

DISEASE STATE MANAGEMENT™

Managing Chronic Illness Across the Continuum

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Physicians slow to intervene with high-risk patients

Cholesterol screening done only half the time

No medical professional would dispute the voluminously documented benefits of exercise, improved diet, smoking cessation, and cholesterol screening for millions of Americans with coronary heart disease.

Yet a recent study published in *Circulation*, the journal of the American Heart Association, shows physicians are woefully deficient when it comes to assessing patients for risk of heart disease and showing them ways to save their own lives. The same is true for physicians treating patients in heart failure, say specialists in that field.

Five years after the National Cholesterol Education Program guidelines recommended widespread screening for cardiovascular risk factors and treatment of high cholesterol, a study led by **Joseph Frolkis**, MD, PhD, of the Cleveland Clinic Foundation showed physicians do cholesterol screening only half the time, even in high-risk patients, and counsel patients in preventive measures even less frequently.

Frolkis' team reviewed the charts of 225 patients in the coronary care unit of a major teaching hospital during the first half of 1996 and found that, of eight possible risk factors listed in the 1993 NCEP guidelines, medical professionals screened, on the average, for 2.4 of them.

KEY POINTS

- Physician counseling on preventive measures is done less than half the time.
- Many physicians are "miscommunicating activity expectations" for CHF patients and still telling them to rest, take naps, and lie around in bed.
- Patients are advised to cut salt, but are often not referred to a dietician, forcing them to figure out a new diet on their own.

Nancy Albert, MSN, RN, CCRN, CNA, clinical nurse specialist for heart failure and transplantation at the Cleveland Clinic Foundation was not connected with the Frolkis study, but she says the conclusions translate well to patients in congestive heart failure.

“From a heart failure and noncompliance standpoint, there are a lot of physicians out there who aren’t good about following the [two sets of] guidelines that have been set out for heart failure,” Albert says.

Many physicians are “miscommunicating activity expectations” for CHF patients and still telling them to rest, take naps, and lie around in bed. “We get patients all the time who tell us their doctors tell them not to exercise. We encourage exercise.

“From a diet standpoint,” Albert adds, “a low-sodium diet is expected for heart failure patients, but they aren’t referred to a dietician for counseling, so patients are forced to figure it out on their own. And physicians aren’t very good about getting very specific.”

Sidney C. Smith Jr., MD, past president of the American Heart Association and professor and chief of cardiology at the University of North Carolina at Chapel Hill, says studies on patients with congestive heart failure “show a similar lack of utilization of newer therapies such as ACE inhibitors which could significantly improve outcome for these patients.”

In addition, heart failure patients, like patients with heart disease, often benefit from lowering cholesterol, dietary changes and smoking cessation. The results of Frolkis’ study complement what needs to be done with CHF patients as well, experts say.

Why are physicians failing to do the recommended screenings?

The Frolkis study points the finger at three “powerful negative incentives” for doctors:

- increasingly limited amount of time a physician is permitted to spend with a patient;

- a lack of reimbursement by insurers;
- lack of training during medical school.

Frolkis told Reuters News Agency, “The data is there that prevention works. By and large, physicians are very bright and very caring and they still don’t do it — that’s what’s so peculiar.”

Physicians treating patients with congestive heart failure are similarly remiss, Albert says. And with rapid developments in the field, particularly since the advent of ACE inhibitors and beta blockers in the past decade, some physicians simply haven’t kept up.

“Physicians who don’t do heart failure for their livelihoods are perhaps too conservative with drugs, so they don’t use the therapies to their maximum,” Albert says. “Most do a good job of starting ACE inhibitors, for example, but they do a bad job of getting it up to the target dose. The symptoms go away, but the heart failure is really worsening.”

Beta blockers critically underused

The situation is even more serious with beta blockers, she says. For some physicians, it is easier not to start the beta blockers than to do the intensive in-office monitoring necessary. And that is quite clearly costing lives, Albert says: “Beta blockers, carvedilol especially, can cause a 67% reduction in heart failure mortality when added to the other three big drugs we use on just about everybody.”

