THE IMPACT OF INCONTINENCE IN CANADA A BRIEFING DOCUMENT FOR POLICY-MAKERS

COMMISSIONED BY:



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EXECUTIVE SUMMARY

The following policy brief has been commissioned by The Canadian Continence Foundation (TCCF) to help government address the unmet needs of Canadians living with incontinence. Incontinence is a chronic condition that continues to carry an enormous stigma. Incontinence can negatively affect all parts of a persons' life: social interactions, sex life, ability to work, travel, play sports, and participate in community life.

An extremely conservative estimate of the prevalence of incontinence in Canada indicates that 7% of Canadian women and 3.5% of Canadian men experience <u>moderate to severe</u> incontinence on a daily basis. Many studies suggest that the prevalence is significantly higher. Incontinence takes a serious emotional toll on those living with the condition. Women living with incontinence are more likely to suffer from depression than their continent peers. In one study, urinary incontinence, Alzheimer's disease and stroke were the three chronic conditions found to most adversely affect an individuals' health-related quality of life.

Incontinence is not only costly to individuals, but also to employers and the health care system. An individual with incontinence will spend \$1,400-\$2,100 per year on products. Furthermore, incontinence costs Canadian employers over 11.5 million person-days of lost work, and over \$2 billion in lost productivity. Incontinence will also add \$3.8 billion in health care costs to the Canadian system on a yearly basis. In total, incontinence will cost Canadians nearly \$8.5 billion annually.

Incontinence Costs in Canada	
Costs to the individual \$2,584,476,950	
Costs to the employer	2,103,292,400
Costs to the health care system	3,843,075,600
Total	\$8,530,844,950

The Canadian Continence Foundation recommends the following to government policy makers:

- Increase education about incontinence to both the public and health professionals.
- Include access to urinary incontinence treatments in wait time strategies.
- Increase funding for more innovative and novel, more cost-effective and less invasive treatments to be provided to people with stress incontinence.
- Fund the creation of community-based continence care clinics.
- Increased funding to allow access to conservative treatments and therapies.
- Include all drugs to treat urinary incontinence on provincial formularies.
- Increase the daily funding allotment for absorbent products in long term care facilities to allow the use of a new diaper as required.
- Increase funding for the purchase of absorbent products for those individuals living on fixed incomes.
- Increase funding for the purchase of single-use catheters for individuals living in the community and in institutions.
- Provide equal access to continence care and treatment across the country.



INTRODUCTION

This paper is intended to be a briefing document from The Canadian Continence Foundation (TCCF) to help policy-makers formulate evidence-informed policies to meet the unmet needs of Canadians living with incontinence. Incontinence is a chronic condition that carries an enormous stigma. Patients are often reluctant to discuss this issue with their family, friends and physician and, as a result, there is significant under-reporting of symptoms. There are over 1 million cases of incontinence reported but The Cameron Institute (TCI) has estimated for TCCF that the real figure is closer to 3.5 million – 10% of the Canadian population in 2014.¹

Incontinence can negatively affect all parts of a persons' life: social interactions, sex life, ability to work, travel, play sports and participate in community life. In the words of one gynecologist working in Ontario:

"I am a Gynecologist that specializes in urinary incontinence in women. This is a common and distressing problem for women after childbirth. Many of my patients tell me that they can no longer exercise or play with their children because of the urinary leakage. Some patients claim that they no longer have relations with their spouse because they leak urine whenever they have relations. Other patients tell me they are on antidepressants for this problem."²

The problem is further compounded by a lack of family physician knowledge of the condition and of current available treatments and products. This combination of stigma and lack of knowledge has led to the overall under-reporting of the condition. There are few accurate Canadian statistics of the overall prevalence of the condition.

This paper will bring together the most up-to-date information related to incontinence in order to provide policy makers with a more accurate view of this chronic condition in Canada. The paper will delve into the stigma and emotional consequences of incontinence, provide an overview of the various types of incontinence, describe the financial implications of the condition for both the individual and society, and will conclude with a discussion of a variety of solutions for decision makers in Canada to consider.

This brief will highlight to policy makers the needs of a large and growing population, and shed light on the many complex issues that those living with incontinence face on a daily basis. The Canadian Continence Foundation's recommendations for positive action and policy change are included at the end of this paper.

¹ Incontinence: The Canadian Perspective (December 2014), The Canadian Continence Foundation: 3, 11. ² Kalbfleisch, R Letter, Ministry of Health and Long Term Care, Ontario, November 10, 2008



PREVALENCE

Determining the prevalence of incontinence in Canada is difficult. Estimates in studies (*see Table 1*) vary from 2% to 50% of the population, depending upon the study, research method and questions posed. For example, asking the question "Are you incontinent?" will garner a dramatically different number of positive responses than the question "Do you suffer from occasional leakage of urine?"

This problem is further compounded by the stigma and embarrassment associated with the condition. Very few, only about 25% of women and men living with incontinence seek professional help; they either assume it is a normal aspect of aging or are simply too embarrassed to bring their condition to the A conservative estimate of the prevalence of incontinence suggests that **7% of Canadian women experience some form of <u>moderate to severe</u> incontinence** on a daily basis. Some studies indicate that the prevalence could be significantly higher.

The stigma and embarrassment often associated with the condition make it difficult to accurately assess the true prevalence.

are simply too embarrassed to bring their condition to the attention of their health care professional.³

There is urinary incontinence (UI), fecal incontinence (FI) and overactive bladder (OAB). For urinary incontinence there is stress incontinence (SUI), urge incontinence (UI), overflow incontinence (OI), mixed incontinence (MI), functional incontinence, and nocturnal enuresis.⁴ There are many levels of incontinence, from mild to moderate to severe and very severe. Individuals who have one episode of urine leakage a week may be considered incontinent, but individuals who experience several episodes a day will require different coping strategies, must spend more money on products, and will experience more profound emotional consequences. However, people experiencing any level of incontinence share some of the same emotional consequences.

In active elderly women, "UI may be transient in up to one third of community-dwelling elderly and up to 50% of inpatients (in hospitals and long-term care faculties), depending on a variety of risk

"Clearly there is still a long way to go in making patients and society aware of the fact that UI is a disorder, which can and should be treated. Consequently, patients must be encouraged to report their problem, while health care providers should raise the issue on routine exams in risk groups."

- Ortiz C (2004) Int. J Gynaecol Obstet 86 Suppl 1:S6-16.

factors."⁵ The surveys and studies, that are reviewed below, report findings as low as 16% of women reporting monthly incontinence, and as high as 65% of women reporting weekly incontinence. In community dwelling middle-aged women prevalence for incontinence ranged from 12 to 42%; among older adults, prevalence ranged from 17 to 55%. SUI predominated in younger women; UI and MI predominated in older women.⁶ Table 1 provides a non-exhaustive overview of the more cited studies that report prevalence of incontinence. The data suggests that a range of prevalence values exist, depending on how incontinence is defined, as well as the age and gender of the study group. Not a reason to ignore incontinence though.

³ Reymert J, Hunskaar S (1994) Why do(sic) only a minority of perimenopausal women with urinary incontinence consult a doctor? *Scand J Public Healt* 12(3):180-183.

⁴ See, Incontinence: The Canadian Perspective (December 2014), The Canadian Continence Foundation: 4-5.

⁵ Viktrup L, Koke S, Burgio KL, Ouslander JG (2005) Stress urinary incontinence in active elderly women *South Med J* 98(1):79-89

⁶ Thom, D (1998) Variation in estimates of urinary incontinence prevalence in community: effects of differences in definition, population characteristics, and study type *J Am Geriatr Soc* 46(4):473-80.



Table 1: Reported prevalence of incontinence	
Study	Conclusion/statement
McDowell, I (1998) Analysis of urinary and faecal incontinence in the Canadian population using data from the Canadian Study of Health and Aging Ottawa: Health Canada.	 Slightly more than 5% of men 7% of the women experienced daily urinary incontinence. After age 84, daily urinary incontinence noticeably increased (men 14.8% and women 23.5%) For seniors in institutions, daily urinary incontinence was nine to ten times higher (men 36.8% and women 36.9%) than among seniors residing in the community.
Thom, D (1998) Variation in estimates of urinary incontinence prevalence in community: effects of differences in definition, population characteristics, and study type <i>J Am Geriatr Soc</i> 46(4):473-80.	"Estimates of urinary stress incontinence vary in the literature from 4% to 50%."
Milsom I (2000) The prevalence of urinary incontinence <i>Acta Obstet Gynecol Scand</i> 79(12):1056-9.	Urinary incontinence is one of the most important health problems confronting modern society. Population studies have demonstrated that approximately 10% of all women suffer from urinary incontinence.
Herschorn S, Corcos J, Gajewski J, Schulz J, Ciu E (2003) Canadian Urinary Bladder Survey: Population-Based Study of Symptoms and Incontinence <i>Neurology and Urodynamics</i> 22(5).	 The Canadian Bladder survey provided the following age- stratified data (% of men and women with any degree of incontinence): 18-40 yrs: 10% men, 16% women 41-64 yrs: 16% men, 33% women 65+ yrs: 30% men, 55% women
Fedorkow DM (2003) Prevalence of urinary incontinence, pelvic organ prolapse and anal incontinence in women, as in Drutz HP, Herschorn S, Diamant NE, eds. <i>Female pelvic medicine and</i> <i>reconstructive pelvic surgery</i> London: Springer, 11- 24	Nearly 9% of all respondents reported urinary incontinence, 56% of whom were below 55 years of age. Over half of the respondents had never consulted a physician about their incontinence,
Milne JL, Moore KN (2003) An exploratory study of continence care services worldwide <i>Int J Nurs</i> <i>Stud</i> 40(3):235-47.	UI is a complex symptom of underlying disorders that affects over one and a half million Canadians. (4.7% based on 2006 Canada Census Data; population of 31.6 million Canadians.)
Fultz N, Girts T, Kinchen K, Nygaard I, Pohl G, Sternfeld B (2005) Prevalence, Management and Impact of Urinary Incontinence in the Workplace <i>Occupational Medicine</i> 55:552-557.	 37% of respondents (women aged 18-60 years) reported urine loss during the last 30 days. Of these: 44% lost urine at least monthly while at work; 21% at least weekly; 8% daily Remaining reported less than monthly.
Miller, D (2007) Office management of stress incontinence: current and future role <i>Clin Obstet Gynecol</i> 50(2):376-82.	Approximately 11 million women in the United States may be regularly incontinent. (3.6% of US population based on Census figures of 305 million US residents)
Farage MA, Miller KW, Berardesca E, Maibach HI (2008) Psychosocial and societal burden of incontinence in the aged population: a review Arch Gynecol Obstet 277(4):285-90	Most adults past the age of 65 suffer incontinence on some level. (100% in adults 65+ years).



Taylor DW, Weir M, Cahill JJ, Rizk DEE (2013) The Self-reported Prevalence and Knowledge of Urinary Incontinence and Barriers to Health Care- Seeking in a Community Sample of Canadian Women American Journal of Medicine and Medical Sciences 3(5) 97-102.	In a study of women 20 years of age or over, living in a mid-sized urban community 36.5% reported having urinary incontinence. Of these incontinent individuals only 55.8% sought medical advice.
Taylor DW, Cahill JJ, Rizk DEE (2014) Denial, Shame and Acceptance: Generating Base-line Knowledge and Understanding of Fecal Incontinence amongst Long-term Care Residents and Care Providers <i>Public Health Research</i> 4(1) 13-18.	Although all residents studied in several long-term care facilities were identified by staff as having fecal incontinence, less than 1 in 5 self-reported being fecally incontinent. More than half of residents did not seek care for their fecal incontinence because of embarrassment or low expectations of what could be done; those who did seek care waited for 6 months

While it is clear that prevalence is difficult to determine, there can be no doubt that there is a large number of Canadians living with incontinence. Incontinence ranges from mild cases, where women and men experience some urine leakage each month, to very severe cases where the individual has lost all bladder and/or bowel control. What is clear, though, is the prevalence of incontinence increases significantly with age.

For the purposes of economic and cost calculations that will be performed in later sections of this paper, the general and conservative estimates that 10% of Canadians experience some form of incontinence, and 7% of women experience moderate to severe leakage of urine on a daily basis. Although, urinary incontinence has not been investigated in men as thoroughly as in women, the evidence shows that the male-to-female ratio is about 1:2 therefore, the prevalence of men in Canada will be estimated to be 3.5% experiencing some form of moderate to severe leakage of urine on a daily basis.⁷

⁷ Strothers L, Thom D, Calhoun E (2004) Urinary incontinence in men, as in: Litwin MS, Saigal CS eds. *Urologic Diseases in America* US Department of Health and Human Services, Public Health Service, NIH, National Institute of Diabetes and Digestive and Kidney Diseases, Washington DC: US Government Publishing Office, NIH Publication No 04-5512



EMOTIONAL AND PSYCHOLOGICAL CONSEQUENCES OF INCONTINENCE

Incontinence takes a serious emotional toll on those living with the condition. Women living with incontinence are more likely to suffer from depression than their continent peers. The results of one study revealed that urinary incontinence, Alzheimer's disease and stroke were the three chronic conditions that most adversely affected an individuals' health-related quality of life.

