiting, ask the information person or check the service directory for the locations of the toilets.
- Are there toilets for people with a disability?
- Are there family-friendly toilets?
- If visiting a friend’s or relative’s house, check to see if their toilet facilities are easy to use.
- What if the person you care for is of the opposite sex? Do you feel comfortable taking them to the toilet in public?
- When disposing of pads, you may be able to use the sanitary bins provided. If not, put the pad in a plastic bag and place it in a rubbish bin.

Other things to consider

If the person is on fluid tablets, timing is important.

- What time of the day do they take the medication?
- When do they go to the toilet? Talk to the doctor to find out if it would be possible to delay the medication until after the outing.

To avoid the person having to pass a bowel motion when out and about, check with their GP to see if any bowel medication could be given later in the day.
Chapter 8: Getting financial help

Having an incontinence problem can be very expensive. Even if the problem cannot be cured, it can be managed. It is important to continue with treatment or management plans as discussed with the GP or continence nurse adviser. These plans will help to decrease costs by reducing the amount of incontinent episodes.

Many people with incontinence have other health problems. Often they are pensioners with limited incomes. Because you are caring for someone with these problems you may be eligible for financial assistance from the government, for example, Carers Allowance or Access Cab vouchers.

To find out if you are eligible for financial assistance, contact:

- Centrelink
- Carers Advisory Service, freecall 1800 242 636
- Department of Veterans’ Affairs (DVA)
- your GP
- any health professional associated with your care.

The Australian Government provides assistance to eligible people to meet some of the costs of incontinence products. Most states and territories also provide assistance.

It is important to remember that each scheme has eligibility criteria and the person for whom you care may not be eligible.

To find out if the person you care for is eligible speak with:

- your GP
- your GP practice nurse
- your pharmacist
- your continence nurse adviser
- the National Continence Helpline on freecall 1800 33 00 66.

The Carers Advisory Service can provide information about the types of financial assistance that carers may be entitled to, phone freecall 1800 242 636.

There is no GST on most incontinence products, but there is GST on the delivery fee. Most medical wholesalers will deliver to your home but may charge a small fee.
Seeking help from a GP

Incontinence is a symptom, telling you that all is not well with the person for whom you are caring.

It is important that this symptom is not overlooked, neglected and ‘put up with’. Seeking help early is always best.

For most people, the starting point will be the GP. GPs provide continence assessments and treatment options; they can also review and prescribe medications, order clinical tests or refer you to a bladder or bowel medical specialist, a continence nurse adviser or a continence physiotherapist.

When making an appointment with your GP, ask for a long consultation to give you both time to explain the problem without feeling rushed. Write down all the things that are happening and questions that you have as this will make sure you speak about all the things that are important to you and the person you care for.

It is important to let the person for whom you care tell their own story where possible.

Some examples of things the person you are caring for might want to say are:

- ‘I am going to the toilet more often than usual’
- ‘I don’t always make it to the toilet in time’
- ‘I am very tired because I am getting up and down to the toilet all night’.

As the carer you might want to explain:

- ‘We no sooner start doing something than we have to rush off to the toilet’
- ‘They (the person you care for) is frightened they won’t make it to the toilet. I feel very tired with all the extra work’
- ‘I worry that the person might fall’
- ‘I worry about the cost of pads’.

When you are taking the person that you care for to the GP it is important to take the following to the appointment. This helps the GP to find out what is happening:

- the fluid diary
- a record of what the person eats in a day
- the bowel diary
- a list of medications they are taking, including those you can buy over the counter (or show the GP the tablet packets)
• your observations of any changes in the person’s behaviour or activities
• a urine sample.

Ten questions you may like to ask your GP are listed below:

1. What is causing the incontinence?
2. Could medications be causing it, or making it worse?
3. Do they need to be examined?
4. How can we prevent it or manage it?
5. Will medications fix it?
6. Will they need tests?
7. Will they need surgery?
8. Where can I get help to buy the pads and products?
9. Are there any benefit schemes to assist with costs?
10. Should they see someone who specialises in this problem, e.g. a continence nurse adviser or specialist doctor?

A visit to the continence nurse adviser does not need a referral from the GP; however, it is helpful if they know about the visit.

At the appointment with the continence nurse adviser they will ask questions about:

• the medical history
• the surgical history
• medications, including all those purchased over the counter at the pharmacy and those purchased from the supermarket or health food store.

The National Continence Helpline on 1800 33 00 66 can tell you where to find a continence nurse adviser near you.
Other sources of help and advice

Further details, including website addresses and phone numbers, are available under the section ‘Contact details for support organisations’ in this section.

