

Caregiver's Workbook



For Groups of Caregivers of Young Children
with Autism Spectrum Disorders

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Table of Contents

Introduction.....	1
Caregiving and Emotions Exercises	3
Exercise 1—Journal activity.....	3
Exercise 2—Sharing	5
Exercise 3—Creating dates with yourself.....	7
Video 1	11
Caregiving and Emotions Handouts.....	13
Handout 1—Fun ideas	13
Handout 2—Exercise	15
Handout 3—Expressing emotions	17
Handout 4—Fact sheet.....	19
Handout 5—Resources for more information	21
Caregiving and Relationships Exercises	23
Exercise 1—Making time.....	23
Exercise 2—Delegating	25
Video 2	27
Caregiving and Relationships Handouts	29
Handout 1—Accessing support systems	29
Handout 2—Activities	31
Handout 3—Communication	33
Handout 4—Fact sheet	35
Handout 5—Resources for more information	37



Caregiving and Family Exercises	39
Exercise 1—Positive reactions	39
Exercise 2—Explaining ASD to family and friends.....	41
Exercise 3—Explaining ASD to siblings	45
Exercise 4—Fun family activities	49
Video 3	53
Caregiving and Family Handouts.....	55
Handout 1—Dividing family responsibilities.....	55
Handout 2—Master calendar	57
Handout 3—Appreciating family	59
Handout 4—Fact sheet.....	61
Handout 5—Resources for more information	63
Caregiving and the Individual with ASD Exercises	65
Exercise 1—Open forum.....	65
Exercise 2—Accurate and reliable information	67
Exercise 3—Celebrating accomplishments	71
Exercise 4—Questions.....	73
Video 4	77
Caregiving and the Individual with ASD Handouts.....	79
Handout 1—Template for recording reliable, valid resources	79
Handout 2—Template for tracking questions and answers.....	81
Handout 3—Fact sheet	83
Handout 4—Resources for more information	85

Caregiving and Services Exercises	87
Exercise 1—Time management	87
Exercise 2—Asking effective questions	91
Exercise 3—Advocacy skills	95
Video 5	97
Caregiving and Services Handouts	99
Handout 1—Information about my child	99
Handout 2—Fact sheet	103
Handout 3—Resources for more information	105
Caregiving and Finances Exercises	107
Exercise 1—Budgeting skills	107
Exercise 2—Fun and affordable activities	111
Exercise 3—Communicating about finances	113
Video 6	115
Caregiving and Finances Handouts.....	117
Handout 1— Family Expenses	117
Handout 2—Fact sheet	119
Handout 3—Resources for more information	121



Introduction

Welcome

Welcome to the Caring for Caregivers (CFC) Caregiver's Workbook. This workbook has been designed to coordinate with the CFC program and to provide concrete, useable resources to help caregivers in their daily lives.

When you participate in a CFC group session, the facilitator will pick and choose various activities, from this workbook, for the group to complete. Because there are so many exercises, there will not be time to finish them all. All of these exercises and handouts can also be used at home, in your own time. Flip through and see what exercises or handouts look helpful to you. Try to set aside a few moments during your day to read and complete one exercise. Most of the exercises should take about 20 minutes.

There are a number of exercises and handouts that can be used over and over again. Use this workbook as a starting point, a building block, to find ideas, methods, and resources that can help you and your family.

Support network

Throughout the workbook there are references to the support network. As the facilitator of the CFC group session you attended explained, a support network is a group of people, with common interests and experiences, who listen, provide guidance, and support. You may have joined a support network consisting of the members of your CFC group, you may find support on the CFC Caregiver Connection Web site, or you may have a group of people in your community. The prompts throughout this workbook are meant as reminders and ideas for ways to connect with the people in your life who can offer support.



Caregiving and Emotions

Exercise 1—Journal activity

Many times, caregivers do not even have time to think about how they feel. They push themselves from activity to activity and appointment to appointment. All of their attention is on their child with ASD. It can be hard to face difficult emotions and easier not to think about them. Writing down feelings on paper can make those feelings seem more real and can be a great step toward moving through them.



You can use this journal activity each day or whenever you have a moment. Think of it as a way to check in with yourself and how you are feeling. You can use the journal to express both positive and negative emotions and experiences.

Right now, ask yourself:

- How are you feeling? Take a moment, close your eyes, and focus on your breathing. Listen closely—how are you feeling?
- Do you like how you feel?
- What would make you feel differently?
- What can you do right now to feel better?

Notes



Caregiving and Emotions

Exercise 2—Sharing

As a caregiver of a young child with ASD, you may not have many opportunities to interact with other caregivers. You may or may not be involved in ASD-related organizations or meet other caregivers at appointments. Having people who are going through similar experiences—who can relate to you and understand your experiences—can feel comforting and empowering. It is a reminder that you are not alone—there are others who understand and can help.



Feeling heard and understood are powerful gifts. You are together on a journey, one that you did not choose, but there are others who travel with you. By sharing your experiences, you can all learn from one another, support each other, and understand each other's feelings. Knowing that other caregivers "get it" can help you feel more open and free. Release tension by sharing.

This activity is meant to be done with a group of caregivers. You can also share your experiences online at the Caregiver Community Web site, www.autismcaregiver.com. The Web site connects caregivers with other caregivers.

Sharing and talking about your story can be overwhelming sometimes, and even upsetting. You may or may not feel comfortable sharing. Share what you are comfortable with sharing, and know that you do not have to share if you do not want to.

Share with the other people in the group:

- Your name
- How many children you have
- The age of your child or children with ASD
- Your child's diagnosis
- When you discovered your child had ASD
- How you and your family have been coping since diagnosis



Support Network Opportunity

Check in with your support network or on the Caregiver Community Web site on a weekly basis. You might want to start sharing the information mentioned on the previous page and then move on to checking in on how your week is going, what new activities are going on, or how you are feeling at the moment. It can be powerful to have other people to share your experiences with.

Notes

Caregiving and Emotions

Exercise 3—Creating dates with yourself

Taking time for yourself is certainly a luxury. It can seem like even finding 5 minutes for yourself in a day is a challenge. Having time for yourself to rejuvenate, relax, and just be yourself is so important. It can recharge you and give you more energy to devote to your family and to feel more relaxed and happier. Think of it like breakfast—they say that breakfast is the most important meal of the day. Creating time for yourself is the most important time you can spend in any day.



What would you do if you had...? (List 2–3 ideas for each item.)

A whole day to yourself?

1. _____
2. _____
3. _____

A half day to yourself?

1. _____
2. _____
3. _____

2 hours to yourself?

1. _____
2. _____
3. _____



1 hour to yourself?

1. _____
2. _____
3. _____

30 minutes to yourself?

1. _____
2. _____
3. _____

Now you have a long list of ideas for activities that you would love to do if you had a certain amount of time. Of these, which seem the most attractive and luxurious? Which seem the most doable?

Let's brainstorm some ways to create time to do an activity. Choose one activity from your list to do in the next week. Give yourself at least 30 minutes for this activity. That's 30 minutes for yourself. From your list, which activity would you choose? Which one would bring you the most happiness, most relaxation, or most peace?

