

Get Creative



About Respite



A Parent's Guide

GET CREATIVE ABOUT RESPITE

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INTRODUCTION

Respondents to a comprehensive survey of Connecticut families that care for a loved one with special healthcare needs indicated that 58% of them get less than five hours per week of in-home relief. Fifty-four (54%) percent believe that the amount of time spent caring for a child with special needs interfered with the amount of time they could spend with other children. More than half reported that they were concerned about the well-being of those other children.

Sixty-eight (68%) percent said that their health has been affected due to the stress of caring for a special needs family member. Half the married respondents reported that caring for a child with special needs has affected their relationship with their spouse, and many indicated they were divorced due to that stress.

While many people who have never had to care for a family member with special needs think of respite as a break for recreation or a vacation, those who do have those responsibilities understand that respite is essential if they are to successfully continue to care for that person at home. Abuse, neglect, surrender of the person for institutionalization, breakup of the family, and illness of the caretaker are all very real outcomes when needed respite is not available.

The Connecticut Lifespan Respite Coalition (CLRC) is a non-profit organization working to improve availability of, access to, and quality of respite care in our state. While trying to affect the system to make these changes, we are also trying to help families advocate for themselves and to find solutions that will offer some help now.

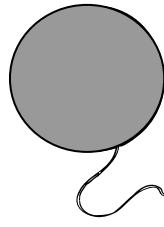
This booklet is one tool designed to help families. We hope that you will find some ideas that will help you see resources in your community you hadn't noticed before, or help you examine your situation and see some ways to allow yourself even "mini-breaks" that will help you ease the stresses in your life.



We're proud to have the chance to serve you!

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Managing Stress

“Stress” is a word used to describe the harmful reaction people have to too much pressure or too many demands placed on them,

- where the person thinks a lot about how stressed they are,
- and the person begins to doubt that they can continue to handle the anxiety and the circumstances that cause it.

Feeling this way for a long time may result in sickness and warning signs of unhealthy emotional, mental and behavioral problems.

Stress Management is the ability of someone to manage the feeling of pressure they feel on a day-to-day basis. There are many things we can do to help us manage our stress.

"LIFE SHOULD BE FUN!"

How many times have you said that to yourself?

Life is very different today than it was a few years ago. Everybody feels like there isn't enough time to do what we need and want to do, and we're often worried about losing our job. Technology is changing daily. Sadly, divorces and partnership breakups are becoming very common.

When caring for a family member with special needs is added, with the sadness, pressures, frustration, loneliness, and other emotions that are involved, it is hardly surprising that, sometimes, the caregivers are at the top of the list of those who feel they just cannot handle it all.

We all need challenges that we can handle and that help us have excitement and fun in life. But sometimes we're faced with challenges that we feel we cannot cope with, and it is then that we may feel stress.

Showing signs of stress does not mean you are a weak individual who cannot cope! It means you are human like everyone else! People react differently to the situations they have to face because everybody is different. What makes one person feel very stressed may not bother someone else, and vice versa! Some people may naturally be very easy-going while others may be very competitive or excitable. Our life experiences are very different, and so is the way we were taught to deal with them. Our overall health will also vary – and it is much more difficult to cope with a lot of long-term stress when we are not feeling really healthy to start with.

Some of the most common signs of stress are:

- Mood swings
- Anxiety
- Skin problems
- Tiredness
- Muscle tension
- Poor concentration
- Poor memory
- Changes in sleep patterns
- Changes in eating patterns, or indigestion
- Low self esteem
- Sense of desperation or fear
- More frequent sickness

It is very important to do something positive about it when faced with stress because if you experience it over a period of time, it can seriously harm your mental and physical health.

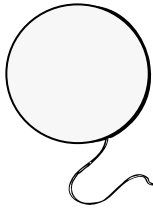
The following proven ways to handle stress can really start to help you reduce its effects in your life.

