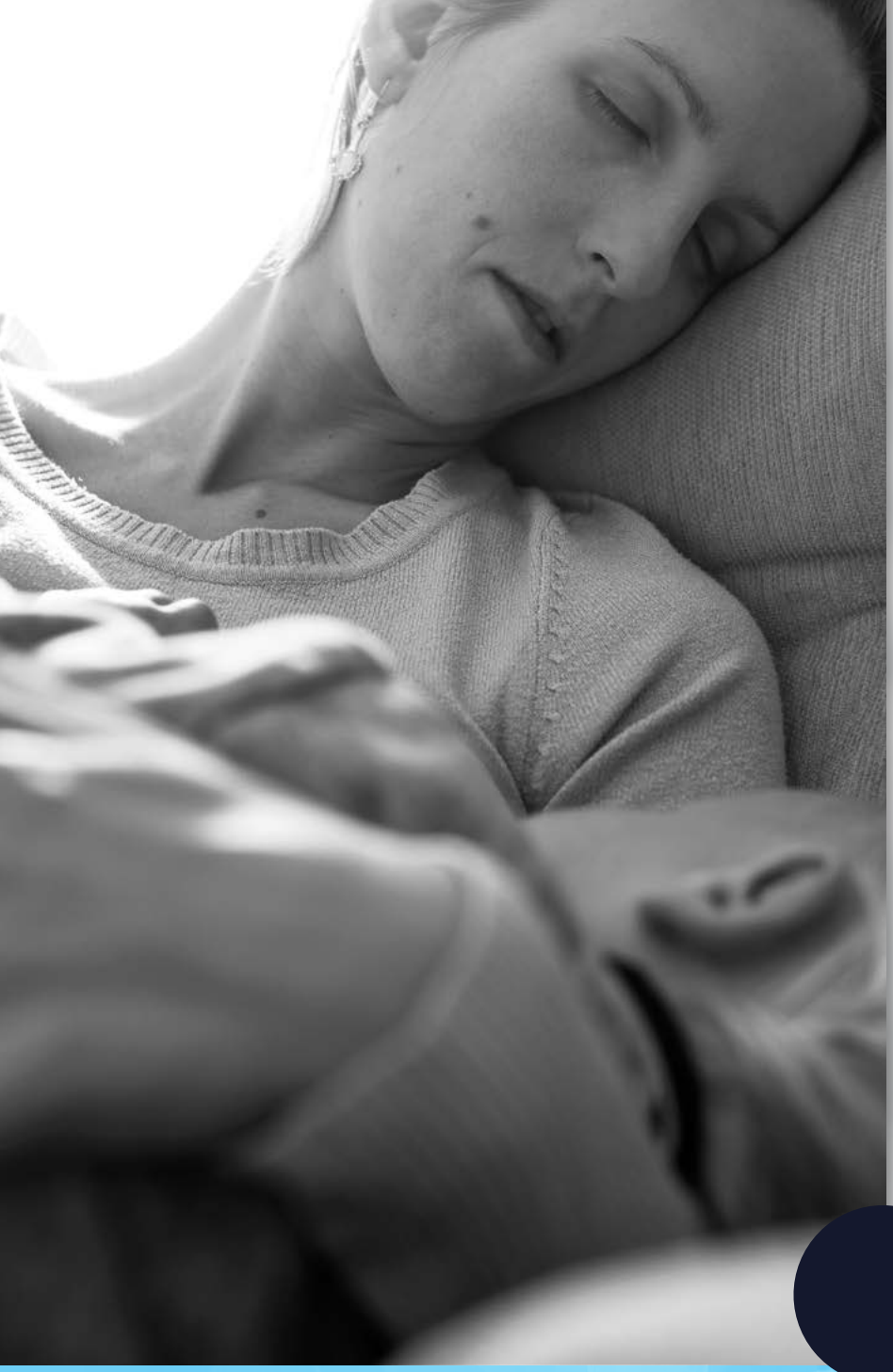


Child Neurology FOUNDATION
Creating a Community of Support

A RESPITE CARE NOTEBOOK

WITH CHARITABLE SUPPORT FROM

gsk GlaxoSmithKline

ACD ASSOCIATION FOR CREATINE DEFICIENCIES

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.

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.

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

–Les Brown

Sincerely,
The Child Neurology Foundation

* This respite care notebook is also available for download at: www.childneurologyfoundation.org/programs/respite-care

ACKNOWLEDGEMENTS

MANY ORGANIZATIONS AND INDIVIDUALS CONTRIBUTED TO CNF'S RESPITE CARE NOTEBOOK.

A number of individuals from CNF Partners network shared their experiences with and perspectives on respite care in their responses to a brief survey. These individuals helped to assure the notebook reflected the immediate insights of families who have used respite care. Our thanks to:

R Ablondi
Rainbow Adams
Dulce Carillo
Beth DeHoff
Melissa Gerads
Natalie Gilmore
Karen Groff
Luisella Magnani
Brandi Mitchel
Debora Moritz
Katie Shipley
Elizabeth Terry
Erica Walker
…and respondents who wished to remain anonymous.

Others reviewed the notebook in draft form, confirming our approach and helping us to finalize and polish the document. The notebook is better than it otherwise would have been, thanks to the keen eyes and ideas of:

Rubontay Buckner
Parent to Parent of Southwest Michigan

Jane Burns
Spotlight Children's Services

Afton Coombs

Linda Cooper
Association for Creatine Deficiencies

Margie Frazier
Batten Disease Support and Research Association

Dena Hook
Tuberous Sclerosis Alliance

Luisella Magnani

Kim Mooney
Ultragenyx

Noreen Murphy
Batten Disease Support and Research Association

Kari Luther Rosbeck
Tuberous Sclerosis Alliance

Whitnie Strauss
Association for Creatine Deficiencies

Sandra Cushner Weinstein
CNF Board of Directors

Sue Yudovin
CNF Board of Directors

We also thank Melissa Capers, our writer and editor.

thank you!

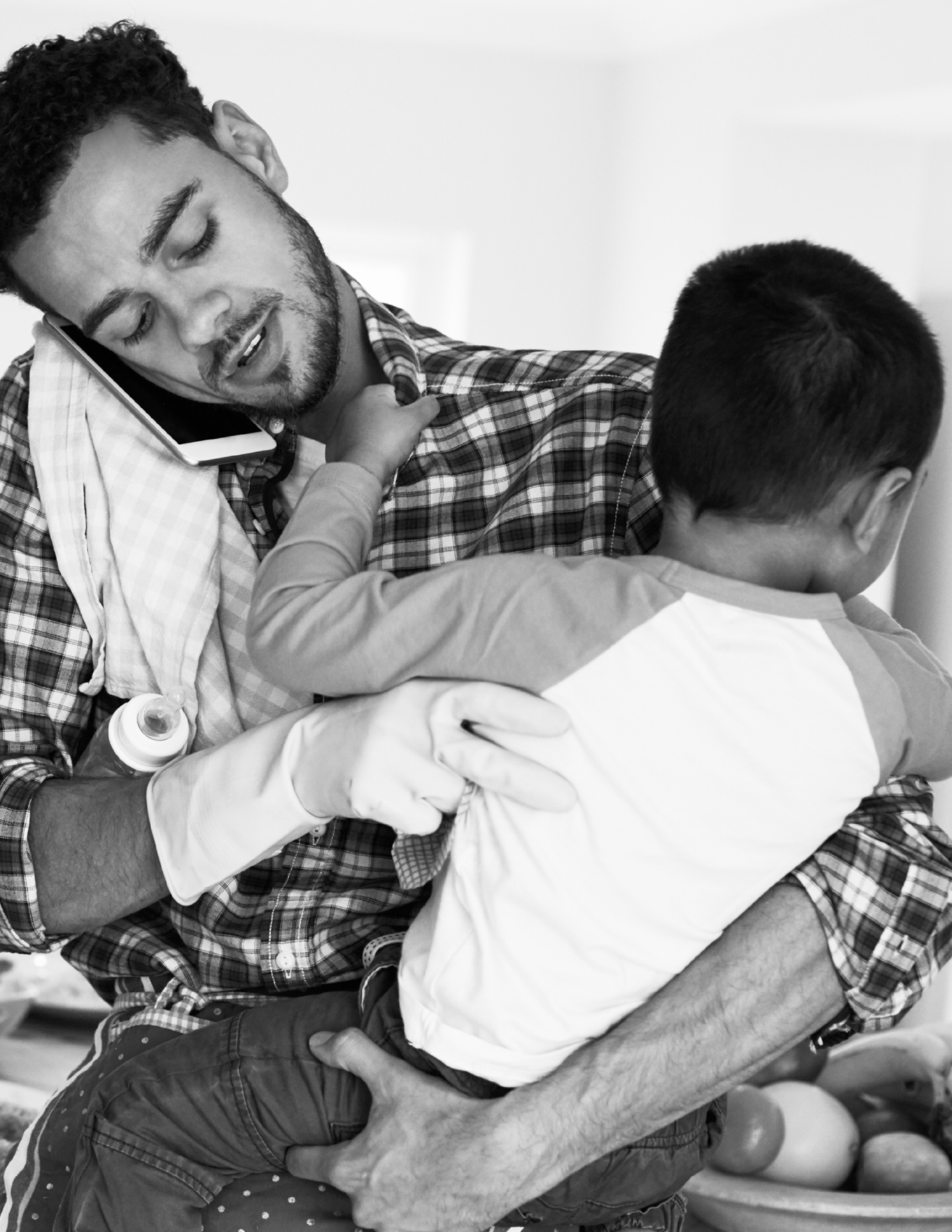
CNF appreciates the generous support of GlaxoSmithKline in development and production of this notebook