Now, look at your calendar for the next week. Find a 30-minute time period where you can do this activity. Schedule it, put it on your calendar, and do not reschedule.

After you do your activity, answer these questions:

- How do you feel now?
- What was your favorite part of your activity?
- Would you do it again?
- What would you like to do next week?

See if you can gradually increase your "date" with yourself by a few minutes each week. Another option is to have a couple of 30-minute dates with yourself per week. Put them on your calendar. Look forward to them and make them just as important as the other

things you do each day. You are important!

*****Support Network Opportunity*****

Your support network can prompt or remind you about your dates with yourself. Tell them about this exercise and the specific "date" or activity you have chosen to do for yourself. Ask them to follow up with you in a week to see how it went.

Notes



Caregiving and Emotions

Video 1



1. What were your feelings after your child was diagnosed with ASD? How do you feel now in relation to the diagnosis? Can you relate to the feelings and experiences of the caregivers in the video?

2. How did you handle these feelings about the diagnosis? What and/or who helped you cope with your emotions?

3. What sources of support did you find helped you after the diagnosis?



Caregiving and Emotions

Handout 1—Fun ideas

If it's been a while since you've done something fun for yourself, here is a list of potential activities you may enjoy. Keep in mind that the possibilities are endless. You are making a commitment to yourself and your health by making time for yourself.



Fun activity ideas

- Play in a sports league
- Work on a scrapbook
- Exercise—run, walk, bike, hike
- Start or continue to work on a journal
- Take a cooking class
- Attend a concert or play
- Take a knitting class
- Go to a museum
- Go to the park
- Bake cookies
- Go to a coffee shop
- Play cards with friends
- Go to the movies
- Call a friend you haven't talked to in a long time
- Take a dance class
- Get your hair cut
- Get a manicure
- Get a massage
- Read
- Listen to music
- Play board games
- Sing or do karaoke
- Watch your favorite sports team with friends
- Do a puzzle (crossword, Sudoku, jigsaw)
- Plan a trip or an evening out
- Invite friends over for dinner or coffee
- Start a garden
- Learn to woodwork
- Meditate



Benefits of taking time for yourself

- Reconnecting with your sense of self
- Recharging, building energy
- Lowering your stress levels
- Having things to look forward to
- Rewarding yourself for your hard work
- Building focus and increasing attention
- Maintaining a positive attitude
- Relaxing

All of these benefits help to make you a better caregiver—not to mention a happier person.

Notes

Caregiving and Emotions

Handout 2—Exercise

Exercise is a great way to relieve stress. It helps you to take care of yourself, stay in shape, and build energy for your daily life. There are many types of things that can be considered exercise. The key is to find something that you like to do so that you'll do it regularly. Exercise can be a solo activity that allows you some alone time. You can also make it a family activity, getting everyone involved.



Here are some ideas to get you moving and out and about, by yourself, or with your family:

- **Yoga.** Find a local studio or gym in your area that offers beginner yoga classes. Yoga not only offers the benefits of physical exercise, but it also helps to quiet the mind and is relaxing.
- **Gym.** Most gyms offer many different types of aerobics classes, swimming, and stationary machines along with weights. You might like to ride a stationary bike for 30 minutes while reading your favorite book.
- **Walk.** Take a walk around your neighborhood, admiring the flowers and trees. You could also race with your children along the sidewalk, making it a game of exercise.
- **Hike.** Go to your local park and explore trails. Try following a new trail each time and see where it leads you.
- **Bike.** Go for a bike ride, feeling the wind on your face. Find a great trail nearby for bikes and ride with the whole family.
- **Swim.** Some gyms or community associations have swimming pools. Swim laps or play fun pool games with your kids.
- **Sports.** Organize a neighborhood soccer game or join a pick-up game of basketball.
- **Leagues.** Join a community softball league or pick up bowling.
- **Dance.** Pretend you're dancing with a celebrity as you turn up the music and



move your body to the beat.

- **Video.** Rent or buy a workout video and work out in your living room.
- **Download.** Many Web sites and online programs have free workouts that you can do while watching them on your computer or smart phone.

Notes

Caregiving and Emotions

Handout 3—Expressing emotions

There are many ways to express yourself and your emotions other than just talking about them. Here are some ideas of creative ways to express yourself.



- **Poetry.** Poetry can be a few words or a page-long dialogue that rhymes. Finding new ways to express yourself through words can bring more insight into your experience as a caregiver.
- **Journaling.** A notebook or blank journal that you carry with you can be an invaluable tool. Whenever you are feeling tense, sad, or even happy, you can jot down your ideas, your thoughts, and your feelings. Expressing yourself on paper—knowing that you can say anything you'd like because it is private—can be liberating.
- **Singing.** Sing along to the radio or sing a made-up song with your children. Really belt it out and be silly! Sing along to your favorite artist or band or find a song that speaks to you, and let your voice ring!
- **Comedy.** Telling jokes or practicing impromptu comedy can be a good creative release. Finding humor in everyday things—even experiences that can be stressful—can help you find humor in stressful situations. The ability to laugh with others or at yourself feels so good!
- **Drawing.** Words or writing may not be your thing, so think about drawing your emotions or your experiences. Representations in pictures can be funny, heartfelt, and poignant. These drawings aren't necessarily for hanging in the house but can be in your journal or on a scrap piece of paper instead.
- **Painting.** The colors, texture, and feeling of painting in itself can feel good and help ease tension. Creating a painting from scratch accesses your creative side. Rather than thinking about what you're going to paint, get out some paint and a brush and see what comes to you.
- **Dancing.** Pump up the music, maybe in your bedroom, and boogie! Moving and shaking along to the radio or your favorite song will release stress, get your blood flowing, and bring some fun into the moment.



- **Blogging.** Just as an online diary does, blogging can be a way of expressing yourself and your experiences. Blogs can either be anonymous or you may share your blog with your friends and family. Forming an online community of support can be great.
- **Collage.** Grab some old magazines and tear out pictures, phrases, or articles that speak to you. Paste these pictures and other items together on a big piece of paper or posterboard. You may choose a theme, like expressing how you're feeling right now, or you may make a collage of how you want to feel soon. Hang your collage up somewhere where you can see it and see how the separate items that you found come together to make an interesting whole.
- **Photography.** Begin bringing your camera everywhere with you. When you see things that make you smile, take a picture. When you see things that move you, take a picture. Capture special moments and then upload your pictures to your computer. You could print them out and make a photo book or a slide show capturing special or important ideas or thoughts that you've had throughout your days.

Notes

Caregiving and Emotions

Handout 4—Fact sheet

The following information is covered in the Caregiving and Emotions section of the CFC program for caregivers of young children with ASD.



Caregivers of young children with ASD may experience a variety of emotions. As you work to understand the diagnosis and learn how to help your child and family, the phases and cycles of emotions can be overwhelming. Some emotions that caregivers talk about feeling include guilt, frustration, sadness, anger, denial, and loss of control.

While every caregiver's experience is unique, all caregivers experience these challenging emotions in some way. You are not alone. There are different ways to cope and various people to turn to for support and encouragement along the way.

