TO TELL OR NOT TO TELL

An Incontinence Disclosure Toolkit

The Simon Foundation
for Continence

Developed from a program called Honest, Open, Proud Version: 12/2019

Dedication

This toolkit is dedicated in memory of Clarinda Valentine, the ultimate continence champion. Clarinda died unexpectedly while our team was developing this toolkit. Although she was not able to see the finished product, her words and ideas live on through this project.

PREFACE

This toolkit is designed as a tool for people who want to think more about disclosing their incontinence to others. This program is *not* meant either to pressure you to disclose **or** to discourage you from disclosing; rather it is meant to help guide you through the decision-making process, challenge any embarrassment you might be imposing on yourself, and allow you to hear the story of others whose lives have been impacted by incontinence.

A Letter from the President of the Foundation

"TO TELL OR NOT TO TELL" an Incontinence Disclosure Program.

If you were curious about this title, you are not alone. You are likely one of a legion of people who live with a bladder health problem and are faced with the dilemma of treating and/or managing that problem day to day. This dilemma is usually complex in both its medical and social aspects. Dealing with it often involves interactions that may feel uncomfortable. How to deal with it effectively is a very individual choice.

It may seem strange that this introduction begins by telling you what this program is not. It is key to understand at the onset that we are *not* attempting to convince you that it is somehow wrong to keep your bladder challenges a secret - nor that you *should* feel differently and *should* tell others about your incontinence. However, a lot of people have found it freeing to talk about their incontinence. This program is about making individual, thought-out decisions, decisions that will differ from one person to the next.

What we do have to offer with this unique program about disclosing a bladder condition is the opportunity to equip yourself with the personal pros and cons, as you see them in your own life, and then a structure to determine whether you wish to: (a) tell others about your incontinence; (b) if so, then to decide with whom you wish to share this knowledge; and lastly (c) how you might tell your story differently if speaking to a doctor vs. sharing with your best friend, family, boss or others.

Taking an analytical approach to incontinence, an issue that often feels emotionally charged, is something few of us have been trained to do. Instead most of us simply react, a typical human response.

Incontinence is a condition that millions of Americans are managing on a daily basis. It creates challenges in a wide variety of situations including the demands of the workplace, fear when traveling or at family events such as long wedding ceremonies; and even while doing everyday tasks like trips to the grocery store. We are all confronted with occasions when we question what to tell and who to tell it to. Will a disclosure help us navigate our circumstance or create an embarrassment?

Throughout this program you will read about others' journeys and how their decision "To Tell or Not to Tell" affected their lives. The program is divided into three parts. The first is designed to help you decide if you'd like to tell others about your incontinence. If you analyze your pro and con list and the answer is no, you'll have completed a thoughtful process and for now your work is finished. If your answer is that you think you would like to be at least somewhat more open about your health issue, then the second section will help you to decide who you wish to tell. The third part of the program helps you to think through not only what you'd like to share, but also the different responses you might receive so you are thoroughly prepared for a variety of reactions to your "news."

On behalf of the entire team that the Simon Foundation for Continence assembled to develop this program, we hope that whatever you decide upon completion of the first section, you'll have practiced a problem-solving technique that will improve your decision-making no matter what the challenges you face going forward.

Sincerely,

Cheryl B Gartley

President and Founder

Authors

Jeff Albaugh, PhD, APRN, CUCNS

I am an advanced practice urology clinical nurse specialist and researcher. Every day I have the honor and privilege of treating patients with urology issues (including incontinence) in my practice. It is not easy to come talk/disclose to a healthcare provider about very personal issues like sexual dysfunction and incontinence. My patients are very brave and teach me so much about how to navigate the challenges of life. Having experienced my own health challenges in the past, I know how difficult disclosure can be for each of us. Although I am already over-committed with my two clinics and the many other activities, I felt this project was very important because all of us must carefully choose who has earned the right to share in our story and our journey. I hope the information provided will help each person to live their own best wholehearted life.

Paul Laporte

I was 22 years old when incontinence became part of my life. At the time, I didn't know why, and I didn't care why, because I was too embarrassed. I had little control, and little control of my personal and professional life. I gave up on promising promotions, and became housebound. My unpredictable bladder kept me close to home. For many years, I was so alone, and worried all the time about being wet and friends finding out my secret. I want to show and support people that are living with incontinence, and to avoid those negative experiences that I had for many years.

Clarinda Valentine

When I first started having bladder problems, due to a traumatic gunshot wound at the age of 15, I remember the embarrassment, shame, and walling myself off from friends and society to keep people from knowing I peed on myself. I had never heard of the word "incontinence" nor knew what it meant. All I understood was I peed on myself. I would do things like pour liquids on myself to make people think I spilled something in my lap. This was a very lonely time for me and an experience I don't want anyone else to have to go through.

Twila Yednock

I have a sad memory of how long it took me to be able to open up to my family and friends about my urge incontinence. It's hard thinking back to how difficult it was to enjoy even simple outings (shopping or short outings), and indeed big trips (like to the Olympics in a foreign country), when I constantly worried about whether there would be a bathroom nearby when I needed one, with no warning. Before I found pads, leaving the house was a nightmare. I want everyone to be able to enjoy removing the weight of secrecy and fear from your life. This program should help a lot of *people, and I am proud to have helped develop it. Choosing who to tell, and being able to say, "Excuse me, I need to stop at or find a bathroom," without explanation, is priceless. It's easier every time, I promise. Our options are better now for management and treatment, too. You'll be happier if you learn to be more open, because so much apprehension goes away.*

Susan Hayward

I have had the privilege of consulting with the Simon Foundation for Continence on many projects since 2012. As a certified and credentialed Life Coach, I work with individuals and groups to improve the quality of their lives, achieve goals, and reach their fullest potential. I created the first Continence Coaching Program for the Foundation and I currently respond to all 800-line callers . I have seen first-hand how the stigma of incontinence affects the lives of so many individuals isolating them from their family, friends, and the life they want to live. I believe this toolkit will empower individuals to ask for what they need from family members, friends, work colleagues, and medical professionals in order to improve the quality of their lives as they manage their incontinence.

Steve Burns

After my Spinal Cord Injury, one of the issues I needed to learn to live with was urge incontinence. Since I was dealing with learning to walk again, muscle spasms, and nerve pain, incontinence was one more thing I needed to adjust to. People seemed to be more understanding or empathetic to seeing me in a wheel chair or using a walker. Incontinence is a different story. Because incontinence can be so embarrassing, I feel it is important for people to know they are not alone. Having to stop people during a conversation in mid-sentence to find a bathroom or having to pull the car over to the side of the road suddenly makes people question your health (and maybe your sanity). I recall a recently injured younger woman at a peer support meeting years ago, whose main focus was on incontinence. The fear of having an accident in public kept her from leaving her home. She was desperate for advice on how to deal with her incontinence. The 'veterans' of the group had some very practical advice that I could tell made her feel better. The fact that they were comfortable sharing and had overcome their fears of having an accident in public seemed to give her some hope. My hope is that this program gives people the confidence to explain their condition and their subsequent needs. Being open to the right people can then lead to support and understanding and eventually a better quality of life.

Lindsay Sheehan, PhD

I am a Senior Research Associate at Illinois Institute of Technology and my work focuses on health-related stigma, disclosure of stigmatized conditions and services for people with mental illness. In community-based participatory research (CBPR) researchers collaborate with community members on projects that are important to them. As a proponent of CBPR, I was excited to partner on this project. I hope this toolkit can touch many peoples' lives.

TABLE OF CONTENTS

Throughout this toolkit, you will see real quotes from people with incontinence. These quotes were gathered from the generosity of our incredible research participants who shared their personal experiences to help others. We cannot thank each of the participants in our study enough for sharing their insights.

