

# Creating a Care Notebook

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# Topics

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Developing a Care Notebook

Communication

Care Coordination and Tools

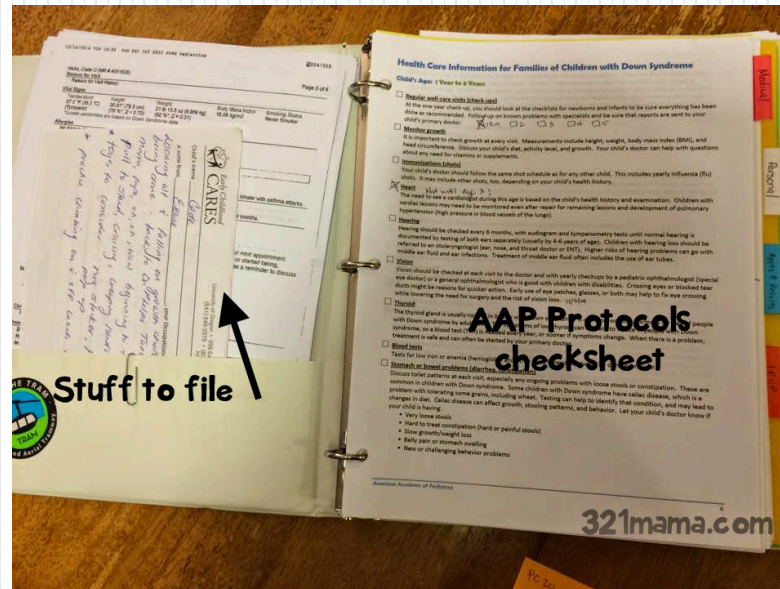
Confidence: Strategies to use when you disagree  
with a provider

# Developing a Care Notebook

Why do you need a care notebook for your child?

What should you include in a care notebook?

Where should you keep it and who should have a copy?



# Why do you need a care notebook for your child?

- Good records
- Convenience
- Transitions
- Documentation
- So you don't have to rely on your memory
- In case of emergency

## Did you know?

*A care notebook can be a helpful tool for foster parents, paid staff, guardians, etc.*



# Developing a Care Notebook

- Decide how you want to keep records. Update regularly.
  - 3-ring binder with hard copies
  - Electronic
  - Copies or backup
- Make sure that the emergency contact for your child knows where you keep the care notebook and/or how to access it
- Store your care notebook where it is easily accessible

# What should you include in your care notebook?

- Recommended essential contents:
  - Emergency medical information
  - Reports, evaluation/assessment results, etc.
  - Medical history
  - Name and contact information for primary doctors
  - Insurance information including copies of cards (front and back)
  - List of medications, including dosages
  - Allergies

**Did you know?**

*American Academy of  
Pediatrics has a template  
for a printable notebook.*



# What should you include in your care notebook?

- Other items to include, as time and space permit:
  - Names and contact info for specialists, therapists, pharmacy, dentist, eye doctor, etc.
  - IEP or 504 plan, including evals and reports
  - Waiver documentation
  - Communication log
  - Notes and questions for your child's providers
- [Care Notebook Documents](#) available for download.
- [www.thecarenotebook.com](http://www.thecarenotebook.com) (fee)

Did you know?

*There are online options  
via cloud or via app*



# Communication



"The single biggest problem in communication is the illusion that it has taken place."

~ *George Bernard Shaw*



# Communication

## *Have you ever...*

- Met with your child's teacher about any issue?
- Told a cashier that an item was not ringing up correctly?
- Reminded your doctor about an important detail like a drug allergy?

**YES? Then you are communicating! You are being an advocate!**

# Communication At Appointments

- Be prepared! [The Well Visit Planner](#) interactive online tool (ages 4 months – 6 years)
- Write down questions and concerns before the appointment.
- “Ask Me 3” are 3 simple questions you ask nearly any provider.
  - (1) What is my main problem?
  - (2) What do I need to do?
  - (3) Why is it important for me to do this?
- Keep a communication log.
- Make an audio recording of the appointment.

## Did you know?

*A “busy bag” can occupy your child while you talk with the doctor.*



# Communicating With Provider Offices

- Know office policies.
- Confidentiality/HIPAA Procedures vary.
- Find out how your provider prefers to communicate (through a nurse or staff member, by phone, by email, etc.).
- Know how to reach your child's doctor after hours.

