

# **GET CREATIVE ABOUT RESPITE WHAT YOU NEED TO KNOW ABOUT ME**

## **AN INFORMATIONAL GUIDE FOR FAMILIES, CAREGIVERS AND RESPITE PROVIDERS**

This book was written and compiled by members of the

### **Connecticut Lifespan Respite Coalition, Inc.**

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Administration of Aging: Lifespan Respite Care Act

**2010 Edition**



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# What You Need To Know About ME

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# INTRODUCTION

**T**he purpose of this booklet 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 needs continuing individual care. We hope that this booklet helps you to describe your loved one and his or her needs, so that the care they receive from others can truly be individualized. Your family member may be able to help you complete some of the information.

You can include information about all aspects of your family member's life and update the booklet as needed. You may also want to include photographs to help the respite care provider get to know him or her. You may want to complete the booklet 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 family member's doctor for a letter to put with this booklet that briefly describes your loved one's condition. Take the letter with you when your family member sees their doctor, to make sure it is still correct. You may also want to include a copy of any immunization records in this booklet, if you are caring for a child.

We also recommend that you *tell your respite provider to always take this booklet with them* if they have to take your family member to the hospital or to their doctor.

While it appears that there are a lot of pages in this booklet, it has been organized so that the respite care provider can easily find necessary information. 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.

Remember, the more information you and your loved one gather and share with the respite care provider, the better the care the provider can give. You will be more comfortable about leaving, and your loved one can have a more enjoyable experience.

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 booklet 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 are 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:

Name	Relationship	What I Call Them

The LANGUAGE I speak and understand best is: \_\_\_\_\_

My Street ADDRESS: \_\_\_\_\_

City: \_\_\_\_\_ State: \_\_\_\_\_ Zip: \_\_\_\_\_

Home Phone #: \_\_\_\_\_ Cell Phone#: \_\_\_\_\_

DIRECTIONS to Home (crossroads, landmarks): \_\_\_\_\_

Pets in the Home: \_\_\_\_\_ Type of Pets \_\_\_\_\_ Names: \_\_\_\_\_

Fire Extinguisher is located \_\_\_\_\_

First Aid Kit is located \_\_\_\_\_

**In Case of Emergency Dial 911**

# **EMERGENCY INFORMATION**

## **WHO TO CALL IN AN EMERGENCY:**

**Name:** \_\_\_\_\_

**Relationship:** \_\_\_\_\_ **Phone #s** \_\_\_\_\_

**Name:** \_\_\_\_\_

**Relationship:** \_\_\_\_\_ **Phone #s** \_\_\_\_\_

**Name:** \_\_\_\_\_

**Relationship:** \_\_\_\_\_ **Phone #s** \_\_\_\_\_

**DOCTOR'S NAME:** \_\_\_\_\_

**Phone #:** \_\_\_\_\_

**HOSPITAL:** \_\_\_\_\_

**Phone #:** \_\_\_\_\_

## **Medical Provider Payment (Insurance) Information**

**Name of Guardian:** \_\_\_\_\_

**Medicaid #:** \_\_\_\_\_

**Medicare #:** \_\_\_\_\_

**Insurance Name #:** \_\_\_\_\_

**If you are a parent of a child or have legal custody of an adult family member have a copy of the THIRD-PARTY CONSENT FORM available that you have signed for each respite 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 family member's primary physician, and a copy of his or her medical history. A SAMPLE form for children is included in these pages.**

# AUTHORIZATION FOR THIRD PARTY CARING

## FOR A MINOR CHILD

### SAMPLE

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*)

\_\_\_\_\_, 20\_\_\_\_\_  
(*Date consent goes into effect*)

**Note: This form is not meant to substitute for advice or forms obtained from your attorney or other advisor.**

This might be a good place  
in this booklet to place a  
letter from your physician  
that would outline your family  
member'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 turn off 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.)

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

Drug Allergies: \_\_\_\_\_

What happens if taken: \_\_\_\_\_

# MY HEALTH

## Medical Conditions and Allergies

<b>Medical Condition</b>	<b>Current Status</b>	<b>Things to Watch For</b>	<b>What to Do</b>

Notes: \_\_\_\_\_

\_\_\_\_\_

# MY HEALTH

## Mobility and Special Equipment

Things to know about moving or lifting me: \_\_\_\_\_

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Things about moving or lifting me that may frighten or hurt me: \_\_\_\_\_

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Adaptive equipment and how to use it: \_\_\_\_\_

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Written instructions for the equipment are located:

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# MY DAY

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

	<b>Weekday</b>	<b>Weekend</b>
<b>6:00-7:00 A.M.</b>		
<b>7:00-8:00 A.M.</b>		
<b>8:00-9:00 A.M.</b>		
<b>9:00-10:00 A.M.</b>		
<b>10:00-11:00 A.M.</b>		
<b>11:00-12:00 noon</b>		
<b>Noon-1:00 P.M.</b>		
<b>1:00-2:00 P.M.</b>		
<b>2:00-3:00 P.M.</b>		
<b>3:00-4:00 P.M.</b>		
<b>4:00-5:00 P.M.</b>		
<b>5:00-6:00 P.M.</b>		
<b>6:00-7:00 P.M.</b>		
<b>7:00-8:00 P.M.</b>		
<b>8:00-9:00 P.M.</b>		
<b>9:00-10:00 P.M.</b>		
<b>10:00-11:00 P.M.</b>		
<b>11:00 P.M.-Midnight</b>		

**MY FAVORITE THINGS TO DO ARE:** \_\_\_\_\_

\_\_\_\_\_

# MY DAY

## *Meals*

	<b>BREAKFAST</b>	<b>LUNCH</b>	<b>SUPPER</b>
<b>Usual mealtime</b>			
<b>What I usually eat</b>			
<b>Foods I don't like</b>			
<b>Special preparations</b> including utensils and dishes I like to use Food consistency (chopped, pureed etc.)			
<b>I need help with</b> (Utensils, drinking, taking small bites, etc.)			
<b>Where I like to eat</b>			
<b>What I like to do after my meal</b>			
<b>Snacks I like and when I am allowed to have them</b>			

**Foods to which I am allergic:** \_\_\_\_\_

**What happens if I eat them:** \_\_\_\_\_

**What to do if I have a reaction:** \_\_\_\_\_

# 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 read: \_\_\_\_\_

\_\_\_\_\_

**THINGS I MAY NEED HELP WITH**

*Physical*

	<b>Yes/No</b>	<b>What kind of help? Suggestions. .</b>
<b>Dressing</b>		
<b>Bathing</b>		
<b>Eating</b>		
<b>Toileting</b>		
<b>Taking my medications</b>		
<b>Care of my teeth</b>		
<b>Care of my Hair</b>		
<b>Going to bed</b>		

# THINGS I MAY NEED HELP WITH

## *Behaviors*

I may try to do \_\_\_\_\_

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 or Frighten Me*

Some things may agitate or frighten 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: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

It may help me if you: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

# THINGS I MAY NEED HELP WITH

## *Communication Tips*

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

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Things I usually say or do to get my needs met:

<b>When I need to go to the toilet</b>	
<b>When I want something to eat</b>	
<b>When I'm tired</b>	
<b>When I'm angry</b>	
<b>When I don't feel well</b>	

# **OTHER COMMUNICATION TIPS**

*(CHECK those that apply)*

**Please accept what I say and use distraction rather than trying to make me understand, if I am incorrect.**

**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:

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My pets: \_\_\_\_\_

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My hobbies: \_\_\_\_\_

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Places I have traveled: \_\_\_\_\_

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Things I am most proud of: \_\_\_\_\_

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Things I cherish: \_\_\_\_\_

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Things I enjoy talking about: \_\_\_\_\_

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Things I'd rather not talk about: \_\_\_\_\_

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Other important things about me: \_\_\_\_\_

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# MY FAITH

My faith is: \_\_\_\_\_ very important \_\_\_\_\_ somewhat important  
\_\_\_\_\_ not of interest to me

I am a member of the \_\_\_\_\_ faith/religion.

Church, Synagogue, etc. 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: \_\_\_\_\_  
\_\_\_\_\_

# **PHOTOGRAPHS**

**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:

Mail comments to:

Connecticut Lifespan Respite Coalition, Inc.  
2138 Silas Deane Hwy.  
Rocky Hill, CT 06067

Attention: Board of Directors

	<b>Very Helpful</b>	<b>Somewhat Helpful</b>	<b>Not Helpful</b>	<b>Comments</b>
Managing Stress				
Do You Need Respite Care?				
What Kind of Respite Do You Need?				
Types of Respite Care				
How to Find a Respite Provider				
Identifying Respite Providers and Informal Community Supports				
Selecting a Provider ...Questions to Ask				
In-Home Agency Care				
Community-Based Respite				
Individual In-Home Providers				
Preparing for Respite				
Respite Recipes				
Time for RESPITE!				
What You Need to Know About Me [A Booklet for Families and Caregivers]				

**Information I would like you to include:** \_\_\_\_\_

\_\_\_\_\_

*Thank you!* (Feel free to use the back of this page.)



## Connecticut Lifespan Respite Coalition

2138 Silas Deane Highway  
 Rocky Hill, CT 06067  
 Telephone: 860-513-0172  
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 Website: [ctrespite.org](http://ctrespite.org)

" 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.

### 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!*

**MEMBERSHIP APPLICATION:** Please print. (Mail completed form to address at the top of page 22.)

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!) \_\_\_\_\_