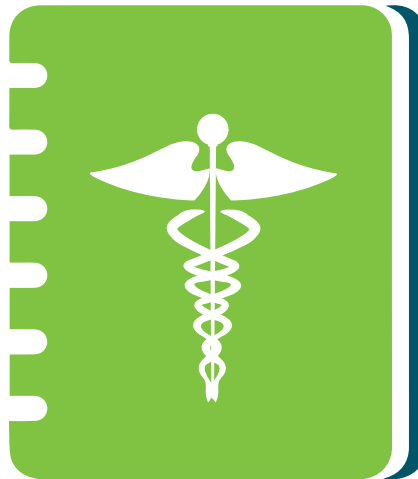


BUILDING A CARE NOTEBOOK

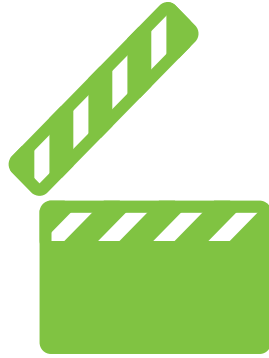
BUILDING A CARE NOTEBOOK



Introduction

This toolkit will help patients and caregivers to maintain a care notebook, a central place for gathering and organizing information relating to the ongoing care of their own or their child's rare disease. Beyond the practical reasons for collecting all of the information relating to a patient's care in a single place, the care notebook is a powerful tool for helping patients take charge of their own healthcare and ensure they play an active role in their care. It will help ensure they are prepared for talking to doctors, insurance companies, or others who are central to providing medical care, insurance coverage and support. Creating a care notebook also will help keep questions at the ready to help patients get the answers they need when they need them.

SECTION 1: FIRST TAKES



Tammy Bowers' son Landon was born with Noonan Syndrome with Multiple Lentigines (NSML), a RASopathy disorder also known as LEOPARD syndrome, a rare genetic disease that can affect the skin, heart, inner ear, head and face, or genitals. By the time he was three months old, he underwent a heart transplant. A month after the surgery when Landon was sent home, the hospital provided Bowers with a binder of information about Landon's disease and forms to record his heart rate and medications. It was her first introduction to a care notebook.

At the time of Landon's diagnosis there were about 200 known cases of NSML in the world. Bowers would find that whenever she would go to a new doctor, they had never heard of the disease. "A lot of my care notebook has education, research papers on the syndrome, what to look for, what it is. When we go to different doctor, I can share that information with them," she said. "We are frequent visitors to the emergency room with his heart condition, so having a list of his medications and tracking has been essential when we go to the hospital."

SECTION 2: CREATING A CARE NOTEBOOK



A care notebook is an organizing tool for patients with complex medical conditions and their families. It allows patients to keep in one place all of the relevant information, documents, and data needed to track and manage a rare disease. Many healthcare providers have recognized the value of care notebooks and may provide assistance to patients with setting one up. Not only is a care notebook helpful for keeping a central record for a patient's care team, it also may be valuable to create a mini-care book for family members, neighbors, babysitters, teachers, school nurses or co-workers.

"It's also a great idea to create a mini care notebook to keep in your work office, with your HR department, or the nurse and office at your child's school. If an emergency arises, your coworkers and those around your child will have immediate access to see that the medical needs are met. We never fall ill or have an emergency that is planned for, so preparing for worst case scenarios will ensure your and your loved one's safety and health will be taken care of."

- Anne Bruns, Parent advocate, Director of Outreach and Advocacy of the aHUS Foundation

There also are many care notebook forms available for free online that people may find useful in creating their own care notebook and that are included in the resource section of this toolkit. Some of these are tailored to meet the needs of patients with specific diseases, but what works for one person may not work for another. The creation of a care notebook is an individualized process. Remember, this is an organizational tool designed to keep needed information at the ready for meetings with doctors, health insurers, school officials and others.