- Recognize your own warning signs – maybe this could be a sudden feeling of anxiety, extreme tiredness, feeling like crying a lot, or feeling hopeless, catching every cough and cold – feeling run down.
- Think about what is really causing stress for you. You could be surprised! For example: Is it because you feel alone? Is it because you don't have someone to talk to about things? How much of your stress is because you expect too much of yourself and others? Think about what action you might be able to take to change things.
- At times of stress we often fall into the trap of not eating properly, or otherwise not taking care of ourselves. Instead:
 - Try and eat a balanced diet.
 - Eat complex carbohydrates (such as whole grain bread, jacket potatoes, etc.) rather than refined (that white bread, sugary cereal, or cookies!) This can really help with those mood swings.
 - Eat plenty of fresh fruit and vegetables and keep sugar and salt intake to a minimum. This can help your body fight against colds and flu – ailments you so often get when run down.

- Drink plenty of water, to help you rehydrate your body, and only drink alcohol in moderation.
- Try and keep caffeine consumption to the minimum.
- Try not to turn to nicotine or any other self-prescribed drugs.
- Do **not** feel guilty about wanting *respite* (a break) to give you time to include some time to relax in every day. We all need to turn off from time to time. Do something you enjoy and that fits into your life. This could be something simple like walking or running, reading, listening to music, doing yoga or meditating, enjoying a long bath or shower with the bathroom door closed, watching TV, or calling or emailing a friend. It does not have to take a long time – or be considered a luxury or time wasting. It is a *necessary* part of life.
- Make sure exercise is part of life. Exercise that is suitable for you. If you have any doubts as to what is right for you, ask your doctor.
- For some people, keeping a journal is a good way to manage stress. You could take time, at the end of the day, to write down their thoughts about the day in a notebook. Or you might find relief in making a list of 5 things from the day—no matter how small—that you can be thankful for.



It is important, both to you and your family, that you take time to think about what simple activity makes you feel better and helps you cope with stress. **Then find a way to DO IT!**



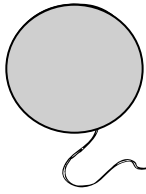
Do You Need Respite Care?

How can you tell if you and your family could benefit from respite care?

Ask yourself the following questions:

1. Do you currently have difficulty finding temporary care for your child?
2. Do you feel that it is important that you and your spouse enjoy an evening alone together, or with friends, without the children?
3. If you had appropriate care for your child with special needs, would you use the time for a special activity with your other children? Do you ever feel guilty that you don't have enough time to spend with your other children?
4. Do you think that you would be a better parent to the child with special needs if you had a break now and then?
5. Are you worried that, if there was a family emergency, there is no one with whom you would feel secure about leaving your child?
6. Would you be comfortable using a trained and reputable respite provider to care for your child?

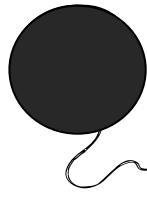
If you have answered "yes" to several of these questions, you and your family could benefit from respite care and should investigate the resources in your community.



What kind of respite do you need?

Before you start to look for a respite provider, ask yourself the following questions. Knowing the answers, or the answers you want to hear from the provider, in advance will help you when you start talking to providers, to make sure they offer the kind of services you want and need:

1. What kind of services do I need? (Long-term, short-term, or both?)
2. Do I prefer services in my home or in an outside setting? (This will depend on the type of service you need.)
3. Does this provider make available the types of service I need?
4. What kind of training will the provider need to adequately care for my child?
5. Is there a cost for the service? Am I able to afford this service?
6. If I can't afford the service, are there funds available to assist me?
7. Who is responsible for the direct payment to the provider? How are the taxes, unemployment insurance, etc. to be handled?
8. If I need it, will the provider take care of my other children as well?
9. Will I have to carry additional insurance to cover the provider while he/she is in my home? (This is a question you should ask your insurance agent that carries your homeowners' or renters' insurance policy, as well as the provider you are interviewing.)



Types of respite care

Respite services may be provided **in your home**. Many parents whose children have complex physical or severe behavioral disorders are uncomfortable considering any other option. If that is the option you wish to consider, ask yourself the following questions:

- Are you comfortable having a provider in your home?
- Will you receive the break you need with in-home respite services?
- Would you prefer using the respite time to complete projects at home, rather than going out and leaving the child alone with the provider?
- Can you arrange transportation for a provider who doesn't drive?

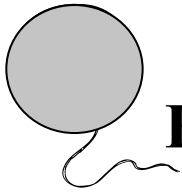
Any respite care provided outside the home is considered **community respite**. The range of settings for community respite is broad.

