

Instructions for Care Providers



Publication of Batten Disease Support and Research Association

INSTRUCTION BOOK FOR CARE PROVIDERS

PARENTS: This workbook is for you to enter all instructions and information that any care provider who cares for your child/ren needs to know, understand and follow. Whether it is respite, home health care or whoever, this is the place to list everything they need to know about your child/ren's routine and care needs. Anything not listed in this book can be added by you. This does not by any means replace instructions that you as parents teach and/or give to care providers. Always take time to thoroughly instruct care providers and then **make certain they understand what is required/expected of them.** The more you tell, show and instruct a care provider regarding your child/ren's needs the more confident they will be and the more at ease you will feel.

RESPIRE CARE PROVIDERS: The parent/s will tell you about Batten Disease and their child/ren. This is meant to be a reference guide for regarding the child/ren's routine, schedule, special needs, etc. With the training you already have you will know how to interpret when a child is asking for something, when to turn the video or music on, or what to do in an emergency, etc. Caring for children with Batten Disease daily becomes quite stressful, especially if there are special feeding, medical, or behavioral needs. Without qualified care providers, these parents would not be able to take the much deserved breaks that they need. The breaks are so necessary to enable them to continue their care for their child/ren. You are providing a much-needed service! Thank you!

Batten Disease Support and Research Association
120 Humphries Dr., Suite 2
Reynoldsburg, OH 43068
www.bdsra.org
Lance Johnston, Executive Director
1-800-448-4570
bdsra1@bdsra.org
Nancy Carney, RN, Medical Liaison/Educator
1-877-642-5512
nancycarney@bdsra.org

THE _____ FAMILY

FAMILY PHOTO HERE

Who is in picture? _____

HOME ADDRESS

Telephone: _____

CHILD PHOTO HERE

Child's Name: _____

Date of Birth: _____

Diagnosis: _____

EMERGENCY NUMBERS

EMS/FIRE/POLICE 911 _____

POISON CONTROL CENTER _____

PARENT'S PAGER/S _____

PARENT'S CELL PHONE/S _____

EMERGENCY CONTACTS IF YOU CANNOT BE REACHED

1. _____

Telephone _____ Cell _____

2. _____

Telephone _____ Cell _____

PHYSICIAN _____

Telephone _____ Answering service _____

PHYSICIAN _____

Telephone _____ Answering service: _____

PHARMACY _____

Telephone _____

INSURANCE COMPANY _____

Telephone _____

EMPLOYER _____

Telephone _____

PREFERRED HOSPITAL _____

Telephone _____

RESPIRATORY THERAPIST: _____

Cell: _____ Telephone: _____

HOME HEALTH NURSE: _____

Cell: _____ Telephone: _____

EMERGENCY INFORMATION

Is there a signed letter authorizing treatment in case of emergency? _____

Is it included with this information book? _____

If not, where is it? _____

Is a copy on file with the hospital and/or physician? _____

If yes, which hospital and/or physician? _____

Is there a DNR (do not resuscitate) letter in place? _____

Is it included with this information book? _____

If not, where is it? _____

Is a copy of the DNR on file with the hospital and/or physician? _____

If yes, which hospital and/or physician? _____

Other emergency information/instructions: _____

HOUSEHOLD PROCEDURES

Where is the first aid kit located? _____

Where is a flashlight or emergency lighting? _____

Where are medications kept? _____

Who, if anyone is allowed to visit your child when you are not home? _____

Is your child allowed to play outside? _____

If so, what are the boundaries? _____

For how long? _____

HOUSEHOLD RULES THAT THE CARE PROVIDER SHOULD OBSERVE WHEN YOU ARE NOT AT HOME (PHONE USAGE, VISITORS, SNACKS, ETC.) _____

MEDICATIONS
PLEASE UPDATE AS DOSAGES AND MEDICATIONS CHANGE

Medication allergies _____

Date updated: _____

1. Medication: _____

Dosage: _____

Time/s given: _____

How given: (oral/Gtube/etc.) _____

Prescribing physician: _____

Possible severe side effects: _____

2. Medication: _____

Dosage: _____

Time/s given: _____

How given: (oral/Gtube/etc.): _____

Prescribing physician: _____

Possible severe side effects: _____

3. Medication: _____

Dosage: _____

Time/s given: _____

How given (oral/Gtube/etc.): _____

Prescribing physician: _____

Possible severe side effects: _____

4. Medication: _____

Dosage: _____

Time/s given: _____

How given: (oral/Gtube/etc.): _____

Prescribing physician: _____

Possible severe side effects: _____

5. Medication: _____

Dosage: _____

Time/s given: _____

How given (oral/Gtube/etc.): _____

Prescribing physician: _____

Possible severe side effects: _____

Is information about these drugs included with these instructions, i.e. pharmacy printouts, etc.?

_____ If yes, where is it? _____

Is anyone else authorized to give medications?