Tips and ideas to help caregivers cope

There are a variety of options to help caregivers cope emotionally to help reduce their stress. These include:

- Journaling about your feelings, your day, and your experiences and writing down everything that you feel can help you move through difficult times.
- Sharing experiences with other caregivers, whether online or in person, can provide a sense of support to caregivers.
- Finding time to dedicate to yourself can go a long way to maintaining your emotional health. Finding and doing a favorite activity, even for just 30 minutes, is important.
- Participating in community activities or groups with other caregivers can provide a sense of community and opportunities to connect with others who may have similar experiences.
- Exercising is a great way to relieve stress and build energy.
- Find common activities that are enjoyable for both you and your children with ASD.



Caregiving and Emotions

Handout 5—Resources for more information



Time for self

- *Top-to-Toe Home Spa: Do-It-Yourself Beauty Treatments for Total Well-Being* by Stephanie Donaldson
- This book offers ideas and detailed instructions for creating your own at-home spa or finding different ways to relax.
- Grab your Wii™, Playstation®, or other video game system and find a game that you enjoy.

Relaxation

- Local Yoga studios: <http://yogafinder.com>
Use this link to search for a yoga studio in your area to try yoga for relaxation.
- *Guided Mindfulness Meditation* by Jon Kabat-Zinn
From the founder of the renowned Stress Reduction Clinic, Kabat-Zinn offers tools to help deal with stress and promote awareness and clarity on this audio CD.
- *The Relaxation & Stress Reduction Workbook* (6th ed.) by Martha Davis, Elizabeth Robbins Eshelman, and Matthew McKay
This book is useful in assessing your stress level and provides tips on stress reduction and descriptions of relaxation exercises.

Support

- Caregiver Community: www.autismcaregiver.com
This Web site is dedicated to connecting caregivers with each other and providing resources throughout the lifespan of ASD.
- Autism Society of America: www.autism-society.org
In addition to online resources, the Autism Society of America has local chapters throughout the United States that offer information and support to caregivers. You can find a local chapter through their Web site.



- AutismWeb: www.autismweb.com
AutismWeb is a Web site created by parents for parents. It offers a message board to connect with other caregivers, to ask questions, and find resources.
- Online Asperger Syndrome Information and Support (OASIS):
www.aspergersyndrome.org
OASIS offers resources for families such as articles, links to local and national support groups, and a moderated message board to connect with caregivers.

Notes

Caregiving and Relationships

Exercise 1—Making time

Many caregivers say that it is really challenging to find time to spend alone with their spouse or partner. At the end of a busy day, there is usually little time to spend together. Connecting and checking in with your loved one is important for remaining aware of what's going on daily, knowing how the other person is feeling, and maintaining your relationship. Use this exercise as a way of brainstorming ideas for creating more time together.

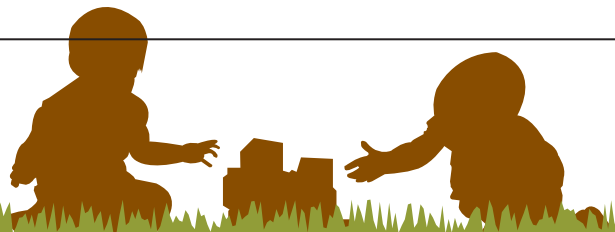


Caregiver: If you are working on this exercise at home, consider scheduling a time to do it together with your partner.

What times of the day are you home together?

Does it feel challenging to find time together with your partner? Why or why not?

What are some potential ideas for addressing the reasons you listed above?



Which one or two of these ideas seem feasible to try in the next week?

What could you take off of your schedule to make more time for each other?

Here are a few simple ideas that you can turn into special moments or time to check in and be with one another. Notice that even the simplest things, such as brushing your teeth, can be moments where you are with one another and not doing anything else.

Ideas

- Brushing teeth
- Getting ready in the morning
- Going to bed 10 minutes early and talking to one another
- Sharing a notebook where you tell each other stories about the day
- Sharing 5 minutes over a cup of coffee
- Meeting for lunch

*****Support Network Opportunity*****

What do members of your support network do to connect with their spouses or partners? How has making time with a spouse or partner helped? What challenges do they have with making time for each other? These are all questions that you can discuss with your support network on the Caregiver Community Web site.

Caregiving and Relationships

Exercise 2—Delegating

Use this exercise to help identify items that you routinely do that maybe could be done by someone else. This can free up some time for yourself and involve more people in your day-to-day activities. Family and friends often want to help but aren't sure how to do so or how to ask. If you have an idea of how they can help, you can delegate tasks, take stuff off of your plate, and receive support from those in your life.



Make a list of things on your to-do list for the day:

Make a list of other items that are on your list for the week:

- Circle the items that you need to do yourself.
- Make a star next to the items that friends, family, or your partner could help with.
- Draw a line through the items that do not have to be done or could be removed from your list.



Use these edits to revise your to-do list, maybe for the day or for the week. Try it and see how it goes. You can do this exercise again for another week, finding new ways to ask those in your life to support you and help you create more time and space for yourself, your child with ASD, and your family.

Some ideas for things that others can help with:

- Shopping for groceries
- Mowing the lawn
- Cooking dinners
- Preparing snacks
- Running siblings to appointments/activities
- Taking the dog for a walk

Even small things can add up to a lot more time for you. The key thing is to know what to ask for, how to ask, and whom to ask. You can't know the answer until you ask.

*****Support Network Opportunity*****

How do members of your social network ask others for help? What types of things do they get support with? Discuss with your network the possibilities of asking for help and why it can sometimes be difficult.

Notes

Caregiving and Relationships

Video 2



1. Has your relationship with your significant other been impacted by the diagnosis? Are there both positive ways and challenging ways that the diagnosis has influenced your relationship?

2. How have friends, either new or old, responded to you and the diagnosis? In what ways have your friendships shifted?

3. Are you able to connect and receive support from your extended family? If yes, in what ways? If no, what challenges do you face?



Caregiving and Relationships

Handout 1—Accessing support systems

Connecting with other caregivers can be a great source of support. Being involved in autism-related organizations can help you not only learn about ASD, but also be involved with groups of similar people with similar experiences. Sources of support can come from the autism community or your general community of neighbors, parents, and friends. Here is a list of some organizations, Web sites, and groups that may help you connect with people in your community.



