

Healthcare **Communication** Review

On Building Health Partnerships: Food-for-Thought, Practical Tips, Resources

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Understanding and Managing

PEDIATRIC CARE

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Active Partners In Healthcare: What It Means & Why Prepare Children For This Role

What It Means

Being an active patient means that patients learn what they can about their conditions – how those conditions will affect their lives if left untreated, what treatment options are available, how each of those treatments might help or hurt them, what their doctors recommend and why. Having learned all this, active patients are then better able to take the next step, which is to decide which treatment path to take and to give their truly informed consent.

Being an active *partner* in healthcare means that active patients (as described above) approach this task with an attitude that what both they and their doctors have to say is worth listening to and discussing before deciding whether or not to follow their recommendations. Being an active *partner* is different from being an active *consumer* (someone who thinks in terms of buying a service and that the customer is always right). Even though patients do pay doctors for their services, theirs is not a typical business relationship where the “buyer beware” message may be appropriate (This message encourages consumers to distrust providers of services or products.) The needs of patients and the duties of doctors in providing services to their patients are much greater, however, than those of salesmen and their customers. Healthcare relationships call for trust, not distrust. A key part of being an active partner, then, is building doctor-patient relationships where each respect and trust the other.¹

Why Prepare Children For This Role

Simply put, if it is important for today’s adults to be active partners in their care, it will be important for tomorrow’s adults as well. And, make no mistake about it, it *is* important for today’s adults. That’s because all the advances in medicine have led not only to greater chances of being helped, but also to greater chances of being harmed. That is a key reason why doctors are now required to get patients’ informed consent and why we so often hear on TV, and read in newspapers and magazines, that patients should keep on top of what is happening with their healthcare – that patients should take charge.

Preparing children for this role, however, may not be easy. First, it hasn’t been all that long since we have been expected to take responsibility for our own healthcare. We are still learning how best to do this ourselves. Second, children – especially young children – are often afraid of doctors and visits to them. Depending upon the reason for the visit, parents may be nervous as well. As a result, it may not be easy for parents to offer comforting information or for their children to feel comforted by that information. But there are steps that parents can take to make this task easier. The article on page 3 takes a look at some of them.□

¹ See <http://www.healthcp.org/hcr/v2n1-trust.pdf> for a more detail discussion of active partners and trust.

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From the Editor

If there is one job at the heart of all the other jobs parents have, we suggest that it is to prepare their children for adulthood – to help them become adults who are able to form their own families, to work, and to otherwise take responsibility for and successfully manage their lives. Managing their lives as adults will also include taking responsibility for their own health and healthcare. We therefore suggest that it is important for parents to help prepare their children for this role as well.

This issue covers why and how to go about doing that. On page one, we begin with the basics – what being an active partner means and why it is important for children to be prepared for this role. In our second article, we report on tested guidelines for raising children – guidelines that can be applied to the healthcare setting. In “Pediatric Care: Helping Children Become Active Partners,” we offer tips for helping children feel comfortable with their doctors and participate in their care in ways that are appropriate for their ages. The following article, on page 5, discusses ways to overcome some of the natural tendencies that prevent children from taking a more active role in their care. Also offered are reviews of two books aimed at helping parents prepare their younger children for visits to their doctors and the day that they will become managers of their conditions as active partners in their healthcare. We then round things off with a report on some online resources for parents and children. As usual, we hope you find this issue of value.

Be Well. *Judith A. Greenfield*



General Guidelines For Parents: Also Useful In Healthcare

Guidelines for raising responsible patients can be drawn from guidelines for raising responsible adults. Such guidelines are offered by the National Institute of Child Health & Human Development (NICHD), in their free booklet, *Adventures in Parenting (Adventures)*.¹ This booklet offers examples of how their “RPM3” approach to raising children was used by parents in three different age groups: Birth to 3 years, 4 to 10 years, and 11 to 14 years.

While it states up front that no one is perfect – we are all successful at times and make mistakes at other times – NICHD claims the approach outlined in *Adventures* will help parents be more effective, consistent, active and attentive. This approach, they report, is based on 30 years of talking to experts, parents and children; collecting statistics, identifying myths, and testing suggestions. The RPM3 approach calls for:

- **Responding** to your child in an appropriate manner
- **Preventing** risky behavior or problems before they arise
- **Monitoring** your child's contact with his or her surrounding world
- **Mentoring** your child to support and encourage desired behaviors
- **Modeling** your own behavior to provide consistent, positive examples for your child

Detailed explanations of what each of the above means and tips for doing them are found in the booklet along with the age-related examples mentioned above. While these guidelines are intended to help build general parenting skills, they can also be applied to the healthcare setting and help children grow into active partners in their care.□.

¹ See http://www.nichd.nih.gov/publications/pubs/upload/adv_in_parenting.pdf or call 1-800-370-2943.

Pediatric Care: Helping Children Become Active Partners

Responsibility for children's healthcare decisions changes in the years between birth and adulthood. In the beginning, parents make all the decisions. In the end, adult children will make all their own decisions. This is not a sudden shift. It occurs gradually over the course of years. During that in between period, parents remain legally responsible for making final healthcare decisions for their children. Even so, they can use this time to help their children build comfortable relationships with their doctors and become increasingly involved in healthcare discussions and decisionmaking.

Partnerships in pediatric care involve three people: the child, the parent and the doctor. It's not enough for parent and child to want to build relationships and participate in care. Doctors must be open to that as well. For this reason, the first step parents can take towards their goal of helping children build relationships with their doctors and participate as partners, is to find physicians that have an inviting manner about them. This is especially important for the very young child. As many parents know, children can be easily "put off" by doctors who make little to no friendly overtures towards them. In their article "Preparing Your Child for Visits to the Doctor," the KidsHealth website states that children may interpret a doctor's all-business approach as "sternness, dislike, or rejection."¹ If this happens, parents will have a harder time helping their children build relationships with their doctors. Finding a doctor who will talk to children in a friendly manner, then, can be very important. Advice on how to do so can be found in another KidsHealth article, "Finding a Doctor for Your Child."²

On Building Active Partners

After finding doctors whose manner invites communication, parents can then focus on preparing their children for visits to those doctors. The first step here is to simply help their children feel comfortable with the doctor. Again, this is especially important for young children since unpleasant impressions of doctors at early ages can have a lasting influence. Because feelings of comfort are the building blocks for good relationships, this helps children not only build relationships with their current doctors, but also sets the stage for building relationships with future doctors. Good relationships, in turn, serve as the building blocks for patient participation in care – whether the patient is

an adult or a child. The work of helping children feel comfortable with their doctors and participating in their care (in ways that fit their age) takes place before, during and after, each doctor visit.

Before the Visit

At any age, children's comfort levels may increase if parents invite them to express their fears and concerns before the visit and if they are told what to expect during the visit – what it is for and what kinds of things the doctor might do. Even knowing that Mommy or Daddy are not sure what to expect, but that he or she will be there with them, can help relieve some concerns. In other words, offering a listening and understanding ear to children, along with giving honest, age-appropriate answers to their questions, can go a long way to helping them feel better about seeing the doctor.

Before the visit parents can also involve children in the process of care by inviting them to help prepare lists of symptoms to report and questions to ask. Depending upon their ages, parents can also invite them to take part in reporting those symptoms and asking those questions. If they are not ready, parents need not force the issue. However, by asking why they don't want to participate and by offering a listening/understanding ear to their concerns, parents may get clues as to how to encourage such participation in the future, if not just then. If children are ready to participate, then parents should talk beforehand, about how this might be handled. Make it clear that Mommy or Daddy will ask questions, too, and that it won't mean that they did not "do well." Explain that even adults tend to forget or not think of things when they are with the doctor.

During the Visit

Children who are able and willing to report their own symptoms and ask their own questions, should do so first. Parents can always add to what their children have said or asked. If children are not ready to participate in this manner, parents can handle it all. However, after reporting symptoms and answering questions, parents might then turn to them and say something like: "Did I forget anything?" or "Do you have any questions?" If they feel comfortable enough at that time, this allows them to participate in the conversation. Even if the answer is a simple "No," an important step will have been taken. That is, it tells children that, when they are ready to participate, they will be heard.

See Helping Children, Pg. 4

Helping Children, continued from Pg. 3

After the Visit

Two important things need to take place after the visit. The first relates to the content of care. That is, it is important for the parent and child to talk about what the doctor said was wrong and what to do about it. This allows parents to see what their children heard and understood. It also gives parents a chance to find out how their children *feel* about what the doctor said. This is important, since how well children follow prescribed treatments will often depend upon how they *feel* about them.

