# Getting to Know You: A Dialogue for Community Health

Discussion Points for Women and Their Health Care Providers



A Publication of The Community Literacy Center and The Rainbow Health Center © 1996



The Community Literacy Center (CLC) is a community/university collaborative of Pittsburgh's 80-year-old Community House and the National Center for the Study of Writing and Literacy at Carnegie Mellon. At the CLC, literacy means not just reading but writing. In the CLC ARGUE Project, community members, like these women and health care workers, build consensus, solve problems, and take action on pressing issues through group dialogue and writing.



Rainbow Health Center

The Rainbow Health Center was founded in 1990 to provide primary health care services in the Mon Valley. By providing low-cost preventative, diagnostic, and treatment programs, the Center aims to improve the health of its surrounding communities. Individual counseling and educational programs that promote healthful lifestyle choices play an important role in the Center's overall goals.

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## Why We Wrote this Book

- Something is wrong. You haven't been feeling too well. Yet, the doctor seems to think it's all in your head. But darn it! It IS your body, and if you know anything, you know your body.
- The patient you are seeing seems so stubborn. Why hasn't she been taking that prescription?
- The doctor is explaining your test results. You can't understand those fancy medical terms that just fly right by you. What's really wrong with you?
- One minute this patient thanks you and nods her head when you explain the treatment she'll need, but later you find out from the nurse she is furious that you haven't diagnosed her as she expected. What's going on with her?

### The Importance of Dialogue in Health Care

Health care specialists are recognizing that effective treatment, regardless of good good technical equipment and medical knowledge, requires genuine cooperation and communication between doctors and patients:

Physicians need rhetoric as much as knowledge....Training in continuing care will be of little value without doctors who know something of the life of the people whom they serve... reading of course, must be accompanied by conversations that broaden the vistas available to us.<sup>1</sup>

The need is not for the distribution of services to passive recipients, but for active involvement of local populations in ways which will change their knowledge, attitudes and motivation.<sup>2</sup>

More than ever, community residents must work in genuine partnership with health care providers to create health in their own lives and in their communities. And yet, residents who are served by urban clinics and the physicians and nurses who work in them often have very different backgrounds. Cultural, educational, and economic differences between caregivers and patients can create barriers to communication and interfere with effective treatment. Patients who misunderstand diagnoses or have personal or cultural reasons NOT to comply with treatment may waste precious resources and may walk away feeling frustrated and misunderstood. Physicians may, in turn, label patients as uncooperative and be disappointed by the lack of results in their prevention and treatment programs.

This booklet addresses these barriers to communication and treatment by bringing together the expertise of caregivers at the Rainbow Health Center, female patients in the Pittsburgh community, and staff from the Community Literacy Center (CLC) in Pittsburgh. We invite you to use the book as a springboard to dialogue in your community or health care institution.

<sup>&</sup>lt;sup>1</sup>Spiro, Howard. (1992). What is empathy and can it be taught? *Annals of Internal Medicine*, 116:843-846.

<sup>&</sup>lt;sup>2</sup>Geiger, H. Jack. (1993). Community-oriented primary care: The legacy of Sidney Kark. Editorial in *American Journal of Public Health*, 83 (7):946-947.

### Strategies for Building a Dialogue

This booklet grew out of a writing workshop based on strategies developed in the Community Literacy Center's ARGUE Project. Three strategies help diverse groups of people, such as patients and health care workers, share their expertise and develop informed solutions to community problems:

### DEVELOPING A PROBLEM CASE

Writing a dialogue, scene, or story, we demonstrate a conflict, its negative effects and the conditions that contribute to it. Each section of this booklet introduces a different health-related problem through one or more powerful narratives. We invite you to use these stories as discussion points in both physician training and patient education programs. The psymbol indicates questions your group might use for discussion at various points in the text.

### • CREATING A SHARED INTERPRETATION

We recruit different stakeholders to the table, to share various kinds of expertise and analyze the problem in greater depth. As the discussion progresses, we weave rival perspectives into our written stories—uncovering rival interpretations, assumptions, cultural knowledge, and communication strategies that different parties bring to the situation. Throughout the booklet, the "Dialogue "and "Questions, Anyone" segments highlight technical and cultural knowledge important for addressing problems in women's health care.

### GENERATING OPTIONS FOR ACTION

Based on this collaborative discussion and writing, we devise new ideas, plans, and strategies that will lead to change. Throughout this booklet, the "What If. . " segments provoke new thinking about health care procedures, policy, and education. We hope that you will sustain these ideas, improve upon them, and bring them into practice in your community.

### **Taking Control: A Note to Female Patients**

Women often have a hard time talking and relating to doctors and vice-versa. In fact, some of us (admit it) get so frustrated that we avoid going to a clinic until it is absolutely necessary, and by then it may be too late. Throughout this booklet, we focus on obstacles to women's health—issues that have been neglected by the medical field and its research up until recently. We discuss not only common diseases and treatments, but the way in which we communicate about our health with health care workers.

The women who have written this book for you are very much aware of the factors that prevent us from getting good care. For example, we know that the color of our skin or even sitting in an emergency room in less than our Sunday finery with our very active kids can sometimes not generate very much sympathy from ER nurses. We have been around long enough to know that being on medical assistance and feeling insecure about ourselves because we have not gone beyond high school prevents us from speaking up and being assertive about what is wrong with us and what is best for our health.

This booklet is about taking control of our health. We know that we sometimes neglect our own health care because we are busy caring for others. But if we are going to work outside the home and raise a family at the same time we definitely need to stay healthy. If we want to feel confident about ourselves when we go to the doctor and develop a relationship of equality, we need to inform ourselves about our bodies and develop productive ways of talking to clinic and hospital staff so that we can make good decisions about our bodies. We need to make sure physicians and nurses who work in our communities understand our needs and concerns.

### What D'Ya Know?

Before reading this book, we suggest you sit down with your friends and co-workers to talk about these issues. Later, you can compare your answers with the perspectives of doctors, nurses, and women in our community who contributed to this book.

### **Questions For Discussion**

- 1. The stories you will read are about serious communication problems related to women's health in the Mon Valley. Can you predict what key issues emerged in a discussion with female patients?
- 2. Why might some African-Americans be reluctant to get tested for AIDS?
- 3. What was the Tuskegee study and how might it affect the relationship between some doctors and their patients?
- 4. Anita's boyfriend, Tony, gave her the clap. He says he probably got it from a toilet seat at a bar he went to last month. You say:
  - A. Poor Tony! He ought to sue them!
  - B. Get a new boyfriend, girl. He's probably been sleeping with an infected woman.
  - C. Anita, didn't your mother tell you to practice safe sex, even with your boyfriend? If you had used a condom maybe this wouldn't have happened.
  - D. Have you had unprotected sex with someone else yourself, Anita?
- 5. Match the problem with the correct resource:
  - 1. I think I may have AIDS.
  - 2. New mom always has baby in stroller and Dr. notices she never talks to baby.
  - 3. I am fearful my husband will hurt me again.
  - 4. New mom cannot afford formula.

- a. Family Resources
- b. Allegheny Health Department
- c. Woman's Place
- d. WIC Program
- 6. A pap smear will tell me if I have cancer of the ovaries. TRUE or FALSE?
- 7. Sexual abusers molest other people because:
  - A. They are horny.
  - B. The person being molested asked for it.
  - C. They have a sick need for power.
- 8. I can get AIDS from drinking after someone who has the virus. TRUE or FALSE?
- 9. Who is more likely to be sexually abused; who is more likely to abuse?

Young girl or boys? OR People with little/more education? OR A woman in her 20s or 40s? OR Children from poor or wealthy families?

10. Who should have an annual pap smear?

### What D'Ya Know... Answers

- 1. Not being comfortable with your body; not understanding medical terms; not knowing how to be assertive and ask questions; not knowing alternatives/steps to take when you are not satisfied with treatment; myths parents teach to their children; feeling intimidated by doctors; stereotyping patients: welfare, racism, body type; doctors' lack of cultural/background knowledge about women; doctors not knowing how to elicit information from and really listen to patients and read their non-verbal cues.
- They fear they will actually be injected with the virus as part of an experiment. The same goes for free TB testing and vaccinations.
- 3. In the Tuskegee study, 400 black men with syphilis were left untreated for forty years so that researchers could observe the course of the disease. This was a flagrant example of government-sponsored abuse, even more notorious because it took place in modern times, beginning in 1932 and continuing through the 1960s. Researchers told the patients that they were receiving free treatment each year. They were never told they had syphilis, and the medicine they received was a placebo. In 1972, the Washington Star reported the story. To this day, such unethical practices in medical history haunt the memories of many, who fear that they will be experimented on. This creates deep distrust between African-American patients and doctors.

Source: Dixon, B. (1994). Good Health for African Americans. New York: Crown.

- 4. B, C, and D. The chances of getting it from a toilet are extremely slim.
- 5. B. A. C. D
- False. A pap smear can detect cervical cancer; have a full pelvic exam to screen for other problems.
- C. Sexual abuse is an act of violence and done for control and power over another person.
- 8. False. AIDS is spread only through direct contact with an infected person's bodily fluids such as blood, semen, and vaginal secretions.
- Sexual abuse happens to and is carried out by people of all ages, of both sexes, and from all kinds of backgrounds.
- 10. Teens and women who have sex, or women over 20, regardless of sexual activity.



# Cancer and Culture

### Ardillia's Fear: No One Will Experiment on Me!

by Kathleen Payne

Ardillia Mitchell was a tiny, thin lady who had lost most of her hair. She always kept a clean vegetable tin can with her to spit her snuff into. She was from Mississippi originally but came up to Pittsburgh in her early twenties. She was now in her late sixties, and she had cancer. This is her story.

She was spraying for bugs in her house, and the floor was wet. She slipped and hit her back against the kitchen table. A couple days later, she started bleeding. She hadn't had a period in a long time. She figured it was caused by the fall.

She went to St. Christopher's Hospital. They told her she had cancer and explained they wanted to do a complete hysterectomy on her. The only problem they said she would have is that she might have to go to a nursing home for a couple of months to heal, but she would recover. She sat there in the chair and agreed with them, shaking her head saying, "Mmm Hmm, you're right." Then when the doctor walked out of the room, BOY! She would tell her relatives how she really felt. She swore they were lying to her and wanted to experiment on her. She thought the doctors were trying to kill her. The relatives told the doctor that she wouldn't give consent for the operation.

How would you interpret this situation? What could be done?

Ardillia was afraid of authority and especially of Caucasians; there is a history of older black people, especially from the South, who are scared of doctors. For example, the Tuskeegee study is on everybody's mind. The U.S. Department of Health aot black men from one little town who had syphilis and, instead of curing them like they promised, they watched them to see the effects of untreated syphilis. They even used black doctors and nurses to convince the men to participate. Miss Evers, a black nurse in the study, promised free medical care. When she drew their blood, they thought they were getting treatment. The men wound up passing on the disease and died.

When Ardillia lived in the South, the hospitals were segregated. Many doctors wouldn't even see black patients. She did not trust doctors.

The doctors at St. Christopher's said it was crucial at that point to get her operated on. They were going to give her a vaginal hysterectomy that would drop her organs down. They told the family, friends, and the home health worker—a white nun—to go and talk to her. When I, her granddaughter, went to convince her, she cussed me out. I explained they would put her to sleep. She said we were going along with the doctors just to get her insurance. Charles, her grandson, could have convinced her, but he was chicken and didn't want her to be mad at him. He didn't understand her women's problem either.

Six months went by. Ardillia was so bad they put her on Dilaudid (a strong pain medicine). She was afraid to even move or show it because she thought someone would poison her with medicine. She hid the medicine in her pillow case. She was in ridiculous pain because she was scared to take the medicine and afraid because of her stereotypes and died a horrible death when she didn't have to. Two weeks before she died, she finally asked for the operation, but it was too late.



# Dialogue





A PATIENT
SAYS . . .

This story shows how a life of discrimination can cause a person to stereotype doctors. After years and years, it is hard to change your mind. In your heart even if you don't agree with the doctors, you will say you do. The only healer she trusted was a man they sent up every year from the South who would exorcise snakes from diseased bodies. It takes time for doctors to explain things to a woman like Ardillia, but it is worth the time. Everybody is talking about the high cost of health care. Medicine is great, but if you can't get it to the people, it' doesn't work.

The doctor might say, "Would you repeat back to me what I just said" to see if the patient really agrees and understands. The doctor might have noticed that Ardillia was shaking her head before he even could say it all—like the little dogs in the back of the car. Maybe if I shake my head, she thinks, he will just get out of here.



A DOCTOR SAYS...

Sounds like she had advanced cervical cancer. That's sad because it could have helped if they caught this earlier with a Pap smear. If someone had managed to break through her mistrust, even if she had not had surgery, the doctor could have helped her in her pain and made her more comfortable.

It sounds like she wouldn't have done well in a nursing home, and that part of it might have scared her. If the doctor knew her better he might not have suggested that.

How do YOU think a doctor could deal with it better?

**Granddaughter:** Knowing some fears older African-American people have about experiments on black people. Lots of black people today don't even like to get AIDS testing because they think you're giving it to them.

**Doctor:** But today? We have medical ethics and laws to prevent this kind of thing. I can't believe people really fear this could happen.

Grandaughter: It happened in this century—not too long ago—and still is. On the radio this summer (1996) they said that Blacks and Latinos in L.A. were just given a new, experimental vaccine for measles, mumps, and rubella without their informed consent. The U.S. Center for Disease Control did this. That's too bad, because some people will now refuse to come and get their kids shots, even though the kids need them. You better believe this will spread through the black community like wildfire.

**Doctor:** I really wasn't aware of how people still have so much fear around these issues. They cover this type of thing in medical school; very quickly, as a mistake of the past. And we don't spend a lot of time on cultural issues in medical training, especially back when I was in school.

## What if. . .? Exorcising the Fear of Medicine

What if... The medical staff appreciated patients' fear of medicine based on historical, racial discrimination in medicine?

What if. . . A group of elderly black women with cancer met with patients like Ardillia in the hospital?

What if... The minister from her church came and met with the patient, family, and doctors to discuss the situation?

What if. , , patients could find one doctor they trust and stick to that doctor?

What if the patient would always question any serious surgery, asking "Why is this necessary? Do I have time to think about it?"

What if...patients like Ardillia got a pap smear every year?

What if . . .patients asked if unfamiliar treatments or drugs are new or experimental before agreeing to them?

Then maybe... The health care staff would have been more sensitive to the problem and brought in family members to break the news and help them relate to the patient.

Then maybe. . . A peer group would have been able to offer support and encouragement and help to explain procedures.

Then maybe. . . since many Black people have strong ties to their churches, Ardillia would have trusted her minister.

Then maybe... in an emergency they wouldn't be at the mercy of some stranger.

Then maybe... they can understand more and get a second opinion or take time to talk to other family and friends who might have had a similar disease.

Then maybe... they could detect cancer early and have more time to decide on treatments.

Then maybe. . . they could protect themselves and have more of a say in their health.

## Questions, Anyone?

Question: My father wouldn't let my mother get a hysterectomy—even after 16 child en—even after her health we poor and the doc told her not to get pregnant again, because he feared she would no longer be a real woman! Many people in our community believe that it you have a hysterectomy, you are not a woman anymore. You can't get pleasure out office.

A hysterectomy removes the uterus or womb where babies grow, so you cannot have children anymore. However, there is much more to being a woman than having babies. You can still have sex, and it should feel the same for you and the man. It doesn't affect the clitoris which is what helps you have an orgasm.

Question: Can you breast feed with cancer?

Cancer cannot spread frough the breast milk, it only spreads through the tissues in the women's own body.

Question: If you get bruised or punched in the breast, you could develop cancer there later, right?

No. A punch or bruise won't cause cancer, but if discoloration or unusual marks appear on your breasts for no reason or persist, show them to your doctor.

Question: of people have told me if cancer hits air, it spreads they don't want to get biopsies or of erations that will open them up. They're better off keeping it sealed up. Is this true?

No. Air does not help cancer spread. In fact, sometimes the only way to diagnose cancer for sure is to go in and take a sample of the tissue. So getting a biopsy can be very helpful.

Question: Does it hurt to get a checkup?

Make an appointment to have a gynecological exam each year. They will do a pap test to check for cervical cancer; It is quick and doesn't hurt. They just insert a cotton swab (like a big Q-tip) and smear it against your cervix to check for cancer cells. The doctor will also check your breasts for lumps. Ask the doctor to show you how to check your own breasts for lumps. A mammography (an X-ray of your breast) doesn't hurt except for a little pressure when they press your breast down on the shelf so they can take a picture of it. It feels like a squeeze and takes a few seconds.

Question: What is cervical and breast cancer, and what should I know about them

Cancer is a group of diseases that are caused by the abnormal growth of cells. These cells multiply out of control and take over the normal cells. Tumors form. Benign tumors are not cancer and do not spread. They can be removed by surgery. Malignant tumors are the bad ones—cancerous. They destroy tissue and spread throughout the body (metastasize). Because cancer can spread, it is important that the condition be diagnosed as soon as possible. Of all women, 33% will get some type of cancer during their lives. Only prevention can reduce this number.





You are at risk for breast cancer if you

- -are older than 40, and especially older than 50
- -have relatives (mother, sister) with cancer
- -have never given birth
- -have a long menstrual history (start early)
- -have a high intake of dietary fats
- -have used birth control pills for a long time -smoke





#### Symptoms:

- -Lump or thickening in breast -change in size or shape of breast -discharge from nipple -change in color or texture of skin -dimpling of breast tissue
- Women with few or none of these symptoms are still not "safe" from breast cancer. It is important for all women to learn and practice health habits that could lead to early detection.

#### Preventive measures:

- -Personally examine your breasts at least once a month. The best time is 7 to 10 days after the start of the period when swelling is over.
- Women ages 40-50 should have a mammogram every one to two years, and women ages 50 and older should have one annually.
- -Mammography does not replace the need to examine your breast on a monthly basis. -Eat healthy (low-fat, high-fiber), exercise, and do not smoke or drink.

The cervix is at the top of your vagina and is the lower part of your uterus. It feels like a bump with a dimple in the middle, a hole where the sperm enter the uterus. This hole expands during childbirth to let the baby come through.

You are at risk for cervical cancer if you:

- -have had more than one sexually transmitted
- disease, especially genital warts
- do not have annual pap smears
- had sex before age 20
- have multiple sex partners

#### Symptoms:

no symptoms until later stages: spotting bloody/watery discharge pain

It is IMPORTANT that you have regular checkups or pelvic exams before symptoms occur.

#### Preventive measures:

 Have a yearly pap smear and pelvic exam
 Report abnormal, vaginal bleeding to doctor.

### My Phantom Surgery: An Alternative View of Hysterectomy

by Janice Felkner

In 1991, I was diagnosed with uterine fibroids. Three years later, I was told I needed a hysterectomy. Because my personal support system, my parents, was located out of state, I decided to try to have the procedure done there. After filling out some paperwork, I thought I had the necessary approval. I contacted a doctor out of state and attempted to proceed with the surgery. However, I found even more forms and paper work, subject to numerous reviews. After weeks of frustrating delays involving phone calls, faxes, forms, letters, patient representatives, doctors, social workers, and insurance specialists, I found I did NOT have approval for the surgery out of state. The out-of-state doctor gave me a higher dose of medicine in the meanwhile, and I returned home in a state of flux. Eventually, it turned out that the medicine improved my health so much that I no longer needed surgery.