If yes, who, when and under what circumstances? _____



6. Vitamins/supplements: _____

Dosage: _____

Time/s given: _____

Additional instructions/information: _____

RESPIRATORY

Does your child have apnea or other respiratory/breathing difficulties? _____

Explain: _____

Does your child need suctioning? _____

What equipment is used and where is it? _____

Specific instructions regarding suctioning: _____

Does your child receive breathing treatments? ____ If yes, when: _____

What equipment, supplies and where is it? _____

Specific instructions regarding breathing treatments: _____

In the event your child stops breathing, your instructions are: _____

SEIZURES

Does your child have seizures? _____

If so, describe in detail: _____

How long do the seizures generally last? _____

What are your instructions in the event the child has a seizure? _____

Under what circumstances do you want the paramedics to be called? _____

Seizures must be recorded by care provider! Where? _____

What usually happens during a seizure? _____

What usually happens after a seizure? (Does your child sleep, etc?) _____

In the event of a second seizure or multiple seizures, your instructions are: _____

Additional information: _____

Does your child use sign language or a communicator? Yes ____ No ____

If yes please explain how this is done. If necessary attach pictures someplace in this book.

How does your child communicate an interest in a particular activity? _____

How does your child communicate the following?

Hungry _____ Thirsty _____

Tired _____ Happy _____

Hot _____ Cold _____

Brother _____ Sister _____

Mom _____ Dad _____

Blanket _____ Bath _____

Toilet _____ Diaper _____

Bed _____

Dog _____

Cat _____

Pain _____

TV _____

Music _____

Hi _____

Bye _____

Car _____

Walk _____

Outside _____

Inside _____

Sad _____

Angry _____

Play with me _____

Leave me alone _____

I want more _____

I'm finished _____

Please _____

Thank you _____

I'm sick _____

Other _____

Is there any additional information that would help the care provider better understand your child's communication? _____

BEHAVIOR

What is the child's normal temperament?

What makes your child happy? _____

Does your child have outbursts, i.e. hitting, anger, belligerence, biting, screaming, yelling, etc.?

If yes, explain: _____

What do you do? _____

DIET

Does your child eat by mouth? _____

IF YES.....

What foods does your child like? _____

What foods disliked? _____

Does your child have any food allergies? (explain) _____

Does your child swallow well? _____

Chew well? _____

Does food need to be prepared a special way? _____

Does your child need assistance eating? _____

If yes, how? _____

Is there a specific position or any adaptive equipment to be used to help your child eat?

Where are your child's food, utensils, and adaptive equipment? _____

Are there any problems with drinking? (if yes, explain) _____

Does your child use adaptive device/s for drinking? _____

If your child is tube fed, is care provider to do feedings? _____

If yes, what is to be done? _____

What do you substitute for formula your child is ill/flu/vomiting? Pedialyte? Gatorade?

Is your child fed bolus or by feeding pump? _____

Where is formula? equipment and supplies? _____

How much formula and when? _____

Any special instructions regarding formula preparation? _____

Do you check for residuals? _____ If yes, when and how? _____

How much water is to be given after feeding and medications? _____

What is to be done in case of a clogged tube or equipment malfunction? _____

If your child has a feeding tube, how often is it changed? _____

What size is the feeding tube? _____

Do have a spare feeding tube? _____

Additional information:

PERSONAL HYGIENE

Does your child use the toilet? _____

Alone? _____

If not, what assistance is needed? _____

Does your child use diapers? _____

Training pants? _____

Potty chair? _____

Can your child brush his/her own teeth? _____

Need assistance? _____

How? _____

Where is his/her toothbrush and paste? _____

If unable to clean own teeth, is there special oral hygiene that needs to be done? _____

Explain: _____

Can your child dress self? _____

What assistance may be necessary? _____

Can your child bathe his/herself? _____

What is bathing schedule? _____

Is there adaptive equipment to be used for bathing? (explain) _____

Additional information: _____

BED AND NAP TIME

When is your child's bedtime? _____

Nap time? _____

Does your child sleep alone? _____

Is your child afraid of the dark? _____

Does a light need to be left on? _____ Which one: _____

Is there special toy, blanket, music or other thing that child likes to sleep with? _____

Are there special positioning requirements when lying down? _____

Does your child need to be turned? If yes, how often? _____

Do you observe any special nap or bedtime routine? _____

Does your child usually sleep through the night? _____

How long does your child normally nap? _____

Additional information: _____

SCHEDULE

Describe your child's expected daily routine, including medications and meals/feedings:

7:00 A.M. _____

8:00 A.M. _____

9:00 A.M. _____

10:00 A.M. _____

11:00 A.M. _____

12:00 P.M. _____

1:00 P.M. _____

2:00 P.M. _____

3:00 P.M. _____

4:00 P.M. _____

5:00 P.M. _____

6:00 P.M. _____

7:00 P.M. _____

8:00 P.M. _____

9:00 P.M. _____

10:00 P.M. _____

11:00 P.M. _____

12:00 A.M. _____

1:00 A.M. _____

2:00 A.M. _____

3:00 A.M. _____

4:00 A.M. _____

5:00 A.M. _____

6:00 A.M. _____

Final Note:

Parents:

You will want care provider/s to keep notes of everything that happens in your absence. Have a notebook or other type paper available for care providers to keep the records. You will want them to include such things as seizures (including time, type, duration, etc.) Times when meals/feedings/ medications, etc. were given. If not on schedule, why not.

You may also want the care providers to keep records of sibling comings and goings, who came to house, who called with return telephone numbers, etc. It is all up to you.