

CHAPTER 3

# Living with ASD

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*I remember thinking it can't be autism. He has such good eye contact and is so affectionate. Our doctor had reassured us that we did not need to worry. He is a boy and boys talk later, we were told. I still worried. I knew something was different, and I began to learn to trust myself as a parent. I didn't know that ASD could be so different for each child, but I knew that my son needed help.*

”

## You Are Not Alone

This chapter provides parents of children with ASD practical strategies and suggestions for how to handle situations that may arise when living with a child/ren with ASD, relating to such topics as toileting, family outings, physician appointments, family issues, finances, etc.

Upon receiving a diagnosis of ASD, parents experience a host of strong emotions. Few forget the day when they realized that their child had a developmental disability and that their journey of parenting might be quite different from what they had imagined. In an article entitled *You Are Not Alone*, Patricia McGill Smith tells of a parent describing it as if a “black sack” was being pulled down over her head, and she could not hear, see, or think in normal ways.

Each person may react differently to the news, but there are some common reactions that are shared by many. Parents grieve the loss of the “typical” child that they expected to have. You may experience some or all of the following:

- **Shock or denial.** You may think, “How can this be happening to me?” or want to make the disability go away.
- **Anger.** You may be angry at yourself or others for “causing” ASD, you may be angry at God, at medical personnel, at your spouse, or even your child.
- **Guilt.** You may think there was something you could have done that would have prevented the diagnosis.
- **Rejection.** Some parents even report having a “death wish” for their child.
- **Confusion.** Confusion is very common for families trying to sort through all the information about ASD and make choices about treatment.
- **Fear.** You may fear the worst or have memories of other children and/or adults with disabilities and wonder if your child will have a similar life.
- **Isolation.** Because of the unique communication, social and behavioral issues presented by children with ASD, you may feel very alone. Eating out, doing things as a family, or finding time alone with your spouse or spending time with your friends becomes a challenge.
- **Envy.** Seeing other parents with their typical children may make you feel envious and resentful.
- **Relief.** Some parents report they are glad to know that their child’s behavior is not caused by poor parenting.

As extreme as some of these feelings may seem, they are normal. One of the ways you can take care of yourself is to realize that you, your spouse, or family members are not bad people for feeling angry or having other negative feelings – you are human. These are common feelings parents and families have reported as they go through the process of adjusting to a child’s diagnosis. You may find yourself feeling waves of grief throughout the lifespan at different times. Events like birthdays, school transitions, holidays, and other big events can trigger feelings of loss. If you get stuck working through the stress and grief of having a child with ASD, seek help and support.

## **Signs That Indicate That You Need Help**

- Trouble sleeping or sleeping all the time
- Feeling tired all the time
- Loss of appetite
- Headaches, or other frequent pains
- Loss of interest in sex
- Thoughts of hurting yourself or others

*See a health care provider and/or counselor for help.*

## **You Can Do This!**

Although at times it may seem almost impossible to handle the challenges that you are facing, you can do this! Remember, your child is not defined by her ASD. You will be able to parent your child successfully if you try to:

- Appreciate the uniqueness of your child. Don't compare her to others.
- Focus on your child's strengths. All children have things they do well.
- Show unconditional love. If you find yourself taking anger out on your child or someone else, get help.
- Get informed. Learn about your child's educational and other rights as well as programs that can help you and your family. Ask lots of questions!
- Don't be overprotective. Let your child do things for herself as much as possible.
- Have fun!! Find things you both enjoy and do them a lot.

## Taking Care of Yourself and Your Family

The demands and challenges of raising a child with ASD can be overwhelming. According to the Autism Society of America, research indicates that parents of children with ASD experience greater stress than parents of children with intellectual disability and Down Syndrome. The best way to help your child is to deal with your own stress.

*Having support can make a big difference, but you must take the initiative. You cannot expect others to come to you.*

- **Share your feelings with your spouse/ partner if you have one.** Reaching out helps both of you.
- **Enlist the help of friends and relatives.** While they can help, be aware they may also be experiencing some of the same feelings of loss and confusion. Talk openly with them about your child and how they can help.
- **Involve your faith community.** Some parents find comfort in their spirituality. See Issues of Faith later in this chapter.
- **See a counselor for individual or marital counseling if needed.** Check with your doctor, mental health agency, or leader of your faith community for possible counselors. Ask if they have experience with special needs families.
- **Find other parents who understand the challenges of raising a child with ASD.**

*I cannot overemphasize the importance of parent-to-parent support. I thought no one else could be experiencing the stress and chaos that I was having when my son was first showing signs of autism. I thought no one else had a child that behaved like mine. I was wrong. I met Sheryn and Darlene and they both talked openly about their children and their families. Their honesty brought great relief to me. We soon began laughing about the many times our boys would take their clothes off and the endless hours of trying to guess what they were saying because they did not have words yet. Our kids were similar, but yet unique. Years later, we still laugh, cry, and support one another. I am thankful I met them early in my journey and for the others that have come since and those I am yet to meet. They make all the difference.*

The importance of parent-to-parent support cannot be overstated. Other parents of children with disabilities can identify with your feelings of loss and frustration, help you find programs and funding for therapies, laugh with you, and possibly even cry with you. Many enjoy the company of another parent because there is no judgment, but a true understanding of how hard parenting can be.

Talking with another parent is a great place to find practical everyday help for issues that may be hard for you right now. You can find support informally by meeting for a cup of coffee, joining an online support group, or locating local organized support groups for parents like local chapters of the Autism Society of America. In Ohio you can call (614) 487-4726 to find out about parent support groups near you.

Parents report that they often learn as much from talking with other parents as they do from professionals and books. Parents before you have learned to negotiate education, funding and other service systems, and they can give you many helpful pointers on how to access services.

## **Online Support**

In this age of technology, many people turn to their computers before going to the library or bookstore when researching information about ASD. The Internet can also be a place of refuge for parents who are hesitant to talk about their personal lives in the more public forum of a support group meeting. There are electronic (online) groups that are organized around the topic of ASD so that individuals can exchange information about topics of common interest. They can also serve an important support function for people who are strapped for time to attend meetings in person or are geographically isolated.

While it is important to have an understanding network of family and friends to count on when the going gets rough, your existing circle of friends may not be able to understand your changing needs and their support may not be adequate. An electronic mailing group can be like having an autism help hotline available 24/7.

For example, on a recent electronic mailing group for parents of children with ASD, a parent reported that his child began having sleep problems again after months of sleeping through the night. The list member soon received responses from several parents who had similar experiences and who suggested strategies they used to deal with the problem. Parents may use the list to locate competent caregivers for their children.

These Internet communities are commonly referred to as **listservs** (the copyrighted name for electronic mailing list or email list). They are also referred to as “**Internet groups**” or just plain “**lists.**” Both Yahoo and Google (two major Internet browsers) have “Groups” under their listings. Yahoo and Google both have thousands of these listservs grouped by categories.

“**Blogs**” (short for web logs) are also increasing in popularity. They are a kind of online journal created by an individual, but made public on the Internet so anyone interested can read about their experiences. Like the listservs, they can link people with common interests.

**Chat rooms** are roundtable discussions in real time where several people who are online at the same time can send messages to one another and discuss particular topics.

**Electronic mailing groups or listservs** are the safest to participate in. Particularly helpful are those that are moderated, meaning that you must ask permission to join and someone reviews the postings to ensure that they are appropriate. There can be varying degrees of restrictions for membership, depending on how the groups were created.

Listservs will have archives of old postings. In order to search the archives of a group, or list, you must be a member. In other words, you cannot just open up a website and begin to participate. This extra level of security means that members can reduce the risk of “spamming.” Further, moderated groups have the ability to “unsubscribe” people who do not abide by the rules set up for the group.

Here are some examples you may wish to try out.

**ASO Website:** [www.autismohio.org](http://www.autismohio.org) Click on Autism Links. From there, click on Mailing Lists. Several will come up that you can explore. Follow the online instructions to join.

**Yahoo Groups:** [groups.yahoo.com/search?query=autism+Ohio](http://groups.yahoo.com/search?query=autism+Ohio) (found by inputting “autism Ohio” into the search function for “Yahoo Groups”): 23 groups for Ohio are listed. Just follow the directions; you can select the areas that interest you.

**Google Groups:** [groups.google.com/](http://groups.google.com/) Search for autism. Then click on “groups matching autism” – 75 different groups are listed.