To one of the Frolkis study’s authors, **Pamela S. Suhan**, RN, MBA, CCRC, clinical research coordinator at Cleveland Clinic, the time pressure doctors find themselves under is driving the noncompliance with the NCEP guidelines.

“They are so limited by the time. I don’t know how much time docs have, depending on the practice. One cardiologist I know is supposed to see a patient every six minutes. How can you even do a follow-up in that time?”

A high percentage of the coronary care unit

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patients in the Frolkis study were never screened for major coronary risk factors:

- One-quarter were not screened for previous heart disease.
- One-third were not tested for high blood pressure.
- More than 40% did not have cholesterol levels checked.

Of other heart risk factors, physicians screened even fewer:

- Only 37% were screened for diabetes.
- Eleven percent were screened for hormone replacement therapy.
- One percent were screened for premature menopause.

Exacerbating the problem, only an infinitesimal number were counseled to eliminate behavioral risk factors:

- Four percent were counseled to stop smoking;
- Fourteen percent were sent to a dietician for assistance in diet modification.
- Only 1% were encouraged to exercise.

By way of contrast, interns at the teaching hospital did relatively well in screening, but even they inquired about only two risk factors, (a history of heart disease and smoking) 70% of the time.

Why? To Suhan, it's a chain of events from bottom to top.

Suhan says interns take histories and sometimes do counseling, then a resident and finally the cardiologist look at the notes and think the counseling has been done.

"Everybody thinks someone else is doing it" when in the end, often no one is, Suhan says.

Strike while the iron's hot

Suhan says another factor is patient noncompliance or lack of education. In those cases, she says, she is an advocate of what she calls the "fear factor."

"We need to hit them while they're in the hospital," she says. "If you get somebody when they have had an event and say, 'Listen, you had this event because your cholesterol is high. We need to get it down and this is how we're going to get it down,' you've made an impact and it is indelible because you've got them when the fear is high."

If doctors followed the guidelines religiously, experts agree than a significant number of the half million deaths of Americans each year from CHD could be prevented, not to speak of the

\$100 million in medical costs that might be saved.

"At a time when cardiovascular disease is the leading cause of death and disability for our society, and at a time when there are so many new promising medications which could alter this toll, it is extremely important that we examine our health care delivery systems, our educational systems and practice patterns to ensure that preventive therapies and medical therapies with patients having significant disease are provided," Smith says.

Suhan, herself an RN, favors a team approach with nurses and other health professionals performing most of the screening and counseling. She says nurses performed even better than interns in many cases in following the NCEP guidelines, and nurses are expected to move into increasingly responsible roles in the management of clinics and practices under physician supervision.

"The nurses have a care plan, a database they follow through. Nurses have a standard set of questions. They have to ask about medications, certain history questions. Doctors don't use a checklist, they just file progress notes," Suhan says.

She also suggests nurses may be doing more counseling than records reflect. "When I talked to the nurses, they say they always counsel

Guidelines for CHF Patients

- Low-sodium diet (3,000 mg of sodium per day for patients with moderate heart failure, 2,000 for patients in severe heart failure).
- Moderate exercise.
- Daily weighing (see doctor immediately with 2 pound weight gain in a day or 5 pounds in a week).
- Fluid management with consumption at a maximum of two liters of fluid a day.
- Medications must be continued, even when symptoms are not present.
- Get flu vaccine in the fall.
- Get pneumococcal vaccine once in a lifetime.
- Patients should not be on prostaglandin inhibitors (nonsteroidal anti-inflammatories like Aleve, Advil, Motrin, or generic ibuprofen, which cause sodium retention).

patients on smoking. I said, 'If you always do, why, in a six-month period, only one person was documented?' The reply? "We must not be charting it."

"If it's not charted, it's not done," Suhan says. "It was a shame."

To rectify a bad situation, Smith favors massive education at all levels — and high-level pressure on managed care companies.

"The American Heart Association has initiated a major campaign to make physicians and patients more aware of the benefit of these therapies. Public education is very important. We are also working with managed care at a national level to see that funding is made available," he concludes. ■

The great salt debate rages on

Counseling patients when there are no definites

While it may be the salt of life, for decades doctors have admonished hypertensives they must reduce their sodium intake in order to lengthen their lives. No ifs, ands, or buts about it.