Additional support for notebook production was provided by CNF's advocacy partner, Association for Creatine Disorders

SOURCES

THE FOLLOWING SOURCES PROVIDED HELPFUL FRAMING AND MODELS:

- Agrawal, Susan. Creating a Care Notebook for Your Child. Complex Child E-Magazine. (2008). http://www.articles.complexchild.com/00018.pdf. Accessed May 24, 2017.
- Alameda Medical Home Project for Children with Special Health Care Needs, California. My Child's Profile. https://medicalhomeinfo.aap.org/tools-resources/Pages/For-Families.aspx. Accessed May 24, 2017.
- American Academy of Pediatrics National Center for Medical Home Implementation. For Families and Caregivers: Building Your Care Notebook. https://medicalhomeinfo.aap.org/tools-resources/Pages/For-Families.aspx. Accessed May 24, 2017.
- Cincinnati Children's. All About Me. https://www.cincinnatichildrens.org/patients/child/special-needs/about/forms. Accessed May 24, 2017.
- Family Connection of South Carolina, Inc. Special Connection: Introducing the ___ Family, families Given Families a Break. http://www.familyvoicesal.org/file-downloads/Respite_Book_1002.pdf. Accessed May 24, 2017.
- McAllister, Jeanne W. Achieving a Shared Plan of Care with Children and Youth with Special Health Care Needs: An Implementation Guide. Lucile Packard Foundation for Children's Health. http://www.lpfch.org/publication/achieving-shared-plan-care-children-and-youth-special-health-care-needs. Accessed May 24, 2017.
- Pediatric Palliative Care Coalition. Care Plan Book. http://www.ppcc-pa.org/care-plan-book/. Accessed May 24, 2017.
- Perkins, E.A. (2011). My Health Passport for Hospital/Clinic Visits. Florida Center for Inclusive Communities, http://flfcic.fmhi.usf.edu/docs/FCIC_Health_Passport_Form_Typeable_English.pdf. Accessed May 24, 2017.
- Swindells Resource Center of Providence Child Center. Swindells Resource Center Care notebook and organizer. http://oregon.providence.org/~/media/Files/Providence%20OR%20Migrated%20PDFs/Patients%20Toolkit/formsinstructions/swindells%20care%20notebook%20and%20organizer%20english.pdf. Accessed May 24, 2017.



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 _____ (NAME) from _____ (DATE/TIME) to _____ (DATE/TIME).

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

I would describe _____ (NAME'S) personality as: _____

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

* See page 10 for information about strategies for helping _____ (NAME) with difficult feelings.

SO FAR, TODAY:

MEALS THUS FAR/SUGGESTIONS FOR MEALS

* See pages 18–20 for complete information on helping _____ (NAME) with eating/drinking.

THIS VISIT (CONTINUED)

TOILETING THUS FAR / NOTES REGARDING TOILETING

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

MEDICATION THUS FAR / NOTES FOR THIS VISIT

* 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.