Even though I am pleased with the outcome, I am still troubled by this episode and the difficulty I encountered getting the system to work with me. Why was I subject to such confusion and inconvenience? I was lead to believe I needed invasive surgery when, in fact, it was not necessary. My questions and concerns were caught up in the complexities of the system and never answered. There is nothing worse than a patient leaving a hospital after a diagnosis and then feeling that things were unresolved. I wonder whether there are other women who have not been encouraged to give other alternatives a fair trial and instead rushed into surgery; while other women who need surgery are subject to unnecessary, costly, and even dangerous bureaucratic delays.



### What If. . .?

 What if women who are considering any expensive procedure double check their insurance coverage before proceeding?

Then maybe they could eliminate a lot of unnecessary appointments and disappointments. This is especially important if you plan to get treatment out of state. It often isn't covered unless it is an emergency or you can't get that specific treatment at home.

 What if women when they are advised to get serious or costly surgery would take the time to get second and even third opinion before making a final decision or discuss with their doctor how they really feel about having surgery.

Then maybe they could avoid the pain and expense of unnecessary surgery and try medication or other forms of therapy instead.

 What if insurance companies allowed the patient to have the surgery performed in a different state if that was what the patient and the doctor agreed to?

Then patients could be nearer to loved ones and get emotional support, helping them heal faster.

## Doctor-Patient Relations

### Miss Ida and Achy Ann: Two Cases of Miscommunication

by Brenda Payne & Charlene Glover

> ISS IDA, a frail 76year-old, sat up, engulfed in her hospital bed.

When nursing student Flo came in to check, Miss Ida told her she had been waiting for her for 45 minutes to get to the bathroom. "Why didn't you push the button?" asked Flo. "If you'd have pushed the button, I'd have come." Miss Ida apologized to the nursing student, saying she didn't want to bother her.

Suddenly, nurse Linda walks into the room and closes the door. She stands shoulder to shoulder with Flo and says sarcastically, "That Dr. Stone is such a jerk! He's been chewing out the nurses all day about their orders. And you can't even say anything to him, because he'll get an attitude."

Flo says to Miss Ida, "I'll be right back," and she and nurse Linda go to the nurse's station and finish talking. Nurse Linda still is griping about the doctor, who comes into the station and gruffly tells Linda, "Come here."

After awhile, Dr. Stone walks into Miss Ida's room (without knocking, mind you). After five minutes, nurse Flo goes into Ida's room to check on her because she seemed so timid.

As Flo enters, the doctor is looking at the chart. Miss Ida is looking straight up at the TV. Doctor is talking into the chart about everything that's happening. Miss Ida had been curious about when her surgery would be, or if she was going to need it. To the doctor, Flo

asks, "Did she ask you about her surgery?"

"No, she didn't say anything," said the doctor.

Flo notices that Ida is still watching TV, staring straight at it. Ida seems not to even notice that anybody is in the room with her. Flo asks, "Does she have her hearing aid in? And is it turned up? 'Cause you know she's hard of hearing?"





He said, "What am I supposed to be? A mind-reader? How do I know if you guys don't tell me?"

"I assumed you'd read her chart," said Flo.

Ida had been in the hospital for four days, and the doctor still didn't know that she's hard of hearing. If she had in her hearing aid and had it turned up and you talked loudly she could understand. She might not hear it all, and she'd ask you to repeat it. But she'd been in there four days! And he didn't know she was hard of hearing.

The doctor walked up to-her and started screaming in Ida's face, real loud. "Do you have any questions?" A this point, Flo felt intimidated because the doctor is screaming at the top of his lungs to her patient. Miss Ida probably couldn't understand what he was saying, because of his accent anyway. Flo feels he is really being rude.

After the doctor left, Ida asked Flo, "Do you know when my surgery is?" Flo said she will look at Ida's chart after the Doctor is gone, to tell her what the plans are.

What would you have done differently in this situation, as the patient, the patient's family, the doctor and nurse?

CHY ANN is 45-years-old, fairly educated, and has been a diabetic for six years and knows what her diabetes is about. Over the year, she has been having some pretty intense pain in her joints, hands, legs, ankles, knees and feet. She figures that she has some type of arthritis because of the swelling and ache in the joints. If it was the diabetes, it would be numbness and tingling in the tips of fingers and feet. But this other pain started in her knees. She knows about neuropathy, a disease of the nerves that occurs when you are a diabetic.

Achy Ann picks up the phone and makes an appointment with her doctor to find out what is going on. Then, on the day of the appointment:

Doc: Good afternoon Miss Ann. What can we do for you today?

A: Well, Doc, I am having pain in my knees, fingers, hands, and feet, and am noticing that they are swelling, tight, and stiff.

Doc: I see here Miss Ann that you've been a diabetic for six years (looking at her chart). How is that going?

A: Very well. I just had a blood workup three months ago. It's under control.

Doc: What I'd like to do is give you a full examination.

A: I just had one three months ago, but another would not hurt.

Doc: (Doctor runs the hammer up and down her legs and feet to check for reflexes. He makes her stand and balance and checks the kidney for enlargement. He completes exam.) Put your clothes on and we'll sit down and talk.

A: Wondering— How come he hasn't checked my ankles, hands and knees for swelling and mobility? Is he thinking of something I'm not aware of? I'm worried he's not getting to the problem. Why does he keep asking about the diabetes and not my joints?

After, Ann sits down and discusses the situation with her doctor. She asks if

he thinks it's arthritis. She expects him to tell her why she is having the joint problem.

Doc: I want you to take a nerve test.

A: What about the knees? My hands?

Doc: We'll give you some lbuprofen for that, and you can take it two times a day. We'll see you in two weeks, after testing.

A: Thinking—He hasn't told me what causes the pain. He hasn't dealt with my problem; he's only dealing with the diabetes. He's fixated on it. He is not listening.

The patient feels ignored. She returns in two weeks to get the test results. The doctor says the test shows a little bit of neuropathy but nothing to worry about. Ann asks again, "What about the joint pain?" He says to double the ibuprofen.

About three weeks later, due to stomach irritation from the ibuprofen, Ann returns to see the doctor again. But the regular doctor she had been seeing wasn't in. Another doctor saw her. After Ann explained, she—the doctor—went straight to the problem. She examined Ann's joints and told her it looked like arthritis, but she couldn't say definitely without testing. She ordered blood tests, X-rays, and referred Ann to a specialist. She took Ann off ibuprofen and prescribed another medication. This helped Ann to feel better because even if wasn't arthritis she could move on to the next step to find out why she is having problems.

The specialist diagnosed the problem as rheumatoid arthritis and started treatment. He gave Ann a cortisone shot, which reduced Ann's pain and stiffness. Ann feels if the first doctor had not ignored the problem she came in with she wouldn't have had to deal with the pain and the uncertainty of not knowing what was going on.

What would you have done in this situation, as the patient, the patient's family, the doctor and nurse?

### What if Miss Ida. . .

- had a doctor who had a better relationship with the nurse? Flo wouldn't have been afraid to talk to him, and would have pointed out that the woman was hard of hearing. She could speak to the doctor privately and see if they could come to an agreement about how to best communicate with each other for the good of the patient. It is important for all health care workers to feel they are equal and important. The health care workers need to work as a team to give the patient the care at the level of quality they deserve and in an efficient way.
- Or what if Dr. Stone checked Ida's chart more closely? He'd have known Ida was hard
  of hearing. Also he'd have known that she was a passive personality, timid, because it
  was noted on the chart. Since he didn't check, anything that he told her during the last
  four days was a waste of time. She couldn't hear him.
- Or what if the other nurse wouldn't have come into the room and discussed the
  doctor's personality. Then Ida might have been more willing to ask questions too. The
  patient should not be afraid to tell the doctor anything, but of course hearing from the
  nurse that a doctor is a grouch and then the doc screaming in your face doesn't help.
- What if the nurse or a family member helped ida figure out a way to voice her concerns and questions to the doctor, maybe by writing down a list?
- What if there were a sign over the bed to identify hard of hearing patients? Then not
  only the doctor, but also lab workers, aides, and food service would know.
- What if the family worked out a way for the doctor to report to someone who can more easily understand him despite his accent.

### What if Achy Anne . . .

- had interviewed a number of doctors on the phone before choosing this one as her primary provider, without really knowing his personality?
- had told the doctor what her suspicions were and why she suspected arthritis? Then
  maybe the doctor could have explained why he ruled out arthritis.
- had been more assertive and had forcefully stated to the doctor that he needed to address the problem, meaning pain in the joints.
- had been assertive enough to tell the doctor that if he would not deal with the problem that she would go to another doctor.
- had expressed to her HMO that she was not satisfied, that this doctor was not addressing her problem, and she would like to deal with another doctor or a specialist.

### Will Mom Go to Jail?

by Beth Tull

I was 21 years old, a single mom on welfare, when my son began to have health problems. When Nick was four months old, he developed a rash. It began at the top of his head and ran down to his groin. I had done the usual, rubbing him down with lotions and oils. However, this rash continued to spread. I began to follow some of the old-fashioned remedies advised by my mother; I browned flour, switched over to cloth diapers, but nothing seemed to be working.

At this time the rash began to get infected, and I became concerned, so I took him to the hospital. This was the first of many trips. He was seen through the Dermatology Clinic and the diagnosis was infantile eczema. The doctors prescribed several expensive lotions that were not covered on my medical card and antibiotics which were. I was unable to get the lotions, so I just got the antibiotics.

My son would be on antibiotics for 10 days at a time; the infection would clear up and the rash would go away. As soon as it cleared up, it would start all over again, getting worse and worse.

I had my son to three different dermatologists. They were poking at him, and taking skin biopsies and still the diagnosis was eczema. Now because of my own intimidation of doctors, and the fact that I believed they knew what was going on, I didn't question their diagnosis.