But now the great salt debate is once again swirling through medical circles as the waters are muddied by emerging evidence that sodium chloride may not be as bad as we've all believed.

The bitter debate has set researchers against one another, amid accusations one side is intractable and the other side has sold out to the salt lobby.

While dozens of studies have looked at the connection between salt and heart disease and high blood pressure, their methodology and interpretation are under fire.

"In the last 20 to 25 years, things have changed greatly in terms of what we know," says **Sanford Miller**, PhD, dean of graduate studies for biomedical sciences at the University of Texas Health Science Center in San Antonio, and perhaps more significantly, director of food safety and applied nutrition at the U.S. Food and Drug Administration 20 years ago, who helped set federal salt consumption recommendations.

"Back then even, the data were not overwhelming," Miller says. "There were some studies that showed substantial effect, some that showed very little effect and other experiments that showed no effect. . . . But 25 years ago, we didn't have any other data so [the group of researchers] agreed that of all the things we knew about coronary artery disease and hypertension, salt was a pretty good thing to take a shot at, because reducing salt intake wasn't going to hurt anybody."

The National Heart, Lung and Blood Institute urges a maximum salt intake of 2,400 mg a day. That's 50% to 75% less than the average American consumes. While the human body only needs about 500 mg daily as a nutrient, researchers are puzzled about the human desire for amounts as great as 12 times what the body needs. Many experts have pointed to the amounts of salt added to baby food which may contribute to a lifelong acquired taste for salt.

Although Miller is far from becoming a turncoat to the legions of salt cautionaries he fostered 20 years ago, he now believes that society is composed of "salt sensitives" and "salt-insensitives."

"If you do a study that has a number of people who are salt-sensitive, you get an effect of reducing sodium. If you do a population that has a larger group of salt-insensitive people, you don't get the effect," Miller says, while at the same time saying a reduction in salt intake is a good idea. "People ought to be conscious about how much sodium they use, but I don't think they ought to be spastic about it."

Identify salt-sensitive patients

Rather than a blanket admonition to avoid salt, Miller recommends identifying salt-sensitives through urinalysis, sodium levels in blood and a variety of means, then making recommendations on salt consumption based on test results.

Edward J. Roccella, PhD, MPH, coordinator of the National High Blood Pressure Education Program in Bethesda, MD, considers himself a traditionalist in the salt debate.

"When we look at the preponderance of the evidence, we know that there's a relationship between salt intake and a rise in blood pressure," says Roccella.

Roccella, who concedes the strength of the effect of salt on blood pressure is in question, says his viewpoint is based on broad public health considerations rather than specific effects

Milestone Studies and the Pluses and Minuses

Date	Name	Supports/Debunks Salt-BP Link	Comments
1972	Dahl et al	supports	rats were fed equivalent of 500 mg/day — irrelevant for humans
1973	Gleiberman et al	supports	less than half her ecologic studies actually tried to measure sodium intake
1979	Cooper et al	unsure	suggests “not wholly negative” relationship
1984	McCarron et al	debunks	says salt is harmless, criticized for ignoring data to the contrary
1988	Scottish Heart Health Study	debunks	criticism: 7,300 population sample was not large enough
1988	Intersalt	weak or no relationship	failed to confirm primary hypothesis of relationship; infers relationship as subjects age
1996	Intersalt	revisited statistical reanalysis	criticism: rife with mathematical errors, based statistical corrections on unsupported data association
1991	Cutler et al	supports	authors say relationship is causal based on large body of consistent, strong evidence
1991	Law et al	supports	says link is substantially higher than previously thought; criticism: work is flawed because it excluded Intersalt and used poorly controlled, biased interpretations
1996	Midgley et al	debunks	benefit from salt reduction is small
1997	Cutler et al	supports	benefit from salt reduction is larger than originally thought, supports dietary recommendations
1997	TOHP II	mixed	long-term reductions result in little or no blood pressure reduction; short term reductions were temporarily effective
1997	DASH	debunks	dietary factors other than sodium have greater effects on blood pressure

on individual patients.

