

What is Care Coordination?*

Care coordination means that your child and family are linked with the right services and resources in a coordinated effort to help your child's health and development. You can choose to be the formal care coordinator or ask for help from your child's physician or nurse with this role. Care coordination services may be provided by the doctor or other primary care provider, an office nurse, or an insurance referral assistant in the practice. Sometimes the care coordinator is a social worker and in other cases it could be an occupational therapist, public health nurse, or other professional. Care coordination happens best when:

- The child's and family's needs and strengths are identified
- The roles of each person are defined and understood
- It is clear who is responsible for making sure what's supposed to happen, happens
- Information is shared fully and in a timely manner between everyone who needs to know
- There is a respectful partnership between everyone involved (child, parents and providers)

There are a number of tools to coordinate your child's care. Some examples are:

- **Care Notebooks and Organizers:** Care notebooks and organizers are electronic or paper-based ways of organizing your child's health information. They can contain lots of information, or just some details you feel are important. Care notebooks and organizers are a way to keep information accessible and current about your child's health, progress, treatment, and services received.
- **Care plans:** A care plan is a written health care plan for your child that may include what medications or services your child needs and which specialists your child needs to see. Care plans are an excellent way to coordinate care across providers and minimize miscommunication. Having written care plans help you share important information with others who care for your child. This may include doctors, nurses, therapists, emergency medics, teachers, child care providers, respite providers, grandparents, friends and neighbors.
- **Emergency care plan:** An emergency care plan provides ready access to the information essential to meeting a child's health needs during an emergency. Children with special health care needs have unique medical histories and sometimes require very special medical treatment. If emergency personnel do not have access to this important information, children are in danger of delayed treatment, unnecessary tests, and even serious errors. It is extremely important that parents and physicians work together to give emergency providers access to the special information they need to properly care for the child.

The Benefits of Care Coordination

Medical care often is fragmented; primary care physicians, specialists, nurse practitioners, genetic counselors, home care providers, pharmacists, early interventionists and others all look at different aspects of your child's genetic condition. Medical service providers do not always have the time or ability to communicate with each other about your child's care. This can result in more costly care, increased miscommunication, and incomplete sharing of information (Curtis & Hodin, 2009). Coordinated care however, has a positive impact on children with special health care needs and their families. *(need something else here, ask Kerry to pull info, and examples)* Parents who receive care coordination services report higher utilization of both primary care and specialist physicians (Lawson et. al, 2010). In another study, parents of children with asthma

who are in “planned-care practices” where care coordination is in place reported 13 fewer days of symptoms per year than children in typical practices, needed a third less rescue medication, and used their medication as prescribed (Lazano, 2004).

Coordinating all of your child’s multiple doctor visits, tests, procedures, medical information, home care and other services is a daunting task and one of the most important in keeping your child well and working to help you child maximize his or her potential. Few doctor’s offices are set up to perform care coordination services that link activities outside of the office setting which impacts your child’s health, well-being and quality of life. While some doctor’s offices do coordinate medical care for their own services and try to integrate information from other healthcare providers, the link between medical and non-medical services is seldom routinely coordinated.

With good and well-coordinated information, everyone involved in your child’s care will be better adapted and more in control of helping you and your child meet the challenges of living with a genetic condition.

Region 4 Genetics Collaborative Care Coordination Workgroup

The Region 4 Genetics Collaborative believes that care coordination engages families in development of a proactive care plan and links them to needed services and supports that address the full range of their needs and concerns. Care coordination is an essential component of an effective system of care designed to optimize the physical and emotional health and well being of the child, improving the child’s and family’s quality of life. The Care Coordination Workgroup remains focused on improving care coordination for children with heritable disorders in Region 4 and nationally. Part of this focus includes the development of products to increase the ease and understanding of care coordination among families and providers.

What follows is the [Guide to the Care Notebook for Parents](#); one of the products the workgroup has developed to increase parents’ competence in coordinating care for their children. A care notebook can help when you have a child with a genetic condition and you want to maximize his health care as well as make the most of healthcare finances, benefits, support services and volunteer services to positively impact your child’s quality of life. A care notebook can help you collect the information you need to address the physical challenges, practical challenges and the emotional stress that goes along with having a child who has a genetic condition.

