Get Creative About Respite

What You Need to Know About ME

A Child / Adolescent Guide For Families and Caregivers
Get Creative About Respite
What You Need to Know about Me:
A Child/Adolescent Guide
For Families and Caregivers

This notebook is adapted for children from material that was written for seniors by
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Connecticut Lifespan Respite Coalition, Inc.
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Second Edition

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# Table of Contents

**Introduction**  
3  
*How to Use the Notebook*

**The Basics**  
4

**Emergency Information Forms**  
5

**Third Party Consent Form**  
6  
Suggested Attachments:  
Letter from your Doctor  
Immunization Record

**Medical Tax Record Form**  
8

**My Home**  
9

**My Medicines**  
10  
*Prescription, Over-the-Counter, Herbal, etc.*

**My Health**  
11  
*Medical Conditions and Allergies*  
*Mobility and Special Equipment*  
12

**My Day**  
13  
*How I Spend My Day*  
*Meals*  
*Bedtime*  
14  
15

**Things I May Need Help With**  
16  
*Physical*  
*Behaviors*  
*Things That Agitate Me*  
*Communication Tips*  
*Other Tips*  
17  
18  
19  
20

**My Story**  
21

**My Faith**  
22

**Photographs**  
23

**Satisfaction Form**  
24

**Connecticut Lifespan Respite Coalition (CLRC) Brochure/Membership Application**  
25  
26
INTRODUCTION

The purpose of this notebook is to provide a way for you, as a family member or other caregiver, to communicate with the people who provide respite care for the special person in your life who has special needs. We hope that this notebook helps you to describe your loved one and his/her needs, so that the care they receive from others can truly be individualized. Your loved one may be able to help you complete some of the information.

You can include information about all aspects of your loved one’s life and update the notebook as needed. You may also want to include photographs to help the respite care provider get to know your loved one. You may want to complete the notebook in PENCIL so that you can change information as your loved one’s needs or information changes...or you can make a copy before you write in it so that you can substitute changed pages as you need to.

We encourage you to ask your doctor for a letter to put with this booklet that briefly describes your loved one’s condition. Take the letter with you when you see the doctor to make sure it is still correct. You may also want to include a copy of your child’s immunization record in this book.

We also recommend that you train your provider to take this book with them if they have to take your loved one to the hospital or to a doctor.

It looks like there are a lot of pages in this book. We have set it up so that it will be easy to find what the provider needs and is easy to read. If some information does not apply to your family member, you can pull out those pages. We are trying to make this usable for everyone.

Besides, the more information you and your loved one gather and share with the respite care provider, the better the care they can provide.

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.

There’s a Satisfaction Form at the back of this book, and an application for membership in CLRC. We very much want your feedback about this tool—to know if it is helpful, and how we can improve it for you. We also welcome your membership in the Coalition. That way we can keep you informed about what we’re doing and, on occasion, ask your opinion about new projects.
THE BASICS

My name: ____________________________________________

What I like to be called: __________________________________

Age: ______  Color of Eyes: _________  Color of Hair: ___________

Height: __________  Weight: __________

Names of those who live with me:

<table>
<thead>
<tr>
<th>Name</th>
<th>Relationship</th>
<th>What I Call Them</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

The LANGUAGE I speak and understand best is: __________________________

My Street ADDRESS: __________________________________________

City: __________________________ State ______ Zip __________

Home Phone #: _________________________________________

DIRECTIONS to Home (crossroads, landmarks) __________________________

________________________________________________

Police Department  ______________________________________

Fire Department _________________________________________

Poison Control __________________________________________

Fire Extinguisher is located _____________________________

First Aid Kit is located __________________________________
EMERGENCY INFORMATION

WHO TO CALL IN AN EMERGENCY:

1) Name: ____________________________________________________________
   Relationship: ____________ Phone #s __________________________

2) Name: ____________________________________________________________
   Relationship: ____________ Phone #s __________________________

3) Name: ____________________________________________________________
   Relationship: ____________ Phone #s __________________________

   When they want to be called: ________________________________________
   __________________________________________________________________

   DOCTOR’S NAME: ______________________________________
   Phone #: _________________________________________

   HOSPITAL: ___________________________________________
   Phone #: _________________________________________

Medical Provider Payment (Insurance) Information

   Name of Guardian: ____________________________________________
   Social Security #: ___________________________________________
   Medicaid #: ______________________________________________
   Medicare #: ______________________________________________
   Insurance name/#: __________________________________________

   Have a copy of the signed THIRD-PARTY CONSENT FORM
   for each provider or agency.
   See next page.
   [You may want to keep several blank copies of this form on hand so that you can
   complete one for each different provider or agency.]