“A reduction of 2 or 3 mm of mercury isn’t much to an individual patient,” he says. “But spread out over a large population, 2 mm of mercury or so could mean a reduction in strokes of 12% on average in the population.”

A large part of the debate seems to center around the conflict between laboratory sciences and public health sciences.

Miller says, “Public health science is concerned with assuring human health. It will decide to accept a set of data as being sufficient to taking public health action if there is some indication it might help and there is a lot of indication it won’t hurt anybody. Laboratory science has a much more rigorous set of standards to assure scientific certainty.”

In its August issue, *Science* magazine surveyed

80 researchers and found a wide divergence of opinion on both sides of the controversy: "This has led to a literature so enormous and conflicting it is easy to amass a body of evidence . . . that appears to support a particular conviction definitively, unless one is aware of the totality of data that doesn't."

The evidence of the beneficial effects of reducing salt intake in hypertensives has been somewhat muddled because accompanying dietary changes also are likely to affect blood pressure.

"Choosing low-salt foods, for instance, inevitably leads to changing other nutrients, as well, such as potassium, fiber, and calories," reports the *Science* article.

And some experts say that harping on the benefits of salt reduction among patients who are notoriously lax in compliance with physician guidelines may actually cause them to be more resistant to other known beneficial behaviors such as weight loss and healthy diets in general.

Roccella emphasizes that NHBEP has never touted salt reduction as a panacea. "We've also advocated increased physical activity, losing weight if the patient is overweight, decreasing alcohol consumption . . . increasing potassium intake. There's no silver bullet. If there were, we'd just say, 'Do it.'"

Despite their fundamental differences on the value of salt reduction on hypertension, the opposing sides come together on the basic issue of a healthy level of salt consumption.

Teaspoon a day is reasonable

Roccella and Miller agree that 2,400 mg of sodium per day, a little more than a teaspoon, is reasonable.

Roccella says, "We're all talking about a goal, an upper limit of 2,400 mg, which is a lot more than the minimum daily requirements of 500 mg."

Miller echoes, "There's no reason for people to consume as much salt as people tend to consume. But if you want to add a little salt to the boiling of spaghetti or put some salt on fresh tomatoes, a little salt isn't going to hurt you."

Compliance is a perennial problem, particularly in hypertension, where guidelines call for lifelong dietary changes. The difficulty of compliance is compounded by the large amount of salt in processed foods. According to Roccella, about 80% of our daily salt intake comes from processed foods. That means simply removing

the salt shaker from the table is not the answer to bringing salt consumption within the guidelines.

The NHBEP is lobbying the food industry to reduce the addition of salt to virtually every type of processed foods.

"We are pleased with the progress food manufacturers are taking," says Roccella. "And they are making small but progressive reductions of salt in the food supply. When we went up to Pillsbury, we saw they are reducing salt in their processed foods."

Food manufacturers have told the NHBEP the reduction of salt in processed foods, including baby food, will be driven by consumer demand and they will do so gradually so it is not noticeable and foods don't taste flat.

And finally, Roccella says, "People have got to make some choices. We're asking them to consider herbs and spices to increase the flavor of food. They can choose fresh or frozen and they can choose food lower in salt by reading the label." ■

Extend Alzheimer's care from hospital to home

Boston hospital finds care continuum works best

Alzheimer's patients and their families will cope better with the devastating disease if they are treated by a multidisciplinary team that continues care into the home, experts say.

"You need a large team to deal with the complex issues, the psychosocial issues, and an internist with 15 to 20 minutes to see a patient cannot deal with those issues," says **Juergen H. Bludau**, MD, medical director of Morse Geriatric Center in West Palm Beach, FL. Bludau also is a member of the Harvard Division on Aging in Boston and is an instructor of medicine at Harvard Medical School in Boston.

Bludau spoke about the critical need for a multidisciplinary team approach with Alzheimer's disease patients at the Seventh Annual Alzheimer's Disease Education Conference, held in Indianapolis this summer.

As part of the continuum of care, the team will refer cases to home care for home safety

assessment, education, and some other aspects of treatment.

The ideal multidisciplinary team includes a geriatrician or internist, a nurse practitioner, a social worker, a geriatric psychiatrist, a behavioral neurologist, and a neuropsychologist, says Bludau. Until recently, Bludau had been a part of such a team at Youville Hospital & Rehabilitation Center in Cambridge, MA.

"In the team setting, we first diagnose what type of dementia a person has and treat accordingly," Bludau says.

Then the team addresses any specific behavioral issues and provides ongoing primary care for the patient, while the social worker educates the family.

It's becoming a little more difficult in light of changes brought about by the Balanced Budget Act of 1997 for home care agencies to seek reimbursement for care of Alzheimer's patients.

If the patient's only diagnosis is dementia, Medicare will say the patient does not need skilled nursing care, says **Karen Dick, PhD, RNC**, director of Beth Israel Deaconess Medical Center Home Care in Boston.

"It may be hard to justify home care if the patient's in early stages of the disease," Dick says.

When the agency receives a referral of an Alzheimer's patient, the staff assess the case closely to decide if Medicare will reimburse for home care services. "We're hospital-based and are able to absorb some of the visits that are not covered," Dick says. "But what often happens is these patients have other unstable conditions besides dementia."

So it's important, Dick suggests, for the home care agency to handle referrals in these ways:

- When a physician or multidisciplinary team makes a referral, the agency should obtain as much of the patient's medical history as possible and ask about secondary diagnoses, Dick says.

Alzheimer's patients often have other, unstable medical problems, such as gait impairment, heart disease, and diabetes. "They may have been hospitalized and need a follow-up," Dick adds.

"We ask the referring person to say to us, 'What is it you'd like us to do? What is your greatest concern?'" Dick says.

- If the physician or team would like home care only to provide a home safety assessment, then the agency could send a physical therapist into the home. The physical therapist could meet Medicare guidelines by providing several

services: safety assessment, safety education, and interventions to make the home safer, Dick says.

Bludau says the safety evaluation is essential, especially in the early stages of the disease when patients still might be driving a car. The potential for fires and falls also need to be assessed.

"Medicare won't pay for an evaluation visit, so we have the physical therapist go out there and do interventions, teaching, and an assessment of the home," Dick explains.

- Check to see if the patient's medications have been changed or if the patient needs therapy to maximize the patient's functional ability.

- Clearly document how the patient is homebound. Alzheimer's patients may not have physical limitations that prevent their leaving the home. But many are homebound because they are afraid to leave the home, or they are unable to leave the home for their own safety.

Once it's determined that Medicare will pay for home care services, then the home care staff become part of the patient's continuum of care.

The multidisciplinary Alzheimer's disease team serves the patient in four domains, Bludau says. Home care may be involved with all of these areas. They include medical care, monitoring the patient's daily activities, psychosocial issues, and patient/caregiver education. (**See story on four domains in serving Alzheimer's patients, p. 128.**)

Dick says the home care team has many case conferences with the hospital team and relies on e-mail to keep physicians updated on cases.

"We make sure everyone agrees on a plan and that we have backup support," Dick says. The agency also may use a hospital psychiatrist and nutritionist who have dedicated hours to the home care agency.

"Our job is to keep the patient stable and out of the hospital," Dick says. "But it's getting more difficult to justify the care and to get paid for it, so we're trying to find alternative payment sources and even have some families pay us privately."

[For more information on multidisciplinary care for Alzheimer's patients, contact:

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Alzheimer's care encompasses four areas

Home care agency finds it takes team approach

Hospital-affiliated home care agencies could be an essential part of a multidisciplinary team that treats Alzheimer's disease patients, experts say.

Home health staff may assist a hospital Alzheimer's team in all four domains of care for these patients, providing a continuum of care that ideally will reduce patients' future hospitalizations. The home health component also helps families cope emotionally and physically with the demands of caring for these individuals.

"Our job is to visit the home and see what kind of support the patient has and to make sure everyone is working together," says **Karen Dick**, RNC, PhD, director of Beth Israel Deaconess Medical Center Home Care in Boston.