Many studies have outlined the emotional and psychological consequences of incontinence. A non- exhaustive summary is provided in Table 2 below:

Table 2: Emotional, Psychological & Social Impacts of Incontinence		
Study	Findings/Conclusion	
Contreras Ortiz O (2004) Stress Urinary Incontinence in the gynecological practice Int. J Gynaecol Obstet 86 Suppl 1:S6-16	UI is a common problem, affecting women in all age groups, and has devastating effects on their social, professional and family life.	
Fultz N, Girts T, Kinchen K, Nygaard I, Pohl G, Sternfeld B (2005) Prevalence, Management and Impact of Urinary Incontinence in the Workplace <i>Occup Med-c</i> 55:552-557	 Of women with severe or very severe symptoms: 45% reported a negative impact on concentration; 64% on physical activity; 77% on self confidence; 74% on completion of tasks 88% reported negative impact in at least one of the four areas above 4% indicated that UI had affected personal decisions about employment; 2% changed the type of work they do; 0.9% decreased the number of hours worked; and 0.8% indicated they no longer work outside the home. 	
Monz B, Pons ME, Hampel C, Hunskaar S, Quail D, Samsioe G, Sykes D, Wagg A, Papanicolaou S (2005) Patient-reported impact of urinary incontinence – results from treatment seeking women in 14 European countries <i>Maturitas</i> 52 Suppl 2:S24-34.	The greatest patient-reported impact of UI symptoms on activities was on exercise, ith more than 45% of patients (with moderate to severe incontinence) moderately to totally limited in this activity. In most countries, more than 60% of the women reported that they were moderately to extremely bothered by their UI symptoms.	
Viktrup L, Koke S, Burgio KL, Ouslander JG (2005) Stress urinary incontinence in active elderly women <i>South Med J</i> 98(1):79-89.		
Vigod, S, Steward DE (2006) Major Depression in Female Urinary Incontinence <i>Psychosomatics</i> 47:147-151.	The prevalence of depression was 15.5% in women with urinary incontinence (30% in women ages 18–44) and only 9.2% in women without urinary incontinence.	



Subak LL, Brown JS, Kraus SR, Brubaker L, Lin F, Richter HE, Bradley CS, Grady D, and Diagnostic Aspects of Incontinence Study (DAISy) Group (2006) The "costs" of urinary incontinence for women <i>Obstet Gynecol</i> 107(4): 908–916.	The health related quality of life impact of incontinence is similar to that observed with other chronic medical conditions like osteoarthritis, chronic obstructive pulmonary disease, and stroke. Our study confirms findings of others that women with incontinence perceive substantial benefits from a
	reduction in the number of incontinence episodesWomen are willing to pay up to \$900 per year for 100% improvement in incontinence, which is similar to the willingness to pay for improvement of migraine headaches or gastroesophageal reflux.
Hägglund D, Ahlström G (2007) The meaning of women's experience of living with long-term urinary incontinence is powerlessness <i>J Clin</i> <i>Nurs</i> 16(10):1946-54.	The meaning of women's experience of living with UI is powerlessness.
Herbruck LF (2008) Stress Urinary incontinence: prevention, management, and provider education <i>Urol Nurs</i> 28(3):200-6.	The costs of urinary incontinence are financially and socially substantial to those who are living with its effectsprevention of these disorders or management at the earliest possible level is indicated.
Farage MA, Miller KW, Berardesca E, Maibach HI (2008) Psychosocial and societal burden of incontinence in the aged population: a review <i>Arch Gynecol Obstet</i> 277(4):285-90.	" significant and often devastating impact on the physical and emotional health of the patient. Incontinence in the older adult is a humiliating and disabling disorder, which causes substantial stress, depression, and limitation. It can impede interpersonal relationships, decrease sexual function, and increase the risk of debilitating falls, institutionalization and even increase mortality."
Subak LL, Brubaker L, Chai TC, Creasman JM, Diokno AC, Goode PS, Kraus SR, Kusek JW, Leng WW, Lukacz ES, Norton P, Tennstedt S, Urinary Incontinence Treatment Network (2008) High costs of urinary incontinence among women electing surgery to treat stress incontinence <i>Obstet Gynecol</i> 111(4):899-907.	Urinary incontinence is associated with substantial costs. Women spent nearly US\$750 per year out of pocket for incontinence management, had a significant decrement in quality of life, and were willing to pay nearly US\$1,400 per year for a cure.

One of the main reasons that women and men with incontinence suffer in silence – fearing even to discuss the issue with their physician – is the great embarrassment and shame that the condition engenders. The internet, with its myriad of chat rooms and anonymous fora devoted to discussing the experiences of people living with incontinence provides a window into the suffering that incontinence produces. Common themes that emanate from these groups include:

- Questions about embarrassment, and the stigma associated with being incontinent;
- Use of diapers
- Fear that family members, work colleagues, and friends will discover that a person is experiencing incontinence.
- Ways to make plastic pants last longer
- Questions about how to deal with the sudden leakage of urine



Many sites encourage members to share their stories so that they can help each other with their incontinence. A few of these stories are reproduced below, to help the continent understand to a small degree what these individuals deal with:

"I was diagnosed with rectal cancer at age 47. It's been almost nine years since finding that tumor which completely changed my life. I had radiation, chemo and surgery where I received a temporary colostomy. After that was reversed, I was left with no control of my bowels. I know I should be happy that I'm beating the cancer but there are times I wish I didn't. For the first year and a half I was almost a virtual shut-in, only venturing out of the house when I absolutely had to. Then there was the constant fear of having an accident. I was going to the bathroom some thirty times a day and I had to get to one fast."

"I am a 45 year old mother of 3, and have had incontinence for over 20 years now. It controls me. I so wish it didn't... but it does. I have suffered from depression over this. I used to teach Sunday school and sing in church, but I don't even go there very much anymore – after singing one day and having an accident while behind the pulpit. I very ashamedly walked home and while in the shower begged God for a reason why. I don't expect an answer, however, I do believe that everything happens for a reason and we have to try to live life to its fullest in whatever capacity that is."

"My doctors have been great but they are at a loss as well. I don't know where to turn anymore but I try to keep on going in life. I know I am not alone but sometimes I feel like no one understands. Thanks for this website, I cried when I read these stories. I don't feel as alone anymore."

TYPES OF INCONTINENCE

Incontinence has been defined by the International Continence Society as the involuntary leakage of urine and /or feces. Urinary incontinence is the more common type of incontinence.

