Part A: Incontinence in Australia

1 Introduction

1.1 Purpose

Incontinence is a considerable but still somewhat unrecognised problem in Australia. While the symptoms of incontinence are generally not life threatening, the impact on an individual can be severe—on a person's ability to participate in many life areas, the costs associated with managing the condition, and associated stigma.

In recognition of the prevalence and impact of incontinence amongst the Australian population, the Australian Government provided $31 million to support the National Continence Management Strategy. Through this scheme, the Government aims to 'improve continence treatment and management so that more Australians can live and participate in their communities with dignity and confidence'.

In 2004 the Australian Government Department of Health and Ageing commissioned the Australian Institute of Health and Welfare (AIHW) to undertake the present study to provide a profile of the Australian population experiencing incontinence. While there is increasing information on the prevalence of urinary and faecal incontinence in Australia, the severity of incontinence experienced, and to some extent the effect incontinence has on a person's ability to participate in life areas, there is limited information on support measures individuals rely on to manage their incontinence, associated health conditions, and the effects on carers caring for someone with incontinence. This report aims to redress this imbalance by presenting analyses on these topics, as well as additional information on effects on participation. Furthermore, the report will also consider the burden of incontinence and associated costs borne by the individual and the health system.

1.2 Outline of Part A

The structure of Part A of the report is as follows:

- Chapter 2 describes definitions of incontinence used in clinical and epidemiological research settings.

- Chapter 3 reviews the wide range of international and Australian prevalence estimates of urinary and faecal incontinence, with reference to the different definitional approaches taken. The chapter also discusses the recognised risk factors for incontinence, and a brief look at the literature on the impact of incontinence on quality of life.

- Chapter 4 presents original analyses of the 2003 ABS Survey of Disability, Ageing and Carers covering areas of need for assistance, use of incontinence aids, health conditions associated with incontinence, and impact of incontinence on participation in education, the labour force and the social context. The final section of this chapter addresses primary carers who care for someone with incontinence, particularly the impact of that care on their physical and social wellbeing.

- Chapter 5 discusses the costs associated with incontinence, including estimates of medical, pharmaceutical, and aids and equipment costs of incontinence, as well as hospital and aged care home expenditure. Costs are projected to 2030–31.
- Chapter 6 provides burden of disease estimates for incontinence in terms of the impact of urinary and/or faecal incontinence on quality of life.

2 Definition and measurement of incontinence

2.1 Definition(s) of incontinence

Incontinence has long evaded a widely accepted definition. Most definitions of urinary and faecal (or anal) incontinence describe a loss of control of urination or defecation respectively. Various reviews of the literature, however, reveal a range of variant definitions applied in the clinical and, especially, epidemiological research environments (Cheater & Castleden 2000).

In response, the 3rd International Consultation on Incontinence recommended urinary incontinence be defined as the 'complaint of any involuntary leakage of urine' (Abrams et al. 2002a: 168). The original International Continence Society (ICS) definition of incontinence incorporated a reference to quality of life, i.e. 'involuntary loss of urine that is a social or hygienic problem' (Hunskaar et al. 2002:168). The ICS, however, conceded that the latter definition is more easily applied in a clinical rather than community-based research setting, and relies on an 'objective demonstration' of urinary incontinence which is not necessarily achievable outside the clinical context. Furthermore, perceiving incontinence as a social or hygienic problem introduces a subjective dimension to what should be an objective assessment, which may influence estimates of prevalence and severity, and other measurable factors.[1,2]

Epidemiological and clinical definitions of urinary incontinence regularly conceptualise incontinence as an involuntary leakage or loss of urine, usually based on the frequency of that leakage or loss over a specified time period. Those time periods, however, differ from study to study, and range from daily episodes to 'ever' experienced. These and other definitions based on volume of urine lost often employ a threshold of severity to delineate between more severe and more moderate forms of urinary incontinence, and are discussed more fully in Section 2.3.

The International Continence Society has argued that definitions based on frequency and loss, with reference to severity, are more a measure of prevalence than a definition *per se* (Hunskaar et al. 2002), and certainly, these 'definitions' are mostly used with the objective of estimating prevalence. However, the application of varying definitions alluded to earlier has led to the publication of widely ranging prevalence estimates (Chapter 3).

The ICS also recognises other, related symptoms that may or may not necessarily result in urinary incontinence. These are:

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[1]   The 3rd International Consultation on Incontinence has also developed a definition of 'social incontinence' which was not available at the time of publication.

[2]   Foldspang and Mommsen (1997) noted that two studies using the ICS definition of incontinence produced questionable prevalence rates that may not be appropriate for biomedical research.

- urgency, or 'the complain of a sudden compelling desire to pass urine, which is difficult to defer'
- increased daytime frequency, or '…void(ing) too often by day'
- nocturia, or 'wake(ning) at night one or more times to void' (Abrams et al. 2002a:168).

While these symptoms may or may not occur with urinary leakage, on every occasion or ever, they may impact just as severely on a person's ability to complete their daily activities, and hence quality of life (see, for example, Hampel et al. 1997).

A unifying definition of faecal (or anal) incontinence has also escaped consensus.[3] Faecal incontinence is usually defined as the inability to control defecation, or an involuntary or inappropriate loss of liquid or solid stool. Some experts, however, also include the involuntary passage of flatus, caused by a loss of sphincter control. The 2nd International Consultation on Incontinence has proposed a working definition for anal incontinence, similar to that recommended for urinary incontinence, i.e. 'the involuntary loss of flatus, liquid or solid stool that is a social or hygienic problem', with the caveat that the subjective interpretation of this definition will vary from person to person (Norton et al. 2002:987).

Faecal urgency is an additional symptom often excluded from faecal incontinence assessment tools but, like urinary urgency, can exert an important influence on quality of life. Faecal urgency relates to a sudden urgency to pass solid stools, and is generally related to external anal sphincter dysfunction. While this urgency does not always or necessarily end with an episode of faecal incontinence, it may be a precursor symptom, and if ignored in clinical assessment may underestimate the severity of the condition (Vaizey et al. 1999).

2.2 Types of incontinence

Urinary incontinence is further classified into types of incontinence, based on symptoms and extrinsic factors. The most commonly described types of urinary incontinence are:

- Stress incontinence, or involuntary leakage of urine occurring on effort or exertion (e.g. bending over, walking up stairs), or sneezing or coughing. Stress incontinence is thought to occur due to weakened pelvic floor muscles or sphincter pathology which leads to urine loss when intra-abdominal pressure is increased.
- Urge incontinence, or involuntary leakage of urine accompanied by or immediately preceded by urgency. Associated symptoms may include frequent urination, nocturia and nocturnal enuresis.
- Mixed incontinence, or the complaint of involuntary leakage associated with urgency and also with exertion, effort, sneezing or coughing.
- Nocturnal enuresis, or involuntary loss of urine occurring during sleep (Abrams et al. 2002a:168).

'Other' or unclassified types of incontinence are occasionally discussed in the literature, such as:

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[3]   Faecal or anal incontinence may be used to describe faecal leakage, although some experts tend to term incontinence as anal incontinence when including flatus incontinence. This report will refer to any faecal leakage, excepting flatus incontinence, as faecal incontinence, and faecal leakage combined with flatus incontinence as anal incontinence.

- Overflow or outflow incontinence (voiding dysfunction), or failure of the bladder to empty due to overdistention or a blockage to the bladder.

- Neurogenic or reflex incontinence, or loss of urine control due to nerve damage. This type of incontinence is often associated with conditions such as spinal cord injury, multiple sclerosis, Parkinson's disease, and stroke.

- Dribbling (terminal, postmictural, postvoid), or constant dribbling of urine, occurring after urination.

An additional type of incontinence, frequently but not exclusively used with reference to urinary incontinence, is functional incontinence or 'urinary leakage associated with inability to toilet because of impairment of cognitive and/or physical functioning, psychological unwillingness, or environmental barriers' (Ouslander 1994:151). This type of incontinence generally occurs for people who have bladder control but become incontinent due to other factors, such as mobility impairment.

Classification of faecal incontinence is less definite, and terms are often interchanged. Furthermore, the literature does not commonly refer to 'types' of faecal incontinence as it does for urinary incontinence, normally classifying this form of incontinence as faecal matter or flatus lost. Terms that may be used, however, include 'idiopathic', 'sensory', 'neurogenic' and 'motor' incontinence. Norton et al. (2002) support the use of idiopathic incontinence, which refers to faecal incontinence not due to trauma, congenital defects or neurological disease, and to some extent, sensory incontinence or the absence of urge or feeling of passage of stools. However, they argue against the use of 'neurogenic incontinence', as it is essentially the same as idiopathic incontinence, and 'motor incontinence', which is ill defined and mostly related to diarrhoea and irritable bowel syndrome.

2.3 Measurement of severity

The severity of incontinence is usually measured with reference to the frequency of incontinent episodes, frequency of urination or defecation, and/or the volume or amount of urine or faecal matter lost at each episode, but may include other symptoms associated with incontinence (Cheater & Castleden 2000; Hunskaar et al. 2002). How much individuals are bothered by their incontinence or associated symptoms is an alternative method used by some epidemiologists to estimate severity.

The frequency of incontinent episodes is usually set against a specific timeframe, measured as the experience of involuntary loss in the last week, the last month or 6 months, the last year, or 'ever', or a more subjective focal period, e.g. never, rarely, sometimes or often. Frequency of urination is usually considered over a daily period, and defecation over a weekly period. The degree of loss is measured as the volume (e.g. for urinary incontinence— 'a few drops' or 'more than just a few drops'), or as a lack of control leading to wetting or soiling of clothes.

Severity is graded using any one or a combination of these measures. Simple grading systems rely on frequency of incontinent episodes alone, and generally consider severe incontinence as that occurring on a weekly or more frequent basis. More intricate measures rely on an index system to grade responses for each measure of incontinence. For example, the Incontinence Symptom Severity Index (ISSI) developed by Sandvik and colleagues (1993) to measure the severity of urinary incontinence is composed of two questions:

- 'How often do you experience leakage?' (never = 0, rarely = 1, sometimes = 2 or often = 3) and

- 'How much urine do you lose?' ('drops or just a little' = 1 or 'more than just drops' = 2).

The index is calculated by multiplying the two responses together. An individual is identified as experiencing slight, moderate, severe or very severe incontinence, depending on the multiplied score.

Other severity indices work on a similar premise, although some determine severity on the 'bothersomeness', rather than the frequency or experience, of incontinence episodes and symptoms. One example is the Urogenital Distress Inventory (UDI), the short form of which asks respondents how much they are bothered by the following:

- frequent urination

- urine leakage related to a feeling of urgency

- urine leakage related to physical activity, coughing or sneezing

- small amounts of urine leakage (drops)

- difficulty emptying the bladder

- pain or discomfort in the lower abdomen or genital area.

A 4-point Likert scale is used to grade responses: 0 = 'not at all', 1 = 'slightly', 2 = 'moderately' and 3= 'greatly'—where a score of 0 indicates no incontinence, 1–3 a slight problem with incontinence, 4–6 a moderate problem, 7–9 a problem, and 10–18 a major problem.

A smaller group of studies and severity indices include environmental and participation measures to determine severity, specifically the use of aids and impact on lifestyle. The Wexner score for measuring the severity of anal incontinence is comprised of the categories of incontinence type experienced, pad use and lifestyle alteration and is scored against a frequency scale of never, rarely, sometimes, usually or always. [4] Potential overall scores range from 0 (continent) to 20 (complete incontinence). (See Table A6.1 in Appendix A).

The measurement of incontinence severity, as for incontinence definitions, differs from study to study and the different approaches are not necessarily comparable. This further complicates the process of understanding not only how prevalent incontinence is amongst a specified population, but also what proportion are experiencing more severe incontinence, and hence the population who are in need of additional support measures.

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[4] The Wexner score frequency scale is defined as follows: 'rarely' = less than once a month, 'sometimes' = once a month or more but less than once a week, 'usually' = once a week or more but less than once a day, and 'always' = once a day or more.

3 Prevalence estimates and risk factors—a review of the literature

3.1 Variation in prevalence estimates

Variation in the use of definitions and measures of severity has inevitably led to a wide range of prevalence estimates. A review by Herzog and Fultz (1990) listed definitional, conceptual and measurement issues, along with sampling and non-response issues, as responsible for producing prevalence estimate variability. Nonetheless, Cheater and Castleden (2000) found less marked inter-study variability, and lower incontinence prevalence rates, when prevalence estimates were based on severity thresholds rather than more broader or inclusive definitions.

Another potentially confounding factor for estimating the real extent of incontinence is reliance on self-report data. The nature and stigma associated with incontinence, especially faecal incontinence, can compromise self-report data, as some individuals may feel uncomfortable or not wish to acknowledge they experience the condition. Others may consider incontinence a normal part of ageing, or not a significant problem, and hence not worth reporting.

This chapter presents a review of published prevalence estimates of urinary and faecal/anal incontinence from international and Australian studies. New prevalence estimates derived from original AIHW analysis are presented in Chapters 4 (Section 4.2) and 6 (Table 6.10).

3.2 International prevalence estimates (community-living population)

There have been an extensive number of studies published on the prevalence of incontinence, particularly the prevalence of urinary incontinence amongst women. The results from studies on urinary incontinence are numerous and the discussion of international prevalence estimates presented here relies on reviews by Cheater and Castleden (2000), Herzog and Fultz (1990), Sandvik (2003) and Thom (1998), which provide detailed descriptions of the range of estimates reported in the literature. The discussion on faecal incontinence estimates relies on individual studies and reports.

Urinary incontinence

Many of the prevalence estimates of urinary incontinence come from studies of people living in the community, resident in the United Kingdom, various parts of Europe, Japan, New Zealand and North America. Ranges are presented in Table 3.1.

While prevalence estimates for urinary incontinence vary considerably, those based on higher thresholds of severity tend to be more consistent. This is probably because more severe forms of incontinence are more obvious and less easily denied by the respondent, and

Table 3.1: Range of international prevalence estimates for urinary incontinence amongst community-living adults (per cent)

Source	Definition	Males	Females
Cheater & Castleden 2000	Ever	9–19	9–58
	Major or significant[a]	5	7–23
Herzog & Fultz 1990	Various	1–5 (Younger men)	4–31 (Younger women)
		6–25 (Older men)	9–42 (Older women)
Sandvik 2003	Significant[a]	n.p.	4–22
Thom 1998	Ever	3–5 (Younger men)	12–42 (Younger women)
		11–34 (Older men)	17–55 (Older women)
	Daily	2–11 (Older men)	3–17 (Older women)

(a)   Major or significant incontinence was defined as wetting of clothes or the of use incontinence pads, 'social or hygienic problem—ICS definition', or daily/weekly episodes of incontinence.

Note: International prevalence estimates are derived from prevalence studies conducted in the United Kingdom, Sweden, Denmark, Norway, the Netherlands, Spain, Republic of Ireland, United States of America, Canada, New Zealand and Japan.

responses are less dependent on question wording than milder forms of incontinence, such as those picked up in questions on leakage events ever experienced (Herzog & Fultz 1990).

Older men and women consistently reported higher rates of urinary incontinence than their younger counterparts, as did women over men. Thom (1998) estimated the ratio of urinary incontinence of older men to older women to range from 1.0 to 2.4, whereas for younger men to younger women it ranged from 3.2 to 4.5. The higher prevalence of urinary incontinence amongst older men compared to younger men, according to Thom (1998), is the likeliest explanation for this difference.

The type of urinary incontinence experienced also tends to vary with sex and age. Around a third to a half of all women with urinary incontinence in these studies had stress incontinence, with a smaller proportion reporting mixed incontinence, and a smaller proportion again with urge incontinence. However, younger and middle aged women are more likely to experience stress incontinence and older women either mixed or urge incontinence (Chiarelli et al. 1999; Diokno et al. 1986; Miller et al. 2003; Samuelsson et al. 1997, cited in Hunskaar et al. 2002; Thom 1998). Men, on the other hand, are prone to urge incontinence, with a small but significant proportion reporting other or unclassified types of urinary incontinence, e.g. constant dribbling (7.4%, in Ueda et al. 2000) and frequent terminal dribbling (12%, in Sladden et al. 2000).

Faecal and anal incontinence

International prevalence estimates of faecal incontinence are presented in Table 3.2. Definitions used in the studies listed referred to loss of control or involuntary leakage, with occasional use of questions on staining and soiling of underwear. Overall prevalence rates for faecal incontinence ranged from 3% to 17%, and anal incontinence from 2% to 20%. Macmillan et al. (2004) regard sampling methods, inappropriate data collection methods and poor response rates as primary influences on prevalence variation, as well as the absence of a standard definition. There was some evidence of faecal incontinence rates being higher for women than men, but this was not a universal finding.

Table 3.2: International prevalence estimates for faecal and anal incontinence amongst community-living adults (per cent)

Source and population	Definition	Males	Females	Persons
Goode et al. 2005 USA, 65 years+	Loss of control of bowels over the past year	12.4	11.6	12.4
Perry et al. 2002 United Kingdom, 40 years+	Soiling or staining of underwear at least several times a month	2.2	4.0	3.1
Thompson et al. 2002 Canada, 18 years+	Any leakage of liquid or solid stool without anatomic or neurologic abnormality	5.4	8.4	6.9
Edwards & Jones 2001 United Kingdom, 65 years+	Difficulty in controlling bowels	1.0	4.0	3.0
Roberts et al. 1999 USA, 50 years+	Leakage of liquid or solid stool in past year	11.3	14.7	13.2
Johanson & Lafferty 1996 USA, 18–92 years	Any involuntary leakage of stool or soiling of undergarments	8.5	13.5	11.0
Lynch et al. 2001 New Zealand, 18 years+	Score of 3 or more on scale including any incontinence of gas, liquid or stool	14.3	19.8	17.0
De Miguel et al. 1999, cited in Macmillan et al. 2004 Spain, 'adult population'	Any leakage of gas, liquid or solid stool	n.p.	n.p.	8.8
Giebel et al. 1998 Germany, 18 years+	Any loss of control of solid or liquid stool, any loss of control of 'wind' or frequent faecal soiling	15.6	22.4	19.6
Nelson et al. 1995 USA, 18 years+	Unwanted, unexpected or embarrassing loss of control of bowels or gas in the last year	0.8	1.4	2.2

3.3 Australian prevalence estimates (community-living population)

Urinary incontinence

Australian prevalence estimates of incontinence are similarly variable. Table 3.3 presents published estimates of urinary incontinence amongst community-living Australian men and women, most of which are derived from reasonably broad interpretations of incontinence.

Prevalence estimates of urinary incontinence amongst men of all age groups ranged from 2.2% to 13%, and for women, 19.3% to 37%. All estimates listed in Table 3.3 were calculated based on reported experience of urinary incontinence episodes and related symptoms, but definitions differed in terms of time frame and, to some extent, the incontinence items covered in survey questions.

The simplest approach to measuring the prevalence of incontinence was adopted by the Millard (1998), Women's Health Australia survey (Chiarelli et al. 1999) and South Australian

Table 3.3: Australian prevalence estimates for urinary incontinence (per cent)

Source and population	Definition of urinary incontinence	Males	Females	Persons
Avery et al. 2004b				
SAHOS 1998	Ever experienced loss of urine (a) 'when they did not mean to', when they coughed, sneezed or laughed, or (b) associated with a sense of urgency and did not reach the toilet in time[a]	4.4	35.3	20.3
15 years+		2.5 (Stress) 2.9 (Urge)	32.4 (Stress) 14.5 (Urge)	
SAHOS 2001		n.p.	n.p.	21.4
15 years+				
Hawthorne & Sansoni 2004				
SAHOS 2004	Urogenital Distress Inventory (UDI) severity score: Level of bothersomeness of 6 symptoms experienced in the last month[b]	0 = Major 1 = Problem 4 = Moderate	3 = Major 4 = Problem 16 = Moderate	2 = Major 4 = Problem 10 = Moderate
15 years+				
Chiarelli et al. 1999 WHA	Experienced leaking urine in the last 12 months			
18–23 years		. .	12.8	. .
45–50 years		. .	36.1	. .
70–75 years		. .	35.0	. .
Chiarelli et al. 2005	No universal definition (see note)	2.2	19.3	10.8
45 years+ (♂) 35 years+ (♀)				
<40 years		—	16.5	n.p.
40–49 years		3.0	20.9	n.p.
50–59 years		4.0	25.7	n.p.
60–69 years		6.8	20.3	n.p.
70–79 years		11.3	23.5	n.p.
80 years+		15.1	28.4	n.p.
Lam et al. 1999	Leaking urine on coughing or sneezing or leaking if unable to reach a toilet in time	3.5 (Stress)	31.5 (Stress)	19.7 (Stress)
18 years+[c]		12.0 (Urge)	25.9 (Urge)	20.1 (Urge)
Gunthorpe 1998, cited in Chiarelli et al. 1999	Incontinence screening question, using 5 items about leaking urine	. .	37.0	. .
18 years+				
Millard 1998	Frequency of urinary loss in last 3 months	13.0	34.0	n.p.
10 years+				

(a) Definition of urinary continence given in Avery et al. 2004b.

(b) Symptoms are: frequent urination; urine leakage related to a feeling of urgency; urine leakage related to physical activity, coughing or sneezing; small amounts of urine leakage (drops); difficulty emptying the bladder; and pain or discomfort in the lower abdomen or genital area. Respondents record level of bothersomeness according to the scale 0 = Not at all, 1 = Slightly, 2 = Moderately, 3 = Greatly. Overall severity score is the total of scores recorded: 0 = No incontinence; 1–3 = Slight problem; 4–6 = Moderate problem; 7–9 = Problem; 10–18 = Major problem.

(c) Mean age for male respondents was 55.3 years and for female respondents 55.7 years.

Note: Estimates published in Chiarelli et al. (2005) were pooled age-stratified prevalence estimates based on 5 and 12 international age-stratified estimates published for men and women respectively.

Health Omnibus Survey (Avery et al. 2004a, 2004b). These three studies asked respondents respectively about their experience of urine leakage in the last 3 months, last 12 months or 'ever'. The 1998, 2001 and 2004 SAHOS differed to the WHA and Millard studies by using questions relating to the experience of stress incontinence (i.e. a loss of urine occurring when

the respondent coughed, sneezed or laughed) and urge incontinence (i.e. accidental wetting associated with an urgency to go, but failing to get to a toilet in time). Interestingly, these three approaches produced similar estimates for women, i.e. just over a third of women were affected by some degree of incontinence, except women aged 18–23 years where an estimated 13% experienced incontinence. However, results were different for men—4.4% from the 1998 SAHOS and 13% from the Millard study. It is possible the more general definition given in the Millard study led to a greater reporting of urinary continence by men. Lower estimates were published by Chiarelli et al. (2005) and Hawthorne and Sansoni (2004), which were calculated from more restricted definitions of incontinence. Chiarelli et al. (2005) estimated that 19.3% of Australian women and 2.2% of Australian men, and 10.8% of the overall population, experienced urinary incontinence. These estimates were based on a selection of international prevalence estimates,[5] and applied to age-stratified Australian population estimates.

Hawthorne and Sansoni (2004) present the only Australian estimates that refer to severity scores. Using the Urogenital Distress Inventory (UDI) in concert with data collected in the 2004 SAHOS (see notes in Table 3.3 for method), it was estimated that 2% of the population aged 15 years and over experience incontinence as a 'major problem', 4% as a 'problem', and 10% as a 'moderate problem'. The sex breakdown for these levels of severity is given in Table 3.3—5% of men and 23% of women experienced urinary incontinence as at least a 'moderate problem'. Further discussion of the association between incontinence and sex and age is presented in Section 3.5.

Estimates of urinary incontinence among Australians living in the community derived for this study finds a total of 240,800 Australians who experience severe urinary incontinence, 723,100 Australians who experience moderate urinary incontinence and 2,877,500 Australians who experience slight urinary incontinence (see Table 6.10).

Faecal and anal incontinence

Prevalence estimates for faecal and anal incontinence tend not to vary as widely as those for urinary incontinence. Table 3.4 presents published estimates of faecal and anal incontinence for community-living Australian men and women.

As for urinary incontinence prevalence estimates, the simplest approach to measuring prevalence was to ask respondents of their experience of this form of incontinence with reference to a specific timeframe. Again, the timeframe given, and the wording of questions, differed between studies. Kalantar et al. (2002) estimated a prevalence of 11.3% for the Australian population aged 18 years and over, based on a positive response to any leakage of bowel movements 'at an inappropriate time or place' in the last 12 months. Women were slightly more likely to experience faecal incontinence than men, 11.6% compared to 10.8%. The Avery et al. (2004b) analysis of 1998 SAHOS data used a similar question, i.e. loss of control of bowel movements, but no timeframe was given. These estimates, however, were much lower—2.9% for the overall population aged 18 years and over, and 2.2% for men and 3.5% for women. Estimates for flatus incontinence were also calculated and were generally higher than for faecal incontinence.

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[5] International estimates were included in the analysis if they came from community-based studies, had a response rate of over 65%, included a minimum of 125 participants for each sex, published results by age and sex, and used a validated instrument to measure incontinence.

The highest prevalence estimates were published by Lam et al. (1999), which defined anal incontinence as positive responses to two of three questions on problems with stool leakage, wearing a pad for faecal soiling, or frequent incontinence of flatus. This study estimated the prevalence of anal incontinence as 15% and in contrast to other Australian studies, men experienced anal incontinence (20%) much more than women (11%). The higher prevalence estimates may be explained in part by measuring the prevalence of anal incontinence, i.e. the inclusion of flatus incontinence within the definition of incontinence.

Some consideration of severity was included in the Lam et al. analysis: around 1.8% of respondents experienced stool leakage more than once per week and 0.8% used pads. Hawthorne and Sansoni (2004) also measured severity of faecal incontinence, using the Wexner score, which recorded the number of faecal incontinent episodes in the last month, for solid and liquid stools, or flatus. Daily episodes of anal incontinence, estimated at 2% of the Australian population, were a little higher compared with Lam et al.'s estimate but again, also included flatus incontinence.

Chiarelli et al. (2005) published the lowest estimates of faecal incontinence (solid and liquid stool only) at 5.4% but indicated that their estimates be treated with some caution due to heterogeneity at the study level.

An estimate of faecal incontinence among Australians living in the community derived for this study finds a total of 202,100 Australians who experience very frequent or frequent faecal incontinence (see Table 6.10).

Table 3.4: Australian prevalence estimates for faecal incontinence (per cent)

Source and population	Definition of faecal incontinence	Males	Females	Persons
Avery et al. 2004b				
SAHOS 1998	Positive response to either or both problems: loss of control of bowel motions or loss of control of wind	8.1	12.8	10.5
18 years+		2.2 (Faecal)	3.5 (Faecal)	2.9 (Faecal)
		6.8 (Flatus)	10.9 (Flatus)	8.9 (Flatus)
Hawthorne & Sansoni 2004				
SAHOS 2004	Reported episodes of leakage of solid or liquid stools, or flatus, in last month	2 = Daily	3 = Daily	2 = Daily
18 years+		3 = Weekly	4 = Weekly	3 = Weekly
		8 = Sometimes	10 = Sometimes	9 = Sometimes
Chiarelli et al. 2005	Pooled age-stratified prevalence estimates based on 3 Australian and 1 US age-stratified estimates published for men and women respectively	5.5	5.3	5.4
25 years+				
Kalantar et al. 2002	Leakage of bowel movements (excluding flatus) at an inappropriate time or place in last 12 months	10.8	11.6	11.3
18 years+				
MacLennan et al. 2000	Faecal incontinence including any loss of control of bowel motions in last year	10.6	12.9	11.8
15 years+				
Lam et al. 1999	Positive response to one or more problems: stool leaking, wearing a pad for faecal soiling and/or frequent incontinence of flatus	20.0	11.0	15.0
18 years+				

3.4 Prevalence estimates from institutionalised populations (International and Australian)

The prevalence of urinary and faecal incontinence is much higher amongst people living in residential care and institutions. Table 3.5 lists prevalence estimates for urinary and faecal incontinence amongst people aged over 60 years living in nursing homes, residential care,

Table 3.5: Prevalence estimates of urinary and faecal incontinence amongst adults living in long-term care facilities (per cent)

Source	Definition	Urinary incontinence	Faecal incontinence	Doubly incontinent
Pearson 2003 Residents of aged care homes, Australia	Requiring at least some support for bladder and bowel management	66.0	72.0	n.p.
Chassagne et al. 1999 Residents of non-medical nursing homes and geriatric care facilities, France	At least one involuntary loss of faeces	n.p.	46.0	n.p.
Peet et al. 1995 Residents of residential or nursing homes, and hospitals, UK	At least one incontinent episode per week	22.7	17.7	17.7
Borrie & Davidson 1992 Residents of long-term care hospitals, Canada	Not defined	62.0	46.0	44.0
Fonda 1990 Residents in nursing homes, Australia	Ever wet during past 4 weeks, not able to void independently or used drainage devices	78.0	42.0	n.p.
Resnick et al. 1989 Residents of long-term care facilities, USA	Not defined	40.0	n.p.	n.p.
Tobin & Brockelhurst 1986 Residents of local authority residential homes for the elderly, USA	Urinary leakage or faecal soiling more than once per week	32.0	10.3	n.p.
Ouslander & Fowler 1985 Residents of nursing homes, USA	Any leakage	41.0	n.p.	n.p.
Ouslander et al. 1982 Residents of nursing homes, USA	Not defined	n.p.	32.0	n.p.

hospitals or other long-term care facilities. The prevalence of urinary incontinence ranged from 23% and 32% for persons experiencing incontinence episodes once or more times a week to between 40% and 78% for people experiencing any leakage. For faecal incontinence, it ranged from 11% and 18% to 46%. Estimates derived from Pearson (2003) are particularly high.

Of the few studies that estimated double incontinence, around 18% of residents in long-term care facilities in the UK had experienced at least one episode of both urinary and faecal

leakage per week (Peet et al. 1995) as did 44% of residents in long-term care hospitals in Canada (Borrie & Davidson 1992).

Dementia and other degenerative neurological conditions, impaired mobility and, in some cases, severe psychiatric conditions typified the residential care population found to experience incontinence (see references in Section 3.4). Other risk factors include age, length of stay at the facility, and, for faecal and anal incontinence, the presence of urinary incontinence.

Incontinence is considered a significant predictor for institutionalisation of older people (see, for example, Nuotio et al. 2003). A recent Australian study by Pearson (2003) reported that 87% of Aged Care Assessment Team (ACAT) respondents identified incontinence as a significant or very significant factor in determining whether an individual be recommended for residential aged care. An overall ranking of critical factors in long-term care decisions placed incontinence, and the ability to manage incontinence, third, after dementia/cognitive function and mobility. This is a trend observed in other countries, such as the US, where it is the second most common reason for requesting nursing home placements (Edwards & Jones 2001).

An estimate of urinary and faecal incontinence among Australians living in cared accommodation derived for this study finds a total of 128,800 Australians who always or sometimes need assistance to manage their bladder or bowel control, i.e. they experience severe urinary and/or faecal incontinence (see Table 6.10).

3.5 Associations with age and sex

Age

Age is the most often cited factor associated with incontinence. Urinary incontinence increases with age in both men and women, but that increase occurs much earlier for women (Table 3.3). Men experience relatively low prevalence of urinary incontinence before the age of 60–70 years (e.g. 3–5%, Thom 1998), after which prevalence rises dramatically (e.g. 11–34%, Thom 1998). This is particularly apparent for urge incontinence.

Women start experiencing incontinence much younger, often in their 30s and associated with pregnancy and childbirth (see Section 3.6). Women then seem to experience two prevalence peaks, the first between the ages of 50–60 years, and again after 70–80 years (Chiarelli et al. 2005; Hannestad et al. 2000; Hawthorne & Sansoni 2004; Lam et al. 1999; Millard 1998); between these two periods the prevalence of incontinence stabilises or, in some studies, is shown to fall. Chiarelli et al. (2005) suggest that this prevalence pattern may be explained by the use of hormone replacement therapy after menopause (which eases milder forms of incontinence),[6] lifestyle changes where activities promoting incontinence are undertaken less often or not at all, and selective mortality of middle-aged women with poorer health, associated with incontinence. However, it is important to note that this pattern is not

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[6] Recent research by Hendrix et al. (2005) contradicts this proposal by reporting the use of menopausal hormone therapy to actually increase the incidence of stress, urge and mixed incontinence amongst women who were continent at the start of the study, and to worsen the frequency of incontinence events and the amount leaked at these events amongst women who already experienced urinary incontinence.

replicated in every study (see, for example, Avery et al. 2004a, 2004b) and may reflect the prevalence pattern for stress incontinence but not urge incontinence.

Faecal and anal incontinence also increases with age. Amongst community-dwelling persons, faecal and anal incontinence may rise with age from around 2–3% to over 10% (Nelson 2004).

Sex

Women generally experience urinary incontinence proportionally more than men, for all age groups. Thom (1998) estimated the prevalence of urinary incontinence in older women (65 years and over) to be 1.3 to 2.0 times greater than for older men. For younger women and men, it is higher, with the ratio of prevalence ranging from 4.1 to 4.5. Chiarelli et al. (2005) found the difference between Australian women and men aged between 20 and 40 years to be even higher—approximately a 7 to 1 ratio. However, in older persons, the sex ratio for urinary incontinence falls to 2:1, probably because of prostate problems, and associated urinary incontinence, men increasingly experience at older ages (see Section 3.6).

Sex differences for faecal incontinence are not so clear cut. Women are traditionally considered to experience faecal incontinence more than men, possibly due to the increased risk of sustaining damage to the pudendal nerve or sphincter muscle during childbirth (Madoff et al. 1992). While some studies show a higher prevalence amongst women (e.g. Kalantar et al. 2002; MacLennan et al. 2000; Nelson et al. 1995; Roberts et al. 1999), others find prevalence amongst men to be similar or higher (Campbell et al. 1985; Lam et al. 1999; Nelson 2004; Thomas et al. 1984).

3.6 Other risk factors

An extensive list of risk factors is proposed for incontinence but only a small number of these have received any rigorous assessment. The majority of research attention has focused on risk factors for urinary incontinence, particularly for women. Only the more prominently studied risk factors for urinary and faecal incontinence are briefly discussed below.

(a) Pregnancy, childbirth and parity: Both urinary and faecal incontinence are commonly associated with pregnancy and childbirth and may predispose women to more chronic episodes of incontinence later in life. Parous women are more likely to experience urinary incontinence compared with nulliparous women (Chiarelli et al. 1999; Thomas et al. 1980 but see Foldspang et al. 1992) and there is some, but still conflicting evidence, that women who have multiple pregnancies (four or more babies) are also more prone. There is conjecture as to whether it is the pregnancy, and the associated weight bearing on the pelvis, or vaginal delivery, which predisposes women to incontinence. For faecal incontinence, childbirth is considered the likelier cause but the mode of delivery does not necessarily differentiate risk. MacLennan et al. (2000) found no significant difference in the prevalence of faecal incontinence in women who had undergone caesarean sections and women who vaginally delivered their child. However, forceps delivery was found to be associated with elevated risks for faecal incontinence.

(b) Menopause: Research on the association between menopause and urinary incontinence has also produced conflicting results. It is suggested that the loss of oestrogen plays a role in urinary incontinence, since the atrophy of urinary tract and bladder tissues,

which can lead to infections and storage problems and occurs with menopause, can be reversed with oestrogen replacement.

(c) Body mass index and obesity: The literature suggests a strong but not unchallenged role for obesity and higher BMI (body mass index) in the development of urinary incontinence (see, for example, Brown et al. 1999; Chiarelli et al. 1999; MacLennan et al. 2000). Similar to pregnancy, the added weight carried by obese persons may put too much pressure on the pelvic floor, and cause significant strain, stretching and weakening of the muscles, nerves and other structures.

(d) Lower urinary tract symptoms (LUTS): Lower urinary tract infections and symptoms such as blood in the urine or cloudy urine, burning, and trouble initiating or shutting off flow substantially have been found to increase risk in both men and women in the development and experience of incontinence (Brown et al. 1999; Chiarelli et al. 1999; Diokno et al. 1986; Ueda et al. 2000).

(e) Constipation: Constipation may be associated with both urinary incontinence (Chiarelli & Brown 1999; Paillard & Resnick 1984) and faecal incontinence (Diokno et al. 1990), particularly in older women. The straining associated with constipation possibly weakens pelvic floor muscles and ligaments, resulting in the dysfunction of pelvic floor muscles (Lubowski et al. 1988). Treatment of constipation may significantly reduce the severity of incontinence (Chassagne et al. 2000).

(f) Surgery: The impact of surgery as a precursor to urinary incontinence is more commonly observed in men than women. Men who undergo prostatectomies are particularly susceptible to urinary incontinence; older men are especially vulnerable with a calculated doubling of risk for every 10 years of age (Catalona et al. 1999). Hysterectomies and surgeries such as prolapse repair may increase the risk of urinary incontinence in women (Chiarelli et al. 1999; Milsom et al. 1993) but results so far are inconsistent. The risk of faecal incontinence from anal surgery is relatively low but sphincterotomies and fistulotomies are reported to be riskier surgical procedures and reported to increase the risk of anal incontinence by 8% and 18–52% respectively (Pernikoff et al. 1984 and del Pino et al. 1996, cited in Nelson et al. 2002).

(g) Mobility impairment: Men and women with mobility impairments have been found to be more prone to incontinence compared with their more mobile counterparts. Research proposing this link mostly stems from studies of older people but whether this incontinence is due to the problems people have with getting to the toilet (and, in some cases, removing their clothes) or urinary incontinence being a precursor to frailty is not yet understood.

(h) Cognitive impairment: Dementia, again amongst older people, is a recognised correlate with incontinence, and men and women are equally affected. People with more severe dementia are reported to be considerably more prone to becoming incontinent; a Canadian study of older demented women calculated odds ratios of 1.2, 4.0 and 12.6 for mild, moderate and severe dementia (Hunskaar et al. 1998, cited in Hunskaar et al. 2002). Both dementia and incontinence are predictors for older people to be admitted to aged care homes (Nuotio et al. 2003; Pearson 2003).

(i) Other health conditions and diseases: Diabetes mellitus and neurological conditions such as Parkinson's disease, spinal cord injury and multiple sclerosis are all associated with higher prevalence of urinary and anal incontinence (Brown et al. 1999; Chiarelli & Brown 1999; MacLennan et al. 2000; Nygaard & Lemke 1996; Thom et al. 1997).

Neuropathy, or nerve damage, is a common complication of diabetes (AIHW 2002a). Autonomic neuropathy affects the nerves controlling involuntary body functions, such as bladder function, and hence can lead to incontinence. Neurological conditions affect a person's mobility and ability to undertake self-care tasks such as toileting, as well as causing diarrhoea and faecal impaction.