Health care providers need to understand that Alzheimer's disease patients need more care than one physician can provide, says **Juergen H. Bludau**, MD, medical director of Morse Geriatric Center in West Palm Beach, FL.

Bludau says Alzheimer's patients need these four different domains of care:

1. Medical treatment.

The team provides some of the patient's medical care, including treatment of any inter-current illnesses, regular health maintenance exams, and assessment of visual and hearing deficits, which may exacerbate behavioral issues.

"We follow patients in the acute and subacute settings," Bludau says.

Home care also is involved. "The most important people are the visiting nurses," Bludau says. "If a person is just not eating right . . . then that could be the sign of an underlying pneumonia or urinary tract infection [URI]."

It's up to the home care nurse to tell the Alzheimer's team that something seems to be wrong with the patient, and perhaps they could see the patient.

"It could be the person is tired or weaker and is just not herself, and this could be a simple viral flu or URI," Bludau adds. "Diseases present themselves differently in elderly people who have cognitive impairment."

2. Activities of daily living.

The team focuses on monitoring the patient's activities of daily living and teaching the patient how to develop memory strategies. The team teaches the family how to deal with stressful situations.

"By the time the families arrive in the office, they're frantic and worried," says **Kathy Lyman**, RNC, GNP, a geriatric nurse practitioner for Beth Israel Deaconess Medical Care Center in Boston. Lyman provides case management for Alzheimer's cases.

"It's sort of like when patients are discharged from the hospital; they are too anxious and don't hear everything that's being said," Lyman explains.

The patient also may be referred to home care so nurses or physical therapists can assess the home for safety and teach the family how to help the patient avoid accidents.

When the home care physical therapist visits, he or she might observe some undiagnosed problems that need to be reported to the physician, Dick says. "We might say, 'This person could benefit from six months of therapy to improve his gait.'"

The home care nurse might be asked to observe the patient after a new medication has been prescribed. Often, physicians prescribe chemical restraints for Alzheimer's patients, to control their restlessness and wandering. The home care nurse would talk to the family about the medications and make sure there is someone to cue the patient to take the pills.

3. Psychosocial issues.

The team then addresses the psychosocial, legal, and ethical issues involved in care of Alzheimer's patients. For example, team members might ask the family to think about placement options once the patient reaches advanced stages of the disease.

"The secret to handling Alzheimer's patients is to have the appropriate caregiving style and caregiving environment," Bludau says. "Since you can't change the disease, you change the environment and caregiving style to suit these clients."

Sometimes the team will encourage caregivers to give up some of their control over the patient's life, Lyman says.

"This might be to convince a wife to agree to send her husband to day care in the mornings," Lyman says.

Ultimately, the team may have to firmly tell the family that the patient needs to be institutionalized, and this psychosocial issue could be one of the toughest. "We try to help families understand that this doesn't absolve them of their responsibility for caregiving, and that placement isn't the death knell they often think it is," Lyman says.

The home care team, which also includes a psychiatrist and psychiatric nurse, meets bi-monthly to review cases, Dick says. If the family is concerned about the patient's unstable behavior, then the psychiatric nurse might visit the family to help them deal with the problems.

The home care staff also will try to assess what kind of support systems and community resources would help the patients and family, Dick says.

4. Family education.

Finally, the team educates the family about medications and side effects, disease progression, and signs and symptoms of other illnesses the patient might have. Family members are told how to manage the patient's difficult behaviors.

The Alzheimer's team teaches families how to change patients' behaviors by redirecting their attention, Bludau says.

The idea is to bring on positive emotions in the Alzheimer's disease patient. Many experts now believe that trying to reorient the patient does not work. Instead, the caregiver needs to accept the patient's reality and try to direct his or her attention to something else. This is called habilitation, Bludau says.

For example, suppose an Alzheimer's patient wants to leave the house in the middle of the night. It doesn't help for a family member to say, "No, are you crazy?" or, "This is ridiculous!" The patient will only become angry or upset and continue to insist on leaving the home.

