

THE PATIENT CHANNEL PRESENTS-Chronic Care:Improving Quality of Life

As we get older each of us will confront some aspect of chronic care. Being armed now with the right information will help you to avoid problems later on.

Hello. I'm Dr. Bruce Dan, Executive Director for The Patient Channel.

Our program, Chronic Care: Improving Quality of Life will detail the many options available to you including how to choose the best professional care, and the right place to get it.

Narrator

Twenty years ago, while in her forties, Toni McKinley worked in a bank and was raising two teenage boys with her husband, Ed. With an active social calendar and lots of travel, it was by all accounts, a busy and good life. But about that time, Toni started experiencing pain....

Antonia McKinley, Arthritis Patient

"I was feeling pain in my wrist and my shoulder and every time someone would go to shake my hand or I would go to touch – I could not. I would back off or touch my shoulder hugging. I could not hug anyone."

Narrator

After seeing several specialists and extensive testing, Toni was diagnosed with Rheumatoid Arthritis, a chronic condition. Relieved she didn't have an immediately life threatening illness, Toni says initially, she had no clue how devastating this news would be.

Antonia McKinley, Arthritis Patient

"And I looked at her and I said, 'You brought me in here today just to tell me I have Arthritis—and I didn't sleep all night for the fear of having cancer and then she really got angry with me because I didn't understand and she explained it all. She did say I would not be able to work and I kept telling her you're crazy. I have a job and I love it.'"

Narrator

Within a few weeks, Toni was forced to quit her job because it was now too painful to use a computer or adding machine for her administrative work. It was then that Toni realized the gravity of her situation. After dealing with a brief depression, she and Ed knew they needed to create a new plan for the rest of their lives. Life would no longer be the same for anyone in the family.

Edward McKinley/ Caregiver

"I had to make some decisions, in terms of my employment. Do I retire? Do I leave? Do I get a job somewhere else? And, I had always talked about retiring early but you know it's one thing to talk about it and another thing to do it. But I did. I just came to the conclusion that for her benefit we just had to get to a warmer climate."

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Narrator

The McKinley's are not alone in their experience or reaction. Chronic conditions are a fact of life for an estimated 99 million Americans today. Of these, 41 million people have their daily activities limited in some way because of their condition, and 12 million are unable to live independently. Longer life spans and an aging population, along with new diagnostic and treatment technologies allow more patients to survive acute life and death circumstances and are thereby, contributing to the increasing chronic disease population.

Natural Sound: "Having more trouble with my shoulder and my back, the bone at the back of my neck"

A chronic condition is a long-term or permanent illness with no known cure and may include Heart Disease; Strokes; Hypertension; Diabetes; Cancer; Emphysema and Bronchitis; Arthritis; Autoimmune Diseases, such as Lupus; Depression; Hip and Other Fractures; Kidney Disease; Alzheimer's; Multiple Sclerosis; and Parkinson's. Such illnesses can and do kill but more often are a burden that people carry from middle age through old age.

Gail Cooney, M.D./Medical Director/ Hospice of Palm Beach County

"An acute medical illness is an event, appendicitis, pneumonia. It's treated and it goes away and your life resumes where it began. With a chronic illness it stays with you over a period of not days or weeks but months and even years and as such chronic illnesses affect not just the way our physical health is on a daily basis but also the way our emotional, spiritual, and psychosocial health goes on."

Narrator

It is a burden Beverly Davis has been living with for the past twenty years.... that's when she was diagnosed with Lupus, a potentially debilitating chronic condition. Beverly still gets emotional when she talks about her illness.

Beverly Davis/Lupus Patient

"When I was first diagnosed they weren't sure what the problem was. I had swelling in my ankles, my knees. I couldn't bend and it was just all the joints and I had inflammation but again to look at me, you really couldn't tell there was a problem."

Narrator

But there was a problem and it would change her life forever.

When someone is diagnosed with a chronic illness, life changes. Up next, we'll explain how to get the best treatment. Stay tuned.

Narrator

When the seriousness of the illness became clear, Beverly and her husband, Wayne, knew they had to really understand what they were dealing with if they were ever going to maintain any control over their lives.

THE PATIENT CHANNEL PRESENTS-Chronic Care:Improving Quality of Life

Wayne Davis/ Caregiver

“She couldn’t do anything. She couldn’t walk. She couldn’t get up to go to the bathroom. We helped her.”

Narrator

To receive the highest quality of care possible, it is critical for patients and caregivers to understand the chronic illness completely. Here are some questions that should be asked:

- what is the diagnosis or disease;
- what is the prognosis or outlook, both in the near and distant future;
- what tests will be ordered and why;
- what medications will be prescribed, any possible side effects and other drug interactions;
- what methods can help to manage symptoms and pain;
- where are ongoing treatments and therapies offered;
- the outcome if recommendations are not followed;
- the expected limitations to your activity or ability; and
- the options available to improve and preserve your quality of life.

Good communication with doctors and other health care providers is key in coordinating and managing a chronic condition effectively.

Wayne Riskin, M.D./Rheumatologist

“I have to know as a physician what’s happening with the patient .I’m not in their home. I’m not in their environment and very often what their complaint is has some bearing on what’s happening in their home situation.”

Narrator

A patient with a chronic disorder must also be painfully honest about limitations with family and health care providers.

Antonia McKinley/ Arthritis Patient

“I can’t cut heavy foods. Meats. That was another problem of readjustment. We would go out to eat and I would just order soft spaghetti, fish—anything that I didn’t have to cut. And then Ed kept saying to me ‘you like steak. Why aren’t you ordering steak? Finally I did and one day he just took the plate from me and cut it up and I said ok I just have to overcome that not embarrassed that my husband was doing it for me but embarrassed because people were watching.”

Narrator

With chronic illnesses, simple activities are often daunting. For example, walking across a room can seem like a mile or driving to the grocery store-- exhausting. Toni had to admit she had trouble with routine tasks like turning the pages of a book, cooking and even styling her hair.

THE PATIENT CHANNEL PRESENTS-Chronic Care:Improving Quality of Life

Beverly Davis/ Lupus Patient

“It’s difficult at times not being able to do the normal everyday things—like take a shower, wash my hair...without being totally exhausted.”

Narrator

Coping with a long-term illness is complex for both caregivers and the care-receiver.

An acute illness, like appendicitis or pneumonia, may be serious, but can be diagnosed, treated, and resolved. A chronic illness is different. Receiving the diagnosis is only the beginning. There is then a host of emotional and practical issues that need to be addressed. Here are some of the most important:

- Is independent living an option?
- Is there a family member or loved one that can act as caregiver and assist in daily activities?
- Are health care providers, services and facilities nearby and accessible?
- What financial restraints are there?
- Is the home “disabled friendly?” Are there stairs to climb, is there a walk-in shower?
- Is there public transportation and nearby shopping?

Family and other caregivers should participate in tackling these issues and in the development of a realistic chronic care plan.

Wayne Riskin, M.D./Rheumatologist

“This may mean moving into somewhere where there’s transportation because your ability to drive may be impaired; going into a first floor rather than a multiple story area if there is no elevator. Things like that which would affect the physical aspect of your function or the person’s function. The other aspect of course is the mental aspect. You would want to be able to live independently if you can handle your own affairs such as pay your bills, do your checking, make decisions that would be reasonable and you want to be able to do that without having clouding on your mental status, either clouding from an illness or clouding from some medications.”

Narrator

For the McKinleys, the answers, though not simple, were clear. Ed would take an early retirement to care for Toni and they would move to Florida where the weather was better for the arthritis.

Edward McKinley/ Caregiver

“We settled on this particular location because it was close to everything for her. She could walk to church, she could walk to the bank, and she could walk to shopping. There’s a pool on the premises where she goes into that pool and the exercises that she can do in that pool are as beneficial for her and is much more than she could ever do just by walking or doing regular exercises.”