3.7 Effect on lifestyle

Many studies of urinary and faecal incontinence describe the negative impact of incontinence on lifestyle and wellbeing but for those studies that attempt to quantify this impact, empirical findings tend to be mixed. For some individuals, incontinence exerts an enormous effect on lifestyle, participation and emotional status; for others, the effects are much milder. Fultz and Herzog's (2001) review of these studies argued that such varying conclusions resulted in part from different analytical designs, the absence of a comparative group (i.e. what do the results mean), and non-validated self-assessment of incontinence symptoms. Furthermore, they found that certain groups of respondents were more prone to reporting negative effects, such as younger adults and males.

Emotional wellbeing is possibly the biggest effect for people experiencing severe incontinence. Depression, frustration, embarrassment and sadness are terms often used in the literature. Up to 20% of people with incontinence have indicated feeling such emotions. For example, Fultz and Herzog's (2001) review estimated that around 10% of people with urinary incontinence felt their incontinence had affected feelings about themselves. Edwards and Jones (2001) reported an even greater impact on emotional wellbeing amongst people with faecal incontinence—20% suffered anxiety, and 15% experienced depression.

Incontinence may also affect ability to maintain lifestyle or participation in particular life areas. For example, 52% of people aged 40 years and over who have 'major' faecal incontinence reported 'a lot' of impact on their life (Perry et al. 2002). Around 16% with minor faecal incontinence reported the same. People with urinary incontinence reported somewhat less impact on their lifestyle—1.4% felt their urinary incontinence affected their ability to carry out daily activities, and 1.6% reported their social life had been affected (Perry et al. 2002). Analysis of the 1998 SAHOS by Avery et al. (2004b) found that 2% of people with incontinence aged 15 years and over did not leave the house because of their incontinence, 2.5% could not work as much as they used to, and 26% did not socialise as much as they used to.

Quality of life

The Continence Outcomes Management Suite project recently reviewed incontinence measures (or tools) for recommended use by primary care practitioners, specialist practitioners and researchers (Thomas et al. 2005). Included within this review was discussion of various studies using multi-attribute utility instruments (or MAU instruments) to measure the effect of incontinence on health-related quality of life.

The decline in utility index values for persons with incontinence compared with those not experiencing incontinence indicates that incontinence does impact to some extent on quality of life (Table 3.6). In fact, a number of studies comparing the effect on quality of life of various chronic conditions suggested that the experience of (urinary) incontinence is a very

influential factor in overall estimation of an individual's quality of life. For example, Schultz and Kopec (2003), who investigated quality of life using the HUI3 with reference to 21 chronic conditions, found that urinary incontinence was third, after Alzheimer's disease and stroke, in its impact on quality of life. This result occurred for both persons with no other co-morbid conditions and those with at least one other chronic condition. A similar finding was found by Mittmann et al. (1999), also using the HUI3. Avery et al. (2004b), using the SF-36 (Medical Outcomes Study Short Form) assessed health-related quality of life of respondents to the 1998 SAHOS and found that people with incontinence were inclined to report significantly lower self-assessed health than people who did not have incontinence. Respondents with faecal incontinence scored lower than respondents with urinary incontinence as did those with more severe forms of incontinence.

The utility scores listed in Table 3.6, however, demonstrate the inconsistencies in utility scores generated for continence and the varying incontinence severities or incontinence types, depending on the type of utility instrument used. For example, Schultz and Kopec (2003), using the HUI3, reported a utility value for 'incontinence' (0.82) higher than the utility value for 'no incontinence' reported by O'Brien et al. (2001) (0.74). Hawthorne, in Thomas et al. (2005), cautioned against comparing results from these studies since they used varying definitions of incontinence and different population samples, and relied on different descriptive systems, assigned weights and scoring mechanisms. The authors also expressed their concern that the range of utility scores implies that scores may be more dependent on the utility instrument employed, and hence introduce flawed interpretation of results in particular studies, such as those considering the benefits of specific treatment strategies.

Table 3.6: Summary of utility scores reported for different continence status

Source	MAU instrument	Continence status	Utility score	Number
SAHOS 2002 (unpublished)	AQoL	No incontinence	0.84	2,729
		Urinary incontinence	0.71	194
		Faecal incontinence	0.58	87
Hawthorne & Harmer 1999 (unpublished)	AQoL	No incontinence	0.78	29
		Incontinence	0.67	16
O'Brien et al. 2001	EQ5D	No incontinence	0.74	6
		Mild	0.72	209
		Moderate	0.69	182
		Severe	0.61	154
Mittmann et al. 1999	HUI3	No incontinence	0.93	7,509
		Incontinence	0.82	22
Schultz & Kopec 2003	HUI3	No incontinence	0.95	71,773
		Incontinence	0.82	195
SAHOS 2002 (unpublished)	SF-36	No incontinence	0.76	2,729
		Urinary incontinence	0.71	194
		Faecal incontinence	0.63	87
Hawthorne & Harmer 1999 (unpublished)	SF-6D	No incontinence	0.70	29
		Incontinence	0.67	16

Note: Partial table replicated from Table 29, Thomas et al. 2005, with kind permission from Graeme Hawthorne (July 2005).

4 Experience of incontinence: need for assistance, associated health conditions and participation

While there is considerable information on the prevalence and severity of urinary and faecal incontinence, there is less detail on the broader effects on people's lives, and on their families and carers. There is also limited information on the health conditions associated with incontinence. The analysis presented in this chapter attempts to answer some of these questions, by presenting data on:

- the need for assistance;
- use of continence aids;
- living arrangements;
- most common associated health conditions;
- participation in education, the labour force and the social setting; and
- the personal effect on primary carers.

4.1 ABS Survey of Disability, Ageing and Carers

The 2003 ABS Survey of Disability, Ageing and Carers (SDAC) is the primary data source used in this chapter, and is an important source of national population data on disability, covering both rural and urban areas in all states and territories. Data are gathered from both households and cared accommodation (hospitals, residential aged care). The ABS conducted previous surveys in 1981, 1988, 1993 and 1998.

The 2003 SDAC defines 'disability' as the presence of one or more of 17 limitations, restrictions or impairments which restrict everyday activities and has lasted or was likely to last for six months or more (Box 4.1). When a survey respondent states that they experience one or more of the 17 listed items, they are 'screened' into the full survey.

Population for analysis

Incontinence is not included as a long-term health condition in the 2003 SDAC Confidentialised Unit Record File (CURF), and so people who experience incontinence are identified from questions on need for assistance with managing bladder or bowel control and the use of continence aids. For the purposes of this chapter, a person with severe incontinence is defined here as someone who always or sometimes needs assistance with managing their bladder or bowel control and/or uses continence aids; this group is used in the majority of analyses presented below. However, there is some consideration of people who experience difficulty with bladder or bowel control but do not need assistance, for comparative purposes. Due to the structure of the relevant questions, incontinence can not be broken down into urinary or faecal incontinence.

The population defined in this chapter as experiencing severe incontinence or experiencing difficulty with bladder or bowel control are those also defined as having a disability, based on a positive response to one or more screening questions listed in Box 4.1. This group is, therefore, a subset of the overall population experiencing incontinence. Incontinence is not always or necessarily an isolated problem and is often associated with or related to other long-term health conditions. The population included in the following analyses represents such a group, and probably those experiencing more severe or chronic forms of incontinence.

Box 4.1: Areas of limitation, restriction or impairment identified by the ABS

Affirmative responses to any of the following categories, where the limitation, restriction or impairment has lasted or was likely to last for six months or more 'screen' the person into the ABS survey:

- *loss of sight, not corrected by glasses or contact lenses;*
- *loss of hearing, with difficulty communicating or use of aids;*
- *loss of speech;*
- *chronic or recurring pain that restricts everyday activities;*
- *shortness of breath or breathing difficulties that restrict everyday activities;*
- *blackouts, fits, or loss of consciousness;*
- *difficulty learning or understanding;*
- *incomplete use of arms or fingers;*
- *difficulty gripping or holding things;*
- *incomplete use of feet or legs;*
- *a nervous or emotional condition that restricts everyday activities;*
- *restriction in physical activities or physical work;*
- *disfigurement or deformity;*
- *head injury, stroke or any other brain damage with long-term effects that restrict everyday activities;*
- *needing help or supervision because of a mental illness or condition;*
- *treatment or medication for any other long-term condition or ailment and still restricted;*
- *any other long-term condition that restricts everyday activities.*

This list thus creates the implicit definition of disability for the ABS 1998 Survey of Disability, Ageing and Carers (ABS 2004a).

This chapter first provides an estimate of the Australian population with a disability experiencing 'severe' incontinence before describing the level and frequency of assistance people need to manage their bladder and bowel control, and the proportion relying on continence aids. The chapter also includes discussion on the living arrangements, associated health conditions and participation of those with severe incontinence (i.e. people with a disability who always or sometimes need assistance with bladder or bowel control and/or use continence aids), and the effects on carers caring for a person experiencing incontinence.

4.2 Population with 'severe' incontinence

In 2003, an estimated 284,500 people with a disability (1.4% of all Australians) experienced severe incontinence, i.e. they always or sometimes needed assistance with bladder or bowel control and/or used continence aids. Within this population group, 128,300 (0.6% of all Australians) always needed assistance with bladder or bowel control, and another 101,300 (0.5% of all Australians) sometimes needed assistance. Around 320,400 people with a disability (1.6%) reported having difficulty with managing their bladder or bowel control but did not need assistance.

4.3 Assistance and the use of aids

Need for personal assistance

Of those people with a disability who always need assistance with bladder or bowel control, 45,600 (36%) lived in households and 82,600 (64%) lived in cared accommodation (Tables 4.1 and 4.2). Of people with a disability who sometimes need assistance with bladder or bowel control, 60,800 (60%) lived in households and 40,500 (40%) in cared accommodation. Almost all persons who reported experiencing difficulty with bladder or bowel control but did not need assistance lived in households (97%).

Of those people with a disability who always need assistance with their bladder or bowel control, the majority living in households were aged 0–19 years (40%) or 70–84 years (27%) (Table 4.1). The high prevalence of incontinence amongst the 0–19 year age group may in part be explained by nocturnal enuresis, or bedwetting, but it should be noted that 78% of children and youth in this age group who always needed assistance with bladder or bowel control were aged over 10 years.

Among people with a disability living in households and sometimes needing assistance with bladder or bowel control, almost a third (31% or 18,500 people) were aged 70–84 years (Table 4.1).

Among people living in cared accommodation and who always need assistance with bladder or bowel control, 50% were aged 85 years or older, and another 39% 70–84 years (Table 4.2). While the preponderance of people over 70 years in cared accommodation facilities influences this finding a comparison of need for assistance within these age groups suggests that the majority of people with disabilities who lived in cared accommodation in 2003 did experience severe incontinence. For example, 62,100 cared accommodation residents with a disability and aged 85 years and over needed some level of assistance with bladder and bowel control, compared with 18,400 who did not experience difficulty or need assistance (Table 4.2). In contrast, 10,600 people aged 85 years and over and living in households needed assistance with bladder or bowel control compared with 111,400 who did not.

Females represented 55% of people living in households who always needed assistance with bladder or bowel control, 52% of people who sometimes needed assistance and 63% of those experiencing difficulty with bladder or bowel control but did not need assistance. Excluding the 0–19 year age group, females' need for assistance to manage bladder or bowel control was higher for age groups 50 years and older, whereas males tended to report needing assistance after the age of 70 years. Females in cared accommodation represented 73% of residents who always need assistance and 71% of residents who sometimes need assistance.

Table 4.1: People with a disability living in households, by age and level of assistance needed with bladder or bowel control, 2003

| | Level of assistance needed | | | | | | | | |
| | Always needs assistance | | Sometimes needs assistance | | Does not need assistance but has difficulty | | Has no difficulty with bladder or bowel control | | |
	'000	%	'000	%	'000	%	'000	%	Total with a disability
Males									
0–19	10.9	53.2	9.1	31.3	*4.2	*3.7	229.1	13.4	253.3
20–49	**1.8	**8.8	*5.1	*17.5	16.1	14.0	558.0	32.7	580.9
50–69	0	0.0	*4.0	*13.8	38.8	34.0	570.0	33.4	612.8
70–84	*6.3	*30.7	9.8	33.8	50.0	43.7	303.0	17.8	369.1
85+	**1.6	**7.8	**1.0	**3.6	*5.3	*4.7	44.2	2.6	52.1
All males	*20.5*	*44.9*	*29.1*	*47.9*	*114.3*	*36.7*	*1,704.3*	*51.6*	*1,868.2*
Females									
0–19	*7.2	*28.4	*4.2	*13.3	*2.9	*1.5	157.0	9.8	171.2
20–49	**2.2	**8.7	*6.1	*19.3	39.0	19.8	487.2	30.5	534.5
50–69	*5.9	*23.6	*8.5	*27.1	69.5	35.3	533.8	33.4	617.7
70–84	*6.2	*24.5	*8.7	*27.4	64.8	32.9	354.5	22.2	434.2
85+	*3.7	*14.8	*4.3	*13.4	20.9	10.6	67.2	4.2	96.1
All females	*25.2*	*55.1*	*31.7*	*52.1*	*197.0*	*63.3*	*1,599.8*	*48.4*	*1,853.7*
Persons									
0–19	18.0	39.5	13.3	21.8	*7.1	*2.3	386.1	11.7	424.5
20–49	*3.9	*8.7	11.2	18.4	55.0	17.7	1,045.2	31.6	1,115.3
50–69	*5.9	*13.0	12.5	20.5	108.3	34.8	1,103.8	33.4	1,230.5
70–84	12.4	27.2	18.5	30.5	114.7	36.8	657.6	19.9	803.2
85+	*5.3	*11.6	*5.3	*8.7	26.2	8.4	111.4	3.4	148.2
All persons	**45.6**	**100.0**	**60.8**	**100.0**	**311.3**	**100.0**	**3,304.1**	**100.0**	**3,721.7**

Note: Estimates marked with ** have an associated relative standard error (RSE) of 50% or more. Estimates marked with * have an associated RSE of between 25% and 50%. These estimates should be interpreted accordingly.

Source: AIHW analysis of ABS 2003 Survey of Disability, Ageing and Carers confidentialised unit record file.

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Table 4.2: People with a disability living in cared accommodation, by age and level of assistance needed with bladder or bowel control, 2003

	Always needs assistance		Sometimes needs assistance		Does not need assistance but has difficulty		Has no difficulty with bladder or bowel control		
	'000	%	'000	%	'000	%	'000	%	Total with a disability
Males									
0–49	**1.8	**8.0	**1.0	**8.4	**0.4	**12.5	*2.9	*16.9	*6.1
50–69	*2.7	*11.9	**1.3	**10.9	**0.4	**12.5	*3.2	*18.6	*7.6
70–84	10.0	44.2	*5.2	*43.7	**1.4	**43.8	*5.7	*33.1	22.3
85+	*8.1	*35.8	*4.4	*37.0	**1.0	**31.3	*5.4	*31.4	18.9
All males	*22.6*	*27.4*	*11.9*	*29.5*	*3.2*	*35.6*	*17.2*	*37.6*	*54.9*
Females									
0–49	**1.2	**2.0	**0.5	**1.8	**0.2	**3.4	**1.8	**6.3	*3.7
50–69	*3.7	*6.2	**1.6	**5.6	**0.1	**1.7	**1.7	**6.0	*7.1
70–84	22.0	36.7	9.9	34.7	**1.9	**32.2	12.0	42.1	45.8
85+	33.1	55.2	16.5	57.9	*3.7	*62.7	13.0	45.6	66.3
All females	*60.0*	*72.6*	*28.5*	*70.5*	*5.9*	*65.6*	*28.5*	*62.4*	*122.9*
Persons									
0–49	*3.0	*3.6	**1.5	**3.7	**0.6	**6.7	*4.7	*10.3	9.8
50–69	*6.4	*7.7	*2.9	*7.2	**0.5	**5.6	*4.9	*10.7	14.7
70–84	32.0	38.7	15.1	37.4	*3.3	*36.7	17.7	38.7	68.1
85+	41.2	50.0	20.9	51.7	*4.7	*52.2	18.4	40.3	85.2
All persons	**82.6**	**100.0**	**40.5**	**100.0**	**9.1**	**100.0**	**45.7**	**100.0**	**177.8**

Notes

1. Younger age groups have been combined due to very small cell sizes.

2. Estimates marked with ** have an associated relative standard error (RSE) of 50% or more. Estimates marked with * have an associated RSE of between 25% and 50%. These estimates should be interpreted accordingly.

Source: AIHW analysis of ABS 2003 Survey of Disability, Ageing and Carers confidentialised unit record file.

Frequency of need for assistance

Table 4.3 assesses the frequency of need for assistance with self-care for persons who always or sometimes need assistance with their incontinence. Due to the structure of the SDAC it was not possible to assess the need for assistance specifically with the management of bladder or bowel control.

For people with a disability who always or sometimes need assistance to manage bladder or bowel control, 60% living in cared accommodation and 19% living in households required assistance six or more times a day. Overall, 96% of people living in cared accommodation needed assistance at least one to two times a day; 52% living in households reported a similar frequency of need for assistance.

Table 4.3: People with a disability who need assistance to manage their bladder or bowel control, by frequency of need for assistance with self-care and residential status, 2003

Frequency of need for assistance	Cared accommodation		Households		Total	
	'000	%	'000	%	'000	%
6+ times a day	75.9	59.9	29.4	18.6	105.3	42.4
3–5 times a day	30.7	24.2	29.0	18.4	59.7	24.1
1–2 times a day	15.1	11.9	24.1	15.3	39.2	15.8
1–6 times a week	**2.3	**1.8	13.7	8.7	16.0	6.4
Less than once a week	**1.2	**0.9	25.4	16.1	9.3	3.7
Not known	**1.3	**1.0	—	—	**1.3	**0.5
Total[(a)]	**126.7**		**157.7**		**284.4**	

(a)   Total includes respondents who have no difficulty with self-care and respondents who have difficulty with self-care but do not need assistance. Percentages therefore do not add up to 100%.

Note: Estimates marked with ** have an associated relative standard error (RSE) of 50% or more. Estimates marked with * have an associated RSE of between 25% and 50%. These estimates should be interpreted accordingly.

Source: AIHW analysis of ABS 2003 Survey of Disability, Ageing and Carers confidentialised unit record file.

Informal versus formal assistance

Around 55% of people with a disability who need assistance to manage bladder or bowel control and live in households relied on informal self-care assistance, and another 22% used a mixture of informal and formal self-care assistance (Table 4.4). Only 7% of people who needed assistance with managing bladder or bowel control received formal assistance only for self-care activities. Of note is the 16% of people who needed assistance with bladder or bowel control who reported not receiving any self-care assistance from either formal or informal sources.

This picture is somewhat different to that reported by persons with a profound or severe core activity limitation[7] living in households. Almost 80% of this group reported that their self-care needs were met by formal assistance and 8% by a combination of informal and formal sources (AIHW 2005a). No self-care assistance was received by 10% of persons with a profound or severe core activity restriction.

Table 4.4: People with a disability who need assistance to manage their bladder or bowel control, by type of assistance received with self-care, 2003

	Type of assistance received				
	Receives formal assistance only	Receives informal assistance only	Receives formal and informal assistance	Receives no assistance	Total[(a)]
'000	*8.7	66.8	26.7	19.3	**121.6**
Per cent	*7.2	55.0	22.0	15.9	**100.0**

(a)   Total does not include people who have no difficulty with self-care or people who have difficulty with self-care but do not need assistance.

Note: Estimates marked with * have an associated relative standard error (RSE) of between 25% and 50% and should be interpreted accordingly.

Source: AIHW analysis of ABS 2003 Survey of Disability, Ageing and Carers confidentialised unit record file.