What may work, however, is for the family member to say, "Let's rest for a moment, then we can do whatever you wish," Bludau suggests. "Then, by the time you sit down and talk with them, they forget they wanted to leave the house."

Lyman often tells family members that the Alzheimer's patient's bad behaviors are not the patient's fault. "They're not to be held accountable for their behavior changes that become manifest with anger, mood changes, disinhibition, or anything that is so troublesome for the family," she says.

"We try to help the family understand that

this is an illness and not willful on the patient's part," Lyman adds.

When family members reach a crisis point or have questions about the patient's behavior, they may call the team for help. Lyman often speaks with families over the telephone, and occasionally she'll visit their homes.

Home care staff will reinforce the education, showing families how to handle the patient's feeding, bathing, dressing, mobility, medications, and safety issues.

So far, the hospital and home care agency have not collected any statistics to show if the multidisciplinary team approach and continuum of care have had a positive impact on patient outcomes. But anecdotal evidence suggests it has, Dick says, and certainly the clients are satisfied.

"We call and ask if they're satisfied, and generally they're very positive and appreciative of the care that's provided," Dick says.

[For more information on Alzheimer's care, contact Kathy Lyman, RNC, GNP, Geriatric Nurse Practitioner, Beth Israel Deaconess Medical Care Center, 330 Brookline Ave., Boston, MA 02215. Telephone: (617) 667-4580.] ■

Disease management unique to each facility

Start process by developing goals and objectives

There is no 'blueprint' for a disease management program, says **Michael Tocco**, RPh, MEd, president of ICPR: Integrated CARE Group in Waltham, MA. Each program must be tailored to fit the disease and the managed care organization or health care facility for which it is designed. However, there are common components in any successful disease management program that should be evaluated for inclusion in your particular one, he says.

"The path an organization follows to a successful disease management program will vary, but fundamentally the components — patient registries, treatment algorithms, provider and patient management, measurement and quality improvement plans — are the same," says Tocco.

Tocco, who has set up several disease management programs for various organizations, advises

health care facilities to begin by setting up a core working group that will oversee the entire process. Members would include an administrator, a primary care physician, a specialist in a target disease state, a pharmacist, and a nurse.

The core group establishes the goals and objectives for the program. "You must articulate what you want to accomplish before you start," explains Tocco. This group also would select members of the full planning committee that would include all disciplines involved in the care and education of a patient for the target disease.

For example, if the disease management program is for diabetes, a dietitian or nutritionist may be included on the committee; for a depression program, a psychiatric nurse may be on the committee. The committee's membership will differ with the disease.

Once the core team has established both the goals and objectives and the committee, the process of developing a program begins. Following are five steps Tocco suggests be included in the development of a successful disease management program.

Step One: Develop a registry of patients based on agreed-upon criteria. The purpose of the registry is to identify patients who are currently diagnosed or treated for a specific disease and to create a benchmark against which to evaluate the effectiveness of the program. This process also could be used to create a method to screen patients for a specific disease.

Step Two: Develop treatment algorithms or protocols. A protocol provides guidelines for the treatment of a patient with a particular disease. An algorithm offers various options at each step of the treatment process. "I see a protocol as a specific treatment process for a physician to follow, such as cookbook medicine, whereas an algorithm is more of a decision tree offering options that may be available to the physician. Hence the art of medicine is left to the physician," says Tocco.

Step Three: Develop provider and patient management tools. These tasks could be assigned to two separate subcommittees. The health care providers must learn how the complete program works. For example, providers need to understand how the patient registries work, how to use the algorithm, when to refer a patient to a specialist, and how to monitor the patient. The patient education committee would develop tools to educate the patients about how they can participate in their treatment.

Step Four: Develop a method to measure the effectiveness of the program. For example, a committee developing a depression management program might decide to monitor whether the screening and diagnosis methods suggested in the algorithm are uncovering more patients suffering from depression at an earlier stage of the condition.

Step Five: Develop a quality improvement plan that ensures the program keeps abreast of new treatments and medications.

