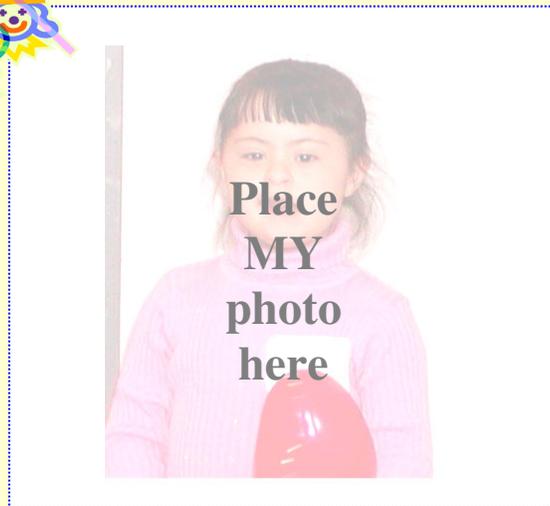


Get

Creative
About
Respite

**What You Need to
Know
About ME**



*A Child / Adolescent Guide
For Families and Caregivers*



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 the provider can give, the more comfortable you will be about leaving, and the more enjoyable and enriching the experience will be for your loved one.

What You Need to Know about Me: A Notebook for Families and Caregivers

This notebook is adapted for children
from material written for seniors
by Susan R. Carlton, Executive Director,
The South Carolina Respite Coalition
and Norma S. Sessions, Training/Development Director,
The (SC) Center for Child and Family Studies
by members of the
Education and Training Subcommittee,
Connecticut Lifespan Respite Coalition, Inc.
and Judith Passmore

Funding for this project was provided to
Connecticut Lifespan Respite Coalition, Inc.
through the
**Connecticut Department of Public Health,
Family Health Division.**
September, 2003

Special Thanks for their support and assistance are due to:
Martha Okafor, Division Director,
Dorothy Pacyna, Supervisor, Child, Adolescent and School Health Unit,
Ann Gionet, Family Advocate,
Department of Communications (for their review of the book),
at the Family Health Division, Connecticut Department of Public Health
and Denise E. Stephens, Ph.D., President, Matrix Public Health Consultants, Inc.

What You Need to Know About ME

Table of Contents

The Basics	1
Emergency Information	2
Third Party Consent Form	3
Suggested Attachments:	
Letter from your Doctor	
Immunization Record	
My Home	5
My Medicines	6
<i>Prescription, Over-the-Counter, Herbal, etc.</i>	
My Health	7
<i>Medical Conditions and Allergies</i>	7
<i>Mobility and Special Equipment</i>	8
My Day	9
<i>How I Spend My Day</i>	9
<i>Meals</i>	10
<i>Bedtime</i>	11
Things I May Need Help With	12
<i>Physical</i>	12
<i>Behaviors</i>	13
<i>Things That Agitate Me</i>	14
<i>Communication Tips</i>	15
<i>Other Tips</i>	16
My Story	17
My Faith	18
Photographs	19

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 #: _____

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.**

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). _____

_____, 20____.
(Signature of parent | guardian having legal custody.) (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 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.)

Name of My Medicine	How Much I Take	When and How I Take It	What I Take It For	Side Effects to Look For
<i>(Example)</i>	<i>One tablet 40 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

Medical Condition	Current Status	Things to Watch For	What to Do

Notes: _____





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:*

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

MY FAVORITE THING TO DO IS: _____

MY DAY

Meals

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



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 have read to me: _____

THINGS I MAY NEED HELP WITH

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





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:

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



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: _____

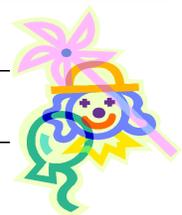
My hobbies: _____

Places I have traveled: _____

Things I am most proud of: _____

Things I cherish: _____

Things I enjoy talking about: _____





PHOTOGRAPHS



Get Creative About Respite

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 tell us how we can improve the books. Thank you for your input!

Mail comments to:
Department of Public Health
410 Capitol Avenue
MS # 11MAT
P.O. Box 340308
Hartford, CT 06134
ATT: Ann Gionet

Get Creative About Respite - Parent Guide

	Don't Know	Strongly Agree (5)	Somewhat Agree (4)	Neutral (3)	Somewhat Disagree (2)	Strongly Disagree (1)
The Parent Guide was helpful.						
Information was presented in a way that was easy to follow.						
The language used was easy to understand.						
The material was respectful of my racial, ethnic, and cultural background.						
I will use the Parent Guide to locate new respite providers.						
I will share this information resource with other parents.						

Get Creative About Respite - Child Guide: What You Need to Know About Me

	Don't Know	Strongly Agree (5)	Somewhat Agree (4)	Neutral (3)	Somewhat Disagree (2)	Strongly Disagree (1)
The Child Guide was helpful.						
Information was presented in a way that was easy to follow.						
The language used was easy to understand.						
The material was respectful of my racial, ethnic, and cultural background.						
I will use the Child Guide as a way to share information about my child with their respite providers.						
I will share this information resource with other parents.						

What information is missing from the Parent and Child Guides? How can we make them better? Please share any additional comments about the Parent and Child Guides in the space below.



Connecticut Lifespan Respite Coalition, Inc.

60B Weston Street
Hartford, CT 06120

Telephone: 860-247-2572

FAX: 860-247-3344

E:mail: CTRespite@sbcglobal.net

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:

- **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;
- **Ascertain national best practices and standards** against which providers can be measured;
- **Inform caregivers and providers** about respite issues, needs, and resources;
- **Devis**e an effective system for assuring that care is available to - and easily accessed by - every caregiver who needs it, 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 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!) _____



Keeping Connecticut Healthy
www.dph.state.ct.us

Prepared for the Connecticut Department of Public Health
by the Connecticut Lifespan Respite Coalition, Inc.
September, 2003