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

INSURANCE INFORMATION, CONSENT FORMS, KEYS CAN BE FOUND:

THESE THINGS MIGHT ALSO BE FUN (SUGGESTED ACTIVITIES)

* 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

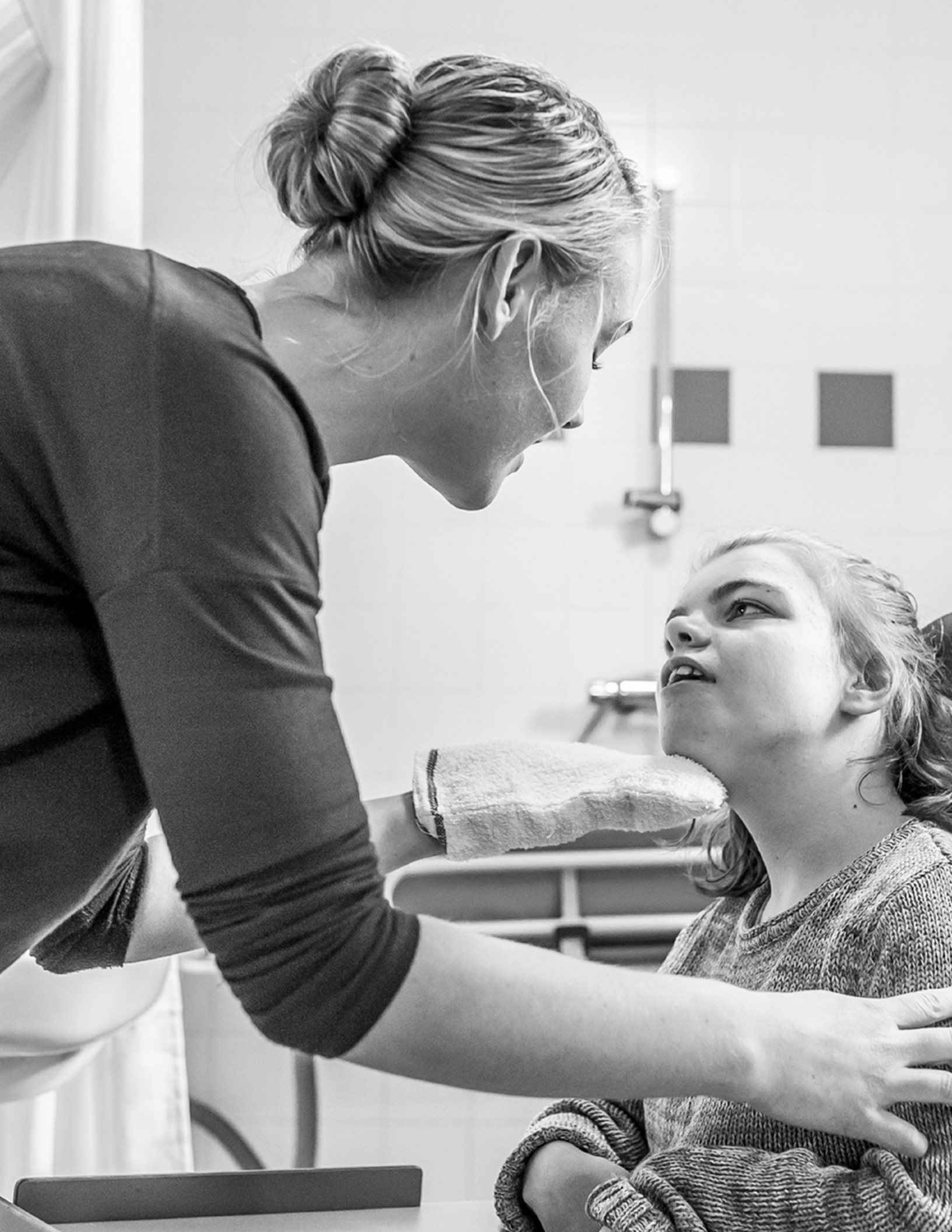
We may be difficult to reach _____
(TIME/LOCATION)

IF YOU CANNOT REACH US, PLEASE CONTACT:

NAME RELATIONSHIP PHONE

- ☐ 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)