> “Being able to connect with other people who are going through the same thing and discuss with other people what the challenges are was a really big deal for me. It makes you feel a lot less alone.”
>
> -Incontinence Focus Group Participant

SESSION 1

Considering the Pros and Cons of Disclosing

SESSION OVERVIEW

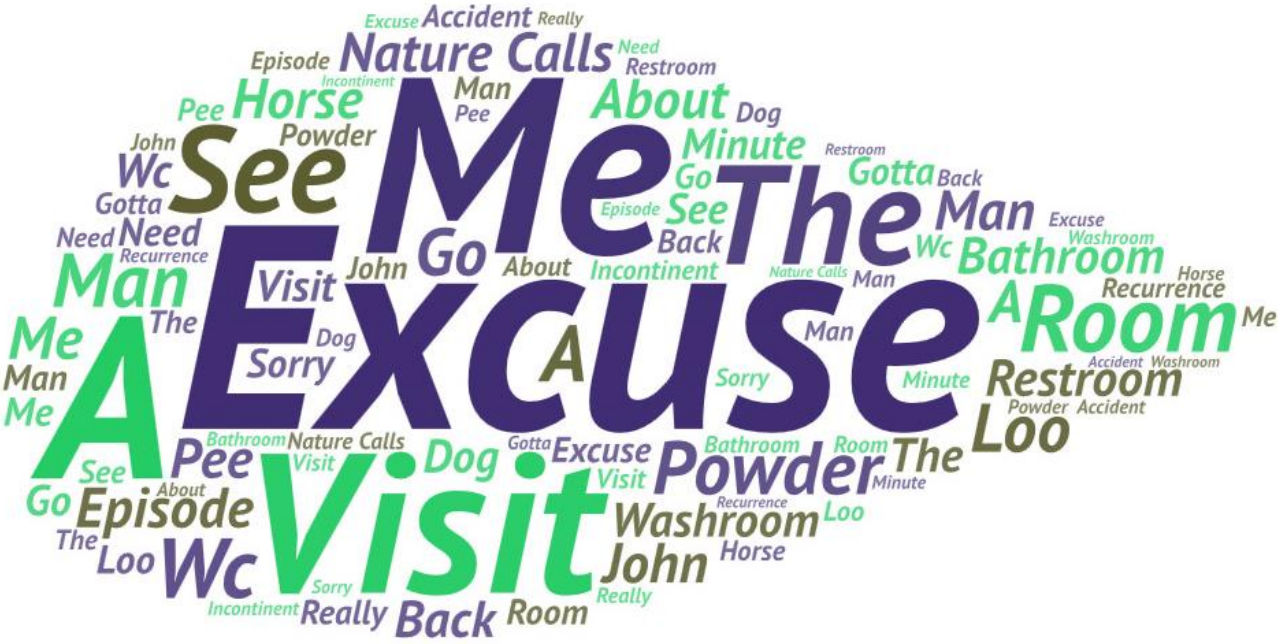
Disclosure is the right decision for some people, but not for everyone. This section is a guide to help people decide what the right decision is for them.

- We discuss the language around incontinence and, the idea of how you view yourself, so you can decide how to frame your identity.
- We discuss stigma and the ways you might have internalized it.
- We help you weigh the costs and benefits of disclosure so that you can decide whether or not to disclose.

The Language Around Incontinence

From an early age, we learn many ways to tell others we have to "go." For example, we say things like "nature calls," "I have to go to the powder room" and "I have to see a man about a dog." Many of these expressions are meant to avoid direct communication, to be polite, and to distance ourselves from the act of urination. The ways in which we have learned to talk in code or hide the fact that we need to use the bathroom contribute to making incontinence a difficult subject to communicate about.

We also have words to describe those times when we don't make it to the toilet in time. Some people call these "accidents" while others prefer the word "episode." While incontinence is the medical term used to describe unintentional leakage of urine, you may prefer using different words. There are also many incontinence management products for which we use different language (diapers, absorbent products, pads, etc.). While there are no right or wrong words to use (nor do we presume to tell you what to do), we do encourage you to think about the language you feel most comfortable using.



How do you tell others you have to “go”?

What words do you use to refer to incontinence? (for example, leakage or loss of bladder control)

Do you use the word “accident” when you don’t make it to the toilet in time or do you use another word?

Reflection: Why do you choose to use the terms that you have listed above?

Recognizing Internalized Stigma

It is hard to decide whether to disclose when you’ve internalized stereotypes. Stereotypes, prejudice, and stigmas are false and unfair, but some of your family, friends, or others in the community may believe stereotypes like these:

- You could do something about it if you wanted to.
- People with incontinence may smell.

Unfortunately, some of us have internalized beliefs like these:

- I should be ashamed.
- I’m less of a person.

> “I’ve definitely been embarrassed when I’ve leaked or even when I’ve been out buying briefs and things. And that’s been embarrassing, but it doesn’t feel like shame for me because I don’t feel like I’m a bad person for it.”
>
> -Incontinence Focus Group Participant

Let’s see if you may have internalized some stigma. Respond to the following statement on a scale of 1-10.

1 2 3 4 5 6 7 8 9 10

|-----------|----------|-----------|-----------|------------|------------|-----------|----------|-----------|

Strongly Disagree

Strongly Agree

______Sometimes I feel embarrassed because I’m unable to control urination.

______Sometimes I feel like less of a person because I can’t do the things I used to do (going on road trips, sitting through a movie, etc.).

______Sometimes I worry that I smell.

_____ I feel like a burden because I have to rely on others or inconvenience them with special requests.

Challenging Internalized Stigma

Here is one way to challenge the internalized stigma. Work through each of the steps below for each hurtful attitude that you may have about yourself.

1. **State the hurtful attitude about yourself:**
   Example: "I'm embarrassed because of my incontinence."

My hurtful attitude is:

2. **Define the assumptions behind your attitude:**
   Example: "My incontinence is my fault and it makes me less of a person."

3. **Challenge the assumptions and collect evidence against the assumptions:**
   Example: "Having incontinence is not something I chose." "I know people with all kinds of health conditions and I don't see them as less of a person because of it."

4. **Restate the attitude so that it does not hurt you.**
   Example: "I don't have to be ___________ (fill in about your own life)—I've just learned to think that way."

> "I've been embarrassed a lot of times, but I've never felt ashamed. I've just kind of felt like, this is a medical condition, I didn't ask for this, just like any other medical condition. Things happen in life you didn't always predict were going to happen, and you just deal with it then."
>
> -Incontinence Focus Group Participant

Considering the Pros and Cons of Disclosing

Now that you've considered some assumptions you might have about incontinence, let's think about why you might want to talk about your incontinence. There are many reasons why people might disclose their incontinence; some of these are listed in the table below. Put checks next to the reasons that especially stand out for you. Are there others? Add them in the blank space at the bottom.

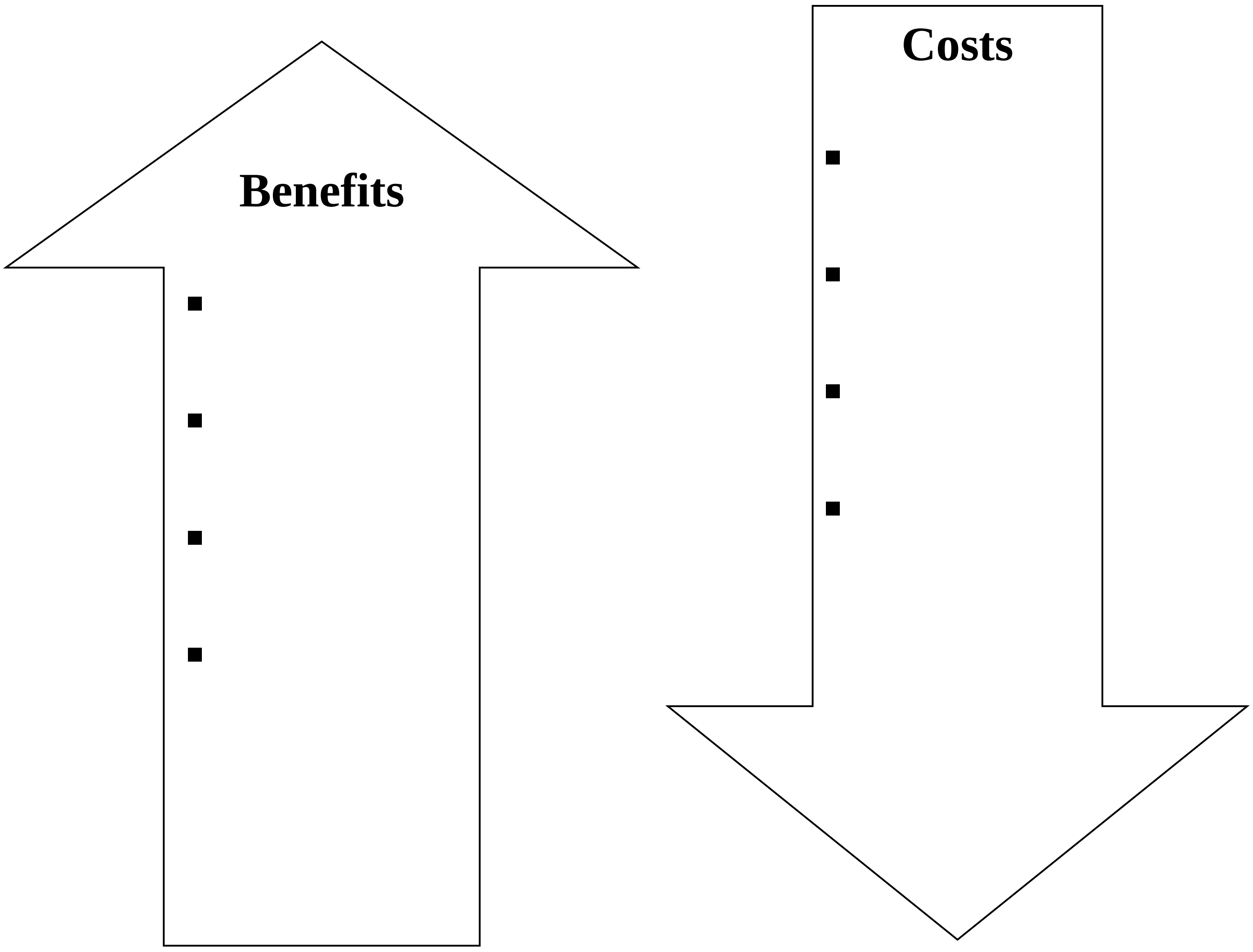
Some Reasons Why People Decide to Disclose Their Incontinence