The following are the main types of urinary incontinence:

- Stress Urinary Incontinence (SUI) the leaking of urine associated with coughing, sneezing, straining, exercise or any other type of exertion; 50% of individuals with urinary incontinence have SUI.
- **Urge Incontinence (UI)** the leaking of urine associated with the sudden uncontrollable urge to empty the bladder; UI is a key symptom of the overactive bladder syndrome (OAB).
- Overflow incontinence (OI) the constant leaking or dribbling from a full bladder.
- Mixed incontinence (MI) a combination of stress and urge incontinence.



Other types of incontinence include:

- Functional incontinence denotes incontinence related to causes outside of the urinary system i.e. a person may have trouble controlling urine, but this problem is exacerbated by functional factors, such as physical barriers to the toilet, a lack of mobility, a degree of unwillingness to comply, medication issues, etc.; this type of incontinence may be managed by addressing the functional factor, such as improving the patient's mobility, motivating the patient, improving access to the toilet, modifying meds, etc.
- **Nocturnal enuresis** bed-wetting in children who are old enough to be "potty trained" and adults who have loss of control at night.

URINARY INCONTINENCE

<u>TERMS</u>

Bladder – the urine storage reservoir

Urethra – the passage through which the bladder is emptied.

Supportive structures and sphincters – these are responsible for preventing leakage.

TREATMENTS FOR INCONTINENCE

A number of treatment options are available for individuals with incontinence, and descriptions of these treatments are provided in detail in other papers;⁸ they are described briefly below:

Behavioral Treatments - conservative measures and are the first treatment option for patients with stress and urge incontinence. Behavioral treatments include bladder retraining, education, and dietary modifications.

Physical Therapy - includes pelvic floor muscle exercises, biofeedback, and electrical stimulation.

Intermittent Self-Catheterization - involves passing a small disposable catheter through the urethra and into the bladder to empty it.

Injectable Treatments - bulking agents, such as collagen, to narrow the urethral walls has been shown to be successful for SUI and is minimally invasive; botulinum toxin therapy (Botox) injections have been used to treat urge incontinence.

Drug Therapies - anticholinergic drugs, tricyclic antidepressants, and combined anticholinergics and smooth muscle relaxants are used for treating overactive bladder.

Surgical Treatments - two main surgical treatments for SUI used in Canada: retropubic suspension (Burch procedure) and sling insertion (mid-urethral sling). The Burch procedure has good long term efficacy for the treatment of SUI; slings provide support under the bladder neck and/or urethra, and can be made from a number of different materials. The traditional harvesting of a patient's own tissue (fascia) over the abdominal muscles has given way to the more minimally invasive outpatient technique of inserting a mesh sling to help support the bladder neck. A technique that uses the pelvic

⁸ Incontinence: The Canadian Perspective (December 2014), The Canadian Continence Foundation: 3, 11; Miller, D (2007) Office management of stress incontinence: current and future role *Clin Obstet Gynecol* 50(2):376-82.



bone, or transobturator area, to support the mesh rather than using the abdominal wall is called the transobturator sling. This procedure is also a minimally invasive outpatient procedure.

A surgical procedure reserved mostly for men, is the insertion of an artificial urinary sphincter (AUS). An AUS is a device made of silicone rubber that has an inflatable cuff that fits around the urethra close to the point where it joins the bladder. The cuff is inflated to keep urine from leaking and when the individual wishes to urinate, he deflates the cuff, allowing the urine to drain out.

Sacral Nerve Stimulation (SNS) - a pacemaker-type device is implanted to electrically stimulate the sacral (lower spinal) nerves in an attempt to improve bladder function and manage incontinence.

PRODUCTS AND DEVICES FOR THE MANAGEMENT OF INCONTINENCE

Absorbent Products - diapers, panty liners and pads are the most commonly used incontinence products, and can be used to help manage any type of incontinence.

Collection Devices - internal devices such as indwelling urethral catheters and suprapubic catheters, as well as external devices, such as condom catheters, can be used to manage severe incontinence.

Mechanical Devices - insertion of a pessary - a rubber device that is inserted into the upper vagina, which presses on the urethra and holds up the bladder neck and uterus - is a nonsurgical method of treating certain problems caused by weak pelvic muscle; in men, soft external penile clamps (such as the Cunningham clamp) can be used to protect against severe leakage.

FINANCIAL AND ECONOMIC IMPACT OF INCONTINENCE

Incontinence costs Canadians over \$8.5 billion annually.

Incontinence is costly to individuals, employers and the health care system. An individual with incontinence will spend \$1,400 - \$2,100 per year on products. Incontinence costs Canadian employers over 11.5 million person-days of lost work, and over \$2.5 billion. Incontinence also adds \$3.84 billion in health care costs to the Canadian system on a yearly basis.

A number of studies have attempted to determine the overall economic implications of incontinence. Herschorn *et.al.* of the Canadian Urinary Bladder Survey showed that 21.8% of Canadians 18 or older had bladder problems, with a cost to Canadians of \$1.5 billion per year.⁹ Viktrup *et. al.* suggested that in 2003, the estimated total economic cost of incontinence in the United States was \$12.02 billion.¹⁰ In 2014 Canadian dollars that would amount to \$2.59 billion.¹¹

International Continence Society accessed at http://www.icsoffice.org/publications/2003/pdf/049.pdf

¹⁰ Viktrup L, et.al. *Stress urinary incontinence in active elderly women* South Med J 2005 Jan.98(1):79-89

¹¹ The discount rate for healthcare is 5% (Canadian Agency for Drugs and Technology in Health); CAD-USD exchange rate of

^{1.1326,} December 1, 2014, accessed at http://www.xe.com/; Canada's population is approximately 1/9th of that of the US.



Keeping in mind that Canada's population is ageing, coupled with the fact that the prevalence of incontinence increases with age, it is quite reasonable to assume that costs associated with incontinence will rise and incontinence will become an increasing burden on society.

The following section determines more specific cost breakdowns to the individual, the employer and society, and the health care system.

Cost to the Individual

In its paper, *Incontinence: The Canadian Perspective*, TCCF has estimated that each year a senior, with incontinence living at home, will spend an average of \$1,400 to \$2,100 on incontinence supplies. These costs, which are paid out-of-pocket by individuals with u rinary incontinence, or their families, include:

- Absorbent Products;
- Additional laundry expenses;
- Additional dry cleaning expenses;
- Additional toilet paper and paper towels;
- Homecare services; and
- Medications not covered by healthcare plans.

According to the 2011 Census, the number of women living in Canada was 17,062,460. The number of women over the age of 15 was 14,326,215. As 7% of women over the age of 15 years experience moderate to severe incontinence, the number of Canadian women living with incontinence in Canada was slightly over 1 million. Therefore on a yearly basis, Canadian women spend over \$1.7 billion on products to manage their incontinence. In 2011, the number of men living in Canada over the age of 15 years was 13,543,125. As 3.5% of men over the age of 15 years experience moderate to severe incontinence, the number of Canadian men living with incontinence in Canada is close to half a million (474,009). Therefore, on a yearly basis Canadian men spend over \$800 million on incontinence supplies. In total, Canadian men and women spend over \$2.5 billion on incontinence products each year.