National Continence Helpline

The National Continence Helpline is a free telephone advisory service funded by the Australian Government Department of Health and Ageing. This service is available to anyone residing within Australia, and may be accessed from Monday to Friday (except public holidays), between 8.00am and 8.00pm Australian Eastern Standard Time.

Freecall 1800 33 00 66.

The helpline is staffed by a team of continence nurse advisers who provide information, advice and referral to callers with incontinence or who are caring for someone with incontinence. It also provides information and advice to health professionals.

Continence nurse advisers

Continence nurse advisers are registered nurses who specialise in the treatment of bladder and bowel dysfunction. They may be found in many areas of the health service, including:

- public and private hospital outpatient departments
- specialist hospital departments
- the community
- aged care facilities
- general practitioner surgeries.

Continence nurse advisers provide professional continence assessments and advice on how to manage incontinence issues.

Continence Foundation of Australia Resource Centres

The Continence Foundation of Australia (CFA) has a branch in each state/territory as well as a resource centre in some states. The resources centres are the Continence Advisory Service in Western Australia, the Continence Promotion Centre in New South Wales and the Victorian Continence Resource Centre.

Continence health professionals, trained to provide advice and information on continence issues and the management of incontinence, are located at the resource centres. There are also continence products that can be viewed.

Call the National ContinenceHelpline on 1800 33 00 66 to find out the location of the CFA Resource Centres.
Carer information

The Carers Association can provide carers with information, advice and referral to services that can assist them in their caring role.

To find out what services exist, call the Carers Advisory Service on freecall 1800 242 636. Information is available on a range of topics, including home help, carer’s support groups, financial entitlements, support services, respite and general assistance.

Information packs are selected to suit the needs of the carer.

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 offers a comprehensive selection of information resources including brochures, help sheets and a library. Alzheimer’s Australia can be contacted through:

- the National Dementia Helpline on freecall 1800 100 500
- the Dementia Behaviour Management Advisory Service on 1800 699 799.

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 depending on your needs. You can contact your local Commonwealth Respite and Carelink Centre on freecall 1800 052 222 during business hours or for emergency respite outside standard business hours freecall 1800 059 059.

Support groups

Carer support groups provide emotional support to carers. These groups vary on the type of advice they can provide but generally are open to most carers. The Carer Information Service can provide information about these groups and give details of local and regional groups. It can also refer carers to condition-specific support groups or condition-specific associations that have information about these groups.

There are many condition-specific organisations, such as Alzheimer’s Australia or the Multiple Sclerosis Society. All offer personal support. The Carers Advisory Service freecall 1800 242 636 can provide more details.
Prostate health

If you are the carer of a man it is important to find specific information about the prostate and prostate health.

Listed below are some useful links about prostate health and where to seek advice:

- www.andrologyaustralia.org
- www.prostatehealth.org.au
- www.continence.org.au
- www.bladderbowel.gov.au

Nurse practitioners

Nurse practitioners are nurses who have advanced skills in continence promotion, advice, assessment, treatment and management.

GP practice nurses

GP practice nurses are nurses who work from a GP practice. Ask at your GP practice if they have a practice nurse who can provide advice and support regarding bladder and bowel problems.

Continence physiotherapists

Continence physiotherapists specialise in the management of bladder and bowel dysfunction. They may be found in:

- public and private hospital outpatient departments
- private physiotherapy practices.

Pharmacists

Pharmacists sell and provide advice and information on medications and continence products. Many may keep information leaflets on incontinence or where to find help.

Bladder or bowel medical specialists

Bladder or bowel medical specialists are doctors who specialise in bladder and bowel dysfunction for either men or women.

You will need a referral from your GP to see a medical specialist.
Community and health nursing services
Community and health nursing services may provide assessment, advice and treatment in your home from qualified registered nurses and continence nurse advisers. Contact your local council or look in the telephone directory.

Community health clinics
Community health clinics are often associated with aged care facilities and offer professional health care services for people over 65 years of age. They may have a continence clinic.

Public hospitals and outpatients clinics
Hospitals may have specialist continence clinics as part of the urology department or women’s health service. A referral from the GP is required to visit these.

Medical wholesalers
Medical wholesalers generally sell continence products to hospitals and nursing homes. Many now also sell directly to the public. By looking in the telephone directory or using the internet you will be able to find those in your state or territory. Your GP, pharmacist or librarian may also be able to assist.