	Support and Assistance	"I'll know I'm not alone in dealing with this issue."
	Understanding	"So that my family will understand why I'm always concerned whether there's a bathroom nearby."
	Authenticity (Revealing the reality of your life)	"If I accept it myself, then other people may too."
	Accommodations	"I needed to tell my boss so I could take more frequent bathroom breaks."
	Relationship Enhancement	"If I'm going to get physically intimate, I tell my partner. If they can't accept me for who I am, then there is no point in being with them anyway."
	Others	

Let's make a list of all the costs and benefits of telling other people about your experiences with incontinence. Benefits represent why you would do it--what you expect to happen that is positive as a result of disclosing to others. Costs are why you wouldn't do it, the negatives or harm that could result from disclosing.

Write benefits and costs down in the figure below. **Don't dismiss any cost or benefit no matter how "silly" it may seem.** Put them all on the list so that you can consider all benefits and costs together.

Benefits and Costs of Disclosing Incontinence



After listing all the costs and benefits, put a star next to one or two that seem to be particularly important. Important items are the ones you spend a lot of time thinking about. If you feel comfortable, discuss these with someone you trust. In the appendix, we have included another sheet if you'd like to fill this out again. Or, you can have a friend or family member fill out the costs and benefits from their perspective to discuss with you.

In developing this toolkit, we talked to people with urinary incontinence, and here are some of the costs and the benefits that they described. If there are any here that apply to you, but you didn't consider before, add them to your own list.

Some Benefits and Costs of Disclosing Incontinence

Benefits	Costs
"It's better that disclosure be on your terms rather than on theirs so you won't be embarrassed."	"I felt ashamed. It just made me feel like lesser of a man."
"Keeping it a secret was really stressful."	"You might find people that don't understand."
"It helps you find out if you can really trust the person."	"I'm afraid they would identify me as 'the one who pees his pants.'"
"It is a fairly common problem and you can kind of bond with other people who have incontinence and help them understand that they have worth."	"I guess one danger of disclosing it to someone is they can also disclose it and others can find out."
"The more awareness that people have about this issue, then I think it'll be more common for them to discuss."	

Considering the Setting, Person, Goals, and Expectations

Now that you've thought about reasons for disclosing, and some benefits and costs of disclosing, let's think about how important the setting will be to your decision. Disclosure at work will have different benefits and costs than disclosure to your spouse or friends. You may have much different goals for disclosing at work. You may also have many different choices in WHO you could disclose to at work, including your boss, coworker, or Human Resources representative. You might think about what you EXPECT will happen when you disclose. Worksheet 1 will help you think through this decision for each setting or situation. Now complete Worksheet 1. There are two copies of Worksheet 1 so you can consider pros and cons for different disclosure situations.

> "I have a couple of friends and when we have our monthly luncheon together, we all discuss our health conditions. And we exchange our feelings, our thoughts, our pains, our fears."
>
> -Incontinence Focus Group Participant

REMEMBER: The decision to disclose is not right for every person or every situation. You have the right to pick and choose who you disclose to. If you don't think disclosure is the decision for you, or you're not sure, then we encourage you to feel empowered in your decision! If you decide not to disclose now, you can always change your mind later.

Worksheet 1

The Benefits and Costs Worksheet

Setting: ______________________________________ **Person**: ____________________

Reason for Disclosing:

____

Disclosure Expectations: What do you want or expect from the person you disclose to?

____

____

Benefits	Costs

Put a star (*) next to benefits and costs you think are especially important.

After considering both the benefits and costs in your situation:

☐ I will probably **NOT talk about my** incontinence in this setting.
☐ I will probably **talk about** my incontinence in this setting.
☐ I have decided **to put off** my decision. I'm just not sure.

Worksheet 1

The Benefits and Costs Worksheet

Setting: ______________________________________ **Person**: ____________________

Reason for Disclosing:

____

Disclosure Expectations: What do you want or expect from the person you disclose to?

____

____

Benefits	Costs

Put a star (*) next to benefits and costs you think are especially important.

After considering both the benefits and costs in your situation:

- ☐ I will probably **NOT talk about my** incontinence in this setting.
- ☐ I will probably **talk about** my incontinence in this setting.
- ☐ I have decided **to put off** my decision. I'm just not sure.

Personal Story: Paul Laporte

I was born and raised in the 1950's, and had a normal and happy life through childhood. That changed, and as a young adult urinary incontinence reared its humiliating head, the result of a growing benign spinal tumour. I was 22 years old, and newly married, and not only was I losing control of my bladder, I felt I was losing control of my day-to-day life. While surgery stopped the growth of the tumour, incontinence worsened during the early years. Managing incontinence was certainly a challenge, as products and devices were limited and not nearly as developed as they are today.

Aside from the obvious physical effects of losing bladder control, the emotional effects in trying to manage incontinence were devastating for me. I felt a failure, and struggled to achieve basic life coping abilities. I struggled through my college years, and later through employment. I feared being found out by my peers, and discouraged promising promotions at work. My talents were being wasted because of my inability to cope with my bladder leakage. Eventually, I welcomed a reclusive lifestyle finding comfort alone in "my closet." A divorce, and the loss of employment opportunities, made me feel I was very much alone, or so I thought.

I realized that there must be others like me, and wondered how they coped. I did some research in libraries and little by little was educated on how my own plumbing was supposed to work, and why it failed at times, and I learned newer coping skills to deal with accidents. However, in my eyes, my emotional well-being was still in the gutter.

In early 1980's I met my second wife, who was more understanding that I ever thought possible. With encouragement and a big push from her, I found the Simon Foundation. Together, my wife and I traveled to Chicago (where the Foundation is headquartered) from Windsor, Canada, so that I could attend my first self-help group meeting. I recall the fear I had prior to the meeting, wondering all kinds of things that could cause embarrassment, and possibly drive me further back emotionally. When I entered the meeting room, I immediately felt comfort seeing other's in my situational position. I was amazed how I opened up, pouring out years of emotional frustration. The meeting lasted a couple of hours, and when I left to re-join my wife, I felt that my life had taken a positive turn, and I kept her up the entire night talking! I participated in more self-help meetings, met more people just like me, and even started meetings in Canada to help others.

Today, I manage my incontinence very effectively. I'm still with my spouse, my children are grown, and my grandkids are very much in my life. I enjoyed a prosperous career with a government legal agency representing workers with their compensation claims. I retired a few years ago, but re-deployed in a mentoring capacity.

Essentially, this could only have been possible by coming out of my closet, and talking about my own incontinence. I thought incontinence was a taboo subject not to be discussed amongst friends and peers, and felt stigmatized when it was brought up. For me, it is now no longer a stigma, and I can talk to anyone about it.

Reflection

In what ways do you identify with this story?

What do you think about Paul's disclosure decisions?

> "I think afterward, I feel unburdened, but in the process of disclosing, I feel very vulnerable, in that moment and in that discussion. But then afterward, it just is a complete weight off my shoulders."
>
> -Incontinence Focus Group Participant

SESSION 2
Different Ways to Disclose

SESSION OVERVIEW

There are two ways that disclosure happens: 1) intentional disclosure and 2) unintentional disclosure. This session allows you to think more about intentional disclosure.

