

# Wyoming Packaging Wisdom

**First Edition 1997** Children’s Special Health, Diane Magill, Parent Coordinator

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**Second Edition 2007** Family Voices, Rick Skagen

**Third Edition 2012** Wyoming Family 2 Family Health Information Center, A project of Parents Helping Parents of WY, Inc.

**Fourth Edition 2014** Parent Information Center, A project of Parents Helping Parents of WY, Inc.

## ***About PIC***

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Parent Information Center (PIC), is a statewide parent center for families of children with disabilities. PIC provides information, support and referrals to families on their rights and responsibilities under the special education law- the Individuals with Disabilities Education Act (IDEA). We help families understand their child’s disability and support them in working as partners with schools and service providers to receive better education programs and services for their children.

We are a non-profit, 501(c) 3 organization; therefore, your donation is tax deductible. We welcome all donations. Every donation helps us strengthen our network of support for families.

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# Section 1 Introduction

## ***What is a family centered care coordination notebook?***

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*Packaging Wisdom* is a care notebook to help you organize information regarding your child's chronic health condition. In caring for your child with special health needs, you may receive information and paperwork from many sources. A care notebook such as *Packaging Wisdom* will help you record important information about your child's health care, and will make it easier to keep track of changes, share information with your child's care team, child care, school, and family members. It has a variety of worksheets that reflect questions most often asked by professionals or information that families most often must provide. These worksheets may be filled out to be used as a reference about your child's health and needs. A care notebook will also help in managing treatment as well as routine health care, and will allow for easier long term planning. Each section also includes useful information pertaining to that particular section's subject matter. Finally, planning for the assorted changes and transitions that will happen at different times throughout your child's life starts now, and your care notebook will help you all along the way.

You know your child best. You also have your child's best interests at heart, so you are in the best position to advocate for your child. You are the one most familiar with your child's history and the best one to document it. For this reason, care notebooks are very personal to your child and ideally should be personalized to reflect your child's medical history, current information and any other information you decide is important to track. A care notebook tells your child's story, and you and your child are the authors.

## ***About Packaging Wisdom***

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Packaging Wisdom was developed by parents with children with special health needs. It is based on their personal recommendations as well as recommendations from national resources such as the American Academy of Pediatrics, Family Voices – National Center for Family/Professional Partnership, and the National Center for Medical Home Implementation. The notebook includes sections for the major areas of consideration when dealing with special health concerns: health care information; insurance coverage and financial resources; educational information; emergency preparedness; and transitioning into adulthood. There are also sections for correspondence, contacts, notes, commonly-used terms, resources and additional information. You may use *Packaging Wisdom* "as is", or you may customize the notebook as you wish, removing pages or sections, replacing them with forms from other sources, and adding articles and information.

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### **Introduction 1.1**

The most important piece of this notebook is your child; therefore, the first section after the introduction is called **All About Me**. This section is devoted to your child, allowing others to not only get to know him or her beyond special health needs or disabilities, but to also understand how these special needs impact all areas of your child's life. **All About Me** can include information regarding your child's communication capabilities and needs, nutrition, friends, stressors and how to manage them and sleep habits. Many families choose to not only include their child in completing this section, but to also decorate the cover of their care notebook with their child's artwork or photos.

## ***Setting up Packaging Wisdom:***

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### **Step 1: Gather information you already have.**

Gather up any health information about your child you already have. Consider information you look up and use often. This may include reports from recent doctor's visits, recent summary of a hospital stay, this year's school health plan and/or Individualized Education Program (IEP for special education), test results, or informational pamphlets.

### **Step 2: Look through the pages of the Care Notebook**

Can any of these pages help you keep track of information about your child's health or care? Use the Care Notebook as it is, remove pages or get more pages that will help you personalize your book to your child's need. Additional pages are available on the Packaging Wisdom CD or at [www.wpic.org](http://www.wpic.org). You may also find additional care notebook resources at the following websites:

National Center for Medical Home Implementation

[http://www.medicalhomeinfo.org/for\\_families/care\\_notebook/](http://www.medicalhomeinfo.org/for_families/care_notebook/)

Family Voices/National Center for Family-Professional Partnerships

<http://www.fv-ncfpp.org/>

Center for Children with Special Needs

<http://www.cshcn.org/planning-record-keeping/care-notebook>

### **Step 3: Decide which information is most important to keep in your child's Care Notebook**

- What information do you look up often?
- What information do caregivers for your child need?
- Consider storing other information in a file drawer or box where you can find it if needed.