- It could be provided in the respite provider's home (licensed or not licensed), or the home of another parent of a child with special needs.
- It could be in a residential center or group home where they are also able to accept children in need of respite care.
- It could be in a recreational setting, day care center, or in an after-school program.
- It could be in a summer camp program.
- Or, it could be in a hospital for children with special medical needs.

Sometimes, once the initial hurdles are overcome, community respite can have added benefits. It can be an opportunity for your child to be with other children. It can provide you with an opportunity to entertain at home or to complete projects that are difficult to accomplish while your child is home. It may provide welcome stimulation and a boost to your child's self-esteem if they are not "left home" while you leave.

In considering community respite you may need to ask yourself these questions:

- Can the change benefit my child?
- Will I truly be able to relax and "take a break" if my child is not in his/her own home?
- Will packing up all the necessary equipment, clothing, toys, etc., be worth the effort?
- Does the community respite program have equipment and atmosphere my child will enjoy?



How to find a respite provider

Before you begin looking:



1. *Prepare a “What you need to know...” guide*, that provides necessary information about your home and your child for the person who will care for him or her in your absence. Make note of emergency procedures, foods and feeding, medications needed, tips for communicating best with your child, etc. There are a number of sample guides available for your use, including the one at the back of this book, so that you can fill in the blanks with the proper information. Give yourself time to think about the information you will want providers to have.
2. Request a letter from your pediatrician that “tells the story” about your child’s medical condition. It will help the providers, and you or they can use it when going to other doctors or the hospital. Some parents also keep a copy of their child’s immunization record with the guide, too.
3. *Look for respite care before you actually need it.* You’ll be less stressed if you know that help is there when you need it...and you’ll have a chance to interview and check out your provider carefully, and train them to provide the best care for your child.
4. Decide what kind of respite care will work best for you. [See “Kinds of Respite Care”]



Ask your doctor, hospital, or care manager for referrals. Your child’s teacher may also have suggestions.

Locate a nearby support group, and ask *other parents* about providers they’ve used and would be happy to use again. Most hospitals can tell you if there is an appropriate support group in your area. In fact, many hospitals sponsor such groups.

Call 2-1-1 (United Way of Connecticut’s InfoLine) or Child Development Info Line 1-800-505-7000 and ask about respite services. Their staff has been trained to ask the necessary questions to connect you with appropriate services they know about.



If you qualify for services or funding through a state agency, ask the agency for help in locating a qualified respite provider in your area. InfoLine (2-1-1) can give you the state agency’s telephone number to call in your area. Some state and local government agencies you could contact might include (depending on your child’s diagnosis(es)):

- Connecticut Department of Developmental Services
- Connecticut Council on Developmental Disabilities
- Connecticut Department of Public Health, or Connecticut’s Program for Children with Special Health Care Needs (CSHCN)—also known as the Title V Program
- Connecticut Department of Social Services
- Connecticut Department of Children and Families
- Office of the Child Advocate
- State and local Departments of Education
- State Protection and Advocacy Agency

Some other organizations that may be able to help you locate an appropriate respite provider include these state and local disability or support groups. Check your telephone book or call information for local listings if InfoLine (2-1-1) does not have them listed.

- The Arc
- United Cerebral Palsy Associations, Inc.
- Autism Society of America (or the Autism Spectrum Resource Center in Hamden)
- Brain Injury Association
- Mental Health Association
- Spina Bifida Association
- National Easter Seal Society
- Parent Training and Information Center
- Parent-to-Parent
- University Affiliated Program(s)
- Community Services Boards
- YMCA/YWCA
- Salvation Army
- Churches
- Recreation Centers

Remember that, even if there is not an association specific to your child's diagnosis and special needs, providers who handle similar behaviors or physical indicators may also be able to help you.

Women's centers may also have information that will help you find a provider. Teen centers and senior centers are also possible resources.

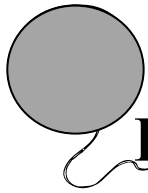
Remember: If you can, prior to actually leaving the child with a provider, *arrange for the provider to come for a training session*—sort of a dress rehearsal—so they can observe you as you care for the child, and then take care of the child themselves, while you are there in the house in case something goes wrong. That will help you feel comfortable leaving that person alone with your child when the time comes.