- Describe ways to disclose, then consider the costs and benefits associated with each strategy
- Select a person you might disclose to
- Consider how others might respond to your disclosure

People who experience incontinence have different preferences for disclosure. The table on the next page summarizes the ways people might decide to disclose or not disclose their experiences with incontinence.

> "I wasn't really embarrassed talking to healthcare professionals about it. I figured they, you know, they've seen everything, they've heard everything, so nothing is going to shock them I don't think."
>
> -Incontinence Focus Group Participant

Ways to Disclose or Not Disclose

Type	Benefit	Cost
SOCIAL AVOIDANCE: Not telling anyone about your incontinence and avoiding situations where people may find out about it.	You don't encounter people who might judge you.	You lose the opportunity to attend family events, concerts, sporting events. You miss out on job opportunities and your quality of life might suffer.
SECRECY: Participating in work and community situations, but keeping your incontinence a secret.	Like social avoidance, you withhold information about your incontinence from others. But you don't avoid important settings like work opportunities or other activities that will enhance your quality of life.	Some people feel remorseful about keeping secrets. You may not receive support from others because they are unaware of your incontinence. You might have an unintended disclosure where someone finds out about your incontinence.
NECESSARY DISCLOSURE: Feeling obligated to tell others about your incontinence because they might find out, or you need to explain some of your needs such as frequent restroom stops on a trip.	You can get accommodations at your job, at school, while traveling, etc.	You may be disappointed if others refuse to accommodate you. You may feel vulnerable because disclosure doesn't feel like a choice.
SELECTIVE DISCLOSURE: Disclosing your incontinence to selected individuals, like coworkers or neighbors, but not to everyone.	You might find people who will understand your situation and provide support.	You may tell people who tell others. Others may judge you or discriminate against you.
SITUATIONAL OPENNESS: Talking openly about your incontinence when it comes up, but not seeking opportunities for advocacy.	You don't worry who knows about your incontinence and you are likely to find people who will be supportive.	You may tell people who tell others. Others may judge you or discriminate against you.
ADVOCATING FOR CONTINENCE EDUCATION: Actively educating people about incontinence.	You don't worry who knows about your incontinence. You are promoting a personal sense of empowerment in yourself. You are striking a blow against stigma and empowering others.	You might meet people who disapprove of your openness and advocacy. You might be judged or discriminated against.

Let’s consider how each of these might play out. Fill in the table below by thinking about the benefits and costs for either Allison or Raymond described below.

Raymond is a mail carrier who volunteers as a soccer coach.

Allison is a wife and mother who works in retail.

Benefits and Costs of Ways to Disclose

	Benefits	Costs
Social Avoidance Not telling anyone about your incontinence and avoiding situations where people may find out about it.		
Secrecy Participating in work and community situations, but keeping your incontinence a secret.		
Necessary Disclosure Feeling obligated to tell others about your incontinence because they might find out, or you need to explain some of your needs such as frequent restroom stops on a trip.		
Selective Disclosure Disclosing your incontinence to selected individuals, like coworkers or neighbors, but not to everyone.		
Situational Openness Talking openly about your incontinence when it comes up, but not seeking opportunities for advocacy.		
Advocating for Incontinence Education Actively educating people about incontinence.		

What do the benefits and costs look like for *you*?

Benefits and costs of disclosing are likely to vary by setting. Select a setting such a place of worship, your workplace, a social event, or at home with family. Write the setting at the top of the following table and then fill in the benefits and costs.

Benefits and Costs of Disclosure

Setting: ______________________

	Benefits	Costs
Social Avoidance Not telling anyone about your incontinence and avoiding situations where people may find out about it.		
Secrecy Participating in work and community situations, but keeping your incontinence a secret.		
Necessary Disclosure Feeling obligated to tell others about your incontinence because they might find out, or you need to explain some of your needs such as frequent restroom stops on a trip.		
Selective Disclosure Disclosing your incontinence to selected individuals, like coworkers or neighbors, but not to everyone.		
Situational Openness Talking openly about your incontinence when it comes up, but not seeking opportunities for advocacy.		
Advocating for Incontinence Education Actively educating people about incontinence.		

Who <u>Must</u> I Talk To?

How do I Know When Disclosure Might be Necessary?

Sometimes disclosure does not feel like a choice and you might need to make a "necessary" disclosure. A necessary disclosure is usually made when you think people might find out about your incontinence anyway (example, through gossip), when you need something (help from another person) or when it might become obvious through your interactions with another person (for example, frequent bathroom breaks). In the next session, you will think about how you can best make those disclosures.

> "I think I will tell my son, because sometimes we're out and I have to go, and then maybe less than a half hour I have to go again, and he says 'Mom, are you okay? Again?' So maybe I need to tell him, you know, about my situation."
>
> -Incontinence Focus Group Participant

Right now, think about some situations where it might be necessary for you to disclose.

When might it be necessary for others to know about *<u>my</u>* incontinence?

Disclosure with Intimate Partners

Incontinence may impact intimacy and/or sex with a partner. The concern may be about the odor from urine or the presence of urine on the genitals. This may impact the ability to be fully present and engaged with a partner. Every person and their partner are unique, and it can be important to discuss any concerns and then strategize on how you want to best enjoy intimacy and sex. There is no doubt that with communication, compassion and creativity, that a wonderfully fulfilling sex life is possible.

However, talking with an intimate partner can be difficult. You might fear their reaction and wonder how it will affect your sex life. Some partners do have a negative reaction, but many others are supportive. Some people with incontinence say that disclosing helped them know whether they could trust that person or led to a stronger relationship.

> "Instead of seeing if we like the same movies or anything, they are just like 'well I've decided you're great to be around, but you can't be romantic or marriage material because you might not make babies or be able to have sex...'"
>
> -Incontinence Focus Group Participant

You might not know at what point in the relationship you want to disclose. Here are some things to consider:

- What is your comfort level with the person?
- How do you think they might react?
- How comfortable do you feel in addressing the issue?
- Are you likely to have sexual contact?
- How will your incontinence affect sexual activities?

Disclosure at Work

In the United States, the Americans with Disabilities Act (ADA) tries to protect people from discrimination at work. The ADA applies to employers with 15 or more employees. Other countries have similar laws. The ADA might require your employer to provide you with some accommodations if you can prove that you need them because of a disability and it is not too difficult or costly for the employer. The employer makes the final decision about whether the accommodation is not too difficult or costly for them; however, the employee has recourse if they don't agree with their decision. Examples of workplace accommodations are: extra bathroom breaks, relocation of desk/office that is closer to the bathrooms, flexible schedule for medical appointments or working from home.

To request an accommodation you might need to:

- Disclose to your supervisor and/or Human Resources representative.
- Provide proof of your medical condition (usually a doctor's note).
- Talk with your employer about what accommodations might be appropriate.

Sometimes what you think is a reasonable request for an accommodation will not be reasonable to the employer. You may have to be flexible or creative.

Your direct supervisor should not need detailed knowledge about your medical condition, but they should know what accommodations have been agreed upon (for example, five-minute bathroom break every hour). Your supervisor or HR representative should not tell your coworkers about your medical condition. However, you may decide to tell them if you are comfortable doing so, especially if the accommodation is very obvious to your coworkers.

If you work for a small company, you will not be covered under the law; however, your employer can still choose to provide you an accommodation. The ADA also protects you during the hiring process, and in all aspects of employment, including receiving training and promotions. If you feel you have been discriminated against because of a disability, in the U.S. you can file a complaint with the Equal Employment Opportunity Commission (www.eeoc.gov). In most cases where the disability is invisible (such as with urinary incontinence), people decide to wait until they have been given a formal offer of employment before they disclose a disability and ask for an accommodation.

Disclosure While Traveling

Incontinence may be more challenging to manage when you are traveling. You may have to disclose to your traveling companion or to complete strangers. Despite your best planning, trains can be delayed, flights cancelled, or traffic jammed up for hours. Some people who use incontinence products have been scrutinized while going through airport security. If you are traveling with someone who doesn't know about your incontinence, you might consider disclosing before the trip so they know what to expect. You may want to think about how you would disclose to a stranger on the plane to get what you need, such as an aisle seat, or how you can disclose to travel personnel (for example, security agents, flight attendants) in advance of needing their help.