This whole ordeal was beginning to take a toll on me. Why could I not make my child well or comfortable in this situation? I began to feel like a failure as a parent. My guilt was getting the best of me. I also felt responsible for his being sick all the time. Worse than that, I resented that Nick was sick. He was such a beautiful little baby,

At age three, he began developing abscesses on his jawbone. They were the size of walnuts, and he always seemed to be running a temperature of 100 degrees or above. He was seen through the emergency room numerous times. The doctors would lance the abscess, prescribe antibiotics, and send him on his way.

One day, Nick's father came to visit and asked if he could take Nick out. Nick wasn't feeling his best and I was a bit apprehensive about letting him go, but I was also exhausted from dealing with a sick child. So I said yes. When I didn't hear from them at 9:00, I got worried. I wasn't exactly sure where they were. By midnight I was absolutely frantic; where was my baby was all I could think of. Just when I was ready to call the police, his father called me from the emergency room. We had just been there a few weeks before. When he called I was furious that he waited so long to contact me; they were at the hospital for hours before I got a phone call. So I'm sure the staff was wondering where the hell is this child's mother. I got to the hospital as fast as I could.

When I got there they were trying to bring down his temperature and arranging the involvement of social services. I was confused. I didn't understand why they were having me investigated for medical neglect. I remember all of the doctors huddled in one corner, and I was sitting in the other. I felt very frightened like I was being tried before I could explain my side. I had no voice in the matter. I had this vision of these powerful men, with long, white beards, and white wigs, and they were discussing my life, my parenting skills as if I weren't even there. Sort of like the Salem witch trials.

Looking back on this now, perhaps they did have reason for concern because Nick had this rash that sort of resembled burns, but why did they not just ask me? At least I would have had the chance to explain. I was put through this grueling process for what seemed like an eternity only for the whole case to be unfounded.

Through this experience I became a little bolder about speaking up. I was so fed up when the abscesses returned, that I demanded to know why my son was constantly sick. They finally admitted him and called the infectious disease doctors.

My son stayed in the hospital 28 days. They discovered that he did NOT have excema but chronic granulomatous. He is now on antibiotics for the rest of his life, as a preventative measure, and I have not had any problems with his health outside of colds and chicken pox.

### What If ...?

What if I had asserted myself by saying to the hospital staff, "I should have been notified earlier. Why didn't you call me?" They might have realized my concern, I didn't because I did not feel I had the right to show my anger to hospital staff.

- What if patients didn't assume that doctors have all the answers and always do the right thing?
- What if I had not been so afraid of his father that I had reminded him to be sure to call me if Nick was not feeling better—to insist he make sure I am involved in emergencies?
- What if patients realized they have the right to insist on more testing?
- What if the doctors were able to see my uncertainty through my lack of questioning and took some extra time to explain? Or what if they told me they weren't exactly sure what the problem was, but they would inform me of all they knew? I might not have beat up on myself so much.





A NURSE SAYS . . .

Doctors do need to be aware of costs of medications such as the lotions prescribed here. They or the nurse should ask, "Is someone paying for your prescriptions; can you afford to get this filled? If you find out you are not covered, call back, and we'll try to make other arrangements." There is often a generic brand, or the doctor could give free samples or could order a part of a prescription at a time if the insurance will cover it that way instead.

ER doctors are often rushed, but certainly in this case with a very thick file, they should have consolidated or skimmed through it to see the history.

Rashes are most difficult todiagnose, and sometimes it is difficult to say, "I really don't know." Some patients imagine

the doctor is God; they need to know that diagnoses aren't always 100% clear.

It is unfortunate that the mom wasn't even asked about abuse, but it is important that they did consider it, because that type of rash can look like burns. Not all physicians pay attention to abuse. It's better to suspect and be wrong. Knowing your doctor and nurse better rather than going to lots of different ERs might have helped avoid the misunderstanding.

# Let's Talk about S-E-

### Contraception, Pregnancy, and Sexually Transmitted Disease

### Fertile Fergie: Stereotyping Welfare Moms

by Joann Brooks

This is a story about a single mother, Fertile Fergie. She had five children. When she was pregnant with her sixth child I had the pleasure of being her next door neighbor. She had no husband, and I offered to be her coach. When she was thirty-four weeks pregnant she went into labor. I called an ambulance. On the ride to the hospital, Fergie told me how scared she was, because she hadn't seen a doctor during this pregnancy. I told her everything would be OK.

By the time we arrived at the hospital and were admitted to the labor room, Fergie was very upset. We were told that Doctor Smith would be in to see us in a few moments. When the doctor came into the room, she looked at Fergie and said "You again. How many does this make, nine? You really should get your tubes tied."

### How would you interpret this situation? What are the concerns of all involved?

I was totally shocked; I couldn't believe this doctor could be so insensitive. After the exam, the doctor left. During all this time, Fergie hadn't said one word. I asked Fergie if she was all right and who the hell that doctor was. She told me that she had delivered her last two children. I told her that the doctor had no right to tell her to get her tubes tied. Her response was "I don't give a #%~@ what that doctor said. She's one of the reasons I didn't go to the doctor during this pregnancy." Fergie then told me she planned to get her tubes tied after this baby.

The nurse came in and gave Fergie some medicine to stop the labor since it was too early. The doctor then came back into the room and said she wanted to talk to Fergie about signing a consent form to get her tubes tied. Fergie said, "Just give me the form and save the lecture." She signed and we left.

Three weeks later, at thirty-seven weeks, Fergie went into labor. By the time we arrived at the hospital, Fergie was in a lot of pain and bleeding. She was admitted to the labor room. When the doctor came in and I saw it was Doctor Smith, I wanted to ask for a different Doctor, but Fergie said it didn't matter. They checked Fergie out and found that she was dilated to two. They put on a monitor and told us we were in for a wait. After three hours, Fergie was in a lot of pain and bleeding heavily. I called for the doctor and when she came, we found out that the baby was in trouble and that they needed to do an emergency C-section. Then she told Fergie that the papers she had signed three weeks ago for her tubal needed to be signed again because enough time hadn't passed and since they were going to do a Csection that they should go ahead and do the tubal now.

I felt that it was not the time to ask Fergie to sign any papers, especially when they had just told us that the baby was in trouble. I felt they were wasting valuable time. Fergie screamed, "Just give me the @\$% papers!" They took Fergie to the operating room. She was there for over two hours. Afterwards, Dr. Smith came to see me. She told me that the baby needed to go to the neo-natal unit and that Fergie was having some trouble breathing and needed to be watched closely. Fergie had no idea what was happening because she was still out of it.

Fergie and the baby both developed more problems after the birth. Fergie had blood clots in her lungs, and the baby had respiratory problems and yellow jaundice. Fergie named the baby Carol. The baby was able to go home before Fergie. I took the baby home, and Fergie remained in the hospital for about seven days. She then was sent home with an IV because her access insurance wouldn't cover any more days in the hospital. It's been four vears since Carol's birth. At this time, she is a little developmentally delayed. I believe that if the doctor had been more interested in the welfare of the mother and child that Fergie and Carol might not have had the problems that they have until this day.



# Dialogue





A PATIENT SAYS ...

Fergie should have gotten pre-natal care no matter what anyone had to say about how many children she had. On the other hand, the doctor should have kept her personal opinion to herself. As a professional, her main concern should have been the welfare of her patient.

Why do doctors think they have the right to tell anyone how many babies to have? Maybe because there are too many children in the world not being taken care of. I know a lot of people who think that there are too many women on welfare having too many babies. It's their hard earned taxes going to raise these children. Also, maybe the doctor thinks it is hard on a woman's body to have baby after baby. And she

wonders if this woman will get health care. Will she be able to provide health care for the child once it's born? One person told me something that sounds vulgar but makes a point: you wouldn't let a dog keep having litter after litter, because it would hurt the dog. But women are not dogs; they make their own choices.

Why do women keep having one baby after another? Some women don't understand birth control. Or women don't feel birth control is for them because of religious beliefs. Some women want to hold on to their man, and think a baby will help. Women want someone to love them and think a baby is going to do that. I myself wanted a big family because I only had one sister.

I see these options in this situation:

Women should get pre-natal care. Doctors should worry more about the welfare of their patients, not if their patients are on welfare. And most important doctor and patient should explore WHY this women is having another baby and how to guarantee that this baby has the best chance at a healthy life.



A DOCTOR SAYS..

There could be resentment towards her—I work all day. That feeling is out there in the system and society—welfare promotes babies. Or bias against single moms.

The doctor might think she can't take care of her kids, and is concerned about the well-being of the kids and the mom. It is risky to have back-to-back babies. The doctor's intentions could have been good, but her approach was harsh. She made her feel bad about having her child, and so uncomfortable she didn't get care she needed. She should not have approached her so harshly while she was in labor and worried.

I would talk to her after the baby is delivered—at discharge. I would find out what SHE wants. For example, I

might ask, "How can we help you? Would you like a break between babies? Are you interested in . . . (there are many methods of birth control and options)."

### **Pregnancy**

by Jane Birschbach

For the best outcome, plan your pregnancy and take care of yourself! All women who may become pregnant should take a multivitamin daily, because the folic acid will decrease your baby's risk of having a spinal defect. Also, you should "tune your body up" be before pregnancy, taking care of any medical problems like diabetes and high blood pressure. Avoid alcohol, drugs, and cigarettes, which cause birth defects, learning and behavior problems, premature birth, and even death of the baby.

Prenatal care can help you and your baby stay healthy. A normal pregnancy lasts 38-42 weeks. Knowing the first day of your last menstrual period helps your doctor/nurse determine your due date. If you do not remember when your period was, ultrasound can help determine the baby's age. Generally, only one ultrasound is done in pregnancy, ideally at 16-20 weeks when doctors can get the most information about the baby's organs, size, and sex.

