INCONTINENCE SUPPORT FOR CHILDREN & YOUNG ADULTS WITH DISABILITIES

Brought to you by the makers of:

Cuties

In Coordination with NAFC FOR CONTINENCE
WHAT IS INCONTINENCE, ACTUALLY?

Many people use the word ‘incontinence’ in different ways and to refer to different things. When we use it here, we’re talking in particular about the involuntary loss of bladder or bowel control.
ADDRESSING A SPECIAL NEED FOR SPECIAL NEEDS FAMILIES

Incontinence is often thought of as an issue for the elderly, and older patients who suffer from it have an existing support community, large selection of products and wide number of therapies available for their treatment.

But it’s not only older people who suffer from incontinence – many children and young adults with physical, mental and emotional disabilities also face incontinence issues. For this sometimes vulnerable population, the commonly available solutions are not always the ones best suited for their individual 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 INCONTINENCE

Incontinence 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 with both mental and physical components.

Common Conditions with Incontinence Issues
- Autism spectrum disorder
- Cerebral palsy
- Downs syndrome
- Fragile X syndrome
- Klinefelter’s syndrome
- Multiple sclerosis
- Paralysis/Spinal cord injury
- Phenylketonuria
- Spina bifida
- Additional intellectual and/or physical development disorders

It’s important to note that intellectual development disorders and similar conditions are not by themselves causes of incontinence. Many people with cognitive disabilities have no incontinence challenges at all, and for those who do, there is a great variety in how severe their symptoms are.

In fact, the level of cognitive impairment is only one factor that can contribute to incontinence. Just as important is the person’s physical ability – people with physical limitations may have toileting issues no matter what their mental capacity happens to be.

Also remember that a person’s abilities are not always locked in at a certain age or stage – there are many people who continue to develop intellectually over time and who improve their physical abilities as they get older. Because of this, caregivers may find that a persons needs change in important ways as time goes on.
GOALS FOR PARENTS AND CAREGIVERS

No matter how many different types of disabilities there are and individual challenges people face, 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. In both cases, a positive, hands-on approach can reinforce the person’s dignity, provide greater freedom and lead to more rewarding relationships for all involved.

This is not a quick process. 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 ordinary challenges of incontinence – looking for patterns that can help predict a person’s needs, working with doctors and therapists to find effective courses of action, and finding products that work well for each person. In the end, small changes can often produce the biggest results, both for those receiving care and those providing it.

THE IMPACT OF
INCONTINENCE

Incontinence in children with disabilities does not always fit our usual sense of what incontinence is. For some children, being incontinent means that they’re delayed in their toilet training. Others are not physically able to perform the necessary hygiene. And in some cases, 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 appear 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 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 can have an impact on your child’s well-being as well as your own.

Consider enlisting the help of professionals – healthcare providers who understand incontinence, of course, but also therapists who can better help you manage the daily stress you face. Approach the situation like any other medical condition the child has – with a sense of purpose and with an understanding that treatment is possible.

THE 5 PS

- Patience
- Persistence
- Planning
- Practice
- Progress
DEALING WITH INCONTINENCE – THE 5 PS

Incontinence may come in many forms, but there are some common ways to approach the situation. We call them ‘The 5 Ps,’ and they can help make treatment more tolerable for caregivers and contribute to a real opportunity for improvement:

Patience – We all know that patience is a virtue, but when it comes to incontinence, it’s often a virtue that’s hard to find. Try not to place blame for setbacks. Instead, provide positive encouragement and do your best to maintain a good sense of humor – it’ll pay off in so many ways.

Persistence – Progress may be slow, but don’t give up. Having a positive outlook and setting sensible goals can reduce frustration for everyone.

Planning – Incontinence is all about surprises, and they’re usually not pleasant ones! Take the time to schedule activities – even simple ones that you do around the house – and make sure to stick to that schedule. Communications planning is just as important – make sure that teachers, caregivers and anyone else who shares responsibility for the child knows what they need to know about the child’s situation and is able to take appropriate action if needed.

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 work for you.

Progress Is Possible – It may not always feel like you’re getting somewhere, but there are thousands and thousands of families who can tell you firsthand that the effort you make today really can turn into results down the road. It may not always be realistic to expect a cure, but there are things you can do – tactics, treatments and products – that can make your loved one much more comfortable and your life much easier.
HOW TO TALK ABOUT INCONTINENCE WITH OTHERS

There are some 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 to do make the discussion easier.

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

You can be confident that 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.

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.
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 major impact on a caregiver’s ability to deal with incontinence – as we know, larger bodies create more waste and they’re harder to move. 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.

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

In many of these cases, family members and caregivers will want to develop a sense of how much the child is able 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 richer, more rewarding life.

PRODUCTS TO EASE TRANSITIONS

The large number of incontinence products on the market means that those caring for children with disabilities have many options to choose from as their children grow.

Most caregivers will find that children with disabilities will graduate from baby diapers to training pants just like 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 what’s available, they’ll want to be aware of the different levels of absorbency, different sizing and different styles that are available.
CHOOSING THE RIGHT PRODUCTS CAN HAVE A BIG IMPACT ON YOUR LIFE.

First Quality® makes a complete range of incontinence products, including sizes and styles to meet the needs of the disabled, from infancy to adulthood.

You may not be familiar with the First Quality® name, but that’s for a good reason. Most diaper manufacturers focus mainly on newborns and toddlers, and they have to spend huge amounts of money to compete for that business. For more than 25 years, First Quality® has been focused on creating incontinence products that are best-in-class for absorbency, comfort and skin care.

First Quality® focuses on a full range of incontinence solutions, so they can invest in research and development instead of advertising. The result? More than 20 different products to choose from, with something to fit every size, style and stage of life.

Here are some of the features to look for when you’re considering which products make the most sense for your child’s needs:

AS CHILDREN DEVELOP…

…their absorbency needs increase as they grow, so finding a product that fits well is very important. They are usually chosen based on the user’s weight and body size, rather than age. Our products increase in absorbency as you progress from diapers through pants - so you’re sure to find a product that works for your child. There are four general categories to choose from:

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<tr>
<th>AGE/WEIGHT</th>
<th>PRODUCT</th>
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<tbody>
<tr>
<td></td>
<td>✔ Baby diapers</td>
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<tr>
<td></td>
<td>✔ Training pants</td>
</tr>
<tr>
<td></td>
<td>✔ Youth pants/briefs</td>
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<tr>
<td></td>
<td>✔ Adult products</td>
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<td>• Pads/guards/liners</td>
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<td>• Underwear</td>
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The different types of garments include:

• **Cuties®: Baby Diaper**
  Soft stretchable sides and waist give these diapers a secure fit for up to 12 hours of leakage protection. The cloth-like outer cover and hypoallergenic inner liner, enhanced with Vitamin E & Aloe, provide a comfy fit for your little one.
  — Available in sizes Newborn through size 7
  — Umbilical Cut-out on Size Newborn
  — Wetness indicator fades when wet on sizes Newborn through size 2
  — For day and night use

• **Cutie Pants™: Toddler Training Pants**
  Step in/pull on protection with the fit and feel of real underpants. Soft, stretchy waist and refastenable sides for easy changes and secure fit. The cloth-like outer cover and soft hypoallergenic inner liner, enhanced with Vitamin E & Aloe, reduce the likelihood of irritation.
  — Available for Boys and Girls in sizes 2T-3T; 3T-4T and 4T-5T
  — Gender appropriate graphics
  — Wetness indicator fades when wet
  — Refastenable sides include finger lift for easy changes
  — For day and night use

• **Wonderpants®: Toddler Training Pants**
  Step in/pull on protection with the fit and feel of real underpants. Soft, stretchy waist and refastenable sides for easy changes and secure fit. The cloth-like outer cover and soft hypoallergenic inner liner, enhanced with Vitamin E & Aloe, reduce the likelihood of irritation.
  — Unisex design in sizes 2T-3T; 3T-4T and 4T-5T
  — Wetness indicator fades when wet
  — Refastenable sides include finger lift for easy changes
  — For day and night use

• **SleepOvers®: Youth Pants/ Briefs**
  Soft, discrete absorbent protection for older children. Soft stretchy sides offer secure, trim fit. The cloth-like outer cover and soft hypoallergenic inner liiner, enhanced with Vitamin E & Aloe, reduce the likelihood of irritation. Odor Guard® helps prevent odors before they even start.
  — White unisex design
  — Available in sizes Small/Medium, Large/X-Large and X-Large
  — For day and night use
• **Protective Pads & Guards**  
  Soft, discreet and individually wrapped with a stay-dry liner to help protect skin  
  — Female and male products available  
  — Pads can be worn with regular underwear  
  — Available in Very Light to Ultimate Absorbency

• **Protective Underwear**  
  Fits, looks and feels like regular underwear  
  — Youth, small, medium, large, XL and 2XL sizes available  
  — For Maximum Absorbency  
  — Elastic at the top and bottom make for a better fit because it’s very similar to traditional underwear  
  — For day and night use

• **Fitted Briefs**  
  Soft leak guards for maximum protection with adjustable tabs for comfort and fit  
  — Medium, large and XL sizes available  
  — For Maximum Plus Absorbency  
  — For day and night use  
  — For any fecal incontinence

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**PRODUCT SELECTION TIPS & TROUBLESHOOTING**

• Sizing – Getting the right fit is critical. Many people think that larger is usually better, but that’s never the case. Larger sizes don’t mean extra absorbency, and a poor fit can lead to leakage and irritation.

• Breathability – Look for breathable side panels or zones to ensure good air flow, comfort and skin protection.

• Elasticity – Make sure the product is comfortable, with a snug fit to protect from leakage. Fasteners that reattach are also helpful, because they create a better fit.

• Wicking and 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.

• Double Trouble – Some people double up on products, thinking that two layers are better than one. That’s not so. Putting one product inside another can cause additional leakage because only the product closest to the skin is absorbing fluid.
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

Spina Bifida Association
www.spinabifidaassociation.org
(800) 621-3141

ONLINE COMMUNITIES
AbilityPath.org – Parents can find wide-ranging information here on a range of disabilities, with insight provided by medical experts

Childrensdisabilities.info – A large collection of articles and resources to empower parents of children with disabilities and special needs; click on their “List of Disabilities Lists” for even more online destinations

Myautismteam.com – A social network for parents of children with Autism

OnePlaceForSpecialNeeds.com – A huge resource of information and support across a wide range of needs

Our-Kids.org – A friendly, welcoming site for parents devoted to raising special kids with special needs

P2PUSA.org – Parent-to-Parent USA is a national non-profit that highlights groups at the state level that focus on parent support and evidence-based medicine

Supportforfamilies.org – Though this group is based in San Francisco, the information they provide is excellent for parents of disabled children no matter where they happen to be; the “Resources” tab has dozens of links to other great sites

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.
To learn more about these products or to request samples go online to www.prevail.com or call our toll free number 1-800-227-3551
The National Association for Continence is a non-profit 501(c)(3) organization dedicated to improving the quality of life for people with incontinence and related disorders.

For more information and to make a charitable donation, please visit www.NAFC.org. All contributions are tax-deductible to the extent allowed by law.