This guide goes beyond what can be included in a care notebook; it strives to help parents more effectively coordinate their children’s care. The guide is divided into ten sections, each covering a different aspect of care planning. Each section contains suggestions about what to include to maximize the quality and usefulness of the information. Along with suggestions about what types of information and records to include, there are also helpful tips from parents of children with genetic conditions who have experience coordinating care for their children. These tips and suggestions came from parents in our region who regularly coordinate care for their children. Each section also contains links to the American Academy of Pediatrics website www.medicalhomeinfo.org where a number of forms can be found to either complete online or

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print and complete on paper. The forms are meant to provide an organized place to record all the information the guide suggests.

We hope that this guide is useful to you as you move from diagnosis to transition and beyond. Coordinating your child's care can be the foundation to gaining control over his or her well being as well as your own time and energy.

SECTION 1 – CARE PLAN COVER PAGE

Brief Description: A letter explaining the guide written by a parent.

Dear Families,

If you have arrived at this resource, you have probably traveled for miles navigating through the difficult terrain of diagnosis and disease. Your journey may have begun with the devastating news of diagnosis through newborn screening or through the words of your caring pediatrician. Your journey may have already taken you to destinations that you never would have imagined – learning the realities of caring for a child or children with special health care needs.

My wife, Melissa, and I have traveled in your footsteps as our twin daughters, Andrea and Alyson, now nine, were diagnosed with cystic fibrosis at age four months. Our news of cystic fibrosis came after a very difficult four-week hospital stay where almost every test you could think of was ran on our infant daughters. Finally and thankfully we arrived at a diagnosis. Cystic fibrosis is a life limiting genetic disease primarily affecting the lungs and the digestive system. With the disease there are many treatments and medications, doctor’s appointments and tests. On the outside, it appears as if our daughters are healthy and normal, but on the inside and behind the scenes there is a daily battle being waged against infection and a struggle to gain weight. It has been quite a journey and we have learned many lessons along the way. Things that we were prepared for and things we could have never planned. We have learned how to become organized and scheduled when things surrounding us were very hectic and stressful. We have learned that it is impossible to journey alone as we rely upon our physicians and care team as well as family in friends. Together, we are committed to making our daughters’ lives stronger and longer.

Whether you have taken a few steps and are just beginning your journey or you find your feet are tired and worn, this resource is for you. This resource has been developed by families for families. The intention of this guide is to help families effectively coordinate their children’s care.

We hope that this resource can be a signpost along your route and that you will find the ideas and suggestions in this guide valuable in making your life and caring for your child easier. No one completely realizes what you are going through as a family – but it is possible for others to journey with you.

David (Father of Andrea and Alyson)

SECTION 2 – EMERGENCY INFORMATION – MyEIF.org

What information does this section help you collect, develop and track?

In this section you will find the suggested information to include for emergency room visits and planning for emergencies such as natural disasters, power outages, etc. In addition to the information that we detail below, parents also offer tips for you to keep in mind when thinking about planning for emergencies. We also provide a link to www.MyEIF.org, which is an online tool designed to communicate critical information in a medical emergency about a child's special needs.

Emergency providers may need:

- Allergies
- Immunizations and Dates
- List of Diagnoses
- Emergency Contact Information (parents and other emergency contacts)
- Current medication record including type of med, amount and frequency

For emergency planning purposes it may also be helpful to track:

- Household Emergency Information
- Emergency Preparedness for Children with Special Needs

Why might tracking this information be useful to parents and/or providers?

Emergency planning is a vital part of caring for a child with special health care needs. It is useful for parents to plan for emergencies to prevent miscommunication or lack of knowledge when in an emergency department. When a child is sick, the stress involved in locating information, communicating effectively with emergency department providers and coordinating care between providers can be very overwhelming without preparation and easy access to information. The information is useful to providers because emergency department providers can immediately begin a course of action based on the information provided. This prevents errors, misunderstanding and fragmented care. With some genetic conditions, it may also save lives or prevent severe complications.

How can it be helpful to you?

The information and tips provided will help you prepare for emergencies and provide a background and information about your child and his or her condition for everyone involved in your child's care during an emergency.

Sample tracking forms

You can find a place to record all of the information at www.MyEIF.org. MyEIF.org is an easy-to-use, proven online tool that prepares for responsive emergency care for hundreds of children. The following information is suggested to record when preparing for emergency care for your child.

Any additional resources

Tips from Parents and Providers

- If your child has no known allergies, make sure include that in this section.
- It may be helpful to provide a letter stating that you give your caregiver (i.e. grandparents, aunts, friends, etc.) specific authorization to allow them authority to make minor medical decisions should an urgent medical situation arise while the child is in their care.
- When you list medications, try to write them in a format that can be easily used by emergency personnel. It helps to include the name of medication, strength, and dosage. Also, include the route (i.e. oral/G-tube etc.) and frequency of the medication. You may want to name the doctor who prescribed the medication as well.
- Include all diagnoses and multiple health issues. For example, if a child has a metabolic disorder, their primary diagnosis might be galactosemia but the secondary diagnoses could include things like “attention deficit hyperactivity disorder” or “developmental delay” or “short stature”, etc...
- If you have a Medical Alert or emergency help letter you will want a copy on file here.
- If your child is on a special formula (or a difficult to obtain med), include the name, supplier, manufacturer, and whom to contact if there is a disaster and you have to relocate. Also, you may need to make special arrangements to get replacements if needed.
- You may want to contact utility companies to let them know that you are a high need for electrical services because of pump, etc.
- Some local 911 lines have a special form to complete if you have a child with special health care needs. This allows the alert to come up when you call for emergency help. Check with your local dispatch and law enforcement to see if this is available in your area.
- If you need to go to the emergency department, you may want to take 24 hours worth of medication and medical supplies for your child. Not all hospitals stock the kind of medication and medical supplies that your child may need.
- Keep an emergency bag in an easy to access place so you can grab it and leave in an emergency.
- If you have a web-based emergency plan, include information about how the emergency department can access it. If your plan is paper-based, you may want to have a section or copies that you can pull out in case of an emergency that the emergency department can keep. If there are special meds/formula/equipment that you need to take with you in an emergency, you may want a checklist to be sure you take everything you need.

SECTION 3 – INSURANCE INFORMATION

What information does this section help you collect, develop and track?

This details insurance information (carrier, provider, holder, contact/plan numbers, contacts for pre-approval, co-pays, etc) and tips about navigating insurance systems.

Insurance information that may be helpful includes:

- Health Insurance Information
- Insurance Plan Additional Detailed Information – information beyond plan numbers, such as premium amount, co-insurance amounts, which things require authorization, waivers, and Title V prompts.

Why might tracking this information be useful to parents and/or providers?

This information will be needed by providers anytime your child needs medical care or plans are being made for additional testing, surgery, or other procedures. It is helpful for parents to have all of the information in one place so you can refer to it easily and have contact numbers available to assist with obtaining additional information or answering coverage questions. Having the needed information available at the time of service can help prevent billing problems and issues.

How can it be helpful to you?

Tracking this information will help you become more familiar with your plan coverage, and understand special requirements of your individual plan such as when prior authorization is required or if you must use a certain lab or facility if possible to avoid out of network charges. This will help get the best use of your plan and help avoid “surprise” charges if using out of network specialists or facilities.

Sample tracking forms:

Here are some sample forms for tracking insurance information:

<http://www.medicalhomeinfo.org> go to for families/Building your Care Notebook/Build your own Care Notebook/insurance information

Form names: Insurance plan Information-VA
Medical insurance information-RI
Insurance funding information-WA
Child’s insurance information-IL-DCC

Any additional resources

Each state should have a website or contact information for learning more about what programs are available for children with special health care needs in your state. The local family services/health department should also be able to guide you to sources for more information.

Family Voices is a national group which may help you find local programs, or persons who can assist you in working with private or public health care insurance programs.

<http://www.familyvoices.org>

Tips from Parents and Providers

- If you have to obtain a special prior authorization or appeal for coverage, it is helpful to save notes of the processes or any substantiating letters of medical necessity that you may have. Also, jot down the name of the person who assisted you in case you need it later.
- Mark the date you completed or filed SSI, Title V, etc.
- Collect information on when the application has been made and include the contact information for SSI or a prompt to be sure to enter case coordinator/social worker information in your child's care team.
- Make a copy of the front and back of your health insurance card.
- Talk with a Social Worker or check with a local parenting group to see if you can get help with navigating insurance systems.
- An insurance case manager may be helpful if your child has complex health care needs requiring special consideration. You may need to ask if one can be assigned.
- If you find someone who can get you what you need for your child, hold on to his or her name and number!

Know when open enrollment for your health care plan is due. If on a state funded program, know when you need to renew or submit financial information. (Do not assume they will contact you.)

If you have applied for special program or waiver, and are on a waiting list, check yearly to be sure everything is in order and information is updated. Keep track of who you spoke with and date.

When going for appointments be sure not only insurance information current, but also any changes in address or other important contact information.

Ask for information on financial assistance for medical bills to see if you might qualify for any special programs.

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SECTION 4 – HEALTH HISTORY

**SECTION 5 – CARE TEAM PROVIDERS LIST (HEALTH CARE PROVIDERS,
OTHER CARE PROVIDERS)**

What information does this section help you collect, develop and track?

This details contact information for all the doctors, specialists, therapists, etc. involved in the child's care, many of these forms could probably be combined.

Why might tracking this information be useful to parents and/or providers?

Children with special health care needs often see many specialists and receive services from several agencies. Having all of this information together will make it easier to find specific information when needed. Often you are asked to supply this information for updating health records for school or other agencies.

How can it be helpful to you?

Keeping this information together can save you time and effort when you need to contact someone in an emergency, or just for general information or concerns. (It's a place to keep the information from all those cards stuck on your refrigerator in case one get lost!)

Having an undated list available can be helpful if you want progress/visit reports sent to multiple providers. If you need to give permission for release/exchange of information you will have this information available. A list is portable so you have it when you need it.

Care Team Contact List including:

- Health Care Providers List (Primary Care and Specialists)
- Home Care Providers List
- Home Care Information
- Hospital Information
- Public Health Care Providers List
- Early Intervention Specialist List
- Child Care Information
- Respite Care Information
- Pharmacy Information
- Medical Supplier Information
- Transportation Information
- Community Resource Information
- Family Support Resources Information
- Care coordinator
- Others

Sample tracking forms

Here are four examples for reference:

http://www.medicalhomeinfo.org/downloads/pdfs/Health_Care_Providers-ME.pdf

http://www.medicalhomeinfo.org/downloads/pdfs/Health_Care_Providers_List-MA.pdf

http://www.medicalhomeinfo.org/downloads/pdfs/Home_Care_Provider_Contact_List-RI.pdf

http://www.medicalhomeinfo.org/downloads/pdfs/Other_Health_Care_Providers-MA.pdf

Any additional resources

In addition to listing care providers, make note on forms or how often routinely seen for check up, if prior authorizations needed, or date if renewal of services or new prescription required. These could be noted on a planning calendar.

Tips from Parents and Providers

- If you have list of care providers you might want to keep multiple copies so you can take them to visits in case you want reports/results sent to another provider or for medical release forms.
- You could list all the doctors whom your child has seen, but be sure to note which doctors are currently caring for your child.
- Remember to include contact information for your pharmacy, including their fax and phone numbers. Some of the new e-script services also ask for address.
- If your child saw a specialist for specific evaluation or testing, note this on the contact for future reference.

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SECTION 6 – HEALTH TRACKING

SECTION 7 – EDUCATION INFORMATION

What information does this section help you collect, develop and track?

In this section you will find details related to the child's educational process through high school and beyond. You will find out how to begin the child's early education by age 3 and continue through the transition to work after school at age 21. There is suggested information including how to prepare for meetings, questions and information to share with teachers, how to understand the laws and parent rights, and available resources.

Education Information will include:

- Birth to Three Program Information
- Preschool Program Information
- School Program Information
- Education Record
- School Schedule

Why might tracking this information be useful to parents and/or providers?

