



THE SIMON
FOUNDATION
FOR CONTINENCE

To Tell Or Not To Tell

A NEW PROGRAM FROM THE FOUNDATION

Incontinence creates challenges in a wide variety of situations including the demands of the workplace, fear when traveling or attending 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 about this health condition and who to tell it to. Will a disclosure help us navigate our circumstance or simply create an embarrassment?

President and Founder of the Simon Foundation for Continence, Cheryl Gartley, stated: "For over three decades I've spoken to men and women of all ages, from all walks of life, about their reaction to living with a misbehaving bladder. And

one fact stands out above all others from these conversations - there is no correlation between the amount of urine leaked and a person's reaction to their incontinence. Also, there

is no right or wrong reaction to incontinence, nor how to adjust to this health condition."

The *To Tell or Not to Tell* Toolkit contains an Incontinence Disclosure Program designed to help people who have been keeping incontinence a secret. The program is designed to provide

a guide to the decision-making process. The information included in the program is based on many hours of research conducted with focus group attendees who shared their experiences of telling others.

The Toolkit is divided into three sections - the first contains methodology to help you decide what the personal pros and cons of disclosing are in your own life.

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Reducing Stigma One by One...

Editor's Note: When you are struggling with loss of bladder and/or bowel control it is often difficult to imagine the possibility of ever again living a life of your own choosing.

Regardless of circumstances, the pursuit of happiness is often dependent on choices, big and small. From time to time the Informer will share the candid stories of individuals from all walks of life and their journeys to living full lives in spite of intractable incontinence.

These stories are shared with permission and shine a spotlight on people in the frontline who have chipped away at the daily inconvenience, the debilitating high hurdles, the persistent stigma that surrounds incontinence; people who by their example benefit us all.

Paul's Story: 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. Products and devices were limited and not nearly as developed as today's.

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Then IF you decide that disclosing, at least to some in your life, might make life better for you, the second and third sections will help you decide how you want to proceed. Next you'll be looking carefully at whom you wish to share this information with (a doctor, your best friend, someone you are dating, your family, or a boss or co-worker); and lastly, in the third section of the program, determining what you want to say. 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 simply react, a typical human response.

To Tell or Not to Tell was developed by the Simon Foundation for Continence in collaboration with a team of psychologists and researchers at the Illinois Institute of Technology (IIT). It is based on the pioneering work of Professor Patrick Corrigan, an internationally recognized psychologist whose research focuses upon the real world experiences of individuals who have dealt with the pros and cons of disclosing various health conditions.

The Simon Foundation's team who developed our program is comprised of individuals who volunteered long hours, because they knew personally in their day to day lives, the impact of incontinence. These volunteers believe deeply in the goals of *To Tell or Not to Tell*. Following are a few brief comments from this team extracted from the Toolkit's more in depth personal stories. (In addition, many personal experiences of participants in the research focus groups are also found in the Toolkit.)

Jeff Albaugh "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 inconti-



nence) in my practice. 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. 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 whole-hearted 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. 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 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. 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 their life. This program should help a lot of people, and I am proud to have helped develop it. You'll be happier if you learn to be more open, because so much apprehension goes away."



Susan Hayward "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 and 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."



Steve Burns "After my spinal cord injury, one of the issues I needed to learn to live with was urge incontinence. 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. 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."

Launching the Program

As part of the launch for this unique new program, the Foundation is embarking on building greater awareness in the medical and nursing communities. Dr. Albaugh from our team presented *To Tell or Not to Tell* and the research supporting it in

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ONE VOICE An Editorial

Cheryle B. Gartley
President and Founder



"The more things change, the more they stay the same" is a fairly common expression, but describing its meaning can be challenging. The following may help - "a proverb that means many things remain consistent even as changes happen."

I doubt there is a better way to describe changes in the world of incontinence over the 40 years that The Simon Foundation for Continence has been at work.

The More Things Change

Since the 1980's when the Foundation took up the challenge, much has, in fact, changed. Today there are a variety of treatment options available and physicians, nurses, and physical therapists are specializing in helping people with both urinary and bowel incontinence. An indication of this expansion of interest among health professionals can be seen in the growth of The Continent Club. In 1971 a small group of 50 professionals met in the UK - primarily researchers who realized they were talking past each other due to the lack of agreement on terminology as it related to the bladder. Their first project was to fix this turmoil by standardizing the nomenclature used to talk about urodynamics.