Dealing with Gossip

One fear that many people have when disclosing is that news of their incontinence will be spread around to other people who they did not intend to find out. While you can ask someone not to share with others, they might either forget or just disregard your request. They may even think that by telling other people about your incontinence that they are actually helping you. Before you disclose, carefully consider the person you are talking with and whether you think they can keep it to themselves (if this is what you want them to do). Think about how you would feel if they did disclose to others. You might also need to remind people from time to time if you want it kept a secret.

> "My dad told his friends that I have bladder problems. I'm like, 'Dad why did you tell them that?' He said: 'Well, I thought maybe they would have suggestions that could help you.'"
>
> -Incontinence Focus Group Participant

Who is a Good Person to Talk to?

There are several reasons why you might pick a specific person to talk with about your incontinence. The following Table describes different types of relationships. For each type of relationship, write in people who you know.

Types of Relationships and People to Whom you Might Disclose

Type	Description	People you know in this category
Functional Relationship	The person provides some function to you where knowing your experiences with incontinence might help accomplish the function. Functional relationships include work supervisors, coworkers, teachers, and team members.	
Supportive Relationship	The person seems to be friendly and will provide support and approval to you when they find out about your experience. These may include coworkers, neighbors, friends, faith leader, or family. Characteristics of a supportive person include pleasantness, open-mindedness, concern for others, loyalty, trustworthiness, and helpfulness.	
Empathic Relationship	An empathic relationship is different than a supportive relationship. People with an empathic relationship have had some kind of similar experience and can really connect to what you are feeling: *"I know what it's like to have incontinence."* Their characteristics include: ▪ personal experience with their own incontinence or with a friend or family members ▪ willingness to listen ▪ an understanding nature ▪ kindness	
Healthcare Relationship	Healthcare providers include doctors, nurses, therapists, or others who can provide you with treatment and support.	

How Might Others Respond to My Disclosure?

LEARNING OBJECTIVES

- Understand how disclosure will affect people around you
- Examine and consider different ways people may respond to your disclosure

Be certain of one thing: disclosure will impact the people around you. You need to consider the various ways in which people may respond and then plan your response accordingly. The table below lists a variety of reactions to disclosure that are sorted into groups by positive versus negative emotional response.

How People Might Respond to My Disclosure

Positive Response	Negative Response
Understanding *"It must be hard living with that."* **Interpersonal Support** *"I'm here for you if you need someone to talk to."* **Assistance** *"Let me know how I can help."* **Neutral** *"Okay."*	**Disrespect** *"It's not that big a deal—it's not like you're losing your job or something."* **Discrimination** *"I can't give you extra breaks. This is the job—either take it or leave it."* **Annoyance** *"Now I have to fill in for you all the time."* **Avoidance** *"I'd rather you didn't ride in my car."* **Gossip** *"Hey, did you hear about Joe? He wet his pants the other day."* **Blame** *"You could control it if you just plan ahead. You're probably just drinking too much water."*

Think about some of the reactions you've actually experienced and/or those you might experience in the future. Then list them below, including both positive and negative.

How Will I React to Negative Disclosure Experiences?

Although you hope disclosure experiences will be positive, you should also be mentally prepared for negative responses. Look at the negative responses you just listed.

How might you feel if you experienced these negative responses in the future?

How would you respond or react to the person?

What Do I Do with My Feelings?

A person's response to your disclosure could bring up some strong feelings for you, such as anger, embarrassment, disappointment and distrust. While there are many ways to cope with these feelings, you might start with reviewing the section *Challenging Internalized Stigma* in Session 1. When someone reacts negatively, you might internalize their responses and start feeling bad as a result. Here are some ways people have used to cope with these feelings:

- Talk through the situation with a person who already knows about your incontinence and who you are **sure** will be supportive.
- Try relaxation exercises like deep-breathing or meditation.
- Express your feelings through art or writing—write in a journal, paint a picture, etc.
- Think about the other person's perspective and why they might have reacted negatively. For example, maybe they were caught off guard, were having a bad day, don't know any better, or have old-fashioned attitudes.
- Even a negative response can have a positive side—try to think about those. For example, "at least I know now that she can't be trusted with a secret" or "well, even though it didn't go that well, I got it off my chest; hopefully next time it will go better."
- Distract yourself by doing an activity you enjoy.

> "Like most uncomfortable things, it [incontinence] becomes a joke, and then it becomes commonplace, and then it becomes passé."
>
> -Incontinence Focus Group Participant

What is your plan for coping with your feelings? What are you going to do with these feelings? Write some ways you plan to cope in the space below.

How Do I Handle Unplanned Disclosure?

Things happen, so how do I deal with it when I have an "accident" or when someone finds out about my incontinence? Our first instinct is often to feel shame and embarrassment, then try to hide it or "play it off." Embarrassment is a reaction that's been communicated to most of us since infancy and may be hard to counteract. When the disclosure is unintentional, we may feel that the other person has the power or control in the situation. While unplanned disclosure can certainly be uncomfortable, it can be an opportunity to reduce the secrecy and stigma that surrounds incontinence. As you learned in Session 1, there are stereotypes about incontinence ("that only happens to old people," "they could control it if they tried" etc.). Unplanned disclosure can be an opportunity to educate others about incontinence and show others that it's possible to live a full and active life despite incontinence. Unplanned disclosure can also be a good time to think about and challenge internalized stigma. If you need to, review Session 1 to see if you might need a refresher in challenging internalized stigma. We have to deal with both our external reaction (what we say to the person who found out) and the internal reaction (how we think or feel in response to the unplanned disclosure).

Examples of external reactions

Secrecy and avoidance: "Please don't tell anyone." "That's never happened to me before."

Anger: "What are you doing in here anyway—stay out of my business!"

Candor: "Well, I'm glad you know now—that's actually why I don't go out to concerts with you anymore."

Humor: "You can't take me anywhere."

Educational: "You know, this is more common than you think."

> Reflect: Which of these reactions might challenge stigma around incontinence? Which might reinforce it?

Examples of internal reactions

Worry: "What will they think of me now?"

Shame: "How embarrassing - I can't believe that just happened."

Indignation: "It's not fair that I have to deal with this all the time"

Relief: "Well, at least I don't have to worry about keeping the secret anymore"

Surprise: "Wow, that actually wasn't bad."

Optimism: "Maybe now I have someone to talk with about it."

Preparing for Your External Reactions

Unplanned disclosures can certainly catch you off guard, but thinking about it in advance can help you feel better prepared and more confident. Do any of the external responses listed above seem like something you might say? You will want to personalize your response so it seems like something you would actually say. In the space below, use your own words to try out some possible external reactions to unplanned disclosure.

What are some things you might say or do after an unplanned disclosure?

Preparing for Your Internal Reactions

It might also be helpful to prepare for the internal reactions to unplanned disclosure. The sections in this toolkit on challenging internalized stigma and dealing with negative responses to disclosure can be helpful here. On the next page, write how you might try to change your internal reactions.

In what ways might you try to change your internal reactions (your thoughts and feelings) to an unplanned disclosure?

Personal Story: Twila Yednock

When I look back on it, I probably had this problem even in high school. I recall having to go to the bathroom more often than my friends, and I remember being embarrassed to ask my date to stop somewhere AGAIN so I could use a bathroom AGAIN! I hated to ask, and therein lies the problem! Why are we so embarrassed by a function everyone has to do?

However, incontinence didn't worsen to the point of maddening until I was in my 40s, although I always had a “frequency” and “lack of resistance to the urge” problem. My husband and I would be out shopping in a store and I'd have an overwhelming urge to pee, and I'd have to squat down or kneel and pretend to be examining the merchandise on the lower shelf until the urge passed, unless I could find a place to sit down. I have no idea why it didn't occur to me to use pads to keep from leaking on my clothing, except that it really wasn't something that was advertised on TV or in print ads way back then. So I muddled along trying to cope with the urges, which in my case sometimes would happen multiple times an hour. If only there was always a chair to sit down on whenever it happened.

My husband finally caught on to what I was doing (of course I couldn't tell him!), and then it made him irritated to see me dancing around in a register line, or pretending to examine a bottom shelf. To this day, he points out bathrooms to me so I'll know where they are just in case. However back then, he was upset and embarrassed that I would have “an episode” and not be able to hold it. People that don't have it cannot imagine what it's really like.

Honestly, there was really nothing I could do about it. Eventually, we were able to calmly discuss it and he understood how bad it was...I just had to be brave enough to admit it. And this was MY HUSBAND! Why do we have such an aversion to matters of the toilet, and why do we put ourselves through the misery of keeping it to ourselves?

