



# "All About Me" Handbook!

A resource to help track your child's progress.



## KEEPING TRACK OF MY BUSY LIFE

### Topics Covered In This Section:

- About This Section
- Making the Most of Medical Appointments
- The Primary Care Physician
- Questions To Ask When The Doctor Has Seen Your Child
- Calendar
- Keeping Track of my Busy Life
- Planning for a Doctor's Visit



### About This Section:

This section of the notebook will help you make the most of contacts with health care professionals. Families express feelings of being stressed when trying to assure that their child's medical and developmental needs are being met. They frequently describe feelings of being rushed, confused, or intimidated by health care professionals. Let us give you some tools that can help you to take some control in these situations. By planning ahead; anticipating what information the professionals may need from you, as well as focusing on what information/concerns you would like to be addressed during appointment or telephone contacts, you will make the most of these opportunities. Remember, if there are follow-up needs; be sure to clarify who is responsible for doing what. The forms in this section will help you keep track of all the important things that happen to your child. You can keep track of questions that come up so you don't forget to ask them and record important medical events on these forms.

### Making the Most of Medical Appointments:

It may be a new experience for caregivers to be faced with frequent and often stressful appointments with a range of health care professionals. Caregivers frequently comment on feeling rushed, confused, or intimidated by health care professionals. They can take some control in this situation by planning ahead and anticipating what the professional's expectations may be related to the specific appointment, as well as focusing their own thoughts on what information/concerns they would like to be addressed during the scheduled contact.



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**The following suggestions may assist caregivers in getting organized before a scheduled appointment:**

1. Put together a notebook to help keep information and paperwork organized. There should be blank paper available for writing notes. Include a place for insurance information, as well as a calendar.
2. Make a list of any questions/concerns you would like to discuss with the health care provider.
3. Write down any information that you anticipate that the provider will need to know. Focus areas include; recent illnesses, current medications, or other related specialty appointments.
4. Plan to be about 10 minutes early to register.
5. Be aware of any procedures that will be part of the appointment, so that you can best prepare yourself and the child.
6. Bring alternative activities, food items, and scheduled medications, to be available should you have to wait for a long time period for the scheduled appointment.
7. Write down any recommendations or changes in your notebook. If there are follow-up needs be sure to clarify who is responsible for doing what.
8. If you have to leave with unanswered questions, ask when time would be available to address these over the telephone.



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#### The Primary Care Physician

It is very important to have one health care professional who knows all aspects of the child's care. This service is best provided by a pediatric specialist who has experience and interest in children with complex medical/developmental special needs. It is important to have a relationship that is based on mutual respect, that promotes a feeling of partnership between the primary care physician and the child's caregivers.



#### The benefits to having a close working relationship with this primary care physician include:

1. The primary care physician can be the initial contact for any concerns related to the child's health and development.
2. The primary care physician can help to determine the need for referral to specialists, as well as helping the caregiver to understand any findings or recommendations that come out of these specialty contacts.
3. The primary care physician assists caregivers in coordinating all the health related services for the child to promote continuity of care.
4. The primary care physician can support the caregiver's efforts to advocate for care that promotes the child's optimal level of health.



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#### **Questions to Ask When the Doctor Has Seen Your Child:**

##### **Questions about an illness:**

1. Can you make a diagnosis this time?
2. Would you recommend a second opinion or a specialist for this illness?
3. Should anything be done immediately? What should we be doing over the next few days? Are there any long term needs/concerns?
4. When will the child begin to feel better? How long does this illness usually last?
5. Are there any symptoms I should be aware of to monitor this illness? What are the indications that he/she is getting better? What are the indications of any complication or worsening?
6. If I do notice any signs of complications, how can I contact you after hours? In an emergency, who should I call?
7. When can he/she go back to school? Are there any special precautions which the school should be aware of?

##### **Questions about general check-ups and development:**

1. Is he/she within the range of normal height and weight for his/her age?
2. Is he/she growing at a normal rate?
3. Is he/she developing normally in the areas of physical abilities, speech, vision, and cognitive development?
4. What are the age ranges typically during which children develop these abilities? Am I right to be concerned at this time? When should I be concerned?
5. Do you think some developmental screening should be done at this time?
6. Do you administer any of these tests yourself as part of the regular check-up? (If answer is no, you may want to have the doctor write a report indicating a concern over development in a particular area which you can send to the school staff working with your child to request that they test your child or arrange for a appropriate testing. If your child is not of school age, you may request these results be sent to the school system to request early intervention screening.)
7. What are the next developmental stages we should be watching for?



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8. What can we do to help our child?
9. Should we be consulting with the early intervention program and/or therapists for our child?
10. Will you collaborate with the school by sending copies of your evaluations or writing a report specifying my child's delays which I can use in talking to the local school system?
11. Can he eat before coming?
12. Are there any precautions I should take either before or after these tests?

#### **Questions to ask about referrals to specialists:**

1. Specifically, why is this referral being made? Is this a second opinion or are we seeing the specialist for a diagnosis?
2. Are there records I should take with me or will they be sent in advance?
3. Is this specialist comfortable with children like mine? Has he/she been fully informed about my child's disability or would it be useful for me to give him a call?
4. Who will get the reports of this evaluation? Who will be interpreting them?  
Who will be discussing these reports with me?
5. What are this specialist's rates? Can arrangements be made to help cover these expenses?

#### **Questions to be asked about surgery:**

1. What exactly will this surgery do or allow my child to do?
2. What are the consequences of not doing it?
3. Would there be any advantage in waiting to see if the situation improves?
4. How long will my child be in the hospital?
5. How long will it take my child to fully recover from this surgery?
6. Will we need any special equipment or help at home when he/she is released?
7. What are the possible complications or side effects?
8. Should we get a second opinion?



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#### **Questions to be asked about surgery:**

9. Do you think any additional surgery will be necessary?

#### **Questions about hospitalization:**

1. Can you estimate the length of my child's stay in the hospital?
2. Who will be attending doctors?





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KEEPING TRACK OF MY BUSY LIFE CHECK-UP FORM			
DATE	WHAT HAPPENED?	QUESTION/CONCERN	ANSWER/FOLLOW-UP





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PLANNING FOR A DOCTOR'S APPOINTMENT		
DATE:	TIME:	PROVIDER:
<b>Update to share with the medical provider:</b>		
1. Current Medications: (name, dose, times given)		
2. Current diet/any concerns:		
3. Has the child had any recent illnesses or changes in their medical status?		
4. Are there any questions or concerns you have today?		



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### Information/recommendations from this appointment:

1. Changes in medications:
2. Changes in diet:
3. Important information shared:
4. Follow-up needs (what is to be done, when and by whom)
5. When is the next appointment scheduled?