

# My Hospital Planning Packet:

## Prepare for a hospital visit during the COVID-19 pandemic

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A hospital visit is always difficult for children with special care needs and their families, but even harder when it happens under stress. Preparing ahead of time can help support your child's hospital experience.

Here are some key things to prepare and have ready to go in case your child goes to the hospital.

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### Create an "All About Me!"

Create an "All About Me" sheet and a Medical Passport to help hospital nurses, doctors, and care providers better understand your child.



### Communication system

Bring your child's communication system, whether that's a high-tech speech generating device, picture communication boards, hearing aids, glasses, visual supports, or anything else your child needs to communicate.



### Behavior Supports

If your child has special behavior needs, pack a copy of behavioral supports to bring to the hospital. This includes a behavior safety plan, token reinforcement systems, and protective strategies.



### Go-Bag

Create a "Go Bag" of items that will help your child be successful in the hospital environment. Pack things like familiar items, sensory toys, chew tubes, weighted blankets, communication tools, and pictures of family members.



### Talk about the Hospital Experience

Prepare for things to expect when you're in the hospital. Read hospital social stories, think about support staff that may be available (child life, speech, occupational therapy, behavior support), and explain that structure and routines may look different.

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For even more resources to help prepare, this packet contains fillable materials, check-lists, and other ideas.



# My Hospital Passport: How to Use

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## Introduction

Inside this passport, you'll find information that is helpful for your doctors, therapists, nurses, and specialists to know about your needs at the doctor or hospital. It was designed to bring to medical appointments and hospital stays, but can be used in any way that makes sense to you!

*My Hospital Passport* is meant to get you thinking about what might be helpful for you in the hospital, but is not an all-inclusive list. Every person is different, and will have different things to add and take away from this packet.

## Personalization

This passport is completely customizable. Fill it out based on what makes sense for your specific needs. Feel free to leave pages out or add in extra information based on what you see fit.

## Use

You can edit this document on your computer or print it out and write on it by hand. On the computer, click on the grey boxes to type inside.

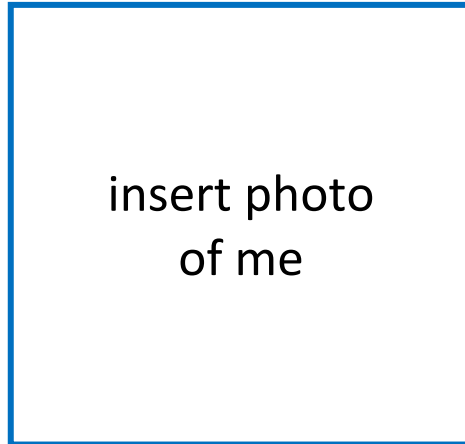
Use this passport in any way you'd like. The "All About Me" page is designed to provide your child's care team a brief overview of how they can best provide support. Other pages can provide the care team with more detailed information. Fill it out ahead of time or ask your team to help.

## More Information

For help preparing for a hospitalization or upcoming appointment, call your hospital's Child Life or Social Work department.



# My Hospital Passport



**My name is:** \_\_\_\_\_

**My Birthday is:** \_\_\_\_\_

Sometimes when I don't feel well, I will need to go to the doctor or hospital. This book needs to go with me. It tells my doctors and nurses important information.

Please ***put this book where my doctors and nurses can see!***

Inside this book, you will find information that will help me participate in my medical care.

**Completed with help by:** \_\_\_\_\_ **Date:** \_\_\_\_\_



**Boston Children's Hospital**

# All About Me

**Name/  
Nickname:**

**How I Identify:**

(e.g. gender pronouns, diagnosis self-identification, etc.)

**A few of my favorite things and interests:**

**Topics that  
interest me:**

**What I like to  
watch:**

(e.g., preferred TV show or character):

**Some of my  
favorite things:**

(e.g., books, characters, movies, games, toys):

**Important things to know about me:**

**The way I best  
communicate  
and  
understand:**

**Things that are  
hard for me:**

**Things that help  
me when I'm  
scared or upset:**

Give this information to your child's care team!