I had been volunteering for the Simon Foundation since 1992. One time, I had to go to Montana for a speech and program. I gave one presentation right off the plane, and the next one was early the next morning. I believe I had 2 cups of coffee, some grapefruit juice, and another bladder irritant of some kind, and then stepped to the podium. Of course, it wasn't long before I had to go. Now, mind you, I was standing there telling these folks that they shouldn't be embarrassed to admit they had to go rather often, and that there was absolutely no reason not to stop in the middle of anything to say “Excuse me, I have to go.... right now!”, so why was I standing there dribbling down my nylons into my heels? Obviously, I didn't think I could stop in the middle of that speech, when it would have been a perfect example.

Having participated in the sport of curling for most of my life, I was excited to go to the Olympics in Italy in 2006. The venues were at least 40 kilometers (approximately 25 miles) into Torino or even further up the mountain for the ski events. Bathrooms were not readily available.

I leaked into so many pairs of pants that I finally had to stay home from events one day so I could wash some things. Although I was with one of my best friends on this trip, she also had invited two of her work friends, including a man, so I didn't really admit to them what my issue was. They may have guessed from my odd behavior, but otherwise must have been mystified. Again, there was undoubtedly help to be had for me, but I didn't look for it, nor did I admit it to people who likely would have understood.

I went to the next Olympics in Vancouver in 2010. Our housing was all the way across town from the curling venue where we spent much of our time. We had breakfast, got a cab to take us to the bus station, and the bus to the train station, then changed trains in downtown Vancouver, and eventually had to walk another half mile to the facility, then wait in Security lines. The bathrooms were port-a-potties. It was pure misery every day, going back and forth....did I mention that the train and bus stations had no bathrooms? By then, I had explained to my friend what my issues were with the overactive bladder, so at least she tried to help in any way she could. We did have to get out of the station in downtown, and go find a bathroom, before we took the last train ride and walk. Again, why didn't I want to admit to my best friend what was wrong, and why didn't I seek help?

Along the way, one female GP I finally mentioned it to gave me a prescription, but even after a few months, it didn't seem to help. A gynecologist suggested I take Premarin, but again, it didn't help. I also worried whether it was appropriate at my age. Informing my friends, being honest about the disease, and finding absorbents finally have made the difference in my life to make urge incontinence manageable. Now the problem is only what size problem should I plan for?

I inform all my doctors now and make sure my friends understand that if I have to use the bathroom, I'm not kidding, nor do I have much wait time. If we are walking around, if I say I need to sit down, they know why and help find something. Openness is the only way, but it is so hard to achieve, and I couldn't believe it could be so hard to just accomplish that. I blame our overall toilet shaming from an early age for much of our reticence, and society's attitude and stigma problems. However, I do wonder why I was so reluctant to seek help, when I knew there would possibly be something I could do. After all, I do work for an organization whose mission is helping people with incontinence. It didn't help that only the female GP, and none of the other doctors, asked about incontinence.

If we can just start removing the stigma, and keep finding new ways to manage or cure incontinence. It will be a great day when it's finally defeated! I do find ads on TV, in magazines, etc. to be helpful with bringing the issues into the open and into the consciousness of the public. But, how do we get folks to realize there is help to be had, and no one is executed for asking for it?

Reflection

In what ways do you identify with this story?

What do you think about Twila’s disclosure decisions?

SESSION 3

How to Tell Your Story

SESSION OVERVIEW

As a result of Sessions 1 and 2, you might have decided that you want to disclose.

Hence, this last lesson has several goals.

- Learn a way to tell your story in a personally meaningful way
- Review how it felt to tell your story
- Think about what you learned from telling your story and how you will move forward with next steps

Following is an example of one way that you might tell your story in a personal and meaningful way.

Personal Story: Steve Burns

In 2009, at the age of 48, I had a disc rupture at the base of my neck causing me to be paralyzed from the chest down. I was fortunate to be in the hospital for testing at the time and underwent emergency surgery to remove the ruptured disc and perform disc fusion surgery. I spent 14 weeks in inpatient rehab followed by 16 weeks of outpatient rehab. I slowly regained the ability to walk over the course of almost a year.

The outward signs of a spinal cord injury (SCI) are fairly obvious-- wheel chairs, walkers, canes. People not familiar with SCI do not realize all the internal issues that accompany the injury; bowel and bladder issues, sexual dysfunction, nerve pain, muscle spasms, etc… One of the internal issues I still deal with daily is urinary incontinence. I am fortunate to be able to void voluntarily for a majority of the time. I need to monitor my intake of liquid, not drink too much at one time, and stop drinking liquids about 4 hours before bed. I also must be aware of how far I am driving or walking so I feel comfortable that a restroom will be nearby when needed.

I use a catheter to void before bedtime, driving long distances, or going for long walks. When the urge to void strikes, it is hard for me to control it. I have had plenty of close calls and a few accidents over the years. I have had to pull my car over while traveling with family, friends, and on a couple occasions new coworkers. I have had to duck behind trees while walking in the neighborhood. On too many occasions I have needed to excuse myself abruptly in the middle of a conversation to find the nearest rest room.

It was fairly easy to tell people who know me about my incontinence. They are aware of the injury I have and most asked a lot of questions about how I was recovering. The fact that I was rushing off to find a bathroom at a moment's notice was an easy lead in to a discussion about bladder issues. I do not look to disclose to people unless they are genuinely curious as to the effects of my SCI or a situation arises where I feel it is probably a good idea to explain the panicked look on my face and the sudden movement that follows.

A few years ago, I was driving my boss (Pete) to a sales meeting in downstate Illinois. I had drank too much water that morning and the urge to void crept up on me quickly. To my relief, I soon saw a sign for a rest stop in 3 or 4 miles. As the urge increased, my foot pressed harder down on the gas pedal. As we reached speeds of 90 MPH, I noticed Pete looking at me with concern. I told him that I really needed to empty my bladder and apologized if I was making him nervous. He told me not to worry, he was ok.

We rounded a curve before the rest area only to find it was closed due to construction. I pulled off the side of the road and ran into the woods to relieve myself. When I got back in the car, Pete didn't say anything but I felt like I owed him an explanation. He knew that I had a spinal cord injury so I was able to explain that my SCI effected my bladder to the point where I did not always have control. He was very understanding and I think he gained a little more respect for the challenges I face on a daily basis.

It does not bother me to disclose that I have urinary incontinence. I do not usually use that terminology though. I tell people I have bladder issues. If they understand incontinence and use that term, then I talk in those terms as well.

Because the effects of my SCI are not very noticeable, I do not feel that people think of me differently because of my bladder issues. I am also the type of person that really doesn't care if they do. In the end, we all have our challenges that we need to overcome. Making adjustments to my daily habits due to my incontinence has just become part of my routine. It is a small part of who I am but definitely does not define me.

Reflection

What do you identify with in the story?

What parts of it might have been hard to tell?

What parts of the story might you have said differently?

Worksheet 2 provides a template to fill out and yield a story that might work for you.

The details of your story will vary depending on where you tell it. For this activity, first select a person who you might disclose to, such as a friend, acquaintance, coworker, boss, or intimate partner. Remember, this is only one way to tell your story and you can complete Worksheet 3 again for each disclosure that you are considering.

Instructions for Telling Your Story

Read each section below for guidance in completing Worksheet 2.

Who are you considering disclosing to?

Identify the person(s) who you might disclose to here. If you haven't done this already, you may want to use Worksheet 1 (from Session 1) to consider the pros and cons of disclosing to this person before you fill in Worksheet 2.

What is your purpose (or goal) for disclosing to this person?

Clearly state why you might want to disclose to this person. Consider your responses from Worksheet 1 (Session 1).

What method will you use to disclose?

Describe the method that you will use to disclose. Examples might be face-to-face, over the phone, or by email.

If speaking to someone face-to-face, what setting and/or timing will you choose for the disclosure?

Describe the setting (e.g. at work, at home, over a meal) that you plan to disclose in. Is there a particular time that might be best? For example, if you are disclosing to your boss at work, it might be best to set up a meeting time that will be convenient for them. If you are disclosing to an intimate partner, you might wait until you can speak privately.

What tone do you want your disclosure to have? How do you want to come across to the other person?

There are many options for the tone of your disclosure: humorous/playful, serious, professional, courteous, casual, instructive, or confident. The tone you choose will depend on the person who is hearing your story and your purpose for disclosing. For example, if you are telling your preschool-aged niece who is visiting your house, you might keep the tone casual or playful. If you are disclosing to your boss, you will likely want to keep a professional and confident tone.