Narrator

Managing a chronic illness can be tough to do alone but there is help available. Coming up we’ll see where to look.

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Narrator

Chronic Care services focus on the social, residential, rehabilitative, supportive and medical needs of individuals suffering from a chronic illness. Finding help when needed can be one of the biggest challenges of chronic care. Through the *Older Americans Act of 2000*, a network of state and local agencies on aging are available to assist patients and caregivers, whether they live next door or in the next state.

Gail Cooney, M.D./ Medical Director/ Hospice of Palm Beach County

“There are more than 22 million informal caregivers who are providing unpaid care to people living in the community... These may be children, spouses, neighbors or friends and the economic value of care they deliver is over 250 billion dollars a year.”

Narrator

Often holding jobs and juggling other responsibilities, caregivers have a tough task. Whether you are expecting to become a caregiver or have been thrust into the role overnight, it is useful to know what options are available and where you can get help.

Wayne Riskin, M.D./Rheumatologist

“If the individual and their family find that maintaining a personal residence—having to cook for yourself, having to clean for yourself, having to go out and get the laundry. If that becomes either physically too difficult to do, or because of mental reasons the person can’t do it, then I think consideration has to be given to assisted type of living— to moving to a situation where these things are either done for you or it’s assisted.”

Narrator

Here’s a brief look at some choices if some help is needed or independent living is not feasible:

Ambulatory Aids can be invaluable in chronic care. For assistance in everyday life, wheelchairs, scooters and walkers enhance independence. It is important to work with health care providers when determining which equipment is right for a particular situation.

Home Health Care. This includes skilled services such as nursing, physical therapy, occupational therapy, speech therapy, dietician services, social services, and home health aide services. It also includes support services like transportation, delivered meals, companion visits, homemaker and grocery shopping assistance. People who receive these services can be of any age but must be homebound.

A Rehabilitation Facility or Skilled Nursing Facility. These may be freestanding or attached to a hospital or nursing home. People stay there after suffering disabling events or injuries, such as a stroke, spinal cord injury, or brain injury. These facilities provide nursing care but things are arranged to resemble real world settings, such as a home, a workplace, or a grocery store. The purposes of rehabilitation are to help people keep or regain the ability to perform daily activities, such as bathing, feeding, dressing, grooming, walking, shopping, traveling, and household tasks

THE PATIENT CHANNEL PRESENTS-Chronic Care:Improving Quality of Life

Assisted living facilities are usually residences where people can live in their own rooms and get minimal assistance.

Gail Cooney, M.D./ Medical Director/ Hospice of Palm Beach County

“For patients that are no longer able to live in their own homes an assisted living facility may offer the best of both worlds, providing both a home-like environment, privacy and independence in a setting where support is readily available—whether it’s meals, housekeeping or simple medical care.”

Narrator

Typically, a common dining room offers a pleasant gathering place for meals and personal care services are available on a 24-hour-a-day basis. Nurse’s aides help with medicines and registered nurses are available for minor health problems. Residents are taken to a hospital for emergency care.

Nursing homes are another option, offering both short and long stays. They are used as a transition from the hospital to the home or to give caregivers of ill patients a chance to go on vacation or get a break from the burdens of care giving. This is sometimes called "respite care."

Long term nursing home stays are suitable for the ill person whose needs become too much for the family to handle. After caring for his wife at home for more than ten years, Ted Moore needed help so he placed his wife, Marion, in a nursing facility. In the advanced and final stages of Alzheimer’s, she is no longer able to talk or walk or eat on her own.

Ted Moore/Caregiver

“I really felt good about being able to care for herI had to feed her, dress her, bathe her, toilet her, the whole business. That became a part of our life then. It was time to let go and let those people take care of Marion and she’s being cared for now, she’s in no pain, she doesn’t suffer at all. She has no illness. She’s in good health other than the Alzheimer’s so I feel that’s working out very well.”