Talking with children about *how* the visit went is also important. It doesn't have to be a "grilling," but it may be helpful for parents to find out how comfortable their child felt with the doctor and process, and why. If there are any concerns, then they can be addressed by talking them over with each other. If necessary, parents can speak directly to their doctors about those concerns, so they might be relieved during future visits.

Children's Participation in Decisionmaking

In legal terms, minor children (under the age of 18) are assumed to be incompetent (unable) to make healthcare decisions while adults are assumed to be competent (able) to make those decisions not only for themselves, but for their children as well. This raises a number of questions, some of which are: What does it mean to be competent? Are all adults really competent? Are all minor children really incompetent? Do all decisions call for the same levels of competency? Are there any decisions that children might reasonably be allowed to make? When parents make their decisions, what should they be based on and how much influence over those decisions should they let their children have? Unfortunately, there are no hard and fast rules that provide answers to many of these questions. It's often a matter of judgment. But we offer, next, information and guidelines that might help parents make those judgments.

What Does It Mean To Be Competent?

In terms of making healthcare decisions and giving informed consent, being competent means; being able to understand the different choices (of tests and treatments), their risks (of harm) and benefits (help) and, based on that understanding, being able to choose from among them without being improperly influenced by others. Arguments can be made that different decisions call for different levels of competency; that not all legally

competent adults are actually competent to give their informed consent; and that some minor children might be as able to make decisions as well as can some adults. Very few studies of informed consent exist, but ethicist and pediatrician, Dr. Lainie Friedman Ross, reports that the studies that have been done suggest that most healthcare decisions by adults and children had not been fully informed ones. Furthermore, many of those decisions had not been made competently and had been improperly influenced by others. The studies also suggest, she adds, that there is no real difference in the abilities of adults and older children to make healthcare decisions.³

Involving Children In Decisionmaking

Allowing children to make some of the more simple decisions may help prepare them for making more difficult decisions later in life. In which arm to get a flu shot, is one example of a simple decision that even the very young can make. Decisions for children with serious diseases, however, often call for a greater understanding than they might be capable of and parents are clearly expected to make them. That is not to say that their children, even younger children, should be kept out of the loop. It is often helpful to involve children in discussions of their choices and to ask for their opinions. Even though they cannot give their legal consent, many times doctors feel better about proceeding if they express agreement with the treatment plan. While Dr. Ross does not support the idea that children should make the final decisions, she feels that out of respect for them, parents should seriously consider their opinions before making the final decision. This is especially recommended when those children can be considered competent, even if that competency is not legally acknowledged.

A Basis For Making Decisions for Children

Guidelines for making decisions for others are based on whether or not the patient was ever legally competent. Because minor children have not yet become legally competent, the generally accepted recommendation is to make decisions that are in their best interests. Though this is a simple guideline, knowing what is in someone's best interest is not always easily determined. Then, again, there is not much about parenting that is easy, is there?□

¹ See www.kidshealth.org, click on 'parents' then 'doctors and hospitals' then on the article title.

² See note 1.

³ Lainie Friedman Ross, *children, families, and health care decision-making*, (NY: Oxford University Press, 2002)

It is often helpful to involve children in discussions of their choices and to ask for their opinions.

Parent-Child-Doctor Communication: Natural Tendencies

Natural tendencies of both doctors and parents can sometimes make it harder for children to take part in discussions during visits to the doctor's office. Doctors, like many of us, have a natural tendency to direct their comments to the people who are in charge. When it comes to talking with children patients, one study found that most of the pediatricians they observed talked mainly to parents, rather than to the children.¹ Although doctors tended to ask the children to describe symptoms, feedback regarding their findings was primarily given to the parents.

Parents, on the other hand, have a responsibility to take charge when it comes to seeing that the needs of their children will be met. This 'take charge' approach is often hard to set aside – perhaps even more so when it comes to matters of healthcare. As a result, it's not unusual for parents to interrupt their children who are trying to answer questions asked of them by their doctors, or to remain in the examining room during a physical – a potentially embarrassing situation for teenagers. How, then, can parents satisfy their need to make sure that the reason for the visit to the doctor is fully addressed and, at the same time, help their children grow into the role of active partners in their care? The following examples offer some suggestions for overcoming these natural tendencies.

Doctor Speaks to Mom, Not Child

From past visits, chances are that Mom and child, 'Tommy,' know, that the doctor speaks to Mom as if Tommy were not there. Efforts to change this might begin at home, before the office visit. It begins with involving Tommy in creating a list of symptoms and questions and deciding, with Tommy, that he will not only report symptoms, but will also ask some of the questions. By asking questions himself, he invites the doctor to respond directly to him. During the visit, if Mom sees the doctor is talking to her and not Tommy, she might do three things to show the doctor that he or she should direct feedback to both her *and* Tommy. She can simply ask the doctor to speak to both of them; she can turn to Tommy and ask him if he has any questions; or she can look at Tommy, rather than the doctor, as the doctor is talking.

Mom Interrupts Child

Answering doctors' questions might be an old habit that is hard to break and, even though she may not want to, Mom might find herself interrupting her daughter, 'Ginny,' who is answering a question the doctor had asked her to answer. Here again, efforts to change this behavior can

begin at home by speaking with Ginny before the visit and discussing what Ginny might say and do if Mom interrupts her. During the visit, if Mom sees that she's jumped in without meaning to, she can either stop herself mid-stream or, after finishing, turn to Ginny and invite her to add anything she wants to add. Mom can also tell the doctor that she is trying to break this habit and ask that, when the doctor wants Ginny to answer, he or she preface the question with something like, "Mom, now I'd like to hear what Ginny has to say about..."

Respect For Privacy versus the Need to Know

In February of 2007, 'Dear Abby' printed a letter she had received from a 14-year-old boy named C.J. In the letter, he expressed his dismay and embarrassment when his mother insists on being present during his physical exams – when he is unclothed. Abby's response, while accurate, did not address the likely reason for the mother's insistence on staying. That is, Mom may have the very valid concern that not everything that needs to get said will get said and/or that not everything that needs to be heard will be heard. Several things can be done, however, to relieve Mom's concerns and give C.J. the privacy he wants. Again, it begins before the visit by reviewing matters to discuss and listing questions and concerns with C.J. so he will

be more likely to speak about them if alone. (Giving the doctor a copy of the list will ensure that the doctor knows what you want to address.) Second, if it is not already the doctor's practice to sit and talk about issues before the actual physical exam, then Mom can request that he do so. She can be there for, that. She can then leave during the actual physical exam and return for a discussion of the doctor's findings after the exam.

Modeling

In each of the above examples, parents are not only helping their children take steps (preparing a list, asking questions) towards becoming active partners, but are showing them what active partners do – get and give information, work out potential problems and respect others. When parents are active partners for themselves and for their children, 'Do as I do' is the message that is sent. It is a powerful message. □

¹ Dulman, Alexandra Maria van. "Children's contributions to pediatric outpatient encounters." *Pediatrics* 102.n3 (Sept 1998): 563(6). *Health Reference Center Academic*. Gale. Mid-Hudson Library System. 11 July 2007 **Gale Document Number:** A21193377

Books For Parents Of Young Children

Editor's Note: Both books, offered by the American Psychological Association through Magination Press, are each 32 pages long with a list price of \$14.95.

Lions Aren't Scared Of Shots:

A Story For Children About Visiting the Doctor

By Howard J. Bennett, Illustrated by M.S. Weber
Reviewed by Kyra Sahasrabudhe

I'm a big believer in book therapy. Just give me a well-written story with good illustrations and I know that my children are going to pay attention and walk away with a deeper understanding of the issue at hand. I'm going to add this book to my collection. In pictures and words that engage young children, ages 4-6, it tells the story of Molly who is anxious about getting a shot during her routine visit to the doctor and how, by the end of that visit, she is ready for the shot she does, indeed, have to get.

Two pages for parents, written by Jane Annunziata, PsyD, offer tips for "Easing Your Child's Anxiety" and "Coping During the Doctor Visit." I was happy to read that many of the issues I've experienced as a parent taking my child to the doctor are valid. I particularly liked her advice about being honest with your child about the purpose of the visit and giving your child some degree of choice during the visit, such as letting her choose which band-aid to put over the teeny-tiny hole made by the needle.