What word(s) will you use to describe your bladder challenges?

Decide what word(s) you will use to describe your bladder challenges. You will want to consider what words your listener will understand, but you also want to avoid perpetuating stigmatizing terms (see Session 1).

How will you initiate the conversation? What is your lead-in?

Write down verbatim a short phrase you will use to begin the conversation. The lead-in will set the tone for the conversation and should give the listener a hint at your purpose.

For example, “Do you have a minute? I want to explain to you why I haven’t been around lately.” or “Can I tell you something in confidence?” or “Can I explain to you why I didn’t want to go on that trip?”

Is there anything you want to ask of the person who is hearing your story?

The purpose of your disclosure might involve the need to ask the other person for something. Sometimes you won’t get what you want unless you ask! Here are some examples:

- “I’m so frustrated, would you just let me vent for awhile?”
- “I would like to request an accommodation.”
- “Could you please come to my doctor’s appointment with me?”

Describe your “ask” in detail here, just as you think you’d like to say it to the person.

What does the person to whom you are telling your story <u>need</u> to know and why?

Again, this goes back to the purpose. If the purpose is to get medical care, you need to describe your physical symptoms in detail. If the purpose is to get understanding and support, you might talk about how incontinence impacts your everyday life. If the purpose is to get an accommodation at work, you might just need to say that you have a condition that requires you to take frequent restroom breaks. Use the space in Worksheet 2 to outline which details of your story that you will share with them.

Is there anything you may want to educate them on?

Sometimes you might need to provide additional information or resources to the person you are disclosing to. For example, you may need to explain your rights under the Americans with Disabilities Act to an employer or the physiology of your incontinence to your partner. Write here what you might need to educate them on and in what form this will be (video, website, book, pamphlet, verbal, etc.).

What else might you want to include in your disclosure?

Maybe you can think of other things you’d like to talk to the person about. Here are some things that others have felt important to include:

- Share some challenges you’ve had in managing your incontinence.
- Share some ways that you’ve been resilient in dealing with or managing your bladder challenges.

- Tell them how difficult it is for you to talk about this with others.
- Describe some of the negative reactions or discrimination you’ve experienced.

How will you consider the needs of the person who is hearing your story?
Think about how much time they have to listen to your disclosure, how overwhelming your disclosure might be for them, and how they might perceive it. Write down what you might need to do to make your listener more comfortable or receptive to what you are saying to them.

How do you want to end the disclosure?
Think about how you want to end the conversation. There are many possibilities; you have to find something that feels natural to you. For example, you might:

- Ask them to not to share this information with others.
- Thank them for listening to you.

Write down the short phrase that you will use to end the conversation. Keep in mind that the close of the conversation will depend on how the disclosure went, so you’ll need to be flexible on this one.

Please note: In the appendix, we’ve included a simple fact sheet on incontinence as a tool in telling your story.

Worksheet 2

A Guide to Telling My Story

Who are you considering disclosing to?

What is your purpose (or goal) of disclosing to this person?

What method will you use to disclose?

What setting and/or timing will you choose for the disclosure?

What tone do you want your disclosure to have? How do you want to come across to the other person?

What word(s) will you use to describe your bladder challenges?

How will you initiate the conversation? What is your lead-in?

Is there anything you want to ask of the person who is hearing your story?

What does the person who you are telling your story <u>need</u> to know and why?

Is there anything you may need to educate them on?

What else might you want to include in your disclosure?

How do you want to end the disclosure?

Try It Out

Now you have a chance to practice. First, review the points you made in Worksheet 2. This is going to be your story. Take five minutes, find a quiet space and run through it in your head. Maybe you want to write out the story on a separate sheet of paper.

If someone already knows about your incontinence, you might want to practice your disclosure with them. You could also practice in front of a mirror or video record yourself. You can try changing the wording or order of your content to see what feels best. You should practice until you feel comfortable with the content, but not so much that you've memorized every word. It might be helpful to create a card with a few bullet points to make sure you cover everything. You want it to feel natural and leave room for some flexibility, depending on the listener's response. Be aware of your body language such as posture, hand gestures, tone of voice, and facial expression. If you are tense, you may want to take some deep breaths or use other strategies to relax yourself. Be aware of the other person's expressions and body language so you can change your approach as needed. Refer back to what you wrote in Worksheet 2 if you need to make changes.

Worksheet 3

Quality of Disclosure Experience

Use this each time you disclose as a tool to help you learn and grow. Rate the quality of your experience telling your story and describe your feelings at the bottom of the page. Don’t discount any feelings you had, even if you think others may think they are silly; these are important in developing your strategy for disclosure.

How therapeutic was it to tell your story?

not at all						very
1	2	3	4	5	6	7

How comfortable did you feel while disclosing?

not at all						very
1	2	3	4	5	6	7

How positive was your experience telling your story?

not at all						very
1	2	3	4	5	6	7

How empowered did you feel after disclosing?

not at all						very
1	2	3	4	5	6	7

Please note anything else not already discussed about the quality of your experience.

Resources

Here are some resources that you may need if you want additional information about support for incontinence.

The American Urogynecologic Society

The American Urogynecologic Society (AUGS) is dedicated to research and education in urogynecology, and the detection, prevention and treatment of female lower urinary tract disorders. AUGS members are practicing physicians, nurse practitioners, physical therapists, nurses and health care professionals, as well as researchers from many disciplines, all dedicated to improving the urogynecologic health of women.

https://www.augs.org/

Association for Pelvic Organ Prolapse Support (APOPS)

APOPS is a USA-based nonprofit advocacy agency founded to generate awareness of pelvic organ prolapse (POP), and to provide support and guidance to women navigating the physical, emotional, and social impact of POP, of which incontinence may be one of the symptoms.

https://www.pelvicorganprolapsesupport.org/

Caregiver Action Network

The Caregiver Action Network is a family caregiver organization working to improve the quality of life for the more than 90 million Americans who care for loved ones with chronic conditions, disabilities, disease, or the frailties of old age. CAN provides education, peer support, and resources to family caregivers across the country free of charge.

https://caregiveraction.org/

Continence Central

Continence Central is a Simon Foundation for Continence website devoted to providing a wide variety of product information for US consumers. The website also includes a decision tree to help consumers locate the most appropriate types of products for their type of incontinence, along with information on reimbursement of incontinence products.

https://continencecentral.org/

Depression and Bipolar Support Alliance

This organization has on line and in person support groups throughout the country.

https://www.dbsalliance.org/

Families for Depression Awareness

The mission of Families for Depression Awareness is to help families recognize and cope with depressive disorders. Their purpose is 1) to help families recognize and manage the various forms of depression and associated mood disorders, 2) to reduce stigma associated with depressive disorders, and 3) to unite families and help them in coping with depression.

http://www.familyaware.org/

HealthUnlocked.com

HealthUnlocked is a social network for health. By finding others with similar health backgrounds people can take on day-to-day health concerns together. And because their communities are set up by leading health organizations, people have access to credible support. The Simon Foundation for Continence has a community on HealthUnlocked.

https://healthunlocked.com/simonfoundationforcontinence

Health In Aging

Health In Aging was created by the Health in Aging Foundation, the official foundation of the American Geriatrics Society. It is a unique site for all older people and their caregivers providing expert information on health issues common in older people.

https://www.healthinaging.org/

National Alliance on Mental Illness

The National Alliance on Mental Illness (NAMI) is an association of more than 500 local affiliates to raise awareness and provide support and education.

https://www.nami.org/

National Association for Continence

The National Association For Continence is an organization dedicated to improving the quality of life of people with incontinence, voiding dysfunction, and related pelvic floor disorders. NAFC provides an online community for those with incontinence.

https://www.nafc.org/

Society of Urologic Nurses and Associates

The Society of Urologic Nurses and Associates is a professional organization committed to excellence in clinical practice and research through education of its members, patients, family and community. SUNA offers patient education fact sheets about overactive bladder and incontinence in English and Spanish. They also have some links to educational videos.

https://www.suna.org/

Talking to Your Doctor About Bladder Concerns

This is an interactive patient education video program that provides information on overactive bladder (OAB) and also on how to discuss all your bladder symptoms with your doctor or healthcare provider. Real patients (not actors) provide more insight as well into the daily struggles of living with different bladder symptoms. The Simon Foundation for Continence collaborated with ProPatient to create this program. https://app.propatient.com/visits/talking-to-your-doctor-about-bladder concerns/scene/5b843bf787cffa000f116709