Table 3: Costs of Incontinence to the Individual	
Women age 15+ years in Canada	14,326,215
Women aged 15+ years with incontinence (7%)	1,002,825
Cost of incontinence per year (average)	\$1,750
Out of pocket costs to Canadian women	\$1,754,961,200
Men age 15+ years in Canada	13,543,125
Men aged 15+ years with incontinence (3.5%)	474,009
Cost of incontinence per year (average)	\$1,750
Out of pocket costs to Canadian men	\$829,515,750
Total out of pocket Costs to Canadians due to incontinence	\$2,584,476,950



Cost of Lost Productivity

People living with incontinence who remain in the workforce find it stressful to manage their incontinence while at work. Some manage by using frequent bathroom breaks; others make extensive use of absorbent products. Still others chose to work from home, or will change their job in order to find a career that will allow them to work around their condition. When employees show up for work but, because of medical conditions, do not put in a full day's work is called "presenteeism". Chronic conditions such as depression, migraine headaches, lower back pain, and incontinence may contribute to presenteeism.

"Chronically ill workers take sick days, reducing the supply of labour – and, in the process, GDP [Gross Domestic Product]. When they do show up for work to avoid losing wages, they perform far below par – a circumstance known as 'presenteeism'... Output loss (indirect impacts) due to presenteeism (lower productivity) is immense – several times greater than losses associated with absenteeism."¹²

For incontinent individuals who remain at work, their condition may lead to a decrease in concentration, performance of physical activities, self confidence and ability to complete tasks without interruption.

It is difficult to accurately determine the exact amount of lost productivity that can be attributed to incontinence. However, some studies do shed some light on the issue. Wu *et. al.* reported that employees with over active bladder (OAB) had 2.2 more lost work days as the result of medically related absenteeism and 3.4 more days as the result of disability compared with employees without OAB.¹³ Collins *et.al.* discovered "the associated absenteeism by chronic condition ranged from 0.9 to 5.9 hours in a 4-week period, and on-the-job work impairment ranged from a 17.8% to 36.4% decrement in ability to function at work."¹⁴

"Leakage or loss of urine is a bothersome symptom that can diminish quality of life and disrupt daily routines. Mounting evidence suggests that employees cannot do their best work when distracted by relatively benign health concerns like allergies, migraines or back pain...Co-workers may not be aware of the prevalence and impact of involuntary urine loss because it is not freely discussed and can often be concealed. Behaviors such as frequent trips to the toilet or lapses in concentration might be misattributed to poor work habits or insufficient commitment to the organization. From the employee's perspective, this could limit opportunities for advancement and diminish job satisfaction. From the employer's perspective, 'presenteeism' may be a greater drain on productivity than is absenteeism."¹⁵

¹² Partnership to Fight Chronic Disease *The 2008 Almanac of Chronic Diseases* Milken Institute accessed at http://www.fightchronicdisease.org/resources/almanac.cfm]

¹³ Wu E, Birnbaum H, Marynchenko M, Mareva M, Williamson T, Mallett D (2005) Employees with overactive bladder: work loss burden *J Occup Environ Med* 47(5) 439-446.

¹⁴ Collins JJ, Baase CM, Sharda CE, Ozminkowski RJ, Nicholson S, Billotti GM, Turpin RS, Olson M, Berger ML (2005) The assessment of chronic health conditions on work performance, absence and total economic impact for employers *J Occup Environ Med* 47(6) 547-557.

¹⁵Fultz N, Girts T, Kinchen K, Nygaard I, Pohl G, Sternfeld B (2005) Prevalence, Management and Impact of Urinary Incontinence in the Workplace *Occupational Medicine* 55:552-557.



Table 4: Labour Force by Gender, 2013		
Men 9,295,700		
Women	8,435,400	
Total 17,731,100		

To quantify the cost of incontinence to employers, in terms of absenteeism and presenteeism, the following assumptions were made:

- 7% of the Canadian working female population suffers from incontinence on a daily basis.
- As the ratio of women-to-men with incontinence is generally 2:1, 3.5% of the Canadian working male population suffers from incontinence on a daily basis.
- Incontinence is a chronic condition that affects individuals in their work life to a similar degree as other chronic conditions.
- According to Statistics Canada, the number of days lost due to Illness or disability in 2006 was 7.6 days per worker.
- Individuals with incontinence are affected in a similar manner as those with other chronic conditions, therefore one can extrapolate that these individuals were absent 7.6 days each year.
- According to the Milken Institute, presenteeism represents 4/5th of all indirect costs of chronic conditions. Extrapolating therefore would indicate that presenteeism would account for another 30.4 days of lost productivity per year. In order to remain conservative in estimates, we will attribute only an additional 5 days of lost work to presenteeism due to incontinence.
- Incontinence therefore costs employers a total of 12.6 days of lost work for each person with incontinence.
- According to Statistics Canada, the number of women employed in the labour force in 2013 was 8,435,400.
- According to Statistics Canada, the number of men employed in the labour force in 20 was 9,295,700.
- According to Statistics Canada, the average weekly earnings in September 2013 were \$911.35.

In summary, as Table 5 below shows, incontinence costs Canadian employers over 11.5 million person-days of lost work, and over \$2 billion. Bringing the condition out of the closet of shame, denial and begrudging acceptance, enhancing access to treatments, providing more treatment options, and encouraging individuals to talk about the condition with their health care providers will help alleviate some of these costs and improve productivity.



Table 5: Calculation of Cost of Incontinence to Employers		
Women in labour force	8,435,400	
Women with incontinence in labour force (7%)	590,478	
Men in labour force	9,295,700	
Men with Incontinence in work force	325,350	
Total employees with incontinence	915,828	
Absenteeism due to incontinence (7.6 days)	6,960,293 days	
Presenteeism due to incontinence (5 days)	4,579,140 days	
Total Days lost due to incontinence	11,539,433 days	
Cost of 1 day of labour (\$911.35/5)	\$182.27	
Total Cost of Incontinence to Employers	\$2,103,292,400	

Costs of Health Care

Individuals living with incontinence will require increased access to health care services. They will require increased numbers of visits to nurse continence advisors, physicians and specialists; those with overactive bladder may require medications, those with stress urinary incontinence may require surgery, and the elderly may require earlier admittance to long-term care facilities.

