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Family FOCUS

A publication of the National Kidney Foundation

Vol 14, No 3
Summer 2005

MENTAL HEALTH

Tips to Coping with Chronic Kidney Disease

By Karren King, MSW, ACSW, LCSW



Receiving support from family and friends is one way you can cope with having CKD.

HOW DO YOU COPE WITH THE MENTAL HEALTH CHALLENGES related to having chronic kidney disease (CKD)? That was the question we asked this quarter and you shared—a lot! This is obviously a question to which many of our readers could relate.

Respondents who shared the type of emotional challenges they face referred often to depression. Research has shown that depression is the most common emotion felt by

those who are on dialysis. When someone is confronted with having CKD, there may be many losses—health, family roles, work, income, social outlets. If losses occur, it is

natural to grieve, which can involve depression. Anxiety and anger or frustration are also emotions individuals may feel. There is no “right way” to feel when you have CKD, as we cannot help how we feel. However, it is what we do about what we feel that can make a big difference in our lives.

Your Own Kind of Faith

Spirituality is what gets many of you through the tough times. It takes many forms, depending on one's faith, and can include prayer, meditation, belief in a higher power and/or attending a place of worship such as a church, temple or mosque. One person shared, “I realized there was just so much I could do...so I turned it over to the Lord and let Him handle it.”



Reach Out For Support

Support from family and friends is also very important; one respondent described it as a “must.” Several shared that expressing feelings—and not keeping them “bottled up”—to family and friends was helpful. One individual suggested surrounding yourself with those who love and support you when you feel down. Simply enjoying family helps lift another respondent's emotions. One man said that not only is his family a support for him, but he is a major figure in their lives. Knowing how much they need him keeps him going.



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A GREAT DEAL OF TIME AND MONEY are devoted to physical health, both for the prevention and treatment of illness, in our society. In comparison, very little attention is given to our mental or emotional health. There is a cyclical effect between physical and mental health. Research has shown that our mental health can affect our physical well-being. For example, there is much evidence that depression may play a part in the development of cardiac disease. We also know that our emotional state may make existing physical problems worse. Also, when we live with physical problems, especially those that are chronic, it is very natural and normal to react with changes, at least

temporarily, in our emotional state.

Most of us will experience some type of emotional problem, such as depression or anxiety, at some point in our lives. Yet, all too often, we will attempt to continue on with our lives, ignoring how we feel emotionally. There are many reasons for this. Some may believe there is a stigma attached to having emotional problems, feeling that others may think they are weak or less than capable. For others, there may be a lack of infor-



Karren King

mation as to where to turn for help. It is not always easy to ask for help, yet I strongly believe it is much harder to deal with our depression, anxiety or anger

experiencing emotional problems. We also want you to be aware of the various options available to help you face them. Know that you do not need to suffer in silence and there is help available.

Lastly, it is almost that time of year again when the *Family Focus* Editorial Board will be appointed for 2006 and we will be convening to plan next year's issues. As always, we want our information to be relevant and timely. We urge you to share with us your ideas for future newspaper topics. 

alone. If we ignore our emotional pain, it not only can take its toll on our physical well-being but it can also impact our relationships, activities and practically all other aspects of our lives.

It is our hope with this issue that you will realize you are not alone if you find yourself

Here's to an emotionally healthy summer!

Karren King, MSW,
ACSW, LCSW
For the Editorial Board

Family Focus

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People Like Us Thanks the Federal Government

ON JULY 25, 2005, People Like Us representative Alice McCall, along with National Kidney Foundation (NKF) staff, presented the United States (U.S.) Department of Health and Human Services Secretary Michael Leavitt with a proclamation officially thanking the U.S. government for providing dialysis and other life-saving therapies to countless people for more than 30 years through the End Stage Renal Disease (ESRD) program.

This moving ceremony to thank the government followed the kick-off of People Like Us, the NKF's patient empowerment initiative, held in the Nation's Capitol in early May. More than 100 people with chronic kidney disease (CKD), transplant recipients, living organ donors, donor families and loved ones gathered from around the country to learn how to become their own best advocates through training workshops and public policy briefings. Interactive and role-playing exercises prepared participants to become proactive advocates and effective spokespeople. At a special reception on Capitol Hill, People Like Us mingled with members of the Congressional Kidney Caucus, and some participants met with their Congressional representatives.

Plans for ongoing People Like Us activities are underway as we continue to build what we hope will become the largest, strongest and most effective patient advocacy group in the country. For more information, please e-mail peoplelikeus@kidney.org 



NKF's Dolph Chianchiano; kidney transplant recipient and People Like Us advocate Alice McCall; U.S. Health and Human Services Secretary Michael Leavitt; and NKF's Tracy Fortson and Troy Zimmerman. (HHS photo by Chris Smith.)

Corrections:

□ In the last issue of *Family Focus* the number of dialysis centers offering nocturnal home hemodialysis was quoted as "approximately 50" in one article and "81" in another. The actual number varies depending on the source. For more information on home hemodialysis go to www.medicare.gov and click on "Compare Dialysis Facilities" or www.homedialysiscentral.org

□ Some readers felt that the article "A New Look at Home Dialysis: A Psychosocial Perspective" in the last issue of *Family Focus* unfairly criticized dialysis technicians' training. The authors did not intend their comments to put into question technicians' training. The authors' goal was to encourage people with chronic kidney disease to believe they could do their own dialysis at home if they received training similar to what new technicians learn. The authors believe that if more individuals were urged to take on an active role in their care and did dialysis at home, they and clinics would both benefit.

Tips to Coping...

Continued from page 1

Have Goals and a Purpose

Having something to strive for, such as going to school, helps one person cope with CKD. Several individuals mentioned that being employed helps them feel more positive emotionally. Many of you said doing something you care about and giving to others are important ways of dealing with depression. Several are involved in advocacy groups for those with CKD or other illnesses, and some share with others what they can do to prevent CKD or about the need for organ donation. Another person has been active in his children's school and athletic activities. One member of the National Kidney Foundation's Patient and Family Council Executive Committee shared how good it feels to simply contribute and feel a part of something. Whatever form volunteer activities take, the constant theme is "giving back." One individual shared her belief that doing something to feel productive is the key to living with CKD. Enjoyable activities, such as gardening or reading, are helpful to another person because it takes her mind off of her concerns.

Take Care of Yourself

Taking care of themselves helps some cope better with the challenges of CKD. Many stressed the importance of exercise, following a healthy diet and taking medications

as prescribed. Another person shared her belief that being proactive with your care is important and that includes not only educating yourself about all aspects of CKD but also putting what is learned into practice. Education allows you to take more control over your treatment and engage in self-care activities and both education and involvement with care were identified as beneficial.



Get Professional Help

Seeking professional help, either individually or in a group, was identified as useful. One individual suggested that a mental health specialist in each dialysis center would be helpful, and it is important to point out that the dialysis social worker is just that person! In addition, it was stressed that talking to others who are going through what you are experiencing can be a great help. Also mentioned was the importance of sharing your feelings with your doctors to allow them to determine if medication for depression or anxiety could be beneficial for you.

Have a Positive Attitude

Lastly, the importance of keeping a positive attitude was mentioned many times. Several suggested taking life one day at a time, doing what you can and trying not to dwell on issues that you can do nothing about. A woman shared that she begins

every morning with thinking how thankful she is to have another day, rather than thinking "another day to have to live with CKD." She stressed that choosing to make the most of every day was a daily choice. Others echoed her sentiments by writing "I choose to live my life to the fullest!" and "I choose to get up each day and have a good attitude....You have to find the positive in life and focus on the good things." The need to be flexible and willing to adjust was stressed. One person believes it is important to not only set goals for your life but also take the time to appreciate it when the goal is reached. Another shared that it helps to view dialysis like "cleaning your teeth, something you just have to do!" A woman who has another illness in addition to CKD shared that she had determined the purpose of her life was in the living of every day and doing it with grace. One gentleman summed it up by sharing, "I do not live for dialysis. I use dialysis to live."

There is no doubt that life with CKD can present great challenges, and with it feelings such as sadness and anxiety. Yet, as one individual pointed out, it can also be very rewarding, as it can help you discover what is really important in your life. Here's wishing you that reward.

Go to www.familyfocusvoices.org

to read other readers' responses. 

letters to the editor



Dear *Family Focus*:

I started dialysis in July 2002. During dialysis at my first unit, I never saw *Family Focus*. I transferred to my current center in August 2004. I began reading *Family Focus* and really enjoyed the issue. *Family Focus* has given me so many things to be thankful for. It has answered so many of my questions and yet it gave me so much information on issues of concern. This is a well-informed newspaper. I am very grateful for *Family Focus* because it advises, updates, informs, teaches and stimulates the reader.

Volume 2, "Fun and Fabulous Foods for Your Dialysis Friends" and Volume 3, "Finding Kidney Disease Early" were excellent. They covered so many areas and were very helpful to me on activities, hobbies, traveling, school, employment, kidney camps, exercise and dining out. The

issues have enriched my life, and I plan to follow some of the ideas. Thank you for *Family Focus*. I look forward to reading each issue.

Sincerely,
Billy Carmon

Dear *Family Focus*:

I am the wife of a person who has not one but two transplants, a kidney and a pancreas. My reason for writing this letter is because I would like to do something with what my family has been through. I also want to say my husband was given the greatest gift that so many people do not even think about.

The last issue of *Family Focus* hit home for me about wanting to become involved in being an advocate. Can you please send me information on becoming a serious advocate? This is something I feel good about.

Thank you.
Judy Klingensmith

Dear Mrs. Klingensmith:

I am glad that the Family Focus issue on advocacy inspired you to become involved. That was our goal! I would suggest that an excellent place would be to contact your local National Kidney Foundation affiliate and offer your services. If you do not know how to reach them, you may contact the NKF national office for information (800-622-9010) or visit the Web site, www.kidney.org Another avenue would be to contact the hospital where your spouse received his transplant and offer to be available to others whose spouses are awaiting a transplant.

Thank you for writing and for your concern for others.

Sincerely,

Karren King, MSW, ACSW, LCSW
Editor-in-Chief
Family Focus

IF YOU LISTEN TO PEOPLE TALKING ABOUT DIALYSIS, what do they talk about? They talk about clinical things like adequate dialysis, calcium and phosphorus management and hemoglobin levels. As a dialysis community, we have come a long way in improving the care of people with kidney failure. Until the last few years, however, a very important part of dialysis care—the “emotional health” of the dialysis clinic itself—has been overlooked.

The emotional health of the dialysis clinic is the attitude (positive or negative) that people in the dialysis clinic have towards each other. Think about your dialysis clinic—is it emotionally healthy or emotionally sick? Does your dialysis clinic have positive “vibes” (feelings) or negative vibes? Do you and your dialysis staff trust and respect each other? Can you discuss problems openly and honestly? Or do people in your clinic walk around on “tiptoe” worrying that something they say or do could make someone mad?

Keeping a dialysis clinic emotionally healthy takes a lot of hard work on everyone’s part. Everyone in the dialysis clinic—staff and people coming in for treatment—has a responsibility to do their part. It is a two way street—you, as the customer, have the right to be treated with respect and dignity by the dialysis staff, and the dialysis staff has the right to be treated with respect and dignity by you, the customer.

Dialysis clinics can be very emotionally charged places. There are a number of reasons why this is so and all of these reasons apply to dialysis staff, as well as to people on dialysis. Sometimes we get so wrapped up in our own lives that we do not consider the emotions and feelings of the other people in the dialysis clinic. Or, if we are

Is Your Dialysis Unit Emotionally Healthy?

By Bobbie Knotek, RN, BSN, CNN

Teamwork will make your unit emotionally healthy.

stressed, worried or not feeling well, we do not always put our best foot forward. To add to that, because we spend so much time around the same people, we often treat each other too casually, possibly with less respect. Over time, “little things” that are said or done which might not usually bother us turn into “big things,” especially if they are repeated time after time. Small disagreements, personality conflicts, hurt feelings or misunderstandings can turn into anger or suspicion, causing us to strike out at the people around us.

You may find that having a chronic medical problem, like chronic kidney disease (CKD) makes it even harder for you to stay emotionally balanced. CKD may change your life—what you eat and drink, how much energy you have, what type of work and/or hobbies you do and many other things. Treatments and travel time take up a lot of your time if you go to an outpatient hemodialysis clinic. Besides the time commitment, many people say they feel they are “putting their lives in someone else’s hands” during dialysis.

Trying to consider other people’s feelings and emotions is one of the keys to an emotionally balanced dialysis clinic. Unfortunately, during periods when we are having a hard time keeping our emotions and feelings balanced, it is difficult to consider other people’s feelings and emotions. This is true whether you are a person receiving treatment, a family member or friend or dialysis staff member. The good news

is there are a lot of little things you can do to show consideration to people at the clinic that do not take a lot of effort or energy. Over time, these little things can have a big impact on the emotional health of your dialysis clinic.

Here are some suggestions you can try in your clinic:

1. REMEMBER the “golden rule”—treat other people the way you would like to be treated.
2. TRY to find the good in people.
3. TRY to find the good in situations, even when there does not seem to be any.
4. APPRECIATE people who care and who try to do the right thing.
5. TELL people “Good morning” or “Good afternoon.”
6. GIVE people compliments—everyone likes to be appreciated!
7. BE patient with people, especially new dialysis staff in your clinic. A friend of mine likes to take new dialysis staff “under his wing.” He volunteers to let new staff cannulate his access so he can teach them cannulation from the patient’s point of view. (He also ends up with staff members he knows will do a good job cannulating his access).
8. THANK dialysis staff who encourage you to ask questions.
9. IF YOU DO NOT LIKE what someone is doing, point out the actions, but do not criticize him or her personally.
10. WHEN THERE IS a disagreement:
 - Try to look at both sides of the story.

- Do not talk about people behind their backs. Talk to the person with whom you have a disagreement.
- Do not ignore or make light of other people’s feelings.
- Offer possible solutions to problems.

11. FINALLY, AFTER YOU READ this article, do your clinic a favor and pass it on. Share it with your peers at the clinic and with your dialysis team.

Remember: It takes everyone working together to keep your dialysis clinic emotionally healthy! 

Decreasing Dialysis Patient-Provider Conflict

Over the last few years in the United States, conflict and violence in all medical settings have become more and more of an issue. In an effort to decrease conflict in dialysis and transplant clinics, the Centers for Medicaid and Medicare Services, the ESRD Networks, kidney professional organizations and the dialysis corporations came together to develop a staff training program known as DPC or Dialysis Patient-Provider Conflict Resolution Initiative. DPC was “launched” across the U.S. during the summer of 2005. Social workers and clinic managers in every dialysis unit across the country were asked to train their staff using posters, pocket cards and videos provided by the ESRD Networks. If your clinic is participating in this groundbreaking staff education program, cheer them on! 

MANY PEOPLE WHO ARE ON DIALYSIS

have the same signs and symptoms of emotional problems as people without chronic kidney disease (CKD). In addition, the stress of dialysis and the feeling of loss of control over one's life, not to mention the physical effects of CKD, can put a strain on most people and may lead to depression, difficulty sleeping, anxiety and other mental health challenges. Depression and anxiety are very common for people on dialysis just as they are in the general population. When psychological counseling and other measures such as a complete medical review including possible medication side effects are not enough, drug treatment may be necessary. This article will review the major types of drugs that are used to treat emotional problems and will provide information about individual drugs in each drug class specifically for people on dialysis.

It is important to remember that mental health treatment is very individual and is best started in a discussion with your kidney doctor about your symptoms and the risks and benefits of any treatment. Occasionally, a formal psychiatric evaluation may be necessary. People on dialysis usually take a number of medicines, which may either interfere with or add to the effects of other prescription drugs you are taking. Another important point for individuals on dialysis is the fact that non-prescription treatments such as supplements, vitamins and herbs may interact with prescribed medicines. Your doctor needs to know if you are taking any of these to avoid bad side effects and assure the ability of your medicines to work well.

Drug Treatment for Emotional Problems for Individuals on Dialysis

By William M. Bennett, MD

Sometimes medication is necessary in treating emotional problems. Read on for the facts.

DRUGS FOR DEPRESSION

Not all people with depression need medication, since many become depressed only for a short period because of what is happening in their lives at the time. This type of depression is called reactive depression and may go away over time. Longer periods of depression, however, can improve with medication. Most antidepressive medications (medicines that fight depression) are metabolized in the liver before they leave the body and therefore dialysis seems to have little effect on how they work or their safety.

The most popular group of drugs used to fight depression is the selective serotonin reuptake inhibitor (SSRI) group of drugs. The first of its kind of this type of drug is fluoxetine (Prozac®). Other drugs of this type include sertraline (Zoloft®), paroxetine (Paxil®), citalopram (Celexa®), trazodone generic and escitalopram (Lexapro®). These drugs should be started at small doses. Positive results are often seen about three to six weeks after starting the drug. Side effects may include sexual dysfunction, such as the inability to reach orgasm or having a lower sex drive, nightmares, nausea and headache. These drugs usually work better than the older antidepressants, such as amitriptyline and imipramine (Elavil® and Tofranil®). These older



medicines begin to work very slowly, may cause heart problems and generally do not work as well as SSRIs. However, they cost less and are available as generics (medicines that are off patent and made by more than one drug company). Many people still use them for the treatment of depression. If these older medicines are stopped, they should be stopped slowly under a doctor's supervision to avoid the risk of depression coming back and the risk of seizures (convulsions).

There are other medicines called atypical antidepressants. They are called atypical because they work differently than SSRIs. An example of an atypical antidepressant is nefazodone (Serzone®). This is a cousin of trazodone and can help people with depression sleep better. They can also be used safely by people on dialysis. Another atypical antidepressant drug used more often in the treatment of depression for individuals on dialysis is bupropion (Wellbutrin®). It can also be used to help people stop smoking. A sustained-release form of the medication (which means small amounts of the medicine are released into the body over a period of time) can be taken once a day. Dialysis treatments do not affect the ability of bupropion to do its job in treating depression. Its main drawback is that it raises the possibility of having a seizure and probably should not be used by people who have a history of seizures or who are on antiseizure medications.

ANXIETY

Anxiety is relatively common in people on dialysis.



Drugs in the benzodiazepine class of drugs such as alprazolam (Xanax®) and diazepam (Valium®) are commonly used. While these drugs do not build up in individuals with CKD and are not lost during the dialysis procedure, they have increased effects in some people on dialysis, particularly those with problems in the nervous system such as previous strokes or brain atherosclerosis. These may include excessive sedation, confusion and, rarely, seizures. Another member of this class is clonazepam (Klonopin®), sometimes used to treat restless leg syndrome in people on dialysis. If these drugs are taken for a long time, they should not be stopped quickly; instead, like the antidepressants described above, they should be stopped gradually under a doctor's guidance to avoid withdrawal symptoms. New benzodiazepines may cause drug dependence; thus, they are best used for short-term problems. These should be avoided in people with alcohol and drug problems.



DRUGS FOR OTHER ILLNESSES

Drugs given for other mental health diagnoses such as schizophrenia, obsessive-compulsive disorder (OCD) or bipolar disorder in general can be given safely to people on dialysis.