Get involved:

- Your local community Autism Society of America chapter
- Local autism-related organizations
- School groups
- Parent-teacher association
- Sports (for you or your children)
- Runs or walks for autism
- Volunteer opportunities
- Community-based groups

Web sites:

- Caregiver Community Web site: www.autismcaregiver.com



Caregiving and Relationships

Handout 2—Activities

Sometimes, it can be tough to get out of a rut and find new things to do with your spouse, partner, and even your friends. Here are some jump-start ideas to try:



- Rent a movie
- Go to a movie
- Take a walk
- Go for a hike
- Play a board game
- Take a class together
- Go bowling
- Play a round of mini-golf
- Attend a sporting event
- Cook dinner
- Go out to dinner
- Have dessert and coffee
- Read and discuss a book
- Volunteer
- Walk around a new area of town
- Check out tourist spots in your hometown or a city that you've never been to
- Window shop
- Watch a sporting event
- Have an at-home spa day
- Go to a museum
- Plan a picnic



Caregiving and Relationships

Handout 3—Communication

Communication techniques can help in any relationship. Here are some tips:



- **Be clear.** Your partner cannot read your mind. When you have a problem or need help, be up-front and open so you can work as a team to find a solution. If an issue is important to you but maybe is not as important for your partner, make sure he or she understands its importance to you. Speak up.
- **Listen actively.** Let your partner talk and make sure you understand what he or she is saying. Do not interrupt. If something doesn't make sense, ask for clarification. Repeat or paraphrase what he or she has said to confirm your understanding and show that you are listening carefully. ("So, I hear you saying that you are overwhelmed and would like some help cooking meals.")
- **Use open and direct body language.** Making eye contact, keeping an open stance with your body (rather than crossing your arms or turning your back), and maintaining a neutral facial expression can promote positive communication.
- **Express your feelings, not your judgments.** If you feel sad when your partner does not remember your birthday, express it. ("It makes me sad when you do not remember my birthday.") Judgments cloud effective communication and result in hurt feelings and communication blocks. Refrain from statements such as: "I think you are a jerk for not remembering my birthday."
- **Avoid absolutes.** When discussing issues with your partner, try to avoid the words *always* and *never*.
- **Use "I" statements.** Express how you feel instead of focusing on what your partner has done. Instead of: "You are always late for dinner," try: "I feel hurt when you arrive home late for dinner."
- **Take a timeout.** If you or your partner needs a break or some time to regroup to avoid getting angry or frustrated, it is okay to take a timeout. This will give each of you time to clear your head. Specify when you'd like to resume your conversation.



- **Ask questions.** If you do not understand your partner’s point of view, ask. Make sure you are clear on what he or she has to say.
- **Reach closure.** At the end of your conversation, summarize what you have talked about and make sure you and your spouse are on the same page. Check in on how you are both feeling.
- **Follow up.** Check in with each other after a few days to see how things are going and whether you need to talk about anything else.

Notes

Caregiving and Relationships

Handout 4—Fact sheet

The following information is covered in the Caregiving and Relationships section of the CFC program for caregivers of young children with ASD.



Marital/partnership relationships

Relationships with partners or spouses can be significantly affected when caring for a young child with ASD. The first few years after the diagnosis can be a stressful time for you and may be filled with uncertainty. Each individual copes with the diagnosis in different ways, and all relationships have challenges. Using open communication and any opportunity to check in with one another and spend time on your relationship is important for all caregivers.

Relationships with friends/social support

Many caregivers of young children mention that it is challenging to get together with friends, given the extra demands and needs of a young child with ASD. Friends may not understand your experiences, may ask difficult questions, or you may not have the energy to give to friendships at this time. Some caregivers express feelings of loneliness and disconnection from others.

Finding ways to connect with friends and other sources of support is really important for caregivers. Maintaining or developing new friendships is a good way to stay involved and connected and also relieves stress by having fun.

Relationships with extended family

It can be challenging to know how to explain the diagnosis of ASD to your extended family. Some caregivers worry about family reactions and responses. With the intricacies of relationships with family, it can be helpful for caregivers to be very clear about their needs.



Tips and ideas to help caregivers cope

Here are some ideas for supporting the relationships in your life:

- Work with your spouse, partner, or significant other to find times during each day when you are home together. Even 5 minutes before going to bed as a time to check in and talk to each other can make a difference.
- Family and friends often want to help but are unsure of how to do so. Delegate some tasks from your to-do list to certain family and friends to give you time for yourself or for your relationships.
- Almost all communities have resources for caregivers of young children with ASD. Look into organizations or groups in your area to find other caregivers to connect with.
- Use the Caregiver Community Web site to connect with other caregivers, www.autismcaregiver.com.

Notes

Caregiving and Relationships

Handout 5—Resources for more information



Marital/partnership relationships

- *"I Hear You, But ..."* Over 101 Effective Communication and Active Listening Skills and Tips by Rick Goodfriend
Focusing on communication and listening skills for all types of relationships, this book promotes quick and easy-to-implement tips that can help your relationships.

Friendships/social support

- Facebook: www.facebook.com
Connect with old and new friends through this popular social networking site. Join groups especially for caregivers of individuals with ASD.
- Caregiver Community: www.autismcaregiver.com
Connect with other caregivers of young children with ASD on this interactive Web site.

Extended family

- AutismVision: Creating Classroom Connections: <http://shop.danya.com>
Developed to educate peers about ASD, this educational program provides easy-to-understand information about what ASD is, how children with ASD are affected, and how to help children with ASD.
- First Signs: www.firstsigns.org
First Signs educates parents and professionals about autism spectrum disorders. They have a number of resources for caregivers as well as extended family members.



Caregiving and Family

Exercise 1—Positive reactions



Responding to reactions

Reactions from others, whether positive or negative, can often catch you off guard. You may be unprepared for questions or reactions from strangers or friends. Strangers, friends, and others who may or may not know you and your child may act inappropriately by asking or saying hurtful things, though they may not mean them. By being prepared and responding in a positive way, you can educate them about your child without contributing to the negativity that can be inherent in an awkward interaction. However, it is not your responsibility to educate everyone about ASD. Sometimes, the most appropriate response may be to simply walk away, guarding your own health and happiness.

For each of the following “reactions,” brainstorm how you would respond in the space provided. Some examples have been provided.

Reaction: “Can you get your child to stop making that noise?”

Example: Actually, the noise that he makes is a comfort to him. I’m sorry if it bothers you. He may stop once he feels more comfortable.

Reaction: “I don’t understand why your son was diagnosed with ASD—he looks perfectly fine to me.”



Example: You actually can't tell if someone has ASD by looking at him or her. I'm glad that you see how beautiful and talented my son is. He does have some challenges related to social interactions and communication, but he's also very good at other things, like drawing.

Reaction: "If you would use more discipline, he wouldn't act that way in public."

Example: Typical discipline does not help my child. He has an autism spectrum disorder. We have found other things that can help him learn appropriate behaviors. The rocking that he is doing now is actually a comfort to him and not something that needs to be disciplined.

Reaction: "Your daughter never shares with mine. I don't think they should play together."

Example: I'm sorry that you feel that way. Your daughter has always been kind to mine. Maybe they can play together another time.

*****Support Network Opportunity*****

Your support network can be a good sounding board if you experience unexpected or negative reactions from strangers or friends. Talk with them about experiences that come up, and brainstorm ideas together on how to address reactions.

Caregiving and Family

Exercise 2—Explaining ASD to family and friends

It can be stressful to imagine telling your close family and friends about your child's diagnosis. You may be confused and scared and not ready to talk to others about it. When the time is right and you feel comfortable and/or need support from those who care about you, you can find the right way—the way that makes you feel the best—to inform them about your child, his or her diagnosis, and how you are moving forward.



This exercise can help you highlight the details you would like to share with your family or friends. You can pick and choose from these prompts, and add more information if you would like and are comfortable doing so. Fill in the blanks with information about your child and your experiences.

