

Preparing for a Meeting with My Baby's Health Care Team:

A Question Prompt List (QPL)

Introduction

A family meeting has been scheduled for you to meet with your baby's health care team. It is normal to have many questions about your baby's condition. Many families do not know what questions to ask, or what information might be important later.

In this book, you will find a list of questions that other families have found useful when meeting with their baby's health care team. The questions in this book are only meant to be a guide; some questions may not apply to you and your baby.

How to Use This Book

- Please read through the question list below.
 - Check the box** of any questions you would like your healthcare team to answer.
 - Circle** any questions that are especially important to you.

- On the final page of the book, feel free to write down questions you have that were not included in this list (or change questions to better suit your family's situation).

- Fill out the worksheet (**at the end**) to help your healthcare team understand what you would like to discuss with them.

Communicating with the Health Care Team

Instructions: **Check the box next to questions you would like answered** by your baby's health care team at the family meeting. **Circle the questions that are most important to you.** At the end, there is also an extra page to write down questions not included in this book.

Understanding my role in my baby's health care team

- Who are the main members of my baby's health care team?
- How do all the members of my baby's health care team communicate with each other and plan for my baby's care?
- How often will I meet with my baby's doctors?
- What is the best way for me to participate when the team makes the plan for the day (rounds)?

Getting help with communication

- If I am worried about how my baby is acting, who should I tell?
- If I think of questions when I am not in the NICU, what should I do?
- If I get conflicting information about my baby's condition, who should I talk to?
- Can you speak directly to my loved ones (spouse, parent, partner, children) about my baby's condition, giving them the same information you have given me?
- Can you help me explain what is happening with my baby to others (my family, friends, or other children)?

Making Decisions with the Health Care Team

Instructions: **Check the box next to questions you would like answered** by your baby's health care team at the family meeting. **Circle the questions that are most important to you.** At the end, there is also an extra page to write down questions not included in this book.

Understanding my role in making decisions

- Are there any decisions that we need to make with the health care team for our baby?
- Who is involved in making health care decisions for my baby?
- What is my role in making this health care decision for my baby?
- How quickly does a decision need to be made?
- If I change my mind about my baby's plans, what should I do?

Getting help with making decisions

- When making a decision, how should I balance my needs with those of my baby?
- Could you make a recommendation about what I should do for my baby?
- How do I clearly express my concerns or thoughts to my baby's health care team when we are making decisions?
- What kinds of decisions do other parents make when they are faced with something like this?

The Big Picture: Now

Instructions: **Check the box next to questions you would like answered** by your baby's health care team at the family meeting. **Circle the questions that are most important to you.** At the end, there is also an extra page to write down questions not included in this book.

Understanding my baby's health

- I've heard details about my baby's condition; what is the big picture?
- What are the major challenges facing my baby right now?
- Can you tell me what caused my baby's problems?
- Did any of my actions cause my baby's problems?
- If I have a baby in the future, could these same problems happen again?

Keeping track of information about my baby's health

- Can you give me a timeline of the important things that have happened with my baby?
- Can you give me a timeline of the important things that will happen with my baby?
- What are the important tests my baby had or will have?
- Are we still waiting on the results of any important tests?
- Where should I look for more information about my baby's condition?
- How should I keep track of all of my baby's information so that it will be useful later?

The Big Picture: Looking Ahead

Instructions: **Check the box next to questions you would like answered** by your baby's health care team at the family meeting. **Circle the questions that are most important to you.** At the end, there is also an extra page to write down questions not included in this book.

Imagining life at home

- What would need to happen before my baby could go home?
- What kinds of day-to-day challenges would I face at home with my baby?
- How would I prepare for day-to-day challenges at home with my baby?
- Could my baby need medical equipment?
- Could my baby need to have health care providers (health aide or nurse) come to the home?

Questions about life and death

- Are you worried that my baby could die?
- Do parents and doctors ever choose to stop life support?

Finding support in the NICU

- How do other NICU families cope with uncertainty?
- How do other NICU families cope with stress?
- Can you tell me more about the Quality of Life Team?
- Can a chaplain or other spiritual support person visit me and my baby?

Infant Development

Instructions: **Check the box next to questions you would like answered** by your baby's health care team at the family meeting. **Circle the questions that are most important to you.** At the end, there is also an extra page to write down questions not included in this book.

Understanding my baby's development

- What outcome is most likely for my baby's development?
 - What is the best possible outcome for my baby's development?
 - What is the worst possible outcome for my baby's development?
- If we have to wait and see what my baby's development will be, when will I know?
- Will my child need speech or physical therapy?
- Will my child need help with school?

How I can help my baby's development?

- Is there anything I can do now to help my baby's development?
- Is there anything I can do after the NICU to help my baby's development?