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

NEARBY FAMILY

NAME	RELATIONSHIP	CONTACT INFORMATION

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

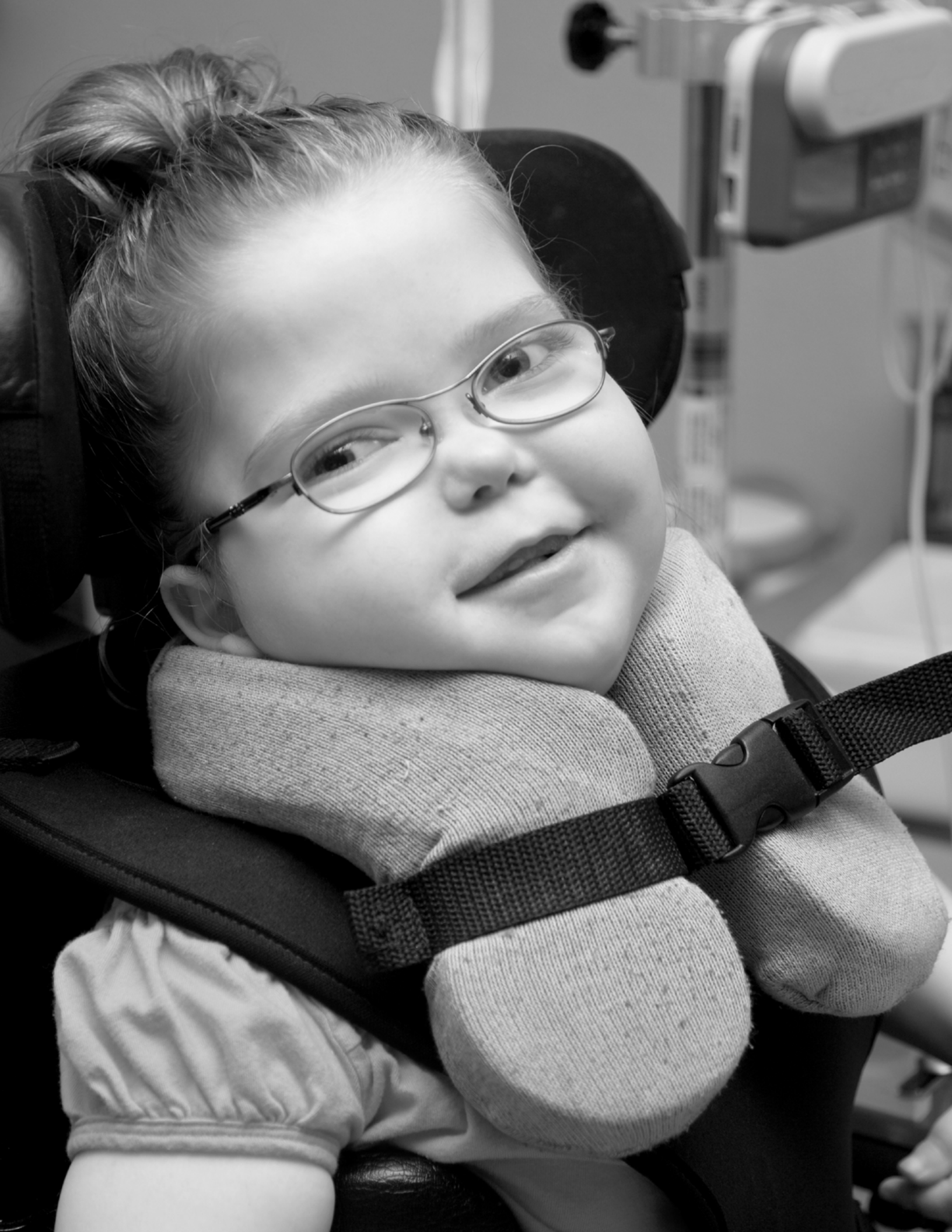
Activity / Item	Strategies for avoiding / soothing

_____ 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

_____ was diagnosed with:

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)

_____ takes the following medications:

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 _____ with _____

NAME (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):

HERE'S HOW TO HELP:

SERIOUS SITUATIONS

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

HERE'S HOW TO HELP:

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

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

THE FOLLOWING CONSTITUTE EMERGENCIES!