When your first concerns arose:

The types of specialists that you've seen:



Special characteristics of your child:

What ASD is (in relation to behaviors or symptoms in your child):

Things that are challenging for him or her:

Things that he or she is really good at:

How you and your family are moving forward (specialists, treatments, homework):

What friends and family can do to support you and your family:

You may find it helpful to role-play to explain what ASD is to family or friends. Divide the members of your group into pairs and have them explain to each other the definition of ASD. You each may have different definitions, depending on where your child falls on the spectrum and what you know or have learned about ASD.

Example: Autism is a spectrum disorder. Sometimes people refer to this spectrum as ASD, or autism spectrum disorder. Autism is a developmental disorder that has an impact on an individual socially, communicatively, and behaviorally. For instance, my son does not speak unless he is prompted, and he's not interested in playing with other children. He loves to read and watch movies—especially movies with animals in them.



Caregiving and Family

Exercise 3—Explaining ASD to siblings

Having a sibling with ASD can be challenging for siblings. Some may wonder why their sibling is different. Others may just accept these differences and not make a big deal out of them. From an early age, it is helpful for siblings to understand what ASD is and how it affects their brother or sister with ASD. This can also help them to find the words to explain it if friends ask questions. Having common language that your family uses to understand and communicate about ASD can be helpful.



Take a moment to answer the following questions. Then discuss them in your group.

Have you explained ASD to siblings? If so, how?

What words have you used to describe the diagnosis?



How have you explained the diagnosis in a way that your other children can understand?

Here are some tips for explaining ASD to siblings:

- **Early and often.** Talking to siblings about ASD on a regular basis can help them understand their brother or sister. Start early, using words that siblings can understand. Demystify the symptoms of ASD in your child with ASD and help siblings learn how to develop a good relationship with their sibling with ASD.
- **Age-appropriate.** Explanations of ASD should be relative to the age of the child. A very young sibling will not understand a comprehensive explanation of possible genetic causes of ASD. Yet, they will wonder if they can catch it, and the best way of playing with their sibling will be important to them. Teenage siblings will be better prepared for more in-depth explanations.
- **Explanations will change.** Additional information and explanations may change as siblings get older. The basic point that your child with ASD has differences and that everyone has something different about them may stay the same. As children get older, they can understand more about ASD in relation to the world.
- **Ask siblings.** Siblings may have concerns or questions. Involve them in the discussion, asking for their opinion and finding out what their understanding of their brother or sister with ASD is. Children will surprise you with their insightfulness and ability to accept and understand.
- **Understanding special qualities.** Explaining ASD to siblings is not about making your child with ASD appear different or challenged. It's about helping the sibling understand the unique qualities of ASD to enhance their relationship with their sister or brother. All children—all people—have unique characteristics that make them special. Understanding what each brings to the other's life is important.

*****Support Network Opportunity*****

How do members of your support network explain ASD to siblings? What types of reactions have siblings had to a sibling with ASD? Caregivers in your support network will have a lot of experiences that can inform how you describe ASD to siblings and how you help develop positive relationships between siblings.

Notes



Caregiving and Family

Exercise 4—Fun family activities

Finding activities that your whole family can enjoy may involve some creativity to accommodate and make your child with ASD comfortable. Use this exercise to brainstorm fun ideas that your whole family will enjoy.

What hobbies do you, your partner, and kids have? List all hobbies that everyone in your family has.

What activities do you do with your family?

What activities do you wish you did as a family?



What sites in your local area would you like to explore?

What parks are in your area?

Do you have autism-friendly organizations or events in your area (movies, museums, etc.)?

What games does your family like to play?

What books do you like to read?

What are your family's favorite meals?

Some ideas:

- Cook pizza together
- Have a themed movie night—meals and movies go together
- Play a game
- Base activity on one of the siblings' or child with ASD's favorite things
- Go to local museum on free or reduced-rate night
- Go on a hike and look for leaves
- Family craft night

*****Support Network Opportunity*****

Your support network from the CFC group may live in your local area, or you can find caregivers who are local to you via the CFC Web site. Brainstorm together fun family activities that everyone has tried in your area. You may discover great places that are easily accessible for you and your family.



Caregiving and Family

Video 3



1. If you are co-parenting, how do you support each other as parents? If you are a single parent, where do you find support for yourself and your family?

2. What kind of relationship do your children have with each other? How do you nurture their sibling relationship?

3. How do you talk about ASD in your family? In what ways and words do you describe what autism is?



Caregiving and Family

Handout 1—Dividing family responsibilities

Every member of your family plays an integral role. Dividing up family tasks and chores can help family members contribute to the family team. By creating a Family Chore Chart, you can easily keep track of everyone's responsibilities and reward your whole family at the end of the week for a job well done.



Remember, even your child with ASD plays a key role in your family. Find appropriate tasks or chores for him or her to do to participate in the family team.

- Materials may include a posterboard, whiteboard, chalkboard, or bulletin board. Find a surface and/or material that is easy to update weekly or monthly and can be hung in a convenient, prominent location in your home.
- There are many different options for creating a Family Chore Chart. You may create a spreadsheet on your computer and post it on a bulletin board. You could spend time as a family using this as a craft project to color and draw on posterboard and then label accordingly.
- Important components to a Family Chore Chart:
 - Lists every family member's name
 - Lists key chores that are done every week (washing dishes, taking out trash, feeding pets, cleaning rooms, etc.)
 - Assigns key chores to a family member or a couple of family members
 - Includes a space to mark whether the chore has been completed
- Make this activity fun. Have fun stickers or magnets to use to mark when items are completed. Talk with your family about fun rewards or activities you could all do together to celebrate jobs well done.



Caregiving and Family

Handout 2—Master calendar

Like the Family Chore Chart, having a master calendar for the family can save you time and keep you organized. Here are some ideas for creating a fun, easy, and useful Family Master Calendar.



- Print a template from the Internet and spend an afternoon with your kids decorating it.
- Use family pictures to create a calendar using an online photo sharing/printing service.
- Use posterboard to make a calendar for each month. Ask your children to decorate the board and have colorful markers and stickers to highlight important appointments and dates.
- Create different types of calendars for your family using Microsoft Outlook software. Computer programs can then merge all of these calendars into one, and you can print it out.
- Put your family calendar on a bulletin board. Use pushpins to hang important documents or notes for the week next to the calendar.



Caregiving and Family

Handout 3—Appreciating family

Being grateful for the little things can go a long way to reducing stress. Saying “thank you” to your family members and expressing your gratitude, even for little things, can create a happier, more relaxed environment for everyone. Here are some ideas:



- **Keep fun stickers handy.** Give members of your family a sticker for little things, such as saying “please” or cleaning up their room.
- **Write notes.** Leave notes in lunches or on dressers with funny jokes or expressions of love.
- **Send text messages.** A quick message can brighten someone’s day.
- **Use self-adhering notepaper** (sticky notes or Post-it® notes) to leave positive messages around your house.
- **Share dinner-time thanks.** Have everyone say one thing they are grateful for that happened during the day.
- **Share bedtime thanks.** Ask kids to tell you one thing they are grateful for before going to sleep.
- **List.** Keep a running list on the fridge or in a visible location in the house with a marker. Everyone can write down fun things that happened during the day.
- **Give prizes.** Keep simple, inexpensive prizes on hand. They can be a fun surprise for a small or big accomplishment.
- **Give surprise desserts.** If after-dinner desserts are not in your normal routine, surprising your family with something special as a treat can be a nice way to say thanks.
- **Prepare favorite meals** for your family on a regular day instead of just for a birthday or special occasion.



