CONTINENCE SUPPORT for CHILDREN with DISABILITIES

1-800-BLADDER
www.NAFC.org
Addressing a Special Need for Special Needs Families

Continence care is often thought of as an issue for the elderly, and older patients who suffer from incontinence have an established support community, broad selection of products and wide number of therapies available for their treatment.

But it’s not only older people who suffer from incontinence – a large number of children and young adults with physical, mental and emotional disabilities also face continence issues. For them, the commonly available solutions are not always the ones best suited for their particular needs.

That’s why we have created this introductory guide. Our goal is to help families and caregivers for children with special needs to understand the range of support that is available to them, and to provide resources and helpful tips that make real, meaningful improvements in their quality of life.

Disabilities and Continence

Continence issues are often associated with a wide range of childhood disabilities, including a number of conditions with physical difficulties, many with mental or emotional challenges and those that have both mental and physical components.

It’s important to note that intellectual development disorders and similar conditions are not in-and-of-themselves causes of continence issues. Many people with cognitive disabilities have no continence challenges whatsoever, and among those who do, there is a great variation in the severity of their symptoms.

In fact, the degree of cognitive impairment is only one component that can contribute to continence difficulties. Just as important is the person’s functional capability – those with functional challenges may have toileting issues regardless of their mental capacity.
Moreover, a person’s abilities are not necessarily locked at a certain age or stage – there are many people who continue to develop intellectually over time and who improve their physical capabilities as they age, and caregivers may find that a patient’s needs change in significant ways as time goes on.

Goals for Parents and Caregivers
As diverse as the range of disabilities may be, as varied as the individual challenges are, parents and caregivers of children with disabilities all share the same goal: to provide a full, rich life for every child, whether at home, at school, in a care facility or beyond.

This is perhaps where the similarity between the treatment of incontinence in older patients and the treatment of incontinence in children with disabilities is greatest: In both cases, a positive, proactive approach can reinforce the essential dignity of the person being treated, provide an enhanced degree of freedom and contribute towards more rewarding relationships.

This is not a speedy process. Unfortunately, when it comes to incontinence, there are no such things as miracle cures or overnight treatments. Instead, successes come from working every day to address the routine challenges of incontinence – identifying particular patterns that may make it easier to anticipate needs, working with physicians and therapists to determine potential courses of action, finding products that work well for each user. In the end, small changes can often be the most impactful, both for those receiving care and those providing it.

The Impact of Incontinence
Incontinence in children with disabilities does not always fit our traditional sense of what incontinence is. For some children, incontinence is best defined as a delay in toilet training. For others, it’s a result of their inability to physically perform the necessary hygiene. For still others, incontinent behaviors may actually be part of the child’s efforts to generate attention from adults.

The fact is, incontinence in the developmentally disabled can reveal itself in a surprising number of ways, all of which require special attention and a good degree of understanding from caregivers.

There’s simply no hiding the fact that incontinence can be incredibly stressful. Even in cases where the child doesn’t understand the nature of the condition, the strain it can put on family members and caregivers is significant.

Try not to let this stress get in the way of your relationship with your child and others in the family – that tension isn’t only harmful in and of itself; it can also edge over into other areas of treatment and have an impact on your child’s well-being – not to mention your own.
Consider enlisting the help of professionals – healthcare providers who understand incontinence, of course, but also therapists who can better help you manage daily stressors. Moreover, approach the situation as you would any other medical condition the child has – with a sense of purpose and with an understanding that treatment is possible.

**Dealing With Incontinence – The 5 Ps**

Incontinence may come in many forms, but there are some consistent ways to approach the situation that can help make treatment of more tolerable for caregivers and contribute to a real opportunity for improvement:

**Patience** – We all know it’s a virtue, but when it comes to incontinence, it’s often a virtue that’s in short supply. Try not to place blame for setbacks and do your best to maintain a good sense of humor – it’ll pay off in immeasurable ways.

**Persistence** – Progress of any sort may be imperceptibly slow – and in some cases, even the idea of progress may not be realistic. Don’t give up – having a positive outlook and setting sensible goals can minimize frustration for everyone.

**Planning** – Incontinence is all about surprises – and they’re rarely pleasant ones! Take the time to schedule activities, even routine ones around the house, and have the discipline to stick to them. Communications planning is equally important – make sure that those who share responsibility for the child have the information they need at their disposal and the ability to properly act on it.

**Practice** – You never know what will work until you’ve tried it – and in most cases, that means trying and trying again. Test out different treatments, ask healthcare professionals for recommendations and see for yourself if there are certain products or programs that generate results for you.

**Progress Is Possible** – It may not always feel like you’re getting somewhere, but there are countless families of children with disabilities who can tell you firsthand that incontinence is not necessarily insurmountable. That doesn’t mean you should expect a cure, but it does mean that there are things you can do – tactics, treatments and products – that can make your loved one much more comfortable and your life considerably easier.

**How to Talk About Incontinence with Others**

There are certain conversations no one looks forward to, and this is one of them. Still, it’s important that teachers, aides and others understand what to expect and how to handle situations as they arise. Fortunately, there are some things you can do to make the discussion easier.

