

Caring requires time, love, patience

Mental illness care not easy

By **STEPHEN ROW**
Staff Writer

Caring for a family member who suffers from a serious mental illness requires time, patience, dedication and tremendous amounts of love.

It also requires one to try and fathom that individual's world, even when their perceptions don't conform to objective reality.

Classes, like NAMI's 12-week family-to-family course, can help tremendously in developing a better understanding of the often tormenting world of hallucinations, unpredictable mood swings and humiliating sense that one is different.

Kathi's husband suffers from schizoaffective disorder — a condition whereby the mood swings associated with bi-polarity often are accompanied by hallucinations.

Her husband not only hears voices but the drone of machinery. Still he manages to maintain a sense of humor about his condition.

"I'm the only person who has volume control in my head," he tells her, explaining how he can turn up the volume of the machines to drown out the voices or visa versa.

Hardworking by nature, Kathi's husband still buries his emotions in his job.

"My husband is a workaholic," she said.

In retrospect, Kathi sees indicators that may have told her something may be wrong, like his compulsive obsession with neatness.

"Everything on his desk is at right angles," she explained.

His behavior may have been dismissed as perfectionism, but two years ago, in August 2001, Kathi's husband suffered a major breakdown.

"The compulsion to take his life was so strong he was hospitalized," she said.

Believing his condition was the result of stress, the doctor

put Kathi's husband on anti-anxiety medication.

The medication worked for nearly a year, until September last year, when his mood shifted from depression to extreme mania. Trying desperately to calm himself down, he overdosed.

"He kept taking (the anti-anxiety medication) because it wasn't working fast enough to stop the mania," Kathi explained.

"When he came out of the hospital he was a complete zombie" taking a "soup" of medications, she remembers.

The drugs' side effects caused him to gain 90 pounds.

Today, at age 35, Kathi's husband is relatively stable, taking a combination of Depakote, Ativan, Effexor and Lemectil.

He continues to work full-time, despite the deleterious side effects from the drugs and the disease's recurring symptoms.

"He has extreme strength of character. He fights it," she said proudly.

While Kathi's husband has

found some degree of equilibrium, she has been learning how to care for him —

and for herself.

One way Kathi — along with other family members — have found help is through NAMI's 12-week family-to-family course.

"Family to family really was a lifesaver to me," she said.

According to Marilyn Goldstein, director and teacher of NAMI New Jersey family-to-family program, the course doesn't just offer textbook information about mental illness, it actually gives first-hand experience of what it's

like to suffer from hallucinations or mood swings.

"It's a very unique experience," said Marilyn, whose son suffers from "a mental illness."

"It gives you all the tools that you need — psychological education, where to get care, coping skills and the empathy exercise."

Graduates of the program say the "empathy exercise" is one of family to family's most effective tools.

The exercise resembles a role play whereby a family member is asked to do a simple exercise, like drawing a diagram, while following instructions from another individual.

While this is being done, another individual will be a "voice" and talk in the family member's ear.

"I saw how much help my husband needed," Kathi said of the experience.

It is through the work of pio-

neers like Marilyn that NAMI now reaches out to many.

"My journey began 23 years ago," she said, relating how she came home one day to find her son — a bright, wonderful honor student — in a catatonic state.

"He was talking to a bird," she said.

Their story is not atypical of some families where someone suffers from mental illness — private hospitals, county hospitals, state hospitals, trying different medications, a group home.

"We've experienced everything there is to experience," she said.

After 13 years, Marilyn's son went to live on his own. The move was scary but liberating.

"I feel like I've been let out of prison," she remembers him saying.

That was 10 years ago. Today, Marilyn's son still lives on his own.

"He's very compliant with medication," she said, adding that he's into martial arts, running and a very careful diet.

"I'm very proud of him," she said, remembering that at one point she was told "he would never live outside of a hospital."



Trentonian Photo/JOHN DULLIGHAN
Kathi's husband suffers from schizoaffective disorder.



Trentonian Photo/JOHN DULLIGHAN
Marilyn Goldstein is director of NAMI's family-to-family program.

"It gives you all the tools that you need — psychological education, where to get care, coping skills and the empathy exercise."

Marilyn Goldstein, director of New Jersey's NAMI family to family program

New tests detect Down syndrome better

By **LINDA A. JOHNSON**
Associated Press

A new combination of blood tests and ultrasound can detect fetuses with Down syndrome sooner and more accurately than standard U.S. screening tests, offering mothers-to-be more peace of mind and more time to decide whether to end a pregnancy, researchers say.

The study of 8,216 women at a dozen U.S. medical centers confirms findings in England and elsewhere, where the combination is already widely used.

"It's earlier by about a month, so we've moved the standard testing to the first trimester and improved its accuracy," said lead researcher Dr. Ronald Wapner, chairman of obstetrics and gynecology at Drexel University College of Medicine in Philadelphia. "The absolute biggest advantage is this allows women to make private decisions" before they are visibly pregnant.

The usual blood screenings done in this country identify up to 75 percent of Down syndrome babies, but do not yield results until about 20 weeks into pregnancy, when abortion is more dangerous for women and often difficult to obtain.

