

This is an invaluable tool for anyone who might need to come in suddenly and help with your child. Additionally, it gives you peace of mind when you train someone and want to leave for the first time. You will know your child's caregiver can look up anything she

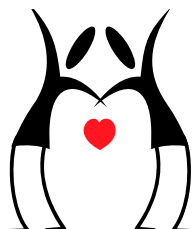
needs to know, and there you will be in a picture showing her all over again.

Additional information, such as emergency numbers, insurance information, family, friends and doctor phone numbers can go in too, as well as releases to seek medical treatment in your absence. You may also want a copy of your instructions regarding life-threatening events and so on.

***Always keep this notebook in the same place.***

Many people today have video cameras and that works beautifully for caregiver instructions. Still, for moment-to-moment questions that arise, it is helpful to have a caregiver notebook where a particular question can be answered at a glance, and one doesn't have time to set up a video and scan through it to find the part that is helpful. The notebook and a video would complement each other well, but for basics, easy accessibility, and emergency phone numbers, the notebook is "hands-on" help. ■

*This was adapted from an article written by Claudia Weisz, Editor, International Rett Syndrome Association Newsletter, Spring 1997.*



***New Hampshire Family Voices***  
*Family to Family Health Information  
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# Caregivers Guide For a Parents Peace of Mind



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## Caregivers Guide For a Parents Peace of Mind


They say a picture is worth a thousand words. Never is that more true than when you are preparing a caregiving guide for others to use to take care of your child.

All the schedules, instructions, positioning helps, and equipment to use can mean endless description and training before you feel you can leave your child with a caregiver.

Are you letting yourself out into the world, or are you locked into a caregiving situation that no one but you can fill? The number one *rule in raising a child with special needs is to never let yourself become indispensable.*


The best way for you to do this is to have people trained, of course. But that is such an overwhelming task that many parents never get help. Some parents fear the caregiver will never be able to do the job well enough, understand the child's signals clearly, or remember all their instructions.

 Here is where you can make a giant stride toward peace of mind. First, sit down and write out a basic overview of your child's hour to hour schedule. This is the schedule "chapter."


 Next, list the various activities you plan to show. For example, eating, bed, brushing teeth, toileting, traveling, positioning, transfers, etc. This list is your table of contents.


**For each subject, or "chapter," use a notebook divider with tabs, to shorten the time it will take to look up a question.**

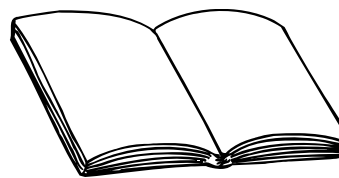
Now, picture in your head how you actually do these things, such as feeding. How is your child positioned to eat in his/her chair - does she need a pillow to help her hold up her arm? Does she drink through a straw? How are her feet positioned? On a stool or flat on the floor? Does she have a special dish or utensils? These details are difficult for a new caregiver to remember, but they are the things that make your child feel secure because of their familiarity.

 Have a friend or someone in the family take pictures of your child throughout the day. Start with rolling her out of bed... using a mechanical lift or do *you* lift her? Where are your arms? Do you first give her a massage? What happens next?



 Have several rolls of film handy. Put her swimsuit on her for bathing pictures, to respect her privacy in case someone else gets hold of the caregiving guide.

 If she walks with help, what is the best way to help her? Have pictures of you walking with her, showing where you support her. Does she use a wheelchair? Explain the transfers. What is her favorite past time? Offer photos of her doing things other than watching television. Get pictures of her interacting with people and pets. Expect to snap at least 100 pictures, and that perhaps one third to one half will be usable.



Organize the photographs according to activity, then affix them to pages in the notebook where you either print additional suggestions or use a computer to make additional notes. Put all these pictures in a three ring binder, and pick a favorite shot for the cover.