Your doctor will recommend a prenatal vitamin and iron pill daily. Some women with anemia or "low blood" require two to three iron pills daily. Other medications safe in pregnancy are Tylenol for pains, Robitussin for coughs, Sudafed for stuffy nose, and Mylanta, Tums, or Milk of Magnesia for heartburn. To keep your stools soft, eat lots of fresh fruits and vegetables, drink lots of water, and eat high fiber cereals (Kellogg's All Bran). Senokot and Colace are safe in pregnancy if dietary changes are not enough to relieve constipation. Before taking any other medications, you should contact your doctor to see if they may be used safely.

"Éating for two" requires lots of fresh fruits, vegetables, and calcium-rich foods (skim milk, low-fat yogurt/ice cream, cheeses). If you cannot tolerate dairy products, Tums are a good source of calcium. You should gain between 25 and 35 pounds during the pregnancy, more if you are a teenager or very thin, less if you are very heavy.

Working is okay, as long as you are not lifting anything more than 15 pounds, and you are allowed to walk around every two hours. Moderate exercise is safe in pregnancy, decreasing time in labor and pushing, and even C-sections in some studies! Traveling is okay unless your are close to your due date. It is important to walk around at least every two hours to decrease the risk of blood clots in your legs. Wear a seatbelt with the lap belt under the belly and across the thighs, the shoulder belt between the breasts.

Tub bathing is safe during pregnancy, and starting three weeks after delivery. Be careful in the tub, as a large belly disturbing your balance may lead to falls.

Call your doctor if you have any of the following symptoms during pregnancy:

- \* Severe, continuous headache
- \* Visual blurring or dimness
- \* Abdominal pain
- \* Vaginal bleeding
- Contractions
- \* Leakage, like you broke water
- \* Persistent vomiting
- \* Fever/chills (higher than 100.5)
- \* Marked change in the frequency or

After you deliver your baby, you should avoid sex, tampons, or douching for six weeks to allow healing. Before you leave the hospital, you may wish to discuss birth control methods with your doctor/nurse, so that you will be protected from pregnancy when you do have sex. Breastfeeding does decrease your chances of becoming pregnant, but it does not guarantee it. The birth control pill and Depo Provera shot are safe during breastfeeding, and may be started soon after the baby is born. In general, allow yourself 4-6 weeks recovery where you are not lifting anything heavier than the baby, not working, and are finding time to rest.

Most women experience "the blues" after the baby is born. You may find yourself crying over things that are not ordinarily sad. If your feelings of sadness interfere with your ability to take care of the baby, or you feel like hurting yourself, baby, or others, this is NOT normal, and you should call your doctor/nurse immediately.

## Questions, Anyone?

### How serious are sexually transmitted diseases? Can I be cured?

Sexually transmitted diseases or STDs are diseases you get from sexual intercourse, oral sex, and anal sex. They are common, with over 13 million cases per year in the U.S. Most occur among young people ages 15-29. Rates are higher among minorities. Anyone who is sexually involved is at risk for catching an STD, with risk increasing as your number of sexual partners increases. You need only have sex once to catch an STD, and there is no limit to the number of different STDs you can get, or to the number of times you may be reinfected with the same STD.

Some STDs are easily cured with antibiotics (chlamydia, gonorrhea (clap), syphilis, trichomonas (trick), while others have no cure (hepatitis, herpes, molluscum, HPV, and HIV.

The consequences can be devastating. Many persons with an STD feel "dirty", hurt, and mistrustful. Gonorrhea and chlamydia cause pelvic inflammatory disease (PID), and are a leading cause of sterility or inability to become pregnant, and ectopic or tubal pregnancies. If tubal pregnancies are not caught early, they can cause a woman to need surgery, lose her fallopian tube, and even bleed to death. The scar tissue from PID can cause lifelong pelvic pain. Infants born to mothers with these diseases may develop eye infections and pneumonia.

Syphilis can damage the brain and heart. Syphilis during pregnancy can cause premature delivery, still births, deformed teeth, nose, or legs, mental retardation and deafness.

During pregnancy and childbirth, herpes can be transmitted to the baby causing mental retardation, seizures, brain infection, and coma. If a woman has an outbreak at the time of labor, she will probably need a C-section to decrease the risk of infecting her baby.

labor, she will probably need a C-section to decrease the risk of infecting her baby.

Certain types of HPV cause abnormal PAP smears, cervical, vaginar, and vulvar cancer.

Other kinds of HPV cause genital warts, which are very difficult to remove. Burning with acid or the laser freezing may destroy visible warts, but does not kill their cause: HPV. The fact that they often return despite painful treatments is very frustrating.

HIV causes AIDS, a group of painful and debilitating diseases which is always deadly.

### How do I know if I have an STD? What should I look for?

99.9% of the time, you get an STD from having unprotected sex. Most STDs have no symptoms at all. You or your partner could easily have one and not even know it. That's why it is important to get tested regularly. Symptoms to check out with your clinic or doctor:

### **Symptoms**

Sores, bumps, or blisters on crotch area or penis Yellow or green discharge in women or drip in men Burning when you urinate Pain in your lower belly Rash (especially on palms of hands and bottoms of AIDS - One or a combination of: purple spotted rash weight loss night sweats diarrhea

### What can do to protect myself?

Don't have sex.
 Yeah, right. Since this isn't very realistic, just keep on readin'

Have SAFE sex; masturbate or use a condom.
 99.9% of these diseases come from... you got it. Sex with an infected person.

Never ever have anal sex without a condom.

It could cause infections and spread AIDS because the inside of your rectum tears easily.

• Have a pap test once a year, and ask for other tests for STDs.

Pap tests tell you if you have cervical cancer and warts. This test does NOT test for chlamydia and some of the other STDs, though. You may have to ask for a separate test for those. Many clinics do not automatically give you these tests. Doctors sometimes decide to test or not test a patient by the way she looks. They might assume that an older women isn't having sex, for example, so they might not test her. They may be wrong. You know best about your sexual activity and that of your partner; that's why you have to speak up and ask. Any women having sex should be tested for STDs with each new partner, or if your partner has had sex with someone else.

Look at your partner's sex organs.

"Brush burns" (often herpes) and warts are very contagious! Encourage your partner to be tested for STDs before you have sex. Most men do not see the doctor/nurse unless they have a problem. Remember, many of these diseases have no symptoms, and men may not even know they are infected. STD screening is conducted at the Allegheny County Health Department free of charge and without an appointment (578-8080).

• Never have oral sex if you have a cold sore. You could spread herpes.

Talk honestly with your partner.

Be real about your sexual activity and your history, especially with a new partner. Women, especially, have to be careful because we are more susceptible to certain STDs than men. And men may not even have noticeable symptoms. Ask: have you been tested? And find out what for.

### **And I Always Thought: Some Common Myths**

### True or False? ALL ARE FALSE!

Don't wash your hair while on your period or take a bath for six weeks after you have a baby, or you'll get sick.

A young girl can't get pregnant if she hasn't started her period yet.

Good looking, clean people don't have STDs.

A douche of Clorox and hot mustard and water or some herbs or a coke bottle used for suction will get rid of an unwanted baby.

IUDs will pinch your man.

Lubricating a man's penis before sex with Vaseline will help the sperm slide out so you won't get pregnant.

Standing up right away after sex will prevent pregnancy.

Birth marks are caused by the mom touching a place on her body when she has a craving while pregnant.

You can get AIDS shaking hands, drinking from a glass,

If you don't want to get AIDS, have anal sex instead.

onica's Myth: When Monica was pregnant, she was at a baby shower, and one friend said, "Don't I hate that I can't take baths when I'm pregnant?"

Monica said, "What do you mean?" and the friend replied, "Well, I know you can take a shower, but if you sit down in the water, won't the water go in the hole and drown the baby?" We all just laughed at her then. But she was serious and still believes this to this day. It's O.K. to bathe while pregnant.

randma Took My Birth Control: When I was 13, I was having a lot of menstrual problems and the doctor said he could give me birth control pills to regulate my period and relieve the cramping. Well, when we got home me and my mom were discussing this, and my grandmother (who is a hypochondriac) said that she had cramps also. So the next morning, I go to take my pills and three are gone. So I ask my mom did she know what happened to my pill? Here comes my Grandmom and she said she took them for her bad cramps the night before and thought if she took three it would go away quicker! My Mom tried to tell my Grandma that she shouldn't take other's medicines and that her cramping may be from other causes. She had to remind her the month prior she took my younger brother's medication for seizures and got very ill. It's always a very bad idea to take other people's medicine!

### ersonal Place:

Girl: (Unpacking groceries) Mom, what are those "Sanary Napkin" things? Should I put 'em in the kitchen?

Mom Honey, come in the bedroom so I can explain to you (closes the door). You are old enough to know now that women bleed from their personal place once a month. The napkins soak up the blood so it doesn't get on your clothes. In a couple of years, this will start happening to you.

Girl: Oh, that's disgusting! (runs out of the room

If you were the mom, what would you say? Did this mom leave any important information out? How will the daughter interpret this information?

(Two years later)

Girl: (Crying in the bathroom) Mark, call mom at work. I think I'm dying!

Mark: Whassup, honey?

Girl: There's blood coming out my bum!

Mark: Didn't mom tell you that's normal? It's your period—

Girl: But mom said from your PERSONAL PLACE.

Mark: Huh?

Girl: It's not coming from here (points to breasts), but down here.

Mark: Not THAT personal place, dummy. You think women bleed from their boobs?

Girl: But that IS a private place. I thought...

(Next Day)

Girl: (Talking to friend)! was so scared Shirl! Now I feel dumb and my brother makes fun of me. I was wondering how they strapped those big bulky napkins under their bras without it showing. I didn't want to ask my mom, so I tried to figure it out myself.

Use proper, specific terms such as "vagina" when answering your children's questions about menstruation and sex. Your doctor can even give you some brochures or help explain if you ask.

