



Complex Child E-Magazine

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Creating a Medical Summary for Your Child by Susan Agrawal

One of the most helpful things you can do for your child is to create a medical summary detailing his or her medical history, diagnoses, and symptoms. Not only is such a document unbelievably useful in an emergency or if something happens to you, but it is also a wonderful way to concisely provide information to new doctors, therapists, school personnel, and so forth.

I recommend creating at least two medical summaries: a one to three page document highlighting the most important aspects of your child's medical history, and a longer version that contains additional information, including test results and a complete history. It may also be helpful to create an emergency form that summarizes your child's care. The standard form used for this purpose is the American Academy of Pediatrics emergency form for children with special needs, available at http://www.medicalhomeinfo.org/tools/emer_med.html

The Short Medical Summary

Even if your child is extremely complicated medically, it is invaluable to create a short medical summary of no longer than three pages. A three-page document is about the maximum a doctor can process in one sitting. Even if your child has had 40 hospitalizations and 30 surgeries, you still need to try to condense all of that information into a very short summary.

When creating the summary, think globally. You do not need to list every surgery, hospitalization, illness, diagnosis, and medication. What you need to do is provide a general overview of your child's history and current status.

Here is a sample for a short medical summary. Notice that only the "highlights" are included. Information about medications and specific hospitalizations is not included. I like to order the short summary by date to give a clear picture of what the child's life has been like over time.

Short Medical Summary for XYZ

Name: XYZ

Birthdate: 1/1/2007

Address: A Very Special House

Phone Number: 555-555-5555

Primary Diagnosis: Spastic Quadriplegic Cerebral Palsy due to prematurity

Relevant Symptoms and Diagnoses: Seizures, reflux, bronchopulmonary dysplasia, reactive airway disease, tracheomalacia, has a trach, on oxygen 3LPM, has a G-tube.

Relevant Medical History:

1/1/2007	Premature birth at 26 weeks due to premature rupture of membranes NICU 122 days Ventilator 56 days MRI/CT show Grade 3 bleed in brain Discharged home with NG tube and oxygen (2LPM 24 hrs/day) On reflux meds, albuterol, and phenobarb
5/07	Hospitalized 8 days with respiratory distress and vomiting
6/07	G-tube placed; 100% tube fed
8/07	Spastic Quadriplegic Cerebral Palsy diagnosed
10/07	EEG shows partial complex seizures; begins Keppra
11/07-4/08	7 respiratory infections, 4 hospitalizations
12/08	Trach placed due to tracheomalacia
1/08	Hospitalized for 18 days with RSV
5/08	Reactive airway disease diagnosed Started on Flovent and allergy medication Oxygen reduced to at night and PRN only
7/08	Hospitalized 16 days for trach infection
8/08	Started on baclofen for tone management Begins using a stander and gait trainer
10/08	Small oral feedings initiated; purees only Passes swallow study for purees and honey-thick liquids
11/08-4/09	4 respiratory infections, 3 hospitalizations Oxygen needs increase to 3LPM 24 hrs/day
5/09	Hospitalized 6 days for trach infection

Primary Issues:

Chronic respiratory and trach infections

Oxygen dependent

Reflux and vomiting with tube feeds

Developmental delays (cannot sit up by self, no speech)

High muscle tone in extremities; low muscle tone in trunk

The Long Medical Summary

The long version of the medical summary fills in all the details that were not included in the short version. This summary can be very helpful to you, especially if your child has a long history and you cannot recall every hospitalization or test result off the top of your head. It can also be very helpful to residents and attending doctors when you visit the Emergency Room, or when you see a new doctor.

In general, the summary does not include care instructions, such as your feeding schedule, how to change your child's feeding tube, or your usual protocol for tracheotomy care. Nor does it contain a list of your child's doctors or therapists. Instead, it focuses on your child's medical history. It may be helpful to also create a Care Book that provides detailed care information. See this previous article on that subject:
<http://www.articles.complexchild.com/00018.html>

Below are the general categories you will want to cover in your long summary. Expect it to run anywhere from two to twenty or more pages. Try to be brief and concise but still provide all of the important information, especially when it comes to test results. I have annotated each category to explain the general type of information that should be included.

Medical Summary for Child XYZ

Name:

Birthdate:

Address:

Phone Number:

Primary Diagnoses

While you do want to be relatively complete, it is not necessary to list every single diagnosis in this section. For example, my daughter has many small diagnoses, such as anemia and keratosis pilaris, that do not need to be listed because they are of secondary importance. Try to stick to the most important diagnoses, and keep it under 15 if possible.