   With the consent form, you may also want to keep a letter from
   your child’s primary physician, and a copy of your child’s
   immunization record.
## Emergency Information Form for Children With Special Needs

<table>
<thead>
<tr>
<th><strong>Name:</strong></th>
<th>Birth date:</th>
<th>Nickname:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Home Address:</td>
<td>Home/Work Phone:</td>
<td></td>
</tr>
<tr>
<td>Parent/Guardian:</td>
<td>Emergency Contact Names &amp; Relationship:</td>
<td></td>
</tr>
<tr>
<td>Signature/Consent*:</td>
<td>Phone Number(s):</td>
<td></td>
</tr>
</tbody>
</table>

### Physicians:

<table>
<thead>
<tr>
<th>Primary care physician:</th>
<th>Emergency Phone:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fax:</td>
<td></td>
</tr>
<tr>
<td>Current Specialty physician:</td>
<td></td>
</tr>
<tr>
<td>Specialty:</td>
<td>Emergency Phone:</td>
</tr>
<tr>
<td>Fax:</td>
<td></td>
</tr>
<tr>
<td>Current Specialty physician:</td>
<td></td>
</tr>
<tr>
<td>Specialty:</td>
<td>Emergency Phone:</td>
</tr>
<tr>
<td>Fax:</td>
<td></td>
</tr>
<tr>
<td>Anticipated Primary ED:</td>
<td>Pharmacy:</td>
</tr>
<tr>
<td>Anticipated Tertiary Care Center:</td>
<td></td>
</tr>
</tbody>
</table>

### Diagnoses/Past Procedures/Physical Exam:

1. Baseline physical findings:

2. 

3. Baseline vital signs:

4. 

Synopsis: 

Baseline neurological status:

*Consent for release of this form to health care providers
Diagnoses/Past Procedures/Physical Exam continued:

<table>
<thead>
<tr>
<th>Medications:</th>
<th>Significant baseline ancillary findings (lab, x-ray, ECG):</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td></td>
</tr>
<tr>
<td>2.</td>
<td></td>
</tr>
<tr>
<td>3.</td>
<td></td>
</tr>
<tr>
<td>4.</td>
<td>Prostheses/Appliances/Advanced Technology Devices:</td>
</tr>
<tr>
<td>5.</td>
<td></td>
</tr>
<tr>
<td>6.</td>
<td></td>
</tr>
</tbody>
</table>

Management Data:

<table>
<thead>
<tr>
<th>Allergies: Medications/Foods to be avoided and why:</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
</tr>
<tr>
<td>2.</td>
</tr>
<tr>
<td>3.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Procedures to be avoided and why:</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
</tr>
<tr>
<td>2.</td>
</tr>
<tr>
<td>3.</td>
</tr>
</tbody>
</table>

Immunizations

<table>
<thead>
<tr>
<th>Dates</th>
<th>DPT</th>
<th>OPV</th>
<th>MMR</th>
<th>HIB</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Dates</th>
<th>Hep B</th>
<th>Varicella</th>
<th>TB status</th>
<th>Other</th>
</tr>
</thead>
</table>

Antibiotic prophylaxis: Indication: Medication and dose:

Common Presenting Problems/Findings With Specific Suggested Managements

<table>
<thead>
<tr>
<th>Problem</th>
<th>Suggested Diagnostic Studies</th>
<th>Treatment Considerations</th>
</tr>
</thead>
</table>

Comments on child, family, or other specific medical issues:

Physician/Provider Signature: Print Name:

AUTHORIZATION FOR THIRD PARTY
(to Consent to Treatment of Minor Lacking Capacity to Consent)

I / We, the undersigned parents having legal custody of (full name of child)
____________________________________________________________, a minor,
do hereby authorize (full name of provider and/or provider’s agency)
_____________________________________________________________ as
agent(s) for the undersigned to consent to any X-ray examination, and anesthetic, medical or
surgical diagnosis or treatment, and hospital care which is deemed advisable by, and is to be
rendered under the general or special supervision of any physician and surgeon licensed
under the provisions of the Medical Practice Act or the medical staff of any hospital,
whether such diagnosis or treatment is rendered at the office of said physician or at the
hospital. It is understood that this authorization is given in advance of any specific
diagnosis, treatment, or hospital care being required but is given to provide authority to
power on the part of our aforesaid agent(s) to give specific consent to any and all such
diagnosis, treatment or hospital care which a physician, meeting the requirements of this
authorization, may, in the exercise of his / her best judgment deem advisable. I / We hereby
authorize any hospital which has provided treatment to the above named minor to surrender
physical custody of such minor to my / or above named agent(s) upon the completion of
treatment.