It begins by understanding that you are not alone. Dealing with childhood disabilities can be isolating, whether or not incontinence is part of the situation, and that sense of isolation often makes it hard to
understand or appreciate how others will respond to your situation.

Rest assured, when it comes to teachers and others who work with disabled children, incontinence is something they deal with on a daily basis. It might be a new conversation for you, but it’s not for them – and if you trust them to be understanding, helpful and considerate, you’re likely to be pleasantly surprised with their maturity, willingness to help and ability to partner with you in treatment.

**Planning for Transitions**

A child’s mental and emotional development isn’t always in sync with his or her physical development, and that’s something parents of disabled children need to prepare themselves for.

Changes in body size and shape can have a significant impact on a caregiver’s ability to deal with incontinence – as we know, larger bodies create more waste and they’re harder to move. Moreover, in cases where children and young adults with emotional difficulties are resistant to incontinence treatment, addressing their hygiene needs can become unsafe, particularly for caregivers who are themselves fragile.

An additional concern as children age is that they become more socially connected with their communities – not only among their disabled peers, but also with other adults, with workers in educational or occupational environments, with bus drivers and restaurant workers and beyond.

In many of these cases, family members and caregivers will want to develop a sense of how much autonomy the child can handle and how able the child is to manage his or her own continence. This is one of those times where the 5 P’s can be especially helpful – for planning outings, for being patient and persistent, for practicing over and again – all in an effort to grow the child’s horizons and provide a more richer, more rewarding life.

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**How I Had ‘The Talk’**

“The one thing we were most afraid of when it came to enrolling Angelo in his new school was his bathroom issue. The idea of having to arrange things with his teacher was frightening enough that we almost kept him home. I’m glad we didn’t. Talking about it wasn’t easy, but it was really just breaking the ice that was the hard part. Once we started talking, we realized how we had gotten ourselves worked up over nothing. It was one of the best decisions we’ve ever made.”

– Angela B.
Products to Ease Transitions
The broad number of incontinence products on the market means that those caring for children with disabilities have a variety of options available to them as their children grow.

Most caregivers will find that children will graduate from baby diapers to training pants as do most children without similar challenges. It’s when kids pass this stage - when they become big enough for youth pants and then, eventually, adult-style products - that many parents find themselves in unknown territory. As they consider products, they’ll want to be aware of the varying degrees of absorbency, different sizing and different styles that are available.

Product Absorbency Definitions
• Light protection: Absorbency for those with slight, occasional leakage.
• Medium protection: Absorbency for those who are typically self-toileting but cannot always avoid an accident en route to the bathroom and in between toileting.
• Heavy protection: Absorbency for those who are lacking bladder or bowel control altogether and experiencing recurrent, daily episodes of urinary or fecal incontinence, including the sudden loss of the entire contents of their bladder or bowel.

Common Sizes and Shapes
The different types of garments include:
Protective Pads & Pantliners:
• Soft, discreet and individually wrapped with a stay-dry liner to help protect skin.
• One size fits all
• Very light, regular, moderate and maximum absorbencies
• Designed for female use
Guards For Men:
• Thin contour shape and special cup design ensure a comfortable, natural fit
• One size fits all
• Extra absorbency
Belted Undergarments:
• Elastic belts provide snug, comfortable fit
• One size fits all
• Extra absorbency
Protective Underwear:
• Fits, looks and feels like regular underwear (for day and night use) o Size: x-small, small/medium, large, x-large
• Extra absorbency
Adjustable Underwear:
• Stretchable tabs adjust to fit and let you change without removing your clothes (for day and night use)
• Sized: small/medium, large
• Super plus absorbency
Fitted Briefs: Soft leak guards for maximum protection with adjustable tabs for comfort and fit (for day and night use)
Absorbent Product Selection Tips

- Sizing – Fit is critical; bigger is not always better.
- Breathability – Look for breathable side panels or zones to ensure optimal air flow, comfort and skin protection.
- Elasticity – Make sure the product is comfortable, with a snug fit to protect from leakage. Reclosable fasteners are also helpful, because they create a better fit.
- Wicking & Absorption – A quality absorbent core will help draw urine away from the skin, hold fluid without leakage and withstand multiple episodes of incontinence between changes.

Where to buy?

Resources

There are a number of outstanding agencies that provide support to families of children with disabilities. Many of the following

Mental and Emotional Disabilities
American Association for Klinefelter Syndrome and Support
www.aaksis.org
(888) 466-5747

Autism Speaks
www.AutismSpeaks.org
(888) 288-4762

National Down Syndrome Society
www.NDSS.org
(800) 221-4602

National Fragile X Foundation
www.FragileX.org
(800) 688-8765

PKU News (phenylketonuria)
www.PKUNews.org
(206) 525-8140

Governmental Agencies
While most every state offers assistance and support for families of disabled youths, each state is different in regard to the nature and breadth of the support they make available. For providers in your state, contact the NAFC at 800-BLADER.

Product Distributors

Online Communities
OnePlaceForSpecialNeeds.com
FriendshipCircle.org
AbilityPath.org

More information can be found at http://www.nafc.org/home/tools-for-patients/#POP.
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