Physician visits will be required to diagnose the condition, to develop management strategies, and, if necessary, to refer to specialists. If a patient is referred to a specialist, then increased physician costs will also include time spent by the specialist on assessment of the patient, evaluation for treatment, implementation of treatment and follow up. Wagner *et.al.* concluded that individuals with overactive bladder (OAB) reported 20% more visits to the physician than those without OAB.¹⁶

A report released by the Ministry of Health and Long-term Care in Ontario concluded "Urinary incontinence...was identified as 1 of the key predictors in a senior's transition from independent community living to admission to a long-term care (LTC) home. For caregivers, UI is often a major driver in the decision to institutionalize elderly family members and if often cited as the "tipping point". Citing earlier studies, "the authors determined that 10% of all admissions for men and 6% of all admissions for women were attributable solely to UI." ¹⁷ Incontinence increases the risk of hospitalization by more than 30%. One study reported that incontinence doubled the risk of admission to a nursing home, independent of age and the presence of other diseases.¹⁸

Examining the incremental costs associated with caring for individuals with incontinence in long term care facilities versus those without incontinence, Shih *et.al.* calculated that the incremental labour cost (per shift) of caring for those residents with occasional incontinence was \$3.31, and \$5.16 for those with frequent incontinence (both in 2002 US dollars). Combining patients with frequent UI (more than 70% of all UI patients) and occasional UI, the weighted average incremental cost per shift was \$4.52. With incremental labor costs of \$4.52 per resident per shift, UI costs an additional \$13.57

¹⁶ Wagner TH, Hu TW, Bentkover J, LeBlanc K, Steward W, Corey R, Zhou Z, Hunt T (2002) Health-related consequences of overactive bladder *Am J Manag Care* 8(19 Suppl) 598-607.

¹⁷ Medical Advisory Secretariat (2008) *Behavioural interventions for urinary incontinence in community-dwelling seniors: an evidence-based analysis* Ontario Health Technology Assessment Series, Toronto: Government of Ontario, 8(3).

¹⁸ Viktrup L, Koke S, Burgio KL, Ouslander JG (2005) Stress urinary incontinence in active elderly women *South Med J* 98(1) 79-89.



per day to treat incontinence per resident per day, or \$4,957 annually per resident.¹⁹ In 2014 Canadian dollars the equivalent would be \$10,082 annually per resident with incontinence. This is also a very conservative figure as wages for comparable healthcare jobs are generally higher in Canada than in the United States; based upon research conducted for this paper a more realistic figure would be \$13,409 per day per long-term care resident with incontinence.²⁰

Table 7 provides an outline of direct health care costs associated with urinary incontinence:

Table 7: Direct Costs Associated with Incontinence, 2014 estimates	
Average Direct Medical Costs/person ²¹	\$10,409 annually
Increased visits to family physician ²²	\$77.20/visit
Increased nursing home costs (above)	\$10,082 annually
Daily LTC Facility rate (basic) ²³ Nursing & Personal Care: \$90.71 Program & Support Services: \$9.05 Raw Food: \$7.87 Other Accommodation: \$53.12 	\$160.75/resident/day ²⁷

In order to calculate the increased costs of incontinence to the health care system (see Table 8), and in an attempt to remain as conservative as possible, the Birnbaum claims data was used. This model does not include the increased costs related to early admission to long term care facilities, or increased costs to the long-term care facilities due to caring for those with incontinence. Therefore incontinence costs the health care system a *minimum* of \$3.84 billion/year.

Cost Summary

Table 9 outlines increased costs to Canadians due to incontinence. Readers should note that the costs outlined in this paper are *conservative* estimates. Other costs could also be taken into account, for example: "(*o*)*pportunity costs incurred through early retirement may be an important aspect of the indirect costs of urinary incontinence*".²⁴ Furthermore, women with incontinence are more likely to also suffer from depression which will also increase costs to the individual and the health care system.²⁵ These additional costs to the individual, society and the health care system have not been included in the estimates below.

²² Based upon a family physician consultation in Ontario as of May 1, 2014, as accessed at

¹⁹ Shih YC, Hartzema AG, Tolleson-Rinehart S (2003) Labor costs associated with incontinence in long term care facilities *Urology* 62(3) 442-6.

²⁰ A comparison by The Cameron Institute of published national wage averages for non-registered nursing home aides showed Canadians making approximately 33% per hour more than their American counterparts, as accessed at http://www.payscale.com/research/CA/Job=Health_Care_Aide/Hourly_Rate, and, http://www1.salary.com/Certified-Nursing-Assistant-Nursing-Home-hourly-wages.html

²¹ Based upon, Birnbaum H, Leong S, Oster E, Kinchen K, Sun P (2004) Cost of Stress Urinary Incontinence: A Claims Data Analysis *Pharmacoeconomics* 22(2) 95-105 – re-calculated in 2014 Canadian dollars assuming a discount rate of 5% and an exchange rate of 1.1326 as done throughout this paper.

http://www.health.gov.on.ca/english/providers/program/ohip/sob/physserv/a_consul.pdf

²³ http://www.health.gov.on.ca/en/public/programs/ltc/docs/loc_funding_summary_092014.pdf

²⁴ Fultz N, Girts T, Kinchen K, Nygaard I, Pohl G, Sternfeld B (2005) Prevalence, Management and Impact of Urinary Incontinence in the Workplace *Occupational Medicine* 55:552-557.

²⁵ Zorn BH, Montgomery H, Pieper K, Gray M, Steers WD (1999) Urinary incontinence and depression J Urol 102:82-84.



Table 8: Calculation of Costs to the Health Care System	
Women aged 15+years in Canada	14,326,215
Women aged 15+ years with incontinence (7%)	1,002,825
Women with incontinence who consult their physician (25%)	250,705
Men aged 15+ years in Canada	13,543,125
Men aged 15+ years with incontinence	474,009
Men with incontinence who consult their physician (*25%)	118,502
Total individuals with incontinence who consult their physicians	369,207
Average direct medical costs/person (Table 7)	\$10,409
Increased health care costs due to incontinence \$3,843,075,60	

In total, incontinence costs Canadians over \$8.5 billion annually. Many of these costs can be avoided if policy makers put a greater emphasis on helping to increase awareness of the condition among Canadians, on helping to reduce the stigma associated with incontinence, and on increasing access to appropriate care and treatments. More detailed recommendations follow.

Table 9: Summary table of increased costs due to incontinence	
Costs to the individual \$2,584,476,950	
Costs to the employer	2,103,292,400
Costs to the health care system 3,843,075,600	
Total \$8,530,844,950	



RECOMMENDATIONS

Incontinence is a serious and problematic issue for millions of Canadian women and men. Individuals with incontinence live in embarrassment and fear of discovery about their condition. Significant advances must be made in order to help people living with incontinence cope with their condition. An important first step is to increase knowledge and education of the condition, which will help reduce the stigma of the condition and encourage individuals to seek help.

