

Health

The New York Times

Six Killers



THE NEW YORK TIMES


This Times special report examines the leading causes of illness and death in the United States: heart disease, stroke, cancer, chronic obstructive pulmonary disease, diabetes and Alzheimer's disease.

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 **ONLINE:** Answers to readers' questions are posted along with video reports on patients and caregivers struggling with these diseases, interactive graphics and related articles at:

nytimes.com/health

This digital newsbook was produced for *The New York Times* at the Donald W. Reynolds Journalism Institute in Columbia, Missouri.
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TODD HEISLER/THE NEW YORK TIMES

Keith Orr in the intensive care unit of a Boston hospital as he recovered from his second heart attack and subsequent angioplasty.

Lessons of Heart Disease, Learned and Ignored

By **GINA KOLATA**

PUBLISHED: APRIL 8, 2007

KEITH ORR thought he would surprise his doctor when he came for a checkup.

His doctor had told him to have a weight-loss operation to reduce the amount of food his stomach could hold, worried because Mr. Orr, at 6 feet 2 inches, weighed 278 pounds. He also

had a blood sugar level so high he was on the verge of diabetes and a strong family history of early death from heart attacks. And Mr. Orr, who is 44, had already had a heart attack in 1998 when he was 35.

But Mr. Orr had a secret plan. He had been quietly dieting and exercising for four months and lost 45 pounds. He envisioned himself proudly telling his doctor what he had done, sure his tests would show a huge drop in his blood sugar and cholesterol levels. He planned to confess that he had also stopped taking all of his prescription drugs for heart disease.

After all, he reasoned, with his improved diet and exercise, he no longer needed the drugs. And, anyway, he had never taken his medications regularly, so stopping altogether would not make much difference, he decided.

But the surprise was not what Mr. Orr had anticipated. On Feb. 6, one week before the appointment with his doctor, Mr. Orr

was working out at a gym near his home in Boston when he felt a tightness in his chest. It was the start of a massive heart attack, with the sort of blockage in an artery that doctors call the widow-maker.

He survived, miraculously, with little or no damage to his heart. But his story illustrates the reasons that heart disease still kills more Americans than any other disease, as it has for nearly a century.

Medical research has revealed enough about the causes and prevention of heart attacks that they could be nearly eliminated. Yet nearly 16 million Americans are living with coronary heart disease, and nearly half a million die from it each year.

It's not that prevention doesn't work, and it's not that once someone has a heart attack there is little to be done. In fact, said Dr. Elizabeth Nabel, director of the National Heart, Lung and Blood Institute at the National Institutes of Health, age-adjusted death rates for heart

disease dropped precipitously in the past few decades, and prevention and better treatment are major reasons why.

But the concern, Dr. Nabel and others say, is that much more could be done. In many ways, scientists' hard-won and increasingly detailed understanding of what causes heart disease and what to do for it often goes unknown or ignored.

Studies reveal, for example, that people have only about an hour to get their arteries open during a heart attack if they are to avoid permanent heart damage. Yet, recent surveys find, fewer than 10 percent get to a hospital that fast, sometimes because they are reluctant to acknowledge what is happening. And most who reach the hospital quickly do not receive the optimal treatment — many American hospitals are not fully equipped to provide it but are reluctant to give up heart patients because they are so profitable.

And new studies reveal that even though drugs can protect

people who already had a heart attack from having another, many patients get the wrong doses and most, Mr. Orr included, stop taking the drugs in a matter of months. They should take the drugs for the rest of their lives.

"We've done pretty well," Dr. Nabel said. "But we could be doing much better. I've heard some people refer to it as the rule of halves. Half the people who need to be treated are treated and half who are treated are adequately treated."

The result, heart researchers say, is a huge disconnect between what is possible and what is actually happening.

Crucial Miscalculations

Keith Orr's story has themes that resonate with every cardiologist. He did many things right, but also made some crucial miscalculations that were so common that nearly every patient makes them, cardiologists say. But not everyone comes out as well.

Mr. Orr anticipated a pleasant

day on Feb. 6, starting with a workout at his gym, then lunch with a friend before he went to work at Smith & Wollensky, a steakhouse where he is a manager.

He arrived at the gym around noon and lifted weights, concentrating on the pectoral muscles of his chest. Then he moved on to an elliptical cross-trainer for cardiovascular exercise.

After half an hour on the elliptical, Mr. Orr felt a tightness in his chest. "I attributed it to the weight training," he said, but stopped exercising, showered, dressed and walked to his car.

"I felt really bad, out of sorts," he said. The pressure in his chest would ease off and then intensify, and now he was sweating profusely and was nauseated. When he arrived at the restaurant, he told his friend Darrin Friedman that he would have to beg off from lunch. "I feel like hell," he told Mr. Friedman.

He went home and lay on his bed.

"I knew at that point that it was not a pulled muscle," Mr.

Orr said. "It's a completely different feeling of pressure and discomfort. You feel as though something is genuinely wrong."

It was 3:15. And the pain was no longer intermittent. It was constant.

Mr. Orr called Mr. Friedman and asked him to drive him to an emergency room. A few minutes later, the two set off for Brigham and Women's Hospital, about a 10-minute drive.

"Keith was hunched over and he didn't put his seat belt on," Mr. Friedman said. "I kept asking him, 'Is it getting better or getting worse or staying the same?' For the first 10 minutes he said, 'It's about the same.' Then, when we were a block or so away, he said: 'I'm not doing well. I think it's getting worse.'"

When they arrived at the hospital's emergency department, Mr. Friedman explained that his friend was having chest pains. Immediately, Mr. Orr was wheeled off for an electrocardiogram, showing his heart's electrical signals. It was ominous,

including one pattern called the tombstone T wave because patients who had it died in the days before there were aggressive treatments to open arteries.

The next thing Mr. Orr knew, he was being rushed to the cardiac catheterization laboratory for a procedure to open his artery.

"They said: 'We're going now. We're going now,'" Mr. Orr recalled. "That really scared me. Someone kept yelling: 'Do you have his labs? Do you have his labs?' Someone else said, 'We'll transfer them later.'"

The electrocardiogram was at 3:45 p.m., roughly 30 minutes after his symptoms changed from intermittent to constant and 5 minutes after he got to the hospital.

At 3:52 p.m., Dr. Ashvin Pande, a cardiology fellow, was chatting in the hallway when he was called to the catheterization lab.

"Big M.I. coming in," a nurse told Dr. Pande, using the abbreviation for myocardial infarction, or heart attack. At the time,

the room was occupied — a patient was lying on the table for an elective procedure. He was quickly wheeled out and Mr. Orr was wheeled in. It was 3:56 p.m.

Within minutes, Dr. James M. Kirshenbaum, director of acute interventional cardiology, assisted by Dr. Pande, threaded a thin tube, like a long and narrow straw, from an artery in Mr. Orr's groin to his heart. They injected a dye to make Mr. Orr's arteries visible to an X-ray and they saw the problem — a huge clot in his heart's left anterior descending artery, blocking blood flow to most of his heart.

The quickest option was to open that artery with a balloon and keep it open with a stent, a tiny mesh cage, if possible.

It worked — the balloon shattered the clot and pushed the debris against the artery wall and the stent held the artery open. Then a different problem arose. When the large clot was pushed aside, the debris was shoved against the opening of a small artery that branched from

the larger one, much as a snowplow clearing a street can block a driveway.

“We made a calculated decision that it would be worth sacrificing the branch to secure the main vessel,” Dr. Pande said. But, fortunately, they were able to insert another balloon through the stent and into the small artery, opening it too.

At 4:43, the procedure was over and Mr. Orr was wheeled to the coronary intensive care unit. He had been awake but sedated and experienced what he said was the amazing feeling of having his artery opened. “As soon as the balloon goes in, all the pain disappears,” he said. “You know immediately.”

The cardiologists who saved his life walked out of the room, grinning and exhilarated.

“This adrenaline rush is why people like me go into cardiology,” Dr. Pande said.

The First Call: An Ambulance

Mr. Orr was incredibly lucky, said Dr. Elliott Antman, director of the coronary care unit at

Brigham and Women’s Hospital. He ended up with little or no damage to his heart, even though he teetered between lifesaving decisions and critical miscalculations in his moments of crisis.

The first lifesaving decision was to go to a hospital soon after his chest pain began. But the miscalculation was to call his friend for a ride. He should have called an ambulance.

Had his friend gotten caught in traffic, Mr. Orr might have been dead or sustained serious injury to his heart. He might have had to go to a rehabilitation center and learn special tactics for conserving energy, like sliding a coffee pot along a counter instead of lifting it.

What few patients realize, Dr. Antman said, is that a serious heart attack is as much of an emergency as being shot.

“We deal with it as if it is a gunshot wound to the heart,” Dr. Antman said.

Cardiologists call it the golden hour, that window of time when they have a chance to save most

of the heart muscle when an artery is blocked.

But that urgency, cardiologists say, has been one of the most difficult messages to get across, in part because people often deny or fail to appreciate the symptoms of a heart attack. The popular image of a heart at-

tack is all wrong.

It's the Hollywood heart attack, said Dr. Eric Peterson, a cardiologist and heart disease researcher at Duke University.

"That's the man clutching his chest, grimacing in pain and going down," Dr. Peterson said. "That's what people imagine a heart at-



TODD HEISLER/THE NEW YORK TIMES

CRITICAL MOMENTS

The time when doctors have a chance to save most of the heart muscle is called "the golden hour."

tack is like. What they don't imagine is that it's not so much pain as pressure, a feeling of heaviness, shortness of breath."

Most patients describe something like Mr. Orr's symptoms — discomfort in the chest that may, or may not, radiate into the arms or neck, the back, the jaw, or the stomach. Many also have nausea or shortness of breath. Or they break out in a cold sweat, or have a feeling of anxiety or impending doom, or have blue lips or hands or feet, or feel a sudden exhaustion.

But symptoms often are less distinctive in elderly patients, especially women. Their only sign may be a sudden feeling of exhaustion just walking across a room. Some say they broke out in a sweat. Afterward, they may recall a feeling of pressure in their chest or pain radiating from their chest but at the time, they say, they paid little attention.

Patients with diabetes might have no obvious symptoms at all other than sudden, extreme fatigue. It's not clear why diabetics

often have these so-called silent heart attacks — one hypothesis attributes it to damage diabetes can cause to nerves that carry pain signals.

"I say to patients, 'Be alert to the possibility that you may be short of breath,' " Dr. Antman said. "Every day you walk down your driveway to go to your mailbox. If you discover one day that you can only walk halfway there, you are so fatigued that you can't walk another foot, I want to hear about that. You might be having a heart attack."

Other times, said Dr. George Sopko, a cardiologist at the National Heart, Lung and Blood Institute, symptoms like pressure in the chest come and go. That is because a blood clot blocking an artery is breaking up a bit, reforming, breaking and reforming. It was what happened to Mr. Orr when he was at the gym and meeting his friend afterward.

"It's a pre-heart attack," Dr. Sopko said. A blood vessel is on its way to being completely blocked. "You need to call 911."

But most people — often hoping it is not a heart attack, wondering if their symptoms will fade, not wanting to be alarmist — hesitate far too long before calling for help.

“The single biggest delay is from the onset of symptoms and calling 911,” said Dr. Bernard Gersh, a cardiologist at the Mayo Clinic. “The average time is 111 minutes, and it hasn’t changed in 10 years.”

‘Time Is Muscle’

At least half of all patients never call an ambulance. Instead, in the throes of a heart attack, they drive themselves to the emergency room or are driven there by a friend or family member. Or they take a taxi. Or they walk.

Patients often say they were embarrassed by the thought of an ambulance arriving at their door.

“Calling 911 seems like such a project,” Mr. Orr said. “I reserve it for car accidents and exploding appliances. I feel like if I can walk and talk and breathe I

should just get here.”

It is an understandable response, but one that can be fatal, cardiologists say.

“If you come to the hospital unannounced or if you drive yourself there, you’re burning time,” Dr. Antman said. “And time is muscle,” he added, meaning that heart muscle is dying as the minutes tick away.

There may be false alarms, Dr. Sopko said.

“But it is better to be checked out and find out it’s not a problem than to have a problem and not have the therapy,” he said.

Calling an ambulance promptly is only part of the issue, heart researchers say. There also is the question of how, or even whether, the patient gets either of two types of treatment to open the blocked arteries, known as reperfusion therapy.

One is to open arteries with a clot-dissolving drug like tPA, for tissue plasminogen activator.

“These have been breakthrough therapies,” said Dr. Joseph P. Ornato, a cardiologist

and emergency medicine specialist who is medical director for the City of Richmond, Va. “But the hooker is that even the best of the clot buster drugs typically only open up 60 to 70 percent of blocked arteries — nowhere close to 100 percent.”

The drugs also make patients vulnerable to bleeding, Dr. Ornato said.

One in 200 patients bleeds into the brain, having a stroke from the treatment meant to save the heart.

The other way is with angioplasty, the procedure Mr. Orr got. Cardiologists say it is the preferred method under ideal circumstances.

Stents have recently been questioned for those who are just having symptoms like shortness of breath. In those cases, drugs often work as well as stents. But during a heart attack or in the early hours afterward, stents are the best way to open arteries and prevent damage. That, though, requires a cardiac catheterization laboratory, prac-

ticed doctors and staff on call 24 hours a day. The result is that few get this treatment.

“We now are seeing really phenomenal results in experienced hands,” Dr. Ornato said. “We can open 95 to 96 percent of arteries, and bleeding in the brain is virtually unheard of. It’s a safer route if it is done by very experienced people and if it is done promptly. Those are big ifs.”

The ifs were not a problem for Mr. Orr. His decision to go to Brigham and Women’s Hospital proved exactly right. But he did not know that when he chose the hospital — he chose it because his doctor was affiliated with Brigham.

A Need for More Angioplasty

Currently, 30 percent of patients who are candidates for reperfusion do not receive it, and of those who do, only 18 percent are treated with angioplasty, said Dr. Alice Jacobs, director of the cardiac catheterization laboratory at Boston University School of Medicine and a past president

of the American Heart Association. Of the nation's 5,000 acute care hospitals, Dr. Jacobs said, only 1,200 provide angioplasty.

Most hospitals, she said, cannot offer angioplasty because they do not have enough patients for a team of doctors to maintain their skills. An obvious solution would be to make heart attack care more like trauma care — sending patients to the nearest hospital that can provide angioplasty as quickly as possible. But that is not always easy, Dr. Jacobs said, because hospitals do not want to lose cardiac patients.

A major reason, she said, is financial. Hospitals are reimbursed by Medicare according an index that measures the acuity of medical conditions they treat.

“If your cardiac patients are transferred, your acuity index goes down, which lowers overall Medicare reimbursement for other problems like pneumonia and renal disease,” Dr. Jacobs said.

It is also difficult for patients who live in rural areas, where community hospitals are too

small to offer angioplasty and larger hospitals that do offer it are hours away. Minnesota is experimenting with a program using helicopters to transport patients quickly. But for most rural patients elsewhere, angioplasty is almost an impossibility.

Dr. Antman suggests that heart disease patients ask their doctor if there is a hospital nearby that does angioplasty around the clock. If so, they might want to discuss with their doctor whether to ask that an ambulance take them there if they are having a heart attack.

It is the sort of advice that makes cardiologists nervous — they do not want to encourage patients to dictate treatment. But, Dr. Antman said, if it is feasible to get to an angioplasty-providing hospital within an hour, “in most cases that would be preferable.”

Getting the Proper Therapy

Opening an artery is only the start of treatment. The next part is at least as problematic:

Patients have to get the right drugs, in the right doses, and have to take them for the rest of their lives.

“Care is getting a lot better,” Dr. Peterson said. “But the only caveat is that they are only really looking at, Did you get therapy? No one is looking too closely at, Did you do it right?”

For example, he said, a recent study found that heart attack patients were getting blood-thinning prescription drugs to prevent clots, as they should, but up to 40 percent were getting the wrong dose, usually one too high.

And even if every prescription were exactly right, as many as half of all patients do just what Mr. Orr did after his first heart attack. They stop taking many or all of their drugs.

Sometimes it is a matter of communication.

“The information did not get to the primary doctor and the primary doctor did not know to renew the prescription,” Dr. Peterson said. “When we talk to patients, they say: ‘No one com-

BY THE NUMBERS

15.8 million

Number of Americans who had been given a diagnosis of coronary heart disease in 2004

451,326

Number of American deaths from coronary heart disease in 2004

19.1%

Percentage of American deaths from coronary heart disease in 2004

1,236

Number of Americans who died each day, on average, of coronary heart disease in 2004

20%

Percentage of American adults age 60 and over with coronary heart disease in 2004

25%

Lifetime risk of a heart attack for an American woman at age 40

42%

Lifetime risk of a heart attack for an American man at age 40

Source: National Heart, Lung and Blood Institute data, National Center for Health Statistics and Framingham Heart Study

municated to me the importance of being on the medications long term. I thought I would only need them for three months, I thought it would be like an antibiotic. I thought they put in a stent so why do I need a drug?"

But there may be more to it than ignorance. There also is the image those pills convey of a sick person.

Mr. Orr said he did not like to think of himself as someone who had to take a fistful of pills every day. Even the recommended daily aspirin seemed superfluous, he thought.

"I think I sort of pooh-poohed the notion that one tablet of aspirin each day would do anything," Mr. Orr said.

What it does is make blood less likely to clot. In Mr. Orr's case, Dr. Antman said, it is likely that when Mr. Orr was exercising on the cross-trainer, an area of plaque ruptured. Then a clot began to form in the area, eventually blocking the artery.

The problem was not exercise, which is good for people

with heart disease, but Mr. Orr's decision not to take his medications, Dr. Antman said. If he had been taking aspirin that clot would have had more difficulty forming and growing.

Dr. Antman has a message for patients: With a disease as serious as heart disease, those who take responsibility are often the ones who survive.

Having a heart attack, even if it turns out well, as his did, is a life-altering experience, Mr. Orr said.

His first heart attack, Mr. Orr said, "came out of the blue." When he was discharged from the hospital, he was terrified that it would happen again when he was alone and unable to call for help. "I had a really hard time with it," he said. "I only stayed in my own house for one night and then I moved to a friend's house for two weeks."

Now Mr. Orr plans to be serious about taking his medication and getting back to his diet and exercise program. He will call an ambulance if he ever has

symptoms again. Still, he hates to think of himself as a patient. "I'm a little freaked out that I will have to take medication for the foreseeable eternity," Mr. Orr said.

But the day after he got home from the hospital, he thought about what had happened.

"The gravity of the situation just sort of clicked," Mr. Orr said. "I started to cry." □

It's Not a 'Plumbing Problem'

HOW IT HAPPENS ►►

The New York Times

HEALTH

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HOW IT HAPPENS

It's Not a 'Plumbing Problem'

By GINA KOLATA

PUBLISHED: APRIL 8, 2007

When Dr. Peter Libby, chief of cardiovascular medicine at Brigham and Women's Hospital in Boston, talks to his patients about heart disease, he often has to start by disabusing them of a popular misconception.

Most think cholesterol silts into arteries, blocking them like a clogged pipe. When, one day, an artery gets completely blocked, a heart attack occurs — no blood is getting through to the heart.

But the plumbing image is not only mistaken, cardiologists say. It can also lead patients to make disastrous errors in trying to protect themselves from a heart attack.

Plaque is actually a pimple-like growth inside an artery wall. The pimples, stuffed with what Dr. Libby describes as a “kind

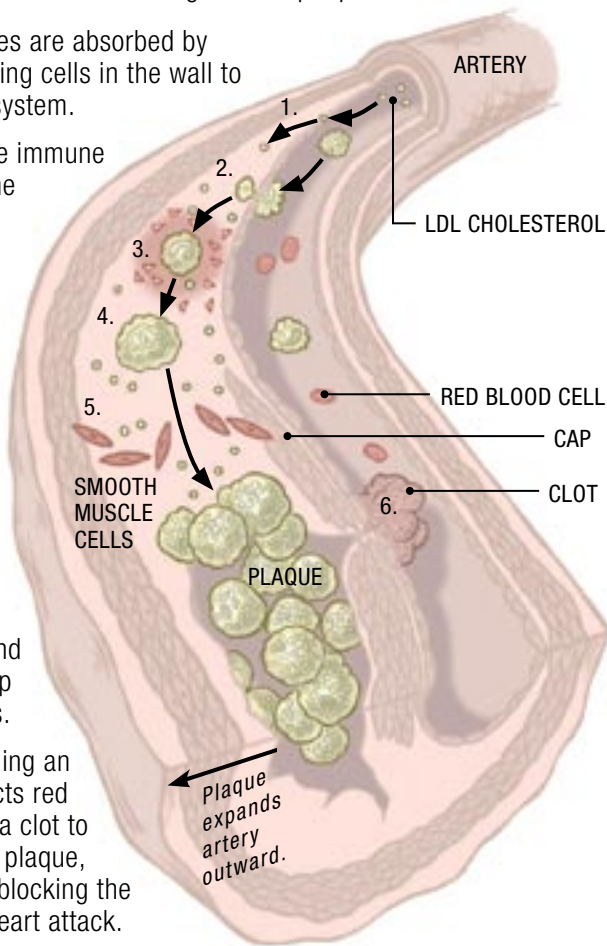
of chronic pus,” usually grow outward so they do not obstruct the blood vessel for many years. But once plaque gets started, Dr. Libby says, it covers the walls of the arteries. “It's likely that no part of the artery is normal,” he adds.

Arteries removed during autopsies of heart attack patients tell the story. “There are all kind of plaques, cheek by jowl,” Dr. Libby says.

There is the large, ugly yellow plaque that led to the heart attack. It popped open one day, attracting red blood cells that formed a clot on its surface, blocking the artery. There also are grayish-white plaques, old ulcerated plaques that became calcified. There is so-called vulnerable plaque, the pustules that are ready to burst. And there are yellowish streaks, thought to be plaques starting to develop.

Heart disease is now believed to occur when excess cholesterol inside an artery's walls incites inflammation and the growth of plaque.

1. LDL cholesterol particles are absorbed by the artery wall, prompting cells in the wall to summon the immune system.
2. White blood cells of the immune system squeeze into the artery wall.
3. The white blood cells send out chemical signals that cause inflammation.
4. The white blood cells grow and start to ingest the LDL cholesterol particles. This is the start of plaque, pimple-like growths.
5. The plaque enlarges and gets covered with a cap of smooth muscle cells.
6. The cap ruptures, forming an open wound that attracts red blood cells. They form a clot to seal the surface of the plaque, but the clot can grow, blocking the artery and causing a heart attack.



Source: Peter Libby, Brigham and Women's Hospital, Harvard Medical School

AL GRANBERG/THE NEW YORK TIMES

Patients typically have dozens of vulnerable plaques, and it is impossible to know which will burst and which of those will result in a blood clot that blocks an artery.