### What Hurts: Emotional/Verbal, Sexual, and Physical Abuse

### **Prisoner in My Own Home**

by Joann Brooks

My name is Joann and my story deals with the insensitive way some professionals handle adult patients that have been sexually abused as children. I was sexually abused as a child and have a hard time with my annual gynecological exam. After not having an exam in four years I went to the doctor's and told her about my sexual abuse. Ever since I was four years (as long as I can remember), my parents had sexually abused me. They would lay me on the kitchen table with my father standing at my head holding down my arms while my mother inserted things into my vagina. We lived in an old house where the only light bulb was the one hanging from the ceiling over the kitchen table. I was totally exposed to the whole world and I had no control over what my mother put inside of me. As you can see, this is very much like an exam situation.

▶ In an exam situation, how would you relate to a patient with a history of sexual abuse?



After I explained my story to the doctor, here is what happened on the examination table.

Doctor: (sincerely - I thought): How are you doing? Are you doing OK?

Joann: Yes. Boy, I wish she would get this exam over with.

Doctor: (She is instructing as she does the exam) I'm going to insert this speculum into you. Remain calm. You are going to feel a little pinch. We are almost done. Just breathe. I am going to remove the speculum and then you are going to feel my fingers. You can sit up now.

Joann: I am so glad that this is over. This isn't bad, she explained what she was doing.

Doctor: (She smiled at me and looked directly at me) Was it as much fun as you remember it was? (Before I could answer her, she left the room. The nurse told me that I could get dressed now.)

Joann: (I gave no response verbally to either the doctor or nurse. The experience numbed me. I couldn't believe that she would say something like that to me. I felt like I had been sexually abused, again).

I went home totally depressed. I thought that it took me so long to speak up and tell a doctor about the sexual abuse and she shot me down in one sentence. Two days later I went to my regular doctor and he asked me if everything had gone OK at my pelvic exam, and I told him what had happened to me. His reaction was that he couldn't believe that she could be so insensitive. He instructed me to remain in his office while he went to confront the gynecologist and her exam room nurse. When he brought it to the doctor's attention, her reply was that she was only trying to break the ice. My doctor told her that he felt that she owed me an apology. But to this day, I have never heard from her.



# Dialogue





A PATIENT SAYS...

In my opinion, doctors and nurses need to be trained on how to talk to patients. Because when you've been abused as a child there are many things that can trigger a memory. The most common things are sex and a gynecology exam. Try to imagine through a child's eyes what a gynecology exam is like when you've been abused. You would be helpless and not in control. The doctors and nurses need to know the impact of their insensitivity on patients. If the doctor feels he cannot handle the situation, then refer them to someone.

Patients also need to take control of their own well being and let doctors know what is appropriate and what is not. Patients should not be intimidated and should be able to get there emotional needs met, which sometimes is very hard for women who've been sexually abused. But we must take control of ourselves stand up for our rights and not let anyone else abuse us. My final comment is that every patient has a right to a beneficial and dignified exam.

### What If...?

- Doctors received in-service classes from sexual abuse prevention centers?
- One nurse in each office received specialized training in sexual abuse and its side effects?
- Patient took a friend
   with her for support
   coming back for future appointments.
- Doctors and nurses might have better relationships with their patients,
  - Doctors and nurses would understand the whole person and not just physical symptoms.
  - Patients might feel more more comfortable.

### A list of things that would be helpful for a doctor or nurse to do:

- 1. Don't dictate to patients; ask them as you proceed with each step of the exam.
- 2. Use open-ended questions so the patient can share what she is comfortable with.
- 3. Ask questions like what is the scariest or hardest part of the exam and how can I help?
- When talking to a patient use eye contact but don't stare.
- 5. Don't try to stop them from crying. Say, "It's O.K. to feel that way." Let them express their feelings.
- 6. Be aware of physical space and distance.
- 7. Focus on the patient, not what your going to say next.
- Refrain from saying "I understand," because even if you are sympathetic, there is no way to understand it. It sounds false.
- 9. Try not to use so many technical words so the patient knows what is going on.
- 10. Discuss with the patient some different options. Let them feel that they have some say in their exam, E.g., Do they want to bring a friend in with them? Do they want to close their eyes or listen to music during the exam? Hold onto a teddy bear?
- 11. Help the patient do deep breathing to relax.

### **Cycle of Secrets**

by Beth Tull

According to the Center for Victims of Violent Crime, 38 million adults were sexually abused as children. One in every three girls and one in every seven boys have been abused before their eighteenth birthday. The odds are even greater if the child lives in an alcoholic household. These are acts of violence that have reached epidemic proportions.

Because of the overwhelming feelings of shame, most victims never tell anyone about the abuse. Victims of sexual abuse have the feeling that they are powerless over their bodies, and their lives; therefore, they are unable to trust their own perceptions, and have even greater difficulty trusting others.

They suffer from low self-esteem, and are confused about the limits and boundaries that determine appropriate and inappropriate behavior. Shame or fear will prevent these victims from talking about the abuse which begins the cycle of secrets.

If at sometime this has happened to you or someone you know it is okay to talk about it. You should know that recovery is possible along with the possibility of building strong, healthy relationships and that it was not your fault. Does this sound impossible? I understand.

I, too, was the victim of childhood sexual abuse. For many years I was a prisoner to my secrets and became locked into many prisons. One of the first being an addiction to food. I had empty space inside of me that should have been filled with love and security. Instead, I filled it with food and other self-destructive behaviors such as alcoholism, drug addiction, and sexual promiscuity. These behaviors almost led to my demise. All because I thought it was my fault, or I was a bad person. I now know that it wasn't my fault, and I am a good person.

Those of us who have survived this would like to make it all go away. The reality is it does not. Left untreated it becomes a spiritual and emotional disease, one that eats away at you. It is not safe to keep these secrets because they manifest in many different aspects of your life. Slowly, we begin to heal by working through the pain. The first thing I had to do was take a risk by trusting one person with whom I felt safe to bare my secret.

### Casualties Of War

I was drafted the day I was born,
Sent to war in a house that was torn,
I lived in a combat zone of an enemy camp,
A prisoner of war, I still wear the stamp,
Abused and brainwashed,
Not to utter a sound,
My only hope was that I would be found,
I lived each day with no hope in sight,
And every moment filled with fright,
Someone must come and rescue me,
I deserve to be set free,
I'm only a child, can't you see.

— Joann Brooks, 1990 —

### What If. . .

• Victims confront their abuse by admitting it happened?

Once I admitted the truth, I no longer carried the burden of keeping secrets. I no longer needed alcohol to help me forget or stuff the feelings. I began to gain back some control in my life. I am no longer a victim, I am a survivor.

Victims are not afraid to tell authorities so that the abuser can be prosecuted?

This person wasn't prosecuted because I was too afraid to tell the authorities. However, he didn't abuse me again when I threatened to tell.

Victims contact a therapist who deals with sexual abuse issues?

This process is not easy, nor does it happen quickly. It is very painful to remember and discuss. . however, the therapist helped me realize that I was not responsible for my abuse and suggested ways for me to develop healthy relationships. The first thing I had to realize was that healthy relationships start with me. I realize that I am deserving of happiness, and I am learning to like myself.

- Victims talk to a trusted friend or family member OR
- Victims join a support group such as Pittsburgh Action Against Rape (765-2731),
   Family Resources (562-9440), Center for Victims of Violent Crime (392-8582), Survivors of Incest, Anonymous (422-6033), or Womansplace (687-4616).

By doing these things I was able to develop a larger support group. Friends and family members were able to see things I didn't see and help me to work through them.

### **Questions, Anyone?**

### Are women usually raped by strangers?

No. The majority know their assailants. The majority of childhood sexual abuse is done by someone the child knows. Between one-half to one-third of sexual abuse involves a family member

### Do attractive women and saxy clothes cause rape?

No. Appearance is not relevant. Women of all ages and body types can be raped. It is not about attraction, but about the rapist's anger and need for power. Incest can happen to anyone too; it is not limited to "backwoods" people, but occurs in all social/economic classes.

#### What is Abuse?

There are different kinds of abuse—physical, emotional/verbal, and sexual. Although physical abuse can be more easily seen than emotional or sexual abuse, all can cause serious pain.

hysical abuse occurs when a child, spouse, or elder is subjected to physical injury.

- a mother slaps a child hard across the face for saying a bad word
- father grabs and bruises mother's arm and shoves her because supper wasn't done on time.
- grandmother who can't walk is left lying in a wet bed with no one willing to change her all day.

Sometimes you have to restrain a child physically from harming herself or others, but it is never all right to hit a child in anger. There are other ways to discipline: time-outs (they sit alone for a short period to cool off and think about their actions and reactions so you talk about it), loss of privileges (take away t.v.. Nintendo. or social events). Even if the bruises don't last, it teaches a child that hitting is O.K. and makes him feel that he is no good.

motional/verbal duse involves continual active efforts to break down a person's self-esteem or self-worth.

- a mother constantly berates her child: You're stupid, you're lazy, you are terrible. She criticizes the person instead of the action. She never balances criticism with praise, which is necessary to build self-esteem. She could say "Taking the candy was not a smart thing to do," instead of "You're dumb," or "I love you, but I'm unhappy that you took the money from my wallet," instead of "You're a lying thief, and I wish I never had you."
- a teacher says, "Johnny, why can't you be more like Jodi?"
- a husband constantly berates his wife, "Why can't I ever come home to a clean house, you lazy b - -"

exual abuse is any involvement of a child or an adult in any involuntary sexual activity. A child is unable to consent to any sexual act, therefore, it is ALWAYS sexual abuse—even touching. Rape is an act of violence and control, not a sexual act.

- a girl on a date says "No," when the boy tries to force her into sex, but he holds her down and continues and says, "I know you want it."
- an uncle slip his hand up his niece's blouse when he gives her a hug goodbye (findling).
- a neighbor exposes himself to children playing in the yard next door.