SECTION 3: GETTING STARTED



Starting a care notebook is about getting organized. A good first step for parents is to gather all of the relevant information including the following:

Patient's medical history

Doctor's reports

Test results

List of medications

Contact information for all of their healthcare providers

Contact information for anyone on the care team

In addition, the care notebook will provide a place to track data about your child, such as vital statistics, diet, behavior, and sleep.

Gathering Supplies

Building a care notebook may bring back memories of the first day of school and shopping for supplies. Plan on making a trip to the local office supply, stationary store, or general retailer to gather some basic supplies that will be helpful in assembling your care notebook.

Suggested materials:

- 1.5 inch or larger Binder
- Dividers with Pockets
- Calendar
- Business card holder pages
- CD holder sleeves
- Loose Leaf Paper
- Plastic Folder Sleeves
- Sticky Note Tabs
- Pencil Case with Pens

SECTION 4:

ORGANIZING THE CARE NOTEBOOK



Once all of the information is gathered, it will need to be organized. In this section, there is a suggested organization for the care notebook, but it is by no means the only way to organize a care notebook. The idea is to be able to easily find needed information. If there are sections that don't seem to serve a purpose, or others that are not included that are needed, make adjustments. The idea is to build a tool that works for each patient.

As a starting point, consider creating the following sections to the care notebook. Patients may find they need alternative sections, but the following list should serve as a good guide to get anyone started. At the end of this toolkit there will be a list of resources that will provide additional suggestions for organization and provide sample pages and forms.

Finding Forms

Many online sources provide forms for inclusion in a care notebook. In addition to obvious forms such as contact pages, medication lists, and calendars, there are many other less obvious forms that may prove useful depending on your individual needs. This includes such things as forms to track equipment and supplies, record out-of-pocket expenses, and maintain a call log to create a record of all phone conversations related to the patient's care. At the end of this toolkit is a list of resources that will allow you to find template forms that can be downloaded and printed out for your care notebook.

Using the Care Notebook

Once built, put the care notebook to work. It should be kept in a safe and accessible place and carried to any appointment involving the patient's health. Use it to prepare for a doctor's appointment and have any new information or questions ready for your doctor. At the appointment, use it to take notes. And after the appointment, use it to incorporate and organize any new information or results provided at the appointment.

SECTION 4: ORGANIZING THE CARE NOTEBOOK

Try setting up the care notebook with the following sections:

- **Cover Page**
Contact information for the care notebook should go on this page in case the notebook is ever lost. It's also a good idea to list who to contact in the event of an emergency.
- **Questions/Notes**
In this section, you can keep your list of questions to ask at the next medical appointment and paper to take notes on during your visit. Once you write down the answers to your questions, you can move that documentation to the specific specialty section.
- **Care Log**
Track vital signs, diet, sleep patterns or any daily activities you feel you need to share with your provider.
- **Medication List**
Keep a list of all of the medications being taken currently and have taken in the past. Be sure to include dose and frequency.
- **Allergy List**
Maintain a list that includes all known allergies to medications, and other allergies that are relevant. For example, an allergy to latex or certain foods should be included here, as well.
- **Calendar**
Keep track of appointments and remind yourself when to schedule the next ones.
- **Medical History**
Write down the patient's and family medical history. This should include a list of any known allergies and all immunizations.
- **Hospitalizations**
Maintain a list of all the dates the patient has been admitted to a hospital and keep discharge summaries here, as well.
- **Medical Contact List**
Obtain business cards from every physician, specialist, testing facility, lab, and therapist you visit. Place them all in business card holders. Even if you stop visiting any of the medical specialists, hold on to their cards so you can refer back to them if you need copies of previous medical records. You can also place your appointment reminder cards in here so you don't lose them.
- **Medical Specialists**
Keep a separate section for each specialist the patient sees. You can place your after visit summaries here.
- **Test Results and Labs**
Keep a list of all test results and labs. You can also store medical imaging CD's in the CD Holder sleeves in this section.
- **Insurance**
Keep copies of your insurance cards, track how much you have been billed, how much insurance has covered, what you have paid, and when. If you need to contact the insurance company, keep a log of who you spoke with, what you spoke about, and when you spoke.
- **Disease 1-page Overview and Research Articles**
Keep the latest research articles and abstracts of articles to share with your providers.