Here are some suggestions for how to start the conversation when you call a provider:

“Hello, this is _____. I am the parent/foster parent/caregiver of a child with special needs and I'd like to know what respite services you can offer my child and family.” *OR* “Hello, I'd like to know what services you provide for children with special needs.” *OR* “Hello, I'm looking for someone to provide some care for my child with special needs. Do you know of anyone who might be interested in the job?”

Another option might be: “Hello, my name is _____ and I'm the parent of an ___ year old child who has a severe disability. I'm considering training and hiring someone to help care for my child on a [daily/weekly/monthly] basis, and I was wondering if you know of anyone through your organization who might be interested.”

The important information to include is your name, a brief description of your child, and how often, when, and where you want to get respite services.



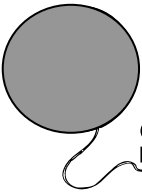
Identifying Potential Respite Providers/ Informal Support in the Community

Identifying caregivers in your community may take a little imagination and some serious consideration. Your child's needs may be very complex, or simply a matter of vigilance and patience. If you are looking for someone with advanced skills, look to the professionals themselves. Don't forget that a lot of professionals may have changed their jobs or retired, but they are still great resources for care. If your child's needs are not so complex, you have more options. And don't be shy—there are a lot of people in your community who would love to help. They may even gain great satisfaction from the opportunity and/or have fun.

The important thing is that you find someone with whom you are comfortable and, even more importantly, someone with whom your child is comfortable. Think of the possibilities:

- Friends
- Family
- Neighbors
- Nurses
- Nurses off duty
- Student nurses
- Retired nurses
- School nurse off duty
- Home health aides
- Home health aides off duty
- Retired home health aides
- Occupational therapists
- Occupational therapy students
- Physical Therapists
- Physical Therapy students
- Retired doctors
- Special education teachers
- Special education student teachers
- Classroom aides
- Social workers
- Students in social work
- Internship programs
- Church members

If you know someone you think might be a good respite provider for your child, don't assume they would not be interested until you ask. One mother reports that she asked an obviously kind and friendly waitress if she would be interested in providing some care for her child. It was the beginning of a very caring and successful respite relationship!



Selecting a provider...questions to ask

When you call a potential provider for your child, it's a good idea to have a list of your important questions in front of you when you call, so you won't forget to ask them all.

If contacting an agency that would provide **in-home care**, the following questions should be on your list:

- Do you have written information about your program?
- How do you select and screen your respite providers?
- In your program, what training and experience have your respite providers had? Does it include certification in First Aid and CPR? Cultural competency training?
- How are respite providers supervised?
- May I meet the person who will be caring for my child before receiving respite?
- May I check references for the person who will be caring for my child?
- Will I usually get the same respite provider each time I request respite?
- If I am uncomfortable with the skills of the provider, may I request a change?
- What is the cost of respite services? Is there an overnight flat rate?
- Will a provider care for my other children also?
- Is there an extra fee for more than one child? For short-notice arrangements?
- How far ahead do I need to call to arrange for services?
- Is respite available on an emergency basis, such as if I become sick?
- How is payment arranged? Is there a cancellation fee?
- Does your program pay all employment taxes, etc.?
- Are there a minimum number of hours that I must use? Am I limited to a maximum number of hours?
- What hours are respite services available?
- Will your program keep up with current information about my child's medical and other needs? Is there a written plan?
- May I provide written instructions to the provider? May I assist in training them with reference to my child's needs?
- What is the procedure for medical emergencies?
- Do you provide transportation?
- What if my respite provider fails to show up at the scheduled time?
- My child's questions: _____

- Other questions: _____

If you are considering **community respite**, plan to visit the site first, while it is in operation. Things to take note of may include:

- The indoor environment...is it pleasant, clean and friendly? Would you like to spend time there?
- Will your child be comfortable with the noise level? The temperature level? Are there unusual odors?
- Is there an appropriate ratio of respite providers to children?
- Do the respite providers interact with the children in a manner my child will like?
- Do they talk directly to the children in a pleasant, appropriate manner?
- What will your child love about this place?
- Is there anything that will make him/her uncomfortable?