“From 100 plaque ruptures, it is only one that causes a heart attack,” said Dr. Valentin Fuster, a professor of cardiology at Mount Sinai School of Medicine in New York.

The only thing proven to reduce the risk of a heart attack in someone with vulnerable plaque is the same thing that works to prevent vulnerable plaque from developing in the first place — controlling cholesterol levels, blood pressure and blood sugar and not smoking.

Excess cholesterol gets stuck in artery walls. The wall becomes inflamed with white blood cells of the immune system. Those white blood cells in turn spew out highly active molecules that change the biology of the artery wall, leading to plaque.

With high blood pressure, the very molecules, angiotensin II,

that raise blood pressure also bring the release of the damaging small molecules that inflame arteries and set off the growth of plaque. Smoking, Dr. Libby added, appears to cause heart attacks for a different reason: it makes blood more likely to clot.

And it turns out that controlling these humdrum risk factors can nearly prevent heart attacks, said Dr. Daniel Levy, director of the Framingham Study, a federal study of heart disease in the population of Framingham, Mass.

Dr. Levy explains: Suppose a 50-year-old man does not have diabetes and does not smoke and keeps his cholesterol and blood pressure in the range recommended by national guidelines. Over the next 45 years, his chance of ever having a heart attack or symptoms of heart disease, like chest pain, is just 5 percent. The same goes for a 50-year-old woman with those risk factors under control. Her chance of symptomatic heart disease is 8 percent, slightly higher than the man's because women live longer.

But only 5 percent of 50-year-olds have those risk factors under control. And give that man just one major risk factor, for example a high cholesterol level, and his chance of having symptomatic heart disease rises to 50 percent. The woman's chance rises to 39 percent.

Only a third of people with high blood pressure have it under control, Dr. Levy said, even though there are dozens of effective drugs.

As for LDL cholesterol, the

dangerous form, Dr. Libby said, "If we applied lifestyles and the drugs we have consistently and according to guidelines, LDL is a done deal."

Dr. Levy thinks he understands why these prevention strategies are given such short shrift. Prevention, he says, "does not have a face." There are no personal stories, no individuals who can be pointed to as the success of prevention. It is just statistics. □

WHAT I WISH I'D KNOWN ►►

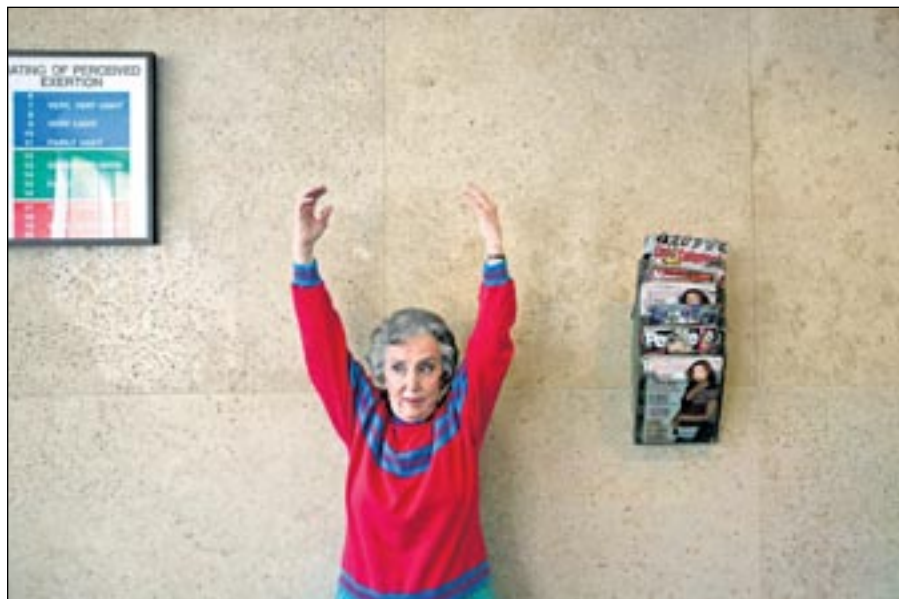
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Health & Fitness Tools

Body Mass Index Calculator:
What's your score?

Calorie Calculator for Goal Weight:
What's your limit?



TODD HEISLER/THE NEW YORK TIMES

Staying Active Naomi Atrubin, 76, who has had two heart attacks, exercises at the Mayo Clinic in Minnesota and participates in book and bridge clubs.

WHAT I WISH I'D KNOWN

Naomi Atrubin, a Survivor of Two Heart Attacks, Shares the Lessons She Has Learned

Naomi Atrubin's life might have been different. She would know what was happening that Christmas Eve when she had her first heart attack.

She would not have blamed spicy mustard for that heavy feeling in her chest. She would have taken an ambulance. She would have kept better track of

her blood pressure and cholesterol.

At 76, Ms. Atrubin gets tired but also stays active with duplicate bridge and book clubs. She had chest pains last summer. But she also is grateful that she lived to tell her story. She wishes everyone could hear its lessons.

1992 **FIRST HEART ATTACK** DEC. 24, 11 A.M., AGE 62 **CHARGES SUBMITTED TO INSURANCE,** **IN 2007 DOLLARS \$15,871.52**

Feeling tired for 11 days. A cardiologist she called that morning had gone home for Christmas. Did not want to bother him.

At lunch with her daughter, "I started to feel much worse. I had no pains, more of a weakness, and I felt dizzy." Lay down on a bench. "I said, 'It's just the drink, that's all it is.'"

Four hours later, at a movie, Ms. Atrubin felt nauseous. Leaving restroom, she thought, "If I don't lie down I'm going to fall down." Daughter saw her lying

on theater floor, called 911.

At the hospital, her arteries are opened with a clot-dissolving drug, streptokinase. Hospitalization from Dec. 24–Dec. 30, 1992. Two days in intensive care, two in intermediate care. Treatment includes: routine blood tests, electrocardiograms, streptokinase and discharge medications, including two to lower blood pressure and aspirin.

1997 **SECOND HEART ATTACK** OCT. 29, AGE 67 **CHARGES SUBMITTED TO INSURANCE,** **IN 2007 DOLLARS \$43,747.66**

Driving to a movie, had mild chest pains and blamed it on spicy mustard. Walked three blocks to theater. Pains worse. Told friend she thought she was having a heart attack. Ms. Atrubin rejected an ambulance. Friend drove her to emergency room. "I am fairly poor and the first time I had a heart attack the ambulance cost me \$600."

So weak in car, could not fasten seat belt. At hospital, her

arteries are propped open with two stents.

Hospitalization from Oct. 29–Nov. 4. Two days in intensive care, four in intermediate care. Treatments include: stress tests, cardiac catheterization with two stents, electrocardiograms, blood tests to look for proteins from damaged heart muscle and medications, including an anti-clotting drug. Nov. 6 1997–Dec 10, 1998. Outpatient treatment includes: rehabilitation, blood tests, stress tests and physician visits.

2006 **HEART SYMPTOMS LATE JULY, AGE 75**

**CHARGES SUBMITTED TO INSURANCE,
IN 2007 DOLLARS \$7,159.94**

Ms. Atrubin woke with mild chest pain. Waited a day to call doctor, not wanting to bother him on a Sunday. Doctor sent her to a cardiologist. Tests, including stress echocardiogram and nuclear stress tests, show abnormalities. Angiogram reveals blockage in an artery branch. She

declined more stents because her pain was not that bad.

2007 **CURRENT STATUS, AGE 76**

**TOTAL SUBMITTED SO FAR,
IN 2007 DOLLARS \$66,737.27**

At age 76, Ms. Atrubin gets tired but does not know if it is her heart or insomnia. “After my heart attacks, I felt like I was cured. I thought I could go ahead and do everything. I don’t feel like that now,” she says. She goes to a gym and walks on a treadmill. And if she had that weak feeling or chest pains again? “I would like to think I would run like hell to an emergency room. But how tired do I have to feel? I don’t really want to be a hypochondriac.” □

Controlling the Risk Factors Can Provide Crucial Aid in Prevention

WHAT YOU SHOULD KNOW ►►

WHAT YOU SHOULD KNOW

Blood Pressure, Cholesterol and Smoking: Controlling the Risk Factors Can Provide Crucial Aid in Prevention

Dr. Elizabeth Nabel, a practicing cardiologist and researcher studying the genesis of plaque in coronary arteries, became director of the National Heart, Lung and Blood Institute on Feb. 1, 2005. A firm believer in prevention, she exercises vigorously nearly every day and can recite her blood pressure, blood cholesterol and body mass index. She thinks everyone should know five things about heart disease:

A KILLER Heart disease is the leading killer, killing one in four women and one in four men.

PREVENTION The overwhelming majority of heart disease could be prevented by controlling blood pressure, cholesterol and cigarette smoking. About 85 percent of people who had fatal



DOUG MILLS/THE NEW YORK TIMES

ONLINE Readers submitted questions to Dr. Elizabeth Nabel when the series first appeared. Her answers are posted at <http://www.nytimes.com/2007/04/17/health/16heartqa.html>.

heart attacks had at least one of these risk factors.

Men 45 and older and women over age 65 should take an aspirin every day to prevent heart attacks and strokes. Those at high risk should take up to 325 mg daily; all other men and women over 65 but at lower risk should con-

sider 81 mg a day or 100 mg every other day. Consult with your doctor before starting aspirin.

SYMPTOMS The symptoms of a heart attack may not be what you think. The most common is chest pain or discomfort. But warning signs also include pain or discomfort elsewhere in the upper body, including the arms, back, neck or stomach.

Women in particular may experience shortness of breath, exhaustion, nausea or vomiting, and back or jaw pain. If you have these symptoms, call an ambulance right away. Prompt treatment can open blocked coronary arteries, preventing areas of heart muscle from dying for lack of blood.

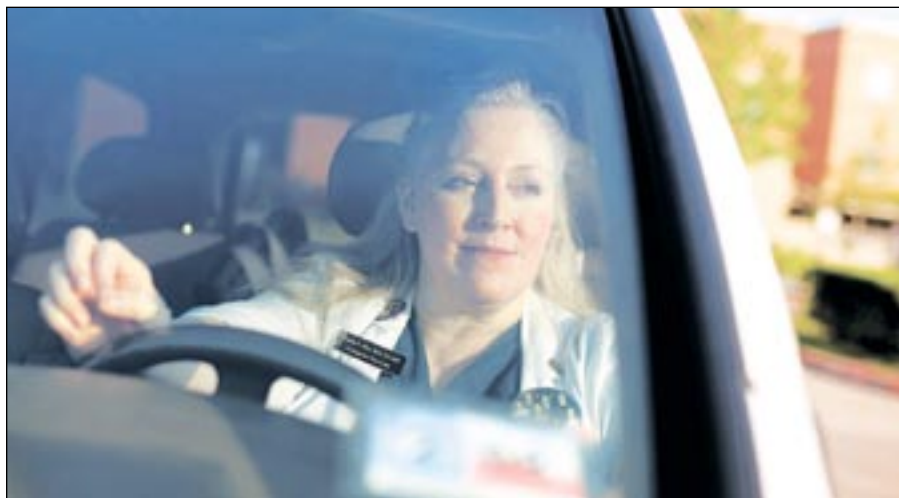
PLANS If you are at high risk, develop a heart attack action plan in consultation with your doctor. That means knowing the warning signs of a heart attack and taking a nitroglycerin, a drug that widens blood vessels, if you have heart attack symptoms. If they don't go away in

five minutes, take a second and third nitroglycerin.

Have a list of your medicines ready for emergency personnel. And plan ahead with your doctor on how to get to a hospital that can provide emergency heart attack care, including angioplasty, a procedure in which a cardiologist opens a blocked artery with a tiny balloon and then, usually, inserts a stent, a tiny metal cage, to keep it open.

Many hospitals do not offer this procedure to heart attack patients, but, if at all possible, you need to go to one that does. If your symptoms stop completely in less than 5 minutes, you should still call your health care provider.

URGENCY Everyone who has symptoms of a heart attack should call 911. Do not drive yourself to the emergency room. And do not dismiss symptoms because you think you are not at risk of a heart attack. Every minute of delay in getting treatment can mean death of heart muscle. Time is muscle, as cardiologists say. ■



TODD HEISLER/THE NEW YORK TIMES

Dr. Diana Fite, an emergency medicine specialist in Houston, has completely recovered since suffering a stroke while driving.

Lost Chances for Survival, Before and After Stroke

By **GINA KOLATA**

PUBLISHED: MAY 28, 2007

DR. DIANA FITE, a 53-year-old emergency medicine specialist in Houston, knew her blood pressure readings had been dangerously high for five years. But she con-

vinced herself that those measurements, about 200 over 120, did not reflect her actual blood pressure. Anyway, she was too young to take medication. She would worry about her blood pressure when she got older.

Then, at 9:30 the morning of

June 7, Dr. Fite was driving, steering with her right hand, holding her cellphone in her left, when, for a split second, the right side of her body felt weak. “I said: ‘This is silly, it’s my imagination. I’ve been working too hard.’”

Suddenly, her car began to swerve.

“I realized I had no strength whatsoever in my right hand that was holding the wheel,” Dr. Fite said. “And my right foot was dead. I could not get it off the gas pedal.”

She dropped the cellphone, grabbed the steering wheel with her left hand, and steered the car into a parking lot. Then she used her left foot to pry her right foot off the accelerator. She pulled down the visor to look in the mirror. The right side of her face was paralyzed.

With great difficulty, Dr. Fite twisted her body and grasped her cellphone.

“I called 911, but nothing would come out of my mouth,” she said. Then she found that if she spoke very slowly, she could

get out words. So, she recalled, “I said ‘stroke’ in this long, horrible voice.”

Dr. Fite is one of an estimated 700,000 Americans who had a stroke last year, but one of the very few who ended up at a hospital with the equipment and expertise to accurately diagnose and treat it.

Stroke is the third-leading cause of death in this country, behind heart disease and cancer, killing 150,000 Americans a year, leaving many more permanently disabled, and costing the nation \$62.7 billion in direct and indirect costs, according to the American Stroke Association.

But from diagnosis to treatment to rehabilitation to preventing it altogether, a stroke is a litany of missed opportunities.

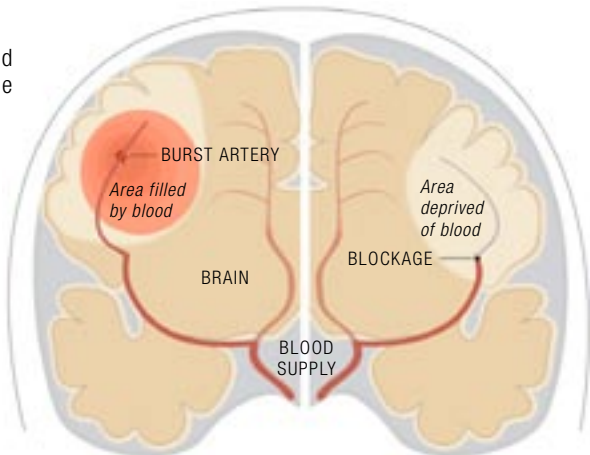
Many patients with stroke symptoms are examined by emergency room doctors who are uncomfortable deciding whether the patient is really having a stroke — a blockage or rupture of a blood vessel in the brain that injures or kills brain cells — or

How a Stroke Occurs

Most strokes occur when an artery in the brain is blocked by a clot. The others, about 13 percent of strokes, occur when a brain artery bursts. Both types can be disastrous.

HEMORRHAGIC STROKE

1. An artery in the brain bursts and either floods the surrounding tissue with blood or floods the surface and grooves of the brain.
2. The blood irritates brain cells, disrupting their functions and causing the brain to swell with fluid.
3. If the swelling continues, the brain is stopped by the skull and squeezed through the opening in the bottom of the skull, crushing the centers for consciousness and breathing.



ISCHEMIC STROKE

1. A blood clot forms and is swept into the brain where it blocks an artery. Clots usually form in the heart or in arteries of the neck that are damaged by atherosclerotic plaque.
2. The brain tries to protect itself by raising blood pressure, trying to clear the artery. Meanwhile, the brain cells, deprived of blood, shut down.
3. If the problem persists, brain cells swell and die

Sources: Dr. Steven Warach, National Institute of Neurological Disorders and Stroke; American Heart Association

THE NEW YORK TIMES

is suffering from another condition. Doctors are therefore reluctant to give the only drug shown to make a real difference, tPA, or tissue plasminogen activator.

Many hospitals say they can-

not afford to have neurologists on call to diagnose strokes, and cannot afford to have M.R.I. scanners, the most accurate way to diagnose strokes, for the emergency room.

Although tPA was shown in 1996 to save lives and prevent brain damage, and although the drug could help half of all stroke patients, only 3 percent to 4 percent receive it. Most patients, denying or failing to appreciate their symptoms, wait too long to seek help — tPA must be given within three hours. And even when patients call 911 promptly, most hospitals, often uncertain about stroke diagnoses, do not provide the drug.

“I label this a national tragedy or a national embarrassment,” said Dr. Mark J. Alberts, a neurology professor at the Feinberg School of Medicine at Northwestern University. “I know of no disease that is as common or as serious as stroke and where you basically have one therapy and it’s only used in 3 to 4 percent of patients. That’s like saying you only treat 3 to 4 percent of patients with bacterial pneumonia with antibiotics.”

And the strokes in the statistics are only the beginning. For every stroke that doctors know about, there are 5 to 10 tiny, si-

lent strokes, said Dr. Vladimir Hachinski, the editor of the journal *Stroke* and a neurologist at the London Health Sciences Centre in Ontario.

“They are only silent because we don’t ask questions,” Dr. Hachinski said. “They do not involve memory, but they involve judgment, planning ahead, shifting your attention from one thing to another. And they also may involve late-life depression.”

They are also warning signs that a much larger stroke may be on the way.

Most strokes would never happen if people took simple measures like controlling their blood pressure. Few do. Many say they forget to take medication; others, like Dr. Fite, decide not to. Some have no idea they need the drugs.

Still, there is much more hope now, said Dr. Ralph L. Sacco, professor and chairman of neurology at the Miller School of Medicine at the University of Miami. Like most stroke neurologists, Dr. Sacco entered the field more

than a decade ago, when little could be done for such patients.

Now, Dr. Sacco said, there is a device, an M.R.I. scanner, that greatly improves diagnosis, there is a treatment that works and there are others being tested. “Medical systems have to catch up to the research,” he said.

In medicine, Dr. Sacco said, “stroke is a new frontier.”

Promise Unfulfilled

One Tuesday morning in March, Dr. Steven Warach, chief of the stroke program at the National Institute of Neurological Disorders and Stroke, met with a team from Washington Hospital Center, the largest private hospital in Washington, to review M.R.I. scans of recently admitted patients. They were joined in a teleconference by neurologists at Suburban Hospital in Bethesda, Md., the only other stroke center in the Washington and suburban Maryland area.

The images were mementos of suffering.

There was a 66-year-old woman with a stroke so big the scan

actually showed degenerating fibers that carry nerve signals across the brain.

There was a 75-year-old who had trouble moving her right arm and right side in the recovery room after heart surgery. At first doctors thought she was just slow to wake up from the anesthesia. Now, though, it was clear she had suffered a stroke. She had lost the right half of her vision in both eyes and her right side was weak.

There was an 88-year-old who slumped forward at lunch, losing consciousness. When he came to, he had trouble forming words.

There was a middle-age man whose stroke was unforgettable. When Dr. Warach saw his initial M.R.I. scan, in his basement office at his home, he cried out in astonishment so loudly his wife ran downstairs. “I have never seen anything so severe,” Dr. Warach said. None of the three arteries that supplied the man’s right hemisphere were getting any blood.

Now the man lay in a coma, twitching on his left side, para-



DOUG MILLS/THE NEW YORK TIMES

PATH TO RECOVERY

Meredith Roberts, an occupational therapist, at a Washington hospital with Michael Collins, a police officer who had to retire after a stroke.

lyzed on his right, breathing with the help of a ventilator. If he survived, he would have severe brain damage.

There was Michael Collins, a 49-year-old police officer who had had a stroke in his police car in Takoma Park, Md. Unlike the others, Mr. Collins seemed

mostly recovered. The next few days, though, would determine whether he was among the lucky 10 percent of stroke patients who escape unscathed or whether he would always be weaker on his left side. If that happened, Mr. Collins said, he could never return to his job.

“You have to be able to shoot a gun with either hand,” he explained. But as time passed, Mr. Collins continued to be plagued by numbness in his left hand and on the left side of his face. He wanted to return to work — “I’m doing great,” he said this month — but the Police Department insisted that he retire, telling him, he said, “it’s an officer safety issue.”

The rest of the patients in the stroke units at the two hospitals that day were less fortunate: almost certain to live, but also almost certain to end up with brain damage. Some would have to spend time at a rehabilitation center.

On average, said Dr. Brendan E. Conroy, medical director of the stroke recovery program at the National Rehabilitation Hospital, which is attached to the Washington Hospital Center, a third of the Washington hospital’s stroke patients die, a third go home and a third come to him.

Those whose balance is affected typically spend 20 days

learning to deal with a walker or a cane; those who are partly blind or paralyzed must learn to care for themselves. Many functions return, Dr. Conroy said, but rehabilitation also means learning to live with a disability.

But what was perhaps saddest to the neurologists viewing the M.R.I. scans that morning was that tPA, which only recently appeared to be a triumph of medicine, had made not a whit of difference to these patients. They either had not arrived at the hospital in time or had been considered otherwise medically unsuitable to receive it.

Few would have predicted that fate for the drug. In 1995, after 40 years of trying to find something to break up blood clots in the brain, the cause of most strokes, researchers announced that tPA worked. A large federal study showed that, without it, about one patient in five escaped serious injury. With it, one in three escaped.

The drug had a serious side effect — it could cause poten-

tially life-threatening bleeding in the brain in about 6 percent of patients. But the clinical trial demonstrated that the drug's benefits outweighed its risks.

When the study's results were announced, Dr. James Grotta of the University of Texas Medical School at Houston expressed the researchers' elation. "Until today, stroke was an untreatable disease," Dr. Grotta said.

But the expected sea change did not occur.

One problem was that patients showed up too late. Many had no choice. Strokes often occur in the morning when people are sleeping. They awake with terrifying symptoms, paralyzed on one side or unable to speak.

"That's the challenge — we have to ask the patient" when the stroke began, said Dr. A. Gregory Sorensen, a co-director of the Athinoula A. Martinos Center for Biomedical Imaging at Massachusetts General Hospital. "If they don't know or can't talk, we're out of luck."

Another problem is deciding

BY THE NUMBERS

700,000

Number of Americans who had a stroke in 2004.

150,147

Number of American deaths from strokes in 2004.

50%

Stroke patients who should be treated with the drug tPA within three hours of onset.

20%

Patients who seek help within three hours of the onset of symptoms.

3%-4%

Americans having a stroke who get the tPA drug.

50%

Stroke deaths that occur outside a hospital.