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7   A person with a profound or severe core activity limitation requires assistance in at least one of three core activities—self-care, mobility or communication.

Need for assistance with toileting

The association between assistance with toileting[8] and assistance with managing bladder and bowel control is presented in Table 4.5. For people with a disability living in households and who always need assistance with toileting, 57% always needed assistance with managing their bladder and bowel control and 8% sometimes needed assistance with bladder or bowel control. However, 33% of this group reported not having any difficulty with bladder or bowel control, suggesting a need for assistance with toileting is not necessarily associated with a need for assistance with bladder or bowel control. A similar pattern is found for people with a disability living in households who sometimes need assistance with toileting— 25% reported sometimes needing assistance with bladder or bowel control and 57% reported not having any difficulty at all.

Table 4.5: People with a disability and need for assistance with toileting, by need for assistance with bladder or bowel control and residential status, 2003

	Assistance with toileting									
	Always needs assistance		Sometimes needs assistance		Does not need assistance but has difficulty		Has no difficulty		Does not use a toilet[(a)]	
	'000	%	'000	%	'000	%	'000	%	'000	%
Assistance with managing bladder and bowel control										
					Households					
Always needs assistance	31.1	57.1	**2.1	**3.8	**1.7	**1.9	10.7	0.3	—	—
Sometimes needs assistance	*4.6	*8.3	13.4	24.9	*6.4	*7.1	36.4	1.0	—	—
Does not need assistance but has difficulty	**0.8	**1.4	*7.8	*14.6	22.7	25.0	279.4	7.9	**0.6	**11.3
Has no difficulty	18.1	33.2	30.5	56.7	60.2	66.1	3,190.4	90.7	*4.8	*88.7
Total	**54.6**	**100.0**	**53.8**	**100.0**	**91.1**	**100.0**	**3,516.9**	**100.0**	**5.4**	**100.0**
					Cared accommodation					
Always needs assistance	71.4	81.7	*5.9	*17.3	**1.2	**10.1	**1.6	**4.1	*2.5	*42.5
Sometimes needs assistance	11.9	13.6	19.9	58.2	*3.5	*30.3	*5.0	*13.0	**0.1	**1.7
Has difficulty but does not need assistance	**1.3	**1.5	*2.5	*7.2	*2.5	*21.5	*2.7	*7.0	**0.1	**1.9
Has no difficulty	*2.8	*3.2	*5.9	*17.3	*4.4	*38.1	29.3	75.9	*3.2	*53.9
Total	**87.5**	**100.0**	**34.2**	**100.0**	**11.7**	**100.0**	**38.6**	**100.0**	***5.9**	***100.0**

(a)   Does not use a toilet includes people using attached aids such as colostomy bags, catheters, etc. and who have no control over their bladder or bowel (i.e. rely totally on continence aids).

Note: Estimates marked with ** have an associated relative standard error (RSE) of 50% or more. Estimates marked with * have an associated RSE of between 25% and 50%. These estimates should be interpreted accordingly.

Source: AIHW analysis of ABS 2003 Survey of Disability, Ageing and Carers confidentialised unit record file.

An association between assistance and toileting is much more pronounced for people living in cared accommodation, especially for those who always need assistance with toileting, where 82% of these people also indicated always needing assistance with bladder or bowel

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8   A need for assistance with toileting refers to any difficulty associated with using a toilet.

control. For those in cared accommodation who sometimes need assistance with toileting, 58% reported sometimes needing assistance with bladder or bowel control, 17% always needing assistance and 17% not having any difficulty with bladder or bowel control.

Use of aids

A total of 83,800 people with a disability aged 10 years and over and living in households reported using continence aids; 64% were female (Table 4.6). Around 100,700 people with a disability living in cared accommodation also used continence aids (Table 4.7). Again, females were the more common users of continence aids, representing 74% of all continence aid users living in cared accommodation.

Table 4.6: People aged 10 years and over with a disability living in households, by sex, age and use of continence aids, 2003

	Uses continence aids		Does not use continence aids but uses other aids		Does not use aids		Total	
	'000	%	'000	%	'000	%	'000	%
Males								
10–19	*3.0	*2.0	44.8	30.1	101.0	67.9	148.8	100.0
20–49	*4.6	*0.8	196.6	33.8	379.7	65.4	580.9	100.0
50–69	*3.2	*0.5	251.5	41.0	358.1	58.4	612.8	100.0
70–84	15.6	4.2	224.6	60.9	128.8	34.9	369.0	100.0
85+	*3.5	*6.7	41.2	79.1	*7.4	*14.2	52.1	100.0
Females								
10–19	**2.0	**1.8	34.9	13.7	72.8	66.4	109.7	100.0
20–49	*6.9	*1.3	191.8	57.1	335.8	62.8	534.5	100.0
50–69	14.7	2.4	277.6	44.9	325.4	52.7	617.7	100.0
70–84	19.1	4.4	252.8	58.2	162.2	37.4	434.1	100.0
85+	11.2	11.7	72.9	75.9	12.0	12.5	96.1	100.0
Persons								
10–19	*5.0	*1.9	79.7	30.8	173.8	67.2	258.5	100.0
20–49	11.5	0.1	388.4	34.8	715.5	64.1	1,115.4	100.0
50–69	17.9	1.5	529.1	43.0	683.5	55.5	1,230.5	100.0
70–84	34.7	4.3	477.4	59.4	291.0	36.2	803.1	100.0
85+	14.7	9.9	114.1	77.0	19.4	13.1	148.2	100.0
Males	*29.9*	*35.7*	*758.7*	*47.8*	*975.0*	*51.8*	*. .*	*. .*
Females	*53.9*	*64.3*	*830.0*	*53.2*	*908.2*	*48.2*	*. .*	*. .*
Persons	**83.8**	**100.0**	**1,588.7**	**100.0**	**1,883.2**	**100.0**	**. .**	**. .**

Note: Estimates marked with ** have an associated relative standard error (RSE) of 50% or more. Estimates marked with * have an associated RSE of between 25% and 50%. These estimates should be interpreted accordingly.

Source: AIHW analysis of ABS 2003 Survey of Disability, Ageing and Carers confidentialised unit record file.

Around 10% of people with a disability aged 85 years and older living in households used continence aids, as did 4% of people aged 70–84 years (Table 4.6). The proportion of similarly aged persons living in cared accommodation using continence aids was considerably higher—58% of persons aged 85 years and older and 55% of persons aged 70–84 years (Table 4.7). This marked difference in continence aid use between household and cared accommodation living persons also occurred for younger persons. The predominance of continence aid use amongst persons living in cared accommodation compared with those living in households may relate to a number of factors, including severity of the incontinence experience and accessibility of aids.

Table 4.7: People aged 10 years and over with a disability living in cared accommodation, by sex, age and use of continence aids, 2003

	Uses continence aids		Does not use continence aids but uses other aids		Does not use aids		Total	
	'000	%	'000	%	'000	%	'000	%
Males								
10–49	**1.8	**28.3	**1.8	**28.7	*2.7	*43.0	*6.2	100.0
50–69	*3.2	*41.4	*2.7	*34.3	**1.9	**24.3	*7.8	100.0
70–84	11.5	50.5	*9.1	*39.7	**2.2	**9.8	22.8	100.0
85+	10.2	52.8	*7.9	*40.8	**1.2	**6.3	19.4	100.0
Females								
10–49	**1.3	**33.2	**1.2	**31.5	**1.4	**35.2	*3.9	100.0
50–69	*4.2	*57.4	**1.9	**26.1	**1.2	**16.5	*7.3	100.0
70–84	26.8	56.8	15.8	33.5	*4.6	*9.7	47.1	100.0
85+	41.7	61.5	22.9	33.8	*3.2	*4.8	67.8	100.0
Persons								
10–49	*3.1	*30.2	*3.0	*29.8	*4.0	*40.0	10.1	100.0
50–69	*7.4	*49.2	*4.6	*30.3	*3.1	*20.5	15.1	100.0
70–84	38.3	54.8	24.8	35.5	*6.8	*9.7	69.9	100.0
85+	51.9	58.1	30.8	34.5	*4.5	*5.0	89.3	100.0
Males	*26.7*	*26.5*	*21.5*	*34.0*	*8.1*	*43.8*	. .	. .
Females	*74.0*	*73.5*	*41.8*	*66.0*	*10.4*	*56.2*	. .	. .
Persons	**100.7**	**100.0**	**63.3**	**100.0**	**18.5**	**100.0**	. .	. .

Notes

1.   Younger age groups have been combined due to very small cell sizes.

2.   Estimates marked with ** have an associated relative standard error (RSE) of 50% or more. Estimates marked with * have an associated RSE of between 25% and 50%. These estimates should be interpreted accordingly.

Source: AIHW analysis of ABS 2003 Survey of Disability, Ageing and Carers confidentialised unit record file.

The need for assistance combined with aid use may denote more severe incontinence. Table 4.8 shows the level of assistance needed by people who use continence aids.

Half of all persons with a disability and using continence aids always needed assistance with managing bladder or bowel control and around a fifth (21%) sometimes needed assistance. An estimated 22% of continence aid users did not need any assistance but experienced

Table 4.8: People aged 10 years and over with a disability and using continence aids, by level of assistance needed to manage bladder and bowel control, by sex, 2003

	Level of assistance needed with bladder and bowel control								Total using continence aids
	Always needs assistance		Sometimes needs assistance		Does not need assistance but has difficulty		Has no difficulty with bladder or bowel control		
	'000	%	'000	%	'000	%	'000	%	'000
Males	29.6	51.1	14.9	25.8	*8.1	*13.9	*5.3	*9.1	57.9
Females	64.0	49.6	23.4	18.2	32.5	25.2	*9.0	*7.0	129.0
Persons	**93.6**	**50.2**	**38.4**	**20.5**	**40.6**	**21.7**	**14.3**	**7.7**	**186.8**

Note: Estimates marked with * have an associated relative standard error (RSE) of between 25% and 50% and should be interpreted accordingly.

Source: AIHW analysis of ABS 2003 Survey of Disability, Ageing and Carers confidentialised unit record file.

difficulty. Males who used aids were much more likely to report sometimes needing assistance with managing bladder or bowel control (26%) compared to 18% of females who used aids, while females who used aids were much more likely to report having difficulty but not needing assistance with managing bladder or bowel control (25%) compared to males (14%).

4.4 Living arrangements

The living arrangements of people with severe incontinence are presented in Table 4.9.

In 2003, an estimated 126,800 people with severe incontinence lived in cared accommodation, and 157,700 lived in households. For people aged under 70 years, the majority with severe incontinence lived in households, and for those aged 85 years and over, the majority lived in cared accommodation. There were slightly more people with severe incontinence aged 70–84 years living in households than cared accommodation (51,200 compared to 48,700).

Males aged 85 years and over with severe incontinence were much more likely to live in cared accommodation (12,800 males) than households (5,000). There were more females with severe incontinence living in cared accommodation at younger ages, with 33,400 females living in cared accommodation and 28,300 living in households. The difference for females with severe incontinence and aged 85 years and over is even greater—51,000 lived in cared accommodation in 2003 and 15,500 lived in households.

The data presented in Table 4.9 confirm the age and sex association with incontinence discussed in Chapter 3. Seventy-nine per cent (226,000) of Australians in 2003 who reported having a disability and severe incontinence were aged over 50 years; 65% or 184,200 were aged 70 years or older. People with a disability reporting severe incontinence were also much more likely to be female (187,000 or 66%) than male (97,500 or 33%). This sex difference was apparent for all age groups presented in Table 4.9, except the youngest (0–19 years), which might be influenced by the higher prevalence of intellectual and similar disabilities amongst boys in this age group (AIHW 2004a), and its association with need for assistance with bladder or bowel control and/or use of continence aids (unpublished analysis of 2003 SDAC CURF).

Table 4.9: People with severe incontinence[a]: age and sex by residential status, 2003 ('000)

	Cared accommodation	Households[b]	Total
Males			
0–19	**0.2	20.6	20.8
20–49	*2.8	*8.4	11.2
50–69	*4.0	*5.5	9.5
70–84	15.3	22.9	38.2
85+	12.8	*5.0	17.8
All males	*35.1*	*62.4*	*97.5*
Females			
0–19	**0.1	11.3	11.4
20–49	**1.8	13.3	15.1
50–69	*5.4	26.9	32.3
70–84	33.4	28.3	61.7
85+	51.0	15.5	66.5
All females	*91.7*	*95.3*	*187.0*
Persons			
0–19	**0.3	31.9	32.2
20–49	*4.6	21.7	26.3
50–69	9.4	32.4	41.8
70–84	48.7	51.2	99.9
85+	63.8	20.5	84.3
All persons	**126.8**	**157.7**	**284.5**

(a)   Severe incontinence is defined for persons with a disability who always or sometimes need assistance with bladder or bowel control and/or use continence aids.

(b)   Households include private and non-private dwellings, where non-private dwellings include hostels, hotels, motels, educational and religious institutions, guest houses, caravan parks, and self-care units in retirement villages which may have cared accommodation on-site.

Note: Estimates marked with ** have an associated relative standard error (RSE) of 50% or more. Estimates marked with * have an associated RSE of between 25% and 50%. These estimates should be interpreted accordingly.

Source: AIHW analysis of ABS 2003 Survey of Disability, Ageing and Carers confidentialised unit record file.

4.5 Associated health conditions

Tables 4.10 and 4.11 list the most common health conditions, reported as 'main disabling condition', associated with severe incontinence, for people living in households and cared accommodation respectively. Due to small cell sizes, health conditions have been clustered in most instances into health condition groupings based on ICD–10 chapter headings. Arthritis and related disorders and stroke are identified separately in Table 4.10, and dementia (including Alzheimer's disease), stroke and arthritis and related disorders are identified separately in Table 4.11.

For people living in households, arthritis and related disorders was the most common associated health condition—22,300 or 14% of people with a disability and severe

incontinence also reported having arthritis and related disorders (Table 4.10). The next most common group of conditions were musculoskeletal conditions, in particular back problems (20,400 people or 13%), followed by neurological conditions (16,200 people or 10.2%) and mental and behavioural disorders (psychiatric) (15,900 people or 10.2%) (see notes in Table 4.10 for related health conditions). These four health condition groups were also most commonly associated with severe incontinence amongst females, although mental and behavioural disorders (psychiatric) were slightly more common (11%) than neurological conditions (9%). The pattern, however, for males was quite different—mental and behavioural disorders (other) was the most commonly associated group of health conditions (13%), followed by neurological conditions (13%). The relatively high proportion of young males (i.e. under 15 years) with severe incontinence reporting intellectual and developmental disorders, autism or ADHD as their main disabling condition has likely influenced the association between severe incontinence and mental and behavioural disorders (other).

A somewhat different picture emerges when considering people living in cared accommodation (Table 4.11). Dementia (including Alzheimer's disease) was by far the most common condition associated with severe incontinence—46,000 or 36% of people living in cared accommodation had either dementia or Alzheimer's disease and incontinence. Stroke (11%) and arthritis and related disorders (9%) were also commonly associated health conditions.

The two most common health conditions associated with incontinence amongst males with a disability in cared accommodation were dementia (including Alzheimer's disease) (30%) and stroke (16%). Around 39% of women in cared accommodation who experienced incontinence also had dementia (including Alzheimer's disease), 10% experienced arthritis and related disorders, and 9% had had a stroke.

Table 4.10: People with a disability living in households with severe incontinence[a]: ten most common associated health conditions, by sex, 2003

Health condition	Males		Females		Persons	
	'000	%	'000	%	'000	%
Arthritis and related disorders	*2.9	*4.7	19.4	20.4	22.3	14.2
Musculoskeletal	*7.6	*12.2	12.8	13.4	20.4	12.9
Neurological	*8.0	*12.8	*8.2	*8.6	16.2	10.2
Mental and behavioural disorders (psychiatric)	*7.4	*11.9	10.8	11.3	15.9	10.2
Mental and behavioural disorders (intellectual/learning)	*8.2	*13.3	*3.2	*3.3	11.5	7.3
Stroke	*4.4	*7.1	*4.2	*4.4	*8.6	*5.5
Respiratory	**2.4	**3.9	*5.0	*5.2	*7.4	*4.7
Injury	*3.0	*4.8	*4.3	*4.5	*7.3	*4.6
Neoplasms	*3.5	*5.7	*3.5	*3.7	*7.1	*4.5
Circulatory (excluding stroke)	**2.3	**3.7	*4.1	*4.3	*6.4	*4.1
All other conditions	12.5	20.0	19.9	20.9	32.4	20.5
Total	**62.4**	**100.0**	**95.3**	**100.0**	**157.7**	**100.0**

(a)   Severe incontinence is defined for persons with a disability who always or sometimes need assistance with bladder or bowel control and/or use continence aids.

Notes

1.   'Musculoskeletal' includes back problems (dorsopathies), osteoporosis, other soft tissue/muscle disorders (including rheumatism), repetitive strain injury/occupational overuse syndrome and other diseases of the musculoskeletal system and connective tissue (ICD Chapter 10).

2.   'Neurological' includes Parkinson's disease, epilepsy, multiple sclerosis, cerebral palsy, migraine, paralysis, chronic/postviral fatigue syndrome and other diseases of the nervous system (ICD Chapter 6).

3.   'Mental and behavioural disorders (psychiatric)' includes depression/mood affective disorders, nervous tension/stress, schizophrenia, phobic and anxiety disorders, mental and behavioural disorders nfd and other mental and behavioural disorders (ICD Chapter 5).

4.   'Mental and behavioural disorders (intellectual/learning)' includes intellectual and developmental disorders, mental retardation/intellectual disability, autism, and attention deficit disorder/hyperactivity (ICD Chapter 5).

5.   'Respiratory' includes asthma, emphysema, and other diseases of the respiratory system (ICD Chapter 10).

6.   'Injury' includes head injury/acquired brain damage, leg/knee/foot/hip damage from injury/accident, complications/consequences of surgery and medical care nec, and other injury and poisoning and certain other consequences of external causes (ICD Chapter 19).

7.   'Neoplasms' includes prostate cancer and other neoplasms (tumours/cancers) (ICD Chapter 2).

8.   'Circulatory (excluding stroke)' includes heart disease, angina, hypertension, other diseases of the circulatory system and other heart diseases (ICD Chapter 9).

9.   'All other conditions' includes dementia, Alzheimer's disease, diabetes, diseases of the genitourinary system (kidney and urinary system (bladder) disorders (except incontinence), other diseases of the genitourinary system), diseases of the digestive system (enteritis and colitis, other diseases of the intestine, abdominal hernia, and diseases of the digestive system), sensory/speech (glaucoma, sight loss, other diseases of the eye and adnexa, diseases of the inner ear, deafness/hearing loss, and speech impediment), certain infectious and parasitic diseases, diseases of the blood and blood-forming organs and certain disorders involving the immune system, other endocrine/nutritional and metabolic disorders, congenital malformations, deformations and chromosomal abnormalities, breathing difficulties/shortness of breath, other symptoms/signs and abnormal clinical and laboratory findings nec, restriction in physical activity or physical work, and other 2003 codes which have no ICD-10 equivalent (all other ICD chapters).

10.   Estimates marked with ** have an associated relative standard error (RSE) of 50% or more. Estimates marked with * have an associated RSE of between 25% and 50%. These estimates should be interpreted accordingly.

Source: AIHW analysis of ABS 2003 Survey of Disability, Ageing and Carers confidentialised unit record file.

