About Respite

What You Need to Know About ME

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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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:

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.

Emergency Information Form for Children With Special Needs

Last name:

American College of Emergency Physicians®

American Academy of Pediatrics

Date form completed By Whom	Revised	Initials
	Revised	Initials

Name:	Birth date: Nickname:
Home Address:	Home/Work Phone:
Parent/Guardian:	Emergency Contact Names & Relationship:
Signature/Consent*:	
Primary Language:	Phone Number(s):

Physicians:	
Primary care physician:	Emergency Phone:
	Fax:
Current Specialty physician: Specialty:	Emergency Phone:
	Fax:
Current Specialty physician: Specialty:	Emergency Phone:
	Fax:
Anticipated Primary ED:	Pharmacy:
Anticipated Tertiary Care Center:	

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

Last name:

Diagnoses/Past Procedures/Physical Exam continued:

Medications:

1.
2.
3.
4.
5.
6.

Significant baseline ancillary findings (lab, x-ray, ECG):

Prostheses/Appliances/Advanced Technology Devices:

Management Data:

Allergies: Medications/Foods to be avoided **and why:**

1.
2.
3.

Procedures to be avoided **and why:**

1.
2.
3.

Immunizations

Dates					
DPT					
OPV					
MMR					
HIB					

Dates					
Hep B					
Varicella					
TB status					
Other					

Antibiotic prophylaxis: Indication: Medication and dose:

Common Presenting Problems/Findings With Specific Suggested Managements

Problem	Suggested Diagnostic Studies	Treatment Considerations

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

Physician/Provider Signature: **Print Name:**

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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)*

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.

MEDICAL TAX RECORDS 20__

Date	Chk#	Amount	To Where	For Whom	Miles	Tolls/Park	Meals	Visit Notes Rec'd

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
(Example)	*One tablet 400 mg*	*Three times a day after meals (with water)*	*Diabetes*	*Dizziness, headache*

Drug Allergies: ____

What happens if taken: ____________________________________

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

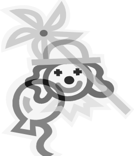
MY HEALTH

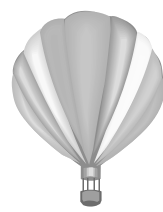
Medical Conditions and Allergies

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: ___________________________

____

____

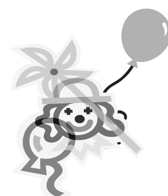
____

Music that may help me sleep: ________________________________

Books I might like to have read to me: ______________________________

THINGS I MAY NEED HELP WITH
Physical

	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: __________________________

____

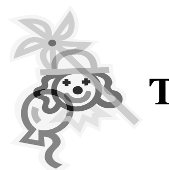
____

Suggestions: ____

____

____

____



THINGS I MAY NEED HELP WITH

Communication Tips

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

____

____

____

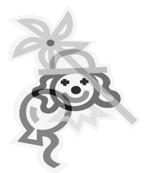
____

____

____

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: _________________________________

____

____

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

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: __________________________________

____

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

Attention: Joy Liebeskind, Coordinator

	Very helpful	Somewhat helpful	Not helpful	Comments
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 Potential Respite Providers / Informal Support in the Community				
Selecting a Provider …Questions to Ask				
In-Home Care Agency				
Community-Based Respite				
Individual In-Home Provider				
Preparing for Respite				
Respite Recipes				
Time for RESPITE!				
What You Need to Know About Me [A Notebook for Families and Caregivers]				

Information I would like you to add: ____

____

____

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
Toll Free: 877-737-1966
FAX: 860-247-3344
E:mail: CTRespite@cox.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:

*W*ithout 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)

*E*xperts 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 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: ____________________

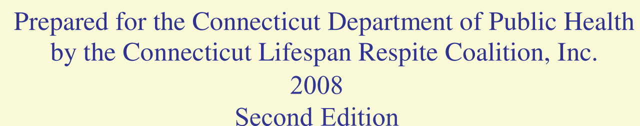
☐ Interested in the mission of CLRC. Please send me information and updates.

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.ct.gov/dph



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