The new combination — two blood tests, ultrasound and the mother's age — correctly identified 85 percent of fetuses with Down syndrome and yielded results at about 12 weeks.

Nine percent of the time, it incor-

rectly indicated a fetus probably had Down syndrome.

About one in 800 babies has Down syndrome, the most common chromosomal birth defect. Children with the syndrome suffer mental retardation and deformities such as a broad, flat face, short hands and a small head and ears.

When the four indicators together show a high probability of Down syndrome, women can choose a definitive — and invasive — test. In chorionic villus sampling, cells are withdrawn from the placenta with a needle, usually at 10 to 12 weeks of pregnancy. In amniocentesis, which is more commonly done in this country, fluid is drawn from the amniotic sac with a needle; it is done at 14 weeks or later. Both techniques carry about a 1 percent risk of miscarriage.

The study was reported in today's New England Journal of Medicine.

Dr. Mark I. Evans, director of the Institute for Genetics and Fetal Medicine at St. Luke's/Roosevelt Hospital Center in New York, said the study will cause a gradual shift from second-trimester screening to this method.

"There have been literally hundreds of thousands of patients evaluated worldwide who confirm these data," said Evans, president of the Fetal Medicine Foundation of America. "It's being routinely used all over the United Kingdom, Israel,

Brazil and many other countries."

But in an accompanying editorial, Drs. Michael T. Mennuti and Deborah A. Driscoll of the University of Pennsylvania School of Medicine wrote that second-trimester screening should continue to be the standard until detailed guidelines can be developed for using the ultrasound and other tests.

Because mothers 35 or older have a higher risk of having a Down syndrome baby — one chance in 270 — most get one of the invasive tests.

In addition to looking at the mother's age, the screening combination tested by Wapner and colleagues looks for low levels of a protein called pregnancy-associated plasma protein A, and for high levels of a type of the hormone human chorionic gonadotropin. The ultrasound test looks for telltale high levels of fluid in the fetus' neck.

Evans, who has researched the ultrasound test and been using it for a decade, said it is the single best marker of Down syndrome. But he also warned that correctly reading the ultrasound requires specialized training and experience. It is available at some U.S. academic medical centers.

Wapner said doctors might cut in half the number of invasive tests by using the combined screening to correctly identify normal as well as Down syndrome fetuses.

Few people provide CPR to victims

By **ANDRE PICARD**

Scripps Howard News Service

The made-for-TV-movie image of Good Samaritans rushing to the aid of heart-attack victims and performing lifesaving CPR is a far cry from life in the real world. New research shows that, in fact, those felled by a heart attack get the aid of bystanders only 14 percent of the time.

That's tragic because heart attack victims who do get help from strangers are three times more likely to be alive a year later than those who had to wait for the arrival of emergency personnel.

Almost 300,000 people die of sudden cardiac arrest each year in North America. Only about 4 percent of those felled by cardiac arrest — defined as the sudden stopping of the heartbeat — survive.

That is because there is only a five- to 10-minute window for resuscitation before death.

"It's the things done fastest and earliest that save lives. It's nothing fancy," said Dr. Ian Stiell, head of the department of emergency medicine at the University of Ottawa, and lead author of the study.

Rapid response by bystanders is essential and Stiell said more people need to know cardio-pulmonary resuscitation.

CPR is a combination of blowing oxygen into a victim's lungs and of chest compressions (to keep the heart circulating oxygenated blood) that is an essential element of all basic first-aid training.

Stiell, who is also an emergency-room physician at Ottawa Hospital, said that in his experience bystanders are not uncaring, but they are often frightened and untrained, so they stand by doing nothing.

The study of out-of-hospital heart attacks is published in this week's edition of the medical journal *Circulation*. The researchers examined the cases of more than 8,090 cardiac-arrest patients in 20 Ontario cities, with a special emphasis on the 316 who survived more than one year.

Among other things, the research refutes the common perception, among medical professionals and people outside the profession alike, that the quality of life of heart-attack survivors is poor. Most people assume that victims of cardiac arrest suffer severe brain damage. The reality is more starkly black-and-white: The vast majority die, but survivors do remarkably well.

In fact, the new study found that 86 percent of survivors had a high cerebral performance and good quality of life.

The challenge now is to improve survival rates, which have hovered in the 4 to 5 percent range for decades.

The research reveals that the worst place to have a heart attack is at home. Eighty-five percent of heart attacks occur in the home, and 15 percent outside the home.

A bystander was present about half the time, but intervened in only about one in seven times.

According to the study, the response time of emergency personnel is good: in 93 percent of cases, the patient was being treated within eight minutes of a 911 call.

Down syndrome detected sooner

A new combination of screening tests can detect fetuses with Down syndrome in the first trimester. The combination is also more accurate than standard U.S. screening tests according to a study reported in Thursday's New England Journal of Medicine.

Accuracy in identifying presence of Down syndrome*

Screening by maternal age alone

9.8%

Maternal age and fetal ultrasound

47.5%

Maternal age, fetal ultrasound and test of blood, protein and hormone levels

63.9%

*with a 1 percent false positive rate

SOURCE: New England Journal of Medicine

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