Table 4.11: People with a disability living in cared accommodation with severe incontinence[a]: ten most common associated health conditions, by sex, 2003

Health condition	Males		Females		Persons	
	'000	%	'000	%	'000	%
Dementia (including Alzheimer's disease)	10.5	30.0	35.5	38.8	46.0	36.3
Stroke	*5.6	*15.9	*8.5	*9.3	14.1	11.1
Arthritis and related disorders	**1.5	**4.3	9.5	10.4	11.1	8.7
Neurological	*4.9	*14.0	*5.8	*6.3	10.7	8.5
Mental and behavioural disorders (psychiatric)	*2.9	*8.3	*7.6	*8.4	*10.6	*8.3
Circulatory (excluding stroke)	**1.5	**4.2	*4.4	*4.8	*5.8	*4.6
Musculoskeletal	**0.1	**1.6	*3.6	*3.9	*4.1	*3.2
Sensory/speech	**0.1	**2.6	*2.8	*3.1	*3.7	*3.0
Respiratory	**1.2	**3.3	**2.2	**2.4	*3.4	*2.7
Injury	**1.1	**2.9	**1.5	**1.6	*2.5	*2.0
All other conditions	*3.3	*9.4	*8.0	*8.7	11.3	8.9
Total	**35.1**	**100.0**	**91.7**	**100.0**	**126.7**	**100.0**

(a) Severe incontinence is defined for persons with a disability who always or sometimes need assistance with bladder or bowel control and/or use continence aids.

Notes

1. 'Neurological' includes Parkinson's disease, epilepsy, multiple sclerosis, cerebral palsy, migraine, paralysis, and other diseases of the nervous system (ICD Chapter 6).

2. 'Mental and behavioural disorders (psychiatric)' includes depression/mood affective disorders, schizophrenia, phobic and anxiety disorders, nervous tension/stress, mental and behavioural disorders nfd, and other mental and behavioural disorders (ICD Chapter 5).

3. 'Circulatory (excluding stroke)' includes heart disease, angina, hypertension, other diseases of the circulatory system and other heart diseases (ICD Chapter 9).

4. 'Musculoskeletal' includes back problems (dorsopathies), osteoporosis, other soft tissue/muscle disorders (including rheumatism), and other diseases of the musculoskeletal system and connective tissue (ICD Chapter 13).

5. 'Sensory/speech' includes glaucoma, sight loss, other diseases of the eye and adnexa, diseases of the inner ear, deafness/hearing loss, tinnitus, other diseases of the ear and mastoid process and unspecified speech difficulties (ICD Chapters 5, 7 and 8).

6. 'Respiratory' includes asthma, emphysema, respiratory allergies, bronchitis/bronchiolitis and other diseases of the respiratory system.

7. 'Injury' includes head injury/acquired brain damage, leg/knee/foot/hip damage from injury/accident, arm/hand/shoulder damage from injury/accident, complications/consequences of surgery and medical care nec, and other injury and poisoning and certain other consequences of external causes (ICD Chapter 19).

8. 'All other conditions' includes diabetes, neoplasms (prostate cancer and other neoplasms (tumours/cancers)), diseases of the genitourinary system (kidney and urinary system (bladder) disorders (except incontinence), other diseases of the genitourinary system), diseases of the digestive system (enteritis and colitis, other diseases of the intestine, and diseases of the digestive system), certain infectious and parasitic diseases, diseases of the blood and blood-forming organs and certain disorders involving the immune system, other endocrine/nutritional and metabolic disorders, congenital malformations, deformations and chromosomal abnormalities, restriction in physical activity or physical work, breathing difficulties/shortness of breath, pain nfd, skin allergies (dermatitis and eczema), other diseases of the skin and subcutaneous tissue, other symptoms/signs and abnormal clinical and laboratory findings nec, and other 2003 codes which have no ICD-10 equivalent (all other ICD chapters).

9. Estimates marked with ** have an associated relative standard error (RSE) of 50% or more. Estimates marked with * have an associated RSE of between 25% and 50%. These estimates should be interpreted accordingly.

Source: AIHW analysis of ABS 2003 Survey of Disability, Ageing and Carers confidentialised unit record file.

4.6 Participation

The effect of incontinence on a person's lifestyle varies from individual to individual, depending to some extent on the severity of the incontinence, the type of incontinence experienced, the support received to manage incontinence, and how people feel about their symptoms.

Participation is discussed here within three participatory spheres—education, the labour force, and the social setting.

Education

In 2003, 24,400 children and youth aged 5–20 years with severe incontinence attended school, representing 93% of such children (Table 4.12) and 17% of all children with a disability at school. While their participation was proportionally higher than other children with a disability (87%), this result may be somewhat misleading given the number of continent children who did not attend school either because they were too young or who had already completed their schooling.

Almost half (49%) of the children with severe incontinence were educated in special schools, compared with 14% of other children with a disability. Children with a disability who did not need assistance or use aids for their incontinence were much more likely to attend an ordinary school (48% compared to 24%).

Table 4.12: Participation of people with a disability aged 5–20 years in education, by incontinence status, 2003

Type of school	Needs assistance with bladder or bowel control and/or uses continence aids		Does not need assistance with bladder or bowel control and does not use continence aids	
	'000	%	'000	%
Ordinary school	*6.1	*23.5	68.2	48.0
Special class	*5.5	*21.1	35.1	24.7
Special school	12.7	48.8	19.7	13.9
Total attending school	**24.4**	**93.4**	**123.1**	**86.5**
Not attending school (because of disability)	**1.2	**4.5	*4.1	*2.9
Not attending school (too young)			**2.5	**1.7
Not attending school (finished school)	**0.5	**2.1	12.6	8.8
Total not attending school	***1.7*	***6.6*	*19.2*	*13.5*
Persons	26.1	100.0	142.3	100.0

Note: Estimates marked with ** have an associated relative standard error (RSE) of 50% or more. Estimates marked with * have an associated RSE of between 25% and 50%. These estimates should be interpreted accordingly.

Source: AIHW analysis of ABS 2003 Survey of Disability, Ageing and Carers confidentialised unit record file.

Labour force participation

Labour force participation is presented in Table 4.13 for people who always need assistance with bladder or bowel control, who sometimes need assistance, and those who experience difficulty with bladder or bowel control but do not need assistance.

The labour force participation of people aged 15–64 years, with a disability and with more severe incontinence (i.e. always needing assistance) was very low in 2003, with a participation rate of 5.2% (Table 4.13). The participation rate of people who sometimes need assistance with managing their incontinence and/or used continence aids was much higher (37%), and comparable with persons who had difficulty managing their incontinence but did not need assistance (40%).

Table 4.13: Labour force participation of people aged 15–64 and 65+ years with a disability, by need for assistance or use of continence aids to manage bladder or bowel control, 2003 ('000)

	Always needs assistance and/or uses continence aids		Sometimes needs assistance and/or uses continence aids		Does not need assistance but has difficulty		Has no difficulty with bladder or bowel control	
	15–64	65+	15–64	65+	15–64	65+	15–64	65+
Employed	—	—	*7.8	**0.8	50.8	*7.7	997.9	54.3
Unemployed	**0.6	—	**0.8	—	*5.0	—	92.2	—
Not in labour force	10.9	19.1	14.6	*8.6	84.5	158.2	922.7	961.0
Total in labour force	**0.6**	**—**	**8.6**	****0.8**	**55.7**	***7.7**	**1,090.1**	**54.3**
Total	*11.5*	*19.1*	*23.2*	*25.8*	*140.0*	*165.9*	*2,012.8*	*1,015.3*
Unemployment rate	100.0	—	9.2	—	8.9	—	8.5	—
Participation rate	5.2	0.0	37.1	3.1	39.7	4.6	54.2	5.3

Note: Estimates marked with ** have an associated relative standard error (RSE) of 50% or more. Estimates marked with * have an associated RSE of between 25% and 50%. These estimates should be interpreted accordingly.

Source: AIHW analysis of ABS 2003 Survey of Disability, Ageing and Carers confidentialised unit record file.

Unemployment rates were the same (9%) for people sometimes needing assistance or not needing assistance but experiencing difficulty. [9]

Labour force participation rates were highest (54%) for people with a disability who had no difficulty with bladder or bowel control, but their unemployment rate was the same at 9%.

The labour force participation of people aged 65 years and over with a disability and either sometimes needing assistance with bladder or bowel control or having difficulty with bladder or bowel control were similar, at 3.1 and 4.6 respectively. For people in the same age group and reporting not having a difficulty with bladder or bowel control, the labour force participation rate was only slightly higher, at 5.3.

Social participation

Table 4.14 compares how often people aged 15 years and over with a disability, and who always or sometimes needs assistance with bladder or bowel control, are able to go out. Male and female differences were quite marked.

Males who felt they could go out as often as they liked were less likely to be using aids (44%) than were females (61%). Whether this indicates differential availability of assistance (as an alternative), differential take-up of aids, or convenience of aids for males can only be speculated about. Males and females who reported not being able to go out as often as they would like were equally likely to use continence aids (66% and 65% respectively).

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[9] The participation rate for people with a disability in 2003 was 53%, and 15% and 36% respectively for people with a profound and severe disability respectively (AIHW 2005a), and the unemployment rate was 9% (AIHW 2005a).

Table 4.14: Social participation of people aged 15 years and over, with a disability and who need assistance with bladder or bowel control, by use of continence aids, 2003

	Can go out as often as would like		Cannot go out as often as would like		Does not leave home at all		Total
	'000	%	'000	%	'000	%	'000
Males							
Uses aids	11.9	43.7	12.8	66.0	*2.5	*100.0	27.3
Doesn't use aids	10.9	62.4	6.7	34.0	0	0.0	17.5
All males	*22.9*	*100.0*	*19.4*	*100.0*	*2.5*	*100.0*	*44.8*
Females							
Uses aids	24.2	60.5	27.9	64.9	**0.5	**22.2	52.6
Doesn't use aids	15.8	39.5	15.1	35.1	**1.9	**77.8	32.8
All females	*40.0*	*100.0*	*42.9*	*100.0*	**2.4*	**100.0*	*85.3*
Persons							
Uses aids	36.1	57.5	40.7	65.2	*3.1	*61.9	79.8
Doesn't use aids	26.7	42.5	21.7	34.8	**1.9	**38.1	50.3
All persons	**62.8**	**100.0**	**62.3**	**100.0**	***5.0**	**100.0**	**130.1**

Note: Estimates marked with ** have an associated relative standard error (RSE) of 50% or more. Estimates marked with * have an associated RSE of between 25% and 50%. These estimates should be interpreted accordingly.

Source: AIHW analysis of ABS 2003 Survey of Disability, Ageing and Carers confidentialised unit record file.

4.7 Carers

In 2003, there were 56,354 primary carers, or 12% of all primary carers, who usually assisted with managing another person's incontinence (Table 4.15). Of these carers, 32% were a spouse or partner, 31% a father or mother and 30% a son or daughter.

Table 4.15: Relationship of primary carer to person requiring assistance with incontinence, 2003

	Usually assists with managing incontinence		Does not usually assist with managing incontinence	
	'000	%	'000	%
Spouse/partner	18.3	32.4	177.3	42.6
Father or mother	17.6	31.2	92.9	22.3
Son or daughter	16.7	29.7	105.1	25.3
Other relative, friend or neighbour	*3.8	*6.7	40.8	9.8
Total	**56.4**	**100.0**	**416.1**	**100.0**

Note: Estimates marked with * have an associated relative standard error (RSE) of between 25% and 50%. These estimates should be interpreted accordingly.

Source: AIHW analysis of ABS 2003 Survey of Disability, Ageing and Carers confidentialised unit record file.

Primary carers who usually assist with managing incontinence reported spending a considerable number of hours per week in their caring role—59% spent 40 hours or more a week actively caring or supervising and another 22% spent between 20 and 40 hours a week (Table 4.16). Among primary carers who did not usually assist with managing incontinence, 41% spent less than 20 hours a week actively caring and 34% 40 hours or more.

Table 4.16: Number of hours per week primary carer spends actively caring or supervising, 2003

	Usually assists with managing incontinence		Does not usually assist with managing incontinence	
	'000	%	'000	%
Less than 20 hours	*6.9	*11.9	170.7	41.0
20 to less than 40 hours	12.1	21.5	74.5	17.9
40 hours or more	33.1	58.8	141.1	33.9
Not stated	*4.3	*7.6	29.9	7.2
Total	**56.4**	**100.0**	**416.1**	**100.0**

Note: Estimates marked with * have an associated relative standard error (RSE) of between 25% and 50%. These estimates should be interpreted accordingly.

Source: AIHW analysis of ABS 2003 Survey of Disability, Ageing and Carers confidentialised unit record file.

For primary carers who assist people with more severe forms of incontinence, the effect of this type of care on the carer can be especially demanding. Table 4.17 compares the general wellbeing of primary carers who usually assist with managing another's incontinence, and primary carers who do not, and finds evidence for a negative effect on wellbeing in the former group. For example, 44% of carers who usually assist with managing another person's incontinence reported a change in their physical or emotional wellbeing since taking on the caring role, compared to 27% of carers who do not assist in managing another's incontinence.

Table 4.17: Physical and emotional wellbeing of primary carers who usually and do not usually assist with managing incontinence, 2003

	Usually assists with managing incontinence		Does not usually assist with managing incontinence	
	'000	%	'000	%
Physical or emotional wellbeing				
Has changed due to caring role	24.9	44.3	111.6	26.8
Has not changed due to caring role	27.0	47.8	275.4	66.2
Not stated	*4.5	*7.9	29.1	7.0
Weariness and lack of energy				
Feels weary or lacks energy due to caring role	24.6	43.7	134.6	32.3
Does not feel weary or lack energy due to caring role	27.3	48.4	252.5	|60.7
Not stated	*4.5	*7.9	29.1	7.0
Worry and depression				
Frequently feels worried or depressed due to caring role	25.2	44.7	112.6	27.1
Does not frequently feel worried or depressed due to caring role	26.7	47.4	274.4	65.9
Not stated	*4.5	*7.9	29.1	7.0
Total	**56.4**	**100.0**		**100.0**

Note: Estimates marked with * have an associated relative standard error (RSE) of between 25% and 50%. These estimates should be interpreted accordingly.

Source: AIHW analysis of ABS 2003 Survey of Disability, Ageing and Carers confidentialised unit record file.

Around 44% of primary carers who usually assisted with managing another's incontinence also reported feeling weary or lacked energy due to their caring role, and 45% frequently felt worried or depressed (Table 4.17). A lower percentage of primary carers who did not usually assist with managing incontinence reported similar feelings, 32% and 27% respectively. It is important to note that this pattern may be an indication of the co-morbidities experienced by the person being cared for, rather than just the incontinence itself.

5 Expenditures for incontinence

5.1 An estimate of incontinence expenditure

The costs of incontinence are large and the impacts are both monetary and non-monetary. This chapter focuses on health system and residential aged care expenditures and expenditures on continence aids. There are a wide range of other personal costs such as laundry, clothing and time costs which have not been captured.

There have been limited studies of the costs of incontinence in Australia. One study estimated the costs of urinary incontinence for women in the community to be $710 million in 1998—$339 million on treatment costs and $372 million on personal costs (Doran et al. 2001). Moore et al. (2005) present much useful data on the costs of incontinence in various settings, but do not attempt to make an overall estimate of the costs of incontinence.

The present study estimates that the monetary costs of urinary and faecal incontinence in Australia in 2003 totalled $1.5 billion. The costs in various areas of the health and residential aged care sector are detailed in Table 5.1.

Table 5.1: Health and residential aged care expenditures for incontinence, 2003

Area of expenditure	Expenditure
Residential aged care	$1,268 million (assistance with bladder/bowel control and toileting)
Admitted patient services in hospitals	$89.8 million
Non admitted patient services in hospitals	Unknown
Unreferred (GP) services	$5.9 million
Pathology & imaging	$4.3 million
Specialist medical services	$3.8 million
Pharmaceuticals requiring a prescription	$12.2 million
Over-the-counter medication	Unknown[a]
Other health professionals	Unknown[a]
Other health services	$4.2 million
Continence aids	$111.7 million (urinary incontinence only)
Total	**$1,500 million**

(a)   Future analysis of the SAHOS may enable an estimation of these costs.

Note: Expenditures listed above are total expenditures whether funded by government or by individuals, except for residential aged care where only government subsidies are included, as contributions by residents are considered to be covering non-health and welfare costs such as food and accommodation and so government subsidies are considered to be covering all of the health and welfare costs of incontinence.

5.2 Residential aged care

The vast majority of monetary costs imposed by incontinence are for residential aged care. It is a large proportion of expenditure because many of the people with severe incontinence are in residential aged care, and because caring for people with severe incontinence is very time

intensive. In residential aged care this time must be paid for, whereas at home there is no payment from the health and aged care budget for the time carers must spend in assisting people with incontinence. (Some carers receive Carer Payments which can be considered to be part-compensation for the care they provide, but there is no valid method for estimating what portion of Carer Payments could be considered to be for incontinence care).

The estimates of expenditure on incontinence in residential aged care are derived from the aged care database using the answers to questions 5, 6 and 7 on the resident classification scale (RCS) questionnaire. The population used for this work are residents who had valid RCS assessments for a period including 30 June 2003. This population was assumed to be representative of the population in residential aged care for the whole 12 months of 2003.

The cost of incontinence in residential aged care has been calculated by first calculating the current level of basic subsidy funding for residential aged care. This includes the current cost of assisting residents with incontinence. Second, the level of basic subsidy funding for residential aged care that would be paid if the residents did not have incontinence is calculated. The difference between the two numbers is the cost due to incontinence.

The level of funding for each client is determined by the RCS. Each resident is classified according to the answers given to the RCS questionnaire. Each answer has a different weight applied and the sum of these weights gives an overall score for the resident. In order to calculate the impact of incontinence the answers recorded on the questionnaire for the toileting, bladder management and bowel management questions have been recoded to give a weight of 0 to these questions. This has the effect of reducing the RCS score for the patient. A new RCS classification was then calculated for each resident and the difference in the level of funding between the new RCS classification and the old was calculated. This difference is the estimate of the cost of incontinence in the residential aged care sector.

This estimated cost (see Table 5.2) is the cost to the Australian Government of incontinence and toileting problems in residential aged care, because the $1.3 billion is the amount by which Australian Government subsidies to aged care homes would be reduced if none of the residents had incontinence or toileting problems. But it is not necessarily the actual cost to aged care homes of incontinence and toileting problems. Whether this is so depends on whether the funding formulas on which the payments are based accurately represent the costs incurred by aged care homes. The funding formulas were based on costing studies done some years ago, and it is possible that the funding formulas now over or perhaps under represent actual costs. There is some evidence, for example, that for bowel management, the current formulas overestimate the actual costs to aged care homes of that problem.

This subsidy of $1.3 billion is 32% of the total basic residential aged care subsidy of $4.0 billion and about 30% of total Australian Government subsidies for residential aged care facilities.

A significant proportion of the costs above are due to assistance with toileting. Is this need for toileting assistance due to incontinence? There is a very large association between the two variables. In residential aged care almost all of those who need major or extensive support with bladder and/or bowel control also need assistance with toileting. The patterns of expenditure for bowel and bladder management and assistance with toileting are very similar, with just under three-quarters of all expenditure attributed to females and one-quarter to males.