SECTION 5: GOING DIGITAL



Care notebooks have their limitations. Not only can they grow fat with paper, but they may not always be where they are needed. Consider the experience of Bowers, the mother of NSML patient Landon. Recently she needed to rush Landon to the hospital. Her husband had their car and she called an ambulance, but she discovered Landon's care notebook had been left in the car. The heart tracking information and list of medications she would normally share with the doctors was not available.

It was that type of experience that helped inspire her to launch Lionheart Innovations, which is developing a care notebook app that is now in beta testing. It's part of a growing number of efforts to move care notebooks from the three-ring binder to the digital age.

Anywhere Anytime

In today's world of technology that allows us to be connected nearly always and instantly, there's a case to be made for an electronic version of the care notebook that can be accessed anywhere via smartphone, tablet, or computer. For some people, this approach will be a preferable way to gather, manage, and share information. Instead of adding printouts of test results, an image of the results can be captured with a smartphone and entered into the electronic care notebook directly. Not only can information be more easily entered and organized, but the electronic care notebook offers the ability to share information with others who may need it.

"Because the process has been so manual over the years, being able to share that information has been really challenging when you come back home and try to support a care team, whether its family members, friends, neighbors," said Todd Kozikowski, CEO and co-founder of Yabidu, the developer of another electronic care notebook. "With the advent of digital technology, the ability to share that in a much more private and secure way, but also to have an index of that information, is really important for our families and for us."

The Yabidu care notebook allows the user to provide access to sections of the care notebook to people who are providing their care. This allows easy access to critical information about medications, schedules, behavioral issues and more for someone, such as a babysitter or relative. It can also be turned off at will.

Building an electronic care notebook is similar to building a traditional one. Some are organized into chapters or sections to help categorize information. For instance, a chapter on the care team may include information about each of the doctors and other healthcare professionals who work with a particular patient. This may include a photograph of the professional, contact information, biographical information, and notes. Some digital care notebook options also allow you to manage your appointment schedule, keep track of daily symptoms and medication, and sync with a mobile smartphone.

SECTION 5: GOING DIGITAL

The Future of Care Notebooks

The electronic care notebook provides the opportunity for an exchange of information, whether it is a provider sharing new disease information to a patient, or a parent sharing information with another member of their child's care team. It's not difficult to imagine the potential in the future to link not only electronic health records to care notebooks so data is automatically updated in the patient's care notebook with each medical visit, but also to allow providers to better monitor patients remotely and intervene when potential problems arise. Providers would have access to key data that can show changes in key health metrics or problems adhering to medication schedules. Eventually, it may be possible to aggregate information from care notebooks to provide real world data to researchers to gain new insight into specific diseases.

RESOURCE GUIDE



A number of websites not only provide further discussion of care notebooks, but a wide range of forms that can be downloaded for use in care notebooks. Below is a sampling of these websites:

American Academy of Pediatrics National Center for Medical Home Implementation
page on Building Your Care Notebook
http://www.medicalhomeinfo.org/for_families/care_notebook/

Seattle Children's Hospital Center for Children with Special Needs
<http://cshcn.org/planning-record-keeping/care-notebook>

Collaborative Care Notebook from Utah Family Voices
http://www.fv-ncfpp.org/files/5813/0721/3621/Care_Notebook_-_entry_enabled1_reduced.pdf

Exceptional Children's Assistance Center
<http://ecac-parentcenter.org/userfiles/F2F/CareNotebookfillable42010.pdf>

If you are interested in learning more about electronic care notebooks or experimenting with them, below are links to several options:

CareSync
<http://www.caresync.com/>

Lionheart Innovations
<http://www.lionheartinnovations.com/>

My Medical App
<http://mymedicalapp.com/>

Yabidu
<https://www.yabidu.com/>

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<http://globalgenes.org/toolkits>