53%

Stroke victims who are female.

Source: American Heart Association

whether a patient is really having a stroke. A person who has trouble forming words could just be confused. Or what about someone whose arm or leg is weak?

“A lot of things can cause weakness,” Dr. Warach said. “A nerve injury can cause weakness; sometimes brain tumors can be suddenly symptomatic. Sometimes people have migraines that can completely mimic a stroke.”

In fact, he said, a quarter of emergency room patients with symptoms suggestive of a stroke are not actually having one.

Most get CT scans, which are useful mostly to rule out hemorrhagic strokes, the less common type that is caused by bleeding in the brain and should not be treated with tPA. Stroke specialists can usually then decide whether the patient is having a stroke caused by a blocked blood vessel and whether it can be treated with tPA.

But most stroke patients are handled by emergency room physicians who often say they are not sure of the diagnosis and

therefore hesitate to give tPA.

Dr. Richard Burgess, a member of Dr. Warach's stroke team, explained the situation: There is no particular penalty for not giving tPA. Doctors are unlikely to be sued if the patient dies or is left with brain damage that could have been avoided. But there is a penalty for giving tPA to someone who is not having a stroke. If that patient bleeds into the brain, the drug not only caused a tragic outcome but the doctor could also be sued. Few emergency room doctors want to take that chance.

Treatment Barriers

There is a way to diagnose strokes more accurately — with a diffusion M.R.I., a type of scan that shows water moving in the brain. During a stroke, the flow of water slows to a crawl as dead and dying cells swell. In one recent study, diffusion M.R.I. scans found five times as many strokes as CT scans, with twice the accuracy.

A diffusion M.R.I. “answers

the question 95 percent of the time,” Dr. Sorensen said.

It seemed the perfect solution, but it was not.

Most hospitals say they cannot provide such scans to stroke patients. They would need both an M.R.I. technician and an expert to interpret the scans around the clock. They would need an M.R.I. machine near the emergency room. Most hospitals have the huge machines elsewhere, steadily booked

far in advance for other patients.

It is simply not practical to demand the scans at every hospital or even every stroke center, said Dr. Edward C. Jauch, an emergency medicine doctor at the University of Cincinnati and a member of the Greater Cincinnati/Northern Kentucky Stroke Team.

“If you made M.R.I. the standard of care before giving tPA, most centers would not be able to comply,” Dr. Jauch said. And



TODD HEISLER/THE NEW YORK TIMES

TEAMWORK

Doctors at Massachusetts General Hospital in Boston on rounds in the neuro intensive care unit.

if it takes more time to get a scan — as it often does — it might be better to forgo it and give tPA immediately if the patient's symptoms seem unambiguous.

Doctors do not need an M.R.I. to diagnose and treat stroke, said Dr. Lee H. Schwamm, vice chairman of the department of neurology at Massachusetts General Hospital. But, Dr. Schwamm added, if the question is whether it helps, there is one reply: "By all means."

It has still not been shown, though, that M.R.I. scans actually improve outcomes. It might depend on the circumstances and the hospital, said Dr. Walter J. Koroshetz, deputy director of the National Institute of Neurological Disorders and Stroke.

But some who use M.R.I. scans, and who have studied them in research, say the system has to change. They say enough is known about the scans to advocate having them at every major medical center that will treat stroke patients.

"All these problems could be solved if there was a will to do it,"

Dr. Sorensen said. In his opinion, it comes down to old and outdated assumptions that there is not much to be done for a stroke, to financial considerations and to a medical system that resists change. But the most significant barriers, he said, are financial.

Another approach, stroke specialists say, is to direct all patients with stroke symptoms to designated stroke centers. There, stroke patients would be treated by experienced neurologists and admitted to stroke units for additional care. For the first time, in its newly published guidelines, the American Stroke Association recommended the routing of patients to stroke centers.

But even with such a system in place, many patients end up at hospitals that are not prepared to treat them, as Dr. Grotta discovered in Houston.

He thought he could change stroke care in Houston with the stroke center idea. The first step went well — the city's ambulance services agreed to take all

patients with stroke symptoms to designated stroke centers.

Then, Dr. David E. Persse, the city's director of emergency medical services, asked every one of Houston's 25 hospitals if it wanted to be a stroke center. While seven have said yes, others have declined.

Stroke patients, unlike heart attack patients, are not money-makers. Because of the way medical care is reimbursed, most hospitals either lose money or do little more than break even with stroke care but can often make several thousand dollars opening the arteries of a heart attack patient. And being a stroke center means finding and paying stroke specialists to be available around the clock.

Soon another problem emerged. As many as a third of the patients refused to let the ambulance take them to a stroke center, demanding to go to their local hospital.

"By law in Texas, we cannot take that man to another hospital against his will," Dr. Persse said.

"We could be charged with assault and battery and kidnapping and unlawful imprisonment."

The Joint Commission, which accredits hospitals, recently started certifying stroke centers, requiring that the hospitals be willing to treat stroke patients aggressively. But only 322 of the 4,280 accredited hospitals in the nation qualify, and most patients and doctors have no idea whether a hospital nearby is among them. (The list is available on the site <http://www.jointcommission.org/CertificationPrograms/Disease-SpecificCare/DSCOrgs/> under "primary stroke centers.") Some states, like New York, Massachusetts and Florida, do their own certifying of stroke centers.

Nonetheless, most ambulances do not consider stroke center designations when they transport patients. And, said John Becknell, a spokesman for the National Association of Emergency Medical Technicians, national programs can be difficult because every community has its own rules for which ambulances pick up pa-

tients and where they take them.

As a result, most stroke patients have no access to the recommended care and even fewer get M.R.I.'s, a situation Dr. Warach said he found appalling.

"How can it ever be in the patient's best interest to have an inferior diagnosis?" he asked. "It borders on malpractice that given a choice between two non-invasive tests, one of which is clearly superior, the worse test is the one that is preferred."

Averting Catastrophe

In those awful moments when she realized she had had a stroke, Dr. Fite, unlike most patients, knew what to do. She told the ambulance crew to take her to Memorial Hermann Hospital, even though it was about an hour away. She knew that it was one of the Houston stroke centers, that Dr. Grotta worked there, and that its doctors had experience diagnosing strokes and giving tPA.

When she arrived, Dr. Grotta asked if she was sure she wanted the drug. Did she want to risk

bleeding in the brain? Dr. Fite did not hesitate. The stroke, she said, "was just so devastating that I would rather die of a hemorrhage in the brain than be left completely paralyzed in my right side."

"In my horrible voice, I said, 'Yes, I want the tPA,' " Dr. Fite said.

Within 10 to 15 minutes, the drug started to dissolve the clot.

"I had weird spasms as nerves started to work again," Dr. Fite said. "An arm would draw up real quick, a leg would tighten up. It hurt so bad I was crying because of the pain. But it was movement, and I knew something was going on."

Now, she looks back with dismay on her cavalier attitude toward high blood pressure. She knew very well how to prevent a stroke but, like many patients and despite her medical training, she found it all too easy to deny her own risk.

Researchers have known for years the conditions that predispose a person to stroke — smok-

ing, diabetes, high cholesterol and an irregular heartbeat known as atrial fibrillation. But the major one is high blood pressure.

“Of all the modifiable risk factors, high blood pressure leads the list,” Dr. Sacco said. “With heart disease, you think more of cholesterol; with stroke you think of high blood pressure.”

The reason, Dr. Sacco said, is that with high blood pressure, the tiny blood vessels in the brain clamp down so much and so hard to protect the brain that they can become rigid. Then they get blocked. The result is a stroke.

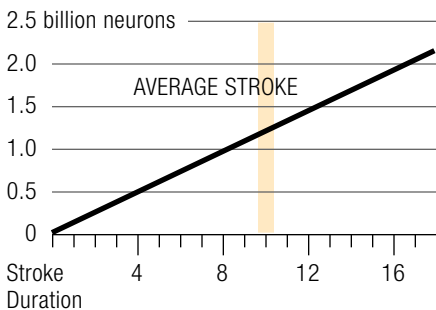
Often, people decide they do not need their blood pressure medication or simply forget to take it because they feel well. But, Dr. Sacco said, patients are not solely to blame. Doctors may not have time to work with patients, monitoring blood pressure, telling them about changes in their diet and exercise that might help, or trying different drugs and combining them if necessary.

And it is not so simple for people to keep track of their blood

Critical Timing

The average human forebrain has about 22 billion neurons. The average stroke lasts 10 hours and kills more than 5 percent of those, along with 5 percent of the synapses and myelin fibers.

Neuron loss from a typical ischemic stroke



Source: American Heart Association

THE NEW YORK TIMES

pressure. Machines in drug-stores and supermarkets are not always accurate. Doctors may require appointments to check blood pressure.

Even when people do try to control their pressure, doctors may not prescribe enough drugs or high enough doses.

“They’re on a couple of drugs, and the doctor doesn’t want to push it,” said Dr. Jeffrey A. Cutler, a consultant to the National

Heart, Lung and Blood Institute and a retired director of its clinical applications and prevention program.

The result is that no more than half the people with high blood pressure have it under control, Dr. Cutler said. He estimated that half of all strokes could be prevented if people kept their blood pressure within the recommended range.

Another lost opportunity to prevent strokes is the under-treatment of atrial fibrillation, in which the two upper chambers of the heart quiver. Blood can pool in the heart and clot, and those clots can be swept into the brain, lodge in a small blood vessel and cause a stroke.

Strokes from atrial fibrillation can largely be prevented with anticoagulating drugs like warfarin. Yet many who have the condition do not know it and many who know they have it were never given or do not take an anticoagulating drug.

Some strokes can also be prevented by procedures to open obstructed arteries in the neck

that supply blood to the brain.

As for Dr. Fite, she completely recovered. And she has changed her ways.

She was sobered by the cost of her treatment and brief hospital stay — \$96,000, most of which was paid by her insurance company. But she was even more sobered by how close she came to catastrophe.

Now, Dr. Fite takes three blood pressure pills, a drug to prevent blood clots and a cholesterol-lowering drug. She plans to take those drugs every day for the rest of her life.

“I was so stupid,” she said. “Boy, when you go through this, you never want to go through it again.”

“I have been given that precious second chance,” she said. “I was so blessed.” □

Technology Puts Costly Stroke Treatment in Reach For Island Hospital

A VITAL LINK ►►

A VITAL LINK

Cost Put a Crucial Stroke Treatment Out of Reach for a Small Island Hospital, Then Technology Made It Possible

By GINA KOLATA

PUBLISHED: MAY 28, 2007

Doctors at Martha's Vineyard Hospital, the only hospital on the small island off Massachusetts, knew only one drug had been shown to work for stroke, tPA. But, until they adopted a new telemedicine system for hospitals like theirs, they had not been giving it to the 25 or so stroke patients they cared for each year.

One problem was the availability of specialists. Ideally, to give tPA, an emergency room doctor should confer with a neurologist to decide whether a patient is having a stroke and whether tPA would help. That, said Dr. Timothy Tsai, director of emergency medicine at the hospital, was all but impossible. The island, with a year-round population of

15,000 and a summer population of about 120,000, has one general neurologist with an office-based practice. She cannot rush to the hospital for stroke patients, and no one covers for her when she leaves the island.

To have a neurologist always available, the hospital would have to hire the equivalent of two and a half neurologists, said Timothy Walsh, the hospital's chief executive. They would be idle most of the time while costing more than a half-million dollars.

"We wouldn't be able to handle it financially," Mr. Walsh said. Ideally, the hospital would also use an M.R.I. machine, the most accurate brain scan for strokes. But keeping the \$1.5 million machine near the emergency department "could never be justified by the business" in diagnosing strokes,



TODD HEISLER/THE NEW YORK TIMES

LONG-DISTANCE DIAGNOSIS Via computer from Boston, Dr. Lee H. Schwamm, director of stroke services at Massachusetts General Hospital, can help doctors at Martha's Vineyard Hospital, where Florence Arnston was treated last fall.

Mr. Walsh said. The hospital's only M.R.I. scanner comes in by ferry on Saturday morning and leaves Sunday night.

And the hospital would also need other specialists, like a neuroradiologist, to interpret the scans and a neurosurgeon to deal with possible bleeding problems. Those impediments left Martha's Vineyard Hospital in the same situation as most hospitals in the United States: stroke diagnosis and immediate care was the sole responsibility of the emergency room doc-

tor, who, Dr. Tsai said, worried about giving tPA.

The concern is bleeding in the brain — it occurs about 6 percent of the time with tPA and can be fatal. The worst fear is to give tPA, cause a fatal bleed and find out the patient had not even had a stroke.

Then the hospital signed up for TeleStroke, a program offered by two Harvard teaching hospitals, Massachusetts General Hospital and the Brigham and Women's Hospital in Boston. For \$10,000 a year, Martha's

Vineyard Hospital links to the Harvard hospitals with video-conferencing and image-sharing technology.

That allows stroke neurologists at the Harvard hospitals to examine patients remotely and assist the emergency room doctor in deciding whether to give tPA. The neurologists must rely on symptoms and CT scans, which are not ideal for diagnosing strokes, but they are experienced enough to often feel confident in their diagnosis.

TeleStroke is what saved Florence Arnston when she had a stroke on Martha's Vineyard last October, on the first day of her vacation.

Mrs. Arnston, who is 76 and lives in Lansing, Ill., was having an ice cream cone after lunch when her left hand suddenly felt

numb and her foot dragged when she walked. She told her husband she did not feel well, and they returned to their tour group.

A nurse in the group called 911. Within 15 minutes, Mrs. Arnston recalled, she was at Martha's Vineyard Hospital. There, with TeleStroke, a Harvard doctor determined that she was having a stroke, recommended tPA, and remotely supervised its administration. "It was very scary," Mrs. Arnston said. "But I recovered and I'm doing very, very well." Now, she said, her only reminder of the stroke is an occasional numbness in her hand.

"It's just remarkable," Mrs. Arnston said. "God was good to me, and I'm very thankful for that." □

WHAT YOU SHOULD KNOW ►►

The New York Times

www.nytimes.com/health

WHAT YOU SHOULD KNOW

Steps Toward Reducing Risk

Dr. Walter J. Koroshetz, deputy director of the National Institute on Neurological Disorders and Stroke, lists five things everyone should know about strokes:

A KILLER Strokes can cause permanent brain damage and are the leading cause of permanent disability in adults. They are the third-leading cause of death in the United States. There are two main types of stroke: ischemic, caused by blockage of a blood vessel in the brain, and hemorrhagic, caused by bleeding into or around the brain.

PREVENTION The best way to prevent most strokes is to keep blood pressure in the normal range.

WARNING SIGNS A number of conditions place people at high risk for stroke and should lead



DOUG MILLS/THE NEW YORK TIMES

ONLINE Readers submitted questions to Dr. Walter J. Koroshetz when the series first appeared. His answers are posted at <http://science.blog.nytimes.com/2007/05/29>.

to intensive investigation and therapy.

¶ The most dangerous warning sign is a transient ischemic attack, sometimes called a T.I.A. or a ministroke. The symptoms usually go away after a few minutes, but are otherwise identical to stroke symptoms. People suddenly cannot speak or move an arm or leg or they cannot see.

Many go on to have a stroke in the next few hours to weeks.

¶ Atrial fibrillation, a heart condition that results in an irregular heartbeat and that occurs in millions of elderly Americans, is a common cause of severe strokes in patients over 65, or in younger patients with other vascular risk factors.

¶ A severe headache that occurs so suddenly that it is often described as a “clap of thunder” can be a sign of bleeding around the brain, called a subarachnoid hemorrhage. Immediate medical attention is necessary to treat the weakened blood vessel, an aneurysm, before it bursts, causing a hemorrhagic stroke.

REDUCING RISK There are ways to reduce stroke risk when these warning signs occur.

¶ People who have had T.I.A.’s or strokes or whose carotid arteries are partly obstructed can protect themselves by taking low doses of aspirin (81-milli-

gram tablets) and a cholesterol-lowering statin even if their cholesterol level is not high.

¶ People with atrial fibrillation can substantially decrease their stroke risk by taking warfarin, a drug that inhibits blood clotting.

¶ Some people with obstructed carotids may reduce their risk of stroke by having the obstruction surgically removed. Stents to hold back the obstruction may help patients who cannot have the surgery and have had symptoms of a stroke.

URGENCY Patients with stroke symptoms should get to a hospital immediately. The brain damage from acute ischemic stroke can sometimes be halted by medications that dissolve the clots blocking blood flow to the brain. But for this therapy to be successful, treatment must be initiated as soon as possible. Minutes count, and therapy may be futile as soon as three hours from the onset of symptoms. □

Cancer Patients, Lost in a Maze of Uneven Care

Sick, Scared and Daunted by Complicated Choices

By **DENISE GRADY**

PUBLISHED: JULY 29, 2007

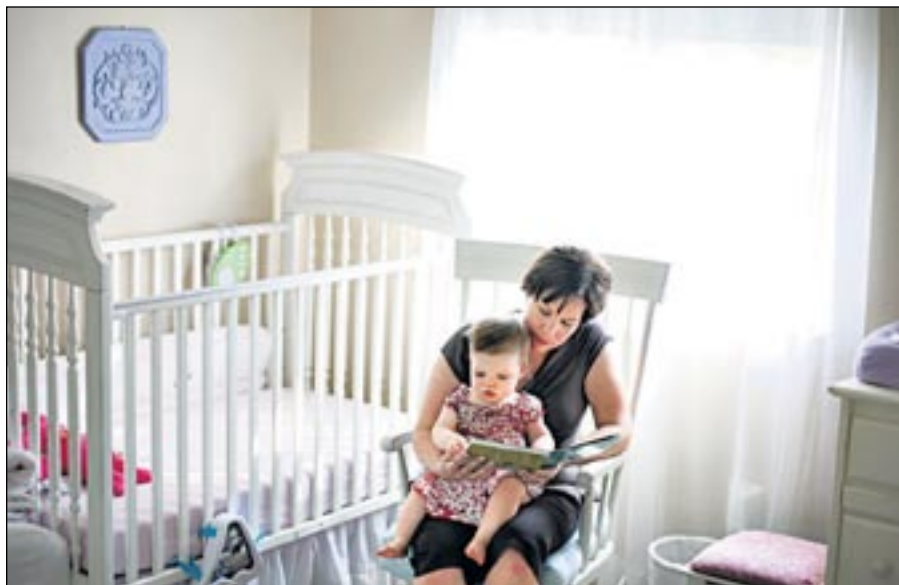
THE FIRST doctor gave her six months to live. The second and third said chemotherapy would buy more time, but surgery would not. A fourth offered to operate.

Karen Pasqualetto had just given birth to her first child last July when doctors discovered she had colon cancer. She was only 35, and the disease had already spread to her liver. The months she had hoped to spend getting to know her new daughter were hijacked by illness, fear and a desperate quest to survive. For the past year, she and her relatives have felt lost, fending for themselves in a daunting medical landscape in which they struggle to make sense of conflicting ad-



TODD HEISLER/THE NEW YORK TIMES

Karen Pasqualetto was only 35 and a new mother when a doctor diagnosed advanced colon cancer and gave her six months to live.



TODD HEISLER/THE NEW YORK TIMES

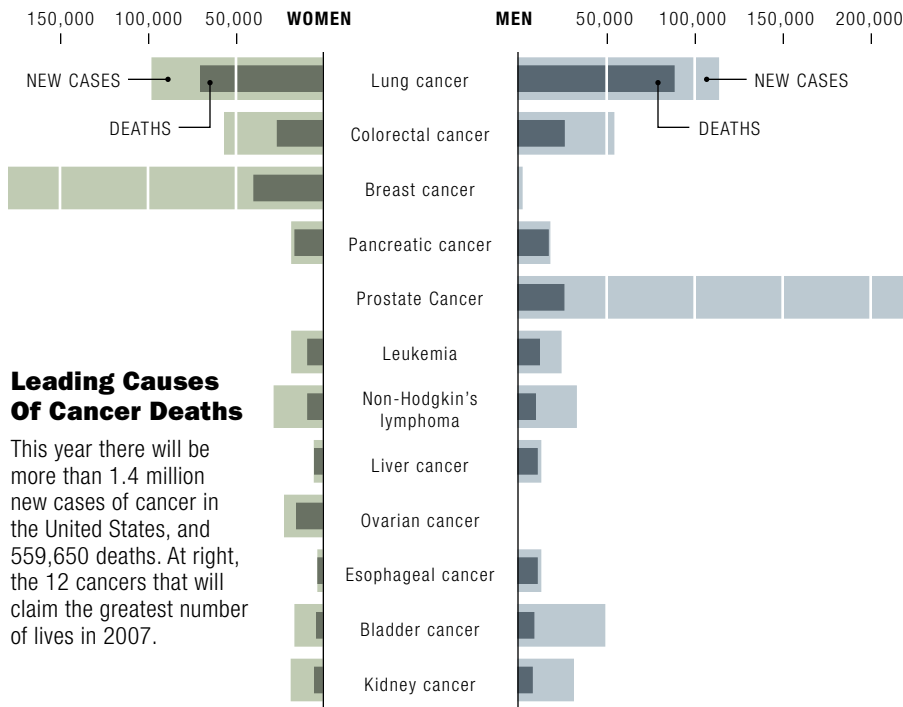
Karen Pasqualetto before her surgery. "I don't feel I have a doctor who is looking out for my care," she said recently.

vice as they race against time in hopes of saving her life.

"It's patchwork, and frustrating that there's not one person taking care of me who I can look to as my champion," Ms. Pasqualetto said recently in a telephone interview from her home near Seattle. "I don't feel I have a doctor who is looking

out for my care. My oncologist is terrific, but he's an oncologist. The surgeon seems terrific, but I found him through my own diligence. I have no confidence in the system."

It was a sudden immersion in the scalding realities of life with cancer. This year, there will be more than 1.4 million new cases



Source: American Cancer Society

THE NEW YORK TIMES

of cancer in the United States, and 559,650 deaths. Only heart disease kills more people.

Cancer, more than almost any other disease, can be overwhelmingly complicated to treat. Patients are often stunned to learn that they will need not just one

doctor, but at least three: a surgeon and specialists in radiation and chemotherapy. Diagnosis and treatment require a seemingly endless stream of appointments. Doctors do not always agree, and patients may find that at the worst time in their lives,

when they are ill, frightened and most vulnerable, they also have to seek second opinions on biopsies and therapy, fight with insurers and sort out complex treatment options.

The decisions can be agonizing, in part because the quality of cancer care varies among doctors and hospitals, and it is difficult for even the most educated patients to be sure they are receiving the best treatment. "Let the buyer beware" is harsh advice to give a cancer patient, but it often applies. Excellent care is out there, but people are often on their own to find it. Patients are told they must be their own advocates, but few know where to begin.

"Here it is, a country with such a great health system, with so many different breakthroughs in treatment, but even though we know things that work, not everybody who could benefit gets them," said Dr. Nina A. Bickell, an associate professor of health policy and medicine at the Mount Sinai medical school in Manhattan.