Narrator

Nursing homes are staffed with licensed nurses, aides and therapists. Doctor's visit the patients in the nursing home at least monthly. The last option, Hospice Care, is for dying patients. It is a philosophy that is found in hospitals, long-term care facilities, and in the home setting. Health professionals who care for hospice patients believe that people with a terminal diagnosis, meaning that they may die within 6 months, should be without pain or discomfort. Hospice care patients receive nursing care, social work services and chaplain visits. The goals of hospice care are to control pain and other symptoms and to care for the patient and family socially, spiritually, and psychologically.

Natural Sound: Singing “Amazing Grace”

Up next....taking the necessary steps to ensure desired medical treatment

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Narrator

Thorough chronic care planning should also entail some introspective legal preparation. Federal law , the 1990 Patient Self-Determination Act, requires hospitals, nursing homes, and other institutions that receive Medicare or Medicaid funds to provide written information regarding advanced care directives to all patients and residents upon admission. Advanced care directives allow patients to make their own decisions regarding the care they would prefer to receive if they develop a terminal illness or contract a life-threatening injury.

Wayne Riskin, M.D./Rheumatologist

“They include such things such a Living Will where you instruct your physician and family members to go to certain extents in terms of resuscitative efforts. The best way to describe this is by example, suppose you’re involved in a serious automobile accident and you have no chance of survival. It helps if you have an advance directive that the physician know how much resuscitative effort you desire when you’re capable of making that decision.”

Narrator

This may include specific procedures, care, or treatments such as CPR, if cardiac or respiratory arrest occurs; artificial nutrition, through intravenous or tube feeding; prolonged maintenance on a respirator, if unable to breathe adequately alone; and blood transfusions. Other directives include a Durable Power of Attorney (or healthcare proxy) naming someone else as the person you'd like to make medical decisions for you should you become incapacitated and, Organ Donation. This may be accomplished by completing an organ donation card and carrying it in your wallet. Many states offer people who are applying for new or renewed drivers' licenses the opportunity to make a decision regarding organ donation and have it recorded on the license at that time.

Gail Cooney, M.D/ Medical Director/ Hospice of Palm Beach County

“There are two really important reasons why people should have advanced directives. The first is to make sure the healthcare you receive is the healthcare you want whether or not you’re able to speak for yourself and tell people what you want. And the second it’s a great relief to your family and those who love you because your decisions are written down on paper and they know that what you want is what’s being done”

Narrator

Today, more people than ever suffer from chronic illnesses. Chronic conditions can seem exhausting and hopeless but with some careful arrangements and help it is possible to cope and accommodate the changes chronic conditions bring.

Antonia McKinley/ Arthritis Patient

“We happened to go to a wedding. It was a family wedding so I had to go and I’m wearing a splint and a collar for my neck and Ed says, ‘ok, come on let’s dance. I said your crazy, you’re crazy. I will not do it but he did, he got me up. We started to slow and we went from slow to a little faster and I said gee, I could do this and that’s the way it went.”

THE PATIENT CHANNEL PRESENTS-Chronic Care:Improving Quality of Life

Narrator

Self-management skills such as pain and fatigue reduction techniques; breathing; relaxation and exercise regimens; and diet therapies can all make a tangible impact on the disease. Such strategies along with thoughtful planning, good communication and the right attitude will help you cope successfully with a chronic illness

Antonia McKinley/ Arthritis Patient

“He encourages me. He pushes me. Sometimes I get so angry with him –it’s like leave me alone but no, you can do it, let’s do it and he knows, he knows I’m in pain.”

Narrator

These steps allowed Toni and Ed to regain control of their lives.

Credits

This program was reviewed by Bruce B. Dan, MD, Managing Editor, The Patient Channel & Robert Moser, MD, Exec. VP Emeritus, American College of Physicians

For more information: State and Area Agencies on Aging @ www.aoa.dhhs.gov/eldfam/

Nat’l Assoc. for Home Care @ www.nahc.org

Nat’l Family Caregivers Assoc. @www.nfcacares.org

ARCH (Nat’l Respite Locator Service) @ www.respitelocator.org/index.htm

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