It may feel overwhelming to narrow down your search. One way of doing this is to begin with those listed on [www.autismohio.org/](http://www.autismohio.org/) since it was established for parents, family members and professionals interested in autism spectrum disorders in Ohio.

## Time for Yourself

Most parents of children with an ASD feel they do not have the time to do anything for themselves, but even a few minutes a day can help relieve stress. When we are stressed, our brains are working overtime and our judgment can be impaired. Sometimes we think we cannot stop out of guilt because we might not be helping our family enough. We continue to work harder and harder while getting more frustrated and possibly making mistakes.

Simple things like taking a short walk, listening to music, or cooking a favorite meal can help you to feel better. Take time to think about your unique abilities and interests that are separate from your role as a parent. It is O.K. to take a break from your child now and then. Taking a break is good both for you and for your child. In fairness to all family members, it is O.K. for your family to occasionally engage in activities without your child with ASD. Take an extended break if you are able. If it seems impossible to do, start small and gradually extend the time.

You may have to learn to relax and let go. Here are some tips that may help.

- Set an alarm or timer to remind yourself to take breaks throughout the day.
- Schedule extended breaks (a few hours a week or whatever you can manage) on your calendar instead of waiting until you think you can fit it in. If it is not scheduled, it usually doesn't happen.

Other ways to consider to reduce stress include:

- Prayer/meditation
- Exercise/walking/stretching
- Deep breathing/relaxation exercises
- Keeping a journal
- Setting realistic expectations, but have a "to-do" list to guide your activities
- Advocating for others; that is, helping another parent take an action or say what they want or get what they need. (See Chapter 7 on Advocacy and Disability Awareness.)

## **Time for You and Your Spouse**

Parenting a typical child can place stress on a marriage. Parenting a child with special needs can be especially challenging. Couples need to have open discussions about their feelings, but they also need opportunities to stay connected and talk about things other than the children. Listening to and respecting your spouse's feelings can go a long way to remaining close. Recognize that your spouse may handle grief differently than you and allow your spouse to do it in his or her way.

*After some time passed, I remember being grateful that my husband and I grieved differently. When I was in the depths of depression, he was still in shock. At first, I felt angry that he was not as sad as I was, but later I realized it was a gift. If we had both been at that level of sadness, it would not have been good for our son. My husband was able to laugh more and interact more while I was working through my emotions.*

## Single Parenting

Many parents face parenting without a spouse or significant other because of death, divorce, or separation. We know that families with children with ASD have higher rates of divorce, some report it as high as 75 to 80 percent. Divorce and death/loss are two of the most stressful events for any family.

When experiencing and living after the divorce, remember to plan for the following:

- Incorporate a visitation schedule into your child's visual or written schedule.
- Help children identify their emotions, even if it makes you or them uncomfortable. This is very important because negative behaviors may occur when children do not acknowledge their emotions.
- Give the child time to adjust to the change in routine.
- Use pictures/video of the different homes the child will be going to help explain the change in living arrangements.
- Try to keep the rules and rewards the same in managing difficult behavior.
- If possible, keep the noncustodial parent involved in child's development and education.

Single parenting may require you to ask for help more often than if you had a live-in spouse or partner. This can be hard, but it is an important part of keeping yourself healthy. Being a single parent, you may find yourself concerned with how you are going to handle all the expenses of raising a child with ASD alone. You may also question how you will be able to date or have a serious relationship with someone in the future, knowing that you have a child with ASD. These are legitimate concerns. Remember, these questions have gone through the minds of many other parents of children with ASD. Other parents can be your best resource. Seek the support of those who have experienced similar circumstances.



For more information on parent reactions and stress, you can check the following websites. If you don't have access to a computer, call OCALI toll free at (866) 886-2254 and ask for a copy of the information.

**Dan Coulter website**

This is a father of two children with significant disabilities. Dan puts into words the questions that many parents have and he gives some good advice.

<http://www.coultervideo.com>

**Autism Society of America: Living with Autism website**

This area of the website addresses daily family and parenting issues

<http://www.autism-society.org/?s=living+with+autism>

**CIPR**

This federally funded program is a clearinghouse that provides a wealth of information for parents of children with disabilities. This article focuses on parenting a child with a disability

[www.kidsource.com/NICHCY/parenting.disab.all.4.3.html](http://www.kidsource.com/NICHCY/parenting.disab.all.4.3.html)

## Siblings

*Siblings will be in the life of a person with ASD longer than anyone else.*

The sibling relationship can have a large impact on the future of both your typical children and your child with ASD. In other words, the way a typical child reacts to having a sibling with ASD will affect the relationship that they have in the future. Again, it is helpful to hear others' experiences. Many see having a brother or sister with special needs as something positive that teaches them to accept others as they are. Siblings can be the strongest protectors and loudest cheerleaders. In contrast, some siblings feel jealous, neglected, or rejected because of the time and energy they see being invested in the child with special needs. Typical siblings may worry about the future of their brother or sister and their future role in care giving. They may be concerned about how peers will react to their sibling with ASD and they may feel embarrassed. Some typical siblings become targets of aggressive behaviors. These can be difficult issues for parents.

## What do siblings need?

- **Information/communication** – Siblings need regular discussions that are suitable for their level of understanding about ASD. They need to be able to ask questions and share their concerns. A young child may be concerned about “catching” autism while older siblings may be more concerned about what is expected of them in future care giving. Try to make no subject “out of bounds” to discuss.
- **Support** – Just like parents, siblings need support. They need a place to talk to other siblings about what it is like to have a brother or sister with ASD. Look for support groups, sibshops, or other programs for siblings in your area. There are also online support groups and listservs for siblings. (See the resources at end of the section.) If there is no formal group in your area, arrange some informal play dates with brothers and sisters of children with ASD that you know to give them the opportunity to interact with each other.
- **Respect and consideration for their uniqueness** – Celebrate even “expected” milestones for siblings. Allow them to have choices about how involved they want to be with their sister or brother.
- **Safety** – Siblings need to have a safe place for themselves and their belongings. Help them to learn to communicate with you and their brother or sister with ASD when they need space and time away. Be sure they know it is O.K. to ask for help.
- **Individual time and attention** – Plan to spend regularly scheduled time alone with your typical children. They need to count on a specific time that is devoted just to them.
- **Acceptance of typical sibling behavior** – Sibling conflict is normal in most households. Expect conflict and know this may help prepare the child with ASD for real-life situations. Don’t always expect the typical sibling to compromise or “know better.”
- **Opportunities to have a “normal” life** – Give yourself permission to take a trip without the child with ASD. Try to find respite resources so siblings can fully experience things they choose. Both siblings and the child with ASD need chores and responsibilities equal to their abilities. Don’t assume that because a child has ASD she does not have the ability to help around the house.
- **Strategies for dealing with their sibling, peers, and their own emotions** – Siblings need to know how to deal with the unusual behaviors that are often exhibited by their sibling/s with ASD. They also need some guidance in how to deal with questions from peers and the general public. Siblings need to know that it is O.K. to feel embarrassed about their sibling or to worry about them. If you think your typical child could use the assistance of a professional counselor, that is O.K. too.
- **Positive parents** – Probably the greatest impact will be the attitude of the parent(s). Being positive will help them meet the challenge. How we choose to deal with our own emotions and attitudes will impact their experience.

## Sibling Resources

Feiges, L. S., & Weiss, M. J. (2004). *Sibling stories: Reflections on life with a brother or sister on the autism spectrum*. Shawnee Mission, KS: Autism Asperger Publishing Company.

Harris, S., & Glasberg, B. A. (1994). *Siblings of children with autism: A guide for families*. Bethesda, MD: Woodbine House.

### **The Sibling Support Project website**

This project is a national effort dedicated to the life-long concerns of brothers and sisters of people who have special health, developmental, or mental health concerns. [www.siblingsupport.org/](http://www.siblingsupport.org/)

## Grandparents and Other Family Members

Like parents, grandparents grieve the loss of the “typical” grandchild they had hoped for and are concerned for their own children in the process. They, too, will need information, open communication, and recognition that they are grieving. Many well-meaning family members offer advice on behavioral issues. However, parents can become frustrated and perceive a lack of support when grandparents do not agree with the parents on how to handle difficult situations with their child with ASD. Open communication and information can help enhance your support and allow family members the opportunity to learn about your child.

There are books and organizations that address the needs of grandparents of children with ASD. The Autism Society of America is one such organization. Listed below are examples of books for grandparents of children with ASD.

### Books

Martin, E. P. (2004). *Dear Charlie, A grandfather's love letter to his grandson with autism*. Arlington, TX: Future Horizons.

Thomas, K. R. (2006). *Grandparenting a child with autism: A search for help and hope*. Louisville, KY: Harmony House Publishers.

### Websites

Autism Society of America: *Life with autism*: <http://www.autism-society.org/?s=living+with+autism>

Center for Parent Information and Resources (CPIR) - The Unplanned Journey: <http://www.parentcenterhub.org/repository/journey/>

## Family/Social Gatherings

Holidays, family reunions, birthdays, visiting relatives, and other special celebrations can be especially stressful for a child with ASD. These activities may bring about unexpected events as well as excessive amounts of sensory input. Such situations can contribute to anxiety, and the child can soon feel overwhelmed.

Writing a letter before family visits can help make the event more enjoyable. Share the things that will help your child feel comfortable, activities that he enjoys, foods he likes, and how family members can expect your child to respond when situations may be too much for him. Bring special toys, videos, games, or other comfort items. Be sure to plan frequent breaks when traveling. Finding a place where your child can take a break from the crowd will help the visit be more enjoyable for everyone.

Holidays bring lots of change and increased social demands. Consider keeping the decorations simple and safe. Make sure your decorations will not choke or harm your child if she were to touch them or place them in her mouth. Send a list of preferred gifts to family members to help everyone feel more fulfilled, that way your child will receive a gift he prefers and the family member may get to witness him enjoying the gift. Prepare your family for the possibility that your child may not want to participate in opening gifts or consider setting a limit on the number of gifts he is expected to open. At home, you may allow your child to open a gift a day so he is not overwhelmed on the actual holiday. Consider using a social narrative to describe what will happen at holidays or birthdays or other special events.

If you plan to attend a family reunion or other large gathering, showing your child pictures of the unfamiliar people and places ahead of time may help ease anxiety. Preparing both your child and your family through open communication is always helpful. For other ideas see the book *Finding Our Way* by Kristi Sakai ([www.aapcpublishing.net](http://www.aapcpublishing.net)).

# Day-to-Day Issues in Living with ASD

This section is a broad overview with suggestions for navigating the many situations and decisions parents face as they negotiate their daily lives and support their child with ASD. It covers friendships, finances, approaching therapy and education decisions, creating a workable daily home schedule, dealing with doctor appointments, and even discusses issues of faith.

## Balancing Life on the Spectrum

*I remember crying at my ultrasound when our doctor told us we were having another boy. I am sure he thought they were tears of joy, but in reality, I was crying because I knew my chances of having another child with ASD could be greater. Ultimately, I came to terms with the thought that I would love our second son no matter what, ASD or not. Our second son does not have ASD, and he has helped my older son in ways I could never have imagined.*

It is easy to feel overwhelmed by all the decisions that you will be making while living with ASD. It can be challenging to find time and ways to help everyone feel valued and get their needs met, not to mention having your own needs met, as discussed earlier. If everything in your family revolves around the child with ASD, other family members can become resentful. Do you define your family as a special needs family or a family with a special needs child? Finding a balance in your decision making and making choices that fit your family will help ease the stress of day-to-day living.

You may be wondering ...

- Should I/we have another child, knowing there is an increased risk for having another with ASD?
- Should we move or sell possessions to get better services?
- How many assessments and therapies are necessary for my child?

Evaluate your decisions carefully and try to keep some balance in your everyday life. Consider how decisions will impact your whole family and not just the child with an ASD. Unfortunately, there are people who take advantage of families that are desperate to help their child. Research carefully the services and/or treatments that are being offered to you and your child with ASD and select them according to what best meets the needs of your child and family. While searching for answers, you will find opinions that may differ even among the “experts.” Take one day at a time and try to keep your routines as normal as possible. It will help provide some consistency when things are hectic.

## Your Changing Circle of Friends

One of the most difficult and surprising aspects of learning that your child has a diagnosis of ASD is discovering that your circle of friends will change. Your friends and close family members can be a true source of support and encouragement. Unfortunately, when we need our friends and family the most, sometimes they are not as supportive as we had hoped. As a result, you may find yourself confiding in total strangers at a support group meeting or seeking comfort in the listening ear of a coworker when you used to share *everything* with your sister, or your best friend.

Individuals are just that – *individuals*. The people who have been closest to you may react to your child’s diagnosis in a variety of ways, just as parents themselves react in a variety of ways. Some may be in denial while others may express a genuine sadness. Keep in mind, though, that your closest friends and family members love and care about you *and* your child. Their concern is for your well-being as much as it is for your child’s.

When an adult friend or relative has experienced a life-changing event, many people do not know how to react. Some friends are uncomfortable in the presence of people with intellectual disability or developmental disabilities. Others withdraw in fear that they would say or do the wrong thing. This may be true if your child has challenging behavior or has yet to attain functional communication. In an effort to be supportive, people may say all the wrong things:

“My cousin’s son didn’t talk until he was 4, and now he’s a sophomore in college.”

“Einstein was autistic, you know.”

“Well at least he can walk.”

“I saw a lady on TV whose son’s autism was cured with (fill in the blank).”

### Others may be blunt:

“That kid just needs a spanking now and then!”

“Get over it!”

You will no doubt hear statements that will hurt your feelings or cause anger. It is difficult enough to ignore a stranger, but we expect much more from those close to us. Parents are vulnerable, especially when new to the diagnosis. If you are having difficulty with feelings of depression or anger, consult a professional counselor who has experience in working with parents of children with chronic disorders. A chaplain at the nearest children's hospital may be able to provide appropriate resources or referrals.

Consider also that, although we have crossed into the 21<sup>st</sup> century, many adults today did not grow up with much exposure to people with cognitive disabilities. And certainly, most adults did not attend school with children with disabilities. So the reactions of your friends and family members, especially the older ones, may simply be due to a lack of knowledge.

The best way to react to these situations is to share information about ASD, and to encourage friends and relatives to spend time with your child. Invite them to your support group meetings or ask them to accompany you on a doctor visit. Explain to them that you not only need their moral support, but you also could use a little respite from time to time. The better they know your child, the more willing they may be to help.

Make a mental note every time someone offers to help, however generic the offer may be. If you are experiencing a particularly difficult week, ask someone to run errands for you, help with laundry, or pick up your children after school. If you are affiliated with a church or a social club, fellow members may be willing to assist in some way on a regular basis. Be comfortable in asking for help when there is a need. Many people are happy to help. You will be supported, and your child will be exposed to a variety of people and personalities in the process.

Your daily routines have probably changed since your child's diagnosis. Much time is now spent with therapists, teachers, medical specialists, and other providers who understand and accept your child. It may be easy to consider these new adults in your life as your new friends. You may look forward to the brief encounters with

professionals who truly understand. Certainly, they may be friendly people, and they can be a tremendous source of support to you; however, your *real* friends should not be forgotten. Include them as much as possible in your new routines. Think outside the box when planning visits with your friends. While your life may have changed, your friends' lives probably have not, so try not to let autism be the topic of every conversation.

*During our engagement, my (then) fiancé and I agreed not to talk about wedding plans on every date. Now that we live with autism in our family, we know how important it is to not let autism dominate every conversation.*

### 10 Things I Want My Friends to Know

1. My life has changed, but I still want you to be my friend. We may need to be creative in thinking of new ways to spend time together.
2. Listen. I want you to know about my child and about how his life is affected by ASD. I may have days when I just need to "vent".
3. Keep what I say confidential. As my friend, you may occasionally be my sounding board. Please respect the privacy of my family by not repeating what I say.
4. Don't judge my child or me. Ask questions if you have concerns about the choices we have made for our child.
5. Respect my feelings. My feelings may run the gamut from desperation to hopefulness and will change largely based on what kind of day my child is having.
6. Encourage and support me. I need to hear positive feedback. Be my guest at a support group meeting, or offer to keep my child while I go.
7. I really am happy for the milestones that your children are reaching. Don't exclude me from your celebrations; however, please understand if I am not always able to attend.
8. Ask questions. I'll be happy that you are interested.
9. Communicate with me. Please let me know if you can or cannot help with my child. It is OK to tell me if you are uncomfortable. I need to know how you feel.
10. Be my advocate. Other friends or acquaintances may not understand or may be judgmental. You may be able to keep them abreast of my child's progress and our family's needs.



*Parents, grandparents, and siblings largely report that support groups have been very helpful. However, others are uncomfortable with the candid expressions of feelings and vulnerability displayed at support group meetings. Attending casual gatherings or informal activities sponsored by autism groups may be an easier way for some parents to meet new friends. Some areas in Ohio have successfully started support groups and other activities just for dads, grandparents, or siblings of kids with autism. These provide opportunities for the attendees to meet other people who share similar experiences.*

You can check the Autism Society of Ohio website at [www.autismohio.org](http://www.autismohio.org) to find out what autism support groups are meeting in your area. If you do not have computer, call OCALI's toll-free number (866) 886-2254 to ask about support groups in your area.

## **Finances**

Having a child with ASD can be a drain on a family's resources due to the cost of expensive evaluations, home programs, and therapies. Besides, one family member may have to give up his or her job because of the care-giving demands of raising a child with autism, and the financial pressures may increase as a result. Because of the challenging behaviors often present in children with ASD, many parents find the need to seek out jobs with flexible hours or work different shifts so one parent is at home all the time. Some have developed their own home-based businesses, and still others rely on some form of government assistance to manage.

Networking with other parents, getting involved with local support groups or chapters of ASA will keep you informed of the latest sources of funding and other supports that could help. It may be difficult for you to ask for help, but there may be untapped resources out there. (See Chapter 6 for more information on Ohio's service systems.)

### **Things to Consider Related to Finances and Funding Services**

- If insurance denies a claim, appeal it.
- Parents in the same insurance company can band together. One company planned to drop coverage for speech therapy, but after several parents called and wrote letters, the benefit was reinstated.

- Ask providers if they have fees based on income.
- Use college students to help. They are more affordable and often are able to earn course credit.
- Use volunteers from your community if you are doing a home-based program.
- Ask that money be given for services to help your child instead of extravagant toys and gifts.
- Consider hosting your own fundraisers.
- Explore possible tax deductions with your tax advisor.

## ***Daily Functioning at Home***

In addition to dealing with friends and finances, parents often find that they must create a daily home schedule that supports the child with ASD and the family as well. Families engage in daily routines within the household that are executed with little thought or planning, and certain activities continue to occur without question over and over again. They are a part of living, a part of being in the household. These includes activities such as:

Bedtime	Going to the grocery store/errands
Bath time	Household chores
Meals	Getting ready for school
Play time	Having other children visit the home
Nap or quiet time	Toileting/self-care

Although a variety of strategies could be suggested here for each activity to help a child with ASD cope more easily, it is important to focus on the underlying characteristics and environmental factors of each child and each home situation as you think about these routines. As you encourage your child with ASD to participate in these routines and gain adaptive skills, consider the following.

### **1. Understand that your child's age may not equal his developmental level.**

It is important to remember that children with ASD often vary in developmental levels across areas. For example, a child may be on level with neurotypical peers in communication skills, but lower in social interactions. Even within one area, a child's skill level can vary, such as being comfortable entering into a conversation, but unable to maintain the conversation. With daily living skills, a child may be able to set the table with utensils for dinner, but may become overwhelmed when asked to clear the table and put away leftover food and dishes.

## **2. Create realistic expectations.**

As expectations are being created for the child, make sure they are appropriate for her ability level. Utilize skills that the child has mastered to build confidence and encourage the use of new, emerging skills. Take time to teach a task in small increments so that if a problem arises, the problem step can be retaught and supported. Look for ways to break down complex tasks into smaller pieces so the child will be successful. For example, if a child is 18 years old, but developmentally 7 years old, do not expect her to do a full load of laundry alone. Expect parts of the skills – gathering the dirty clothes, sorting by color and whites, or putting away the clothes when the laundry is complete. As the child masters one skill, add a step to build the child's ability to complete the entire task.

## **3. Understand the difference between schedule versus routine.**

Maintaining routine is different from keeping a schedule. For example, a bedtime routine may be flexible in the schedule because it is not always precisely at the same hour. However, the bedtime routine stays structured in that the child always gets to have one book read, is tucked in by a parent, and goes to sleep with his teddy bear. This allows for flexibility within the schedule while maintaining a routine.

For more detailed information on intervention strategies for a specific routine, refer to *Everyday Solutions: A Practical Guide for Families of Children with Autism Spectrum Disorders* by Mindy Small and Lisa Kontente ([www.autismohio.org](http://www.autismohio.org)).

## **Hygiene**

Hygiene can pose challenges for individuals with ASD in multiple areas. Most hygiene tasks involve lots of sensory information that can be overwhelming. Self-care usually involves many steps and as well as motor planning. Socially, many with ASD miss the importance of good hygiene and the unwritten rules that go with visiting public restrooms and other social situations that relate to care of their bodies. The seemingly obvious, such as bathing regularly or wearing clean clothes, may not be important to children with ASD since they may not understand their significance. This understanding and the skills related to hygiene will need to be taught.

## The Unwritten Rules

There are many unwritten social rules related to self-care. Early on, we may be worried about just teaching the tasks, but as children get older and more self-aware, it is important to teach them the social behaviors that many of us take for granted. The following are just a few examples of the “hidden curriculum” that must be directly taught to children with ASD.

### Public vs. Private Behavior

- Teach proper urinal behavior for boys such as not lowering pants fully to the ground or looking at others’ body parts while toileting.
- Make it clear that scratching or adjusting one’s private parts or underwear is not to be done in public.
- Teach that it is not appropriate to pick one’s nose in public.

### For Teenagers

- Help them learn what is “in” and what is “out.”
- Help them understand how much first impressions count.
- Help them see how hygiene can affect relationships and even employment.

## Resources

### Books

Crump, M. (2005). *No B.O.: The head-to-toe book of hygiene for preteens*. Minneapolis, MN: Free Spirit.

Myles, B. S., Trautman, M. L., & Schelvan, R. L. (2004). *The hidden curriculum: Practical solutions for understanding unstated rules in social situations*. Shawnee Mission, KS: Autism Asperger Publishing Company.

Schaefer, V., & Bendell, N. (1998). *The care and keeping of you: The body book for girls* (American Girl Library). Middleton WI: American Girl.

Although challenging, teaching children to take proper care of themselves is a huge step towards independence. Many of the tools used to help in other areas are equally helpful when it comes to personal hygiene. For example, visual/written schedules, social narratives, desensitization, and gradual exposure to a task can all be used to help individuals with ASD learn new tasks. (See Chapter 4 for a list of current interventions and strategies used to teach and treat individuals with ASD.)

## ***Haircuts, Hair Combing, and Nail Trimming***

Consider the sensory issues that are involved with these tasks. Hands and heads are some of our most sensitive areas. Select among the following options for making this a less traumatic experience for your child with ASD.

- If your child is a sound sleeper, trim hair and/or nails at night.
- Find a hair stylist who will come to your house.
- Play relaxing music or find a distracting toy, video game, or favorite show to occupy the child while the haircut or nail trim is occurring.
- If going to a stylist, visit the shop several times before actually going for a haircut. Use pictures or video to illustrate what is going to happen.
- Pick a time when the shop is not so busy.
- Go frequently, even for just a small trim, rather than wait a long time between haircuts.
- Experiment to determine whether clippers or scissors are better. Some children like clippers because they can make the cutting go faster, but they can also sound louder.
- Consider combing hair more than once a day to get used to the sensation.
- For nail trimming, do a finger at a time with breaks in between until more tolerable.
- Put hygiene checks in schedules. Remember: If it is not seen, many do not think about it. Simply reminding them to look in the mirror may be enough.

## ***Hand and Body Washing***

Preferences are important for motivation. Consider the following:

- Does your child prefer aromas or textures for soap? Consider foam vs. bar vs. liquid.
- Does your child prefer a certain water temperature?
- Does your child like soft or rough washcloths and towels?
- Does your child prefer a schedule or list of tasks to be performed while washing?
- Is hand-over-hand support provided to help the motor planning and memory?

## **Toileting**

Becoming toilet trained is one of the most important skills that your child will need to learn, and it is not easy. It takes real commitment from parents and caregivers, but it can be achieved with a systematic approach. This text is only a brief outline of one method. Refer to the resources after this section for more information on toileting.