BY THE NUMBERS

1,444,920

Estimated number of new cancer cases that will be diagnosed this year in the United States

559,650

Number of Americans expected to die this year from cancer

1 in 4

Number of American deaths that are because of cancer

168,000

Number of Americans who will die this year from cancer caused by tobacco use

1 in 3

Cancer deaths this year related to obesity, physical inactivity and nutrition

77%

Percentage of all cancers that are diagnosed in people age 55 or older

\$206.3 billion

Estimated overall cost of cancer in 2006, including medical expenses and the cost of lost productivity because of illness and premature death

*Source: American Cancer Society;
National Institutes of Health*

Death rates from cancer have been dropping for about 15 years in the United States, but experts say far too many patients receive inferior care. Mistakes in care can be fatal with this disease, and yet some people do not receive enough treatment, while others receive too much or the wrong kind.

“It’s quite surprising, but the quality of cancer care in America varies dramatically,” said Dr. Stephen B. Edge, the chairman of surgery at the Roswell Park Cancer Institute in Buffalo. “It’s scary how much variation there is.”

Government and medical groups acknowledge that the quality of care is uneven. In 1999, a report by the Institute of Medicine in Washington said, “For many Americans with cancer, there is a wide gulf between what could be construed as the ideal and the reality of their experience with cancer care.” The institute noted that there was no national system to provide consistent quality.

In March, cancer organizations including the National Quality Forum tried to address the problem by issuing the first set of quality measures that can be used to judge whether hospitals are giving patients up-to-date care for breast and colon tumors, two of the most common cancers.

The list of measures calls for treatments that seem so basic even to a layperson that it is shocking to think any hospital would skip them. For instance, it says that women under 70 who have lumpectomies for breast cancer should also have radiation, and that doctors should consider chemotherapy for people with colon cancer that has spread to their lymph nodes.

Dr. Edge, who worked on the measures, said, “While they’re fairly simple and straightforward, and they seem very basic, it’s quite surprising how many people do not get the care that’s recommended.”

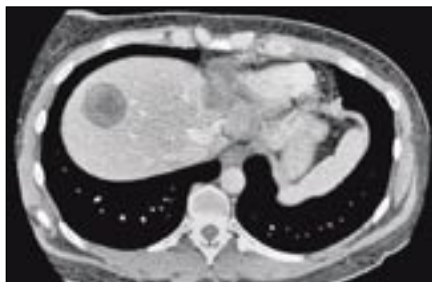
Treatment guidelines approved by experts already ex-

ist for 70 to 80 types of cancer (<http://www.nccn.org/>), but the new measures are the first to be formally endorsed by cancer organizations to assess whether hospitals are performing up to par. The measures were developed by the American College of Surgeons' Commission on Cancer, the American Society of Clinical Oncology and the National Comprehensive Cancer Network, and are available online at www.facs.org/cancer/qualitymeasures.html.

It took more than two years, Dr. Edge said, before experts even agreed on these basic principles. The first goal is to give doctors and hospitals a chance to see how they stack up to national standards. Eventually, the measures may be used by regulators and payers, including Medicare, he said.

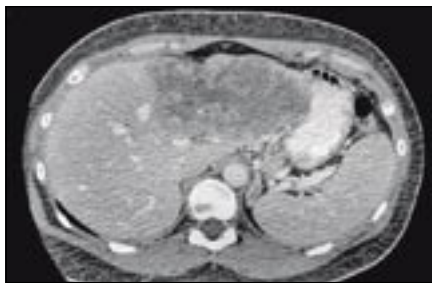
First Sign of Trouble

Karen Pasqualetto is slight and dark-haired, with a soft voice that belies how tough she is. After giving birth by Caesarean



Above: Ms. Pasqualetto's liver. The dark mass at the top left is a tumor.

Below: A view of a different tumor in Ms. Pasqualetto's liver. It is the larger dark mass at the top.



section last July, she noticed a lump under her ribs. It was the size and shape of a banana. Doctors noticed it but did nothing. She was sent home and was told it was probably a bruise. Within a week she was back in the hospital, terribly ill — swollen with

fluid, vomiting, so anemic she needed a transfusion and suffering from severe abdominal pain. Tests found colon cancer that had already spread, or metastasized, to her liver — stage 4, the final chapter of the disease.

“The doctor came in with a tear in his eye,” she recalled. “‘It’s bad.’ Those were his exact words. ‘You have maybe six months.’”

Surgery was not recommended because the liver tumors were too extensive. She was referred to an oncologist, who offered “palliative” chemotherapy, given strictly to ease symptoms, not to try for a cure.

“His attitude was that it wouldn’t really make a difference,” Ms. Pasqualetto said.

Palliative treatment was all her health plan would cover. But she had read enough about the disease to know that the proposed regimen did not include the full program of drugs typically recommended for stage 4.

Look for other opinions, her family urged. Her husband had

a new job that provided better health coverage, and they switched to a different insurer.

“I think I’d be dead if I’d stayed with the first provider,” she said.

Ms. Pasqualetto, a self-described Type A go-getter, knew better than most how to find information. She has a law degree and worked for several technology start-ups. She had made enough money to quit that career and do something she loved, teaching sixth grade at a Catholic school in Seattle.

She rejected the first oncologist after one visit and consulted the well regarded Seattle Cancer Care Alliance and Swedish Cancer Institute. Both recommended aggressive chemotherapy. Surgery might be possible, they said, if the drugs would shrink the tumors enough. She chose an oncologist at the Swedish institute Dr. Philip Gold, who brushed aside her six-month death sentence and assured her that people with stage 4 colon cancer could live three to four times that long.

“His message to me as a patient was, ‘I have a lot of tricks up my sleeve, this is what we start with, and if it doesn’t work I have this, and then I have a clinical study,’ ” Ms. Pasquale said. “The feeling I got was, there was hope, and a plan of attack.”

Eleven months later, after 22 courses of treatment, she gave Dr. Gold credit for keeping her alive and giving her extra time with her daughter, Isabel.

Location, Location, Location

Where patients are treated can make all the difference. Some doctors and hospitals may not see enough cases to stay sharp, especially when it comes to rarer kinds of tumors, complicated operations or advanced stages of the disease — all areas in which studies have shown that experience counts. This factor may leave people in rural areas or smaller cities, and poor people, at a distinct disadvantage.

Communication also plays a crucial part: some patients may

not understand that surgery alone is not enough and that they also need chemotherapy or radiation or both.

Even when treatment guidelines are based on solid evidence, hospitals or doctors may not stick to them. But sometimes, the science is not clear, and experts do not agree on the best course — or even on whether there is a best course.

“In cancer, there is frequently no one best doctor and no one best treatment,” said Dr. John H. Glick of the Abramson Cancer Center at the University of Pennsylvania.

When patients consult him for second opinions or to transfer their care to his center, Dr. Glick estimated that he and his colleagues concur completely with the original doctor in about 30 percent of cases. But in another 30 to 40 percent of cases, they recommend major changes in the treatment plan, like a totally different chemotherapy regimen or the addition of radiation. Sometimes his

team makes a completely different diagnosis.

In about another 30 percent of cases, his team recommends minor changes in chemotherapy, or additional tests. “We interpret things differently, maybe because we have more experience,” Dr. Glick said. “We see hundreds of patients with Hodgkin’s disease. A community oncologist may see only a couple.”

Warning Signs Overlooked

Looking back, Karen Pasqualotto thinks she had cancer symptoms that were dismissed by doctors in 2003 or 2004 — at least two years before the disease became horribly obvious. She noticed blood in her stool, a classic warning sign of colon cancer. But it lasted only a few days, and such bleeding can also be caused by minor ailments like hemorrhoids. Many doctors do not even think of colon cancer in a young person with no family history of the disease, and her doctor said anal fissures had probably caused the bleeding.

There is no way now to know whether that was correct. No sigmoidoscopy or colonoscopy was done to examine the inside of her colon or rectum. Other warning signs were also missed or ignored: anemia and blood in her stools during pregnancy and in the hospital after giving birth.

Ninety percent of colorectal cancers occur in people 50 and older — the reason screening generally starts at 50 — but that still leaves more than 15,000 new cases a year in younger people, some of whom have no symptoms.

The sad paradox of colon cancer is that it is often preventable — but not prevented. It is one of the cancers for which screening tests can find cancers or precancerous growths early enough to cure the disease or even prevent it with surgery alone.

Only 39 percent of colon cancers are detected early. The disease is still the second leading cause of cancer death in the United States (lung cancer is

first), with about 154,000 new cases and 52,000 deaths expected this year.

Doctors say the main reason the death toll remains so high is that not enough people are screened. Screening is unpleasant: it requires stool tests or scopes inserted into the rectum. It should start at age 50 for most people, earlier for those with risk factors like a family history of colon cancer. But many people refuse the tests or put them off. Some cannot afford colonoscopy, which costs \$2,000 to \$4,000; not all insurers cover it, even for people over 50.

Whatever the reason, only about half of those who should be tested actually are. Deaths could be cut in half, experts say — meaning 26,000 lives a year could be saved — if all those who need screening were to receive it. It is possible that screening tests have saved President Bush from developing cancer. He has had colon polyps removed on several occasions, including last Saturday, when five were

snipped out. Most polyps do not become malignant, but they are removed when found because nearly every colon cancer starts out as a polyp.

Screening has no advocate like a patient who has been through it all — surgery, radiation and chemotherapy, or slash, burn and poison, as some people call it — for a tumor that might have been easily cured if it had only been found sooner.

“If people knew what they had to go through with colorectal cancer, they wouldn’t hesitate to have this silly little colonoscopy,” said Rebecca Michalovic, who has rectal cancer that was diagnosed in 2003. Ms. Michalovic, 60, has had the works: radiation, three operations and a half-dozen ferocious drugs. Despite it all, the cancer has spread to her lungs. Even so, she continues to work full time as a counselor and administrator at Daemen College in Amherst, N.Y. But one drug after another has stopped working, and she is down to the last two.

She was 56 and had always been healthy when the disease was diagnosed, after she noticed a bit of rectal bleeding. She had never been checked for colorectal cancer.

"I should have done it," Ms. Michalovic said.

Elation and Then a Setback

One aspect of Karen Pasqualetto's care has particularly troubled her. She was told that the first few months of chemotherapy had shrunk the liver tumors enough to make them operable, and surgery was scheduled for last January. She was elated, figuring that removal of the tumors was her best shot at staying alive. But in December a hospital review panel known as the tumor board refused to approve the surgery.

"I was adamantly told it was off the table, and I don't know why," Ms. Pasqualetto said. Even she, the feisty patient, felt powerless.

"Who is this tumor board, and do they hold the keys to my

life?" she asked.

"You feel a total lack of control when you're in a position like mine," she said.

Her oncologist, Dr. Gold, who is chairman of the tumor board, said it was a group of doctors who met informally to review cases and decide what treatment would help a patient most. In Ms. Pasqualetto's case, the board thought chemotherapy would accomplish more than surgery.

"Patients don't always hear what you're telling them," Dr. Gold said.

The decision haunts Ms. Pasqualetto because it soon became clear that her tumors had been at their smallest in January. By March, they were growing again, defying the chemotherapy. She feared she might have lost her best chance.

In May, she said: "I didn't even think I'd make it to today. The baby is starting to talk. I feel happy to be here for that moment. Next thing, maybe I'll get to see her walk."

Last month, she watched her daughter take her first steps.

But she had a severe allergic reaction to a new cancer drug in which she had placed a great deal of hope. With that reaction, another opportunity was gone. It was a huge setback.

The same day she had the reaction, a surgeon who had reviewed her case said he thought he could help her.

"It was almost like life and death in one day," she said. "I know my chances are dwindling."

The surgeon was Dr. Michael Choti, at Johns Hopkins, whom her sister had found through a patients' advocacy group, the Colon Cancer Alliance. He specializes in colon cancer that has spread to the liver. Though the surgery would be difficult and more than one operation might be needed, he told her that she seemed young and strong enough to withstand it.

She was torn. Her oncologist in Seattle hinted that it might be too late to operate, and that surgery could even make matters

worse by spreading tumor cells around inside her body. She trusted him, and the thought of leaving his care frightened her.

But she clung to the hope of becoming "cancer free," and though surgery offered only a slim chance of that, she believed it was her only chance.

"It would almost be easier if there was somebody telling me what to do," she said. "But there's nobody saying, 'This is what you should do.'"

Missing the Right Treatment

Studies suggest that significant numbers of patients miss out on cancer treatments that could prevent recurrence, prolong survival or save their lives.

Among women with breast cancer, 15 to 25 percent who should have radiation do not receive it, and 20 to 30 percent do not take the anti-estrogen drugs that are a mainstay for most patients, Dr. Edge said.

Women miss out for various reasons.

"Because they don't get re-

ferred to the right doctor,” he said. “Or the doctor doesn’t explain things well and they get afraid of side effects. Or they don’t have insurance and the drug costs \$200 a month.”

Race and ethnicity come into play in ways that are not understood. A study published last year in the *Journal of Clinical Oncology* by Dr. Bickell and other researchers assessed how likely a woman who had surgery for breast cancer was to miss out on other needed treatments — drugs or radiation — at several high-quality teaching hospitals. If she was white, she had a 1 in 6 chance of failing to receive the treatment; black, 1 in 3; and Hispanic, 1 in 4.

A second study published last month by the same group suggested that breakdowns in communication played a part: a third who did not receive the recommended treatment had refused it, and another third missed out because of “system failures,” meaning it was recommended but, for some reason, never hap-

pened (and in another third, doctors ruled out the treatment for medical reasons).

With pancreatic cancer, one of the deadliest types, people at early stages have a chance of surviving only if they have surgery. But a study released in June by the American College of Surgeons found that 38 percent of patients who were eligible for surgery were not even offered it.

With ovarian cancer, a deadly disease for which inadequate surgery has been proved to shorten a woman’s life, many do not receive the correct operation, which may require the removal of tumors from the intestine, diaphragm, liver, spleen and bladder.

“A third of the women in the United States are not getting the right surgery, not even close,” said Dr. Barbara Goff, a gynecologic oncologist at the University of Washington in Seattle. “We have so many resources, but we still do so poorly with ovarian cancer.”

For complex operations, nu-

merous studies have shown higher success rates if the hospital and doctor have a lot of experience. But Dr. Goff and other researchers have found that 25 percent of ovarian cancer patients are operated on by surgeons who see only one case a year, and 33 percent in hospitals that treat fewer than 10 cases a year. Too many women are operated on by gynecologists or general surgeons, Dr. Goff said, adding that ovarian cancer operations should be done by gynecologic oncologists, who train specifically in cancer surgery. But she also said that many women do not know what kind of surgeon they need, or they cannot get to that surgeon.

In addition, although a major study in 2006 showed that pumping chemotherapy directly into the abdomen, instead of dripping it into a vein, added an average of 16 months to women's lives and the National Cancer Institute endorsed the technique, some oncologists still do not offer it.

Uneven quality persists even in colon cancer, one of the most common types. Dr. Jane Weeks, a professor of medicine at Harvard, said half a dozen studies had found that in stage 3, when tumor cells have spread to lymph nodes, only about 65 percent of patients are given chemotherapy — even though it has been proved beneficial and is recommended for about 80 percent of patients.

Numerous studies have suggested that men with prostate cancer face the opposite problem — too much treatment, which wastes resources and money and needlessly subjects men to the pain and risks of surgery or radiation.

Prostate cancer, particularly in older men, often grows so slowly that men can be treated with “watchful waiting,” which means monitoring the cancer and treating it only if it starts to grow rapidly or turns more aggressive.

But a study last year of records of men treated from 2000 to 2002 found that among 24,405 with

cancers considered to be of relatively low risk, 10 percent were overtreated with radical surgery, and 45 percent with radiation.

The surgeon's expertise is crucial in prostate cancer. A study published this month in *The Journal of the National Cancer Institute* found that the cancer was less likely to come back in patients whose doctors had performed 250 or more operations. Their recurrence rate was 10.7 percent, compared with 17.9 percent in men whose doctors had performed the operation only 10 times.

A Plan for Action

On June 17, a Sunday, Karen Pasqualetto, her husband and Isabel caught a red-eye flight to Baltimore. Ms. Pasqualetto made a point of bringing Isabel, 11 months, to her first appointment with Dr. Choti, hoping that the baby's blue eyes and cheerful grin would remind him just how high the stakes were and inspire him to try even harder to save her.

She emerged from the meeting a bit wistful. Though Dr. Choti had not criticized her previous care, he did say he would have operated much sooner, after a few months of chemotherapy.

In an interview, Dr. Choti said that Ms. Pasqualetto was a borderline case because the liver tumors were so extensive, and he could understand why the doctors in Seattle had decided not to operate.

Laughing as Isabel tottered around a hotel room in Baltimore, Ms. Pasqualetto looked so healthy it was hard to believe she was not. Only her stubbled scalp, mostly hidden by a bright pink ball cap, gave her away.

"I have fears about dying and about getting sicker, but I don't explore them, except maybe 10 percent of the time," she said. "The rest of the time, I just think it will all work out. I don't know what that really means."

If all the tumors could be removed, she might not even need more chemotherapy.

"Think of what a perspective

I'd have on life," she said. "I don't allow myself to go there."

'A Complex Operation'

"They got them all," Ms. Pasqualetto's husband, Chris Hartinger, said shortly after her operation ended on June 21. "It turned out to be five tumors."

Four were in her liver. The one in her colon was the size of a tangerine. Dr. Choti operated for eight hours, removing 12 to 18 inches of intestine and about 70 percent of her liver.

The day after surgery, Dr. Choti said, "I think we got away with quite a complex operation."

The tumors were gone, but metastatic disease can be tough to beat in the long run.

"Roughly a third of patients will remain cancer free for a long time," Dr. Choti said. "About half will still be alive after five years. In a minority, there's a long-term cure. In some, we turn it into a chronic disease, if you will. She may recur, and we might be able to reoperate. We can prolong survival significantly."

A few days after surgery, Ms. Pasqualetto was walking laps around the hospital corridors, thinking about things she had not allowed herself to consider, plans she had not dared to make, like whether Isabel would someday like to have a horse.

"I can't believe it," she said. "This is pretty exciting."

But weeks later, at home again, she found herself back in the trenches, unsure of what the next step in her care would be. Her oncologist refused to see her until he spoke with the surgeon, and yet neither of them had called the other. Meanwhile, she was trying to decipher a worrisome report indicating that a CT scan had found minute lesions on her spleen.

"It's like I'm flapping in the wind," she said.

Far From Typical

Karen Pasqualetto is exceptional not only for her determination and confidence in dealing with problems that would intimidate many other people, but also for

her financial wherewithal. So far her treatment has cost more than \$400,000, almost all of it covered by health insurance from Starbucks, where her husband works in disaster-response planning.

When she joined a cancer support group, she recalled, "It was amazing to me the different experiences people were having based on what they could afford or who their provider was. I was able to say, 'If the provider won't pay, my family will. I don't care, I'm going for a second opinion.'"

In the support group, it saddened her to hear other patients with advanced disease take the word of a single oncologist, because she believes that if she had done that, she would already be dead. She has come to think that

survival may depend on money and access, and, she said, on "your own drive and motivation — are you Type A? — your education and your ability to sort through the medical world and the insurance world terminology."

Ms. Pasqualetto's doctors have accepted her insurance payments, but if they had not, she said, "I would find resources. I would get people to pay. I do have resources. I have access to people who wouldn't sit by and let me die because of \$200,000." □

Doing Battle With the Insurance Company in a Fight to Stay Alive

OBSTACLES TO CARE ►►

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ROB MATTON FOR THE NEW YORK TIMES

Gordon Hendrickson of Albuquerque won a long legal fight with his insurance company after it refused to cover his life-saving treatment for pancreatic cancer in Houston.

OBSTACLES TO CARE

Doing Battle With the Insurance Company in a Fight to Stay Alive

By **DENISE GRADY**

PUBLISHED: JULY 29, 2007

A glorious blend of forces came together to save Gordon Hendrickson's life: smart doctoring, luck, kindness, and his own wisdom and abundant grit.

Only his insurance company tried to stand in the way.

Five years ago, when Mr. Hendrickson was 66, routine blood work found something amiss with his liver. One test led to another, and then to an awful diag-

nosis: pancreatic cancer, one of the deadliest kinds.

His doctors thought he was among the lucky few with pancreatic cancer found early enough to be cured by surgery. But they warned him not to have the surgery in his home city, Albuquerque. They said the operation he needed, a Whipple procedure, was so risky and complicated that it should be done only by a surgeon who performed it often and at a hospital with many similar cases. But neither was available locally.

Albuquerque's population was less than half a million, and the entire state of New Mexico had fewer than two million people, not enough to give local surgeons much practice with a relatively uncommon operation.

An experienced surgeon and hospital can significantly increase the odds of survival for people with pancreatic cancer, studies have found. Lower complication rates can also minimize the cost.

Mr. Hendrickson, a retired administrator for the YMCA and

the Spina Bifida Association, had taken care in choosing his internist, Dr. Kristine Bordenave. They liked and trusted each other, and one morning, Dr. Bordenave canceled her other appointments to spend hours on the phone finding a major cancer center that would quickly admit him. It turned out to be the M. D. Anderson Cancer Center in Houston.

But his insurer, the Presbyterian Health Plan, refused to pay for treatment in Houston. The company insisted that the operation be done in Albuquerque and sent him a list of five local surgeons.

He went to M. D. Anderson anyway. But because Presbyterian would not pay, the hospital required a \$5,000 deposit. Mr. Hendrickson and his wife had little money and normally threw away any credit cards mailed to them. But his wife happened to have one new card that she had not gotten around to cutting up yet. They decided that this was the one time when they should not worry about money, and they

used the card to pay the deposit.

“I was a person who wanted to live,” Mr. Hendrickson said, adding that he assumed it would be cheaper for the insurance company to let him die.

The surgeon at M. D. Anderson told him that without an operation he had virtually no chance of surviving, and even with an operation his chances would be slim. Despite the long odds and the high cost, insurers cover the Whipple operation in patients who are candidates for it — less than a quarter of those with pancreatic cancer — because it offers the only hope of a cure and can prolong life.

Figuring that a small chance was better than none, Mr. Hendrickson had the surgery. It went well. But he was left with more than \$80,000 in medical bills, which Presbyterian Health Plan refused to pay.

Dr. Bordenave said she was appalled: “No patient fighting for their life should have to fight for their insurance too.”

Mr. Hendrickson waged a

long battle with Presbyterian. “I fought with the insurance company for over a year,” he said.

After Presbyterian rejected two appeals, he took his case to a state review board, where he represented himself because he could not afford a lawyer. Presbyterian showed up with two lawyers, a doctor and a nurse. Dr. Bordenave and a gastroenterologist from Albuquerque testified on Mr. Hendrickson’s behalf.