Now, 50 years later, the Continent Club, renamed the International Continence Society (ICS) is a thriving organization with a membership of over 3,000 worldwide (comprised of urologists, uro-gynecologists, physiotherapists, nurses, basic scientists, researchers, and leaders of organizations like The Simon Foundation) who meet annually to progress all aspects of the science of incontinence.

Another marker of change was long warranted signage finally appearing over drugstore aisles reading "Incontinence Products." Yet in this same era the magazine published by AARP would not accept advertisements for incontinence products, while network television executives refused product advertisements by national brands, forcing major corporations producing

incontinence products to purchase air time on individual local TV stations all across the country in order to obtain national coverage.

The educational landscape has also changed, growing from a time when library shelves on this topic were completely bare, to a host of books for people with incontinence, not only found in libraries, but increasingly on the shelves of bookstores. Nonprofits addressing incontinence have grown too, not only individually and with expanded information to offer, but also in number, each with a slightly different focus, all welcome and needed.

Medications, absorbent products, devices, implants, and new surgical approaches that weren't even dreamed of 40 years ago are creating hope and changing the future of incontinence. On the homepage of the Simon Foundation's main website's (www.simonfoundation.org) under Research, Industry, Medical and Scientific News, is a plethora of information regarding advances in every category of incontinence treatments and management.

The More Things Stay the Same

But, alongside all this positivity lurks much that has stayed the same. A long list of entrenched attitudes still exist- for example the stigma, shame, and embarrassment many people continue to feel. And way too many physicians (in fact just one would be too many) still respond to patients seeking help with unhelpful statements that don't reflect a decent standard of practice - "This happens as you grow older." or "You've had four children, what do you expect?" In the patient's own area of responsibility is the contributing issue of individuals who do not report the problem to their healthcare providers or uncritically accept these unsatisfactory and outmoded answers.

Although there are many things that have stayed the same, the ones above are the things in particular that got me thinking about the phrase "The more things change, the more they stay the same." And of course the pandemic entered into the mix with so many facing job losses and the knock down effect of loss of health insurance; fear of seek-

ing healthcare during a pandemic; and people losing ground in terms of mental health leading to increased depression and anxiety.

Like most, the pandemic has challenged me in countless ways, some of which I'm still uncovering. I started the lockdown saying to myself each morning, well let's see what you are made of today. For awhile asking myself that question was motivating, but soon I found most days I needed to be made of sterner stuff than I had ever imagined. So I changed my self talk to a precautionary statement that I'd read somewhere - "I've become 93% feral, and cannot be reintegrated into society." I hoped it would serve as a reminder not to let this isolation turn me into a disheveled hermit. And to be honest, so far this isn't working real well either!

Many speak about how their young children have regressed since the lockdown began. However, much less is discussed about how we adults have also regressed. I have proof of regression in my own life, taught to me by the neighborhood squirrels who come for their daily dose of peanuts when I whistle for them precisely at 4 p.m. each day. Feeding them at their demanded time (yes they sit staring at the door) is not regression, naming them is.

As a child, my turtles were Orangey and Greenie, the cat was Mewsette, and the dog was Hobo...we won't go into the bird's name. I thought the names I assigned to my pets later in life indicated increasing maturity. My first Siamese was named Natasha and then came Marchioness Lavidia of the Wold (AKA Precious). However, the pandemic's batch of squirrel friends have received pretty infantile monikers: Tufts; Chubby; First-up, Blackie - need I go on to prove my point that regression isn't just for kids during the pandemic? Health conditions like incontinence can add their own impact.