To begin the process, your child should be able to:

- Follow simple directions.
- Sit in a chair for 5 minutes.
- Stay dry for 1-1/2 hours.

### ***Skills Involved in Toileting***

Initially, focus on just teaching the child to eliminate in the toilet. Later, teach the other skills needed to be completely toilet trained, including:

1. Recognizing when he has to go
2. Waiting to eliminate
3. Entering the bathroom
4. Pulling pants down
5. Sitting on the toilet
6. Eliminating in the toilet
7. Using toilet paper correctly
8. Pulling pants back up
9. Flushing the toilet
10. Washing hands
11. Drying hands

## Elimination Records

About two weeks before you are ready to start toilet training, start recording when your child urinates and has a bowel movement to establish her elimination pattern – the times of each day when she is most likely to wet and/or soil her pants.

Elimination Record														
	Sunday		Monday		Tuesday		Wednesday		Thursday		Friday		Saturday	
Time	Pants	Toilet	Pants	Toilet	Pants	Toilet	Pants	Toilet	Pants	Toilet	Pants	Toilet	Pants	Toilet
7:00														
8:00														
9:00														
10:00														
11:00														
12:00														
1:00														
2:00														
3:00														
4:00														
5:00														
6:00														
7:00														
8:00														
9:00														
10:00														
11:00														

In the Pants column, you will record every hour:

D=dry

U=Urinated in pants

BM=Bowel movement

U/BM=Both

If you are putting the child on the toilet, record the results in the Toilet column in the same way. Do not begin the toilet training process while collecting these data.

D=Did not eliminate in toilet

U=Urinated in toilet

BM=Bowel movement

U/BM= Both

During these two weeks, there is no failure or success. You are only trying to see what your child's elimination pattern is so that you can set up a toileting schedule that makes sense for her.

### ***Determining a Toileting Schedule***

Carefully analyze the Elimination Record. At this point, decide whether you will focus on urine or bowel training. For this example, we focus on urine training.

1. Circle all the U's on the forms and add them up.
2. There will be a greater number of times for urination. Select four or eight times during the day when your child is most likely to eliminate. No two times should be closer than 1-1/2 hours.
3. Arrange the toileting schedule so that your already established toileting times for bowel training become a part of it.
4. Take the child to the toilet at all the schedule times.

### ***Putting the Child on the Toilet***

The bathroom routine should be:

1. Bring your child to the bathroom on schedule or when she signals. Pull her pants down to below the knees, encouraging her to do the rest.
2. Have her sit on the toilet for 5 minutes. Stay with her, praise her, and explain what is expected in a straightforward, non-demanding way.
3. If she eliminates, praise her and give her a reward.
4. If she does not eliminate, remove her from the toilet, and take her out of the bathroom for 10 minutes. Return to the bathroom for another 5-minute sitting.

In the beginning, going to the toilet should be a casual matter with little required on the child's part other than to sit. In a 20-minute period, give your child two 5-minute chances to eliminate with a 10-minute break in between.



## ***Using Visual Cues***

You may create visual cues, consisting of photographs or pictures, to support the toilet-training process. A good aid to use during toilet training is a visual schedule to help the child through the toileting procedure. See an example of a visual schedule at the end of this section.

In addition, a special visual prop can be helpful in setting the tone and in alerting your child to the activity. An example is to give the child a rubber duck when you want him to use the bathroom. Parents of nonverbal children may also consider incorporating sign language into the routine and teaching the child the sign for toilet so the child will learn to indicate when he needs to use the restroom.

## ***Intensive Training***

Another method is called “intensive training” or “weekend training.” It consists of spending the entire day in the bathroom focused entirely on toilet training. This approach also uses the Elimination Record to record times when the child was placed on the toilet.

Using this method, the child is dressed in only a shirt and remains on the toilet until he eliminates. Once the child eliminates, he is given a 5- to 10-minute break, then placed on the toilet again. The child is given plenty of fluids and salty snacks to encourage elimination. Parents use favorite toys in the bathroom to occupy the child.

## ***Sensory Issues***

Parents face some consistent problems relating to sensory dysfunction when trying to toilet train a child with ASD. Many children on the spectrum are sensitive to such things as the feel of the water splashing from the toilet, the texture of the toilet paper, the sound of the flushing, the feel of the toilet seat, and the list goes on. It is not uncommon to see the following demonstrated by some children with ASD:

- Flushing or playing with water in the toilet
- Playing with toilet paper
- Smearing feces
- Being “addicted” to diapers
- Refusing to wash hands
- Refusing to eliminate in toilet
- Afraid of flushing
- Refusing to sit on toilet

## ***Set the Stage for Success***

*Be consistent:* Keep the toileting routine as consistent as possible so that your child will come to expect it and be at ease with it.

*Use a regular toilet from the beginning:* If your child is too small, place a smaller seat on top of the regular toilet.

*Avoid distracting toys and people:* It is important for your child to learn that the bathroom is not a playroom; he is there for one reason only, to eliminate in the toilet.

*Avoid distracting talk:* Talk to your child about what he is supposed to be doing and what the toilet is for. Avoid talking about unrelated matters.

### **Resources**

Azrin, N., & Foxx, R. M. (1988). Toilet training in less than a day. New York: Pocket Books.


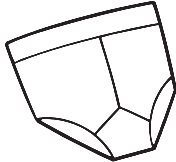

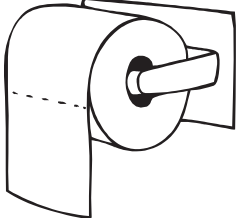
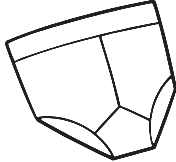

Baker, B. L., Brightman, A. J., Blacher, J. B., & Heifetz, L. J. (2003). Steps to independence: Teaching everyday skills to children with special needs. Baltimore: Brookes.

Coucovanis, J.A. (2008). The Potty Journey, Guide to Toilet Training Children With Special Needs, Including Autism and Related Disorders. Shawnee Mission, KS: Autism Asperger Publishing Company.

Dalrymple, N. J. (1991). Toileting: Functional programming for people with autism. Indianapolis: Indiana Resource Center for Autism.

Wheeler, M. (1998). Toilet training for individuals with autism and related disorders: A comprehensive guide for parents and teachers. Arlington, TX: Future Horizons.

# Toilet Training Visual Schedule

	<p><b>Pull down pants</b></p>
	<p><b>Pull down underwear</b></p>
	<p><b>Sit on toilet</b></p>
	<p><b>Use toilet paper</b></p>
	<p><b>Pull up underwear</b></p>
	<p><b>Pull up pants</b></p>

## Human Sexuality

When children become teenagers, their bodies start to dramatically change. They begin to grow pubic and underarm hair. They start to break out with acne. Girls begin to menstruate. Boys' voices change. For teenagers with ASD, these changes to their bodies may be frightening if they are not forewarned and prepared.

Parents need to decide the best way to talk with their teenagers with ASD about human sexuality based on their beliefs and traditions. Basic introductions should address the following topics:

1. Describe the basic physical changes that occur on the outside of the body during puberty.
2. Describe the basic physical changes that occur inside of the body during puberty.
3. Describe the basic emotional changes that occur during puberty.
4. Identify ways to manage or handle these changes.

Puberty can be an exciting time in a young adult's life. It's the time when the body makes many changes – both physical and emotional – to prepare for adulthood. It is a good opportunity to teach teenagers with ASD about their bodies and how they work.

### Puberty

#### **Typical Changes**

- Increased attention to physical appearance
- Interest in romantic love
- Increased need for independence
- Masturbation
- Unpredictable changes in mood
- Desire to be accepted and liked by your peer group
- Pubic and underarm hair

#### **Changes in Girls**

- Growing breasts
- Beginning periods
- Premenstrual syndrome

#### **Changes in Boys**

- Erections
- Wet dreams

## Elopement or Wandering

Have you ever found yourself worrying about your child wandering off and getting lost? All parents are concerned about their child's safety – whether the child has special needs or not. However, the concern of parents of children with ASD is often heightened due to the child's deficits in communication and socialization.

You can use direct instruction to teach your child that wandering away is not appropriate. You can use stories to explain that it is dangerous for your child to leave your house or yard. Still, some children and adolescents with ASD have an overwhelming desire and talent for leaving their homes and wandering unattended. This does not only happen at home. Children often wander away from a parent at a busy store or at the park. This is very dangerous because most children with ASD do not understand or obey the rules of the road or private property.