Mr. Hendrickson and his wife had studied the details of their insurance policy and had also learned — with the help of M. D. Anderson — that in the previous five years, the five surgeons Presbyterian had recommended had performed a total of five Whipple operations.

Ultimately, Mr. Hendrickson won the case, and Presbyterian Health Plan paid the entire bill.

A spokesman for Presbyterian said the case had led the company to allow more patients to be treated at high-volume centers if there was evidence that the results would be better.

Mr. Hendrickson said it was “tough to stand up to attorneys and doctors. I don’t know why I was able to do it. I’m stubborn, I guess. I don’t like to be told what to do. Too many people, I know, they just let it go and they die.”

In June, Mr. Hendrickson went back to M. D. Anderson for a five-

year checkup with his surgeon, a visit paid for by Presbyterian.

“He told me that I was cured of pancreatic cancer,” Mr. Hendrickson said in an e-mail message. “I shouted from the rooftops.” □

WHAT YOU SHOULD KNOW ►►

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WHAT YOU SHOULD KNOW

Push Hard for the Answers You Require

By DENISE GRADY

PUBLISHED: JULY 29, 2007

How can people with cancer make sure they are receiving the best treatment?

"The advice I would give every patient is to take the time to find help," said Dr. Richard C. Wender, president of the American Cancer Society and chairman of the department of family and community medicine at Thomas Jefferson University in Philadelphia. "Get more than one opinion."

But how to do that? Picking a doctor out of the phone book or going down the hall to a colleague of the first doctor may not accomplish much.

"If you're going to get another view, use it wisely," Dr. Wender said. "Go to a higher-volume site."

Even if it requires traveling, make the trip, Dr. Wender said. "You're in a fight for your life, and it's worth the inconvenience," he said.

If there is a disagreement, the opinion of the cancer center that is more expert, which may reflect the judgment of multiple doctors, carries more weight.

"Frankly, if you have a less common cancer, or a more common one at an advanced stage, if you can get an opinion from a place doing more of it, there is value, in many cases," Dr. Wender said. He said patients should ask how many cases like theirs a doctor has seen.

If the operation or therapy is complex, treatment at the highest-volume hospital may be the best choice. But in some cases the more specialized center may confirm what has already been recommended, or provide advice that can be followed by a hospital closer to home.

There are several ways to find expert centers, Dr. Wender said. One is to look for a hospital that has been designated for excellence by the National Can-

cer Institute. The list is online at cancercenters.cancer.gov/cancer_centers/cancer-centers-list.html or can be obtained by calling 1-800-4-CANCER.

The American College of Surgeons also has a Commission on Cancer that evaluates cancer treatment programs and lists approved ones at www.facs.org/cancerprogram/howto.html. The American Cancer Society (cancer.org) has a 24-hour help line (1-800-ACS-2345) that can locate accredited programs. Advocacy groups for specific diseases may also know which centers treat the most cases and have the best track records.

Rules about paying for second opinions vary from one insurer to another.

Once treatment begins, Dr. Wender said, another good strategy is to ask one doctor to be “captain of the team,” the person who receives all the test results and reports, and helps the patient make treatment decisions and coordinate care. The captain can be a primary care

doctor or one of the cancer specialists treating the patient.

“If you’re feeling rudderless as a cancer patient, you should not allow that to occur,” Dr. Wender said. “Cancer patients have too much on the line.”

Lack of money, insurance and education can block access to cancer care. According to a report by the Institute of Medicine, in 2002, “Uninsured cancer patients generally have poorer outcomes and are more likely to die prematurely than persons with insurance, largely because of delayed diagnosis.”

Being unable to afford treatment is one of the main reasons that people call the 24-hour help line set up by the cancer society, Dr. Wender said. “State by state, we are able to help 20 percent who call to get the financial resources they need for treatment,” he said. “We are unable to help 80 percent.”

He went on: “In cancer, people often ask, why haven’t we found a cure? We have, in many. But you have to find it in one patient at a time. A cure a person can’t afford is not a cure at all.” □



ALLEN BRISSON-SMITH FOR THE NEW YORK TIMES

Dave Smith of Fairmont, Minn., did not realize his diabetes put him at high risk for heart disease.

Looking Past Blood Sugar To Survive With Diabetes

By **GINA KOLATA**

PUBLISHED: AUGUST 20, 2007

DAVE SMITH found out he had Type 2 diabetes by accident, after a urine test.

“Whoa, look at the sugar in here,” his doctor told him. Mr.

Smith’s blood sugar level was sky high and glucose was spilling into his urine.

That was about nine years ago, and from then on Mr. Smith, like so many with diabetes, became fixated on his blood sugar. His

doctor warned him to control it or the consequences could be dire — he could end up blind or lose a leg. His kidneys could fail.

Mr. Smith, a 43-year-old pastor in Fairmont, Minn., tried hard. When dieting did not work, he began counting carbohydrates, taking pills to lower his blood sugar and pricking his finger several times a day to measure his sugar levels. They remained high, so he agreed to add insulin to his already complicated regimen. Blood sugar was always on his mind.

But in focusing entirely on blood sugar, Mr. Smith ended up neglecting the most important treatment for saving lives — lowering the cholesterol level. That protects against heart disease, which eventually kills nearly everyone with diabetes.

He also was missing a second treatment that protects diabetes patients from heart attacks — controlling blood pressure. Mr. Smith assumed everything would be taken care of if he could just lower his blood sugar level.

Blood sugar control is important in diabetes, specialists say. It can help prevent dreaded complications like blindness, amputations and kidney failure. But controlling blood sugar is not enough.

Nearly 73,000 Americans die from diabetes annually, more than from any disease except heart disease, cancer, stroke and pulmonary disease.

Yet, largely because of a misunderstanding of the proper treatment, most patients are not doing even close to what they should to protect themselves. In fact, according to the federal Centers for Disease Control and Prevention, just 7 percent are getting all the treatments they need.

“That, to me, is mind-boggling,” said Dr. Michael Brownlee, director of the JDRF International Center for Diabetic Complications Research at the Albert Einstein College of Medicine in New York. “It makes me ask, What is going on? I can only conclude that people are not

aware of their risks and what could be done about them.”

In part, the fault for the missed opportunities to prevent complications and deaths lies with the medical system. Most people who have diabetes are treated by primary care doctors who had just a few hours of instruction on diabetes, while they were in medical school. Then the doctors typically spend just 10 minutes with diabetes patients, far too little for such a complex disease, specialists say.

In part it is the fault of proliferating advertisements for diabetes drugs that emphasize blood sugar control, which is difficult and expensive and has not been proven to save lives.

And in part it is the fault of public health campaigns that give the impression that diabetes is a matter of an out-of-control diet and sedentary lifestyle and the most important way to deal with it is to lose weight.

Most diabetes patients try hard but are unable to control their disease in this way, and

BY THE NUMBERS

73,000

Number of people who die from diabetes each year in the United States

1.5 million

New cases of diabetes diagnosed in 2005 among people age 20 or over

4.25%

Percentage of adults last year who were taking both diabetes medication and a statin to lower cholesterol

20.8 million

Number of Americans who had diagnosed or undiagnosed diabetes in 2005

20.9%

Percentage of people over the age of 60 who have diabetes

\$132 billion

Estimated overall cost for diabetes in 2002, including medical expenses and the cost of lost productivity because of illness and premature death

Source: Centers for Disease Control and Prevention

most of the time it progresses as years go by, no matter what patients do.

Mr. Smith, like 90 percent of diabetes patients, has Type 2 diabetes, the form that usually arises in adulthood when the insulin-secreting cells of the pancreas cannot keep up with the body's demand for the hormone. The other form of diabetes, Type 1, is far less common and usually arises in childhood or adolescence when insulin-secreting pancreas cells die.

And, like many diabetes patients, Mr. Smith ended up paying the price for his misconceptions about diabetes. Last year, he had a life-threatening heart attack.

The Heart Disease

Just after returning from church last October, Mr. Smith had a discomfiting sensation. Deciding to focus on something else, he went to a local newspaper office where he was weekend editor. But the strange feeling persisted and intensified.

"I felt a pain in my chest," Mr. Smith recalled. "It wasn't sharp — it was more of a kind of pressure, a feeling like something is contracting."

The pain spread, to his neck, along his shoulder, down to his biceps. Mr. Smith, alone and frightened, looked up heart attack symptoms on the American Heart Association's Web site. They were exactly what he was experiencing.

An hour later, Mr. Smith was at the Mayo Clinic in Rochester, Minn., in the throes of a major heart attack, transported by helicopter while his wife and two young sons frantically drove two and a half hours to be with him. A main artery to his heart was 90 percent blocked. If he had waited to seek help or if his local hospital and doctor had not acted quickly and sent him to the Mayo Clinic, he probably would have died.

Mr. Smith thought his biggest risk from diabetes was blindness or amputations. He never thought about heart disease and

had no idea how important it was to control cholesterol levels and blood pressure. He said his doctor had not advised him to take a cholesterol-lowering or blood pressure drug and he did not think he needed them.

Most people with diabetes are equally unaware of the danger that heart disease poses for them.

A recent survey by the American Diabetes Association conducted by RoperASW found that only 18 percent of people with diabetes believed that they were at increased risk for cardiovascular disease.

Yet, said Dr. David Nathan, director of the Diabetes Center at Massachusetts General Hospital, “when you think about it, it’s not the diabetes that kills you, it’s the diabetes causing cardiovascular disease that kills you.”

Dr. Brownlee said he was stunned by the results of the diabetes association poll. “If you are one of those 82 percent who don’t think you are at increased risk,” he said, “finding out that you are and that you can de-

crease that risk substantially could literally change your life.”

The science is clear on the huge benefits for people with diabetes of lowering cholesterol and controlling blood pressure. After multiple studies, costing hundreds of millions of dollars and involving tens of thousands of subjects, national guidelines were rewritten to reflect the new data, and professional organizations issued recommendations for diabetes care.

With cholesterol, the guidelines say that levels of LDL cholesterol, the form that increases heart disease risk, should be below 100 milligrams per deciliter and, if possible, 70 to 80. Yet, Dr. Brownlee said, diabetes patients with LDL cholesterol levels of 100 to 139 often are told that their levels — ideal for a healthy person without diabetes — are terrific.

“Many practicing doctors just don’t know that an LDL cholesterol number that is normal for someone without diabetes is not normal for someone with diabetes,” he said.

Mr. Smith found all that out too late. The heart attack, he said, “really blindsided me.”

He also did not know the other measures proven to prevent complications in diabetes. He was correct that high blood sugar is dangerous. It can damage the small blood vessels in the eyes, leading to blindness; the nerves in the feet, leading to amputations; and the kidneys, leading to kidney failure.

But no matter how carefully patients try to control their blood sugar, they can never get it perfect — no drugs can substitute for the body’s normal sugar regulation. So while controlling blood sugar can be important, other measures also are needed to prevent blindness, amputations, kidney failure and stroke. Mr. Smith was doing none of them.

He also made the common assumption that Type 2 diabetes is simply a consequence of being fat. And that losing weight will help cure it.

Obesity does increase the risk

of developing diabetes, but the disease involves more than being obese. Only 5 percent to 10 percent of obese people have diabetes, and many with diabetes are not obese. To a large extent, Type 2 diabetes is genetically determined — if one identical twin has it, the other has an 80 percent chance of having it too. In many cases, weight loss can help, but, as Mr. Smith has learned, most who lose weight are not cured of the disease. He lost 40 pounds but still has diabetes.

“Everybody in the act of losing weight will have a pretty dramatic improvement pretty quickly,” said Dr. C. Ronald Kahn, a diabetes researcher and professor of medicine at Harvard Medical School. Blood sugar levels drop precipitously and the disease seems to be under control. But that is because the metabolic process of weight loss lessens diabetes. Once weight is lost, he added, and people stabilize at a lower weight, their diabetes may remain.

When it comes to weight loss, Dr. Kahn said, “there is a range of susceptibilities in how people react.”

Complex Regimens

Before he left the hospital, Mr. Smith’s doctors told him about his new diabetes regimen: a statin to drive his cholesterol level very low, two drugs to lower his blood pressure, an aspirin, insulin and two drugs to reduce his blood sugar levels. That new list of drugs was what he should have been taking all along.

Mr. Smith is taking them now, terrified that his heart disease will progress.

“I’ll never be out of the woods,” he said. “I’ve got to face that.”

Diabetes researchers say stories like Mr. Smith’s are all too familiar.

The statistics are grim: A quarter to a third of all heart attack patients have diabetes, even though diabetes patients constitute just 9.3 percent of the population. Another 25 percent of heart attack patients are verg-

ing on diabetes with abnormally high blood sugar levels.

Most worrisome are diabetes patients who already have symptoms of heart disease, like chest pains or a previous heart attack. “That is a terrible situation,” said Dr. James Cleeman, coordinator of the National Cholesterol Education Program at the National Institutes of Health. Those patients, Dr. Cleeman said, are set up for a fatal heart attack and should be stringently controlling their cholesterol and blood pressure.

And it is not just that many diabetes patients are overweight, as people with Type 1 diabetes, who often are thin, also have a high risk of heart disease. There is something about diabetes itself, researchers say, that leads to high levels of LDL cholesterol and a form of LDL cholesterol particles that is particularly dangerous. Diabetes also leads to increased levels of triglycerides, which are fats in the blood that increase heart disease risk, and in diabetes is linked to high blood pressure.

Medication for Complex Diabetes

A 42-year-old woman's regimen for treating complex diabetes includes at least 15 types of oral medication, 2 over-the-counter products, 7 to 10 injections and 4 blood tests a day, costing more than \$1,800 a month retail.

Key

○ Taken orally

◐ Inhaled

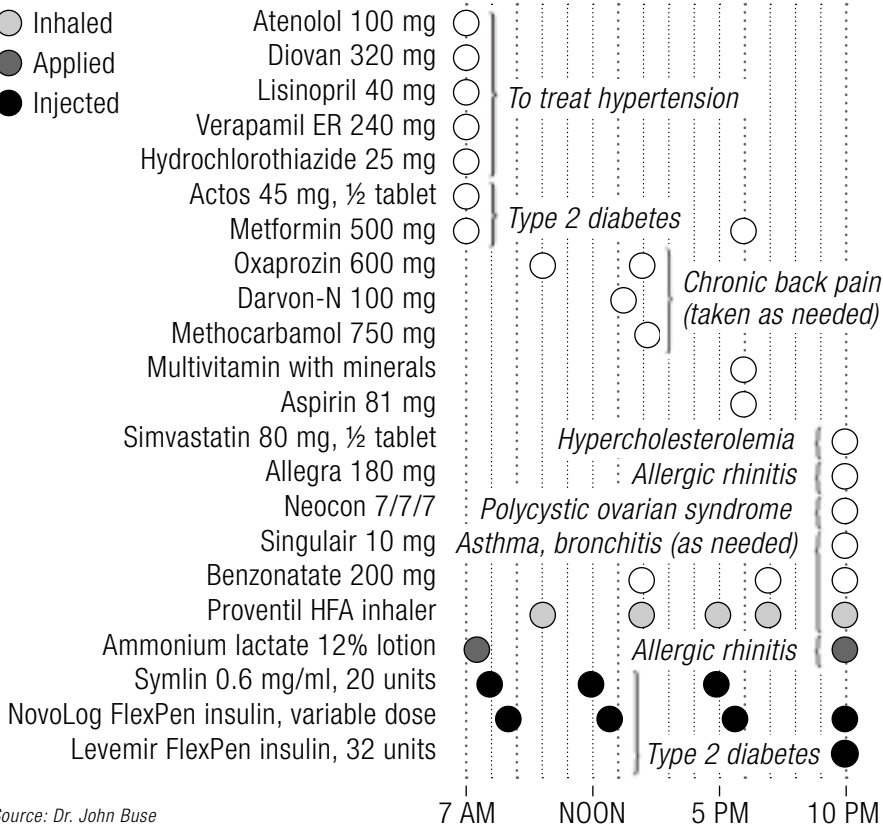
◑ Applied

● Injected

Morning

Meals

Bedtime



Source: Dr. John Buse

THE NEW YORK TIMES

Being obese or overweight, in contrast, are “weak contributors to heart attack risk,” Dr. Nathan said.

Type 2 diabetes “does not exist in isolation,” Dr. Nathan said. “Underlying diabetes are all these cardiovascular risk factors.”

Somehow, though, it has taken quite a while for the alarm bells to go off.

One reason might be that it was heart disease researchers, not diabetes researchers, who conducted the seminal studies.

The key to saving lives is to reduce levels of LDL cholesterol to below 100 and also control other risk factors like blood pressure and smoking. The cholesterol reduction alone can reduce the very high risk of heart attacks and death from cardiovascular disease in people with diabetes by 30 percent to 40 percent, Dr. Cleeman said. And clinical trials have found that LDL levels of 70 to 80 are even better for people with diabetes who already have overt heart disease.

Studies of blood sugar control

have been more problematic than those of cholesterol lowering.

In Type 2 diabetes, the most ambitious effort was a huge study in Britain. It found that rigorous blood sugar control could lower the risk of complications that involved damage to small blood vessels, a list that includes blindness, nerve damage and kidney damage. But there was no effect on the overall death rate. There was a small decrease in the number of heart attacks but it was not statistically significant, meaning it could have occurred by chance.

The National Institutes of Health is trying again, with a larger study of blood sugar control that includes enough patients to detect more subtle effects on the heart attack rate if they exist. For now, though, the answer simply is not known.

In Type 1 diabetes, a large federal study did find evidence that rigorous blood sugar control could reduce heart disease risk. But the effect emerged 12 years after the study ended and most

of the patients, in those years, had not been able to sustain the blood sugar control that they had had during the study. Did the short period of rigorous control exert a delayed effect on heart disease or was the effect caused by some other factor during the study or afterward, some asked? While most think it was caused by blood sugar control, it is impossible to know for sure.

The result, notes Dr. John Buse, president-elect for science and medicine at the American Diabetes Association, is that for people with Type 1 and, especially, for those with Type 2 diabetes, there are still questions about whether and to what extent blood sugar control protects against heart disease and saves lives.

That leaves cholesterol lowering, for patients with Type 1 and Type 2 diabetes, as the most effective and easiest way by far to reduce the risk of heart disease and the only treatment proven to save lives. But doctors say achieving the recommended cholesterol levels usually means taking a sta-

tin. Some patients resist, wary of intense drug company marketing to patients and afraid of side effects like muscle or liver damage which, although extremely rare, have frightened many away from the drugs, Dr. Brownlee and other diabetes specialists said. (Dr. Brownlee said he had no financial ties to statin makers.)

Others point to drug company advertising itself.

Statin advertising, said Dr. Irl B. Hirsch, a professor of medicine and director of the diabetes clinic at the University of Washington, is all about heart disease, and the advertisements do not mention diabetes. The diabetes advertisements are all about blood sugar. Dr. Hirsch has seen few that put the two together.

Yet lowering cholesterol with statins, Dr. Hirsch and others said, is much simpler than anything else diabetes patients are asked to do. And, he added, the drugs are among the best studied and the safest on the market. (Dr. Hirsch said he had no financial ties to statin makers.)

Dr. Hirsch has a message for diabetes patients: If he had to rate the different regimens for a typical middle-age person with Type 2 diabetes, the first priority would be to take a statin and lower the LDL cholesterol level.

Dr. Brownlee agreed, but added that the two other measures to protect against heart disease, blood pressure control and taking an aspirin to prevent blood clots, should not be neglected.

“Right now, without waiting for lots of exciting things that are almost in the pipeline or in the pipeline, starting tomorrow, if everyone did these things — taking a statin, taking a blood pressure medication, and maybe taking an aspirin — you would reduce the heart attack rate by half.”

The Burnout

Even when patients do take the right steps to control diabetes, the grueling process can simply wear them down.

Virgil Umbarger learned that he had Type 2 diabetes when he

was 39 and had a medical exam for a life insurance policy.

That was 25 years ago, and the start of a journey that diabetes specialists say ends up fundamentally changing a person's world. Unlike Mr. Smith, who has just awakened to the danger he is in, Mr. Umbarger, a funeral director in Yakima, Wash., has lived with diabetes and its increasingly complex regimen for decades. And, as happens with most diabetes patients eventually, he feels he is reaching a point where he just cannot continue to do all that he should to protect his health.

In a sense, Mr. Umbarger said, he was not completely surprised when he learned he had diabetes, because it runs in his family. But he never thought it would happen to him. At 6 feet tall and 195 pounds, he was not heavy.

Still, Mr. Umbarger's first thought was to lose weight. “I starved myself,” he said, and lost 15 pounds. But he still had diabetes and the pounds crept back on.



MELANIE CONNER FOR THE NEW YORK TIMES

Virgil Umbarger of Yakima, Wash., gave up checking blood sugar six times a day; now he checks it once or twice. He relaxes by working in his orchard.

Dr. Buse said his patients knew how important it was to diet and exercise, but most could not do it enough to make a difference, and some were also thwarted by medications to control blood sugar that make patients gain weight.

In the end, Mr. Umbarger decided to seek care from a dia-

betes specialist. He chose Dr. Hirsch, even though it meant driving nearly three hours each way for an office visit. There was no one nearby with that kind of expertise, Mr. Umbarger said.

On his first visit, Dr. Hirsch gave him a fistful of prescriptions, including a statin, blood pressure medications and one for

the drug Mr. Umbarger dreaded — insulin. He also told Mr. Umbarger to have regular checks for eye, nerve and kidney damage. And he has to watch what he eats and count carbohydrates.

Dr. Hirsch and other diabetes specialists say they are well aware of how daunting the program can be.

“Many come here once or twice and walk away saying, ‘I don’t want to do this,’ ” Dr. Hirsch said.

Not Mr. Umbarger. For years, he tried to do all that was required. He can cope with the medications and the long drives to see Dr. Hirsch. The problem for him, as for most diabetes patients eventually, is the blood sugar monitoring. He is supposed to prick his finger six or more times a day to measure his glucose levels and adjust his insulin dose accordingly.

Every time he checks his blood sugar is like getting a report card — was he eating too many carbohydrates? Did he get the insulin dose right?

“I don’t want to look,” he said.

“Pricking your finger, seeing that number day after day, it wears on you,” Mr. Umbarger said. “It’s like a ball and chain.” He confesses that he has only been checking his blood sugar once or twice a day, guessing at many of his insulin doses. His blood sugar levels have been rising and guilt hangs over him.

Meanwhile, no matter what they do, most people with Type 2 diabetes get worse as the years go by. Patients make less and less insulin and their cells become less and less able to use the insulin they do produce.

“That is why it is not uncommon to start initially with diet therapy, then after a few years we need to add a drug that improves insulin sensitivity,” Dr. Kahn said. “Then when that drug isn’t enough, we add a second drug that improves insulin sensitivity by a different mechanism. Then we add a drug that stimulates that pancreas to make more insulin.”

Then, he added, patients with Type 2 diabetes may need insulin itself, but when that happens they have to take even more than a person with Type 1 diabetes — two or even three times as much — because their cells no longer respond adequately to the hormone.

While it is not easy to re-energize burned-out patients, Dr. Hirsch said, at the very least, doctors and patients should know what is important.

“We already have the miracle pills” — statins and blood pres-

sure medications, he said. And they are available for pennies a day, as generics.

“We need patient education and physician training that this stuff is out there and this is what we should be focusing on to make a difference in lives.” □

Obesity May Be Only One Piece Of Diabetes Puzzle

CONTRIBUTING FACTORS ►►

The New York Times

www.nytimes.com/health

Health & Fitness Tools

Body Mass Index Calculator:
What's your score?

Calorie Calculator for Goal Weight:
What's your limit?

CONTRIBUTING FACTORS

Obesity May Be Only One Piece Of Diabetes Puzzle

By GINA KOLATA

PUBLISHED: MAY 28, 2007

The havoc diabetes wreaks is clear. But researchers are puzzled by many aspects of the disease. Why, for example, are most people with Type 2 diabetes overweight or obese, yet most overweight or obese people do not have diabetes?

One clue may lie in the fat cells themselves. The cells release fat and breakdown products of fat — triglycerides and free fatty acids — into the blood. These substances may make cells less able to respond to insulin, increasing the body's demand for the hormone. Another clue is a paradoxical finding about a hormone, adiponectin, made by fat cells. Adiponectin makes cells more responsive to insulin.

“Oddly enough,” said Dr. C. Ronald Kahn, a diabetes re-

searcher and professor of medicine at Harvard Medical School, “the fatter people become, the less adiponectin their fat cells produce.”

So one way obesity might increase the risk that a person will develop diabetes is by leading to a release of more fatty acids and a decline in adiponectin. This would lead to more insulin resistance and a demand for more insulin. If that demand cannot be met, the result, eventually, would be diabetes.

But figuring out why obesity predisposes some people to diabetes is only part of the puzzle. Researchers also are struggling with a fundamental question. Why does high blood sugar lead to any of the disease's complications — heart disease, stroke, nerve damage, kidney damage and sight-threatening eye damage?

“On the surface, it seems a little odd,” said Dr. Michael Brownlee, director of the JDRF International Center for Diabetic Complications Research at Albert Einstein College of Medicine in New York. “If your blood has high levels of glucose and it’s bathing every cell in your body, why are only a relatively restricted number of them damaged and the rest just fine?”

It turns out that the unscathed cells are those that can keep out excess glucose. They do this by reducing the number of molecular glucose pumps that every cell uses to transport glucose from the blood to the cell’s interior.

The cells that get damaged lack this ability to tamp down their glucose pumps. They include cells lining arterial blood vessels, small blood vessel cells in the eye and kidney, nerve cells in the legs and feet, and pancreas cells that make insulin — exactly those that are involved in diabetic complications.

But focusing on blood sugar in isolation can give a misleading picture of Type 2 diabetes, said

Dr. David Nathan, director of the diabetes center at Massachusetts General Hospital. Going hand in hand with diabetes, for most with the Type 2 form of the disease, are high blood pressure and lipid abnormalities that are linked to heart disease and strokes.

And even though blood sugar levels are the diagnostic hallmark of diabetes, the central fact of diabetes is that patients are not making enough insulin. Insulin, Dr. Kahn said, controls more than just blood sugar. The hormone, he added, also control the body’s use of fats and proteins.

“It is likely that high glucose levels aren’t causing all the complications of diabetes,” Dr. Kahn said. And that is one reason, researchers say, why diabetes care has to include more than just glucose control. □

An Increase in Diagnoses May Not Mean a Higher Rate of the Disease

THE STATISTICS ►►

THE STATISTICS

An Increase in Diagnoses May Not Mean a Higher Rate of the Disease, a Survey Shows

By GINA KOLATA

PUBLISHED: MAY 28, 2007

The number of diagnosed cases of diabetes increased by 61 percent from 1991 to 2001, according to the federal Centers for Disease Control and Prevention. That went along with a 74 percent increase in obesity, the agency noted, “reflecting the strong correlation between obesity and the development of diabetes.”

But those numbers may or may not reveal that the actual number of people with diabetes has exploded. It may just be that more people are learning they have the disease, not that the number of those with it is increasing.

To get a better idea of whether the disease is striking more people or whether more people who have the disease are receiving diagnoses, statisticians have turned to another set of federal data. It

is from the National Health and Nutrition Examination Survey, a periodic survey of a representative group of Americans that not only asks whether people have been told they have diabetes but that also includes blood tests to find undiagnosed cases.

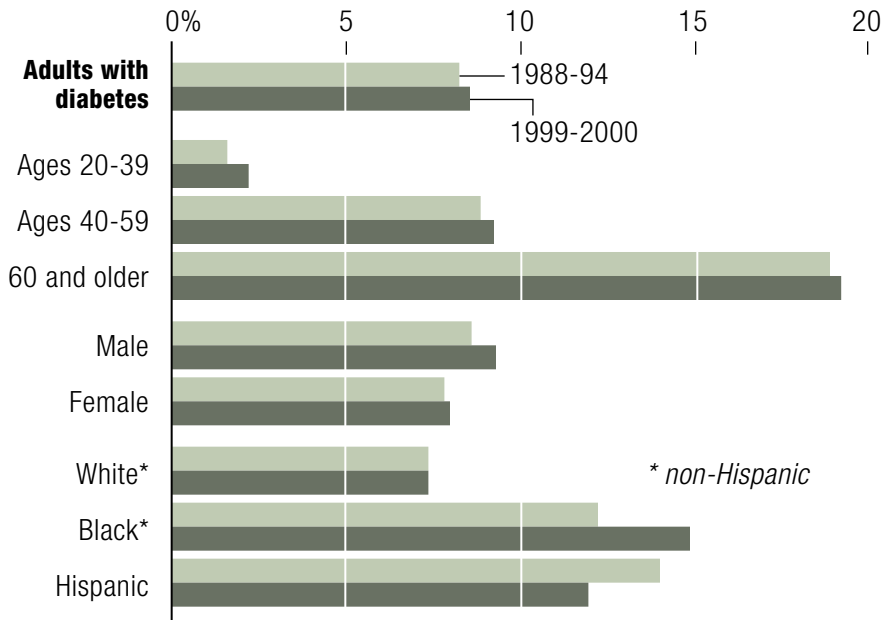
In a paper published last year in *Diabetes Care*, federal scientists used those data to ask what was the total proportion of the population with diabetes — diagnosed and undiagnosed.

Their surprising conclusion, said Katherine M. Flegal, an author of the paper and an epidemiologist at the National Center for Health Statistics, was that the overall age-adjusted proportion of the population that has diabetes had not really changed from 1988 to 2002, the most recent year for which federal data are available.

In two subgroups, though —

Diabetes Rates

More screening has led to a rise in diabetes diagnoses, but a periodic health survey suggests that the overall rate of adult diabetes has changed little since 1988.



Source: Centers for Disease Control and Prevention

THE NEW YORK TIMES

men and non-Hispanic blacks — there was a small but statistically significant increase in the diabetes rate. In general, blacks, Hispanics and Asians are more likely to develop diabetes than

whites, and regions with many immigrants of those racial and ethnic groups may experience a surge in the population of people diagnosed with diabetes. But that, of course, does not reveal

whether the nation as a whole is experiencing a sharply increasing rate of diabetes.

Still, says James Smith, a senior economist at the Rand Corporation, who independently analyzed data on men from the national survey, the data are puzzling. Why would there be a significant increase in the diabetes prevalence in men but not in women, since the changes in underlying risk factors like obesity are similar? And why is there no increase over all?

Dr. Smith suspects that the prevalence data were distorted by data on diabetes in women that may not be as reliable as those involving men. If he is correct, he said, it may be because the surveys in different years were not consistent in dealing with gestational diabetes, an of-

ten temporary condition that can occur during pregnancy. When he takes that out of the data, he sees similar rises for men and women.

Dr. Smith said he did not want to diminish the significance of the diabetes problem in this country. Indeed, he said, the problem is increasing. But he said there is little question in his mind that the confusion between the number of people who have been told they have diabetes and the actual number of people who have the disease has led to an exaggerated perception of how rapidly the disease is spreading. □

Tips to Help Patients Manage Their Care

THINGS TO KNOW ►►

The New York Times

www.nytimes.com/health

THINGS TO KNOW

Tips to Help Patients Manage Their Care

Dr. John Buse, director of the Diabetes Care Center at the University of North Carolina, Chapel Hill, is president-elect for science and medicine at the American Diabetes Association and a principal investigator in a federal study asking whether blood sugar control can protect against heart disease in people with Type 2 diabetes.

“Diabetes is underdiagnosed, undertreated and underappreciated as a cause of death and disability,” Dr. Buse said. “Despite the fact that almost 20 percent of all health care dollars are spent on the management of people with diabetes, the diabetes epidemic and its associated pain and suffering grow and grow.” Here, he says, are five things that everyone with diabetes should know:

1. If you are overweight, get screened for diabetes with



BRUCE R. FEELEY FOR THE NEW YORK TIMES

Dr. John Buse, director of the Diabetes Care Center at the University of North Carolina.

a fasting glucose test, starting at puberty, at least every three years. If you are not, start at age 45. A normal result is less than 100 mg/dl.

2. If you have diabetes or prediabetes, engage in moderate-intensity exercise like brisk walking for at least 30 minutes at least five days a week. If you are overweight, reduce

calories with a goal of losing at least 5 percent of body weight (10 pounds if you weigh 200 pounds). Working with a dietitian can be extremely helpful.

3. If you have diabetes, make sure to have an A1C test, which measures glucose levels, at least twice a year, regular blood pressure checks and annual cholesterol checks. The A1C should be less than 7 percent, blood pressure less than 130 over 80 and LDL cholesterol under 100 mg/dl. If you are not reaching all three goals, ask for a referral to a diabetes education program, start a new drug, see a specialist and keep working toward getting what is known as your ABC's (for A1C, blood pressure and cholesterol) under control. If you

are over 21, discuss taking low-dose aspirin with your doctor. Do not smoke.

4. If you have diabetes, have annual checkups for complications including a dilated eye exam by an eye-care professional, a urine microalbumin-to-creatinine ratio and a comprehensive foot exam including testing with a 10-gram filament. If the results are not normal, you will need additional treatment to avoid disability. Make sure you get it.

5. People with diabetes who work with their health care team to do the best they can to control diabetes, its related disorders and its complications should expect to live a long and healthy life. □

The New York Times

www.nytimes.com/health



DAMON WINTER/THE NEW YORK TIMES

Madeline Gallagher, 65, an emphysema patient, after doctors at New York-Presbyterian/Columbia hospital removed 30 percent of each of her lungs.

From Smoking Boom, A Major Killer of Women

By DENISE GRADY

PUBLISHED: NOVEMBER 29, 2007

FOR JEAN ROMMES, the crisis came five years ago, on a Monday morning when she had planned to go to work but

wound up in the hospital, barely able to breathe. She was 59, the president of a small company in Iowa. Although she had quit smoking a decade earlier, 30 years of cigarettes had taken their toll.

After several days in the hospital, she was sent home tethered to an oxygen tank, with a raft of medicines and a warning: "If I didn't do something, life was going to continue to be a pretty scary experience."

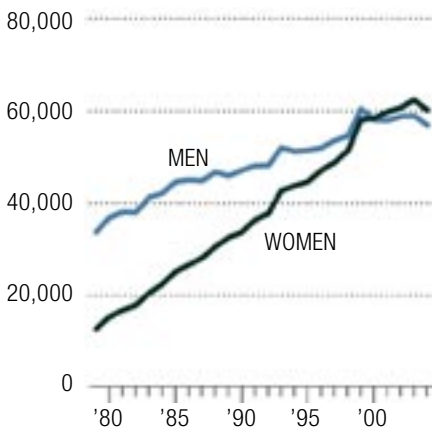
Ms. Rommes has chronic obstructive pulmonary disease, or C.O.P.D., a progressive illness that permanently damages the lungs and is usually caused by smoking. Once thought of as an old man's disease, this disorder has become a major killer in women as well, the consequence of a smoking boom in the 1950s, '60s and '70s. The death rate in women nearly tripled from 1980 to 2000, and since 2000, more women than men have died or been hospitalized every year because of the disease.

"Women started smoking in what I call the Virginia Slims era, when they started sponsoring sporting events," said Dr. Barry J. Make, a lung specialist at National Jewish Medical and Research Center in Denver. "It's now just catching up to them."

Deaths Among Women

Although chronic obstructive pulmonary disease was once considered an old man's disease, the number of women who died from it nearly quadrupled since 1980, largely due to their increased smoking in recent decades.

Deaths due to C.O.P.D. each year



Source: Centers for Disease Control and Prevention

THE NEW YORK TIMES

Chronic obstructive pulmonary disease actually comprises two illnesses: one, emphysema, destroys air sacs deep in the lungs; the other, chronic bronchitis, causes inflammation, congestion and scarring in the air-

ways. The disease kills 120,000 Americans a year, is the fourth leading cause of death and is expected to be third by 2020. About 12 million Americans are known to have it, including many who have long since quit smoking, and studies suggest that 12 million more cases have not been diagnosed. Half the patients are under 65. The disease has left some 900,000 working-age people too sick to work and costs \$42 billion a year in medical bills and lost productivity.

“It’s the largest uncontrolled epidemic of disease in the United States today,” said Dr. James Crapo, a professor at the National Jewish Medical and Research Center.

Experts consider the statistics a national disgrace. They say chronic lung disease is misdiagnosed, neglected, improperly treated and stigmatized as self-induced, with patients made to feel they barely deserve help, because they smoked. The disease is mired in a bog of misconception and prejudice, doctors say. It is

commonly mistaken for asthma, especially in women, and treated with the wrong drugs.

Although incurable, it is treatable, but many patients, and some doctors, mistakenly think little can be done for it. As a result, patients miss out on therapies that could help them feel better and possibly live longer. The therapies vary, but may include drugs, exercise programs, oxygen and lung surgery.

Incorrectly treated, many fall needlessly into a cycle of worsening illness and disability, and wind up in the emergency room over and over again with pneumonia and other exacerbations — breathing crises like the one that put Ms. Rommes in the hospital — that might have been averted.

“Patients often come to me with years of being under treated,” said Dr. Byron Thomashow, the director of the Center for Chest Disease at New York-Presbyterian/Columbia hospital.

Still others are overtreated for years with steroids like predni-

sone, which is meant for short-term use and if used too much can thin the bones, weaken muscles and raise the risk of cataracts.

Adequate treatment means drugs, usually inhaled, that open the airways and quell inflammation — preventive medicines that must be used daily, not just in emergencies. It is essential to quit smoking.

Patients also need antibiotics to fight lung infections, vaccines to prevent flu and pneumonia and lessons on special breathing techniques that can help them make the most of their diminished lungs. Some need oxygen, which can help them be more active and prolong life in severe cases. Many need dietary advice: obesity can worsen symptoms, but some with advanced disease lose so much weight that their muscles begin to waste. Some people with emphysema benefit from surgery to remove diseased parts of their lungs.

Above all, patients need exercise, because shortness of breath drives many to become inactive,

and they become increasingly weak, homebound, disabled and depressed. Many could benefit from therapy programs called pulmonary rehabilitation, which combine exercise with education about the disease, drugs and nutrition, but the programs are not available in all parts of the country, and insurance coverage for them varies.

“I have a complicated, severe group of patients, but I will swear to you that very few wind up in hospitals,” Dr. Thomashow said. “I treat aggressively. I use the medicines, I exercise all of them. You can make a difference here. This is an example of how we’re undertreating this entire disease.”

Little-Known Epidemic

Researchers say there is so little public awareness of how common and serious C.O.P.D. is that the O might as well stand for “obscure” or “overlooked.”

The disease may not be well known, but people who have it are a familiar sight. They are the ones who cannot climb half

a flight of stairs without getting winded, who have a perpetual smoker's cough or wheeze, who need oxygen to walk down the block or push a cart through the supermarket. Some grow too weak and short of breath to leave the house. The flu or even a cold can put them in the hospital. In advanced stages, the lung disease can lead to heart failure.

"This is a disease where people eventually fade away because they can no longer cope with life," said Grace Anne Dorney Koppel, who has chronic lung disease. (Ms. Dorney Koppel, a lawyer, is married to Ted Koppel.) "My God, if you don't have breath, you don't have anything."

Most cases, about 85 percent, are caused by smoking, and symptoms usually start after age 40, in people who have smoked a pack a day for 10 years or more. In the United States, 45 million people smoke, 21 percent of adults. Only about 20 percent of smokers develop chronic lung disease.

BY THE NUMBERS

119,000

Number of deaths from chronic obstructive pulmonary disease in the United States in 2000

182%

Increase in the death rate for women due to C.O.P.D. from 1980 to 2000

12.1 million

Number of people age 25 or over who reported having C.O.P.D. in a 2001 national health survey

24 million

Total number of Americans with impaired lung function, indicating a possible underdiagnosis of C.O.P.D.

2020

The year by which C.O.P.D. is projected to become the third leading cause of death in the U.S.

\$32.1 billion

Estimated overall cost of C.O.P.D. in 2002, including medical expenses and the cost of lost productivity because of illness and premature death

Source: Centers for Disease Control and Prevention

The illness is not the same as asthma, but some patients have asthma along with their other lung problems. Most have a combination of emphysema and chronic bronchitis. In about one-sixth of cases, emphysema is the main problem. Women are far more likely than men to develop chronic bronchitis, and are less prone to emphysema. Some studies have suggested that women's lungs are more sensitive than men's to the toxins in smoke.

Worldwide, these lung diseases kill 2.5 million people a year. An article in September in *The Lancet*, a medical journal, said that "if every smoker in the world were to stop smoking today, the rates of C.O.P.D. would probably continue to increase for the next 20 years." The reason is that although quitting slows the disease, it can develop later.

Cigarettes are the major cause worldwide, but other sources are important in developing countries, especially smoke from indoor fires that burn wood, coal, straw or dung for heating and cooking.

Women and children are most likely to be exposed. Outdoor air pollution plays less of a part: it can aggravate existing disease, but is believed to cause only 1 percent of cases in rich countries and 2 percent in poorer ones. Occupational exposures in cotton mills and mines may contribute.

Researchers have differed about whether passive smoking plays a role, but a *Lancet* article in September predicted that in China, among the 240 million people who are now over 50, 1.9 million who never smoked will die from chronic lung disease — just from exposure to other people's smoke.

Many patients with lung disease have other illnesses as well, like heart disease, acid reflux, hypertension, high cholesterol, sinus problems or diabetes. Compared with other smokers, those with C.O.P.D. are more likely to develop lung cancer as well. Researchers suspect that all the ailments stem partly from the same underlying condition, widespread inflammation, a reaction

by the immune system that can affect blood vessels, organs and tissues all over the body.

Lung disease can creep up insidiously, because human beings have lung power to spare. Millions of airways, with enough surface area to cover a tennis court, provide so much reserve that most people would not notice it if they lost the use of a third or even half of a lung. But all that extra capacity can hide an impending disaster.

"If it comes on gradually, the body can adjust," said Dr. Neil Schachter, a lung specialist and professor at Mount Sinai Medical Center in New York. "Some of these patients are at oxygen levels where you and I would be gasping for breath."

People adjust psychologically as well, cutting back their activities, deciding perhaps that they just do not enjoy sports anymore, that they are getting older, gaining weight or a bit out of shape. But at some point the body can no longer compensate, and denial does not work anymore.

"It's like trying to breathe through a straw," Dr. Schachter said. "It's very uncomfortable."

By then, half a lung might be ruined. On a CT scan, he said, the lungs may look "moth-eaten," full of holes where tissue has been destroyed.

Often, the diagnosis is not made until the disease is advanced. Even though breathing tests are easy to perform and recommended for high-risk patients like former and current smokers, many doctors do not bother. People who do get a diagnosis frequently are not taught how to use the inhalers that are the mainstay of treatment. Access to pulmonary rehabilitation is limited because Medicare has left coverage decisions to the states. Some programs have shut down, and there are bills in the House and Senate that would require pulmonary rehabilitation to be covered by Medicare. Medicare may also reduce coverage for home oxygen.

Meanwhile, billions are spent on treating exacerbations, episodes of severe breathing trouble

that are often caused by colds, flu or other respiratory infections.

A recent study of 1,600 consecutive hospitalizations for chronic lung disease in five New York hospitals found that once patients were in the hospital, their treatment was generally correct, Dr. Thomashow said. But “most upsetting,” he said, was that the majority had been incorrectly treated before going to the hospital.

For many, trying to control the disease, rather than be controlled by it, is a daily struggle. Diane Williams Hymons, 57, a social service consultant and therapist in Silver Spring, Md., has had lifelong problems with bronchitis, allergies and asthma. In the last five or 10 years, her breathing difficulties have worsened, but she was told only three years ago that she had C.O.P.D. It motivated her to give up cigarettes, after smoking for more than 30 years.

“I have good days, and days that aren’t as great,” she said. “I sometimes have trouble walking up steps. I have to stop and catch my breath.”

She is “usually fine” when sitting, she said.

Her mother, also a former smoker with chronic lung disease, has been in a pulmonary rehabilitation program. Ms. Williams Hymons’s doctor has not recommended such a program for her, but she has no idea why. They have discussed surgery to remove part of her lungs, which helps some people with emphysema, but she said no decision had been made yet because it is not clear whether her main problem is emphysema or asthma. She is not sure what her prognosis is.

A Risky Approach

Ms. Williams Hymons has been taking prednisone pills for years, something both she and her doctor know is risky. But when she tries to cut back, the disease flares up. She has many side effects from the drug.

“My bone density is not looking real good,” she said. “I have cramps in my hands and feet, weight gain and bloating, the moon face, excess facial hair,

fat deposits between my shoulder blades. Yes, I have those.”

She has broken two ribs just from coughing, probably because the prednisone has thinned her bones, she said. She went to a hospital for the rib pain last year and was given so much asthma medication to stop the coughing that it caused abnormal heart rhythms. She wound up in the cardiac unit for five days, and now says “never again” to being hospitalized.

Her doctor orders regular bone density tests.

“I know he’s concerned, like I’m concerned,” Ms. Williams Hymons said, “but we can’t seem to kind of get things under control.”

A recent study of 25 primary care practices around the United States treating chronic lung disease found that most did not perform spirometry, a simple breathing test used to diagnose or monitor the disease, even when they had the equipment to do so. The test takes only a few minutes, but doctors said there was not enough time during the

usual 15-minute visit. Similarly, the practices did not offer much help with smoking cessation.

The author of the study (published in August in *The American Journal of Medicine*), Pamela L. Moore, said many of the doctors felt unable to help smokers quit, and believed that as long as patients kept smoking, treatments for lung disease would be for naught. But Dr. Moore said research had found that people are more likely to quit or start cutting back if doctors recommend it.

Labeling the disease self-induced is “an unbelievably painful concept,” Dr. Thomashow said. “Patients blame themselves, their family blames them, we even have evidence that health providers blame them.”

Shame and Blame

Indeed, a patient at a clinic in Manhattan, with nasal oxygen tubing attached to equipment in a backpack, said, “This is one of the evils you must suffer for the things we did in our life.”

Smoking also contributes to heart disease, Dr. Thomashow said, and yet people “don’t waste time blaming the patient.”

“This disease quite frankly has an image problem,” said Dr. James Kiley, the director of lung research at the National Heart, Lung and Blood Institute, which started a campaign last January to educate people about the disease.

In one way or another every patient seems to have encountered what John Walsh, president of the C.O.P.D. Foundation, calls the “shame and blame” attached to this disease.

It is a familiar theme to Ms. Dorney Koppel, who agreed to become a spokeswoman for the institute’s education campaign. She was surprised to be asked to help, she said, because the campaign needed a celebrity, and she is merely married to one. She asked the person who invited her, whether there were no famous people with C.O.P.D.

“I was told, ‘None who will admit it,’” she said.

Ms. Dorney Koppel, who is

candid about being a former smoker, calls the illness the Rodney Dangerfield of diseases.

“You don’t get no respect,” she said. “I have to pay publicly for my sins. I have paid.”

Like many patients, Ms. Rommes has both emphysema and chronic bronchitis, along with asthma. She had symptoms for years before receiving the correct diagnosis.

She began smoking in college during the 1960s, when she was 18. People whom she admired smoked, and it seemed cool. She smoked for 30 years.

When she quit in 1992, it was not because she thought she was ill, but because she realized that she was organizing her day around chances to smoke. But she almost certainly was ill. She was only 50, but climbing a flight of stairs left her winded. From what she found in medical dictionaries, she began to suspect she had lung disease.

By 2000 she was so short of breath that she consulted her doctor about it.

He gave her a spirometry test. In one second, healthy adults should be able to blow out 80 percent of the total they can exhale; her score was 34 percent, which, she knows now, indicated moderate to severe lung disease.

"I honestly don't know whether he knew," she said of her doctor. "I suspect he did, but he didn't call it emphysema."

"He put me on a couple of inhalers and he called it asthma," Ms. Rommes said. "I sort of ignored the whole thing, because the inhalers did make me feel better. I started to gain some weight, and things got progressively worse."

She cannot help wondering now if she could have avoided becoming so desperately ill, if she had only known sooner what a dangerous illness she had.

The turning point came in February 2003 when she tried to take a shower and found that she could not breathe. The steam all but suffocated her. She managed to drive from her home

in Osceola, Iowa, to her doctor's office, struggle across the parking lot like someone climbing a mountain and collapse, gasping, onto a couch inside the clinic. Her blood oxygen was perilously low, two-thirds of normal, even when she was given oxygen. The hospital was next door, and her doctor had her admitted immediately.

Fear and Anger

She had Type 2 diabetes as well as lung disease, and her doctor told her that losing weight would help both illnesses. But she said, "He made it pretty clear that he didn't think I would or could."

Motivated by fear and anger, she began riding an exercise bike, walking on a treadmill, lifting weights at a gym and eating only 1,200 to 1,500 calories a day, mostly lean meat with plenty of vegetables and fruit.

"I kind of came to the conclusion that if I didn't, I probably wasn't going to be around," Ms. Rommes said. "I wasn't ready to check out. And my husband was

beginning to show the signs of Alzheimer's disease. I knew that if I couldn't continue to manage our affairs, it wasn't going to work out."

By December 2003, her efforts were starting to pay off. She went from needing oxygen around the clock to using it only for sleeping, and by January 2005 she no longer needed it at all. She was able to lower the doses of her inhalers and diabetes medicines. By February 2005, she had lost 100 pounds.

The daily exercise also helped her deal with the stress of her husband's illness. He died in June.

"I had no clue that exercise would do as much for ability to breathe as it did," she said, adding that it helped more than the drugs, which she described as "really pretty minimal."

She is hooked on exercise now, getting up every morning at 5 a.m. to walk for 45 minutes on the treadmill. She goes at it hard enough to break a sweat, wearing a blood oxygen monitor

to make sure her level does not dip too low (if it does, she slows down or uses special breathing techniques to bring it up). She walks outdoors, as well, and three times a week, she works out with weights at a gym.

"Exercise is absolutely essential, and it's essential to start it as soon as you know you have C.O.P.D.," she said.

Exercise does not heal or strengthen the lungs themselves, but it improves overall fitness, which people with lung disease need desperately because their shortness of breath leads to inactivity, muscle wasting and loss of stamina.

"Both my pulmonologist and my regular doctor have made it really, really clear to me that I have not increased my lung capacity at all," Ms. Rommes said. "But I've improved the mechanics. I've done everything I know how to do to make the lung capacity as efficient as possible. That's the key for me; I know there are lots of people with this disease who don't exercise, who

I guess just give up.”

She realizes that she has two serious chronic diseases that could shorten her life. But it does not worry her much, she said, because she figures she is doing everything she can to take care of herself, and would rather spend her time enjoying life — work, reading, opera, traveling, children and grandchildren.

“I will tell pretty much anybody that I have emphysema,” Ms. Rommes said. “They say, ‘Did you smoke?’ I say, ‘Yes I did,

for 30 years, and I quit in 1992.’ Maybe it’s why I’ve attacked this the way I did. O.K., I did it to myself, and so I better do everything I can to get out of it. We all do things in our lives that are stupid, and then you do what you can to fix it.” □

Operations to Remove Damaged Tissues Have Fallen Sharply

SURGERY ►►

The New York Times

www.nytimes.com/health



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Body Mass Index Calculator:
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SURGERY

After Early Success, Operations to Remove Damaged Tissues Have Fallen Sharply

By DENISE GRADY

PUBLISHED: NOVEMBER 29, 2007

Intently watching the rise and fall of Madeline Gallagher's abdomen as she lay on the operating table, Dr. Mark Ginsburg said, "Her diaphragm is finally moving. That's a really good sign."

He had just removed 30 percent of each of her lungs. Now, he said, she was breathing normally, for the first time in many years.

"It's counterintuitive," he said. "Patients have poor lung function, and you help them by taking out part of their lungs."

Mrs. Gallagher, 65, has emphysema, first diagnosed in 1993. She had smoked for 35 years, starting when she was 15, and quit in 1992. Initially not severe, the disease worsened over the years until cleaning the house, shopping,

just walking down the street became a struggle. More and more, she needed oxygen. Pneumonia put her in the hospital twice. Already thin, she lost 15 pounds, a danger sign in emphysema.

On Oct. 17, at NewYork-Presbyterian/Columbia hospital, she had lung-volume reduction surgery. It is not a cure, but has been found to help certain people with emphysema — possibly 10 percent — those with such poor lung function that they can barely exercise, and with disease mostly localized to parts of the lungs that can be removed. With the surgery many feel better, and some also live longer.

Lungs damaged by emphysema lose their elasticity and trap stale air. As a result, they can enlarge, or hyperinflate, to 150 percent of



DAMON WINTER/THE NEW YORK TIMES

Madeline Gallagher, 65, an emphysema patient, after doctors at NewYork-Presbyterian/Columbia hospital removed 30 percent of each of her lungs.

their normal size, or more, preventing the diaphragm from moving normally. Instinctively, patients begin working other muscles to compensate, and sometimes become barrel-chested or raise their shoulders so much that they look like they are wearing shoulder pads. On X-rays, abnormally wide spaces between the ribs are a telltale sign of the disease. Doctors and nurses can spot patients in

waiting rooms, sitting straight up on the edges of their seats, leaning on their hands with elbows stiff and shoulders up as if they are about to push off. But no matter how hard they try, they cannot take in enough air.

In theory, by cutting away the most diseased tissue, the operation should stop some of the air trapping, and by restoring the lungs to their proper size, it should

let the diaphragm work so that the chest can move more normally.

The surgery has had a rocky history. Reports of fantastic recoveries made it popular in the 1990s, but health officials wanted a rigorous study. A government-sponsored experiment began in 1996, and ultimately found the operation beneficial only for some types of emphysema, and useless or even harmful in others. In 2003, Medicare decided to cover it only for people like those who had done well in the study, and only at experienced hospitals.

The number of operations has fallen sharply, from thousands a year to under 200 in 2006. Some researchers praise the outcome as a triumph of data over wishful thinking, but others say that the pendulum has swung too far, and that many patients who could be helped are missing out.

Meanwhile, researchers are experimenting with valves and other devices that are implanted in the lungs through scopes passed down the throat, without cutting through the chest. The devices



DAMON WINTER/THE NEW YORK TIMES

A nurse at NewYork-Presbyterian/Columbia hospital, top, with a tool that cuts and staples the lungs. Center, Dr. Steve Xydas works on Mrs. Gallagher's left lung. Above, X-rays of Mrs. Gallagher's lungs.

are meant to vent trapped air into the airways, where it can be exhaled, and to deflate diseased parts of the lungs — without having to cut out any tissue. In some cases, the implants might replace surgery, but they might also help patients who are not candidates for the surgery.

After Mrs. Gallagher's second bout with pneumonia, doctors recommended lung-volume reduction, and she agreed to it in the hope that it would give her back some of her life — let her be more active, take trips with her husband, keep up with her grandchildren.

Dr. Ginsburg operated through tiny slits, rather than opening the entire chest. He inserted a camera, and guided by a monitor, cut away a cellphone-size slab of each lung. The operation took about 90 minutes.

"We did exactly what we wanted to do," Dr. Ginsburg said. "The question is, will it work?" Ideally, the operation can set the clock back three to five years, he said, but added, "At the end of the day she's only as good as

what she has left."

Mrs. Gallagher had a rough recovery. She spent 10 days in the hospital, twice as long as expected. She had trouble breathing and could not keep food down, which worried her family because she was already frail.

A few days after leaving the hospital, she was supposed to resume exercising in a pulmonary rehabilitation program that had begun before the surgery. Her daughter wondered how she would manage, when she was too weak even to dress herself.

But she bounced back quickly. Two weeks later, she said, "I'm doing terrific," adding that she had just walked 25 minutes on a treadmill without needing oxygen, something she could not do before. Her appetite was back, and she had polished off a dinner of veal parmesan and baked ziti.

"My breathing isn't as shallow as it used to be," Mrs. Gallagher said. "I can take a deeper breath. I'm very, very happy." □

SEARCH FOR TREATMENT ►►

SEARCH FOR TREATMENT

Researchers Focus on Genes and Inflammation in Search for Clues to Chronic Obstructive Lung Disease

By DENISE GRADY

PUBLISHED: NOVEMBER 29, 2007

Two big ideas dominate the latest thinking about chronic obstructive pulmonary disease: one, genes determine who develops it, and two, it involves systemic inflammation that affects far more than the lungs.

Genetics may explain why only about 20 percent of smokers ever get C.O.P.D.: researchers think the lungs of some people have an inherited sensitivity to smoke.

One genetic disorder is known to cause emphysema, a condition called alpha-1-antitrypsin deficiency, which accounts for a small percentage of cases. Patients lack a protein that normally protects the lungs. They can develop emphysema even if they never smoke, and are high-

ly prone to it if they do smoke. Identifying the deficiency made it possible to develop a treatment, an intravenous form of the needed protein.

Several studies are under way to look for other genes involved in chronic lung disease. The hope is that finding them will lead to other treatments, methods of prevention or at least a way to warn people who might be at high risk from smoking.

"I would love to develop the Lipitor equivalent for cigarette smokers," said Dr. Ronald Crystal, who is directing a genetic study at NewYork-Presbyterian/Weill Cornell hospital.

Just as people take Lipitor to lower high cholesterol, he said, those who cannot stop smoking, and who have a high risk of C.O.P.D., might be offered a drug

to protect their lungs.

“It may not be the politically correct thing to say, but it may save a lot of lives,” Dr. Crystal said, noting that nicotine addiction is so powerful that some people simply cannot quit.

Another study, just starting at 16 medical centers, will include people who have chronic lung disease or are at risk for it because of smoking.

“We’ll analyze their entire genome to find the genes that cause this disease,” said Dr. James D. Crapo of National Jewish Medical and Research Center in Denver.

He said he expected to find five or six genes, including one that codes for a strong antioxidant.

“If you have high levels, you’ll be resistant against getting C.O.P.D.” he said. “It would teach us to make drugs that could intervene. We’re not talking about giving people a drug so they can smoke. We want to give something to prevent progression of the disease.”

The study could also have broader applications, Dr. Crapo said, because many other chronic diseases seem to involve the same underlying condition — inflammation, which is what happens when a cut or an insect bite turns red, hot and swollen. It is a defense mechanism involving armies of immune-system cells that spew out potent biochemicals to fight germs, toxins or foreign bodies, and in the short term it is a good thing.

But chronic inflammation, which can be brought on by smoking, obesity and other factors, is another story. “Even if you don’t smoke, you’re exposed to a wide variety of inflammatory agents throughout your lifetime, and we can learn what components of our genetic code protect us,” Dr. Crapo said.

“I think it’s going to lead to a breakthrough in understanding and a cure for diseases related to environmental and occupational stress.” □

WHAT TO KNOW ▶▶

WHAT TO KNOW

Certain Symptoms Should Raise Red Flags for Doctors

By **DENISE GRADY**

PUBLISHED: NOVEMBER 29, 2007

Not everyone needs to be tested for chronic obstructive pulmonary disease. But certain symptoms are cause for concern: shortness of breath, chronic coughing or wheezing, congestion or clogging of the airways with mucus.

Smokers and former smokers have the greatest risk, but 10 percent to 15 percent of cases occur in people who never smoked. Persistent respiratory problems should always be checked, regardless of smoking history. Shortness of breath can also be a symptom of heart disease.

People are not always aware of the symptoms, maybe because they have become used to them or do not want to believe they could be ill, and, during the

usual rushed office visit, doctors may not investigate deeply enough.

"We're missing people who have real disease, not just people with minor disease," said Dr. Byron Thomashow, director of the Center for Chest Disease at NewYork-Presbyterian/Columbia hospital.

Dr. Thomashow said doctors should ask, "How's your breathing compared to six months or a year ago? Can you exercise and function the way you did in the past?"

If a problem is suspected, the next step will probably be a breathing test called spirometry that takes a few minutes and can be done in many doctors' offices. Some doctors think that anyone who has smoked a pack a day for 10 years or more should have spirometry, even if there are no

symptoms. A poor result might motivate a smoker to quit, or at least identify a condition that should be monitored. Others say that only people with symptoms should be tested because a symptom-free smoker may have a normal result and then think it safe to continue smoking.

This month, the American College of Physicians issued new guidelines for the disease. They recommended spirometry only for people with symptoms and said those scoring below a certain level should be given inhaled medicines to open the airways or treat inflammation, or both. It also recommended oxygen for patients with low blood oxygen while resting, and pulmonary rehabilitation pro-

grams for those with symptoms and poor spirometry readings. Many specialists advocate starting treatment even earlier than the guidelines recommend. □

Information about lung disease is available from:

The National Heart Lung and Blood Institute: Phone: (301) 592-8573; nhlbi.nih.gov/health/public/lung/copd/index.htm.

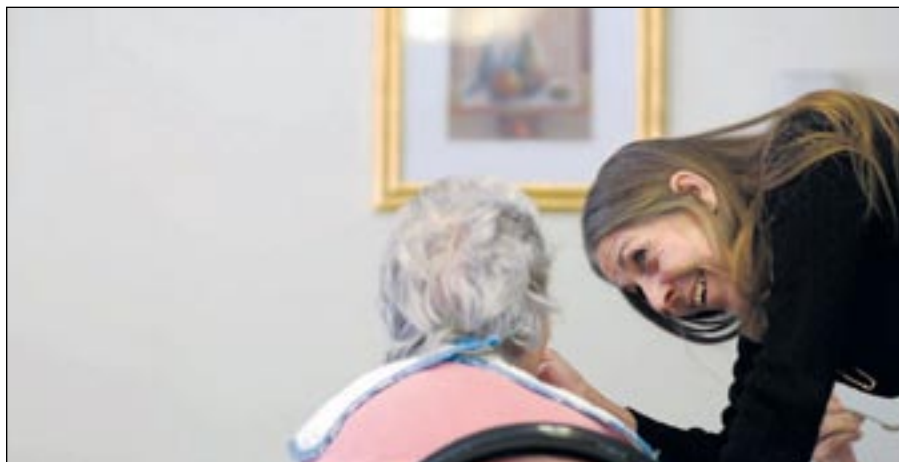
The C.O.P.D. Foundation: (866) 316-COPD (2673); copdfoundation.org. (It also has a registry that patients can join to learn about and join in clinical trials.)

The American Lung Association: (800) 548-8252; lungusa.org.

"Life and Breath," a book about C.O.P.D. by Dr. Neil Schachter.

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Dianne Kerley is tending to her mother, who has Alzheimer's disease, and helping Alzheimer's researchers.

Finding Alzheimer's Before a Mind Fails, an Urgent Quest

By **DENISE GRADY**

PUBLISHED: DECEMBER 26, 2007

FOR A PERFECTLY healthy woman, Dianne Kerley has had quite a few medical tests in recent years: M.R.I. and PET scans of her brain, two spinal taps and hours of memory and thinking tests.

Ms. Kerley, 52, has spent much of her life in the shadow of an illness that gradually destroys memory, personality and the ability to think, speak and live independently. Her mother, grandmother and a maternal great-aunt all developed Alzheimer's disease. Her mother, 78, is in a

nursing home in the advanced stages of dementia, helpless and barely responsive.

"She's in her own private purgatory," Ms. Kerley said.

Ms. Kerley is part of an ambitious new scientific effort to find ways to detect Alzheimer's disease at the earliest possible moment. Although the disease may seem like a calamity that strikes suddenly in old age, scientists now think it begins long before the mind fails.

"Alzheimer's disease may be a chronic condition in which changes begin in midlife or even earlier," said Dr. John C. Morris, director of the Alzheimer's Disease Research Center at Washington University in St. Louis, where Ms. Kerley volunteers for studies.

But currently, the diagnosis is not made until symptoms develop, and by then it may already be too late to rescue the brain. Drugs now in use temporarily ease symptoms for some, but cannot halt the underlying disease.

Many scientists believe the best hope of progress, maybe the only hope, lies in detecting the disease early and devising treatments to stop it before brain damage becomes extensive. Better still, they would like to intervene even sooner, by identifying risk factors and treating people preventively — the same strategy that has markedly lowered death rates from heart disease, stroke and some cancers.

So far, Alzheimer's has been unyielding. But research now under way may start answering major questions about when the disease begins and how best to fight it.

A radioactive dye called PIB (for Pittsburgh Compound B) has made it possible to use PET scans to find deposits of amyloid, an Alzheimer's-related protein, in the brains of live human beings. It may lead to earlier diagnosis, help doctors distinguish Alzheimer's from other forms of dementia and let them monitor the effects of treatment.

Studies with the dye have al-

ready found significant deposits in 20 percent to 25 percent of seemingly normal people over 65, suggesting that they may be on the way to Alzheimer's, though only time will tell.

"PIB is about the future of where Alzheimer's disease needs to be," said Dr. William E. Klunk, a co-discoverer of the dye at the Alzheimer's research center at the University of Pittsburgh. "PIB is being used today to help determine whether drugs that are meant to prevent or remove amyloid from the brain are working, so we can find drugs that prevent the underlying pathology of the disease."

Though PIB is experimental now, studies began in November that are intended to lead to government approval for wider use.

Currently, for the most common form of Alzheimer's disease, which occurs after age 65, there is no proven means of early detection, no definitive genetic test. But PIB tests might be ready before new treatments emerge, making it possible to

Seven Stages of Alzheimer's

- 1 NO IMPAIRMENT**
Normal function with no memory problems.
- 2 VERY MILD DECLINE**
Small memory lapses, especially in forgetting familiar words or the locations of everyday objects.
- 3 MILD DECLINE**
Possible early-stage Alzheimer's.
Friends and family begin to notice problems with memory.
- 4 MODERATE DECLINE**
Early-stage Alzheimer's.
Decreased knowledge of current events and ability to perform complex tasks.
- 5 MODERATELY SEVERE DECLINE**
Mid-stage Alzheimer's.
Major gaps in memory, confusion about date or season. Some assistance required with daily tasks.
- 6 SEVERE DECLINE**
Mid-stage Alzheimer's.
Continued memory loss, significant change in personality and behavior. Extensive assistance required.
- 7 VERY SEVERE DECLINE**
Late-stage Alzheimer's.
Unable to speak or respond to the environment. Eventual loss of movement and muscle control.

Source: Alzheimer's Association THE NEW YORK TIMES

predict who will develop Alzheimer's — without being able to help.

Researchers are also using M.R.I. scans to look for early brain changes, and testing blood and spinal fluid for amyloid and other “biomarkers” to see if they can be used to predict Alzheimer's or find it early.

Studies of families in which multiple members have dementia are helping to sort out the genetic underpinnings of the disease.

Finally, experiments are under way to find out whether drugs and vaccines can remove amyloid from the brain or prevent its buildup, and whether doing so would help patients. The new drugs, unlike the ones now available, have the potential to stop or slow the progress of the disease. At the very least, the drug studies will be the first real test of the leading theory of Alzheimer's, which blames amyloid for setting off a chain of events that ultimately ruin the brain.

Some scientists doubt the amyloid theory, but even a staunch skeptic said the studies were important.

Among the skeptics is Dr. Peter Davies, a professor at Albert Einstein Medical College, who said: “You've got to try. Somebody's going to get this right.”

But if the amyloid hypothesis does not hold up, much of Alzheimer's research could wind up back at Square 1.

Answers are urgently needed. Alzheimer's was first recognized 100 years ago, and in all that time science has been completely unable to change the course of the disease. Desperate families spend more than \$1 billion a year on drugs approved for Alzheimer's that generally have only small effects, if any, on symptoms. Patients' agitation and hallucinations often drive relatives and nursing homes to resort to additional, powerful drugs approved for other diseases like schizophrenia, drugs that can deepen the oblivion and cause severe side effects like

diabetes, stroke and movement disorders.

Alzheimer's is the most common cause of dementia (artery disease, Parkinson's and other brain disorders can also lead to dementia). Five million people in the United States have Alzheimer's, most of them over 65. It is the nation's sixth leading cause of death by disease, killing nearly 66,000 people a year and probably contributing to many more deaths. By 2050, according to the Alzheimer's Association, 11 million to 16 million Americans will have the disease. "Sixteen million is a future we can't countenance," said William H. Thies, the association's vice president for medical and scientific relations. "It will bankrupt our health care system."

The costs are already enormous, \$148 billion a year — more than three times the cost of chronic lung disease, even though Alzheimer's kills only half as many people. To a great extent, increases in dementia are the price of progress: more

BY THE NUMBERS

100 billion

Number of nerve cells or neurons, in a healthy adult brain

1 in 8

Estimated number of Americans over 65 who have Alzheimer's disease

65,829

Number of Americans who died from Alzheimer's disease in 2004

32.8%

Increase in the number of deaths due to Alzheimer's disease from 2000 to 2004

70%

Percentage of people with Alzheimer's disease who live and are cared for at home

\$148 billion

Estimated overall cost of Alzheimer's and other dementias, including medical expenses and the cost of the lost productivity because of illness and premature death.

Source: Alzheimer's Association

and more people are living long enough to get Alzheimer's, some because they survived heart disease, strokes or cancer. It is a cruel trade-off. The disease is by no means inevitable, but among people 85 and older, about 40 percent develop Alzheimer's and spend their so-called golden years in a thicket of confusion, ultimately becoming incontinent, mute, bedridden or forced to use a wheelchair and completely dependent on others.

"It makes people wonder whether they really want to live that long," Dr. Klunk said.

The potential market for prevention and treatment is enormous, and drug companies are eager to exploit it. If a drug could prevent Alzheimer's or just reduce the risk, as statins like Lipitor do for heart disease, half the population over 55 would probably need to take it, Dr. Thies said.

If new drugs do emerge, they will come from studies in patients who already have symptoms, Dr. Thies said. But he said

the emphasis would quickly shift to treating people at risk, before symptoms set in. Many researchers doubt that even the best preventive drugs will be able to heal the brains of people who are already demented.

Treating preventively, Dr. Thies said, "will be more satisfying to patients and physicians, and there will be an economic incentive because you'll wind up treating more people."

The only thing that could slow the drive for early treatment, he said, would be serious side effects — and Dr. Morris, at Washington University, said drugs powerful enough to treat Alzheimer's would probably have strong side effects.

Researchers are especially eager to study people like Ms. Kerley, because the children of Alzheimer's patients have a higher-than-average risk of dementia themselves, and tracking their brains and minds may open a window onto the earliest stages of the disease.

"I want to do anything I can

possibly do to help find a cure or find a way to identify it earlier," Ms. Kerley said. "We need to stop this. I don't know if it will help my generation, but it will help my son's."

She figures that being a research subject may have advantages, too.

"We're the first ones in line," she said. "If I am genetically predisposed, and they have a preventive medication, they'll tell me right away."

Alzheimer's Beginnings

Some forgetfulness is normal. Distraction, stress, fatigue and medications can contribute. A joking rule of thumb about Alzheimer's is actually close to the truth: it's O.K. to forget where you put your car keys, as long as you remember what a key is for. But worsening forgetfulness is a cause for concern.

Doctors use standard memory and reasoning tests to diagnose dementia, along with symptoms reported by the patient and family members. The term "mild cog-

nitive impairment" is sometimes applied to small but measurable memory problems. But its meaning is unclear: some studies find that the impairment can resolve itself, while others suggest that it always progresses to dementia.

Even if older patients think more slowly or take longer to remember, as long as they can still function independently, they are not demented, Dr. Morris said.

In her heart, Ms. Kerley suspects that her mother's Alzheimer's disease began long before the official diagnosis in 2001 or even the tentative one in 1995 — years before, maybe decades. She wonders if the disease might explain, at least in part, her mother's difficult personality and lack of interest in reading or education.

When does Alzheimer's begin? The question haunts families and captivates scientists.

Dr. Morris said, "We think that by the time an individual begins to experience memory loss, there is already substantial brain damage in areas critical to

memory and learning.”

No one knows whether the disease affects thinking, mood or personality before memory fails. Researchers think that the brain, like other vital organs, has a huge reserve capacity that can, at least for a time, hide the fact that a disease is steadily destroying it.

“I’m speculating that it does affect you throughout life,” said Dr. Richard Mayeux, a professor of neurology, psychiatry and epidemiology at Columbia University, and co-director of its Taub Institute for Research on Alzheimer’s Disease and the Aging Brain. “I think there’s a very long phase where people aren’t themselves.”

If Dr. Mayeux asks family members when a patient’s memory problem began, they almost always say it started a year and a half before. If he then asks when was the last time they thought the patient’s memory was perfectly normal, many reply that the patient never really had a great memory.

Several studies in which people had intelligence tests early in life and were then evaluated decades later have found that compared with the healthy people, those with Alzheimer’s had lower scores on the early tests.

“It raises the possibility for me that this is a genetic disorder that starts early in life,” Dr. Mayeux said.

He said those findings also made him wonder about the widely dispensed advice to read, take courses, solve puzzles and stay mentally active to ward off Alzheimer’s. The advice is based on studies showing that highly educated people have a lower risk of Alzheimer’s than do less-accomplished ones. But does that mean that mental activity prevents Alzheimer’s — or vice versa?

‘I Have Lost Myself’

The disease is named for Alois Alzheimer, a German doctor who first described it in Auguste D., a 51-year-old patient he saw in 1901. Her memory, speech and

comprehension were failing, and she suffered from hallucinations and paranoid delusions that her husband was unfaithful. Unable to finish writing her own name, she told Alzheimer, "I have lost myself."

She died in 1906, "completely apathetic," curled up in a fetal position and "in spite of all the care and attention," suffering from bedsores, Alzheimer wrote.

A century later, patients still die in much the same way. Although Alzheimer's itself can kill by shutting down vital brain functions, infections usually end things first — pneumonia, bladder infections, sepsis from bedsores.

When Alzheimer dissected Auguste's brain, he found it markedly shrunken, a wasteland of dead and dying nerve cells littered with strange deposits.

There were two types of deposits, plaques and tangles. Plaques occur between nerve cells, and are now known to consist of clumps of beta amy-

loid, an abnormal protein. Tangles form inside nerve cells, and are made of a protein called tau that is normally part of a system of tubules that carry nutrients to feed the cell. Once tau is damaged, the nerve cells essentially starve to death.

Until the 1970s Alzheimer's disease was considered a rare brain disorder that mysteriously struck younger people like Auguste D.

It was thought to be different from "senility," which was assumed to be a consequence of aging. But then researchers compared the brains of younger people who had died of Alzheimer's with those of elderly people who had been senile, and discovered the same pathology — plaques and tangles. Senility, they decided, was not a natural part of aging; it was a disease.

The Amyloid Hypothesis

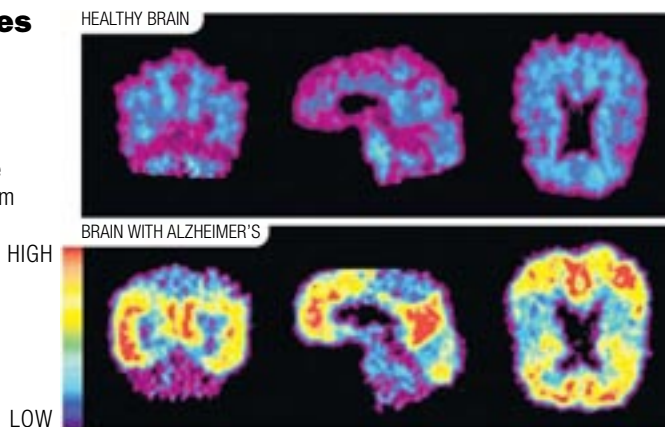
The leading theory of Alzheimer's says that beta amyloid, or A-beta, is the main culprit, building gradually in the brain over

Amyloid Plaques In the Brain

Images of a healthy elderly brain (right) and the brain of a patient with Alzheimer's disease (below right), viewed from the front, side and top.

Bright spots indicate deposits of amyloid, an Alzheimer's-related protein that forms plaques between neurons.

Source: University of Pittsburgh Medical Center



THE NEW YORK TIMES, PET SCANS COURTESY OF WILLIAM KLUNK

decades and short-circuiting synapses, the junctions where nerve cells transmit signals to one another. Gradually, the theory goes, the cells quit working and die.

Everybody produces A-beta, but its purpose is not known. People who develop Alzheimer's either make too much or cannot get rid of it. Although scientists once blamed plaques for all the trouble, more recent research suggests that the real toxins are smaller bundles of A-beta molecules that form long before plaques do.

Dr. Dennis J. Selkoe, a professor of neurologic diseases at Harvard, said that just as lowering cholesterol can prevent heart disease, lowering A-beta may prevent Alzheimer's or slow it, particularly in the early stages — provided that drugs can be created to do the job.

Several drugs and vaccines are now being tested that either block the production of A-beta or help the body get rid of it.

Researchers are also testing anti-amyloid antibodies, which are proteins made by the immune system, as well as blood

serum that contains the antibodies.

Eventually, Dr. Selkoe said, screening tests for Alzheimer's "will be like getting an EKG in the doctor's office at 45 or 50, and you'll start treating right away to prevent Alzheimer's rather than treat it."

Other researchers are less enthusiastic, noting that there have been numerous failures and disappointments along the way. A vaccine study had to be halted in 2002 because 18 of 300 patients developed encephalitis, and 2 died. Some scientists worry that anti-amyloid vaccines in general could be dangerous, in part because the role of amyloid is not well understood and the brain may actually need it.

No Choice but to Cope

Even if current research yields new drugs, there is not likely to be a miracle pill that will bring people back from deep dementia. For now, there is no choice but to cope with the disease. Seventy percent of Al-

zheimer's patients are cared for at home, and millions of families are struggling to look after them, piecing together a patchwork of relatives, friends, paid health aides and adult day-care programs.

Barbara Latshaw, 79, lives with her husband, David, and her sister in Crafton, Pa., near Pittsburgh. Ms. Latshaw, whose dementia was diagnosed in 1991, has not spoken in four years, and she can no longer smile. But she locks eyes with visitors and will not let go.

"There is still something alive in there," said her sister, Fritzie Hess, 69. "I'm convinced of it."

The family believes that, at least some of the time, she still understands them. They speak to her as if she does. She is with them, and yet gone, and they miss her terribly.

"We hope to keep her here at home until she passes on," Ms. Hess said. "She's a joy to us."

Many families hope to keep Alzheimer's patients at home, but not all can manage it, espe-

cially if family members have to go work or patients become combative, incontinent, immobile or unable to sleep at night.

"There are three of us taking care of my sister, and it works out beautifully," Ms. Hess said. "We spell each other. I don't know how these spouses manage, when it's one on one."

Ms. Hess and her brother-in-law are retired, and Ms. Latshaw's daughter, Becky Bannon, 53, is free to visit many mornings to help them get her mother out of bed, massage and exercise her arms and legs, change her diaper and dress and feed her.

Ms. Latshaw used to be full of life. She loved to cook, played tennis and bridge, raised two children and took charge of redecorating the grand old family home. Then her memory began to slip: guests would arrive for dinner, and she would have no memory of inviting them. She forgot to look before pulling into traffic, and nearly caused an accident. She would wander out of the house, and local store

clerks would take her home. She never turned hostile or angry, as many demented patients do, but she had vivid hallucinations of strings being caught in her teeth, and little men getting into her bed and jabbing her with broom straws. On especially bad nights, her husband would get up with her at 2 or 3 a.m. and make the two of them hot chocolate.

Aricept, an Alzheimer's drug, made the hallucinations worse, while another drug, an antipsychotic used for schizophrenia, seemed to quell them. But the second drug had side effects: after taking it for several years, Ms. Latshaw began to grind her teeth, and could not stop moving her arms and legs.

Their father also suffered from dementia, Ms. Hess said, admitting that she wonders about herself.

"Naturally I'm a little bit concerned, but I think worry is such a waste of time, so I don't dwell on it; I just don't," she said. "My friends always said, 'You always had a bad memory.' I see Barba-

ra and David's children having that same kind of memory."

Ms. Hess has volunteered for studies at the University of Pittsburgh Medical Center, where she became the first person in the United States to have a PIB study of her brain.

"I'm very anxious to get to the bottom of this whole Alzheimer's thing," she said.

Nothing Left to Give

In an interview in the summer of 2006, Ms. Kerley described her mother this way: "She's completely withdrawn in herself. She hasn't recognized us for a few years. Basically she hums one line of one song over and over again. She seems to be stuck somewhere in her life between age 4 and 5."

Ms. Kerley said she and her son Michael, then 21, visited every week or two.

"She loves getting her back rubbed, being smiled at, being hugged," Ms. Kerley said. "She doesn't know who we are. We're going for us, not for her, because

she doesn't remember us the minute we walk out the door."

She had signed her mother up for hospice care at the nursing home, meaning that she would receive medical care to keep her comfortable but no extraordinary measures like resuscitation if she began to fail. She said her mother would not want to be kept alive in her present condition.

"She has nothing left to give the world, and the world has nothing left to give to her," Ms. Kerley said.

Nearly a year and a half later, her mother is still alive, even though Ms. Kerley has declined liquid nutritional supplements, antibiotics and flu and pneumonia shots.

Her mother does not even hum anymore, and spends much of her time in a fetal position, except when she is at the dinner table. She can still walk, if led.

"If my mother had her own choice, she would have offed herself a long time ago," Ms. Kerley said. "There is no quality to her life.



GERIK PARMELE FOR THE NEW YORK TIMES

Kerley, 52, washes the hand of her 78-year-old mother.

“When she does go, it will be a blessing.”

Ms. Kerley has already arranged to donate her mother's brain and her own to Washington University. She seriously doubts that she will develop Alzheimer's. She is more like her father than her mother, she said, and she is the most educated person in

her family, reads constantly and stays in shape by swing dancing two to five nights a week. And her students keep her sharp.

“If you want to keep up with me until you retire, that's fine,” she said. “I'm betting I'm not going to have that problem.” □

COPING WITH ALZHEIMER'S ►►



ALEX QUESADA FOR THE NEW YORK TIMES

Programs like this in Palm Beach Gardens, Fla., with day care for Alzheimer's patients and children in the same building, have been found successful.

COPING WITH ALZHEIMER'S

Disease Brings Drastic Changes to Patients, and Stress to Family Members

By **DENISE GRADY**

PUBLISHED: DECEMBER 26, 2007

Family members are sometimes shocked and mortified to hear a relative with Alzheimer's disease blurt out uncharacteristic, awful remarks — swear words, racial slurs, bitter complaints about a spouse. Many cannot help wondering if the disease has peeled back inhibitions

to expose an ugly side that the patient was repressing all along. Was he or she a closet bigot, unhappily married, pleasant on the outside but hostile underneath? Or should the harsh words be dismissed as random sparks from sick and dying brain cells?

"To put a meaning on it is tough," said Dr. Steven T. DeKosky, director of the Alzheimer's

Disease Research Center at the University of Pittsburgh. "I think it's unfair. Half of what they say is so nonsensical to begin with, to impute lifelong suppression, I would doubt that. It's too Freudian for me."

Those episodes are just one example of the many painful changes that families struggle to understand and deal with as Alzheimer's progresses. The disease scrambles far more than memory. It plays havoc with mood, personality, perception and thought, and can require constant adjustments by friends and relatives just to keep life on an even keel. Calm, easygoing people may turn anxious and prone to fits of rage. Patients may wander and get lost, sleep by day and stay up all night, demand to drive when they no longer can, turn on an empty oven, refuse to bathe and accuse others of stealing items they have lost.

It is pointless to argue, correct, reason, explain or try to teach someone with dementia. Instead, experts say, agree, soothe and dis-

tract; enter the patients' skewed world and try to see things their way. Enjoy the sunset — the same one, six times.

But that is easier said than done, especially as exhaustion mounts, patience wears thin, and the disease only gets worse.

"It's very hard to give care with dignity to a severely impaired person who can't use the toilet and is frightened of anyone who tries to help," Dr. DeKosky said.

Dr. Richard Mayeux, a professor of neurology, psychiatry and epidemiology at Columbia University, and co-director of its Taub Institute for Research on Alzheimer's Disease and the Aging Brain, said relatives suffered enormous stress from not understanding the disease or knowing what to expect.

For instance, Dr. Mayeux said, a patient may tell a close relative: "I don't know who you are. Take me home." He recalled one patient who called her daughter, frightened because there was a stranger in the house — her husband.

"I spend more time with the caregivers than with the patients," Dr. Mayeux said.

For some, support groups for caregivers are a lifeline, along with adult day-care programs. Among the most successful are programs that let Alzheimer's patients spend time around children. In some communities, night-care programs are also available for restless patients, to give caregivers a chance to sleep.

Information for families is available from the Alzheimer's

Association, <http://www.alz.org>, 1-800-272-3900; and the Alzheimer's Disease Education and Referral (Adear) Center, <http://www.nia.nih.gov/Alzheimers/>, 1-800-438-4380.

Useful books include "The 36-Hour Day" (Grand Central Publishing, 2001), by Nancy L. Mace and Peter V. Rabins, and "Learning to Speak Alzheimer's" (Houghton Mifflin, 2003), by Joanne Koenig Coste and Robert N. Butler. □

THE RISK FACTORS ►►

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THE RISK FACTORS

When Both Parents Suffer Dementia, Children Suspect It Is Also in Their Future

By DENISE GRADY

PUBLISHED: DECEMBER 26, 2007

"I've seen a number of adult children that have not one but two parents with dementia," said Dr. Daniel I. Kaufer, a neurologist and director of the memory disorders program at the University of North Carolina in Chapel Hill. "It's like the perfect storm of dementia care."

"With the sheer numbers of people who are going to develop dementia, it's going to happen more and more," Dr. Kaufer said. He sometimes calls it "the double-parent dementia dilemma."

(The Alzheimer's Association does not track the number of couples in which both partners have dementia, a spokesman said.)

Some doctors wonder if the stress of caregiving somehow accelerates the mental decline of the second spouse.

The children must confront



PETER NEWCOMB FOR THE NEW YORK TIMES

Dr. John C. Morris is an Alzheimer's expert at Washington University.

their own increased risk. Having just one parent with Alzheimer's triples the risk; when both parents are affected, the amount of extra risk is not certain. The children of Alzheimer's patients "live in dread," said Dr. John C. Morris, director of the Alzheimer's Disease Research Center at Washington University in St. Louis.

Since 2003, both of Marjorie Hinsdale-Shouse's 84-year-old parents have been living with her and her husband in Chapel

Hill. Her father has advanced Alzheimer's disease, and her mother has mild cognitive impairment, a memory disorder that often progresses to full-blown Alzheimer's disease. Her mother had been looking after her father, but began to lose track of her own medications and was hospitalized twice as a result.

Ms. Hinsdale-Shouse's husband, Marshall Shouse, quit his job managing a supermarket meat department to take care of his wife's parents, while Ms. Hinsdale-Shouse works as a project manager for a research company. Her mother is easy-going, but her father has been difficult at times, she said, aggressive and strong enough to break door handles trying to get out. She has resorted to psychiatric medications to calm him and keep him from hurting anyone, but switched doctors when she realized he was taking multiple drugs that were not helping.

"Everything about living with dementia is like a roller coaster," she said. "Anger, anxiety, depres-

sion, calm, oversleeping, not sleeping at all. They cycle through. You can't even predict it."

She and her husband have considered nursing homes, but fear that the care might not be good, that her father could be injured by another patient and that his mind would disintegrate even faster. He was an actuary and the senior vice president of an insurance company, "a smart numbers guy and the epitome of a workaholic," she said. Now, he no longer speaks or appears to understand speech. Like an infant, he puts things in his mouth and grabs anyone who touches him. But his grip can leave bruises. He does not recognize anyone, but will return a smile.

"The saddest thing is to not have his brain, so smart, so kind, to see that person disappear," Ms. Hinsdale-Shouse said.

She and her husband think they are doing the right thing, but at times they feel overwhelmed.

"The most difficult time for me, and I wonder if we can do this or not, is in the middle of

night when you're cleaning up something, and you have to go work the next morning," Ms. Hindsdale-Shouse said. "I flash back to what my mom and dad were like when I was a little kid and they took care of me and it was unconditional, and I think that's what my husband does, too."

She cannot help wondering if

she will also wind up with dementia.

"When you have two parents with Alzheimer's, what else can you think about?" she said. "To me it seems inevitable. But that doesn't mean it absolutely has to happen." □

TESTING FOR ALZHEIMER'S ►►

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TESTING FOR ALZHEIMER'S

In the Absence of a Gene That Says 'Yes' or 'No,' the Value of One That Says 'Maybe' Is Questioned

By DENISE GRADY

PUBLISHED: DECEMBER 26, 2007

Genes play a role in Alzheimer's disease, but in most cases the role is not fully understood. In some rare forms of the disease, which start early in life, in the 40s or even younger, single genes have been identified that make Alzheimer's inevitable. In affected families, genetic tests can predict who will become demented.

But in the more common late-onset Alzheimer's, there is no single yes/no gene. Instead, researchers think a combination of genes work together, maybe with other risk factors like diabetes, diseased arteries or head injuries. Each gene merely adds to the risk. Few have been identified.

So far, the strongest influence comes from a gene called APOE, for apolipoprotein E. Everybody

inherits two copies, and each copy can come in one of three types, e2, e3 or e4. When it comes to Alzheimer's, e4 is bad. People with one copy of e4 have three to five times the risk of someone who has no e4, and those with two copies of e4 have about 15 times the risk.

But APOE is by no means definitive. Many people with e4 never become demented, and more than a third of Alzheimer's patients have no e4.

Because of the uncertainty, the medical profession, the Alzheimer's Association and genetic counselors have for years steadfastly advised against APOE testing, saying that the results are not definitive and if misunderstood could be needlessly upsetting, especially since there is no way to prevent or cure the disease.

But researchers decided to test those concerns, in a study called Reveal, in which people who have a close relative with Alzheimer's are told their own APOE status, their risk of developing Alzheimer's (which usually ranges from 13 percent to 57 percent) and how their risk compares to that of the rest of the population. The study has been under way for seven years.

"What we've been showing is that we can disclose APOE to people who are interested and they do not seem to have a whole lot of ill effects," said Dr. Robert C. Green, a director of the study and a professor of neurology, genetics and epidemiology at Boston University. "There is some temporary increase in distress at six weeks, but at six months it's gone."

Some want the information to make financial and legal arrangements in case they become demented, and some who find out that they have e4 start trying to take better care of themselves. Not surprisingly, those who find out they do not have

e4 are relieved, even though it does not guarantee that they are in the clear.

"Not everyone wants to know, but the people who want to know really want to know, and they have their own reasons," Dr. Green said. "I think it's a little patronizing for the medical establishment to say, 'We could give you that test, but we don't think you can handle it.'"

When the study began, he said, the idea of disclosing APOE information was extremely controversial, but the landscape has been changing quickly, as more and more genetic tests become available and private companies spring up on the Internet to sell them to consumers — not definitive, predictive tests, but just estimates of risk for heart disease, diabetes and other ailments.

"People are eventually going to understand that genetic risk factors are just risk factors, not determinants," Dr. Green said. "I think this blanket resistance to APOE exposure is not going to last too much longer." □