Questions to ask the community respite site operators include:

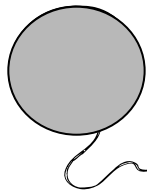
- How many respite providers will there be to care for my child? How many other children will be here?
- What happens during the program? What is the daily routine? Are there organized activities?
- How are meals handled? Who administers medication?
- Will my child have an opportunity to rest or nap if needed?
- What leisure equipment is available for my child to use?
- How much time per day will be spent outside? Will there be trips out into the community?
- How is transportation handled?
- Is there a TV? How long is it usually on per day? What programs do the children usually watch?
- What should my child bring from home to make the stay more enjoyable?
- Is discipline administered? What types of rewards and punishment are used?
- Has the structure been inspected by health and safety officials? Are there regularly scheduled health and safety inspections?
- Is there medical oversight for children with complex needs?
- What is the procedure in the event of a medical emergency for my child?
- What is the procedure if I am unable to pick up my child (or am not home when my child is brought there) at the agreed time?
- May I talk with other parents whose children participate in your program?
- My child's questions: _____

- Other questions: _____

If you are hiring an **individual in-home respite provider (licensed or unlicensed)**, the following are some questions you may want to ask during your interview with them:

- Tell me about yourself.
- Are you over 18 years of age? (Possible: Do you have a green card?)
- Have you had experience working with people with a disability similar to my child's?
- Why are you interested in providing respite services?
- Tell me about your personality. What things do you like about yourself? What are the things you would like to change?
- What makes you the best person to care for my child?
- Can you provide me with references from other families you've worked with?
- Do you have any special training or experience (first aid, CPR, other)?
- If my child has a medical emergency, what steps would you take?
- How would you find out what kinds of activities my child likes to do?
- Do you have any special interests or hobbies you might like to share with my child?
- What would you do if you asked my child to do something and he/she refused?
- How will we handle disagreements if they occur?
- What hours are you available to work? What about holidays or weekends?
- Are you available for emergency situations?
- What is your hourly rate? Do you have a flat overnight fee? Are you paid on a consultant basis?
- Will you sign a consulting contract?
- What are your thoughts on discipline? What types of discipline have you used in the past?
- What would you do if you found my child with an open bottle that you suspected was poison or medicine?
- Are you comfortable taking my child out into the community?
- If my child cries when I leave, how will you handle it?
- Have you had a criminal background and child protective services check to determine that you have no history of child abuse? Would you be willing to have a check done?
- To request a Criminal Conviction Record check contact the Connecticut Department of Public Safety, State Police Bureau of Identification at 860-685-8480 or on-line at www.ct.gov/dps. There is a charge for each request.
- Would you be willing to take a drug test?
- My child's questions: _____

- Other questions: _____



Preparing for Respite

Prepare your home: Be organized in advance to make things easier for the provider. Before your respite provider arrives, consider these ideas:

- Complete your “What you should know about me” book about your child
- Prepackage individual doses of medicine in plastic storage bags
- Prepare food/meals in advance
- Have a first aid kit handy
- Write down key phone numbers
- Fill out necessary forms
- Put your valuables in a safe place
- Have activities for your child ready for the respite provider

Prepare yourself: It’s normal to be a little nervous the first time you leave your child with any new respite provider. Most parents have mixed feelings about sharing their child with another person. Good planning is the best way to ensure a successful respite break and to create a good working relationship with the provider from the start.

These are some pitfalls to avoid to make respite successful:

Take small steps. Many families have discovered the benefits of scheduling the first one or two respite sessions in the home while a parent is home. Others have arranged for the provider to arrive an hour or so before the family leaves, to permit some orientation time. You can probably think of a number of ways your child and a new provider can get off to a good start. The idea is to build a relationship that will last.

Never ‘better late.’ Even the most responsible people can get stuck in a traffic jam, have a flat tire, forget to check the time, or... However, one of the quickest ways to lose a good respite provider is to fail to return when promised. Be on time. If something beyond your control happens, call the provider to let them know.

The case of the lost parent. Any change in plans regarding your location should be communicated as quickly as possible to the respite provider. If you have a pager or cell phone, make sure the provider knows how to reach you with them. Emergency notification plans are essential, but are useless if you can’t be located.

“You didn’t tell me...” It is very important to sit down with your respite provider and talk about household rules before the first respite session. Items to discuss include access to food, use of the kitchen, visitors, use of appliances, telephone, and so forth.