Pre-planning is a vital part of getting the best education for a child while meeting his/her special health care needs. Parents want to inform themselves of the process and the laws regarding that process. The process of educating a child with special health care concerns can be daunting and overwhelming. By keeping track of information a parent will be able to go back and review information at a time that is less stressful.

How can it be helpful to you?

The information and suggestions for you will help you navigate the educational system so the child will receive maximum benefit from his/her education. To be an active partner with a teacher and/or school system a parent must maintain open dialog.

Some information to share with teachers:

- Changes at home
- Child's attitude toward school
- Child's likes and dislikes
- Child's favorite things to do
- Child's habit
- Health issues such as allergies or medication

Some questions to ask the teacher and/or the school:

- Expectations regarding school work and homework
- Social activities
- General procedures such as the cafeteria, field trips, fees, and activities

When developing a program for a child, there are four areas to examine.

- Academic areas
- Social areas
- Communication skills
- Ways the child learns best.

Sample tracking forms

www.medicalhomeinfo.org has information on creating a care notebook for your child. These can easily include sections on education as listed below.

Any additional resources

www.ed.gov – website has federal policies, laws, resources as well as links to individual state websites.

Individual school districts as well as individual schools have websites that can be accessed easily. Some districts may have a parent resource center that has information and help for parents.

www.parentingcenter.com Links to state centers

Tips from Parents and Providers

- Begin a filing system for all the papers a parent accumulates over the years. These files will include copies of yearly IEP's, meeting agendas and summaries, parental rights, district policies and procedures, and federal and state regulations.
- Also include ideas or notes about programs you will want to check into later for your child. List programs that were the most successful in helping your child and what you might want to include in future educational programs. List any concerns or problems with programs.
- Include notes of names and phone numbers of people who were beneficial to you as well as a log of conversations with personnel.
- This is also a good place for an immunization record.
- List websites and resources that may be helpful.

Include Health Information for Educational Settings such as:

- Individualized Healthcare Plan for School
- School Medical Emergency Plan
- Return to School Checklist
- Additional Information for School Staff
- Health Related School Log
- Permission to Release Information:
 - Between health care providers
 - Physician to School
 - School to Physician
- Physician's Orders
- Request for Assisted Self-Administration of Medications
- Information to allow self-administration of medications
- Special diets/Diet letters – substitute juice for milk, etc.
- Adaptive PE Recommendation
- Other

Tips from Parents and Providers

- Provide a note of who provided special letters and the date so they can be updated if needed. Always keep letters provided to the school in case they are lost or they need to provide on a yearly basis.
- Your child's school may have its own "required forms". Completing these forms can help ensure that all the necessary information is at your fingertips for transferring to the school required forms.

Individual Education Plan or 504 Plan Information including:

- IEP Notes/Plan
- IFSP, IEP, IPP Notes
- Reviewing and Correcting My Child's Student Records
- Due Process Hearing Request Form
- Special Education Administrative Complaint
- Special Education Mediation Request

Tips from Parents and Providers

- Note when these plans were done, and when they recommend re-evaluation to track progress.

SECTION 8 – TRANSITIONS & CHILD AND FAMILY GOALS

What information does this section help you collect, develop and track?

This details a broad section for transitions to include things like school, work, medical, and social aspects of transition. Also, goals for the child and family are included. Some examples of transition forms include the following:

- Adolescent Autonomy Checklist
- Keeping Track of My Own Healthcare
- Transitions Notes
- Transitions Developmental Checklist
- Life Planning Checklist
- Living Arrangements
- Moving Checklist
- Child's Page – Now and Later
- Transition from home to school
- Other types of transition experienced throughout the lifespan
 - How to handle refusing foods offered that are not on diet
 - Learning to make choices
 - Learning to do own blood testing, etc.
 - List types of transitions

Goals may include:

The goals/outcomes your child has with each of his/her care providers as well as goals written in his/her care plans. Be sure to note which provider(s) are working with your child to help him/her attain these goals.

Why might tracking this information be useful to parents and/or providers?