Caregiving and Family

Handout 4—Fact sheet

The following information is covered in the Caregiving and Family session of the CFC program for caregivers of young children with ASD.



Parenting/co-parenting

Your parenting approach often changes when you have a child with ASD. You and your partner or the other parent in your child's life may have different opinions on how to best help your child. This can lead to stressful interactions sometimes.

There may also be a tendency for each caregiver to take on different roles in their parenting relationship. One may take on the financial responsibility role, while the other learns everything about ASD. This can lead to each caregiver feeling left out.

Impact on family life

The diagnosis of ASD affects the whole family. Finding a balance between the whole family's needs and the needs of your child with ASD can be challenging. Many families with children with ASD find that establishing a community where they live can support the whole family.

Siblings

Siblings can be confused about what ASD is and what it means for them. They may be unsure of their role in the family in relation to their sibling with ASD. Feelings of anger, jealousy, and resentment may be common. Helping siblings to understand ASD as it relates to your child can make siblings feel more comfortable and secure.



Tips and ideas to help caregivers cope

Here are some ideas for managing stress related to your family life:

- Finding proactive ways to respond to reactions from friends and strangers can help you feel prepared and give you a positive way to educate others about ASD.
- Preparing information to share with family and friends about ASD can be helpful.
- Talking about ASD with siblings early and often helps them to understand their brother or sister and develop a good relationship with them.
- Finding activities to do together as a family can bring everyone together in a fun way.
- Organizing a master calendar for your family can keep you organized.

Notes

Caregiving and Family

Handout 5—Resources for more information



Parenting/co-parenting

- *Empowered Autism Parenting: Celebrating and Defending Your Child's Place in the World* by William Stillman
Written by an adult with Asperger syndrome, this book offers parents a different perspective on relating to their child with autism.

Chore charts

- Examples of chore charts and how to make them can be found at www.successfulfamilychores.com and http://kids.lovetoknow.com/wiki/Family_Chore_Charts

Family life

- PBS Parents: www.pbs.org/parents/fun-and-games/
PBS Parents provides games for children to learn from and educational activity ideas for parents to share with children.
- Organized Families: <http://organizedfamilies.com>
This online resource features organization tips for busy families, with resources that can be used by any type of caregiver.

Siblings

- Sibling Support Project: www.siblingsupport.org
The Sibling Support Project is dedicated to helping siblings of people with special health or developmental concerns. The Web site offers reading lists, information on local sibling meetings, and online resources for siblings.
- Autism New Jersey, Inc.: www.autismnj.org
The New Jersey Center for Outreach and Services for the Autism Community (NJCOSAC) matches siblings with pen pals around the country and internationally.



Caregiving and the Individual with ASD

Exercise 1—Open forum

As a caregiver of a young child with ASD, you may not often have time to interact with other caregivers of young children with ASD. In this CFC group format, you have met a number of other caregivers who are raising children with ASD. One goal of CFC is to provide you with opportunities to interact with and learn from other caregivers.

This exercise will be an open forum to ask questions of the facilitator and of each other to get advice, feedback, and information.



Caregivers—if you are completing this exercise on your own, this is a great opportunity to use the Caregiver Community Web site. The discussion boards at Caregiver Community Web site are designed for you to ask other caregivers questions and have a discussion.

Take a moment to write down 3–5 questions that you have for other caregivers. These may pertain to any topic, such as coping with your emotions, relationships, family life, individuals with ASD, accessing services, or finances—or all of these.

We'll take turns asking and answering questions in a discussion format in our group.

1. _____
2. _____
3. _____
4. _____
5. _____

Support Network Opportunity

Your support network can always be available for questions, whether through e-mail or on the CFC Web site. Having a constant source of support and information is so valuable.



Caregiving and the Individual with ASD

Exercise 2—Accurate and reliable information

By finding accurate and reliable information sources on ASD, you can make sure you are reading the best and most useful articles and research regarding autism in young children.



- **Accurate:** Information that is accurate provides correct and true information regarding the illness.
- **Reliable:** Information that is reliable means that it is consistent and dependable. Information from a reliable source will be fair and well-rounded.

Here are a few tips on how to do this:

- **Make sure the information is up to date.** The information should have a date of publication on it. A general rule is to stick with sources from the last 2 years or maybe even more recent sources if the subject is about treatment.
- **Consider where the information came from.** Is it from a research journal article, a newspaper, a magazine, a Web page, the government, an organization, or an advocacy group? Research journal articles, government and organization Web pages, and advocacy groups most likely offer the most accurate and reliable information.
- **Be careful using the Internet.** Searching can yield a lot of hits, but it may not bring back useful or credible information.
- **Consider who wrote the information.** Who is the author? Who funded the research? An article funded by a drug company may present biased information about its medication, for instance.
- **Is the information based on research or on someone's opinion?** An opinion could offer ideas of where to look for more information but most likely should not be considered a reliable source.
- **Where is the research published?** If a research article is not published by a



government or known agency or a scientific journal, consider ignoring it. Research that has not been reviewed by experts in the field may not provide helpful information.

- **How can the information help your family?** Does the information you find answer questions you have?

It can be really helpful to keep a log of good places to find information. Then you can go back to these resources when you want to read them again or find additional information.

Go around the group and share one resource that you have found useful to you and your family about ASD. This resource may be a Web site, book, organization, or local community contact. As each caregiver shares his or her resource idea, fill out the table on the next page. This way, you will have a good start on a new resource list.

Notes

Resource Name	Where to Find it	What kind of information is it?
Example: Caregiver Community Web site	On the Internet: www.autismcaregiver.com	Community of caregivers of children and/or adults with ASD, discussion boards, resources for caregivers



Caregiving and the Individual with ASD

Exercise 3—Celebrating accomplishments

Normal everyday things that typical children do may not be seen as something to celebrate or make a big deal out of. For you and your family, however, every small and large milestone for your child with ASD is worthy of a celebration. You work so hard to provide for your child and help him or her to excel. Small moments, such as an impromptu hug or a smile, may make your day, and rightfully so.



As a group, discuss the following questions:

How do you and your family celebrate small and/or big accomplishments?

Do you think it's important to celebrate the everyday little things? Why or why not?

How do everyday accomplishments make you feel?

How do you think focusing on the little things, the small steps, and celebrating goals achieved can help you and your family?

How can you incorporate these celebrations into your family life, not just with your child with ASD?

Ideas for everyday celebrations:

- Telling the child how proud you are of him or her
- Making something special for dinner
- Having a special dessert that's reserved for everyday celebrations
- Using a special plate or plates for dinner
- Giving stickers
- Awarding ribbons
- Having a dance party

The key is to find something small that feels special to you and your family as a way to honor and celebrate all of the good accomplishments in your life.



Caregiving and the Individual with ASD

Video 4



1. How do you celebrate milestones or the accomplishments of your child with ASD?

2. What do the everyday accomplishments of your child with ASD mean to you? How do you acknowledge them with your child?

3. Where do you find information that is helpful in learning about ASD? How do you determine that the information is relevant to your child and is from a reliable source?



Caregiving and the Individual with ASD



Handout 1—Template for recording reliable, valid resources

Use the following template to keep track of helpful ASD-related resources as you find them, along with how helpful they were and if you would use them again.

Resource	Where to Find It	What Is It	What was Helpful About It	Would you Use It Again?



Caregiving and the Individual with ASD

Handout 2—Template for tracking questions and answers



Questions	Category of Question	Resources for Answers
Questions as they arise	<ul style="list-style-type: none">• Emotions• Family• Relationships• ASD specifics• Services• Finances	2–3 possible ideas



Caregiving and the Individual with ASD

Handout 3—Fact sheet

The following information is covered in the Caregiving and the Individual with ASD session of the CFC program for caregivers of young children with ASD.



The minute you learn about your child’s diagnosis, you begin to be inundated with all kinds of information about ASD. While gathering information is very important to understanding ASD and how to help your child, it can also be quite overwhelming to filter it to find reliable sources.

The vast amount of information available on ASD is a wonderful resource to you and your family. At times, it can be difficult to know how to apply the information you find to your situation. The professionals your child works with can help sort through information with you. Many caregivers want to do everything possible to help their children, but the financial, time, and emotional commitment needed to devote to learning about and trying new interventions can be overwhelming.

You have a beautiful child. He or she is learning and accomplishing things, but these gains may be at a different pace than other children of the same age. Celebrate all accomplishments, whether big or small, knowing that you and your child are moving forward and making progress.

Tips and ideas to help caregivers cope

There are a variety of options to help caregivers cope with the stress related to helping individuals with ASD:

- Having opportunities to talk to other caregivers can give you a chance to ask questions and learn from their experiences. Caregivers of children slightly older than your own can provide new perspectives and ideas.



- Finding accurate and reliable information on ASD is very important. Make sure the information you read is up to date, and consider where it came from. Research articles and government and organization Web pages are often helpful and reliable sources of information.
- Find ways to celebrate everyday milestones with your child and family.

Notes

Caregiving and the Individual with ASD

Handout 4—Resources for more information



- *1001 Great Ideas for Teaching and Raising Children with Autism or Asperger's* by Ellen Notbohm and Veronica Zysk
This book offers tips, advice, and strategies for raising your child with ASD.
- *The Autism Answer Book: More than 300 of the Top Questions Parents Ask* by William Stillman
Presented in a question-and-answer format, this book provides answers to some of the main questions that parents of young children with autism have.
- *Ten Things Every Child with Autism Wishes You Knew* by Ellen Notbohm
This short book highlights the key characteristics of children with autism and how they are special.

Evaluating Internet Information

- Johns Hopkins University:
<http://guides.library.jhu.edu/evaluatinginformation>
Johns Hopkins offers a resource to help evaluate information found on the Internet.
- National Dissemination Center for Children with Disabilities (NICHCY):
<http://nichcy.org>
This site offers a central source of information on disabilities in infants, toddlers, children, and youth; education laws; and research-based information on effective educational practices.
- Autism Speaks: www.autismspeaks.org
Autism Speaks provides a variety of information about autism, in particular their free 100-day kit for newly diagnosed families.



Caregiving and Services

Exercise 1—Time management

It can be difficult to fit everything into 1 day when you are running between appointments, providers, and coordinating care for your child with ASD. It can feel like all you do is run to appointments! There can be chunks of time in your day that can be reallocated either for other appointments, time for yourself, or time to spend with your partner or other children.



Think about your day yesterday. Using the chart on the next page, write down, hour by hour, as much as you can remember that you did. Try to account for everything, including meal preparation, checking e-mail, phone calls, appointments, and the like.

Notes



	One day of activities/appointments/"to-dos"
6–7 a.m.	
7–8 a.m.	
8–9 a.m.	
9–10 a.m.	
10–11 a.m.	
11 a.m.–12 p.m.	
12–1 p.m.	
1–2 p.m.	
2–3 p.m.	
3–4 p.m.	
4–5 p.m.	
5–6 p.m.	
6–7 p.m.	
7–8 p.m.	
8–9 p.m.	
9–10 p.m.	

Caregiving and Services

Exercise 2—Asking effective questions

Different kinds of questions yield different answers. Simple yes/no questions will give you yes/no answers, and often, this is not enough information to learn more about ASD. The way you approach questions can help you obtain information, establish clear communication with the other person, and promote teamwork. Effective questions also provide opportunities to clarify information, enhance your understanding of your child and ASD, and help you feel more in control and informed.



Before asking an effective question, it is important to:

- Be clear about what you want to know
- Write down what you want to ask

Types of effective questions:

- **Open-ended questions.** Questions that require more than a yes/no answer.
- **Factual questions.** Questions that ask for more detail on definitions, confirmation of facts, or asking how a fact or information relates to something else.
- **Clarifying questions.** Ask for more information about something. What does this mean? How would you measure this? What is your goal? What are the next steps?
- **Evaluation questions.** Questions that compare or examine information. What can you conclude from this? How would you interpret these results? What does this mean?
- **Solution questions.** Questions that build on clarification and evaluation answers intended to understand upcoming actions and goals based on information learned. How can we use this information to help my child? How will this information inform treatment decisions? How can we apply this information to the intervention?



What or how questions often yield the most information. Why questions can make the receiver feel defensive.

Transform the questions or statements below into effective questions.

Has this treatment worked with other children with ASD?

Make this an open-ended question.

Your child care provider has mentioned that your child had a difficult day.

Ask a factual question.

You've read an interesting article on a new social skills approach.

Ask a professional a clarifying question.

Why would you recommend this type of medication?

Turn this into an effective evaluation question.

Your child just participated in a lengthy early intervention planning evaluation.
Ask the evaluator a solution-focused question.

Questions are important and, obviously, so are the answers. Ask the question. Pause and breathe. Listen. Repeat the answer to ensure you understood. Ask follow-up questions.

Notes



Caregiving and Services

Exercise 3—Advocacy skills

You know your child best, and you are his or her best advocate. An advocate supports and champions another person, helping to speak for, lobby for, and boost the person. Being an advocate can be very rewarding and sometimes very challenging.



Think about the following questions and jot down some of your answers. Then we will discuss them as a group.

What does being an advocate for your child mean to you?

How would you define someone who is an autism advocate?

How do you already advocate for your child?



What do you think makes a good advocate?

Notes

Caregiving and Services

Video 5



1. How have you advocated for your child to receive services?
What types of advocacy skills did you learn or use?

2. How do you manage your time and your family's time in coordinating services?
How do you stay organized?

3. Do you feel like an expert on your child? In what ways? How can you use your expertise to feel empowered when interacting with service providers?



Caregiving and Services

Handout 1—Information about my child

Finding a good child care provider for your child with ASD can be a challenge. When you are interviewing and/or when you find one, it can be helpful to provide them with as much information about your child as possible. Use this template to compile a great resource for your child care provider (or others who help you) about your child with ASD.