Presenting Symptoms

Some children do not have a firm diagnosis but have a clear set of symptoms. This is the relevant section for listing out any symptoms that are not explained by the diagnoses listed in the Primary Diagnoses section. In some cases, it may also be useful to expand on the diagnoses listed above if your child has a "catch-all" diagnosis like Cerebral Palsy or a Metabolic Disorder.

Birth History

Indicate if your child was born at term or premature. List any major problems during pregnancy and delivery. Detail the length of NICU stay and what interventions were necessary, such as ventilation or heart surgery.

Past Medical History

This section will likely be one of the longest sections. List out, by specialty, the relevant history over your child's life for each area. Listed below are the specialties I cover in my daughter's medical summary. Note that I collapse some specialties together, such as putting ENT, allergy, and pulmonology under the general category "Respiratory."

- Neurological
- Gastrointestinal / Nutrition
- Respiratory
- Infectious Disease / Immunology
- Urological
- Hematological
- Dermatological / Circulation
- Cardiac
- Endocrine
- Vision
- Motor
- Orthopedic

Tests and Results

This is another long section, and one that is likely to continue growing. It will also need to be updated frequently. I list all forms of imaging (CT, MRI, ultrasound, Xray, scopes, and scans) in this section. Other tests, such as EEGs and EKGs, should also be listed here. Studies such as Sleep Studies or pH probes also belong in this section. Basically, anything that is not a blood, urine, or other body fluid/substance test should go here.

Significant Laboratory Findings

This section is for blood and urine test results, along with tests such as cerebral spinal fluid, cultures, biopsy results, pathology, and so on. Genetic testing should also be included in this area. This is another section that is apt to be long and will need to be updated frequently. Note that the title of the section is "Significant" Laboratory Findings. You do not need to list every single White Blood Count and Hemoglobin your child has ever had. Instead, summarize trends, such as "low hemoglobin from 7.4-9.0 during illnesses" or "chronic high White Blood Cell count." If there are certain tests that you track over time, it may be useful to create a separate flow sheet that lists those tests and the results by date. You can create your own or input your information into Google Health, which will do it for you with graphs and averages.

Surgical History

List out every surgical procedure your child has had and the date or age of your child when it was performed. Most people include anything that required general anesthesia, such as scopes and biopsies done in the operating room.

Hospitalizations

List all hospitalizations of one night or longer. Day hospitalizations can be omitted, as they are usually listed in different categories, such as the surgical history. List the dates of each stay, how long each stay was, what the general reason for it was, and if any days were spent in an ICU setting.

Medications

List out all of your child's current medications, including route (oral, G-tube, IV, etc.), strength, and dosage. Try to list medications in milligrams instead of amounts like teaspoons or milliliters. Remember to list out all medications, including over-the-counter drugs, vitamins, and supplements. Some parents choose to also include a list of discontinued medications, including when they were used, why they were discontinued, and what the effects and side effects were.

Allergies

List any drug, environmental, or food allergies in this section, including the severity of the response and what happens (hives, difficulty breathing, etc.)

Family History

If a sibling, parent, or other relative has a similar disease, it is important to list it in this section. General family history may also be given, such as "multiple extended family members with allergies" or "history of high blood pressure on father's side."

Social History

This section should include who lives with your child (parents, siblings, grandparents, etc.) as well as who cares for the child, such as nurses, nannies, and so on. Include a list of pets as well. Any information about the family, such as whether anyone smokes, if there is lead in the house, if there is a history of abuse, and so on, should also be placed in this section.

Diet

List out a general description of your child's diet, including route (oral, G-tube, J-tube, IV), what type of food or formula, frequency of administration/eating, any religious dietary restrictions, and any food sensitivities.

Immunizations

If immunizations are up to date, all you need to do is say "Up to Date." Explain any immunizations that are not current and why.

Development

For children who are typically developing, this section may be excluded or just listed as "normal." Children with delays should have their delays briefly listed by category, such as cognitive, speech, gross motor, fine motor, motor planning, social, visual, etc.

Therapies

If your child receives therapies, list out the type of therapy and how frequently you attend (for example, Physical Therapy once a week for 60 minutes).

Education

If your child is in school, list out the type of program (regular education, special education, autism program, etc.), your child's attendance record, and summarize your child's progress in school.

A Template for a Medical History At-a-Glance

A frequent contributor to Complex Child, Jennifer Peterson, has created a very useful Microsoft Excel template for her child's medical history and other pertinent information. She has kindly agreed to share it here. You may download it at <http://www.articles.complexchild.com/july2009/mhg.xls>