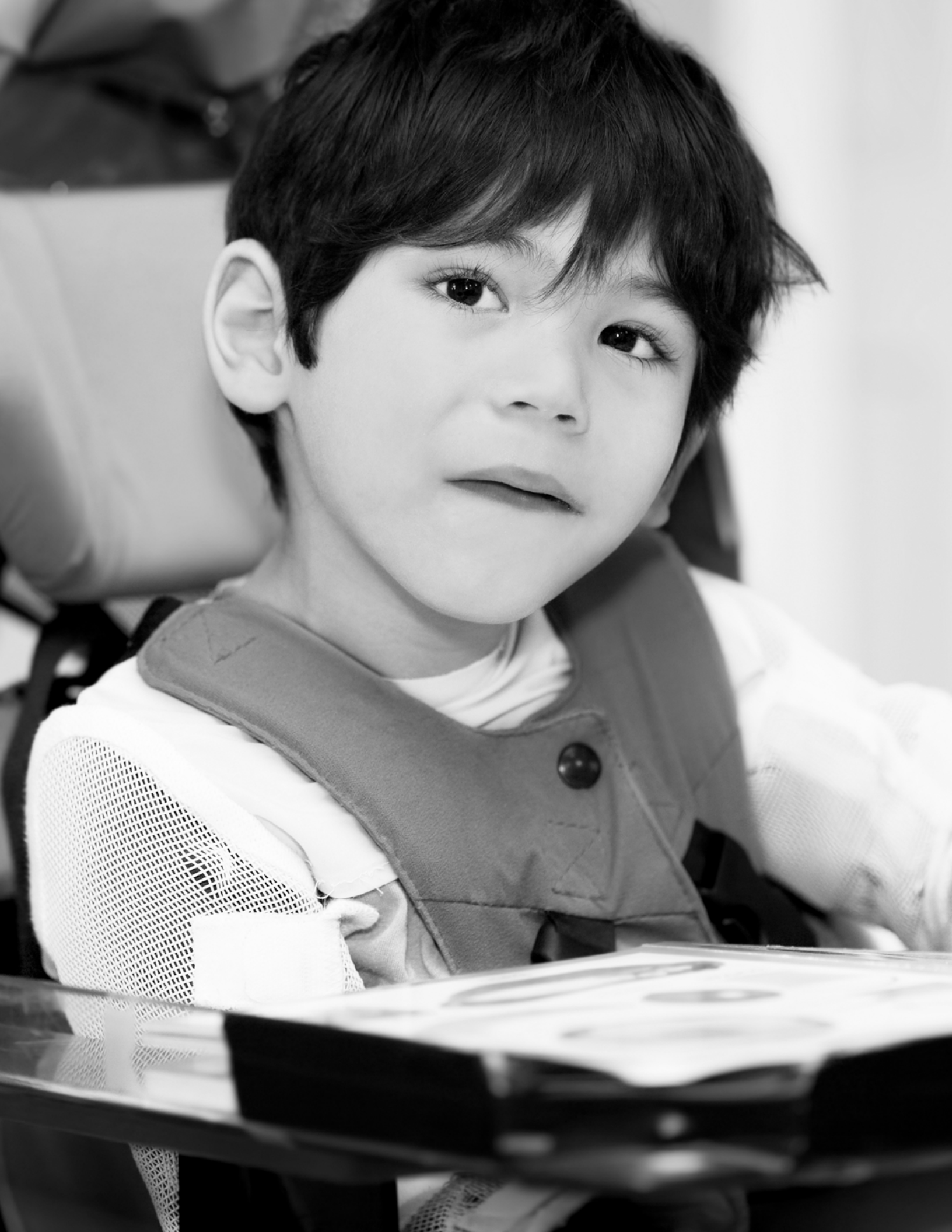
TAKE THESE STEPS:

AND CALL 9-1-1!

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

	Contact Name & Title (e.g., the primary care doctor, the specialist, etc)	**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 _____ NAME COMMUNICATES

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

MOBILITY/HOW _____ NAME MOVES AROUND

Can do these things without assistance	Needs help with
☐ sit up ☐ crawl ☐ stand	☐ sit up ☐ crawl ☐ stand
☐ walk ☐ walk with assistance	☐ walk ☐ walk with assistance
☐ climb stairs ☐ run	☐ climb stairs ☐ 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:

Describe transfer routines and strategies:

Other comments about mobility:

EATING / DRINKING

Is _____ likely to eat non-food items? ☐ YES ☐ NO
NAME

Prevention / interventions:

Any special positioning:

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 _____

NAME

(CONTINUED)

☐ **CLAPPING (CPT)**

Frequency: _____

OTHER COMMENTS / INSTRUCTIONS:

_____

_____

_____

_____

_____

_____

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

EMOTIONAL REGULATION / BEHAVIOR

How _____ (NAME) shows affection: _____ (E.G., HUGGING, SMILING, PETTING)

How _____ (NAME) shows fear: _____ (E.G., HIDING, ROCKING, SILENCE, CRYING)

How _____ (NAME) plays with other children: _____ (E.G., EASILY? SHY? AGGRESSIVE?)