### What are some signs that a woman is being abused by her husband?

constant tiredness frequent injuries (cuts, bruises on both sides of the body patterns from belt buckles, bite or fist marks, burns on the skin) vague, evasive explanations for injuries

ulcers
poor self-esteem
depression, anxiety
frequent visits to emergen room
suicide attempts
eating disorders, substance abuse

### Why is abuse an important health problem?

Abuse can kill and cause serious physical injury as well as psychological injury. If everyone took more of an active part in stopping abuse, we could avoid many social problems. Many victims of abuse become alcoholics or drug addicts and have compulsive behaviors. They have low self-esteem which affects the quality of their lives and sometimes those they live with and care for.

### What are some signs of child abuse (sexual or other)?

poor hygiene hunger not dressed right/ weather tiredness broken, missing teeth bites marks, cuts, bruises burns, and welts fractures low self-esteem

headaches eating & sleeping disorders

depression

afraid of physical contact withdrawal or aggression frightened of parents ruptured eardrum begging food

begging food flashbacks runs away from home
missing school
stained, bloody underwear
STD
covers up w/ long clothes
promiscuity

tenderness in abdomen, rib cage itching, pain, swelling in genital area unattended health problems can't form healthy relationships menstrual/developmental problems



### If a person were really abused, wouldn't she leave or tell?

Women should leave abusive situations and seek help immediately, but many do not because they feel bad about themselves (they may believe they deserve it) or they fear for themselves and their children. They may stay for financial or religious reasons or because they believe it is better to keep a family together. Family members, friends and outsiders may need to help an abused women get out and get help. Children should not stay with an abusive parent. Witnessing abuse can have lasting psychological effects on young children. Rape victims often fear no one will believe them, and they may feel ashamed even though it is not their fault.

### **Myths about Sexual Abuse**

True or False? All are FALSE.

She asked for it.

If it really happened she would have told someone. She must have liked it or wanted it.

It only happens in poor families.

Only men sexually abuse. Only girls are sexually abused. You can tell an abuser by the way he looks.

If you can't see bruises and broken bones, it's not serious. He beats me because he cares so much. I made him hit me.

If I'm married to him/he's my boyfriend, it's not rape. Verbal abuse is not that serious a problem.

### **Substance Abuse**

### The Big High or the Big Lie?

by Renee Williams

Troy, a 30-ish African-American female, came into the OB/Gyn Center for her first OB visit. She was uncertain of her last menstrual period. She also had no idea who fathered her child. During her initial interview, she fidgeted in her chair, stared off into the room, looking everywhere but at her interviewer. She seemed reluctant to answer questions directed toward her, giving vague or unintelligible answers.

How would you relate to a patient like this in an exam situation? At this point, what do you predict might be going on? How would you interpret the situation? How would you approach Troy?

Finally, the nurse interviewer stopped the interview and spoke directly to Troy She asked her to look at her when she spoke and to try to focus on the interview questions. The nurse asked Troy if there was anything that she needed to talk about before the interview resumed. Troy began to cry stating that she needed help because she was tired of hurting her baby. She explained that she had hidden several cocaine-laced cigarettes in different places along her return route to her apartment, to maintain her high on her way home. She now regrets having done this, and does not want to go home.

### What can be done to help Troy?

The nurse asked her how serious she was about getting help. Troy responded that she had been in recovery before, but she is really ready this time. A call was placed to the staff social worker, who would provide referral information and placement assistance. A discussion

of Troy's support system revealed a very traumatic childhood. Troy had been living with her mother until the beginning of October, when her mother threw her out, calling her names and hurling verbal abuses at her. She was presently staying with an older gentleman who exchanged room and board for sexual favors. She was feeling degraded and dirty because of this, but felt that she deserved this because of her drug habit, which in fact, also indirectly led to her pregnancy. She had "turned a few tricks" to earn drug money. The nurse asked her why her mother had treated her so badly, "What did you do, kill somebody?" Troy answered, "Yes, I did." She explained that when she was a youngster, she and her twin sister had been playing alone in their home, when they found a loaded gun. While playing, she accidentally pulled the trigger and the gun discharged, the bullet killing her twin sister instantly. That was in October, over 20 years ago. And every October, her mother reminded her that she killed her sister, calling her a murderer. Troy tried to hide behind drugs because they helped her forget.

Sometimes, her mother would get high with her, especially if Troy was buying.

Troy didn't always have to buy her drugs. Her other sister lived with a dealer, who would pay Troy in drugs for baby-sitting her sister's children. Drugs were plentiful and easily accessible. Previous attempts at rehabilitation had failed, but now, Troy really wanted to quit. Her other three children had been removed from her custody, and two had been placed for adoption. She really wanted to keep this child, and to regain custody of her youngest child, a daughter, who was still in foster care.

After the interview and examination, Troy was seen by the social worker, who helped her gain admission into a local hospital rehab program (inpatient) and continue as an outpatient in the Sojourner House, which would also assist her in regaining custody of her daughter. Troy did very well initially, remaining clean throughout most of her pregnancy. She avoided her family and moved out of her apartment into Sojourner House.

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Her self-esteem began to grow, which was reflected in her improved personal appearance and attitude. She stayed in constant contact with her nurse and the social worker, who provided her with as much support as they were able. But, just a few weeks short of her due date, Troy ran into her sister, who was celebrating some good fortune. She invited Troy to join her. Troy did, and she gave into her sister's request to get high with her. Apparently, the high led to preterm labor, and Troy was rushed to the hospital by her sister. The sister told the doctor that they had "just a few hits of cocaine." The doctor contacted CYS. The newborn baby boy had traces of cocaine in his /stem.

CYS removed the baby from the ospital and placed him in foster care oy was devastated. Her nurse, who as also present at the delivery,

uraged her not to give up hope back into her drug habit, using this as an excuse. She directed Troy to the Delores Howze Treatment Center in the Hill District. That particular program is culturally specific for African-American women. Day care, child development, and parenting classes were provided, along with nutritional counseling and supplements. The recovery program was tough and included peer counseling and group sessions. The specifics of each person's addiction, and how they were racially or sexually linked to the recovery process were discussed. Once Troy completed this recovery program, she returned to the Sojourner House program. She and several other 'graduates' of the Sojourner House program were featured in an article published in the local paper. Troy found an apartment, and, after regaining custody of her son, she began having visitations with her daughter, in hope of having her come home for good. Troy recognized how difficult things were, but she looked back at where she had been, and did not want to go back there ever again.

In October 1995, she visited her nurse for the last time, to show off her family pictures. She still does not talk to her mother, but she does not look to drugs to help her get through her Octobers anymore. She is in therapy to deal with the loss of her sister, but she no longer overtly blames herself for her death, nor will she listen to those voices who continue to blame her.



### **Myths about Addictions**

### All are FALSE.

Addicts are immoral, weak-willed, and irresponsible.

Addicts are poor people or skid row burns.

Alcoholics get drunk every day, not just on weekends.

Knowledge about drugs prevents addiction.

Addiction is a sin.

If you teach people about drugs, they'll use them.

If you can stop drinking for any length of time, you are not an alcoholic.

The best thing I can do is be nice and support my alcoholic friend by cleaning up after him and taking care of him when he's drunk.

If you only drink one kind of alcohol you're not an addict.

You can drink herbal tea to wash drugs out of your system.

Only hard liquor really hurts the baby—beer and weed are O.K.

Since I have a prescription for it, I'm not really addicted.



## Dialogue





A NURSE SAYS ...

Once I discovered she was on drugs, I would assess her readiness to quit. You should always offer help, but lecturing at patients who aren't ready for help can be a waste of time and drive them away. If the patient is not ready, I would give her my number so she can contact me again when she is. Troy DOES want help—she revealed information she didn't have to. I'd ask how she would like help. You have to establish trust first, talk person-to-person. Comfort her. You have to acknowledge the guilt people feel. Tell her, "You're not a bad person.", Explain the power of drugs.

The degradation she must feel for selling her body, her low self-image, needs to be dealt with. As a nurse, I can't get too involved in the details, but have to work as a team with the social worker who can refer Troy and follow up. Some good programs that can offer her all kinds of support—emotional, social, and medical—are Narcotics Anonymous (391-5247), Alcoholics Anonymous (471-7472), Center for Substance Abuse (675-8500), lelase Institute (261-2817), Family Services (261-3623), and The Pittsburgh Recovery Center (263-2999).

### Pat, Age 25 Recovering Alcoholic

It was marijuana, after my grandfather died and my parents split up, then cocaine and alcohol. By age 13, I was uncontrollable. But I didn't see it at first, not till four years after mom kicked me out of the house. I don't know if there was anything doctors could have said to influence me; I felt hopeless.

I was 17, on the streets, when I realized, and went to rehab. It took six years and lots of AA and ALANON meetings to get completely off alcohol.

I respect my mother because she was strong enough to do what she needed to. Tough love may sound harsh, but sometimes it's the only answer.

What upsets me now is every time I have a medical problem, the first question they ask is are you on heroin, just because I still have tattoos and my head is shaved. Doctors need to see more than the outside person.

### Maggie, Age 31 Heroin Addict

I started using different drugs around 15.

I've lost some jobs, mainly because I've stolen things. Yeah, I've been arrested theft, possession, shoplifting. Minor stuff. Do I spend my money on drugs instead of bills? Of course. All the time.

If you told me I was going to die? No, I wouldn't quit. it wouldn't matter. I get a lot of infections from shooting up, but they go away.

I don't like it when doctors rag on my addiction.

Do I see myself as having a problem? No. It's my business.

### Sandi, Age 52 Recovering Addict

I started taking pain pills for my cancer. I was 42 and just had my bladder removed. I was O.K. at the beginning, but later I got hooked. I kept telling the doctor I was in more and more pain, to get refills.