Table 5.2: Basic subsidy funding to residential aged care facilities that can be attributed to toileting, bladder management and bowel management, 2003 ($ million)

Type of assistance	Cost
Bladder management only	$184.971
Bowel management only	$351.504
Both bladder and bowel management[a]	$528..480
Assistance with toileting	$598.695
Assistance with toileting without bowel or bladder management[b]	$0.147
All bladder and bowel management and assistance with toileting[a]	$1,268.191

(a) The cost associated with 'Both bladder and bowel management' and 'All bladder and bowel management and assistance with toileting' is not that associated with the sum of the costs of the individual parts. The removal of bladder management may cause a drop in the RCS classification from RCS1 to RCS2; however while bowel management may have a similar effect, the combination of bowel and bladder management may not be sufficient to reduce the classification any further and thus incur a change in the applicable subsidy. In addition the change in the level of funding between each classification is not the same. Therefore a change from RCS1 to RCS2 will incur a different level of subsidy than a change between RCS2 and RCS3.

(b) Expenditure due to assistance with toileting when the resident did not have bowel or bladder management problems.

Source: AIHW analysis of DoHA ACCMIS database.

The International Classification of Functioning, Disability and Health (ICF) (WHO 2001) sheds light on this issue. As will be discussed in Part B of this report, urinary continence is the function of control over urination (ICF b6202) and urinary incontinence is an impairment of this function. Toileting is not a body function like urinary continence, but is an activity. It is the planning and carrying out of the elimination of human wastes and cleaning oneself afterwards (ICF d530). Many people have activity limitations, and require assistance to carry out those activities. Those who have toileting limitations may have these limitations because of intrinsic bladder dysfunction and so have lost the function of control over urination. Or they may have toileting limitations because their dementia leads to a cognitive impairment which leads to lack of awareness and in turn a toileting limitation.

Most people who need assistance with toileting need that assistance because of a lack of control of urination (or defecation). Even those who need assistance with toileting because of, for example, mobility problems have, in one sense, a urination problem. It is not a problem with bladder functioning, but it is a problem with getting to the toilet which if not attended to results in inappropriate urination (see discussion of functional incontinence in Chapter 2.2, Part A, where functional incontinence is defined as 'urinary leakage associated with inability to toilet because of impairment of cognitive and/or physical functioning, psychological unwillingness, or environmental barriers').

Thus, needing assistance with toileting and lack of control of urination or defecation are so tightly linked that one can say that toileting limitation is the other face of continence impairment. It is therefore appropriate to consider that the costs of assisting with toileting in aged care homes are part of incontinence management costs.

Estimates for expenditures on assistance with bladder and bowel control and toileting in residential aged care are presented in Table 5.3; they do not include the costs of dealing with catheters and stoma aids as these costs cannot be separately estimated from the residential aged care data base.

Table 5.3: The amount of residential aged care basic subsidy funding that can be attributed to assistance with toileting, and bladder and bowel management, by age and sex, 2003

Age group	Bladder and bowel management		Assistance with toileting		All bladder and bowel management and assistance with toileting	
	cost ($ million)	per cent	cost ($ million)	per cent	cost ($ million)	per cent
Male						
0–49	1.8	0.3	2.4	0.4	4.7	0.4
50–69	16.0	3.0	19.7	3.3	40.3	3.2
70–84	70.5	13.3	83.4	13.9	174.0	13.7
85+	51.6	9.8	57.7	9.6	123.0	9.7
Total	**139.9**	**26.5**	**163.2**	**27.3**	**342.1**	**27.0**
Female						
0–49	1.9	0.4	2.4	0.4	4.9	0.4
50–69	17.1	3.2	20.4	3.4	42.5	3.4
70–84	146.6	27.7	165.5	27.6	352.7	27.8
85+	223.1	42.2	247.2	41.3	526.0	41.5
Total	**388.6**	**73.5**	**435.5**	**72.7**	**926.1**	**73.0**
All persons	**528.5**	**100.0**	**598.7**	**100.0**	**1,268.2**	**100.0**

Source: AIHW analysis of DoHA ACCMIS database.

5.3 Hospital expenditure

Expenditure in hospital for patients with incontinence is hard to measure. The Economic Framework Report (Moore et al. 2005) showed that the coding for incontinence as a principal diagnosis on hospital morbidity records is inadequate. And even if it were adequate, most of the expenditure in hospital that is due to incontinence is for patients whose principal diagnosis is not incontinence.

One source of data that provides us with information about the continence status of long stay patients in hospital is the ABS Survey of Disability, Ageing and Carers. The 2003 survey showed that at any one time 45% of long stay hospital patients always needed help with bladder or bowel control and 23% sometimes needed help. The Hospital Morbidity Database records 6,001 people with a length of stay greater than 3 months. The patient's incontinence is estimated to impose the same burden on hospital staff as incontinence in residential aged care facilities imposes but at a higher cost to allow for higher cost structures in hospitals, i.e. $36 per day in hospitals compared with $24 per day in residential aged care facilities (Moore et al. 2005). The annual incontinence cost then for these long stay hospital patients who always or sometimes need help with bladder/bowel control is $35.3 million.

Analysis of the Hospital Morbidity Database provided an estimate for the number of patients in hospital for less than 3 months for whom an additional diagnosis of incontinence was recorded. The cost of incontinence for these patients was also determined by applying a cost of $36 per day to their length of stay. The estimate of expenditure due to incontinence amongst hospital patients with a length of stay shorter than 3 months is $29.5 million. This is

expected to be an underestimate because incontinence as an additional diagnosis is often not recorded in the hospital morbidity database, in circumstances when it should be. In addition there is expenditure in hospitals for patients where the principal diagnosis is incontinence—this expenditure is $25 million. Total hospital expenditure for incontinence in 2003 was therefore estimated to be $90 million (Table 5.4).

5.4 Medical and other health system expenditures

Medical services

Of the 20.3% of the 1998 South Australian community population who had urinary incontinence, only 29% said they had consulted a health professional about it, i.e. 5.9% of the South Australian community population (Avery et al. 2004b:59). The time frame in which they had seen a health professional was not ascertained. Of those who had consulted a health professional, 70% said they had seen a GP and 41% said they had seen a specialist.

The Bettering the Evaluation and Care of Health (BEACH) survey collects information about the number of people who have seen their GP about incontinence and who are referred to specialists because of their incontinence. It is estimated, using this data, that there were 94,000 GP attendances and 30,000 out-of-hospital specialist attendances for urinary incontinence nationally in 2000–01. If there were two GP attendances per person this is 0.3% of the adult population. This BEACH data are compatible with the 1998 SAHOS if the time frame the SAHOS respondents answered regarding their consultation with a health professional for incontinence was in regard to the last 1 or 2 decades. This is possible given that the duration of the condition is frequently decades and many people do not often seek their doctor's advice on their incontinence.

In addition, Dowell et al. (1999) found that of the 97 women who came to a Sydney clinic for treatment of stress, urge or mixed incontinence by nurse continence advisors, 52 had seen a GP in the last year, and 51 had seen a specialist.

Both the Sydney clinic data and the 1998 SAHOS indicate a greater use of specialist services relative to GP services as compared to the BEACH data. The BEACH estimates of specialist referrals are subject to high uncertainty, therefore the estimate of use of specialists has been increased, so the number of specialist attendances is assumed to be 41/70 of the GP attendances. The 41/70 is derived from the SAHOS results where 70% said they had seen a GP and 41% said they had seen a specialist. Estimated costs are increased proportionally.

Medical services costing (see Table 5.4) uses the BEACH data for its GP expenditure estimates because it is the only survey which indicates the actual provision of GP services for urinary incontinence in a particular year. The numbers are much lower than the numbers estimated by Doran et al. (2001), based on Dowell et al. (1999), but that is not surprising, because their estimate of use of services is based on a group of women who are actively seeking treatment, whereas most people with incontinence are not actively seeking treatment in any one year.

Pharmaceuticals

It is estimated using the BEACH data that in 2000–01, 260,000 pharmaceuticals were prescribed and used for incontinence. This is an average of 2.8 pharmaceuticals used per GP attendance. The total expenditure on pharmaceuticals was estimated to be $12 million (Table 5.4).

The pharmaceuticals prescribed for incontinence fall into two main areas—urinary incontinence and faecal incontinence. The main pharmaceuticals prescribed were antidiarrheals (24.9%), antibacterials (15.2%), urologicals (10.2%), psychoanaleptics (10.1%), drugs for functional gastrointestinal disorders (7.4%), pituitary and hypothalamic hormones (5.8%), sex hormones (5.5%), mineral supplements (5.1%) and analgesics (3.4%). These 9 groups of drugs make up 88% of prescriptions written for urinary or faecal incontinence by GPs. Most of the antidiarrheal drugs (99%) were prescribed for faecal incontinence, the antibacterials were prescribed more often for urinary incontinence (62%), the urologicals were only prescribed for urinary incontinence and the psycholanaleptics were prescribed more often for urinary incontinence (63%) than for faecal incontinence.

Drugs prescribed for constipation are not included in the costs of incontinence. There were 45% more prescriptions for constipation than for both urinary and faecal incontinence combined, accounting for approximately $18 million. Around 93% of these prescribed drugs were laxatives.

Other health services

It has not been possible to estimate expenditures for incontinence in the areas of non-admitted patient services, other health professional services and over-the-counter medicaments. It is known that people with incontinence do quite often see physiotherapists, and the use of non-admitted patient services in hospitals is considerable. However, some of the expenditure for non-admitted patient services is included in the specialist service expenditure calculated above.

The Australian Government provided $31 million from 1999 to 2006 to support the National Continence Management Strategy (NCMS). In 2003–04, $4.2 million was spent. This expenditure funds specific projects aimed at continence issues such as the Continence Helpline and a communications strategy. This expenditure is included in 'other health services' in Table 5.4.

5.5 Continence aids

The 1998 SAHOS asked people the average amount of money they spent each month on aids or products to help with their urinary incontinence (Avery et al. 2004b). The average expenditure for those using aids was $18.48 per month. This number was increased by the rate of inflation between 1998 and 2003 and the percentage of the 1998 population using aids was applied to the 2003 community-living population. The resulting estimated expenditure for 2003 was $101 million.

Continence Aids Assistance Scheme (CAAS) expenditure was $10.6 million in 2003–04 (Intouch 2005). This included $8.19 million on continence items, $14 million on administration and $1.09 million on freight.

Table 5.4: Expenditure by governments and individuals for incontinence, excluding residential aged-care, 2003 ($ million)

	Admitted patients including private medical expenditure	Un-referred (GP) medical services	Imaging and pathology	Specialist medical services	Total out-of-hospital medical expenditure	Pharmaceuticals requiring a prescription	Contine-nce aids	Other	Total expenditure excluding residential aged care
Males									
0–19	1.7	0.67	0.31	1.98	2.96	1.66	4.9	0.02	11.2
20–49	6.4	0.15	0.11	0.00	0.26	0.51	31.3	0.29	38.8
50–69	6.2	0.21	0.24	0.17	0.62	0.66	14.6	0.31	22.4
70–84	12.4	0.32	0.25	0.00	0.57	0.64	4.4	0.19	18.2
85+	5.2	0.08	0.02	0.12	0.22	0.29	0.5	0.03	6.2
Females									
0–19	1.4	0.76	0.85	0.36	1.97	1.11	4.8	0.08	9.3
20–49	12.0	1.14	0.52	0.40	2.06	1.57	30.9	1.68	48.2
50–69	16.9	1.28	0.76	0.55	2.59	2.75	14.5	1.11	37.8
70–84	17.9	0.98	1.07	0.25	2.30	1.98	5.2	0.40	27.8
85+	9.7	0.35	0.19	0.00	0.53	1.03	0.8	0.06	12.1
Persons									
0–19	3.1	1.43	1.16	2.33	4.92	2.77	9.7	0.10	20.5
20–49	18.4	1.28	0.63	0.40	2.31	2.08	62.2	1.97	86.9
50–69	23.1	1.49	1.00	0.72	3.21	3.41	29.0	1.42	60.2
70–84	30.3	1.30	1.32	0.26	2.88	2.62	9.6	0.59	46.0
85+	14.9	0.43	0.20	0.12	0.75	1.31	1.3	0.09	18.3
Total	**89.8**	**5.93**	**4.31**	**3.83**	**14.08**	**12.20**	**111.7**	**4.2**	**232.0**

Note: Unreferred (GP) medical services, imaging and pathology and specialist medical services together add up to 'Total out-of-hospital medical expenditure'.

Source: AIHW disease expenditure database.

Industry sources indicate that the wholesale expenditure for continence aids for the community and supermarkets was about $45 million. Of this, $8 million was through the CAAS, leaving $37 million. This wholesale cost of $37 million is not inconsistent with the retail costs of aids estimated from the SAHOS of $101 million.
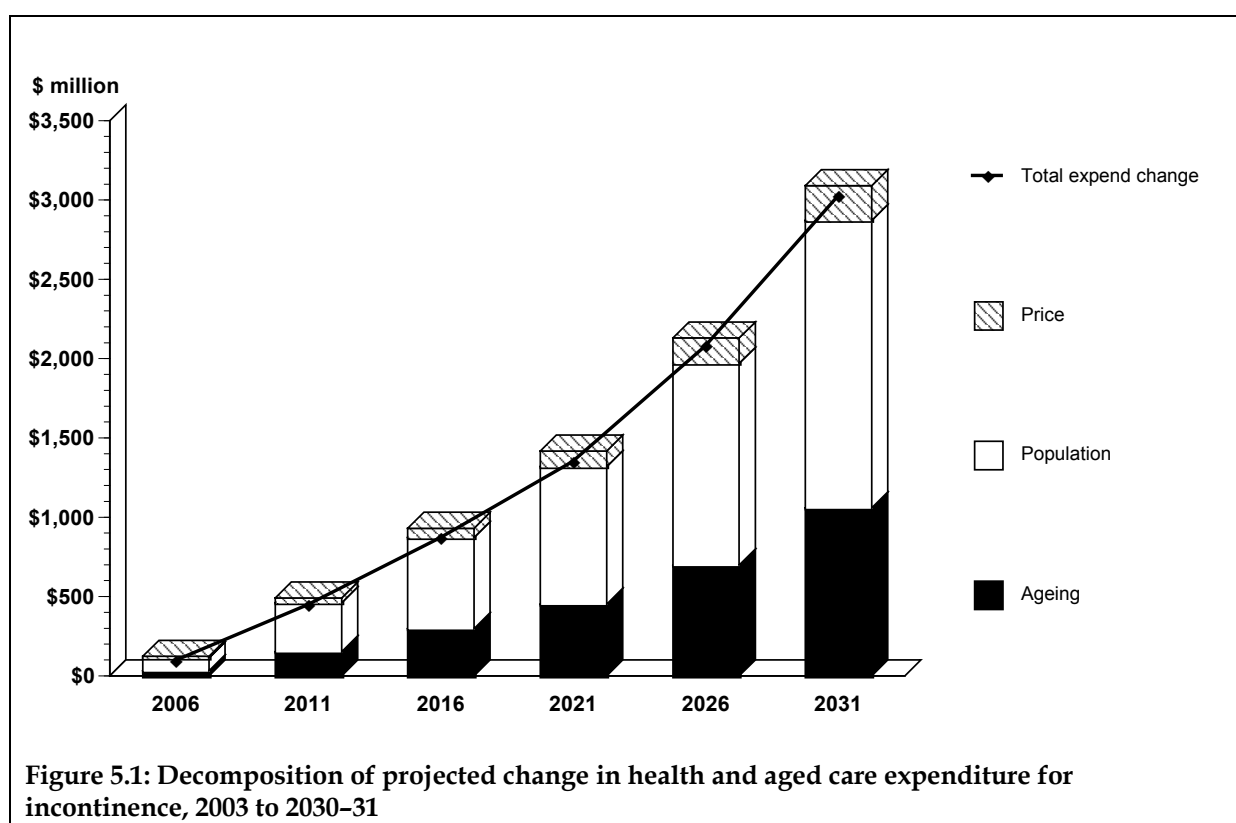
5.6 Projection of expenditure due to incontinence to 2031

The total expenditure for incontinence is projected to increase by 201% from $1.5 billion in 2003–04 to $4.5 billion in 2030–31 (Table 5.5). The sector with the greatest projected increase is residential aged care (220% increase between 2003 and 2030–31). Admitted patient expenditure is expected to increase 141% and other expenditures show an increase of 91%. Expenditure for continence aids is projected to increase by 61% over the 27-year period.

Table 5.5: Expenditure for incontinence 2003 to 2030–31 ($ million)

	2003	2010–11		2020–21		2030–31		
	Expen-diture	Expen-diture	Change since 2003 (per cent)	Expen-diture	Change since 2010–11 (per cent)	Expen-diture	Change since 2020–21 (per cent)	Change since 2003 (per cent)
Residential aged care	1,268	1,668	32	2,495	50	4,065	63	220
All out-of-hospital, pharmaceutical, medical and other	30	36	17	45	27	58	28	91
Continence aids	112	129	15	154	20	179	17	61
Admitted patients	90	110	23	153	38	216	42	141
Total expenditure	**1,500**	**1,942**	**29**	**2,847**	**47**	**4,518**	**59**	**201**

The factors driving the projected increase in expenditure for incontinence are population growth, demographic ageing and excess health price inflation (increases in health prices above the overall inflation rate). Figure 5.1 shows the impact of these factors on health system expenditure for incontinence.

Figure 5.1: Decomposition of projected change in health and aged care expenditure for incontinence, 2003 to 2030–31

5.7 Sensitivity analysis

The projected growth in expenditure for incontinence is driven in part by an assumption of the future rate of excess health price inflation. The base assumption is for annual growth in

excess health price inflation of 0.7%. Table 5.6 shows the effect of changing this base assumption by ±0.2%. The low excess health price inflation (0.05%) results in an expenditure of $4.4 billion for incontinence in 2030–31 compared to $4.9 billion with the higher excess health price inflation of 0.9% per year. The percentage increase in expenditure for incontinence ranges from 185% to 217% for the different assumptions. This is a difference of 0.03% as a percentage of GDP in 2030–31 (Table 5.6).

Table 5.6: Expenditure for incontinence with different health price growth assumptions, 2003 to 2030–31

Annual growth in excess health price inflation (per cent)	$ million			Percentage of GDP	
	2003	2030–31	Per cent change	2003	2030–31
0.5	1,500	4,278	185%	0.22%	0.31%
0.7	1,500	4,518	201%	0.22%	0.33%
0.9	1,500	4,772	218%	0.22%	0.34%

6 Burden of incontinence

6.1 Burden of disease analysis

Burden of disease analysis is a method for analysing the mortality and morbidity impact of health conditions and impairments. Too often analyses focus on the impact of a health condition on mortality, and ignore its impact on quality of life. The burden of disease approach combines the impact of morbidity and premature mortality in one measure called the disability adjusted life year (DALY). The premature mortality component is measured in terms of years of life lost (YLL) and the morbidity component in terms of years of life spent living in states of less than full health (YLD) (Salmon et al. 2002). The YLD is a measure of the impact of a health condition or impairment in restricting activity and participation.

The burden of disease for Australia for all health conditions has been estimated (AIHW: Mathers et al. 1999). These 1996 results are currently being updated to 2003 and will be published in 2006 by the Australian Institute of Health and Welfare and the University of Queensland.

In this chapter, the burden of incontinence is estimated by analysing the number of people with incontinence and then estimating the severity of the condition or the degree to which quality of life is reduced.

Sections 6.2 to 6.4 discuss the measurement of the prevalence and severity of incontinence (in terms of its effect on 'quality of life') for the purpose of burden of disease analysis. Section 6.5 discusses measuring severity in such a way that different levels of severity can be added up, and Sections 6.6 to 6.8 estimates the burden due to incontinence in terms of healthy life years lost.

6.2 Prevalence and severity of faecal incontinence in households (SAHOS)

The most common way to measure the prevalence of faecal incontinence is with the Wexner instrument. This measure was recommended in the Continence Outcomes Measurement Suite Report (Thomas et al. 2005).

The Wexner is scored from five questions in the 2004 SAHOS, which describe the frequency of problems with solid stool (Question X4), liquid stool (X5) or gas (flatus or wind) (X6), the need to wear a pad to protect underwear (X8) and the impact on lifestyle of bowel or stool leakage (X1) (see Table A6.1, Appendix A for Wexner scoring system and Appendix B for the full text of questions).

There are many people in the 2004 SAHOS who only have problems with flatus incontinence (802 out of 1,099 in the survey showing any problem with faecal incontinence on the five Wexner questions). The Assessment of Quality of Life (AQOL) for 'flatus incontinence only' is shown below (Table 6.1)—not many with only flatus incontinence have a decreased AQOL.

Table 6.1: AQOL scores for different severities of flatus incontinence only by age and sex, 2004

	AQOL score for different frequencies of flatus incontinence only				
	None	Rarely	Sometimes	Often	More than daily
Males					
15–19	0.90	0.87	0.90	1.00	0.91
20–24	0.91	0.91	0.94	—	0.84
25–29	0.90	0.82	0.83	0.85	0.86
30–34	0.86	0.78	0.73	0.63	0.00
35–39	0.84	0.79	0.85	0.76	0.63
40–44	0.85	0.82	0.92	0.66	0.61
45–49	0.81	0.79	0.90	0.97	—
50–54	0.83	0.73	0.72	0.73	—
55–59	0.77	0.85	0.74	0.74	0.37
60–64	0.81	0.75	0.50	0.66	0.69
65–69	0.81	0.76	0.82	0.91	0.36
70–74	0.80	0.86	0.82	—	—
75+	0.75	0.76	0.80	—	0.50
All males	**0.84**	**0.81**	**0.81**	**0.84**	**0.65**
Females					
15–19	0.83	0.76	0.54	—	—
20–24	0.85	0.82	0.99	—	—
25–29	0.84	0.79	0.91	0.73	0.76
30–34	0.87	0.84	0.80	0.77	0.52
35–39	0.88	0.81	0.82	0.65	0.72
40–44	0.87	0.83	0.74	0.94	0.93
45–49	0.82	0.80	0.74	0.54	0.61
50–54	0.80	0.75	0.72	0.81	0.59
55–59	0.80	0.84	0.73	0.67	0.79
60–64	0.80	0.80	0.79	0.72	0.50
65–69	0.84	0.81	0.59	0.65	0.71
70–74	0.78	0.75	0.66	0.55	0.61
75+	0.70	0.64	0.70	0.58	0.69
All females	**0.82**	**0.79**	**0.76**	**0.70**	**0.68**

Note: The 'Flatus incontinence only' group has flatus problems as indicated by question X6 but indicate no problems on X4, X5, X8 and/or X10.

Source: AIHW analysis of 2004 SAHOS.

This is particularly so for men who 'rarely', 'sometimes' and 'often' have flatus incontinence. They have similar AQOL scores to those men who report no flatus incontinence. For women the 'sometimes', 'often' and 'more than daily' groups have lower AQOL than women who report no flatus incontinence. However, for those who do have a decreased AQOL score, it may be due to conditions other than flatus incontinence.

Table 6.2 shows the relationship between flatus incontinence only and the elimination question (Question Y8) in the SAHOS. This question asked whether there were slight, marked or serious problems or no control with bladder and bowel functions. Of the 802 people with 'flatus incontinence only', 675 (84%) considered their bladder and bowel worked normally and without problems. Of the remaining 127, 109 considered they had slight problems with bladder and/or bowel functions, 16 considered they had marked problems, and 3 considered they had serious problems.

Table 6.2: Flatus incontinence and bladder and/or bowel problems for SAHOS respondents, 2004

Flatus incontinence only (X6)[a]	Problems with bladder and/or bowel (Y8)					All persons
	No problems	Slight	Marked	Serious	No control	
Never	1,819	134	10	4	0	1,966
Rarely	417	51	6	2	0	476
Sometimes	168	37	5	0	0	210
Often	55	15	5	1	0	75
More than daily	35	6	1	0	0	41
Flatus rarely or more often	*675*	*109*	*16*	*3*	*0*	*802*
All persons	**2,493**	**242**	**26**	**6**	**0**	**2,768**

(a)   Group with no problems on X4, X5, X8 and/or X10.

Note: There were 3,015 respondents in the SA Health Omnibus Survey (SAHOS).

Source: AIHW analysis of 2004 SAHOS.

In light of this data, we consider that it is unhelpful to analyse the flatus incontinence only group in company with those suffering solid and liquid faecal incontinence. Those who have flatus incontinence only do not seem to have significant quality of life problems and almost all consider they do not have a bladder and/or bowel function problem. Thus the analysis below includes 'flatus incontinence only' as a separate category and applies a zero severity weight. This means it makes no contribution to the overall burden of incontinence. However, the estimate of 660,000 people with flatus incontinence only is included in Table 6.10.

The four remaining Wexner questions have some significant overlap. The people who use pads or have their lifestyle affected by bowel or stool leakage are largely a subset of the people who report problems with leaking or losing control of solid and/or liquid stool.

The question arises as to how much extra information is obtained from including the pad and lifestyle questions as compared to using just the liquid and solid stool questions. An index was calculated just using the liquid and stool questions, and this was compared with an index based on the four questions—liquid, stool, pads and lifestyle. The correlation between the two indexes was 0.94. Thus the ranking of people on these incontinence scores does not change very much by adding in the pads and lifestyle questions, i.e. there is little additional information value in adding in the pads and lifestyle questions. Thus the analysis below uses information from the solid and/or liquid stool questions only.

Table 6.3 shows the impact on prevalence estimates of using just these two Wexner questions rather than the four Wexner questions. Occasional solid and/or liquid problems occur for 5.8% of the community dwelling population, and frequent or very frequent problems occur for 1.3% of the population.

Table 6.3: Prevalence of faecal incontinence by different sub-scales of the Wexner scale, 2004

Category	Score	Solid & liquid (per cent)	Score	Solid & liquid plus pads and lifestyle; occasional & higher (per cent)
None	0	92.9	0	92.1
Occasional	1–2	5.8	1–3	6.4
Frequent	3–4	1.1	4–8	1.3
Very frequent	5–8	0.2	9–12	0.2
Occasional and higher	1–8	7.1	1–12	7.9
Frequent and very frequent	3–8	1.3	4–12	1.6

Note: The scoring system is described in Table A6.1 in Appendix A.

Source: AIHW analysis of 2004 SAHOS.

Adding in those who have an occasional + score on the pads and lifestyle questions, but who are not already in the solid and liquid group adds 0.6 percentage points to the occasional group, and 0.2 percentage points to the frequent group, i.e. 0.8 percentage points added overall. The group who are added in have some rather inconsistent answers, e.g. there are 8 people who say they frequently need to wear pads to protect underwear from stool and/or have their lifestyle altered by bowel or stool leakage, but who also say they never leak, have accidents or lose control with solid or liquid stool.

For the burden of disease analysis the 'frequent' and 'very frequent' prevalence of 1.3% is used for the prevalence of faecal incontinence. This is 202,000 people living in the community who at least sometimes, i.e. more than once a month, have solid or liquid stool leakage or accidents.

Of this group the 'very frequent' group (32,000 people) should have a high severity weight in the burden of disease analysis. The SAHOS analysis of AQOL, EQ5D, HUI3 and SF6D by Hawthorne and Sansoni (2004), indicates the severity weight for daily faecal incontinence relative to no faecal incontinence is between 0.35 and 0.11. (15D is excluded as it seems not to be valid in measuring incontinence). A simple average of the relative scores on these four instruments gives 0.24. Allowing for the impact of comorbidity, a severity weight of 0.2 was assumed for 'very frequent' faecal incontinence. For the 'frequent' group, a severity weight of 0.06 is applied. The international literature indicates that very frequent faecal incontinence deserves a high severity weight, but is unhelpful as to the exact level. The SAHOS data seems to be the best data available. It is odd that the very frequent faecal incontinence weights are lower than the very severe urinary incontinence weights (see Table 6.9), but this is in line with the SAHOS results. Sensitivity analysis was done on the severity weights for very frequent faecal incontinence. Using a severity weight of 0.3 instead of 0.2 increased healthy life years lost by 1,863 years (see Table 6.11). This results in an overall increase of 1.6% in healthy life years lost due to incontinence.

6.3 Prevalence and severity of urinary incontinence in households (SAHOS)

The Incontinence Symptom Severity Index (ISSI) is made up of two questions (W7 and W8 in the 2004 SAHOS; see Appendix B). People are asked how often they experience urine leakage and how much urine leakage occurs. There are five response levels for the question of how often urine leakage is experienced (never, less than once a month, several times a month, several times a week and every day or night) and they are scored as 0, 1, 2, 3 or 4.

There are four response levels for the question related to quantity of urine leakage—none, a few drops, a little, and more and they are scored respectively as 0, 1, 2 or 3. In this analysis, the severity of urinary incontinence has been allocated according to the ISSI score as shown in Table A6.2 (Appendix A).

Some level of urinary incontinence was reported by 24.4% of the population (10.2% of males and 38.1% of females) (Table 6.4). Severe or very severe urinary incontinence was reported by 1.5% of the population (0.3% of males and 2.6% of females). For males the level of severity increases with age to 85+ years where 40% of men report some level of urinary incontinence. For females the proportion reporting some level of urinary incontinence is 34% for ages 20–49 years and peaks at 52% for those aged 50–69 years.

Table 6.4: Proportion of urinary incontinence at each severity level, by age group and sex, 2003 (per cent)

| | Severity of urinary incontinence as measured by ISSI | | | | | |
	None	Slight	Moderate	Severe	Very severe	Total
Males						
20–49	95.0	4.6	**0.4	—	—	100.0
50–69	84.5	12.0	*3.0	**0.4	—	100.0
70–84	73.4	20.8	*4.9	**0.5	**0.3	100.0
85+	*59.6	—————————40.4—————————				*100.0
All males	*89.8*	*8.2*	*1.6*	*0.3*	***0.0*	*100.0*
Females						
20–49	65.6	27.5	5.7	*0.8	**0.4	100.0
50–69	47.6	36.3	12.2	*2.6	*1.2	100.0
70–84	59.7	24.5	10.4	*4.8	**0.5	100.0
85+	60.4	————————————29.6————————				100.0
All females	*61.9*	*27.9*	*7.6*	*1.9*	**0.7*	*100.0*
Persons						
20–49	80.4	16.0	3.0	*0.4	**0.2	100.0
50–69	65.8	24.4	7.7	*1.5	*0.6	100.0
70–84	65.7	22.9	8.0	*3.0	**0.4	100.0
85+	60.2	————————————29.8————				100.0
All persons	**75.6**	**18.2**	**4.7**	**1.1**	***0.4**	**100.0**

Note: Estimates marked with ** have an associated relative standard error (RSE) of 50% or more. Estimates marked with * have an RSE of between 25% and 50%. These estimates should be interpreted accordingly.

Source: AIHW analysis of 2004 SAHOS. Rates from 2004 SAHOS data applied to 2003 household population from ABS 2003 Survey of Disability, Ageing and Carers.

Stress and urge incontinence

The two principal types of urinary incontinence—stress incontinence and urge incontinence—are identified from the 2004 SAHOS using questions W2 and W3 (urine leakage related to a feeling of urgency and urine leakage related to physical activity, coughing or sneezing; see Appendix B). There are four response levels on each question—not at all, slightly, moderately, and greatly.

For males, the prevalence of some stress incontinence is fairly constant and small until the age of 65 and then the prevalence increases with age (Table 6.5). For females the picture is different with prevalence increasing with age up to the age of 69 years when the prevalence drops and then remains fairly constant as a proportion of the population. The peak prevalence for females is for 65–69 years when it reaches 58% of the population.

Table 6.5: Proportion of the population suffering from stress incontinence by severity, sex and age, 2003 (per cent)

	Not incontinent	Slightly incontinent	Moderately incontinent	Greatly incontinent	Refused to answer	Total
Males						
20–49	98.2	*1.4	—	**0.1	**0.3	100.0
50–69	95.4	*3.8	**0.3	—	**0.4	100.0
70–84	89.5	*7.5	**1.9	**0.5	**0.6	100.0
85+	*81.7	———————————————18.3———————				*100.0
All males	*96.5*	*2.7*	*0.3*	***0.2*	**0.3*	*100.0*
Females						
20–49	64.2	29.7	3.6	2.5	—	100.0
50–69	43.8	45.1	7.9	*3.2	—	100.0
70–84	58.2	27.3	11.1	*3.2	**0.3	100.0
85+	63.2	———————————————36.8———————————				100.0
All females	*60.6*	*31.3*	*5.5*	*2.6*	***0.0*	*100.0*
Persons						
20–49	81.3	15.4	1.8	1.3	**0.1	100.0
50–69	69.3	24.7	4.1	*1.6	**0.2	100.0
70–84	71.8	18.7	7.1	*2.0	**0.4	100.0
85+	68.4	———————————————31.6——————————				100.0
All persons	**78.2**	**17.3**	**2.9**	**1.4**	***0.2**	**100.0**

Note: Estimates marked with ** have an associated relative standard error (RSE) of 50% or more. Estimates marked with * have an associated RSE of between 25% and 50%. These estimates should be interpreted accordingly.

Source: AIHW analysis of 2004 SAHOS. Rates from 2004 SAHOS data applied to 2003 household population from ABS 2003 Survey of Disability, Ageing and Carers.

For males, the prevalence of some urge incontinence is fairly low in younger ages and increases to 30% for those aged 70–84 years and 50% for those 85 years and over (Table 6.6). For women the prevalence is 34% for those aged 50–69 years, 38% for those aged 70–84 years and 37% for those 85 years and over.

Table 6.6: Proportion of the population suffering from urge incontinence by severity, sex and age, 2003 (per cent)

	Not incontinent	Slightly incontinent	Moderately incontinent	Greatly incontinent	Refused to answer	Total
Males						
20–49	95.7	3.5	**0.4	**0.1	**0.3	100.0
50–69	85.8	9.6	*3.2	**1.0	**0.4	100.0
70–84	69.2	22.5	*5.1	*2.6	**0.6	100.0
85+	*49.8	————————————50.2————————————				*100.0
All males	*89.9*	*7.3*	*1.7*	*0.7*	*0.3*	*100.0*
Females						
20–49	79.5	16.2	2.3	*2.0	—	100.0
50–69	65.8	24.3	6.6	*3.4	—	100.0
70–84	61.9	24.4	10.0	*3.4	**0.3	100.0
85+	63.2	————————————36.8————————————				100.0
All females	*74.5*	*18.4*	*4.6*	*2.4*	***0.0*	*100.0*
Persons						
20–49	87.7	9.8	1.3	1.1	**0.1	100.0
50–69	75.7	17.0	4.9	2.2	**0.2	100.0
70–84	65.1	23.5	7.9	*3.1	**0.4	100.0
85+	59.4	————————————40.6————————————				100.0
All persons	**82.1**	**13.0**	**3.2**	**1.6**	***0.2**	**100.0**

Note: Estimates marked with ** have an associated relative standard error (RSE) of 50% or more. Estimates marked with * have an associated RSE of between 25% and 50%. These estimates should be interpreted accordingly.

Source: AIHW analysis of 2004 SAHOS. Rates from 2004 SAHOS data applied to 2003 household population from ABS 2003 Survey of Disability, Ageing and Carers.

6.4 Prevalence and severity of incontinence in residential aged care (RCS)

The data for incontinence in residential aged care facilities are derived from the aged care database using the answers to questions 5, 6 and 7 on the RCS questionnaire. The population used for this work are residents who had valid RCS assessments for a period including the 30 of June 2003. This population was assumed to be representative of the population in residential aged care for the whole year. Prevalence estimates are presented in Table 6.7.

Table 6.7: Permanent residents of residential aged care who are reported as requiring support with bladder or bowel management or assistance with toileting, by age and sex, 30 June 2003

Age group	Total permanent residents as at 30/6/2003	Needs assistance with toileting		Needs support with bladder management		Needs support with bowel management	
		Permanent residents (no.)	Per cent of total residents	Permanent residents (no.)	Per cent of total residents	Permanent residents (no.)	Per cent of total residents
Males							
0–49	538	419	83.3	357	70.9	455	90.5
50–69	5,037	3,450	68.5	2,919	58.0	3,896	77.3
70–84	19,962	14,099	70.6	12,769	64.0	16,535	82.8
85+	14,985	9,677	64.6	8,962	59.8	12,261	81.8
Total	**40,522**	**27,645**	**68.2**	**25,007**	**61.7**	**33,147**	**81.8**
Females							
0–49	503	420	83.5	363	72.2	447	88.9
50–69	4,749	3,465	73.0	3,259	68.6	3,932	82.8
70–84	40,566	27,597	68.0	28,204	69.5	33,558	82.7
85+	60,299	40,808	67.7	42,873	71.1	50,443	83.7
Total	**106,117**	**72,290**	**68.1**	**74,699**	**70.4**	**88,380**	**83.3**
All persons	**146,639**	**99,935**	**68.2**	**99,706**	**68.0**	**121,527**	**82.9**

Source: AIHW analysis of 2003 ABS Survey of Disability, Ageing and Carers confidentialised unit record file (CURF) and the Residential Aged Care System.

6.5 Severity of incontinence

Severity of incontinence has been described in general terms in the sections above. However in order to measure the overall severity of incontinence a common metric for describing the impact of incontinence must be used. This is done by weighting each level and type of incontinence with a severity weight so that the different levels and types can be added together. The severity weight must be derived from a multi-attribute utility measure in order for such addition to be valid. These severity weights are often called utility weights or disability weights.

Review of literature on severity weights for incontinence

A household survey of 32,781 people across ten countries asked people to characterize urinary incontinence in terms of six key dimensions of health (Salmon et al. 2002). Urinary incontinence was defined as 'loss of control over urination'. Respondents varied significantly in their responses but the median respondent considered that such urinary incontinence would cause mild difficulty for mobility, no difficulty with self-care activities of washing and dressing, mild difficulty with usual activities, moderate difficulty with pain, moderate difficulty with affect, and mild difficulty with cognition. Consistent with these ratings on the six domains, respondents considered urinary incontinence to be quite a severe state, giving an overall rating on the visual analog scale of 0.415 (where 0 good and 1 is worst possible health state).

A Canadian survey asked people to evaluate the severity of their own health conditions using the HUI3 instrument (Shultz & Kopec 2003). Those with urinary incontinence showed quite high severities compared to other conditions, and this was also the case when only those with urinary incontinence were compared with others who only had one condition. Urinary incontinence was the third most severe condition with a deviation from normal health of 13% after Alzheimer's disease (34% deviation from normal health) and the effects of stroke (17%). Urinary incontinence was considered a bigger problem than epilepsy (8% deviation from normal health), heart disease (6%), arthritis/rheumatism (9%) and cataracts (8%). The severity levels for many of the conditions in this survey were surprisingly low. This may be partly due to the fact that respondents were those with the conditions; most other utility surveys ask experts or the general population. These groups are asked the theoretical question as to what they consider the impact of the disease would be if they or someone else had it. These views are different to those with a health condition as this group tend to adapt to the condition in such a way that the impact of that condition on their wellbeing is moderated (Cummins 2003). Thus they consider the utility decrement due to the condition to be less than the assessment of experts or the general population.

The 2004 SAHOS measured the HUI3, the EQ5D, the AQOL, the 15D, and the SF6D. On all multi-attribute utility instruments there were reductions in utility as the severity of urinary incontinence increased. The 15D showed higher levels of utility than the other instruments which were quite consistent. For the other four instruments the utility score if there was no urinary incontinence was 0.86, for slight urinary incontinence (as defined by the UDI) 0.8, for moderate urinary incontinence 0.72 and for problem or major incontinence a mean of 0.63 (Hawthorne & Sansoni 2004).

These studies show that, though there is great variability in attitudes towards the severity of the impact of urinary incontinence, on average urinary incontinence is considered a severe condition which has impact on a number of key domains of health.

The SAHOS results do not allow for comorbidity. The Canadian survey showed that comorbidity makes a large impact on the HUI3 scores (Shultz & Kopec 2003). Those with urinary incontinence alone had HUI3 scores of 0.82 (1 perfect health, - 0.36 worst possible state), but those who had urinary incontinence with other chronic conditions had an HUI3 score of 0.61, and the score for all people who had urinary incontinence was 0.64, i.e. the overall score is significantly affected by the other conditions that a person has in addition to urinary incontinence. Utility scores for people in the SAHOS with different severities of incontinence are listed below.

Utility scores are presented in Table 6.8 but do not allow for comorbidities, so much of the low utility level that people with severe incontinence record is due to other conditions, i.e. only part of the reduced utility is due to the incontinence. To properly adjust the utility scores for comorbidities a detailed analysis of the full 2004 SAHOS is needed. This analysis requires obtaining permission from all contributors to the 2004 SAHOS to use their data, and then doing a multivariate analysis of the full data set. It is recommended this analysis be done.

Table 6.8: Utility scores for people with different levels of urinary incontinence, 2004

ISSI	Average of AQOL	Average of EQ5D	AQOL relative to group without urinary incontinence	EQ5D relative to group without urinary incontinence	Average of AQOL & EQ5D
0	0.823	0.835	1.00	1.00	1.00
1 (Slight)	0.750	0.760	0.91	0.91	0.91
2 (Moderate)	0.661	0.688	0.80	0.82	0.81
3 (Severe)	0.449	0.499	0.55	0.60	0.57
4 (Very severe)	0.435	0.456	0.53	0.55	0.54
All persons	**0.792**	**0.805**	**0.96**	**0.96**	**0.96**

Source: AIHW analysis of 2004 SAHOS.

In the meantime, for this report, an interim comorbidity adjustment was made based on the Canadian study, i.e. the AQOL and EQ5D utility scores derived from the SAHOS are increased by the ratio 0.82/0.64 =1.28. So, for example, the 0.53 AQOL score for very severe urinary incontinence relative to those without incontinence is increased by 1.28 to give a score of 0.68, and similarly for the EQ5D the 0.55 is increased by 1.28 to give a score of 0.70. The average is 0.69, which, converted to the burden of disease severity weights used here, comes to 0.31. The severity weights used in this preliminary analysis are listed in Table 6.9.

Table 6.9: Provisional severity weights for different types of incontinence

Residential aged care	Severity weight
Profound problems with bladder/bowel control in residential aged care	0.35
Severe problems with bladder/bowel control in residential aged care	0.25
Difficulty with bladder/bowel control in residential aged care	0.15
Urinary incontinence in the community	
Very severe incontinence	0.31
Severe incontinence	0.24
Moderate incontinence	0.02
Slight incontinence	0
Faecal incontinence in the community	
Very frequent faecal incontinence	0.2
Frequent faecal incontinence	0.06
Flatus incontinence only	0

Note: Severity of problems in residential aged care defined by extent of need for assistance with bladder/bowel control as measured in the 2003 ABS Survey of Disability, Ageing and Carers. Severity of urinary incontinence is defined by ISSI (see Tables 6.4 and A6.2). Severity of faecal incontinence is defined by answers on SAHOS liquid and solid stool questions (see Tables 6.3 and A6.1, and questions X4 and X5 in Appendix B).

6.6 Healthy life lost due to incontinence

The overall healthy life lost due to incontinence is calculated by multiplying the number of people with incontinence by the severity weights for this condition (see Table 6.10 for prevalence of type of incontinence and severity).

Table 6.10: Prevalence of incontinence by type of incontinence, severity and sex, 2003

	Males	Females	All persons
Profound problems with bladder/bowel control in residential aged care	19,245	56,066	75,311
Severe problems with bladder/bowel control in residential aged care	14,093	33,908	48,001
Difficulty with bladder/bowel control in residential aged care	1,340	4,174	5,514
Total in residential aged care	**34,678**	**94,148**	**128,826**
Very severe incontinence	2,064	62,400	64,464
Severe incontinence	29,417	146,963	176,380
Moderate incontinence	123,196	599,923	723,120
Slight incontinence	621,872	2,255,690	2,877,562
Total urinary incontinence in households	**776,549**	**3,064,976**	**3,841,526**
Very frequent faecal incontinence	13,918	18,042	31,960
Frequent faecal incontinence	32,786	137,384	170,170
Total faecal incontinence in households	**46,704**	**155,426**	**202,130**
Flatus incontinence only	312,065	345,097	656,939
Total very severe, severe, moderate and frequent incontinence in households	**201,381**	**964,712**	**1,166,104**
Total very severe, severe and frequent incontinence in households[a]	**74,687**	**341,526**	**416,213**
Total very severe, severe, moderate and frequent incontinence	**205,882**	**939,755**	**1,145,637**
Total very severe, severe and frequent incontinence[a]	**109,365**	**435,674**	**545,039**

(a)   'Total very severe, severe and frequent incontinence in households' and 'Total very severe, severe and frequent incontinence' excludes those with 'flatus incontinence only'. It also counts only once the overlap group, i.e. 3,498 men and 23,263 women, who have both very frequent or frequent faecal incontinence and severe or very severe urinary incontinence.

Note: Severity of problems in residential aged care defined by extent of need for assistance with bladder/bowel control as measured in the 2003 ABS Survey of Disability, Ageing and Carers. Severity of urinary incontinence is defined by ISSI (see Tables 6.4 and A6.2) and severity of faecal incontinence is defined by answers on SAHOS liquid and solid stool questions (see Tables 6.3 and A6.1, and questions X4 and X5 in Appendix B).

Source: AIHW analysis of 2004 SAHOS and 2003 ABS Survey of Disability, Ageing and Carers confidentialised unit record file (CURF). Rates from 2004 SAHOS data applied to 2003 household population from ABS 2003 Survey of Disability, Ageing and Carers.

Overall it is estimated that about 117,700 healthy life years were lost in 2003 due to incontinence (Table 6.11). In the 75 years and over age group, 69,000 healthy life years were lost due to incontinence (Table 6.12). This compares to about 300,000 healthy life years lost due to all health conditions in 2003 in the 75 years and over age group (AIHW unpublished).

Incontinence is therefore responsible for about one-fifth of the healthy life years lost for those 75 years and over. In comparison, dementia is responsible for about one-fifth of healthy life years lost for this age group and hearing and vision disorders are responsible for about one-sixth of healthy life years lost (AIHW unpublished).

The estimates of the burden of disease due to incontinence in this study are made on a somewhat different basis to the estimates in the national burden of disease report (AIHW: Mathers et al. 1999). In that report, the burden of disease due to urinary incontinence included only urinary incontinence due to parity, overweight and obesity, constipation and surgery. Urinary incontinence due to bowel problems, urinary tract

Table 6.11: Healthy life years lost in 2003 due to different types of incontinence by sex

	Males	Females	All persons
Profound problems with bladder/bowel control in residential aged care	6,736	19,623	26,359
Severe problems with bladder/bowel control in residential aged care	3,523	8,477	12,000
Difficulty with bladder/bowel control in residential aged care	201	626	827
Total in residential aged care	**10,460**	**28,726**	**39,186**
Very severe incontinence	640	19,344	19,984
Severe incontinence	12,543	79,524	92,067
Moderate incontinence	2,464	11,998	14,462
Slight incontinence	0	0	0
Total urinary incontinence in households	**8,105**	**56,326**	**64,431**
Very frequent faecal incontinence	1,039	2,661	3,727
Frequent faecal incontinence	2,281	8,034	10,349
Total faecal incontinence in households	**3,320**	**10,695**	**14,076**
Flatus incontinence only	0	0	0
Total in households	**11,425**	**67,021**	**78,507**
Total	**21,885**	**95,747**	**117,693**

Note: Severity of problems in residential aged care defined by extent of need for assistance with bladder/bowel control as measured in the 2003 ABS Survey of Disability, Ageing and Carers. Severity of urinary incontinence is defined by ISSI (see Tables 6.4 and A6.2) and severity of faecal incontinence is defined by answers on SAHOS liquid and solid stool questions (see Tables 6.3 and A6.1, and questions X4 and X5 in Appendix B).

infection and other conditions is estimated as part of those other conditions, not as part of urinary incontinence. Faecal incontinence is not included as a separate condition, but as part of other conditions. Also the burden of disease study reports estimates on the burden due to the *incidence* of incontinence in 1996, whereas this study estimate is calculated from the *prevalence* of incontinence in 2003. These differences mean that the burden of disease estimates in this report for incontinence are not comparable with the 1996 study or the 2003 burden of disease estimates for urinary incontinence that will be published in 2006 as part of the national burden of disease study.

It should also be noted that part of the dementia burden of disease that is mentioned above is due to the incontinence burden borne by people with dementia, and part of the incontinence burden is due to dementia, especially for residents in aged care homes, where the comorbidity of dementia and incontinence is very common.

Table 6.12: Healthy life years lost in 2003 due to different types of incontinence by age group

	20–49	50–69	70–84	85+	65–74	75+	All
Profound problems with bladder/bowel control in residential aged care	224	1,686	10,945	13,504	2,420	22,796	26,359
Severe problems with bladder/bowel control in residential aged care	66	777	4,886	6,271	1,093	10,436	12,000
Difficulty with bladder/bowel control in residential aged care	5	51	330	442	77	720	827
Total in residential aged care	**294**	**2,514**	**16,161**	**20,217**	**3,590**	**33,951**	**39,186**
Very severe incontinence	5,109	7,643	2,051	5,181	2,704	6,627	19,984
Severe incontinence	17,752	42,457	21,986	9,872	18,523	24,239	92,067
Moderate incontinence	5,310	6,284	2,457	411	1,414	1,117	14,462
Slight incontinence	0	0	0	0	0	0	0
Total urinary incontinence in households	**27,405**	**54,005**	**25,430**	**15,193**	**22,641**	**31,983**	**122,034**
Very frequent faecal incontinence	2,378	4,894	1,920	1,156	1,471	2,196	10,349
Frequent faecal incontinence	688	2,205	0	833	1,201	833	3,727
Total faecal incontinence in households	**3,066**	**7,100**	**1,920**	**1,990**	**2,672**	**3,029**	**14,076**
Flatus incontinence only	0	0	0	0	0	0	0
Total in households	**30,471**	**61,105**	**27,350**	**17,183**	**25,313**	**35,012**	**136,110**
Total	**30,765**	**63,619**	**43,511**	**37,400**	**28,903**	**68,963**	**175,296**

Note: Severity of problems in residential aged care defined by extent of need for assistance with bladder/bowel control as measured in the 2003 ABS Survey of Disability, Ageing and Carers. Severity of urinary incontinence is defined by ISSI (see Tables 6.4 and A6.2) and severity of faecal incontinence is defined by answers on SAHOS liquid and solid stool questions (see Tables 6.3 and A6.1, and questions X4 and X5 in Appendix A).

6.7 Different health conditions and other factors associated with incontinence

What proportion of the prevalence and burden of incontinence can be associated with other health conditions and other factors? The factors associated with incontinence are covered in detail in Section 3.6. The 1996 burden of disease study estimated that, based on Chiarelli et al. (1999), about 60 to 70% of urinary incontinence was attributable to parity, overweight and obesity, constipation and surgery. Around 30–40% of the incontinence in middle-aged women is attributable to parity, whereas only 8% in older women is.

6.8 Projection of burden due to incontinence to 2031

As the population grows and ages there will be an increasing number of people living with incontinence and so the burden will grow. There is no reason to believe however, that, on average, the prevalence of incontinence in each age group will increase, as most of the factors that are associated with incontinence are expected to stabilise or decline. Birth rates are likely

to be stable or fall rather than increase. Rates of prostate operations are not expected to increase. Overweight and obesity are expected to increase and if this does occur will lead to an increase in incontinence rates. But this may well be balanced by a decline in other factors. So the estimates below assume stability in the rates of incontinence in each age group. The projected increases, then, in the burden of disease are due to population growth, and to ageing.

Healthy life years lost due to incontinence in people under 50 is expected to increase by 17% between 2003 and 2031 (Tables 6.13 and 6.14). In contrast for those aged 70–84 years, the increase will be 119%, and for those 85 years and over the increase will be 263%. The highest growth of the burden due to incontinence will occur in the period 2026 to 2031 where the growth is 15%, and the lowest growth will be 13% in the period 2021 to 2026. The higher growths occur in the periods when the population aged 85 years and over is growing the most.

Overall it is expected that the burden of incontinence will increase by 110% between 2003 and 2031, with 53% of the increase occurring in the 85+ population, 27% in the 70–84 years population, and 20% in those aged under 70 years.

Table 6.13: Healthy years of life lost due to incontinence by age group, persons, projected to 2031

Age group	2003	2006	2011	2016	2021	2026	2031
<49	30,765	31,526	32,989	33,989	34,851	35,444	35,856
50–69	63,619	68,596	78,457	86,682	94,005	97,765	101,744
70–84	43,511	45,515	49,881	58,661	69,948	83,514	95,250
85+	37,400	42,566	56,241	70,317	82,677	103,273	135,597
Total	**175,296**	**188,203**	**217,568**	**249,649**	**281,481**	**319,996**	**368,447**

Table 6.14: Percent change in healthy years of life lost due to incontinence by age group, persons, 2003–2031

Age group	Per cent change						
	2003–06	2006–11	2011–16	2016–21	2021–26	2026–31	2003–31
<49	2	5	3	3	2	1	17
50–69	8	14	10	8	4	4	60
70–84	5	10	18	19	19	14	119
85+	14	32	25	18	25	31	263
Total	**7**	**16**	**15**	**13**	**14**	**15**	**110**

Appendix A

Table A6.1: Scoring of solid stool/liquid stool of the Wexner sub scale, 2004

Do you leak, have accidents or lose control with liquid stool?	Do you leak, have accidents or lose control with solid stool?				
	Never/ Refused	Rarely, i.e. less than once in the past four weeks	Sometimes i.e. less than once a week, but more than once in the past four weeks	Often or usually, i.e. less than once a day but more than once a week	Always, i.e. more than once a day, or whenever you have a bowel movement
Never/refused	0	1	2	3	4
Rarely, i.e. less than once in the past four weeks	1	2	3	4	5
Sometimes i.e. less than once a week, but more than once in the past four weeks	2	3	4	5	6
Often or usually, i.e. less than once a day but more than once a week	3	4	5	6	7
Always, i.e. more than once a day, or whenever you have a bowel movement	4	5	6	7	8

Note: 'Occasional' faecal incontinence is a score of 1 or 2 on the solid and liquid sub-scale. 'Frequent' is a score of 3 or 4. 'Very frequent' is a score of 5 to 8.

Table A6.2: Scoring of incontinence symptom severity index (ISSI) measure

ISSI score		How much urine is lost each time?			
		None (0)	A few drops (1)	A little (2)	More (3)
How often is urine leakage experienced?	Never (0)	0	0	0	0
	Less than once a month (1)	0	1	2	3
	Several times a month (2)	0	2	4	6
	Several times a week (3)	0	3	6	9
	Every day or night (4)	0	4	8	12

Note: 'Slight' urinary incontinence is defined as a score of 1–2, 'moderate' as 3–6, 'severe' as 7–9 and 'very severe' as 10–12.

Appendix B

Questions from the SA 1994 Omnibus health survey

Many people are inconvenienced by urinary problems.

Could you please tell me if you experience these problems and, if so, how much you are bothered by them?

W1.   Frequent urination?

　　　Not at all……………………..

　　　Slightly……………………….

　　　Moderately…………………..

　　　Greatly……………………….

　　　Refused……………………..

W2.   Urine leakage related to feeling of urgency (a sudden desire to urinate)?

　　　Not at all……………………..

　　　Slightly……………………….

　　　Moderately…………………..

　　　Greatly……………………….

　　　Refused……………………….

W3.   Urine leakage related to physical activity, coughing or sneezing?

　　　Not at all……………………..

　　　Slightly……………………….

　　　Moderately…………………..

　　　Greatly……………………….

　　　Refused……………………….

W4.   Small amount of urine leakage (drops)?

　　　Not at all……………………..

　　　Slightly……………………….

　　　Moderately…………………..

　　　Greatly……………………….

　　　Refused……………………….

W5.   Difficulty emptying your bladder?

　　　Not at all……………………..

　　　Slightly……………………….

　　　Moderately…………………..

　　　Greatly……………………….

　　　Refused……………………….

W6. Pain or discomfort in the abdominal or genital area?
Not at all……………………..
Slightly…………………………
Moderately……………………..
Greatly…………………………
Refused…………………………

W7. How often is urine leakage experienced?
Never…………………………………….
Less then once a month…………………
Several times a month…………………..
Several times a week……………………
Every day or night………………………
Refused…………………………………...

W8. How much urine is lost each time?
None………………………….
A few drops…………………..
A little………………………...
More………………………….
Refused……………………....

X4. Do you leak, have accidents or lose control with solid stool?
Never……………………………………………
Rarely, i.e. less than once a week, but more
than once in the past four weeks………………………
Often or usually, i.e. less than once a day
but more than once a week…………………………….
Always, i.e. more than once a day, or
whenever you have a bowel movement……………..
Refused………………………………………………….

X5. Do you leak, have accidents or lose control with liquid stool?
Never……………………………………………
Rarely, i.e. less than once a week, but more
than once in the past four weeks…………………………..
Often or usually, i.e. less than once a day
but more than once a week……………………………..
Always, i.e. more than once a day, or
whenever you have a bowel movement………………
Refused…………………………………………………..

X6.   Do you leak, have accidents or lose control with gas (flatus or wind)?

Never…………………………………………………

Rarely, i.e. less than once a week, but more

than once in past four weeks…………………………..

Often or usually, i.e. less than once a day

but more than once a week…………………………….

Always, i.e. more than once a day, or

whenever you have a bowel movement………………

Refused…………………………………………………….

X7.   Do you leak stool if you don't get to a toilet in time?

Never…………………………………………………

Rarely, i.e. less than once a week, but more

than once in the past four weeks…………………………..

Often or usually, i.e. less than once a day

but more than once a week…………………………….

Always, i.e. more than once a day, or

whenever you have a bowel movement………………

Refused…………………………………………………….

X8.   Do you need to wear a pad to protect your underwear from stool?

Never…………………………………………………

Rarely, i.e. less than once a week, but more

than once in the past four weeks…………………………..

Often or usually, i.e. less than once a day

but more than once a week…………………………….

Always, i.e. more than once a day, or

whenever you have a bowel movement………………

Refused…………………………………………………….

X9.   Does stool leak so that you have to change your underwear?

Never…………………………………………………

Rarely, i.e. less than once a week, but more

than once in the past four weeks…………………………..

Often or usually, i.e. less than once a day

but more than once a week…………………………….

Always, i.e. more than once a day, or

whenever you have a bowel movement………………

Refused…………………………………………………….

X10. Does bowel or stool leakage cause you to alter your lifestyle?

Never……………………………………………………

Rarely, i.e. less than once a week, but more

than once in the past four weeks…………………………..

Often or usually, i.e. less than once a day

but more than once a week…………………………….

Always, i.e. more than once a day, or

whenever you have a bowel movement………………

Refused…………………………………………….