_____ (NAME'S) favorite activity with others:

What encourages _____ (NAME) to cooperate:

What helps _____ (NAME) change from one task to another:

GETTING TO KNOW _____ NAME

(CONTINUED)

How _____ NAME responds to too much or not enough stimulation:

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)

POSITIONING/TURNING:

STRATEGIES FOR WAKEFULNESS:

EMERGENCY INFORMATION / MEDICAL SUMMARY

Date of last revision _____

Completed by: _____
NAME / RELATIONSHIP

Signature: _____

Name: _____ Birthday: _____

Address: _____ Gender: _____

Primary Language / Means 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: _____

_____

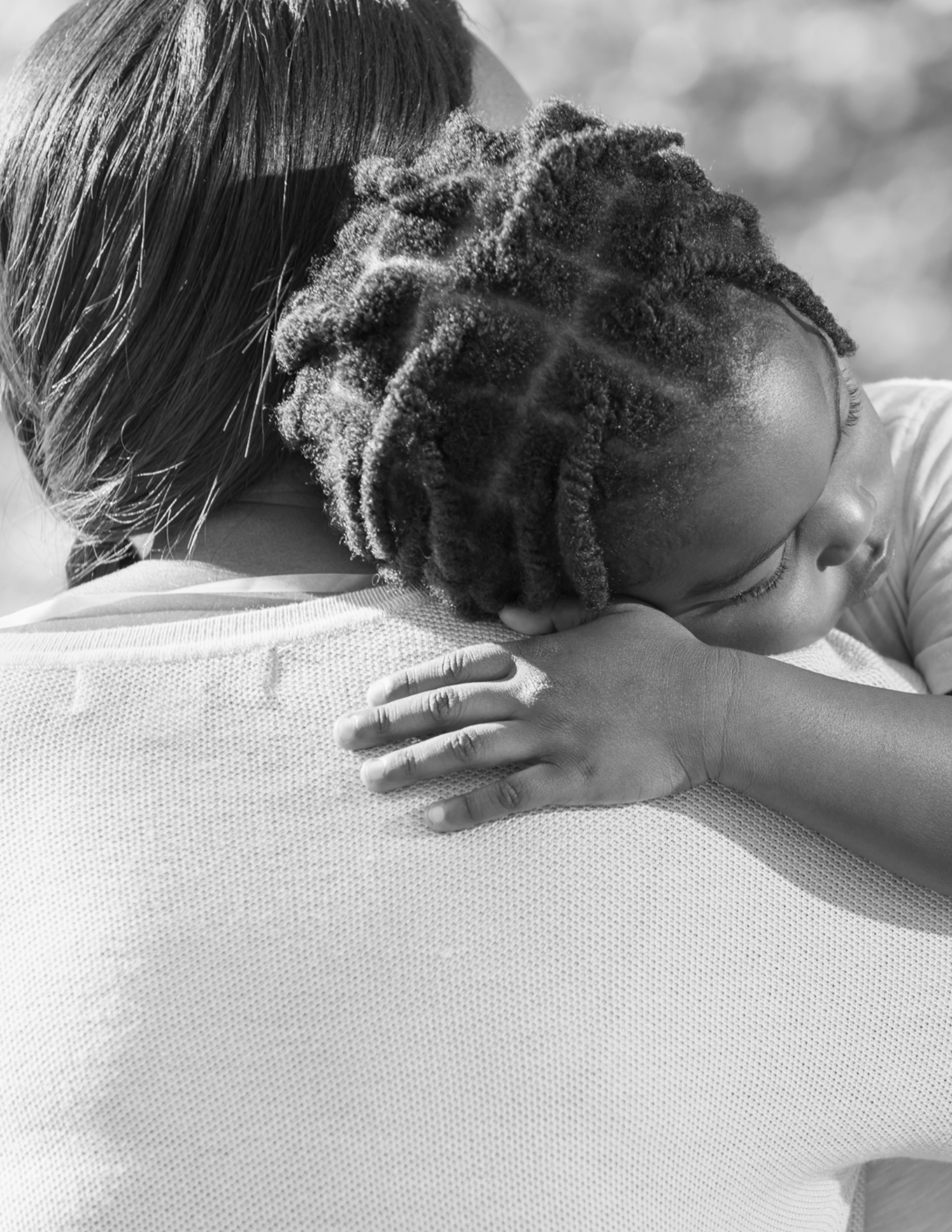
Other: _____

_____

_____

_____

☐ 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 _____ (NAME) in: ☐ your vehicle ☐ our vehicle.