**Boston Children's Hospital**

Name:

# Important Information

|   |                            |
|---|----------------------------|
| <b>Parent / Guardian:</b>                     | (name(s) and contact info) |
| <b>Emergency Contact:<br/>(Relationship):</b> | (name(s) and contact info) |
| <b>Languages spoken:</b>                      | Primary Language:          |
| <b>Vision and hearing status:</b>             |                            |
| <b>Allergies:</b>                             |                            |
| <b>Blood Type:</b>                            |                            |

## Medications

| Name | Dosage | Frequency |
|------|--------|-----------|
|      |        |           |
|      |        |           |
|      |        |           |
|      |        |           |
|      |        |           |
|      |        |           |



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# Communication

These are the ways that I communicate and how I understand language  
(check all that apply):

## EXPRESSIVE:

- Age appropriate speech and language
- Speak in shorter phrases
- Minimal speech/single words
- Use sign language
- Use picture-based system
- Use an electronic communication device
- Nonverbal behavior
- No functional speech
- Other: \_\_\_\_\_

## RECEPTIVE:

- Age appropriate understanding
- Understands 2-step directions
- Understands 1-step directions
- Understands short phrases
- Understands single words
- Understands visuals
- Understands sign language
- Limited understanding
- Other: \_\_\_\_\_

## Communication Details:

(Fill in any additional information or details that my care team should know)



Name:

# Medical Tolerance

Some medical tasks may be hard for me. I need support with these things  
(check the appropriate box):

Note: Your child's medical team can help complete this page if unable to complete ahead of time

|                                 | Independent    | Do not tolerate | Tolerate with support | Comments: |
|---------------------------------|----------------|-----------------|-----------------------|-----------|
| Temperature                     |                |                 |                       |           |
| Heart Rate Monitor              |                |                 |                       |           |
| Pulse Oximetry                  |                |                 |                       |           |
| Blood Pressure                  |                |                 |                       |           |
| Blood Draw                      |                |                 |                       |           |
| IV Placement                    |                |                 |                       |           |
| Medication                      | Swallow Pills? | Crushed?        | Liquid?               |           |
| ID Band                         |                |                 |                       |           |
| Hospital Gown                   |                |                 |                       |           |
| Lines / Tubes / Medical Devices |                |                 |                       |           |



# Behavior Supports

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

**When I am having a hard time with things that feel difficult, I may display these behaviors (check all that apply):**

## AGITATION:

These behaviors could mean that I am feeling upset/frustrated, or that I am in pain:

- Speech (vocalizations, yelling)
- Shutting down (quiet, despondent)
- Pacing
- Self-Stimming (rocking, flapping)
- Pushing people away
- Repetitive speech/perseverations
- Other: \_\_\_\_\_

## ESCALATION:

These behaviors could mean I am escalated and could be unsafe to myself or others:

- Aggression to self (hitting, head banging)
- Aggression to others (kicking, hitting)
- Biting
- Bolting/running away
- Crying or yelling
- Pulling at or removal of lines, tubes, or medical devices
- Property destruction
- Repetitive motor behaviors (stim)
- Tantrum
- Other: \_\_\_\_\_

## These things may be difficult for me while in the hospital:

- |  |   |
|--|---|
| <input type="checkbox"/> Being touched                 | <input type="checkbox"/> Hospital Environment                     |
| <input type="checkbox"/> Bright Lights                 | <input type="checkbox"/> Needle procedures                        |
| <input type="checkbox"/> Feeling pressured or stressed | <input type="checkbox"/> Lack of information regarding my care    |
| <input type="checkbox"/> Lack of control               | <input type="checkbox"/> Sounds (yelling or unpredictable noises) |
| <input type="checkbox"/> Presence of medical staff     | <input type="checkbox"/> Waiting                                  |

## Additional Information:

(Fill in any additional information that my care team should know):





# Behavior & Reinforcement Plan

Name:

If your child has a behavior plan or reinforcement schedule at home or at school, please attach or describe the plan here. This will help medical staff understand how they can best support your child.