Education

The Canadian Continence Foundation urges governments to implement programs to better educate the medical community and public-at-large about incontinence.

It is clear from the incontinence literature that education about incontinence should be directed at *all* organizational levels to reduce embarrassment, promote communication and provide women and men with information about prevention and treatment.

The education of physicians is a vital step in helping Canadians who live with incontinence, as research has found that there are wide variations in knowledge, attitudes and comfort levels among family physicians when dealing with incontinence.²⁶ Herbruck suggests that education should begin in medical schools to educate physicians to approach these topics with sensitivity as well as up-to-date information.²⁷

Education should also be directed at nurses and allied health professionals and aides, such as PSWs, who are often the front line contact for patients. The most recent research conducted by TCCF and TCI discovered that nurses and personal support workers (PSWs) also did not feel confident in their knowledge or skills to manage well their patients" incontinence.²⁸ Nurse continence advisors must be provided with the latest information and training to aid those living with incontinence. Occupational health professionals need the information to educate employees and advocate for the time and facilities to manage their incontinence; they in a unique position to provide insight relating incontinence to the nature of work.²⁹

Finally, an emphasis must be placed on providing more and better education for individuals living with incontinence, so as patients with greater knowledge of their condition they can feel more liberated, feel more confident asking questions, take a more active role in their treatment, and are more compliant with treatment. The Canadian Continence Foundation and other appropriate organizations need government support to provide more widespread education to patients.

²⁶ Swanson JG, Skelly J, Hutchison B, Kaczorowski J (2002) Urinary incontinence in Canada. National survey of family physicians' knowledge, attitudes and practices *Can Fam Physician* 48:86-92.

 ²⁷ Herbruck LF (2008) Stress Urinary incontinence: prevention, management, and provider education *Urol Nurs* 28(3):200-6.
 ²⁸Taylor DW, Cahill JJ, Rizk DEE (2014) Denial, Shame and Acceptance: Generating Base-line Knowledge and Understanding of Fecal Incontinence amongst Long-term Care Residents and Care Providers *Public Health Research* 4(1) 13-18.

²⁹ Fultz N, Girts T, Kinchen K, Nygaard I, Pohl G, Sternfeld B (2005) Prevalence, Management and Impact of Urinary Incontinence in the Workplace Occupational Medicine 55:552-557.



Wait Times Strategy

The Canadian Continence Foundation urges government to include urinary incontinence in any and every wait times strategy.

It is important that incontinence, urinary incontinence in particular, and stress urinary incontinence most particularly, be included in any and every wait time strategies developed by government to help Canadians living with incontinence obtain *timely* access to appropriate treatments. If a Canadian with incontinence eventually overcomes his or her reticence and discusses the condition with his or her physician, who often take 6 months or more to do so if at all³⁰, he or she will often have to wait 6-9 months before an appointment with a specialist is available. Another 4-6 month wait is generally required to assess the incontinence, and if surgery is an option, patients can wait up to two years to receive the surgical treatment that they require.³¹

"In some of our major Canadian cities right now there are waiting lists of at least one year to see a specialist in incontinence and waiting times for surgery to address incontinence are as long as two years. Women are left without access to physiotherapists. In many, physiotherapy could be useful and even prevent the need for surgery. However, where surgery is required, those who suffer from SUI are too often denied access to the care they need.³²⁵

Performing More Cost Effective Surgical Procedures

The Canadian Continence Foundation urges provincial governments to fund innovative and novel, more cost-effective, less invasive treatments for people with stress incontinence on an on-going basis.

As discussed above there are surgical options for the treatment of stress urinary incontinence if all other more conservative methods of treatment fail. Sling insertion and retropubic suspension procedures both have been found to be effective methods of treating SUI, which is the most common form of incontinence.

Until recently, the 'gold standard' for SUI surgery was the retropubic suspension – the so-called "Burch" procedure - as it is effective and has good long-term viability. However, the newer sling procedures have taken over from this method. Effective sling insertion was first introduced 15-20 years ago. There have been many patients treated with this technique but it was with the publication of

³⁰ Taylor DW, Weir M, Cahill JJ, Rizk DEE (2013) The Self-reported Prevalence and Knowledge of Urinary Incontinence and Barriers to Health Care-Seeking in a Community Sample of Canadian Women *American Journal of Medicine and Medical Sciences* 3(5) 97-102.

³¹ Carr L, (2006) *Shedding light on a neglected women's health issue stress urinary incontinence* presentation at Sunnybrook Health Sciences, September 22.

³² Baker K, Fortier M, Chaplain Local Health Integrated Network (LHIN) correspondence, October16, 2008



the first prospective randomized trial of the sling versus retropubic suspension that it became much more widely accepted.³³ The study compared the two techniques at 6 months and again at 2 years in the same groups of patients and found the durability and effect on SUI was equivalent. However, the overall patient morbidity and quality of life was better with the sling compared to the retropubic suspension procedure. Table 10 provides an outline of costs for the two procedures:

Table 10: Costs of sling insertion versus retropubic suspension		
Economic Comparison	Sling Insertion	Retropubic Suspension
Average Total Cost	\$3,032	\$6,047
Device Cost	\$730	0
Average length of hospital stay	0 days	5 days
Surgery Time	30-45 minutes	60-90 minutes
Procedure performed at ambulatory centers?	YES	NO
Source: Ministry of Health and Long Term Care, Ontario as presented in. "Impacts of Incontinence in Canada, TCCF, 2009.		

A Ontario Health Technology Advisory Committee (OHTAC) report concluded that "(m)idurethral slings are highly effective in treating stress urinary incontinence in women who have failed conservative treatments. Midurethral slings are as effective as colposuspension and are less invasive."³⁴ The Committee recommended increased access to midurethral slings through development of an appropriate fee code, as well as the development of guidelines and training for surgeons in the use of midurethral slings. Funding was increased in Ontario and, as a result, midurethral slings have become the predominant surgery for SUI today in that province

Where all else is equal, or even favors innovation and novel technology and procedures, The Canadian Continence Foundation urges provincial governments to fund more cost-effective, less invasive treatments for people with stress incontinence, such as was done for the surgical correction of stress incontinence with midurethral slings.

Creation of Community Clinics

The Canadian Continence Foundation urges government to set aside funding for the creation of community-based Continence Care Clinics.