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

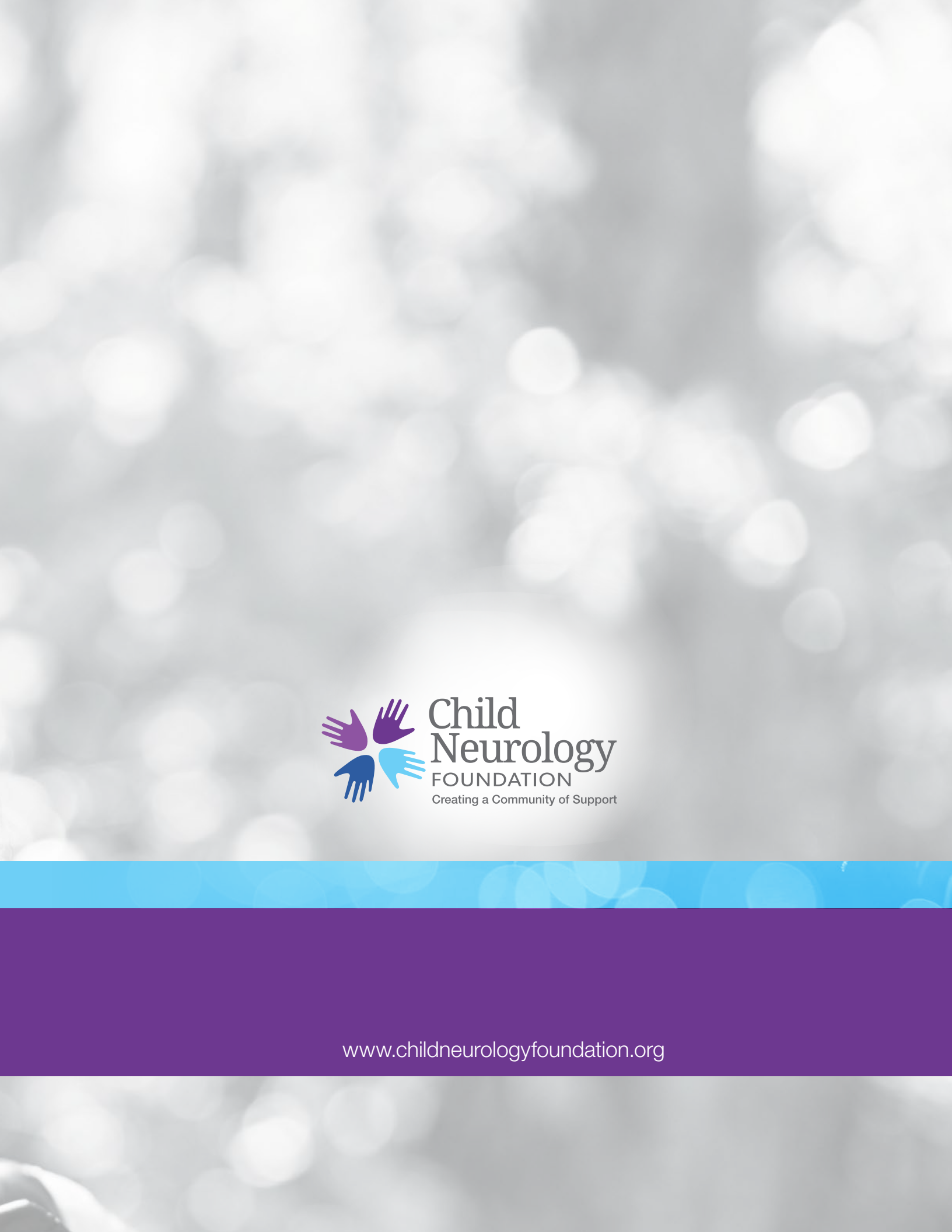
Other hazardous materials? ☐ YES ☐ NO

Instructions: _____

Name and phone number of neighbor: _____

Address: _____

NOTES



www.childneurologyfoundation.org