After I went and told him how I had been overtaking the drugs, he was very considerate. He helped me get off the medications.

My doctor treated me good. His understanding helped. I guess he could have suggested a counselor for me. Later, I went to one on my own, and it helped.

### **Even Wild Women Get The Blues**

By Joyce Barrow

At age 37 when I worked as a nurse in the military, I had triplets. It added much stress to my life which was already overloaded. Our first child, who was so much desired, overwhelmed my husband who had no experience with babies or young children because he

was an only child.

At age 42, after the triplets, I missed another period. I went to the OB Clinic and they gave me a "shot" to bring it on, but it didn't. One evening when I was working in the emergency room, the medical officer looked at my feet and asked me what was wrong. I told him my feet were swollen. I told him about my missed period, and he said I was probably pregnant. STRESS! I didn't need anymore children.

I was getting angry easily at the children, a "real short fuse," and life was becoming difficult at home. On top of it, I thought to myself that I must be losing my mind, because my weekly pregnancy tests were always negative. What was wrong with me?

Right around this time, one of my coworkers started riding me. Things escalated. I cried more often, I was more anxious and angry all the time. STRESS!

Things became so intolerable. reauested an overseas assignment, and had my entire family transferred to Europe, leaving a beautiful home, almost paid for, in a town in the northeast where I had planned to retire.

But running away didn't help. While in Europe, my mother died. My dad, who had deeded me his house, called me and now asked me to buy it. I felt alone and overwhelmed, and I had a "panic attack," which placed me in the hospital at 2 a.m. one Sunday night. I got dizzy, started to vomit, and couldn't control my bowels. It was then a medical psychiatrist finally diagnosed me as having depression, which started a year ago. My first symptom was anger at my husband and kids and coworkers, but I did not recognize it as depression. I attributed my feelings to being pregnant (which I was not).

Talking to a psychiatrist about my feelings as well as my physical symptoms finally got me the help I needed. After more testing, we discovered that I wasn't putting out enough estrogen (female hormone). Estrogen produces a feeling of "well being" in our bodies and minds, and without enough of it, I had no good feelings! After a few months of therapy to talk out my recent losses and some medication to correct the estrogen imbalance, my husband said the old wife was back and the wicked witch had left.

### What If

my husband and I sought out counseling to get some support with our new triplets?

... I had not run away from my stress, but insisted that the doctors keep looking or refer me to someone who could help with my anger?

icians were trained to treat the whole person—and not just look at physical ympt ms but at the emotional well being and life situation of patients?

Sometimes when you are depressed you are too angry, hurt, or sad to think clearly. Don't be afraid to ask for help from your doctor or a friend or family member who can help you get an appointment with a psychiatrist. It is hard to diagnose your own depression, because it can be caused by physical reasons (a chemical imbalance in your brain or a hormone imbalance), by stressful situations in your life, or both. Tell your doctor what's going on in your life, if you feel it is affecting you. And if you are still not feeling yourself, ask to see a counselor or therapist.

# **Questions, Anyone?**

### How do know if I'm depressed, and can I get out of it myself?

If you heeling down for a long period—more than two to three weeks—feeling so low you cannot get out of bed in the morning, have lost interest in family and work, have feelings of guilt and worthlessness, or have a plan to hurt yourself, don't assume you can make it go away yourself. Signs of depression are:

- can't sleep/sleep too much
- waking up at night
- feeling helpless and hopeless
- loss of appetite/eating too much
- social withdrawal
- mood swings
- constant upsetting thoughts

Lots of people say, "Don't worry, be happy." But when you are depressed, you can't force yourself to be happy. Sometimes we need another person's perspective to really see what is causing our depression. Many people get depressed at some point in their lives. Asking for help is not a sign of weakness, but a sign you are smart enough to care for yourself.

### What should I do if I'm feeling this way?

Confide in your best friend, a family member, or your doctor. Find a therapist or a support group that offers counseling.

Your depression can be caused by a physical problem or by a sad or traumatic life experience. A therapist can help pin-point the causes and give you medication and/or counseling to get you through this period ome doctors will advise exercise and special diets to help you feel better. Medications such as PROZAC and ZOLOFT can restore the correct chemical balance in your brain, if that is one cause of your depression. There ARE effective ways to treat depression. Once you take the first step of asking for help, you will be on your way to feeling better!

### What is PMS all about?

Symptoms of premenstrual syndrome usually occur sometime in the two weeks right before your period: breast tenderness, tiredness, bloating and weight gain, cravings (chocolate, sugar, and salt), headaches, acne, mood swings, difficulty concentrating, and crying jags.

Keep an accurate record of your periods and these symptoms if you have them, and talk to your gynecologist about them. There are medications available that can help with PMS. Practicing a healthy lifestyle can also offer relief. Get 30 minutes of exercise each day and adequate sleep. Eat healthy foods: fruit, vegetables, rice, pasta, and whole wheat bread. Cut down on caffeine, alcohol, smoking, sugar, salt, and packaged foods with artificial ingredients. Source: Villarosa, L. (1994). Body and Soul. New York: Harper.

### Rights and Responsibilities

### Choose your own doctor—wisely

Ask to speak to the doctor before your first appointment so that you can ask questions and decide whether or not you will be comfortable with her. Or get a reference from a friend or family member.

Once you find a doctor you trust, see him (for yearly check-ups and medical emergencies).

If you don't like a doctor, ask your insurance company if you can switch to another. If you have doubts about your doctor's advice or treatments, tell him why. Get a second opinion—and a third— if you feel it is necessary.

Don't use the emergency room as a doctor's office; they don't know you as well, and you don't know them.

Encourage your patient to get a second opinion if she seems uncomfortable with the course of action you are prescribing.

### Develop a partnership with doctors and nurses.

Be honest, not just about physical symptoms but about your life circumstances and how you are feeling. Offer your interpretation of your problem and your feelings about it; you may see things the doctor doesn't. You know the most about your own body and lifestyle.

Write down your symptoms and questions before going into the office, to help you remember to cover all points. If you wrote a description of your problem ask the doctor to read it.

If the doctor or nurse seems not to listen, be persistent

Remind the doctor of previous visits, treatments, or medicines that you feel may be relevant to the present problem.

If you feel uncomfortable for any reason, tell the doctor why.

Don't assume doctors are always right. They can make mistakes

- Consider the patient's background during diagnosis and treatment. For example, one might offer a 20-year-old a diaphragm as birth control, but this would not be the best alternative for most 13-year-olds. Do not, however, make assumptions about a patient's character, sexual practices, or health habits based on physical appearance alone.
- Get to know the whole person. Learn about your patients so that you can prescribe treatment that is relevant and sensible in the context of their lives. Their financial situation, religious beliefs, style of communication, customs, and values might dictate whether and how they respond to treatment.
- \* Keep family members informed (with patient permission), and be aware of how a patient's illness can affect the larger family and support system.

- Barring emergency situations, let the patient take time to explain or write down her symptoms and concerns in her own words.
- When you don't feel the need to address specific complaints or hypotheses the patient brings to you, explain why you are taking a different course.
- Explain/define the exam process and procedures you will use, before you undertake them, and ask what you can do to make the process more comfortable (e.g., some patients may prefer to have a friend present).
- Use and define medical terms so the patient can learn them.
- Encourage informed choice by giving the rationale for your diagnosis and treatment, offering alternatives, and eliciting the patient's preferences.
- Always look directly at the patient and ask if she has questions—and pause so that she has time to reflect and answer.
- After the exam, ask the patient to repeat instructions or explain your diagnosis in her own words so that you can compare interpretations.

### Inform yourself about tests, treatments, medications, and insurance

- What tests are being given to me and why?
- What will happen to me during these tests/treatments?
- How long will it last?
- How and when will I learn the results?
- Does my medical coverage pay for it; if not, what other options are available to me?
- Please explain again what is wrong with me.
- Do you have any brochures or booklets, so I can read about this?
- Will you write that down for me?
- What is the medicine for?
- What are the side effects?
- Has it been tested or is it a new drug?
- Will it interact with other drugs I am taking right now?
- How long should I take it?
- What happens if I miss a dose or take too much?
- How much will it cost me, and is there a cheaper brand? Do you have samples?
- What is my coverage for treatments and medications?
- Do I need to get approval or a referral first?
- How much does the doctor charge?
- Can I make payments?
- Commit to a lifetime of learning about the physical as well as emotional, social and spiritual dimensions of healing. Develop a network of social workers, human service and educational agencies, and churches to which you can refer patients for additional support. "Where to Turn," is a helpful resource updated periodically by United Way.

### Practice Preventative Health Care

Pay attention to how you are feeling - physically and emotionally. If anything seems unusual, write down your symptoms and feelings. Notice patterns and possible causes. Talk to someone about it.

Learn about your body. There are plenty of good videos and books out there. For starters, we recommend "The New Our Bodies, Ourselves," by the Boston Women's Health Collective. Local hospitals often have free lectures and courses.

Take courses in emotional literacy - parenting classes, stress reduction courses, yoga, and meditation.

Find out about health hazards in your workplace, home, and neighborhood and fight for the health and safety of you and your children.

Don't wait until you are sick; see the doctor each year for a physical.

Have your teeth cleaned and examined at least once a year.

Have a complete gynecological exam once a year.

Keep track of your periods.

Examine your breasts after each period.

Practice safe sex.

Learn to shop for and cook fresh, healthy foods.

Find exercise you like; try to do some thirty minutes a day at least three times a week.

Avoid drugs, alcohol, tobacco, caffeine, and processed foods.

Avoid using harsh chemicals in your home and yard.

### In Conclusion...

- Given the stories in this booklet, what changes would you make in your daily interaction with patients, doctors, and nurses?
- What kind of policy changes would make for better partnerships between patients and health care workers?
- What rights and responsibilities are you willing to stand by both for patients and health care workers?