My child's strengths are:

My child's challenges are:

The types of foods that my child likes are:



The types of foods that my child does not like are:

My child is allergic to:

My child finds these things comforting:

The social challenges that affect my child are:

The communication challenges that affect my child are:

The behavioral issues that are challenging are:

Certain environmental situations or scenarios are difficult for my child. These include:

The routines and/or patterns that help my child are:

The rewards that are meaningful to my child include:



Caregiving and Services

Handout 2—Fact sheet

The following information is covered in the Caregiving and Services section of the CFC program for caregivers of young children with ASD.



With a young child with ASD, you are in the middle of learning about treatment options, finding what may work best for your child, and then coordinating these services. For young children with ASD, understanding and accessing early intervention services are key. However, learning how to access these services and pay for services can be daunting.

Finding and working with appropriate child care providers for your child with ASD can also be stressful. Finding someone to take care of your child while you work or to give you a few hours of rest can be a challenge.

As the caregiver of a young child with ASD, you are your child's best advocate. Being an advocate means that you are his or her voice and you are an expert on his or her needs. Learning the best ways to communicate to others, as an advocate, can be difficult for some people. Open discussion, honesty, and effective questions go a long way to working with others.

Tips and ideas to help caregivers cope

When learning about and accessing services, caregivers may find these ideas helpful:

- Time management strategies, such as using your time effectively or delegating certain tasks to others, can give you more time for appointments or more quiet time.
- Asking effective questions, such as open-ended questions rather than yes/no questions, can yield a lot more information.



Caregiving and Services

Handout 3—Resources for more information



- Wrightslaw:
www.wrightslaw.com/info/autism.index.htm
Wrightslaw offers a variety of resources on autism. Specifically, it can educate caregivers about the rights of parents and children with autism. This resource also offers a lot of information about becoming an advocate for a child with ASD.
- National Association for the Education of Young Children (NAEYC):
www.naeyc.org
NAEYC offers resources to parents and professionals who care for young children with ASD.
- Autism Speaks: www.autismspeaks.org
Autism Speaks has a special initiative dedicated to helping caregivers and other interested individuals advocate on behalf of children with ASD.
- Autism Society of America: www.autism-society.org
The Autism Society of America offers a wealth of resources about services and advocacy for individuals with ASD.



Caregiving and Finances

Exercise 1—Budgeting skills

Creating a monthly budget can help you deal with financial stress. Complete the following worksheet with your spouse/partner, and, at the end of each month, regroup to see how you did. Be sure to note the “For Fun” categories. Complete the following worksheet with your spouse/partner and regroup to see how you did at the end of each month.



Category	Monthly Budgeted Amount	Monthly Actual Amount	Difference
INCOME:			
Salaries			
Miscellaneous income			
INCOME TOTAL			
EXPENSES:			
Mortgage or rent			
Electricity/gas			
Water			
Home repairs/maintenance			
Other household expenses			
Groceries			
Toiletries			
Clothing			
Home phone			
Cell phone			



Category	Monthly Budgeted Amount	Monthly Actual Amount	Difference
INCOME:			
Salaries			
Miscellaneous income			
INCOME TOTAL			
EXPENSES:			
Mortgage or rent			
Electricity/gas			
Water			
Home repairs/maintenance			
Other household expenses			
Groceries			
Toiletries			
Clothing			
Telephone (land line)			
Cell phone			
Cable/satellite TV			
Internet service			
Health insurance			
Medical/dental			
Car payments			
Gasoline			

Auto insurance			
Other transportation			
Misc. loan payments			
Daycare			
Pets (food, vet)			
Gifts			
School-related costs			
Savings deposits			
FUN EXPENSES:			
Dining out			
Movies			
Gym membership			
Hobbies			
Vacations			
Other fun activities			
TOTAL EXPENSES			

*****Support Network Opportunity*****
 How do members of your support network budget for their family? What other resources can they share? Check in with them to get more ideas.



Caregiving and Finances

Exercise 2—Fun and affordable activities

Finding fun, affordable, and accessible activities for you and your family can be really challenging. As a group, let's discuss the types of activities that you each do with your families. In this way, we can get ideas from each other about great activities to do at home or in our local area.



Take a moment to think about these questions and maybe write down a few answers. Then we will share our ideas as a group.

What types of activities does your family like to do together?

Where do you go in the community for different family activities?

Have you found free or low-cost activities in the area that are fun for your family? What are they?



How do you afford family activities?

How do you get ideas for new activities?

Notes

*****Support Network Opportunity*****

This is a great activity to do with your support network. Pose these questions to other caregivers (maybe even on the Caregiver Community Web site) and get even more ideas.

Caregiving and Finances

Exercise 3—Communicating about finances

Communicating with your spouse or partner about your household finances is always important. It may be that one of you takes the lead in paying bills and maintaining the family budget. This can be a good way to divide up household tasks. However, it is also important that each of you knows and understand your family's common expenditures. Better communication leads to more understanding and less conflict around money issues.



Take a moment to think about these questions and write in your answers.

Do you take the lead in paying your household bills? Why or why not?

Does your spouse/partner help with the bills? Why or why not?

Does your partner know where your main monthly income expenditures go?



Would you like to work on the bills together? Why or why not?

How could you both be informed about the family expenditures?

Notes

Support Network Opportunity

Use this exercise as a discussion prompt with your support network. What have they tried that has worked to open communication about finances? What has not helped? How can you apply these ideas to your relationship?

Caregiving and Finances

Video 6



1. How has your career been affected since your child's diagnosis?

2. How do you and your family balance work with caring for a child with ASD?

3. In what ways do you manage financial challenges?



Caregiving and Finances

Handout 1— Family Expenses

Use the following template to track your family expenses. This can be a valuable tool to see where you are spending your money and how, if you need to, you can restructure your family budget. You can fill out this template each week or month.



Type of Expense	Cost	Reason for Expense	Running Total



Caregiving and Finances

Handout 2—Fact sheet

The following information is covered in the Caregiving and Finances section of the CFC program for caregivers of young children with ASD.



Paying for treatment, services, and evaluation can take its toll on your bank account and stress level. Caregivers may feel a constant source of worry related to finances and the extra costs of getting the services that your child needs. Add to that the challenges of maintaining employment while caring for and supporting a child with ASD, and caregivers often express significant anxiety about their family's finances. Many caregivers need a job that is flexible and understanding of their situation; not all caregivers have this.

Money worries are a significant cause of stress for caregivers. Simple techniques—such as establishing a family budget, communicating openly with your partner about finances, and even finding fun, affordable activities for your whole family—can go a long way in alleviating some of the stress associated with finances.

Tips and ideas to help caregivers cope

Some ideas for coping with financial stress include:

- Establishing and maintaining a family budget can keep you on track each month.
- There are a lot of free or very affordable activities available in most local communities. Asking other caregivers of young children with ASD for ideas on free activities in the area can reveal some fun and relatively easy things to do together.
- Open communication between partners about finances and bills helps keep everyone involved and creates more understanding and less conflict about money issues.





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