The manipulative child. Give a very clear picture of your child’s daily routine, in writing. If you suspect that your child may take advantage of your absence by changing the rules a bit, be sure to alert the respite provider or discuss the rules with the provider in front of the child.

Prepare for the unexpected. With any planned activity, some complications may arise. For example, the respite provider may become locked out of the house with your child, or a car pool may forget to pick them up or take them somewhere. The respite provider may become ill. If at all possible, you and the respite provider should have a basic back-up plan in place for such circumstances. Options may include getting in touch with a neighbor or nearby relative, or going to the provider's home to await contact. Remember to be forgiving. The respite provider is human, and unforeseen events can happen even with the best!

Additional children. Added children, with or without special needs, mean added responsibilities. Never assume that an extra child or two can be tossed in without warning. You and the respite provider should establish a clear understanding from the outset regarding the number of children to be involved in respite time.

Not enough communication. Not enough communication means miscommunication. It is very important to talk with the provider before and after each respite. Before the session, fill in the provider on what kind of day your child has had, your child's appetite, and fatigue level. After the respite session, ask for information on what happened during your absence. Ask the provider open-ended questions, such as:

- How did things go while we were gone?
- What did you do?
- What did my child eat?
- Were there any problems? How did you handle them?
- Did my child miss us? How did my child express this? How did you handle it?

The debriefing is to identify what information and support the respite provider might need to provide good care. Sometimes they can occur when you first arrive home, and sometimes they may have to occur later by telephone. Try not to sound like a lawyer questioning a tough witness, but be alert to possible problems and follow through to make sure you have the whole story. You need to know if things got out of control, if the provider became angry or upset, or if the provider used questionable judgment.

Be sure to talk to your child, too. Ask them how the session went, what they did, what they ate, whether the child liked the provider, if they'd like the provider to come again to stay, what the child liked best, and what they liked least.

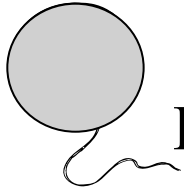
Adapted from The Family Respite Handbook, produced by the Respite Coordination Service Project under grant #90CN002901 to the Tennessee Department of Mental Health and Mental Retardation from the US Department of Health and Human Services.

Prepare your child: The best way to prepare your child is to maintain a positive and upbeat attitude about their sharing time with the respite provider. Children are experts at interpreting their parents' moods and will be able to detect anxiety on your part, which will, in turn cause anxiety in them! If your child is not used to being cared for by another adult, separation anxiety may occur.

First and foremost, you shouldn't feel guilty about leaving your child. Both children and parents are often happier with occasional separations. By a developmental age of 6 months, children are able to understand that separation is not permanent. So tears and anxiety, or other acting out, are not only normal, but are good signs that a warm and close relationship has been developed.

Some ideas for making the separation easier include:

- Leave your child at another place with a security blanket, book, or favorite toy.
- Use an established good-bye ritual, including a hug and kiss and such things as waving or honking as you drive away.
- Remind the child that you always come back. Try to be back when you say you will be. Call if you're delayed. Talk to the child on the telephone (as well as the provider) if that is appropriate.
- It may help your child to forewarn him/her well in advance. Talk about the provider and the exciting things they'll do. If it's practical for the provider to come a day or so before, it may help to introduce the child to them.
- Try not to rush off hurriedly. Spend a few minutes with the child after the provider arrives, and before you go.
- Have the respite provider come early and have an activity started so that the child will be busy before you leave.
- Assure that the provider is prepared to present activities that will entertain or enrich your child. The anxiety of separation will be significantly lower if your child is having fun while you are away.
- Keep family pictures handy so the child can look at them for reassurance.
- Use your common sense. You know what will help your child feel comfortable with the separation, and what might make it more difficult or stressful for them.



Respite Recipes

Some parents of children with special needs dream of the Bahamas, Disney Land, a long train ride through the Swiss Alps. One mother suggested a cruise where the children received respite care on board while parents enjoyed the cruise activities. If you can get there, go for it...you deserve it. However, many parents don't have the time, energy or funds for exotic get-aways. But you can get Respite that is just as restful and invigorating as a cruise on the Nile, without wandering far from home. Hire a Respite Caregiver and try one of the following recipes for a memorable break.

Stay At Home

While a caregiver watches your child in another room:

- Watch a video and eat popcorn
- Take a long bath by candlelight
- Take a long shower and a nap
- Work in the garden
- Paint your bedroom walls
- Play with your other children in another room or outside in the yard
- Have a picnic in the yard
- Bake bread
- Have a friend in for lunch
- Have a romantic dinner with your spouse
- Read a book or a newspaper
- Write a book

Go Out On The Town

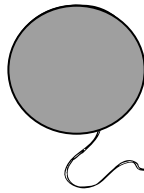
While a caregiver looks after your child at home:

- Go to a movie
- Spend an afternoon at the library
- Have a massage or a pedicure
- Go out to dinner at a restaurant with your spouse, friends, or family
- Go to a sporting event with your other children or cheer for them while they play
- Go grocery shopping alone and undisturbed
- Take a long walk
- Attend a lecture at a local college or university
- Go to a school play or concert and watch your other children perform
- Go to church

Take The Day

If you are comfortable with your child's caregiver, leave them at home and

- Go to the beach for the day
- Take the train to another city and explore
- Visit family or old friends
- Take in a concert, museum, art gallery, or Broadway show, then have lunch
- Take your other kids to an amusement or water park
- Use your imagination, relax and have fun!



Time for RESPITE!

Families spend their respite time in many different ways. How you make use of your respite break will depend upon your schedule and your personal choices for how to use your time. However, before you consider the number of appointments, household chores, paying bills, and "things that you should be doing," mull over some of the things that you would really like to do. For most parents, this is difficult. It's hard to remember the things that you used to do before the responsibilities of parenthood took over.

In an article entitled, "Finding the Fun: The Importance of Play for Parents" (*Exceptional Parent*, July/August 1993) authors Jill Baughan, Patricia Brown, and Monica Uhl urge parents to be spontaneous. "Try to respond to the voice that's telling you what you really want to do, with or without your child. Blow bubbles, fly a kite, go to the library and drink in the silence, buy a water pistol and use it, try juggling or a few tricks with a yo-yo." The stress associated with being a parent of a child with special needs may seem to take away from your own sense of self, or from your relationship with your spouse. It can be very difficult to remember how to play again, and how to liberate yourself from life's responsibilities. Authors Baughan, Brown, and Uhl offer these five pointers to help us remember how to play.

Let go of time. Don't be afraid to block off a period of time and intentionally forget your watch. Curiously, you may actually have to plan in order to do this!

Be spontaneous. So maybe it's been a while since you dusted under the bed. Or, your schedule may dictate that you've got to clean the house. Society may pronounce you "too old for that stuff" when you entertain the desire to turn cartwheels in the yard. But spontaneity, another prerequisite of play, has its own reward—liberation.

Maintain a sense of humor. This should make it easier to keep your sense of humor – a third precursor to play. If you've forgotten or you're out of practice, it's necessary to relearn how to be silly. And if you're afraid of looking foolish when you're acting silly, consider this: much of play's therapeutic value comes from a childlike vulnerability that delights in the absurd. In other words, who cares if you look goofy, as long as you're having fun.

Take some risks. Playing might well involve trying something new, so don't be afraid to take some risks. Be a participant, not a spectator. Take up roller-blading!

Keep a positive attitude. One final requirement for a playful mind-set is an upbeat attitude. Granted, this is easier said than done. But try this: at the end of each day, in a special notebook designated for just this purpose, take 5 minutes to write down a few of the day's pleasures. Sometimes this takes *some* serious digging, but even the worst days have their redeeming moments: a soak in the tub, extra cheese on your pizza, an "I love you" in word or deed from someone you care about. Sharing what was your "favorite part of today" with your child and hearing his/her favorite is a good addition to the bedtime ritual to end the day on a positive note. It can help you both!

Adapted from: *A Practical Guide to Respite for Your Family*, Dellinger-Wray, Molly, and Uhl, Monica, Virginia Partnership for People with Disabilities, 1996. Reprinted with the expressed consent and approval of *Exceptional Parent*, a monthly magazine for parents and families of children with disabilities and special health care needs. Subscription cost is \$39.95 per year for 12 issues; Call (877) 372-7368. Offices at 65 E. Rte. 4, River Edge, NJ 07661

NOTES



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