Continence products manufacturers
Companies that manufacture and import continence products usually supply to medical wholesale companies, hospitals and nursing homes, chemists and supermarkets. Some supply free samples to the public. Your GP, GP practice nurse or pharmacist will help you make contact with these companies.

Independent Living Centres
The Independent Living Centres provide information and advice only. You may also see a display of different products. They are located in each state/territory, except for the Northern Territory. Contact details can be found in the telephone directory.

By using the telephone directory or asking the GP or pharmacist you will be able to contact these centres. Alternatively, the ‘Contact details for support organisations’ section in this part of this book will provide further information.
Resources

Information leaflets

There are many information resources and factsheets available for carers and people living with incontinence. The Australian Government, through the National Continence Program, provides factsheets in 20 languages on many of the important topics.

These information resources and factsheets brochures can be accessed by ringing the National Continence Helpline. Or, you can visit www.bladderbowel.gov.au to download information sheets.

The Carer Information Service provides:

- information on managing money
- A Carers Guide to Financial Support, Respite Coordination and Information Services
- A Quick Guide to Assistance for Carers

The Carers Advisory Service can be contacted on freecall 1800 242 636

Books

These books can be obtained through various association helplines, book stores and libraries. The titles available are correct as of June 2011.

- Live Better with Urinary Incontinence (2008)
- Looking after Your Bowel (2008)
- Improving Bowel Function after Surgery (2008)
- Questions and Answers about Overactive Bladder and Urinary Incontinence (2005)
- Mayo Clinic on Managing Incontinence (2005)
- Men’s Health Concerns Sourcebook (2009)
Contact details for support organisations

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<thead>
<tr>
<th>Organisation</th>
<th>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><a href="http://www.alzheimers.org.au">www.alzheimers.org.au</a></td>
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<td>Andrology Australia</td>
<td>1300 303 878</td>
<td><a href="http://www.andrologyaustralia.org">www.andrologyaustralia.org</a></td>
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<tr>
<td>Beyondblue</td>
<td>1300 224 636</td>
<td><a href="http://www.beyondblue.org.au">www.beyondblue.org.au</a></td>
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<td>Bladder and Bowel website (Department of Health and Ageing)</td>
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<td><a href="http://www.bladderbowel.gov.au">www.bladderbowel.gov.au</a></td>
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<td>1800 242 636</td>
<td><a href="http://www.carersaustralia.com.au">www.carersaustralia.com.au</a></td>
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<td>Commonwealth Respite and Carelink Centres</td>
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<td>After Hours</td>
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<td>Centrelink</td>
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<td><a href="http://www.centrelink.gov.au">www.centrelink.gov.au</a></td>
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<td>1800 33 00 66</td>
<td><a href="http://www.continence.org.au">www.continence.org.au</a></td>
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<tr>
<td>Dementia Behaviour Management Advisory Service</td>
<td>1800 699 799</td>
<td>(24 hours, 7 days)</td>
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<tr>
<td>Department of Veterans’ Affairs</td>
<td>1300 555 727</td>
<td><a href="http://www.dva.gov.au">www.dva.gov.au</a></td>
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<td>Dietitians Association of Australia</td>
<td>1800 812 942</td>
<td><a href="http://www.daa.asn.au">www.daa.asn.au</a></td>
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<td>Independent Living Centre</td>
<td>1300 885 886</td>
<td><a href="http://www.ilcaustralia.org">www.ilcaustralia.org</a></td>
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<tr>
<td>MensLine Australia</td>
<td>1800 789 978</td>
<td><a href="http://www.menslineaus.org.au">www.menslineaus.org.au</a></td>
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<tr>
<td>National Public Toilet Map (Department of Health and Ageing)</td>
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<td><a href="http://www.toiletmap.gov.au">www.toiletmap.gov.au</a></td>
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<tr>
<td>Prostate Health</td>
<td></td>
<td><a href="http://www.prostatehealth.org.au">www.prostatehealth.org.au</a></td>
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<tr>
<td>Technical Aid to the Disabled</td>
<td>1300 663 243</td>
<td><a href="http://www.tadaustralia.org">www.tadaustralia.org</a></td>
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<tr>
<td>Victorian Continence Resource Centre</td>
<td>03 9816 8266</td>
<td><a href="http://www.continencevictoria.org.au">www.continencevictoria.org.au</a></td>
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Your local community health service, council office or medical equipment store will also be able to provide further information.
Glossary of terms

**Absorbent bed sheet**
A drawsheet constructed of thick absorbent layers to absorb larger amounts of urine

**Agitation**
How people behave when they are anxious and worried

**Antibiotic**
A medication prescribed by the doctor to treat infections

**Antidepressant**
A medication prescribed by the doctor to treat depression

**Aperient/laxative**
A laxative or ‘opening medicine’ to help the bowel to work

**Assisted toileting**
A toileting program used by the carer to help a person get to the toilet

**Barrier cream**
A thickened moisturising cream used to protect the skin from the damaging effects of faeces or urine

**Bottle**
Receptacle for men to pass urine into. Also called a urinal

**Bowel motion**
The remains of food once it has passed through the bowel. Also called ‘bowel action’ or ‘faeces’

**Bowel tone**
The normal degree of strength of movement in the bowel

**Capacity**
The amount of urine that can be held in the bladder, pad or collection bag

**Catheter**
A flexible tube inserted into the bladder to drain urine

**Commode**
A collection pot mounted in a chair with a cover

**Condom catheter**
See ‘sheath’

**Confusion**
Disorientation, lack of orderly thought

**Constipation**
When stools become hard and dry and are more difficult to pass. The bowel motion becomes less frequent
Continence nurse adviser
For the purposes of this book, either a registered nurse or physiotherapist specialising in the treatment of incontinence

Continence physiotherapist
A physiotherapist specialising in the treatment of incontinence

Continence
The ability to control the passing of urine and bowel motions in the right place at the right time

Cross infection
Spreading infection to yourself and others

Dehydration
The lack of or loss of fluid from the body

Dexterity
Ability or skill in using the hands

Diarrhoea
Frequent loose bowel motions

Diuretic
A medication prescribed by the doctor that increases urine production

Drainage bag
A bag used to collect urine from catheters or sheaths

Drawsheet
A sheet placed across the middle of the bed to protect the mattress from soiling by urine or faeces; used with a waterproof plastic sheet

Dysfunction
Where something has gone wrong, for example, where the bladder or bowel do not work as they should

Enema
A liquid put into the rectum to stimulate a bowel motion

Faeces
The remains of food once it has passed through the bowel. Also called ‘bowel action’ or ‘bowel motion’

Faecal incontinence
The passing of bowel motions without control

Fluid tablet
See ‘diuretic’
**Frequency of bowels**
Frequent passing of small amounts of bowel motion

**Frequency of urine**
Frequent passing of small amounts of urine

**Haemorrhoids or piles**
Swollen veins in the bottom (anus) usually caused by long-term straining to pass a bowel motion

**Health care professional**
Someone who has taken advanced education and special training in one of the health care disciplines, such as medicine, nursing, physiotherapy, occupational therapy, speech pathology, etc

**Incontinence**
Loss of urine or bowel motion without control

**Infection**
Disease caused by germs (organisms) invading part of the body, for example, the bladder or bowel

**Laxative/aperient**
A medication that stimulates a bowel motion. Also called an aperient

**Mobility**
The person’s ability to move around from sitting to standing or lying and walking

**Parkinson’s drug**
A medication prescribed by the doctor to treat Parkinson’s disease

**Prolapse**
When the muscles supporting an organ, for example, the bowel, become too weak to support that organ. The organ then sags away from its normal position

**Prompted toileting**
A program of reminding a person to go to the toilet

**Prostate**
The gland in the male pelvis that lies beneath the bladder, surrounding the tube (urethra) that leads from the body

**Retention of urine**
When the bladder does not fully empty

**Scheduled toileting**
A program of taking a person to the toilet at regular intervals

**Self-help bed pole**
A piece of equipment (a pole) that a person uses to help them get out of bed
Sheath
An appliance used in men for urinary drainage. Also called an ‘external catheter’ or ‘condom catheter’

Stay-dry surface
The surface of a pad or garment that stays dry to the touch even after absorbing urine

Stress urinary incontinence
A small leak of urine that happens during activity that causes pressure on the bladder, for example, coughing, sneezing, bending over

Suppository
A solid form of medication inserted into the rectum to stimulate a bowel motion

Urge urinary incontinence
A larger loss of urine that happens when the urge to pass urine is too strong for the person who cannot get to the toilet in time

Urinary frequency
The repeated need to go to the toilet. This may be caused by infection, bladder contractions, poor bladder emptying or lack of control

Urinary outflow obstruction
When the bladder is unable to empty properly, for example when the prostate has grown too large

Urinary tract infection
An infection in the urinary bladder

Urinary urgency
When the person gets the feeling that their bladder is very full and they cannot wait to empty it
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