**Did you know?**

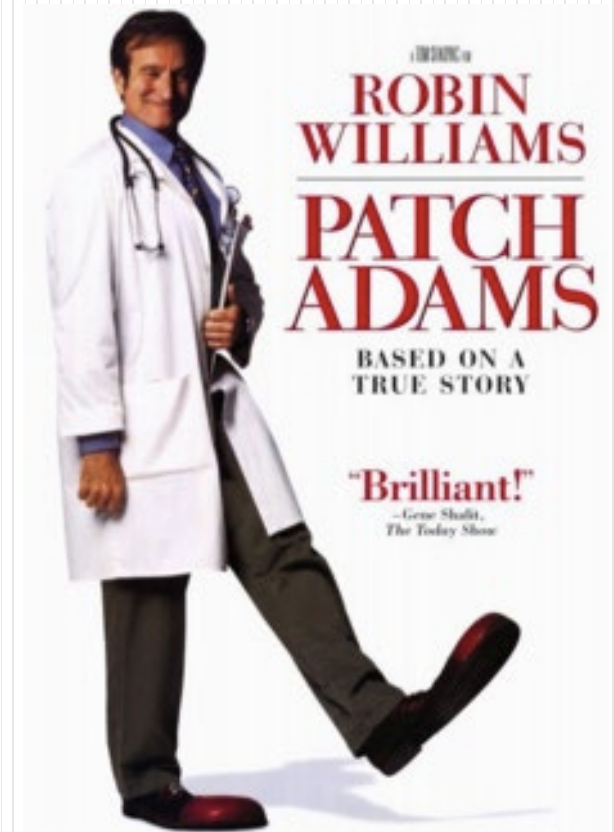
*It is okay to contact your  
child's doctor between  
appointments.*



# Care Coordination

“You treat a disease, you win,  
you lose. You treat a person,  
and I guarantee you’ll win, no  
matter what the outcome.”

~ *Patch Adams*



## What is care coordination?

It is patient & family-centered, assessment driven, continuous, team-based activity designed to: meet the bio-psychosocial needs of children and youth, while enhancing person & family care-giving skills and capabilities.

### Elements of **Quality Care Coordination**

- **Respectful partnership exists between the family and the care team.**
- **The care team is truly concerned about what matters most to the family**
- **As a child develops and the family changes, priorities may change too;**
- **The knowledge of everyone, including the family, is used to create best strategies and solutions and a team to carry them out.**
- **Helps a family become a better and more skilled advocate, reporter, and decision maker for their child**

# Care Coordination

## *Who is involved?*

- First and foremost: **THE PATIENT**
- Caregiver
  - **Coach and Captain**
  - **Constant** in the life of the child
  - **Expert** on their child
  - **Supervisor** of those who provide care
  - **Visionary** who sees the “big picture”

Caregiver and patient are central to the process and should be viewed by all others as equal participants.

# Care Coordination

## *Who else is involved?*

- **Medical Case Managers:**
  - Medicaid managed care option
  - Children's Special Health Care Services (CSHCS)
- **Medical professionals:** doctors, nurses, pharmacists, etc.
- **Others:** social workers, school health aides, etc.
- Friends and Family Members
  - <https://www.carecalendar.org/>

## Key Components

- Comprehensive
- Developed with the team
- Culturally effective
- Measurable goals
- Accessible
- Monitoring/oversight

## Benefits

- Improves relationship between provider(s) and family
- Supports family-centered care
- Addresses both medical and social needs of the patient



# Care Coordination

## *What should you do?*

- Get health insurance coverage
- Understand your insurance coverage
- Get a copy of the entire policy for your records.
  - Know the basics
  - Understand cost-sharing
  - Know whom to contact
  - Problems and Appeals
  - Prior authorization

### Did you know?

*You can have several types of insurance for your child at the same time.*



# Care Coordination

## *What else can you do?*

- Save time and energy with technology
  - Apps: Care Zone, [www.mymedicalschedule.com](http://www.mymedicalschedule.com), Photo Mind, Pillboxie, Voice Cue, iPill
  - Use text reminders
  - Use automatic refills
  - Use online medical charts
- Use a medical summary tool (kind of a mini-version of a notebook)
  - Transition Quickguide
  - Portable Medical Summary
  - Wellness Passport

# Ready, Set, Go

## *You've got this!*

When you disagree with your provider...

- Breathe. Stay calm.
- Be assertive.
- Look confident even when you don't feel it.
- Always focus on the needs of the patient/your child.
- State the goal. Define the problem. Identify solutions.
- You have the right to seek a second opinion.

# Contact Info & References

- Family Voices Indiana
  - 1-844-323-4636
  - [www.fvindiana.org](http://www.fvindiana.org)
  - **Follow us on Facebook, Twitter, and Blogger**
- Some content adapted from
  - “Skills for Effective Parent Advocacy” A curriculum created by the National Family Advocacy Support and Training (FAST) Project, a project of PACER Center: **fastfamilysupport.org**
  - “Communication” webinar by INSOURCE on October 27, 2015: **insource.org**
  - “Care Coordination” training developed by Region 4 Genetics Collaborative, a project of Michigan Public Health Institute

Questions?



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