Understanding infant development

- Where can I find resources or information about infant development?
- How will I know if my baby's development is on track?
- Could you define:
 - Milestones
 - Delays
 - Early intervention
 - Physical therapy
 - Occupational therapy
 - Speech Therapy
 - Cerebral Palsy
 - Intellectual disability
 - Learning disability
 - Cognitive impairment

Preparing for Life at Home

Instructions: **Check the box next to questions you would like answered** by your baby's health care team at the family meeting. **Circle the questions that are most important to you.** At the end, there is also an extra page to write down questions not included in this book.

Appointments and Medications

- How many appointments will my baby have in the first few months?
- What kinds of doctors will my baby have?
- Will I have to give my baby medications at home?
- Will my baby need a hearing test after NICU discharge?
- If questions come up after my baby is discharged, who should I call?

Work, child care, and medical bills

- Will I be able to work once my baby comes home?
- Will people caring for my child require special medical training?
- Is there someone that can help me understand my insurance coverage?
- Is there someone that can help me understand my medical bills?

Ventriculoperitoneal Shunt

Instructions: **Check the box next to questions you would like answered** by your baby's health care team at the family meeting. **Circle the questions that are most important to you.** At the end, there is also an extra page to write down questions not included in this book.

Understanding shunts

- What is a shunt?
- If my baby gets a shunt, will s/he have it forever?
- Where can I find more information about ventriculoperitoneal or subgaleal shunts?

Risks and benefits of shunts

- How could a shunt help my baby?
- What are the risks of getting a shunt?
- What could happen if my baby does not get a shunt?

Taking care of a shunt

- What are signs that my baby's shunt is not working properly?
- What will I need to do at home to take care of the shunt?

Gastrostomy Tube (G-tube)

Instructions: **Check the box next to questions you would like answered** by your baby's health care team at the family meeting. **Circle the questions that are most important to you.** At the end, there is also an extra page to write down questions not included in this book.

Understanding G-tubes

- What is a G-tube?
- If my baby gets a feeding tube, will s/he have it forever?
- Where can I find more information about gastrostomy tubes (G-tubes)?
- Can my baby eat anything while s/he has a feeding tube?
- When I'm at home, who will help me know how much formula my baby needs?

Risks and benefits of G-tubes

- How could a G-tube help my baby?
- What are the risks of getting a feeding tube?
- What will happen if my baby does not get the feeding tube?

Taking care of a G-tube

- What will I need to do at home to take care of the feeding tube?
- Will I need to clean the feeding tube? If so, how do I clean it?
- Can my baby go to daycare with a feeding tube?

Therapeutic Hypothermia (“Cooling”)

Instructions: **Check the box next to questions you would like answered** by your baby’s health care team at the family meeting. **Circle the questions that are most important to you.** At the end, there is also an extra page to write down questions not included in this book.

Understanding cooling

- What is therapeutic hypothermia (“cooling”)?
- Why is my baby being cooled?
- Where can I find more information about therapeutic hypothermia (“cooling”)?
- How long will my baby be cooled?
- Can you tell me about the outcomes of other babies who have been cooled?

Benefits and side effects of cooling

- How does cooling help my baby?
- Are there any side effects of the cooling?

Seizures

Instructions: **Check the box next to questions you would like answered** by your baby's health care team at the family meeting. **Circle the questions that are most important to you.** At the end, there is also an extra page to write down questions not included in this book.

Understanding seizures

- What are seizures?
- Why is my baby having seizures?
- Will seizures cause brain damage?
- Will seizures cause physical damage?
- Will my baby always have seizures?
- Where can I find more information about seizures?

What to do if my baby has a seizure

- How will I know if my baby is having a seizure?
- What should I do if my baby is having a seizure?
- Is there anything I can do to prevent my baby from having future seizures?

Seizure medications

- Is my baby on medicine for seizures?
- Do seizure medications have any important side effects?
- Will my baby always have to be on seizure medications?

Additional Questions

Please use this space to write down any of your own questions that you would like answered by your baby's health care team at the family meeting.

1) _____

2) _____

3) _____

4) _____

5) _____

6) _____

7) _____

8) _____

9) _____

10) _____

11) _____

12) _____

Preparing for a Meeting with the Health Care Team

A meeting with the health care team is a time to ask questions about your baby.

These are some things you might wish to do before the meeting:

- Invite any family or friends who you would like to come with you.
- Ask your nurse which members of the health care team will be at the meeting.
- Let your nurse know if there is a specific staff member you want to be included.
- Fill out the **QPL worksheet (on the next page)** with questions that you want to ask and add your own.
 - You may wish to share the worksheet with your health care team before the meeting, so they know what is on your mind.

Worksheet for Question Prompt List (QPL)

Thank you for reviewing the questions in this book. Please look back through the pages to find the questions that were the most important to you. Write down your top three below. It is okay if some, or all, of the questions in your top three are not listed in the book.

After you complete the worksheet, please flip the page and answer the questions on the following page.

These are the TOP 3 questions I wish to discuss with my baby's health care team:

1) _____

2) _____

3) _____

Any additional questions I wish to discuss with my baby's health care team:

4) _____

5) _____

6) _____

7) _____

Notes: