



Child  
Neurology  
FOUNDATION  
Creating a Community of Support

# A RESPITE CARE NOTEBOOK

WITH CHARITABLE SUPPORT FROM





# WHAT FAMILIES HAVE TO SAY ABOUT RESPITE CARE

We're sure you'd agree that caring for our children requires lots of love and lots of patience. If you have a child with special needs, that care can also be challenging, at times. Respite care providers can help you. Families who have used respite care tell us that respite helps them **"create a better balance"** in their lives. Respite care helps parents take time for themselves, to be with their partner or spouse, or with their other children. Some parents pursue their own interests, with support from respite care. In a small survey of 17 families, one parent reported returning to work, and another parent said she went back to school—thanks to respite care.

Respite care can also be good for your child. **"Respite caregivers have helped my son participate in fun activities,"** said one family. Respite care allowed another child to attend a weekend camp. Respite care can encourage friendships, build trust, and expand social skills. Respite care "is just as useful to our son as it is to us," reports a parent. "We get a chance to have a break and our son has a chance to meet new people and form other relationships outside his own family. Even though he is non-verbal and has severe and profound intellectual impairment, it is very obvious to us that he enjoys his time in respite care."

**"Respite care expanded our circle of caring adults capable of providing high quality care for our son,"** says one mother. In case of an emergency, it can be critical to have someone to call whom you trust to care for your child. If you can't be available, respite care can step in.

The Child Neurology Foundation (CNF) created this notebook for families who now use respite care services, and families who are thinking about respite care services. It is a tool to help guide the respite care provider in caring for your child. Some things to keep in mind:

Respite care can be used for a few hours, several days or even longer.

You decide how to use respite, depending on your family's needs, available services, and coverage/costs.

The forms in this notebook bring information about your child's needs—and wants—into one place.

You fill out the forms that apply to your child's needs and situation. Skip any questions or pages that don't apply.

This notebook is designed with a 2–3-day respite in mind. You may find that some of the information we ask for isn't needed for shorter visits. For a longer visit, you may need to include more information, like how to restock the supplies, or how your child will be taken to school or therapy. Additional forms are provided, starting on page 29, with items to think about as you prepare for longer respite care visits.

You might find that the notebook also helps remind other family caregivers of changes in medication or routine. As you update forms, you might keep the old ones, and build a record of your child's care, growth, and use of respite services.

We want this notebook to be useful for you, your child, and other families with special needs. As you become familiar with using respite services, we hope you will share your experiences with other families. If you need more information, or have questions or comments, email us at [info@childneurologyfoundation.org](mailto:info@childneurologyfoundation.org).

Above all, we know you may feel nervous letting someone else come into your home and care for your child. But please remember that caretakers need care too! As one family member told us, **"Primary caregivers often don't realize just how stretch[ed] and stressed they are until they get a real break and can look back."** We hope this notebook will help you create a complete plan for your respite care provider so that your mind can be at ease while you are away from your child.

Sincerely,  
The Child Neurology Foundation

**"Ask for help.**  
Not because you are weak. But because you want to **remain strong.**"

—Les Brown

# ACKNOWLEDGEMENTS

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# SOURCES

## THE FOLLOWING SOURCES PROVIDED HELPFUL FRAMING AND MODELS:

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# THIS VISIT

Complete this section before each new respite visit. These items will help get the respite care provider “up to speed” on what’s happening with your child and family at each visit. Completing this page may help to remind you of other areas of the notebook that also need to be updated.

Thanks for taking care of \_\_\_\_\_ from \_\_\_\_\_ to \_\_\_\_\_.  
NAME DATE/TIME DATE/TIME

We hope this information will help you both/all be safe, comfortable, and enjoy your time together.

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I would describe \_\_\_\_\_ personality as: \_\_\_\_\_  
NAME'S

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Note child’s mood, any unusual activities or circumstances, or if the routine has been regular.

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\* See page 10 for information about strategies for helping \_\_\_\_\_ with difficult feelings.  
NAME

## SO FAR, TODAY:

### MEALS THUS FAR/SUGGESTIONS FOR MEALS

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\* See pages 18–20 for complete information on helping \_\_\_\_\_ with eating/drinking.  
NAME

# THIS VISIT

(CONTINUED)

## TOILETING THUS FAR/NOTES REGARDING TOILETING

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\* See pages 22–23 for complete information on helping \_\_\_\_\_ with toileting  
NAME

## MEDICATION THUS FAR/NOTES FOR THIS VISIT

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\* See page 13 for complete information on \_\_\_\_\_ medications.  
NAME'S

Here's what we've planned for you and \_\_\_\_\_  
NAME

Note scheduled activities: day, times, location, transportation arrangements, and contact information.

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You ☐ will  
☐ will not be driving \_\_\_\_\_ in your or our vehicle.  
NAME

## INSURANCE INFORMATION, CONSENT FORMS, KEYS CAN BE FOUND:

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### THESE THINGS MIGHT ALSO BE FUN (SUGGESTED ACTIVITIES)

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\* See pages 10–11 for information on \_\_\_\_\_ activities.  
(NAME'S)

I/We will be \_\_\_\_\_ during your visit.  
(LOCATION/ACTIVITY)

You can reach us at \_\_\_\_\_  
(PHONE)

- ☐ With questions
- ☐ With updates
- ☐ In an emergency

We may be difficult to reach \_\_\_\_\_  
(TIME/LOCATION)

### IF YOU CANNOT REACH US, PLEASE CONTACT:

NAME	RELATIONSHIP	PHONE
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- ☐ With questions
- ☐ With updates
- ☐ In an emergency

An emergency information/medical summary form can be found on pages 25-27;  
refer to it for physician's contact information and in any emergency.



# GETTING TO KNOW US

## FAMILY

### THE GROWN-UPS

NAME	RELATIONSHIP	OCCUPATION & WORK ADDRESS	PHONE(S)
NAME	RELATIONSHIP	OCCUPATION & WORK ADDRESS	PHONE(S)

### SPECIAL NEEDS CHILD

NAME	AGE	SCHOOL & GRADE (OR ANALOGOUS)
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### SIBLINGS

NAME	AGE	RELATIONSHIP	SCHOOL & GRADE (IF APPLICABLE)
NAME	AGE	RELATIONSHIP	SCHOOL & GRADE (IF APPLICABLE)
NAME	AGE	RELATIONSHIP	SCHOOL & GRADE (IF APPLICABLE)

### PETS

NAME	TYPE
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### NEARBY FAMILY

NAME	RELATIONSHIP	CONTACT INFORMATION
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### Religious beliefs/customs in our family that may impact care (e.g., diet, dress, treatment restrictions)


# GETTING TO KNOW US (CONTINUED)

\_\_\_\_\_ has some special needs related to \_\_\_\_\_ (more on that later).  
NAME DIAGNOSIS/CONDITION

But \_\_\_\_\_ is more than that diagnosis! Here are some words we use to describe  
NAME

\_\_\_\_\_ ! [insert words to describe personality/disposition].  
NAME

## WHEN THINGS DON'T GO SO WELL

These are some ways we help \_\_\_\_\_ :  
NAME

With transitions between activities:

When \_\_\_\_\_ is frustrated, anxious, upset:  
NAME

These are some ways \_\_\_\_\_ calms down on his/her own:  
NAME

.....  
\_\_\_\_\_ likes the following activities and things:  
NAME

Activity/Item (e.g., TV, stuffed animal, swimming)	Where/when/how—and any limits (e.g., no TV after 8 p.m., only pre-selected videos)

\_\_\_\_\_ doesn't like the following activities and things:  
NAME

Activity/Item	Strategies for avoiding/soothing

\_\_\_\_\_ is good at:  
NAME

Activity/Skill	Ways to practice or acknowledge

\_\_\_\_\_ has trouble with:  
NAME

Activity/Skill	Ways to Help (or see pages 17–24 for more detail)
Communication	See page: 17
Mobility	See page: 17
Eating/Drinking	See page: 18
Bathing/Toileting	See page: 22
Emotional Regulation	See page: 10





# 'S MEDICAL NEEDS

NAME

NAME

CONDITION(S) AND TIME/CIRCUMSTANCE OF DIAGNOSIS (e.g., at birth, after a car accident, when s/he was 10 years old).

These conditions cause (DESCRIBE SIGNS AND SYMPTOMS)

NAME

	Medication Name & Brief Description (e.g., yellow capsule, liquid in green bottle)	Dose / Route	Next Dose Due
1			
	Special Instructions:		
2			
	Special Instructions:		
3			
	Special Instructions:		
4			
	Special Instructions:		
5			
	Special Instructions:		

	Medical Supplies	Location
1		
	Special Instructions:	
2		
	Special Instructions:	
3		
	Special Instructions:	

We also support NAME with (DESCRIBE TREATMENTS/THERAPIES)

. We hope you can help with those that we've underlined.



# 'S MEDICAL NEEDS

NAME \_\_\_\_\_

(CONTINUED)

## SCARY, SERIOUS, AND EMERGENCY SITUATIONS

Sometimes, \_\_\_\_\_ can cause other symptoms. You might not experience these, but we'd like you to be prepared.

NAME'S CONDITION

### SCARY BUT NOT DANGEROUS

The following situations might be scary for you, but they are generally not dangerous (describe situations such as common seizures, etc. If you have a video of a seizure, note here where the video is kept):

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### HERE'S HOW TO HELP:

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### SERIOUS SITUATIONS

These situations are problematic (e.g., seizures lasting more than X minutes):

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### HERE'S HOW TO HELP:

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In addition, please contact me and the following for further instructions:

	Contact Name & Title <small>(e.g., the primary care doctor, the specialist, etc)</small>	Phone Number
1		
2		
3		
4		

THE FOLLOWING CONSTITUTE EMERGENCIES!

TAKE THESE STEPS:

AND CALL 9-1-1!

Then, please contact me & the following for further instructions:

	Contact Name & Title <small>(e.g., the primary care doctor, the specialist, etc)</small>	Phone Number
1		
2		
3		
4		

An emergency information/medical summary form can be found on pages 25-27;  
it provides information for EMS and emergency care providers—  
detach this page and give to these providers.



# GETTING TO KNOW \_\_\_\_\_

NAME

## HOW \_\_\_\_\_ COMMUNICATES

NAME

Check all that apply	Describe (use of tools, signs, etc)
<input type="checkbox"/> Talking <input type="checkbox"/> Sign language <input type="checkbox"/> TTY <input type="checkbox"/> Picture board <input type="checkbox"/> Gesture/facial <input type="checkbox"/> Other <input type="checkbox"/> Computer keyboard	
Gestures/images to show fear	
Gestures/images to show hunger	
Gestures/images to show toileting needs	
Other gestures/images	

## MOBILITY / HOW \_\_\_\_\_ MOVES AROUND

NAME

Can do these things without assistance	Needs help with
<input type="checkbox"/> sit up <input type="checkbox"/> crawl <input type="checkbox"/> stand <input type="checkbox"/> walk <input type="checkbox"/> walk with assistance <input type="checkbox"/> climb stairs <input type="checkbox"/> run	<input type="checkbox"/> sit up <input type="checkbox"/> crawl <input type="checkbox"/> stand <input type="checkbox"/> walk <input type="checkbox"/> walk with assistance <input type="checkbox"/> climb stairs <input type="checkbox"/> run

## TOOLS/EQUIPMENT THAT AID IN MOVEMENT:

Equipment and Brand Name	Used For	Trouble-shooting / If the alarm sounds, try	Phone for repair



# GETTING TO KNOW

NAME \_\_\_\_\_

(CONTINUED)

Describe position routines and preferences:

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Describe transfer routines and strategies:

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Other comments about mobility:

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.....

## EATING/DRINKING

Is \_\_\_\_\_ likely to eat non-food items? ☐ YES ☐ NO

NAME

Prevention/interventions:

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Any special positioning:

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EATING / DRINKING (CONTINUED)

ASSISTANCE NEEDED

- ☐ none
  - uses: ☐ knife ☐ fork ☐ spoon
- ☐ supervision
- ☐ limited assistance
- ☐ complete assistance
- ☐ Feeding tube
  - ☐ NG ☐ OG ☐ GT ☐ G/J tube

TUBE FEEDINGS

- ☐ gravity
- ☐ pump (pump rate: \_\_\_\_\_ )

Formula Name/location:

\_\_\_\_\_

\_\_\_\_\_

Formula Amount:

\_\_\_\_\_

\_\_\_\_\_

Flush Amount:

\_\_\_\_\_

\_\_\_\_\_

How often:

\_\_\_\_\_

\_\_\_\_\_

Feeding tube care:

\_\_\_\_\_

\_\_\_\_\_



# GETTING TO KNOW

NAME \_\_\_\_\_

(CONTINUED)

Location of extra feeding tubes:

How often are feeding tubes changed:

Care of skin around feeding tube:

Favorite foods:

Foods to avoid:

Food allergies & signs of allergic reaction:

Required foods/supplements:

**FOOD PREPARATIONS**

- ☐ none
- ☐ cut into pieces
- ☐ lightly blended
- ☐ pureed

**DRINKS FROM**

- ☐ does not take anything by mouth
- ☐ bottle
- ☐ sippy cup
- ☐ regular cup/glass

## BREATHING/RESPIRATORY CARE

### CHECK ALL THAT APPLY:

- ☐ **OXYGEN**      Liters: \_\_\_\_\_ Route: \_\_\_\_\_
- ☐ **SVN**      Medication: \_\_\_\_\_ Amount: \_\_\_\_\_ Frequency: \_\_\_\_\_
- ☐ **SUCTIONING**      Route: \_\_\_\_\_ Catheter Size: \_\_\_\_\_ Frequency: \_\_\_\_\_
- ☐ **TRACHEOSTOMY**      Size/Brand: \_\_\_\_\_ Change Frequency: \_\_\_\_\_
- ☐ **VENTILATOR**      Type: \_\_\_\_\_  
Settings: IMV \_\_\_\_\_ SIMV \_\_\_\_\_ Volume \_\_\_\_\_  
Peak Pressure \_\_\_\_\_ PEEP \_\_\_\_\_ Rate \_\_\_\_\_
- ☐ **PULSE OX**      Type: \_\_\_\_\_  
Settings: Low Alarm \_\_\_\_\_ High Alarm: \_\_\_\_\_
- ☐ **APNEA MONITOR**      Type: \_\_\_\_\_  
Settings: High Heart Rate \_\_\_\_\_ Low Heart Rate \_\_\_\_\_  
Apnea settings in seconds \_\_\_\_\_
- ☐ **CPAP**      Type: \_\_\_\_\_  
Settings: Pressure \_\_\_\_\_
- ☐ **MEDICATIONS**
- ☐ **Albuterol**  
Nebulizer \_\_\_\_\_ Dose: \_\_\_\_\_ Frequency: \_\_\_\_\_  
Puffs \_\_\_\_\_ Frequency: \_\_\_\_\_
- ☐ **Intal**  
Nebulizer \_\_\_\_\_ Dose: \_\_\_\_\_ Frequency: \_\_\_\_\_  
Puffs \_\_\_\_\_ Frequency: \_\_\_\_\_
- ☐ **Provental**  
Nebulizer \_\_\_\_\_ Dose: \_\_\_\_\_ Frequency: \_\_\_\_\_  
Puffs \_\_\_\_\_ Frequency: \_\_\_\_\_

# GETTING TO KNOW

(CONTINUED)

NAME \_\_\_\_\_

## ☐ CLAPPING (CPT)

Frequency: \_\_\_\_\_

## OTHER COMMENTS/INSTRUCTIONS:

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## BATHING/TOILETING

### BATHING

☐ Tub ☐ Shower ☐ Other: \_\_\_\_\_

Assistance needed:

☐ none ☐ supervision  
☐ limited assistance ☐ complete assistance

### TEETH BRUSHING

Assistance needed:

☐ none ☐ supervision  
☐ limited assistance ☐ complete assistance

### TOILETING

Assistance needed:

☐ none ☐ supervision ☐ limited assistance ☐ complete assistance

How often?

☐ reminders needed

\_\_\_\_\_ will let you know s/he needs to go by \_\_\_\_\_  
NAME

## TOILETING (CONTINUED)

Location of menstrual supplies, if needed

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## EMOTIONAL REGULATION / BEHAVIOR

How \_\_\_\_\_ shows affection:

NAME

\_\_\_\_\_  
(E.G., HUGGING, SMILING, PETTING)

How \_\_\_\_\_ shows fear:

NAME

\_\_\_\_\_  
(E.G., HIDING, ROCKING, SILENCE, CRYING)

How \_\_\_\_\_ plays with other children:

NAME

\_\_\_\_\_  
(E.G., EASILY? SHY? AGGRESSIVE?)

\_\_\_\_\_ favorite activity with others:

NAME'S

What encourages \_\_\_\_\_ to cooperate:

NAME

What helps \_\_\_\_\_ change from one task to another:

NAME



# GETTING TO KNOW

NAME \_\_\_\_\_

(CONTINUED)

How \_\_\_\_\_ responds to too much or not enough stimulation:

NAME

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Meltdowns: ☐ YES ☐ NO

Can be caused by: \_\_\_\_\_

Warning signs: \_\_\_\_\_

How to help: \_\_\_\_\_

## BEDTIME ROUTINE

### ACTIVITIES

- ☐ Read a story (location / title of favorites) \_\_\_\_\_
- ☐ Sing a song (name of song) \_\_\_\_\_
- ☐ Recite a standard prayer (location / title / text) \_\_\_\_\_
- ☐ Say our own prayers

### ANY BEDTIME PROPS? DESCRIPTION / LOCATION:

(E.G., STUFFED ANIMAL, BLANKET)

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### POSITIONING / TURNING:

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### STRATEGIES FOR WAKEFULNESS:

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# EMERGENCY INFORMATION / MEDICAL SUMMARY

Date of last revision \_\_\_\_\_

Completed by: \_\_\_\_\_  
NAME/RELATIONSHIP

Signature: \_\_\_\_\_

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

Birthday: \_\_\_\_\_

Address: \_\_\_\_\_

Gender: \_\_\_\_\_

Primary Language/Mean of Communicating: \_\_\_\_\_

Interpreter needed: ☐ YES ☐ NO

Glasses: ☐ YES ☐ NO      Hearing aids: ☐ YES ☐ NO

.....

Parent/Guardian Name/Relationship: \_\_\_\_\_

Address: \_\_\_\_\_ Phone: \_\_\_\_\_

Primary Language: \_\_\_\_\_

Interpreter needed: ☐ YES ☐ NO

Primary Care Physician Name: \_\_\_\_\_

Emergency Phone: \_\_\_\_\_ Fax: \_\_\_\_\_

Specialty Physician name/specialty: \_\_\_\_\_

Emergency Phone: \_\_\_\_\_ Fax: \_\_\_\_\_

Specialty Physician name/specialty: \_\_\_\_\_

Emergency Phone: \_\_\_\_\_ Fax: \_\_\_\_\_

Anticipated ED: \_\_\_\_\_

Address and Zip Code (for GPS): \_\_\_\_\_

Phone: \_\_\_\_\_

Pharmacy: \_\_\_\_\_

Phone: \_\_\_\_\_

# EMERGENCY INFORMATION / MEDICAL SUMMARY

(CONTINUED)

Diagnosis	Past Procedures	Physical Exam Findings
COMMENTS:		

Baseline physical findings: \_\_\_\_\_

\_\_\_\_\_

Baseline vital signs: \_\_\_\_\_

\_\_\_\_\_

Baseline neurological status: \_\_\_\_\_

\_\_\_\_\_

Medication	Dose	Prescribed by

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

\_\_\_\_\_

Prostheses / Appliances / Advanced Technology Devices: \_\_\_\_\_

\_\_\_\_\_

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

\_\_\_\_\_

Procedures to Avoid	Why	Per

Immunizations: \_\_\_\_\_ Date of last tetanus shot: \_\_\_\_\_

Common presenting problems: \_\_\_\_\_

Suggested diagnostic studies: \_\_\_\_\_

Treatment considerations: \_\_\_\_\_

Other: \_\_\_\_\_

☐ Full code    -or-    ☐ Allow Natural Death



# LONGER RESPITE CARE VISITS

## THINGS TO CONSIDER FOR LONGER RESPITE CARE

THERE IS NO AVERAGE LENGTH OF A RESPITE CARE VISIT. EVERY FAMILY AND EVERY SITUATION IS DIFFERENT. WE'VE TRIED TO ADDRESS THE INFORMATION A RESPITE CARE GIVER WILL NEED IN MOST SITUATIONS. HOWEVER, IF THE RESPITE CARE WILL LAST LONGER THAN A DAY OR TWO, YOU MIGHT CONSIDER ADDING SOME OR ALL OF THE FOLLOWING INFORMATION:

### TRANSPORTATION

You will be driving \_\_\_\_\_ in: ☐ your vehicle ☐ our vehicle.

NAME

Insurance information, consent forms, keys can be found: \_\_\_\_\_

School transportation company: \_\_\_\_\_

Contact person: \_\_\_\_\_ Phone: \_\_\_\_\_

Website: \_\_\_\_\_

Tips for successful scheduling: \_\_\_\_\_

Days using school transport: ☐ Monday ☐ Tuesday ☐ Wednesday ☐ Thursday ☐ Friday

Medical appointment transport company: \_\_\_\_\_

Contact person: \_\_\_\_\_ Phone: \_\_\_\_\_

Website: \_\_\_\_\_

Tips for successful scheduling: \_\_\_\_\_

Days using school transport: ☐ Monday ☐ Tuesday ☐ Wednesday ☐ Thursday ☐ Friday

### SCHOOL

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

Address: \_\_\_\_\_

Phone: \_\_\_\_\_ Fax: \_\_\_\_\_

Email: \_\_\_\_\_ Website: \_\_\_\_\_

Principal: \_\_\_\_\_ Teacher(s) \_\_\_\_\_

### BEFORE OR AFTER-SCHOOL PROGRAMS

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

Address: \_\_\_\_\_



# LONGER RESPITE CARE VISITS

(CONTINUED)

Phone: \_\_\_\_\_ Fax: \_\_\_\_\_

Email: \_\_\_\_\_ Website: \_\_\_\_\_

Director: \_\_\_\_\_

Days attending:

☐ Monday   ☐ Tuesday   ☐ Wednesday   ☐ Thursday   ☐ Friday

**ADDITIONAL INFORMATION ABOUT OUR HOME**

**Where can I find?**

Thermostat: \_\_\_\_\_

Water shut-off: \_\_\_\_\_

Gas shut-off: \_\_\_\_\_

Circuit-breaker/Fuse box: \_\_\_\_\_

Flashlights: \_\_\_\_\_

Extra batteries: \_\_\_\_\_

Vacuum cleaner: \_\_\_\_\_

Mop/broom: \_\_\_\_\_

Other cleaning supplies: \_\_\_\_\_

In case of power outage, call: \_\_\_\_\_

Loss of power an emergency? ☐ YES ☐ NO

Back-up generator? ☐ YES ☐ NO

Location/instructions: \_\_\_\_\_

Security system? ☐ YES ☐ NO

Code: \_\_\_\_\_

Other instructions: \_\_\_\_\_

Fire arms in the house? ☐ YES ☐ NO

Other hazardous materials? ☐ YES ☐ NO

Instructions: \_\_\_\_\_

Name and phone number of neighbor: \_\_\_\_\_

Address: \_\_\_\_\_

32 | RESPITE CARE







[www.childneurologyfoundation.org](http://www.childneurologyfoundation.org)