I will certainly read this book to my three-year old before our next well care visit to her pediatrician. Sooner or later, there is going to be another shot.□

Imagine a Rainbow:

A Child's guide for Soothing Pain

Written By Brenda S. Miles, PhD,
Illustrated by Nicole Wong
Reviewed by Jeff Slater

Pain is a part of life – most of the time a briefly passing part. For those times when pain lingers, "Imagine a Rainbow" gives parents and children two important methods to help manage pain: **imagery and deep breathing.**

From Hippos in skirts to clouds in a sky filled with blue there is no doubt that the combination of words and beautiful illustrations are a great way to show children how breathing deeply and thinking positive thoughts can help ease their pain. The images are thoughtful, comforting, and span a wide range of ideas, bound in some way to capture the attention of young children.

A few pages at the end tell parents how to use this book with their children. Though I hope as a parent I won't ever need this book, I recommend it for those that do. In addition, the idea of using **deep breathing and imagery** is useful to all of us in just dealing with life's day-to-day aches and pains.□

Books, DVDs/Videos, Websites: Health Information Recommended By Teens For Teens

By Barbara Clapp

In the era of myspace, text messaging, and access to media of all forms, teens need to know how to evaluate what they're seeing and where to find reliable information to help them make informed lifestyle decisions. To address these needs, the Mid-Hudson Library System's **Health Information Project** provides access to teen recommended DVDs/videos, books and websites focusing on health and social issues of concern to young people, their families, educators and youth agencies. These materials may be borrowed free from libraries in the System's five counties or with a fee through interlibrary loan from any public library in the US. Videos have public performance rights for educational use.

As part of a 10-week summer Teen Intern Program, funded by the New York State Office of Alcoholism and Substance Abuse Services (OASAS) and New York's Dutchess County, teenagers aged 14-19, are trained in media literacy skills and critical evaluation techniques. They then work to evaluate selected, age-appropriate DVDs, websites addressing a wide variety of health and social issues, such as alcohol, drug and tobacco use; nutrition and body image, interpersonal relations; violence prevention; mental health and teen parenting. They also review books purchased for the collection and speak to a variety of area health classes and community organizations about their experience in the program.

Project staff use the teens' evaluations to purchase top-ranked DVDs for the library, and post links to top-ranked websites on the Project website: www.hip.midhudson.org. This site also serves as a bibliographic tool for educators and service providers seeking to build on their own collection of information resources.□

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Our Values
Personal Choice &
Self Direction
Teamwork
Communication
Genuine Caring

Our Vision
We envision a healthcare system where patients who want to be active participants in their healthcare will be encouraged and supported by the healthcare professionals who provide that care.

Our Mission
Our mission is to improve patients' understanding of, and participation in, their healthcare by fostering meaningful communication between patients, their caregivers and healthcare professionals.

Our Method
Our method is to focus on helping healthcare professionals, patients and their advocates build relationships and shared decisionmaking skills.

Our Means
Publications and Programs

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Online Resources For Parents And Children

Note: Those who do not have home access to the Internet, can access it from most public libraries. Librarians are more than willing to help explain how to do it.

One site that offers parents, children and teenagers comprehensive information on many conditions, diseases and much more, is the KidsHealth website (www.kidshealth.org). For good reason, this site was named as one of the Medical Library Association's top ten most useful websites for health information. There parents can find information related to general health, infections, emotions & behavior, growth & development, nutrition & fitness, pregnancy & newborns, medical problems, positive parenting, first aid & safety, doctors & hospitals and more. Children and teenagers can also get a wide range of information on topics that not only address medical matters but also many of the health/social related issues faced by their age group. KidsHealth also provides teachers with a variety of educational resources for helping children become and stay healthy – especially through nutrition and fitness. Materials are offered for all grades and even for subject areas. Educators can access his information by first clicking on 'Parents site,' then on 'teachers.'

Many disease-specific organizations also offer information for children with those diseases and for their parents. These include, but are not limited to, the American Cancer Society (www.cancer.org), the American Diabetes Association (www.diabetes.org, click on 'For Parents and Kids') and the American Heart Association (www.americanheart.org, click on 'Children's Health.'). If links to information for and about children cannot be found on other sites, then enter 'children' in the search box and see what comes up.

Other helpful sites include the American Academy of Pediatrics (www.aap.org/family/healthychildren/), which offers a quarterly online magazine for parents of young children, and the National Institute of Child Health & Human Development (NICHD), www.nichd.nih.gov/publications/pubs.cfm, both of which offer publications, in English and Spanish. On the NICHD site, scroll down on the keyword selection list and choose from among their selections, which includes adolescent health and child health.□