The Simon Foundation for Continence

The Simon Foundation for Continence is dedicated to bringing the topic of incontinence out into the open, removing the stigma surrounding incontinence, and providing help and hope for people with incontinence, their families, and the health professionals who provide their care.
https://simonfoundation.org/

Trudy Triumph

A blog written by Trudy Triumph that shares personal experiences and challenges faced by those with a neurogenic bladder and/or bowel.
https://trudytriumph.com/

Urology Care Foundation

The Urology Care Foundation is the official foundation of the American Urological Association. They partner with physicians, researchers, healthcare professionals, patients, caregivers, families and the public to support and improve the prevention, detection and treatment of urological diseases. The site hosts a “Find a Urologist” directory and has extensive information on stress urinary incontinence and overactive bladder.
https://www.urologyhealth.org/

Us Too

Us Too helps empower men diagnosed with prostate cancer, providing educational resource and support services to fight prostate cancer. Us Too offers information for men with prostate cancer and their partners about incontinence, sex and intimacy after prostate cancer diagnoses and treatment. Their website offers information to help make informed decisions on testing, active surveillance, treatment options, and the management of side effects, including incontinence. https://www.ustoo.org/

FINAL WORD

A Word from the Simon Foundation for Continence

For over three decades, I've had the privilege to speak one on one with individuals about their reaction to living with a misbehaving bladder. I've spoken to men and women of all ages, from all walks of life, with every type of incontinence from a wide variety of causes. And one fact stands out above all I have learned from these conversations - there is no correlation between the amount of urine leaked and a person's reaction to their incontinence. There is no right or wrong reaction to incontinence, nor how to adjust to this health condition.

For many, if not most, it is hard emotional work to come to a point where the bladder can be ejected from the center of their universe - others may need only to practice the various steps described here to become comfortable with the idea of disclosing their incontinence - and others are tough realists who simply recognize their misbehaving bladder as another body part subject to the whims of luck and health. Whichever category you fall into, the authors hope that this toolkit has been of help to you.

Many hours of work from a very dedicated team have gone into creating this toolkit, with one primary objective in mind - to help you live a full and productive life by achieving the ability to view incontinence like every other health condition. As each of us affected by incontinence achieve this goal we will be helping to heal ourselves, educate others and defeat the stigma that too often still surrounds the loss of bladder control.

Although we would like it to be otherwise, it is a common feature of social change that change happens only when people directly affected by a stigmatized condition or characteristic shed their own self-doubt and act from a position of empowered self-respect.

You know the expression *Become the change that you wish to see in the world* (Mahatma Gandhi). Everyone will take a different path, will evolve or disclose at a different pace, but we each have some power to shape our own lives and how the world sees us. We hope the tools here will contribute to what you do along your path.

We wish you the best.

Cheryl B Gartley

President and Founder

APPENDICES

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Appendix 1
My Disclosure Journal

My Disclosure Journal

Use this to keep track of who you tell your story to. Fill this out each time you disclose so you will have a record of disclosure. Print additional copies of this form or just write your answers on a sheet of notebook paper.

Name of the person to whom you disclosed: _______________________________________

Date: ____________ Place: _____________________

My goal or purpose for disclosing

What I said:

How the person reacted:

How satisfied was I with the exchange? (1-10 scale)

How positive was the exchange? (1-10 scale)

What would I do differently next time?

Appendix 2
Did this Program Help?

Did this Program Help?

We are interested in your feedback to improve this program.
Please answer the following questions and send or email to:

The Simon Foundation for Continence
P.O. Box 815
Wilmette, IL 60091
info@simonfoundation.org

1. What did you learn from the program?

2. What did you find most helpful?

3. What could be added or improved upon?

4. How would you rate your experience with the toolkit?

poor									**excellent**
1	2	3	4	5	6	7	8	9	10

5. Would you recommend this toolkit to someone else? Yes or No?
   Why or why not?

Appendix 3
Extra Forms

Worksheet 1

The Benefits and Costs Worksheet

Setting: ______________________________________ **Person**: ____________________

Reason for Disclosing:

____

Disclosure Expectations: What do you want or expect from the person you disclose to?

____

____

Benefits	Costs

Put a star (*) next to benefits and costs you think are especially important.

After considering both the benefits and costs in your situation:

☐ I will probably **NOT talk about my** incontinence in this setting.
☐ I will probably **talk about** my incontinence in this setting.
☐ I have decided **to put off** my decision. I'm just not sure.

Worksheet 2

A Guide to Telling My Story

Who are you considering disclosing to?

What is your purpose (or goal) of disclosing to this person?

What method will you use to disclose?

What setting and/or timing will you choose for the disclosure?

What tone do you want your disclosure to have? How do you want to come across to the other person?

What word(s) will you use to describe your bladder challenges?

How will you initiate the conversation? What is your lead-in?

Is there anything you want to ask of the person who is hearing your story?

What does the person who you are telling your story need to know and why?

Is there anything you may need to educate them on?

What else might you want to include in your disclosure?

How do you want to end the disclosure?

Worksheet 3

Quality of Disclosure Experience

Use this each time you disclose as a tool to help you learn and grow. Rate the quality of your experience telling your story and feelings that you experienced. Don’t discount any feelings you had, even if you think others may think they are silly; these are important in developing your strategy for disclosure.

How therapeutic was it to tell your story?

not at all						very
1	2	3	4	5	6	7

How comfortable did you feel while disclosing?

not at all						very
1	2	3	4	5	6	7

How positive was your experience telling your story?

not at all						very
1	2	3	4	5	6	7

How empowered did you feel after disclosing?

not at all						very
1	2	3	4	5	6	7

Please note anything else not already discussed about the quality of your experience.

Appendix 4
Urinary Incontinence Fact Sheet

Urinary Incontinence Fact Sheet

Urinary incontinence (UI) is the involuntary leakage of urine and is estimated to affect 200 million people worldwide. There are many types of incontinence.

- **Stress incontinence:** urine leakage from physical exertion, coughing, sneezing, or laughing
- **Urge incontinence:** urine leakage accompanied by a strong urge to urinate, also called overactive bladder or OAB
- **Mixed incontinence:** both stress and urge incontinence
- **Overflow incontinence:** release of urine from an over-full bladder, often in the absence of any urge to urinate
- **Enuresis**: incontinence while asleep, sometimes called bedwetting
- **Functional incontinence**: Cognitive or physiological factors prevent individuals from reaching the toilet effectively

Myths and Facts

Myth: Incontinence only happens to older adults.

Fact: Urinary incontinence is a common problem that affects all age groups, although the risk increases with age. The female young adult population has a 20% to 30% prevalence rate. Males ages 15 to 64 have a 2% to 15% prevalence rate.

Myth: Urinary incontinence is an inevitable aspect of old age.

Fact: Incontinence is not a normal part of aging. It is an indication of something else happening in the body. The risk increases with age because of the many medical problems that may occur over time. That being said, many people leave the planet continent.

Myth: UI is a result of childbirth.

Fact: Childbirth may contribute to incontinence in some women. Childbirth can weaken pelvic floor muscles and result in UI.

Myth: Once you have UI, you just live with it. It is permanent.

Fact: There are a variety of treatments and management options for UI. Treatment may or may not require drugs or procedures and can improve incontinence. Every treatment may have both positive and negative effects. The success rates vary in different people and each person must determine if and how they want to engage in a treatment plan based upon the pros and cons and how the selected treatment will impact them. Management of UI depends on the type of UI and the individual's unique preference.

Myth: Restricting fluid intake can improve UI.

Fact: Restricted fluid intake can result in concentrated urine that irritates the bladder. Adequate fluid intake dilutes urine and maintains a normal bladder capacity. Restricting fluid intake can help, especially prior to bedtime, but it can also cause harmful side effects like dehydration.

Myth: You can be too old for treatment.

Fact: There is no age limit for UI treatments. Treatments vary based on the type of UI. Treatment and management options include: biofeedback, bladder retraining, physical therapy, diet and exercise, medications, surgery, Kegel exercises and pelvic floor stimulation, external electrical stimulation (E-stim), implanted neural stimulator, absorbent products, external catheters, intermittent catheterization, indwelling catheters, penile clamps, portable urinals, and pessaries. New products and devices are coming to the marketplace as stigma around incontinence decreases and companies become aware of the need for innovation. Individualized assessment by a healthcare professional can help to find the best intervention.

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