Neighbors can be very helpful in keeping an eye out for your child. Talk to them and explain what to do and how to approach your child if they should see him out alone. You can also inform neighborhood children and teenagers about what to do if they see your child out alone.

Make sure to contact your local police and fire department to alert them about your child and his tendency to wander. They should be able to “red flag” your telephone number and home if you ever call 911. This specific information may be embedded in the 911 database, so that the dispatcher will be able to tell the police and fire department about your child before they arrive.

If wandering is a typical problem for your child, you can install extra locks on all exterior doors high enough so the child cannot reach them, even when standing on a chair. Many parents have installed sliding bolt locks on the top frame of the door. There are also bed and door alarms available to signal when a child or adolescent is out of bed or opens a door or window. You can even get an alarm that plays a recorded message when a door is open, like “Jack! Do not leave the house!” and then sounds a siren to alert the parent. Children or adolescents can also wear bracelets that trigger an alarm once they pass through a protected doorway.

A very helpful precaution is to have a medical identification tag for your child to wear that lists name, diagnosis and contact information. These can be ordered at a drug store or online from MedicAlert. These medical emblems can be worn on the wrist, around the neck, or laced into a shoelace.

To be prepared, parents can create an emergency handout about their child for the time when they do wander off (see box).

### **Sample Autism Emergency Contact Handout**

If your child is a habitual wanderer, keep a copy of this handout at home, at school, in the car and on the child in case of an emergency. The sheet should include the following information:

- Name of child
- Current photograph and physical description, including height, weight, eye and hair color, any scars or other identifying marks
- Names, home, cell and pager phone numbers and addresses of parents, other caregivers, and emergency contact persons
- Sensory, medical, or dietary issues and requirements
- Inclination for wandering and any atypical behaviors that may attract attention
- Favorite attractions and locations where child may be found
- Likes, dislikes – approach and de-escalation techniques
- Method of communication. If nonverbal – sign language, picture boards, written word
- ID jewelry, tags on clothes, printed handout card
- Map and address guide to nearby properties with water sources and dangerous locations highlighted

## **Out in the Community**

As parents of a child with ASD, we are familiar with our son's or daughter's behavior, but others may not be accustomed to this disorder. Most of our children appear normal to others. It is only when they start to exhibit bizarre or out-of-control behavior that they come to the attention of others. Outings in the community can be a great challenge for most parents.

### **Tips for Successful Outings**

- Keep outings short.
- Do what you say you will do in the order you say you will do it.
- Decide on the optimal number of stops.
- Do the most important things first.
- Prepare a visual schedule for your child.
- Offer a reward at the end of the outing for good behavior.

## ***Shopping Trips***

One of the biggest challenges a family faces is the weekly shopping trip. Sometimes it is considered more trouble than it is worth. However, shopping is a basic skill that needs to be learned by children with ASD. Indeed, shopping trips are a good opportunity to teach your child to become more independent.

1. Create a visual shopping list using visual symbols with the list on one side and a completed list on the other side that may be used during the shopping trip (see example at the end of this chapter).
2. Involve the child in the selection process. For example, if you are buying a dozen apples, have the child select them. Point out if one has a bruise so he can learn.
3. Bring handheld toys or action figures to occupy the child.
4. Allow the child to help push the cart once she is older and no longer fits in the cart.

## ***Issues of Faith***

For many families, attending religious services is an important part of family life. It is intended to be a time of worship and quiet reflection, but when a child with ASD attends, it can be anything but quiet.

Nevertheless, a family's place of worship can be a source of comfort and support. While some families are established within a faith community, others may be new to religious life, having turned (or returned) to their faith as a source of strength upon the diagnosis of their child. Dedicated members of your faith community may be able to assist your family in various ways, from offering a listening ear to providing assistance in your home. A faith community may provide a comfortable setting for companionship and support.

Including a family member with ASD in religious services and activities may require some creative planning. Many religious bodies have programs for people with disabilities within their religious communities (see Resources at the end of this section). While not autism-specific, these programs may provide a blueprint for personalizing a program for your child.

It may be beneficial to request a meeting with the appropriate leader(s) in the faith community to discuss options for including your loved one in religious activities. Ask a teacher or service provider who may be of the same religious affiliation to accompany you and provide information about the kind of structure and support your child needs. This "team" can be a valuable resource.

Consider all the sensory stimulation during a service, including music, singing, stained glass windows, candles, flowers, and incense, which all together may be a lot for your child with ASD to handle. Here are some ideas to help entertain your child:

1. Personal stereo with headphones to block out extraneous sounds
2. Coloring books and washable crayons/markers
3. Picture books
4. Stuffed animal or another comfort item

Some have questioned whether or not it is wise to teach religion to a person on the spectrum, the argument being that religion is too abstract to grasp. If your faith is an important part of your family tradition, do not be discouraged from seeking an appropriate environment for religious training and fellowship. If you are not looking for an in-depth religious program, it may still be wise to teach your child about the various religions and denominations to which he may be exposed. In her adult life, she may receive services from a faith-based organization and should be respectful of the caregivers' beliefs. Likewise, it may be necessary to teach your child strategies for politely declining unwanted invitations from religious organizations she (or you) do not wish to be affiliated with.

## Resources

**Autism Society of America** includes two articles on religion and autism  
<http://www.autism-society.org/living-with-autism/community-inclusion/autism-and-faith/>

**Bethesda Lutheran Homes and Services, Inc.**, is dedicated to sharing Christ's love and providing services and benefits to individuals with developmental disabilities, their families, and others who support them. [www.blhs.org](http://www.blhs.org)

**Council for Jews with Special Needs** works to provide the necessary supports and resources for individuals with disabilities to participate in the Jewish Community. [www.cjsn.org](http://www.cjsn.org)

**Friendship Ministries** is a not-for-profit organization that helps churches and organizations share God's love with people who have cognitive impairments. [www.friendship.org](http://www.friendship.org)

**Jewish Council for Disabilities** is an organization dedicated to enhancing the life opportunities of individuals with special needs insuring their participation in the full spectrum of Jewish life. [www.njcd.org](http://www.njcd.org)

**National Apostolate for Inclusion Ministry** has joined forces with the National Catholic Partnership on Disability (NCPD): supports the inclusion of persons with intellectual disability in the Catholic Church. <http://www.ncpd.org>

**National Organization on Disability** has a section of their website devoted to religious participation. It includes a variety of interfaith resources and information. [www.nod.org](http://www.nod.org) (link on left of page for religious participation)



## **Restaurants**

Eating out can be a fun family excursion as long as you keep some basic strategies in mind. Don't let autism keep you from the activities and places you and your family enjoy.

1. Sit in a booth with the child with ASD on the inside to prevent bolting.
2. Have plenty of napkins available.
3. Remove all condiments and drinks from the child's reach.
4. Have a snack or activity ready for the child when you sit down to occupy her until the food arrives.
5. Take walks to the bathroom or arcade games to allow the child to explore the restaurant under your supervision.

## **Vacations**

Family vacations – no matter how longed for – can pose difficult issues. The most important thing to remember is to maintain as much of a routine as possible for a child with ASD. For example, have the child awake at his normal time, followed by breakfast and maybe watching television as a way to start the day. It is also important to keep the child's sleep schedule the same.

Creating a travel book may be a good planning device for your child. It can include pictures of the kind of transportation you will be using, who you are going to visit, where you will sleep, and what you will do or see at your destination. Also, remember to pack some of his smaller toys that will occupy him and remind him of home.

Use your vacation destination as a way to experience new sensory activities, without overlooking your child's fragile nervous system. Textures, sounds, sights, colors, and music are just some examples of sensory experiences. Here are some ideas for guiding sensory experiences on vacation.

1. Going to the beach and playing with sand.
2. Walking through a forest and feeling the different leaves.
3. Exploring a museum, identifying colors and shapes.

Make sure to take a lot of photographs of the places you visit to make a special memory scrapbook once you return home. Collect items from your trip like brochures, postcards, rocks, leaves, and other mementos to use in the scrapbook (remember to bring an empty coffee can or ziploc bags to store the nature items).