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## **Introduction 1.2**

Packaging Wisdom: A Family Centered Care Coordination Notebook  
Parent Information Center | 500 W Lott St Suite A Buffalo, WY 82834 | 307-684-2277

#### **Step 4: Assemble your Packaging Wisdom care notebook.**

Everyone has a different way of organizing information. The KEY is to make it easy for you to find again. Here are some suggestions for supplies used to create care notebooks:

- 3-ring notebook or large accordion file to hold papers securely.
- Tabbed dividers to create your own information sections.
- Pocket dividers or sheet protectors to store reports.
- Plastic pouch for notebooks for holding notes, miscellaneous items.
- Plastic pages to store business cards and photographs.

#### ***Filling in and updating Packaging Wisdom:***

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- Track changes in your child's medicines or treatments.
- Add new information whenever your child's treatment changes.
- List telephone numbers for providers and contacts.
- Prepare for appointments.
- File information about your child's health history.
- Have information such as insurance documents.

#### ***Helpful Hints for using Packaging Wisdom:***

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- Store where it is easy to find. This helps you and anyone who needs information when you are not there.
- Share new information with your child's primary care physician, therapists, family members, school nurse and school staff, daycare staff, and others caring for your child.
- Take Packaging Wisdom with you to appointments and hospital visits so that information you need will be easy to find.
- Include your child when working on Packaging Wisdom. Let them know that the care notebook contains information about them and their care.

#### ***Access to Information:***

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You may wish to obtain copies of your child's medical records to assist you in the management of your child's health care. In recent years legislation has been enacted at both the state and federal levels to define when and how you can obtain this information.

Although your child's hospital and physician's records are their (the provider's) property, the information contained in that record is considered to be your property (or your child's, if he or she is over eighteen years of age).

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#### **Introduction 1.3**

You have the right upon written request to review or receive copies of records. You can review and copy your child's medical history, bedside notes, charts, pictures and x-rays, and other information included in the hospital chart. Send your request to review and/or copy portions of the record **in writing** to the records administrator of the hospital or provider's office.

Again, in order for you to obtain copies of medical records, your request must be put in writing.

Often a hospital or physician will have a preprinted release form that you can complete and sign to request the reports. A handwritten note will usually be sufficient; however, the following information should be included in your note, or request:

- The date of the request, your contact information and where to send the information.
- Identifying information regarding your child, such as his or her full name, birth date and address.
- The name of the hospital, physician, or facility from whom records are being requested.
- A specific description of the material being requested, including the dates when your child received services, when possible. The more detailed the information, the easier it is for the physician or facility to promptly honor your request.
- Your signature, if your child is less than eighteen years of age, or your child's signature, if he or she is eighteen or older. If your child is older than eighteen and has a guardian, the guardian would sign the release.

### ***Confidentiality:***

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Medical information is considered to be confidential and cannot be released by a physician or hospital without your written consent (or your child's consent, if he or she is eighteen years of age or older). Certain information may, however, be considered "non-privileged." This means that it can be shared without consent. This information includes the name, age, gender and address of your child and whether he or she is known to the facility or physician. Information can also be released in "statistical" form, if it does not reveal the identity of your child.

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#### **Introduction 1.4**

## Section 2 All about Me!

My name is: \_\_\_\_\_

My nickname is: \_\_\_\_\_

My birthday is: \_\_\_\_\_

Insert Picture Here

The color of my eyes is: \_\_\_\_\_

The color of my hair is: \_\_\_\_\_

I am: \_\_\_\_\_ right \_\_\_\_\_ left handed

I like to: \_\_\_\_\_

I don't like to: \_\_\_\_\_

I have a pet: \_\_\_yes \_\_\_no My pet is a: \_\_\_\_\_ and is named: \_\_\_\_\_

My friends are: \_\_\_\_\_

My caregivers are: \_\_\_\_\_

When I am happy I: \_\_\_\_\_

When I am sad I: \_\_\_\_\_

I need help with: \_\_\_\_\_

I can do these things for myself: \_\_\_\_\_

If you need to know something else, call: \_\_\_\_\_

### ***My Favorite Things***

Colors: \_\_\_\_\_

Toys: \_\_\_\_\_

TV shows: \_\_\_\_\_

Games: \_\_\_\_\_

Hobbies: \_\_\_\_\_

Types of music: \_\_\_\_\_

### **All about Me! 2.1**