On the upside, what the pandemic has done is forced upon us all a chance to reflect. Race, political leanings, church affiliations, rich or struggling, continent or incontinent- no matter which of these categories

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To Tell Or Not To Tell

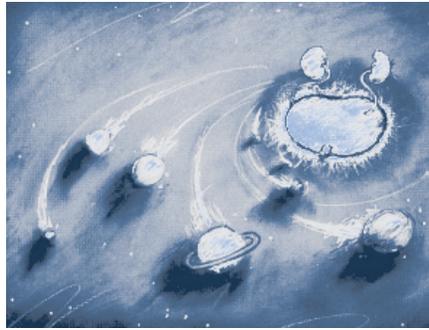
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a keynote speech to the Society of Urologic Nurses and Associates (SUNA) and also gave a presentation to the International Continence Society. Physicians and nurses are aware of the importance of the diagnosis of bladder leakage to rule out the small chance of something else going on in the body that might be serious. Thus, their response to this program was very enthusiastic, hoping it may help people to tell their doctors and nurses about bladder leakage with more confidence and sooner rather than later.

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. Some people may follow the process set out in *To Tell or Not to Tell* and decide that they are managing reasonably well and their privacy about their incontinence outweighs the possible benefits of disclosing their condition more

widely. Even if the decision is “not to tell”, the process described in the Toolkit is still a valuable exercise. You’ll come away knowing that you made a choice not out of fear, but after thoughtful, systematic consideration.

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. Everyone will take a different path, or evolve and disclose at a different pace. We each have some power



to shape our own lives and how the world sees us. We hope the tools in *To Tell or Not to Tell* will help many along their path.

To obtain a copy of the Toolkit go to www.totellornot.org.

An introductory price for a bound copy is \$5.00 or you may download it for free. You may prefer to work through this process by yourself and at your own pace or alternatively, to join one of the program’s four week series of hour long weekly phone sessions.

Led by specially trained Life Coaches and other professionals, the sessions are an opportunity to learn from the experience of others and to share your own ideas if you wish. To register or obtain more information, email info@simonfoundation.org or call 1-800-23SIMON 1-800-237-4666

Reducing Stigma One by One

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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 than I ever thought possible. With encouragement and a big push I found the Simon Foundation. Together, we traveled to Chicago 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 others in my situation. 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 took a positive turn, and I now had the “go to” education.

I participated in more self-help meetings, met more people just like me, and even started meetings in Canada.

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 to be discussed amongst friends and peers, and felt stigmatized when it was brought up. For me, it is no longer a stigma, and I can talk to anyone about it.

Watch Us Grow



We are delighted to welcome Ms. Dominique Waldman who recently joined the staff as Patient Advocacy Coordinator.

Dominique is a graduate of Southeastern College (Wendell, NC) with a BA in Elementary Education and a proficiency in English. In addition to assisting our Vice President, Elizabeth LaGro, in moderating the Foundation's Facebook page and online support community, Health Unlocked, she also monitors the Foundation's emails, information packet requests, and book orders.

Ms. Waldman has attended several meetings on the Foundation's behalf, among them the Annual American Urology Advocacy Summit where Dominique participated in Virtual Meetings on Capitol Hill asking representatives to co-sponsor two bills that would contribute to patient care and doctor accessibility. The AUA Summit also included insight from urology professionals on the impact of COVID-19 on patients. This insight contributed to relevant responses on the Foundation's Health Unlocked patient forum.

Ms. Waldman also attended the Bladder Health Alliance Roundtable. The agenda included planning for Bladder Health month when the Foundation posted key topics for the month of November on its Facebook page. One of the advantages of virtual meetings is the low cost of inclusion at meetings held in Europe, such as the World Federation of Incontinent Patients' recent meeting which Dominique attended that included planning for World Continence Week.

When not at work, she joyfully spends most of her time taking care of her two little boys and volunteering at her local church. One of her primary passions is advocating for all around healthful living.

A Salute To One Of The Finest



James Partridge, OBE (Order of the British Empire, an honor bestowed by the Queen of England to British citizens) died recently of cancer. James did much to help people with facial disfigurements live with pride and to transform public attitudes. As a burn survivor himself from a car fire, he pioneered a movement for face equality as the founder of both Changing Faces, and Face Equality International. To the Simon Foundation for Continence he was a champion helping us lead the way to reducing stigma around incontinence.

How do journeys related to facial disfigurement and incontinence cross paths? It was the wonderful luck of a dedicated board member hearing James speak at a London meeting.