## ***Preventing Meltdowns in a Public Place***

As any parent knows, when your child (typical or ASD) has a meltdown in public, it can be embarrassing and frustrating for you and other family members. Prepare ahead of time for going out in public. You can do this by creating a schedule of events, including pictures or drawings to illustrate what will occur and review it with the child before the trip. Sometimes you can even prepare a basic schedule on a napkin or a piece of paper to help your child understand what is going to happen. You can also bring an object that your child finds comfort in, or read a social narrative about the event ahead of time to prepare for the outing. These are just a few suggestions on how you can provide some predictability for your child before going into the community.

## ***Handling a Meltdown in a Public Place***

Always remember that your child with ASD does not want to have a meltdown, so be patient and compassionate. However, when a meltdown does occur, the child is usually in extreme distress and may lose control of her raging emotions. When a meltdown does occur, try to remember the following:

1. **Only move the child if there is an immediate safety concern.** Moving the child while he is having a full-blown meltdown can be dangerous for you and the child, because he is unable to process what is happening.
2. **Do not try to give your child whatever he was asking for before the meltdown to stop it.** This advice is not to say you should not give in and let the child have his way. It is because during the meltdown he is unlikely to be able to respond to the object or even process the fact that he has it.
3. **Step back and do not intervene unless your child asks you to.** At this point, your job is not to try and calm him down; it is to wait. A child can rarely express his immediate needs during a meltdown.
4. **If there are others close by, move them.** Well-meaning people may try to help, but tell them very clearly to stay back because their presence will only escalate the situation. This is when the autism awareness cards may be helpful (see box).
5. **Make sure your own reactions don't escalate.** Try to step back and disconnect enough so that you are not caught up in your child's intense emotions and try to think rationally.
6. **Try not to take it personally.** It hurts when our children are angry and lash out at us, but try thinking of it as a symptom of something your child *has*, not who he *is*.
7. **Take this opportunity to step back to observe your child carefully.** Pay attention to his environment to determine if there are triggers – lighting, noise level, etc.
8. **Do NOT restrain your child.** However tempting, restraints may reinforce future meltdowns because some children find deep pressure relaxing. It is not only potentially dangerous for you and the child, in the long term, restraining is ineffective. THE ONLY EXCEPTION is when your child is hurting himself or others, or is in danger.

## Resource

Myles, B. S., & Southwick, J. (2005). *Asperger Syndrome and Difficult Moments: Practical Solutions for Tantrums, Rage, and Meltdowns* (2<sup>nd</sup> ed.). Shawnee Mission, KS: Autism Asperger Publishing Company.

## ***When the Child Hits the Parent***

There may come a time when your child hits you. First and foremost, do not take it personally. Your child is trying to communicate with you and may not be able to do so in a functional manner when in a state of distress. The following are important things to keep in mind.

1. Your child may not remember she did it.
2. Determine if he purposely hit you, or if he was flailing and randomly and accidentally hit you.
3. Review what you might have done to inadvertently contribute to the child physically acting out toward you during a meltdown.
4. Decide whether to bring up the hitting after the incident.
5. Make sure your child knows that you forgive her when she makes a mistake, whether intentional or not.
6. Call on your support group to get emotional support and to discharge some of the emotions you are feeling if necessary.
7. When you are of a clear and rested mind, you will need to ask some questions – is this an ongoing pattern and do I need to seek help from a behavior professional?

The following are some examples of cards that may be carried by people with autism or their caregivers to briefly explain autism to strangers. You can make these cards yourself or purchase them from local Ohio Autism Society chapters. You may also call OCALI at (866) 886-2254 to ask for the address of the Autism Society Chapter nearest you.

If you want to make your own autism awareness cards, here is the copy you can put on each side of the card.

### **Examples of Autism Awareness Cards**

#### **Side One**

If you are puzzled by my child's behavior? It is not boldness or lack of discipline!  
My child has autism ...

#### **Side Two**

*Autism is a life-long neurological disorder that prevents the person from understanding what he sees, hears, or otherwise senses. People with autism often become confused and respond inappropriately in social situations. Autism strikes out of every 68 people.*

*You can also make a card with the following messages:*

*Our son has autism, a severe language and behavioral disorder. He sometimes becomes confused, disoriented, or upset and may throw temper tantrums or scream. We are committed to teaching him how to function in the community and would appreciate your patience and understanding. If you would like to learn more about autism, please feel free to contact us or the American Autism society (1-800-3Autism).*

*This young person has autism/Asperger Syndrome. It is a developmental disability that affects social and communication skills. People with autism tend to behave in an odd and unpredictable way as a result of their disability. Please help us by being understanding and showing tolerance.*

### **Resources**

#### **Books**

Sakai, K. (2005). *Finding our way: Practical Solutions for Creating a Supportive Home and Community for the Asperger Syndrome Family*. Shawnee Mission, KS: Autism Asperger Publishing Company.

Sicile-Kira, C. (2004). *Autism spectrum Disorders: The Complete Guide to Understanding Autism, Asperger's Syndrome, Pervasive Developmental Disorder and Other ASDs*. New York: Perigee.

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## ***Preparing Your Child for a Medical Appointment***

Not unlike most children, children with ASD are not particularly fond of going to doctors. The experience can be traumatic because there are many sounds, sights, and smells that can seem frightening to them. It is extremely important that before going to a physician's appointment, the child is prepared and provided with an understanding of what will take place at the appointment.

## ***Preparing the Medical Environment***

When initially setting up the appointment, whether for a routine pediatric visit, a dental appointment, or a visit to the hospital, mention your child's diagnosis to be sure it is added to the chart, if it is not already included. Ask that it is noted in a prominent spot so that all involved will be aware prior to meeting your child. This is meant to benefit your child. With proper information, even the initial interaction with the nurse or receptionist can set a positive tone for your child's visit.

Three to four days prior to your child's visit, call the office to touch base again. Ask what the routine and wait time will most likely be for your child's appointment. They should be able to tell you about transitions and specific steps (such as being weighed, measured for height) that will be included in the routine. Confirm that they are aware of your child's diagnosis. Explain the specific characteristics of your child and express any stress triggers that might bother him. Suggest adaptations that could be made to ensure that the transition and actual appointment will proceed quickly and smoothly for everyone. Suggestions may include the following:

- With medical professionals, reviewing the environment with the child in mind
- Limiting the number of people who will be involved in the child's care
- Designating a medical team member as the child's procedure coach
- Providing sensory items to help the child self-regulate
- Preparing the child for surgery or a physician's appointment according to the child's developmental level, not the child's chronological level
- Using visuals to help the child understand what will occur
- Providing simple, step-by-step information
- Developing coping techniques that are specific to your child, such as talking about the visit ahead of time and looking at pictures of the physician's office and equipment

If the visit to the hospital is an emergency and advance notice was not given, be sure to let the medical team know about your child's characteristics, needs, stress triggers, and sensory preferences as soon as possible. Putting these items in writing prior to arrival and bringing them with you will make it easier to convey the child's needs to the medical staff as well as give them a framework for how best to interact with your child in this emergency situation.

## ***Preparing Your Child for the Medical Environment***

Tell your child she will be making a visit to the doctor or dentist. Do not surprise her with this information upon arrival. All children are nervous about a medical visit, but giving them information in advance allows them to process, anticipate, and better absorb the reality of what will occur around them. It allows them to predict what will occur so they are not caught off guard by the flood of new sights and sounds around them – a major consideration for children with ASD.

### ***Giving Information***

Information should be given on your child's level, in the amount and manner in which your child can best understand it. If you are able to obtain pictures of the actual office, use them. Often major children's hospitals have online virtual tours, with photos describing a visit to the hospital, or they allow you to visit the hospital for a tour prior to your actual visit. If these options are not available, consult children's books that depict a visit to the doctor, dentist, or hospital. It is important to familiarize your child with titles of people, equipment that might be used, the routine of the environment, and steps of the actual procedure, if at all possible.

Create a story specific to your child's visit. Include details such as:

- Steps in the routine
- Making transitions to different rooms
- Waiting in certain areas
- Wearing special pajamas during the visit
- People your child will meet
- Equipment your child will see
- Sights, smells, and sounds that your child will encounter

Add details that make your child's trip unique such as:

- Who will accompany him
- What he can bring with him
- What he will do when the visit is over

Ask your child open-ended questions about what he is feeling and which steps seem hard or easy. Help him make a plan to be successful, and remind him that it is okay to ask questions if something comes up he does not understand. Create a portable, step-by-step visual, such as a photo flipbook or a written schedule of each step. Make sure the schedule outlines the details you have discussed and the coping techniques chosen by your child to help him with the visit. This predictability will give your child a sense of control as he ventures into an often unsettling encounter.