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

# Accommodations

**What are some strategies or items that may make me more comfortable while I am in the hospital? (check all that apply)**

## Medical Accommodations:

These are strategies that might be helpful in preventing distress:

- Avoid rushing when possible
- Access to communication tools and strategies
- Access to my favorite things
- Do not have medical conversations in front of me
- Incentives / reinforcements
- Limit the amount of times you take my vitals
- Talk about what is going to happen before it happens
- Use visuals and social stories to help me understand
- Other: \_\_\_\_\_

## Environmental Accommodations

These environmental considerations can help keep me calm:

- Minimize the number of people in the room
- Plan for additional people to help manage my agitation
- Keep important items within reach
- Ask before moving items around my room
- Allow me to wear my clothes from home
- Other: \_\_\_\_\_

## Additional Information:

(Fill in any additional information that my care team should know):



Name:

# Coping Needs

When I'm feeling overwhelmed or unsure, these are things that can help me cope.

## Coping

These are strategies and items that might help me cope with the medical environment and unfamiliar routines (check all that apply)

- Distraction
- Movies, TV, or hand-held games
- Music
- Sensory items and toys
- Weighted materials (blanket, lap pad)
- iPad or Tablet
- Books
- Noise reducing headphones
- Other: \_\_\_\_\_

## Additional Information:

(Provide additional coping needs and strategies)



Name:

# Important Contacts

**Parent / Guardian:**

(name(s) and contact info)

**Emergency Contact:**

Name:

Relationship:

Phone Number:

**My school or place of work:**

Name:

Phone Number:

**BCBA:**

Best Contact Number:

E-mail Address:

**Teacher(s):**

Best Contact Number:

E-mail Address:

**Therapist(s):**

Best Contact Number:

E-mail Address:

**Other:**



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Name:

# Additional Information

**This is what I understand about my medical diagnosis:**

**How I eat and drink:**

**Sensory Needs:**

**How to know when I'm in pain:**

**How to know when I'm happy:**

**How to know when I'm angry:**

**I calm down by:**

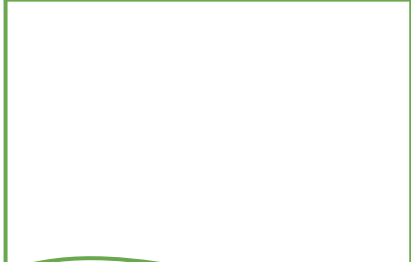
**Other:**

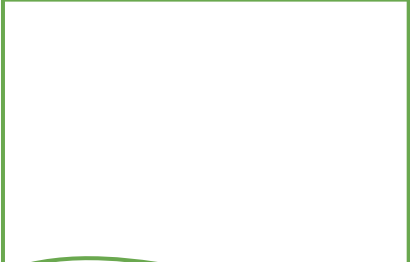


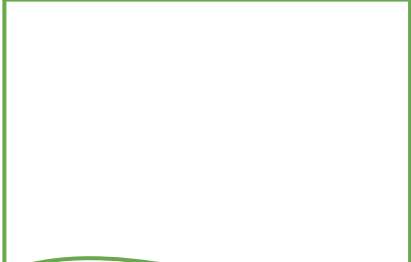
Name:

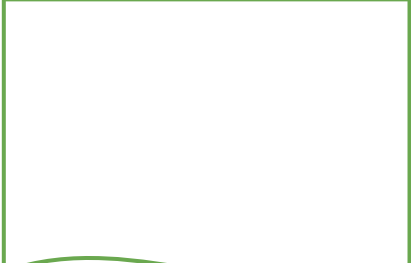
# My Important People

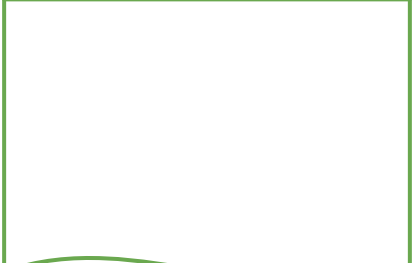
Insert pictures and name of people that are important to your child. This can be helpful for your child to reference if you are unable to be at the bedside. (Staff can reference it with your child as well)

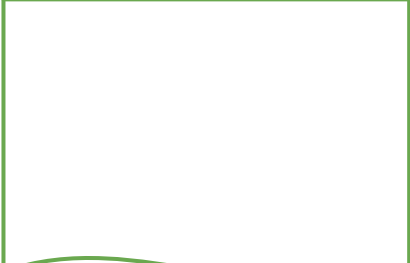
|   |
|---|
| Relationship  |
|  |
| Name  |

|  |
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| Relationship   |
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| Name   |

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| Relationship  |
|  |
| Name  |

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| Relationship  |
|  |
| Name  |

|  |
|--|
| Relationship   |
|  |
| Name   |

|   |
|---|
| Relationship  |
|  |
| Name  |

# The Hospital Experience

It is important to think about the medical environment and possible new sensory experiences your child could face.

Preparing ahead can help to support your child during their visit.

## Structure and Routine

The medical environment can be very unpredictable, making it hard to follow your child's typical routine. Try to normalize the environment when possible:

- **Bring comfort items and sensory items (stuffed animals, blanket, favorite toy, fidget toys)**
- **Bring communication devices and materials**
- **Wear everyday clothes if possible**
- **Create a simple daily schedule (sleep, meal, play times)**
- **Hang up "All About Me" and pictures from home**

Keep in mind that playrooms, resource rooms and common areas may be closed for patient safety. There may be fewer providers entering the room. Some members of your child's team may visit with you and your child virtually with the use of an iPad or computer.

### Hospital Staff

Your child's nurse and medical team will likely be wearing face masks, gloves, gowns, and eye wear.

This helps to protect staff and your loved one.

You can prepare your child for what to expect using **pictures** and **social stories**.



### Sensory Experience

If your child has, or is being tested for, COVID-19 you can ask about the care that they will receive. **Social stories** and **visuals** can be helpful in preparing your child for what to expect.

These are *some* sensory experiences your child might have:

- **Nasal Swab**- a flexible q-tip placed into the nose to test for COVID-19. Children may feel pressure or a tickle in the nose and their eyes may water.
- **Nasal Cannula**- flexible tubing that sits under child's nose and wraps around their ears to provide fresh oxygen. This air can blow at different speeds.
- **I.V.**- tiny, flexible tubing that is placed into a vein. This can be used to give medicine or fluid. Additional material may be wrapped around the IV to discourage a child from touching it.

## Advocate

**REMEMBER!** : Your child has the right to access communication devices, hearing aids, glasses, and necessary adaptive equipment (e.g., wheelchair or device mount).

**EDUCATE!** : Learn about your hospital's current rules and guidelines around COVID-19. You can ask about your rights as a caregiver and your rights as a patient.

**ASK!** : Ask about available resources at your local hospital! (Child Life Specialists, Social Work, Augmentative Communication/Speech, Psychology/Psychiatry, Behavior Support Team, Occupational Therapy, Physical Therapy, Chaplaincy, Music Therapy, Feeding Team)



# My Hospital “Go Bag” Checklist



Create a “Go Bag” of items that will help your child be successful in the hospital. Pack a bag and keep it by the front door so it’s ready to go.

Below are examples of thing you might include:

## Comfort Items

Familiar items from home:

- Comfort toys / items
- Stuffed animals
- Blanket
- Comfortable clothes
- Chew Tube

- Noise cancelling headphones
- Sensory items
- Weighted blanket
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_



## Personal Tools and Information



- “All About Me” sheet
- Medical Passport
- Contact info for important people
- Hearing aids
- Glasses

- Communication tools
  - High-tech device & charger
  - Low-tech backup
- Visual tools
- Pictures of family members
- \_\_\_\_\_
- \_\_\_\_\_

## Other Items

- Mobile device to talk to people at home
  - Phone
  - Tablet
  - Charger
- Preferred snacks

- Favorite books
- Magazines
- Coloring books
- Favorite toy
- \_\_\_\_\_
- \_\_\_\_\_





# Visual Supports

Visual supports can benefit children during their hospital admission.

The visuals in this packet can be used to increase participation and support your child's understanding of upcoming events.

They are designed for you to print out and bring with you to the hospital.



# First/Then Display

Use this board to make expectations clear.

For example:

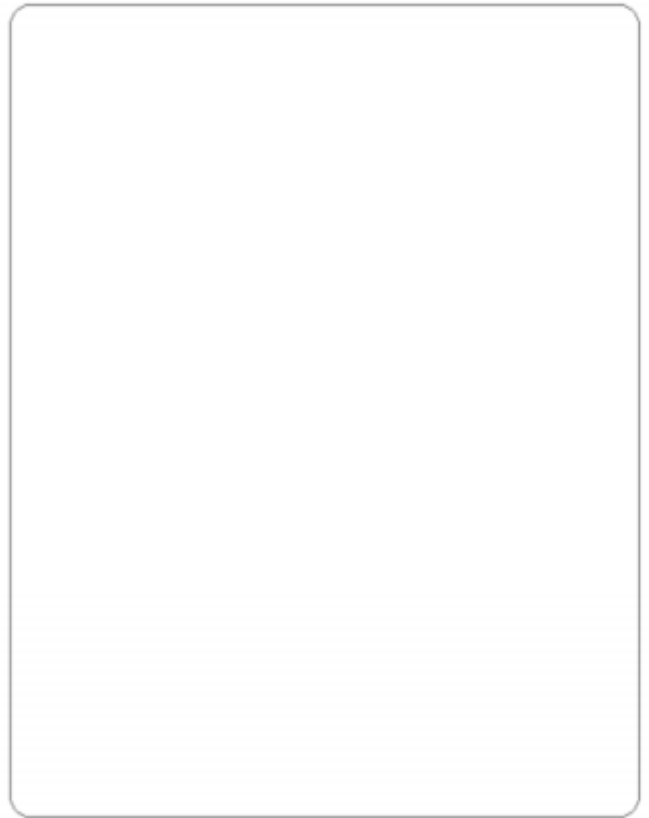
Say: “First the nurse will take your blood pressure, then iPad” while pointing to the corresponding picture. Written text or drawings may also be appropriate.



# Template for First/Then Display

## First

## Then



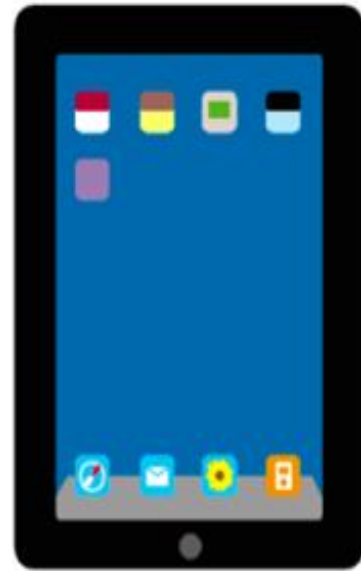
Example First/Then Display

# First

# Then



get blood pressure taken



iPad



# Visual Schedules

Visual schedules inform children of what is going to happen next.

Say, “Time to take your medicine” and point to the picture. Check off each item as it is completed.

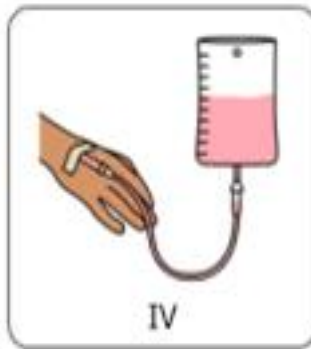
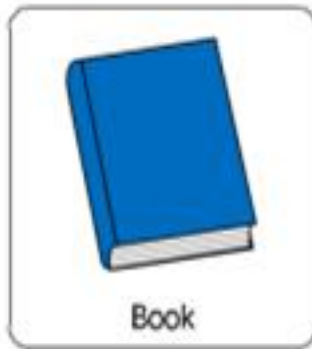
This may help patients understand what is about to happen and participate in their care.



# Template for Visual Schedule

|  |  |  |  |
|--|--|--|--|
|  |  |  |  |
|  |  |  |  |

# Visual Schedule Example



# Countdown Boards

Countdown boards inform children of how long they are expected to participate in a task.


For example:

Say: “Only 4 more, then we will be all done.” Use a marker to check off each number as the child completes the task.






# Template for Countdown Boards

|          |          |          |          |          |  |
|----------|----------|----------|----------|----------|--|
| <b>5</b> | <b>4</b> | <b>3</b> | <b>2</b> | <b>1</b> | <b>All Done</b>  |
|          |          |          |          |          |  |

## Example Countdown Board

| 5 | 4 | 3 | 2 | 1 | All Done  |
|---|---|---|---|---|---|
| ✓ | ✓ |   |   |   |  |

Example scenario: A child participating in a shared reading activity.

Expectation: Answer five questions about the book

Say, “Five more questions, then we will be all done.”

# Token Boards

Use this board to support participation during non-preferred tasks.

For example:

Say, “You are working for X. You need to...”



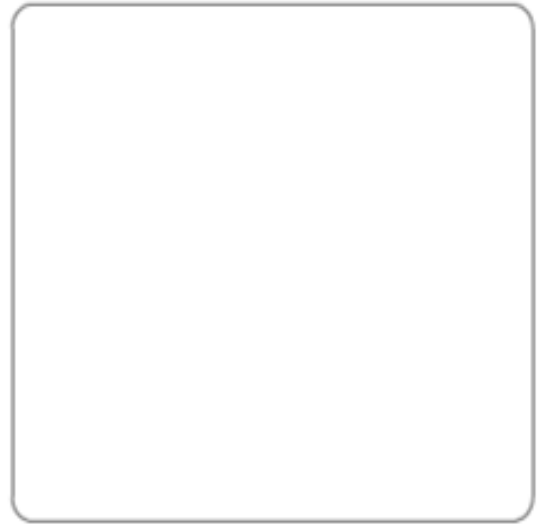
# Template for Token Board

I am working for ...



# Template for Token Board

I am working for ...



|  |  |  |  |  |
|--|--|--|--|--|
|  |  |  |  |  |
|  |  |  |  |  |

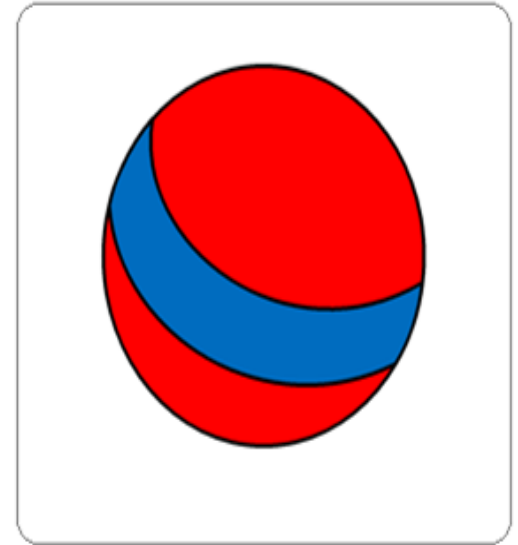
# Example Token Board

I am working for ...



# Example Token Board

I am working for ...



|   |   |   |  |  |
|---|---|---|--|--|
| ✓ | ✓ | ✓ |  |  |
|   |   |   |  |  |

# Social Story Template

## What are Social Stories?

Social stories describe appropriate social responses to specific situations in an easy-to-understand and reassuring manner. These narratives are recommended to increase your child's understanding of a specific situation or task.

## How to Create a Social Story:

- Choose a specific event or situation that may be unexpected or difficult for your child
- Determine what appropriate response you want to model
- Use first person language (e.g., "I")
- Include personal photographs and short video clips (if available)

## How to Use Social Stories:

- Read the story with your child prior to the event and/or after the emotional situation

Example social stories can be found at <http://myhospitalstory.org/mobile/index.html>.





# [Child name]'s [Topic] Book

[insert picture]



**Sometimes I have to [insert difficult situation]**

[Describe the situation](e.g., Sometimes I get sick and I might have to go to the doctor's office)

[insert picture]



**[insert text describing event or situation]**

**(e.g., I will have to wear a mask)**

[insert picture]

**[insert text describing event or situation]**

**(e.g., A nurse will take my temperature)**

[insert picture]



## This might make me feel...

[insert your child's emotions and behaviors during that situation]  
(e.g. angry and I want to throw a toy; nervous, etc.)

[insert picture]



**[insert text]**

[insert picture]



I can...

[insert appropriate/alternative actions] (e.g. take 10 deep breaths, take a walk, ask for a hug/break/preferred item/something different, etc.)

[insert picture]

**[insert text]**

[insert picture]





**[insert text]**

[insert picture]