James never declined a request to come to Chicago (our headquarters) to lend his expertise on lessening stigma. From our very first stigma conference in 2013 until a couple years prior to his death, he addressed the impact of facial disfigurement, creating models that health issues like incontinence could adopt.

He enabled many people who might have been inclined to hide from the world to find confidence and to be a visible presence in our world - a shared goal with the

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Thank You

Editor's Note: This issue of *The Informer* was underwritten by an educational grant from NorthShore Care Supply. The Simon Foundation for Continence does not endorse specific incontinence products or medical treatments. Inclusion in this column in no way implies endorsement.



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ONE VOICE An Editorial

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you may fall into, most can agree on one thing - we face the challenge of a lifetime, collectively and individually.

As for those of us who live with incontinence, it is an opportunity to also reflect upon how incontinence pre-Covid negatively impacted life and why, or in what ways, we might have allowed a misbehaving bladder or bowel to cause us to miss out on the fuller life we could have enjoyed then.

Over the years prior to the March 2020 shutdown of life as we knew it, thousands of individuals have contacted the Foundation with stories of their own life regressions. True, no one used the word "regression", yet their letters and emails described exactly that, an all too common pattern of feelings of shame, embarrassment, and fear of being wet in public that led to individuals being isolated in

their home. Without any indication of making a careful thought-out decision, people talked about narrowing their lives, giving over jurisdiction to their bladder or bowel. In other words before the Covid shutdown, millions were already shutdown...no movies, no church, no long flights, no staying with friends.

Today much is being written about what this past year's isolation has done... all of us who live with intractable incontinence can see our past lives reflected in what is being talked about and learned now. What a good time to re-evaluate the choice and impact of compromise and isolation. It might be just the time to explore the Foundation's *To Tell or Not to Tell* Toolkit and actually intentionally decide how you want to live the rest of your life. It may be an unanticipated opportunity in the time of pandemic.

How history will write the story of how we faced this pandemic collectively remains to be seen. However,

how we are facing it individually and what histories we are each writing for ourselves can be examined much sooner, even today.

A Salute To One Of The Finest

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Simon Foundation's work to encourage people with intractable incontinence (leakage which cannot be cured) to live life to the fullest. In 2009, leading by example, James spent a week as a national television newscaster in the UK as part of a campaign to create more exposure for the work of Changing Faces. "I live with my very distinctive face with pride," he said. His ambition was for all those with some sort of facial difference to feel the same.

It cannot be said of many they will be missed worldwide. Of James this truth can be said. We at the Simon Foundation for Continence will miss his leadership dearly.

The Simon Foundation for Continence Websites.

The Simon Foundation for Continence:

www.simonfoundation.org Our main website contains a variety of information on the Foundation and also incontinence types and management, the stigma associated with incontinence, life stories by people with incontinence, and how to support the Foundation's work.

Continence Central:

www.continencecentral.org This is a product focused website for patients and caregivers. Information on how to select products, purchase products, find other resources, and get reimbursed is included on this website.

Innovating for Continence Conference Series:

www.innovatingforcontinence is devoted to the conference series and information on past programs, abstract books, and speaker biographies,

Managing Life with Incontinence:

www.managinglifewithincontinence.org is devoted to our latest book, and it can be ordered here. The site also includes

a global listing of country specific organizations that support people with incontinence.

Rude 2 Respect:

www.rude2respect.org is a national campaign whose mission is to build awareness of the impact of stigma related to seen or unseen health conditions; to start dialogue to help the public understand respectful behaviors; and provide coping skills and resilience training to stigmatized individuals.

To Tell or Not to Tell:

totellornot.org is devoted to helping individuals to decide the pros and cons of incontinence disclosure in their own lives. The site includes a Toolkit to help each individual reach a well thought through conclusion to this question.

HealthUnlocked:

healthunlocked.com/simonfoundationforcontinence is The Foundation's Online Community. It provides the ability to anonymously post questions and learn from others within the community.

The Simon Foundation for Continence is dedicated to:

- Bringing the topic of incontinence out into the open
- Removing the stigma surrounding incontinence
- Providing help and hope for people with incontinence, their families, and the health professionals who provide their care.

This Special Edition of *The Informer* was sponsored by NorthShore Care Supply