[For more information on setting up a disease management program, contact Michael Tocco, RPh, MEd, President ICPR: Integrated CARE Group, 255 Bear Hill Road, Waltham, MA 02451-9392. Telephone: (781) 890-3434. Fax (781) 890-2766. E-mail: tocco@icpr.com.] ■

Self-help focus of fibromyalgia courses

Tailor information to specific needs of patients

Six years ago when the Mayo Clinic in Rochester, MN, launched a course for patients with fibromyalgia syndrome, the chronic condition was not well-known even within the medical community. Today this 90-minute class is scheduled every weekday at 3:30 p.m. and Mayo is opening a fibromyalgia center designed to specifically treat patients who have been diagnosed with the syndrome.

"People with fibromyalgia do better in a group setting for they need to know that others can identify with what they have because it is so unique, complex, and difficult. They have gone through a lot to get the condition diagnosed," says Marilyn Smith, RN, MS, program coordinator for the Mayo Patient and Health Education Center.

Fibromyalgia is a form of soft tissue or muscular rheumatism that causes pain throughout the body. About 90% of people with the condition experience moderate or severe fatigue, lack of energy, and decreased exercise endurance. Changes in mood are common and many feel "blue."

Headaches and abdominal pain, bloating, and alternating constipation and diarrhea are

common. The skin and circulation are often sensitive to temperature and moisture changes and some people have numbness and tingling in various parts of their body

The Atlanta-based Arthritis Foundation also recognized the special needs of people with fibromyalgia by creating a fibromyalgia self-help course. Although fibromyalgia patients were enrolling in the arthritis self-help course, they wanted more in-depth information on their condition and certain issues unique to fibromyalgia were not being adequately addressed, explains **Michele Boutaugh**, BSN, MPH, vice president for patient and community services for the Arthritis Foundation.

“Fibromyalgia patients felt there was value in just being with people who had been diagnosed with fibromyalgia and who understood the unique patterns of the disease,” she says.

The need for a course that addresses the special concerns of fibromyalgia patients is great, agrees **Christine Marschinke**, RN, BSN, who co-authored *The Fibromyalgia Survivor Course* with Mark J. Pellegrino, MD. “The goal of this course is to help patients cope as effectively as they can and empower them to function as independently as possible with their fibromyalgia,” she explains.

People need to understand what fibromyalgia is, its signs and symptoms, and related conditions. “They need to know what the syndrome entails and what is going on with their bodies. They hurt and are fatigued but they look so good on the outside,” says Marschinke.

Focus on management techniques

Once people understand what is happening in their bodies, they can learn coping skills and ways to manage the symptoms, says Marschinke. For example, patients need to identify their baseline of pain and how they can help control pain flare-ups. They might try alternative medicine like chiropractic or biofeedback. Certain kinds of drugs, vitamins, or herbs might also help their condition.

“Patients can’t expect one thing to work. It’s like having several pieces to a puzzle,” she explains. “Each individual has to work with their doctor to make that puzzle complete so they can function at their best.”

In the course taught at the Mayo Clinic people are told that there are things they can control and things they can’t control in their life. They focus

on the “can control” and spend time learning strategies to improve their quality of life.

For example, they learn proper posture so they are not straining or fatiguing muscles. “Fibromyalgia patients have a very narrow path to follow. If they have bad posture it will add to their fatigue and pain so it is important to know the proper posture for standing, sitting, and lying down,” says Smith.

Also, they are taught a breathing technique for relaxation and encouraged to practice it at home a couple of times a day whether or not they feel stressed. Many times, fibromyalgia patients don’t recognize the level of stress they are under, or the tension in their muscles, explains Smith.

It’s important for patients to do more than just sit and listen to the information. They need to set goals. For example, instead of just planning to exercise they should set a goal to walk two minutes a day three times a week, says Smith.

In the course created by the Arthritis Foundation, participants agree to make specific

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changes in their life based on the information they have learned in the lesson.

"Each week participants share how difficult it was to make the change and whether or not they succeeded. The group interaction is important," says **Karen Downey, RN**, Arthritis Foundation Fibromyalgia Self-Help Course leader and trainer. Participants help each other. For example, if one person didn't succeed, the other group members can offer suggestions based on what has worked for them, she explains.

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