## ***Medical Play***

In addition to specific information about the encounter, allow your child to play through the medical experience. Refer back to the children's books and provide your child with a medical doctor's kit. Encourage your child to be both the doctor and the patient during various play series. Do not interrupt your child even if she engages in hostile or aggressive play, unless it is endangering her own or others' safety. Sit back and observe what your child is expressing through words and actions. After the play sequence is finished and your child is in a state of attention, talk with her about what you observed and directly answer all the questions you can. Give honest information, using soft language so as to not frighten your child, but provide accurate information.

## ***Use a Transitional Item***

Plan a transitional item that your child can bring to accompany him on his journey. This may be a favorite stuffed animal, a blanket, or some special treasure. This item allows

the child to cling to something he is familiar with in the midst of an unfamiliar and invasive environment. Create a plan with the child as to who will hold the item during various steps in the procedure. The object may have to be out of the child's hands at times, and it is better if this is discussed prior to the moment when the child is being asked to release the item. If a plan is in place, the child can be reminded that the item will only be out of his hands for a few moments and returned during the next step.

### ***During the Medical Encounter***

In addition to all the advance preparation, your child will need you as a coach during the actual medical encounter. Encourage him to bring along the portable visual you created to support him through his visit. Be sure to leave space for flexibility, as the medical environment often entails emergencies or unforeseen delays.

As each step takes place, indicate to your child that it is over by crossing it off or turning the page of her special book or visual. Reiterate the lessening number of steps left. Remind your child that she successfully completed previous steps and then guide her through the step that is next. For example, "Great job getting weighed. You have already finished three steps. You arrived at the doctor's office, waited in the waiting room, and got measured and weighed by the nurse. Now we are waiting for the doctor to come in."

You can also review previously chosen coping techniques or offer new choices on the spot. In the midst of the medical encounter, provide your child with limited choices. For example, "While we wait for the doctor to come in, do you want to play 'I Spy,' read your book, or talk about *Star Wars*?" Be sure to only offer choices that are available. Coping choices may change for different steps because of restrictions of body movement, room changes, or the effect of medication.

### **Resources**

Hudson, J. (2006). *Prescription for success: Supporting children with autism spectrum disorders in the medical environment*. Shawnee Mission, KS: Autism Asperger Publishing Company.

"Your Next Patient Has Autism," North Shore Long Island Jewish Health System:  
<https://www.northshorelij.com>



## **Leisure Activities**

Leisure activities are something everyone enjoys and looks forward to. To the extent possible, children with ASD should participate in leisure activities as individuals, in groups of peers, and with their families. By using your child's interests and strengths, encouraging skill building in small steps, and creating a fun and well-supported environment, leisure activities can be enjoyed by all.

### **Sample Community Activities to Consider for Your Child**

Playing on a sports team	Playing outdoors
Visiting the library	Visiting a museum
Scouts	Reading
Religious groups	Playing board games
Going to a birthday party	Watching a parade, event or sport
Camps	

The following are some ways to adapt activities and build in support to create success for your child, given her special needs.

### **Provide a Framework**

Prime your child in advance with information that will create a visual for him and prepare him for the overall experience. In your description, review items such as:

#### **The overall environment**

- Sounds
- Sights
- Smells

#### **The people present**

- Names
- Descriptions
- Role or function
- Designated "safe person" such as a counselor, activity leader, etc.

**The activity taking place**

- Rules
- Why he is participating
- Working as a team
- Being an individual

**Boundaries and rules**

- For the activity
- Social “hidden curriculum” rules the child may not know

***Provide Opportunities***

If your child wants to participate in leisure activities, provide the opportunity for her to do so. You may need to ease her into a group function, so practice first at home playing one-on-one with your child. Eventually, invite three or four children over to play. Provide a structured activity for a predetermined, short length of time. As your child develops, transition her into a larger group, a bigger arena, or a lengthier interaction using increasingly more skills.

- If your son wants to play Little League, teach the basic skills one-on-one or invite boys to play baseball. Practice throwing, catching, and batting. After your son learns the subtle rules of team play and develops basic skills, invite the boys over again for a short game. Eventually, your child will be ready to transition into a full Little League team.

If your child wants to participate in non-sport leisure activities, practicing at home can also be beneficial. Create a scenario and role-play with your child prior to an actual encounter.

- Pull out shelves of books and a plastic card to pretend you are at the library. Review rules of being quiet and how to look for a book.
- For lunch, create a menu of choices. Present it to your child and ask her to make a selection. Review table manners, what to do while she waits, and choice making.

## **Encourage Your Child's Strengths and Interests**

Ask your child in which activities he wants to participate. Getting consent from your child will increase his desire to participate. Find avenues to pursue the interests and activities that he loves and in which he excels, and then adapt them for his level of participation and skill. Create leisure activities and social opportunities out of your child's interest. For example, if your child enjoys reading, start a small reading group, having the children read a story and complete activities that pertain to the theme. If your child enjoys playing a particular game, for example, chess, invite others over and create a chess tournament. If your child likes to play baseball, start a small, informal team in your neighborhood.

## **Talk with the Leaders**

Prior to the event or start of a sport season, visit with the director, coach, or a parent of a peer to exchange information and create a plan of success for your child. Take time to explain your child's strengths and needs, providing information about sensory needs, need for visual supports, stress triggers, and how to anticipate and support a potential meltdown. Ask for information about the routine of the event, gathering as many details as possible. Also discuss adaptations that would be beneficial and determine how they will be incorporated.

Often when a child is starting or encountering a new leisure activity, parents participate in a leadership role, such as being a coach or facilitating a troop. This allows you to add needed support and make accommodations for your child.

## **Bullying**

Bullying is a pressing issue for many schools. While this damaging behavior affects both typical children and children with special needs, children with special needs are at more risk for being targets of a bully. Being bullied can cause kids to experience fear and anxiety and interfere with school work and self-esteem.

### **Types of Bullying**

- Physical – hitting, kicking, pushing, etc.
- Verbal – name calling, teasing
- Emotional – excluding and ignoring others
- Sexual – touching, teasing, coercing
- Cyberbullying – sending threatening emails, text messages, harassing cell vphone calls, etc.

Because children with ASD have trouble with language and social cues, they can become easy targets for bullies. Further, one of the main ways children protect themselves from being bullied is to predict the behavior of others and respond accordingly. Children with ASD have a very difficult time predicting what others may be thinking. For example, a group of students may talk a child with ASD into doing something he knows is wrong, but he may think they are trying to be friends and not realize what they are doing and comply after all. Students with ASD may also mimic what others do, including bullying others, without understanding the consequences. They may also try to retaliate.

The best bullying prevention programs involve the whole community and all staff at your school. Children not only need to learn ways to handle a bully, they also need to be able to address students who may watch, called bystanders. If your child is reporting increased headaches, stomachaches, or other physical problems or complaining about going to school more than usual, consider explaining what bullying is and ask if it is happening to her.

If your child is being teased, excluded, or harmed repeatedly by schoolmates, take action.

- Ask about school policies, training, and programs for bullying.
- Ask if there is supervision in hot spots like hallways, lunchrooms, bathrooms, and locker rooms. Bullying typically occurs under the radar of adults.
- Ask if there are classroom discussions about bullying.
- Look for teachers who are flexible and can help your child feel more alike than different.
- Consider using a social story and/or power cards to help your child know how to respond to bullies.
- If needed, you can address it on the IEP.

### Resources

#### Books

Heinrichs, R. (2003). *Perfect targets – Asperger Syndrome and bullying: Practical solutions for surviving the social world*. Shawnee Mission, KS: Autism Asperger Publishing Company.

#### Websites

Stopbullying.gov: <http://www.stopbullying.gov/index.html>

Stop Bullying Now: [www.stopbullyingnow.com](http://www.stopbullyingnow.com)

Pacer Bullying Prevention Center: <http://www.pacer.org/bullying/>

# GROCERY LIST

## *Items to Find*

*Velcro Strips for Picture*

*Velcro Strips for Picture*

*Velcro Strips for Picture*



## *Items to Buy*

*Velcro Strips for Picture*

*Velcro Strips for Picture*

*Velcro Strips for Picture*