Transition from the pediatric to adult setting can be a complex and stressful process for patients, parents and providers. There are often many issues that need to be addressed within a number of different areas – including such as medical, work and social contexts. Also, there are years of information and experience that has been collected and needs to be shared. Having this information readily organized and readily available improves communication and helps make the transition process a smoother one.

How can it be helpful to you?

Goal and Value Setting – This process can help the adolescent and family clarify and communicate future goals and values.

Planning – This process can help prepare everyone for unforeseen circumstances in which easy access to medical and social history is important.

Communication – This process helps the adolescent and family to communicate their history, needs, and values to the new provider or new participant in their care.

Sample tracking forms

You can find a place to record all of the information at www.MyEIF.org. MyEIF.org is an easy-to-use, proven online tool that prepares for responsive emergency care for hundreds of children.

Comment [BT1]: Sally - Are these specific forms within the notebook that we are referring to here.

The following information is suggested to record when preparing for emergency care for your child.

Comment [BT2]: Sally - can we use this language?

Any additional resources

Tips from Parents and Providers

- Ask for input from specialists so you can have an agreement on expectations and the ability to achieve goals. Ideally, if possible, your child should help with the goal setting.
- Transition is a process, not just a quick handoff.
- The transition process should be started as early as possible.
- There is no right age to begin the transition process. Timing depends upon the child's development and the family's readiness.
- Transition is a team process that requires clear and frequent communication among all involved.
- Transition often requires adjustment as everyone (adolescent, family, provider) is adjusting to a new role. Be patient.
- As much as possible, the adolescent should be given more responsibility and be an active participant in planning and executing the transition process.
- Encourage independence by teaching your child self-help skills and additional skills related to their specific health needs.
- Become familiar with the resources available to your child (i.e., Supplemental Social Security; Vocational Rehabilitation; Medicaid; Independent living centers; Disability Resource Centers at public colleges and universities.
- Be clear about your child's needs and values. Everyone's transition needs are different.

SECTION 9 – EXPENSE TRACKING

What information does this section help you collect, develop, and track?

This section of the Guide to Care Notebook will help you keep track of your child's health-related expenses.

Why is tracking this information useful to parents and/or providers?

Keeping track of all your family's health-related bills can be a daunting and overwhelming task. Having your information organized and categorized can help you more efficiently communicate with your child's healthcare providers.

How can it be helpful to you?

Keeping your health-related bills organized will help you feel more in control and less stressed, especially at tax time. Keeping the information categorized will help you determine on which services you are spending the most financial resources. In addition, should an insurance question arise, you will have all the information at-hand and ready to respond.

Sample Tracking Forms:

- If you are computer savvy, you might consider creating a personalized Access database or Excel spreadsheet to track your child's health-related expenses. Some of the key fields you might want to capture are: patient name, provider, provider's mailing address, provider's phone number, date of service, description of service, date primary insurance billed, date secondary insurance billed, invoice number, amount I owe, amount I paid, my mileage to appointment, date mileage reimbursement submitted, date co-pay reimbursement submitted, notes.
- A variety of sample medical expense, communication, and travel logs can be found online at:
http://www.medicalhomeinfo.org/for_families/care_notebook/medical_bill_tracking.aspx

Additional Resources:

- The Internal Revenue Service (IRS) will reimburse you for your mileage to/from medical appointments. To read more about this tax deduction, please see the IRS website at:
<http://www.irs.gov/newsroom/article/0,,id=232017,00.html>
- IRS Publication 502: what medical/dental expenses you can deduct on your taxes:
<http://www.irs.gov/publications/p502/index.html>

Tips from Parents/Providers:

- Keep a copy of all your medical bills. Keep them all in one place and in date order (if possible).
- If your bank has online banking, you may be able to export your expenses into an Excel spreadsheet (or other financial management software). This can save you a lot of data entry time.
- Be sure to investigate whether or not your employer offers a Flexible Spending Account or Health Savings Account. These two types of tax-deferred accounts can help you save a LOT of money!

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- The IRS calculates that the average person/family will spend about 7.5% of their adjusted gross income on medical expenses. The IRS calls this your “standard deduction”. If you think you will exceed the standard deduction, make sure you keep all your medical receipts.