These authorizations shall remain effective until ________________, 20___ unless
sooner revoked in writing delivered to said agent(s). ______________________________

(Signature of parent | guardian having legal custody.) (Date consent goes into effect)
This might be a good place in the book to place a letter from your physician that would outline your child’s healthcare needs and any recommendations or information the physician thinks is important to have on hand.
MY HOME

This home is heated by:

☐ Gas . . . The turnoff valve is ________________________________

☐ Electricity . . . You turn it off by __________________________

☐ Oil . . . You turn it off by __________________________________

Water is turned off by: ______________________________________

___________________________________________________________

Utility company phone numbers:

Electricity_____________________________________________

Gas  _________________________________________________

Oil Company ___________________________________________

Water   _______________________________________________

Rooms I prefer to be in:_____________________________________

_________________________________________________________

Rooms that are “off limits”: _________________________________

_________________________________________________________

Other information about my home: ___________________________

_________________________________________________________

_________________________________________________________
### MY MEDICINES

*(Prescription, Over-the-Counter, Herbal, etc.)*

<table>
<thead>
<tr>
<th>Name of My Medicine</th>
<th>How Much I Take</th>
<th>When and How I Take It</th>
<th>What I Take It For</th>
<th>Side Effects to Look For</th>
</tr>
</thead>
<tbody>
<tr>
<td><em>(Example)</em></td>
<td>One tablet 400 mg</td>
<td>Three times a day after meals (with water)</td>
<td>Diabetes</td>
<td>Dizziness, headache</td>
</tr>
</tbody>
</table>

**Drug Allergies:** ____________________________________________

**What happens if taken:** _____________________________________
### MY HEALTH

**Medical Conditions and Allergies**

<table>
<thead>
<tr>
<th>Medical Condition</th>
<th>Current Status</th>
<th>Things to Watch For</th>
<th>What to Do</th>
</tr>
</thead>
<tbody>
<tr>
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</tbody>
</table>

**Notes:** ____________________________________________________________

______________________________________________

Prepared for the Connecticut Department of Public Health by the Connecticut Lifespan Respite Coalition, Inc.
MY HEALTH
Mobility and Special Equipment

Things to know about moving or lifting me: __________________________
_________________________________________________________________
_________________________________________________________________

Things about moving or lifting me that may frighten or hurt me: ______
_________________________________________________________________
_________________________________________________________________

Adaptive equipment and how to use it: __________________________
_________________________________________________________________
_________________________________________________________________
_________________________________________________________________
_________________________________________________________________

Written instructions for the equipment are located:
_________________________________________________________________
_________________________________________________________________
_________________________________________________________________
_________________________________________________________________
**MY DAY**

*Usually, this is how my day is spent:*

<table>
<thead>
<tr>
<th>Time</th>
<th>Weekday</th>
<th>Weekend</th>
</tr>
</thead>
<tbody>
<tr>
<td>6:00-7:00 A.M.</td>
<td></td>
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<tr>
<td>7:00-8:00 A.M.</td>
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<td></td>
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<tr>
<td>8:00-9:00 A.M.</td>
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<tr>
<td>9:00-10:00 A.M.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>10:00-11:00 A.M.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>11:00-12:00 noon</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Noon-1:00 P.M.</td>
<td></td>
<td></td>
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<tr>
<td>1:00-2:00 P.M.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2:00-3:00 P.M.</td>
<td></td>
<td></td>
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<tr>
<td>3:00-4:00 P.M.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4:00-5:00 P.M.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5:00-6:00 P.M.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6:00-7:00 P.M.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>7:00-8:00 P.M.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>8:00-9:00 P.M.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>9:00-10:00 P.M.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>10:00-11:00 P.M.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>11:00 P.M.-Midnight</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**MY FAVORITE THING TO DO IS:** ___________________________

________________________________________________________
# MY DAY

## Meals

<table>
<thead>
<tr>
<th></th>
<th>BREAKFAST</th>
<th>LUNCH</th>
<th>SUPPER</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Usual mealtime</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>What I usually eat</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Foods I don’t like</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Special preparations</strong> including utensils, dishes I like to use</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>I need help with</strong> (Utensils, drinking, taking small bites, etc.)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Where I like to eat</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>What I like to do after my meal</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Snacks I like and when I am allowed to have them</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Foods to which I am allergic: ______________________________

What happens if I eat them: _______________________________

What to do if I have a reaction: ____________________________

---

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MY DAY

Bedtime

The time I usually go to bed: _______________________________

What I normally do before I go to bed: _______________________________

Things I may need help with include: _______________________________

Do I need a diaper at night? ___ Yes ___ No

Things that help me rest well include: _______________________________

If I get up in the middle of the night, here are some suggestions:

If I have trouble going back to sleep, you might try: _______________

If I get upset, here are some suggestions: _______________________

Music that may help me sleep: _______________________________

Books I might like to have read to me: ___________________________
## THINGS I MAY NEED HELP WITH

**Physical**

<table>
<thead>
<tr>
<th>Yes/No</th>
<th>What kind of help? Suggestions. . . .</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td><strong>Dressing</strong></td>
</tr>
<tr>
<td></td>
<td><strong>Bathing</strong></td>
</tr>
<tr>
<td></td>
<td><strong>Eating</strong></td>
</tr>
<tr>
<td></td>
<td><strong>Toileting</strong></td>
</tr>
<tr>
<td></td>
<td><strong>Taking my medications</strong></td>
</tr>
<tr>
<td></td>
<td><strong>Care of my teeth</strong></td>
</tr>
<tr>
<td></td>
<td><strong>Care of my Hair</strong></td>
</tr>
<tr>
<td></td>
<td><strong>Going to bed</strong></td>
</tr>
</tbody>
</table>
THINGS I MAY NEED HELP WITH

Behaviors

I may try to_____________________________________________________

but not be able to do it. Here are some suggestions: ____________

________________________________________________________________

I may misplace my _____________________________________________

(glasses, etc.).  It is likely to be _________________________________

________________________________________________________________

If it is not there and we can’t find it, a helpful thing to say is:

________________________________________________________________

(for example, “We’ll look for it tomorrow.”)

If I start to argue with you, a helpful response is: ________________

________________________________________________________________

When I am angry, I usually say or do: _____________________________

________________________________________________________________

and a helpful response is: _________________________________

________________________________________________________________

Other general suggestions: _________________________________

________________________________________________________________
THINGS I MAY NEED HELP WITH

Things That Agitate Me

Some things may agitate me.

Television: (Yes or no? Suggestions...) _______________________
_______________________________________________

Stereo:  _____________________________________________
_______________________________________________

Computer: ___________________________________________
_______________________________________________

Other people in the house:  _______________________________
_______________________________________________

People who are allowed into the house:  __________________
_______________________________________________
_______________________________________________
_______________________________________________

People who are NOT allowed into the house:  _________________
_______________________________________________

Other things which are upsetting to me: ______________________
_______________________________________________
_______________________________________________

Suggestions:  _________________________________________
_______________________________________________
_______________________________________________
_______________________________________________
THINGS I MAY NEED HELP WITH

*Communication Tips*

How best to communicate with me (to make sure I understand you:)

________________________________________________________________________________________

________________________________________________________________________________________

________________________________________________________________________________________

________________________________________________________________________________________

________________________________________________________________________________________

Things I usually say to get my needs met:

<table>
<thead>
<tr>
<th>when I need to go to the toilet</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>When I want something to eat</td>
<td></td>
</tr>
<tr>
<td>When I’m tired</td>
<td></td>
</tr>
<tr>
<td>When I’m angry</td>
<td></td>
</tr>
<tr>
<td>When I don’t feel well</td>
<td></td>
</tr>
</tbody>
</table>
OTHER COMMUNICATION TIPS

(CHECK those that apply)

__Please accept what I say and use distraction rather than trying to make me understand.

__Listen to me, even if you cannot understand my words or gestures. I will be happier if you are at least paying attention to me.

__DO NOT ARGUE.

__Don’t take things personally.

__Unless an item is dangerous, do not try to remove it from my hands. I may just want to hold your pocketbook and go for a walk. I’ll put it down soon enough.

__I especially like touching or holding _______________________________

________________________________________________

__If I can’t sit still, walk and pace with me. You are keeping ME company.

__Other tips: ____________________________________________

________________________________________________

________________________________________________

________________________________________________
MY STORY

I was born (when): __________________________ (where): __________________________

Other important people in my life (friends, relatives) not living with me:
______________________________
______________________________
______________________________

My pets: __________________________
______________________________

My hobbies: _______________________
______________________________
______________________________

Places I have traveled: _________________
______________________________
______________________________

Things I am most proud of: _______________________
______________________________
______________________________

Things I cherish: _______________________
______________________________

Things I enjoy talking about: _______________________
______________________________

Things I’d rather not talk about: __________________________________________
______________________________________________________________________
______________________________________________________________________

Other important things about me: ________________________________________
______________________________________________________________________
______________________________________________________________________

MY FAITH
My faith is:     ____ very important     ____ somewhat important
                 ____ not of interest to me

I am a member of the __________________________ faith/religion.

Church names I might mention: ________________________________

My favorite religious song(s): ________________________________
______________________________________________________________________
______________________________________________________________________

I like to hear you read from: (e.g., The Bible, devotional literature, etc.)
______________________________________________________________________
______________________________________________________________________

I pray before my meals: ____yes ____no

Praying with me is ___welcome ___OK ___not welcome

The way I pray/words I use: __________________________________________
______________________________________________________________________
Satisfaction Form
Tell Us What You Think

We’re very interested in knowing whether you find the materials in this package to be helpful for you and your family.

Please rate the following sections:

<table>
<thead>
<tr>
<th>Section</th>
<th>Very helpful</th>
<th>Somewhat helpful</th>
<th>Not helpful</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Managing Stress</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do You Need Respite Care?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>What Kind of Respite Do You Need?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Types of Respite Care</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>How to Find a Respite Provider</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Identifying Potential Respite Providers / Informal Support in the Community</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Selecting a Provider … Questions to Ask</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>In-Home Care Agency</td>
<td></td>
<td></td>
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<td></td>
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<td>Community-Based Respite</td>
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<td>Individual In-Home Provider</td>
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<td>Preparing for Respite</td>
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<td>Respite Recipes</td>
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<td>Time for RESPIE!</td>
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<tr>
<td>What You Need to Know About Me [A Notebook for Families and Caregivers]</td>
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Information I would like you to add: ______________________________________
______________________________________________________________________
______________________________________________________________________

Thank you! (Feel free to use the back of this page.)
We believe that respite is a fundamental family support that is critical to those caring for all individuals with special needs.”

—CLRC Vision

Respite Care

- is planned or emergency short-term care for an individual of any age with disabilities, chronic or terminal illnesses, or other special needs.
- provides needed relief for family or foster family caregivers responsible for the well-being of special needs persons.
- can occur for a few hours a day to a week or more.
- can occur in the home, another home, or a community setting, depending on the needs of the caregiver family and available resources.

Lifespan

...conveys our concern for caregivers of all persons with special needs...across the span between birth and death... regardless of diagnosis, age, economic status or geographic location.

Did you know:

Without adequate family support—such as respite—it is estimated that children with disabilities are 3.76 times more likely to be victims of neglect, 3.79 times more likely to be physically abused, and 3.88 times more likely to experience emotional abuse than children without disabilities. (Sullivan & Knutson, 2000)

Experts estimate that as many as 32 out of 1,000 elderly people are victims of elder abuse by caregivers. (Journal of the American Geriatrics Society, 2000)

RESPITE has been shown to be a key component—one that families and caregivers most often request—of child care, elder care, comprehensive family and family caregiver support, health and long-term care, family violence or child abuse prevention strategies. Yet respite remains in critically short supply for all age groups, for all families in crisis, and for caregivers of the elderly and individuals with disabilities. (National Respite Coalition, 2000)
The Connecticut Lifespan Respite Coalition will:

- **Ascertain national best practices and standards** against which providers can be measured;
- **Inform/educate caregivers, providers, legislators and the public** about respite issues, needs, and resources;
- **Devise an effective system** for assuring that care is available to - and easily accessed by - every caregiver who needs it, throughout the state;
- **Determine the need** for respite care and the types of care needed, in each part of the state;
- Seek out and **map all types of available respite care** programs throughout the state;
- **Establish a State Task Force and state legislation** to recognize and support the need for respite care;
- **Raise funds** to support itself and to facilitate availability of respite care to all who need it.

**MEMBERSHIP APPLICATION**: Please print. (Mail completed form to address at the top of page 1.)

Name: ________________________________________________________________

Mailing Address: _______________________________________________________

____________________________________________________________________

Telephone: ____________________________ FAX: __________________________

E:Mail: ________________________________________________________________

I am: (Please check all that apply)

- [ ] a caregiver of
  - [ ] a developmentally disabled person
  - [ ] other special needs person
  - [ ] 0-3 years
  - [ ] 3-18 years
  - [ ] 19-65 years
  - [ ] Over 65

- [ ] Representing a private agency providing respite for caregivers:

- [ ] Representing a state agency for special needs persons: __________________________

- [ ] Interested in the mission of CLRC. Please send me information and updates.

It would help us a lot if you would list any respite providers you know about in your area. (A telephone number would be helpful, too!) __________________________

We’re looking for members ...

Caregivers, or providers, or people who are simply interested in hearing about or assisting us with our work. We’ll keep you informed—and we may get in touch to ask for your help or your opinion! Thank you!

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26