There is a clear need for Continence Care Clinics to be established within communities across Canada. Numerous studies have shown that those individuals living with incontinence in the community are underserved, and that continence services should be "community focused, multi-disciplinary, and generalist in nature."³⁵ These clinics would provide access to general practitioners and specialists for

³³ Ward K, Hilton P. *Prospective multi-centre randomized trial of tension-free vaginal tape and colposuspension as primary treatment for stress incontinence. BMJ* 2002; **325**: 67–73

³⁴ Ontario Health Technology Advisory Committee *Advancing Health Evidence-Based Advice on Health Technology* 2003-2008 accessed at: http://www.health.gov.on.ca/english/providers/program/ohtac/pdf/progress/full_report_2008.pdf

³⁵ St John W, Wallis M, James H, McKenzie S, Guyatt S (2004) Targeting community-dwelling urinary incontinence sufferers: A multi-disciplinary model community-based model for conservative continence services *Contemp Nurse* 17(3) 211-222.



diagnosis, to physiotherapists and nurse continence advisors for treatment and, to others for access to a range of continence-related information. Community-based Continence Care Clinics will:

- Improve access to continence care;
- Provide awareness, support and education about incontinence in the community;
- Maximize access to effective non-surgical therapies;
- Triage patients to appropriate continence care providers to optimize patient flow within the health care system; and
- Collaborate for the purpose of education, research, and professional development.

Access to Conservative Treatments

SEP

The Canadian Continence Foundation urges government to increase funding for conservative treatments for people with incontinence.

P SEP

Conservative treatments such as physiotherapy and behavioral treatments are often the most effective and least invasive of all incontinence treatment solutions. Increased information about, and access to these types of therapies is necessary in Canada.

Increased Access to a Choice of Medications

The Canadian Continence Foundation urges the provincial governments to include all urinary incontinence drugs on provincial formularies.

The Canadian Continence Foundation also urges provincial drug plans to ensure that the most effective OAB medications are uniformly and fairly covered.

There are a number of medications available for the treatment of overactive bladder. Some of the older medications are available on provincial formularies. However many of the newer medications have not been included and some of these drugs are easier to take and have less unpleasant side effects.

Increased Funding for Absorbent Products

The Canadian Continence Foundation urges the government to increase its daily funding allotment for absorbent products in long-term care facilities.

The Canadian Continence Foundation also urges the government to increase funding for the purchase of absorbent products for those individuals living on fixed incomes.



Current funding for paper products in long-term-care facilities is minimal at best. Given that funding levels are so low, nurses are allowed to change diapers a limited number of times each day. Residents are therefore often forced to sit in a wet or soiled diaper for hours at a time. Barrier creams and other 'diaper rash' remedies are often required. This is an indignity that should not be tolerated.

Similarly, Canadians living on fixed incomes often cannot afford to buy enough absorbent products. Increased funding for the purchase of absorbent products is required both for individuals living in the community and in long term care facilities.

Increased Funding for Catheters

The Canadian Continence Foundation urges provincial governments to increase their funding for catheters for individuals living in the community and in institutions.

Access to catheters varies greatly across the country and provincial reimbursement for catheters is different in each province. In order to avoid urinary tract infections, it is suggested that individuals using catheters use them only once (single use). This would require that the catheter be changed five to six times each day. There is also a wide variety in quality of catheters, ranging in price from \$0.75 for a lower quality catheter, to \$5.25 for higher quality catheters. If each catheter is used only once, this indicates a yearly cost of \$1,370.00 - \$8,200.00 per year. This represents a significant investment and most affected individuals have difficulty absorbing this cost without aid from the government.

Equality in Access to Treatment Among Provinces

The Canadian Continence Foundation urges provincial governments to provide equal access to continence care and treatment.

Canadian men and women who need treatment for incontinence face widely varying levels of access to care across the country. It is unacceptable that whether someone with incontinence receives treatment in a timely manner is often dependent upon where the individual lives. This wide variation applies to access to pelvic floor surgery, drug coverage and access to surgical materials.



APPENDIX: INCONTINENCE WEB SITES, CHAT ROOMS and FORA

The Canadian Continence Foundation http://www.continence-fdn.ca/

mtp://www.continence-tun.ea/

Bladder and Bowel Foundation http://www.bladderandbowelfoundation.org/

Depend Message Board www.Depend.com

I am Incontinent http://www.experienceproject.com/groups/Am-Incontinent/2090

InContact http://www.incontact.org/chat.html

Incontinence Resource Center http://www.incontinencesupport.org/

Incontinence Support Center http://www.incontinentsupport.org/

International Continence Society http://www.icsoffice.org/ASPNET_Membership/Membership/Home.aspx

International Foundation for Functional Gastrointestinal Disorders http://www.aboutincontinence.org/site/about-incontinence/courageous-profiles/

Mayo Clinic, Incontinence Section http://www.mayoclinic.com/health/urinary-incontinence/DS00404

National Association for Continence

http://www.nafc.org/

National Urologic and Kidney Diseases Information Clearinghouse http://kidney.niddk.nih.gov/kudiseases/topics/incontinence.asp

SeekWellness

http://www.seekwellness.com/incontinence/

The Simon Foundation for Continence http://www.simonfoundation.org/



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THE CANADIAN CONTINENCE FOUNDATION

Founded in 1986, The Canadian Continence Foundation (formerly The Simon Foundation for Continence Canada) is the only national non-profit organization serving the interest of people experiencing incontinence. The organization is led by people with incontinence and by professionals from all health disciplines. The Canadian Continence Foundation is supported by donations from public healthcare professionals and private industry.

The mission of the Canadian Continence Foundation is to enhance the quality of life for people experiencing incontinence by helping them, and/or their caregivers, to confidently seek and access cures and treatment options. To this end, the Foundation will implement and encourage important public and professional education, support, advocacy and research to advance incontinence treatment and/or management.

ACTIVITIES:

- The Canadian Continence Foundation offers a wealth of information on incontinence. Books, videotapes, and newsletters are available. We operate a toll free number which is **1-800- 265- 9575.**
- Each year the Canadian Continence Foundation responds to thousands of requests for information and education from people experiencing incontinence, healthcare professionals, and industry.
- The Foundation interacts with the media to increase public awareness and knowledge of incontinence and to encourage people to seek help. It also provides individuals with lists of specialists in their local area.
- The Foundation initiated and now coordinates Incontinence Awareness Month in November of each year promoting public and professional awareness-building and educational activities about incontinence around the country.
- The Canadian Continence Foundation encourages and supports research to advance incontinence management/treatment.

THE CAMERON INSTITUTE

The Cameron Institute is a not-for-profit, public policy think tank specializing in the independent study of health, social, and economic issues. It is the goal of The Cameron Institute to provide decision makers with analyses that will better inform choices. The Institute is also dedicated to educating and better preparing patients, providers, and payers to make appropriate clinical decisions. The Cameron Institute's values are:

Freedom, Choice, Responsibility