Lithium, a drug used to treat bipolar disorder (also known as manic depression) is monitored by measuring the level of the drug in your blood. While some of the medication is lost

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MANY PEOPLE WITH KIDNEY DISEASE FIND IT HARD to give up habits that may be harmful to their health. However, there are some people who make major changes in their lifestyle, despite feelings of low energy and sadness that may go along with dialysis sessions. These changes may include stopping smoking, eating better or getting help from an exercise specialist to improve physical conditioning. Some people make changes on their own without the help of another person and others get support from a friend, family member or health care professional.

So what triggers change? What motivates people? Why are some people more ready to change than others? These are not easy questions to answer. Clinical psychologists such as Dr. James Prochaska from the University of Rhode Island and Dr. William Miller from the University of New Mexico have been studying human behavior for the past 30 years in an effort to find some answers.

Dr. Prochaska's research has shown that when it comes to behavior change, people have different levels of motivation to

Are You Ready, Willing and Able to Live a Healthy Lifestyle?

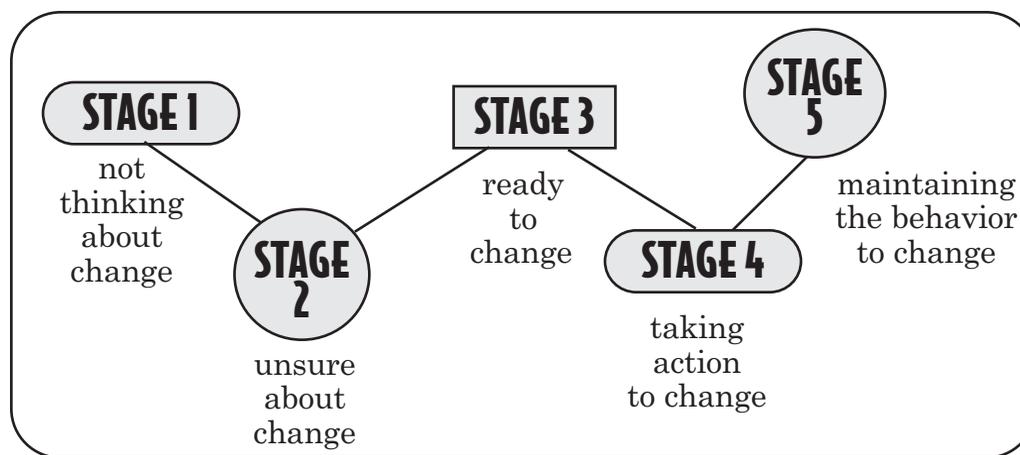
By Robert Scales, PhD

Making big changes does not happen overnight.

change, which he calls the Stages of Change. People might be in one of five stages of readiness to change, ranging from not wanting to change in the future to having taken action and stayed with the changes for at least six months. Here are the Stages of Change described by Dr. Prochaska:

shown that a smoker will typically quit seven times before eventually quitting for good.

Dr. Prochaska suggests that it is helpful to know which stage of change a person is in before trying to help him or her change some aspect of his or her lifestyle. Efforts to help people change tend to fail



People who reach the point of taking action may fall off track and relapse back into one of the earlier stages. However, that is not to say that all is lost and the person cannot take action again in the future. For example, it has been

when the strategies that are used to help do not match the person's stage of readiness to change. For example, in the earlier stages of change (Stages 1-2), it is a good idea to help the person take a closer look at his or her lifestyle in

an effort to get him or her to think about some of the not so good things about the behavior. Whereas in the later stages of change (Stages 3-5), it may be better to help the person set goals and develop the skills necessary to put a plan into action.

At some point we have all felt the frustration of being on the receiving end of someone trying to convince us to change some aspect of our behavior, and the harder they try to persuade us, the less interested we become. Dr. Miller's research has shown that in health care, providers will often give advice in an effort to get patients to change harmful behaviors. This can easily lead to conflict and may result in resistance, particularly when we are unsure about changing our behavior.

Consequently, when it comes to behavior change, it is crucial that you communicate your feelings to help the health care provider understand your point of view. To achieve this, it is usually more effective to take part in the conversation rather than letting someone order you to try something new. For example, before starting an exercise program, share your concerns about your physical and emotional limitations as well as your strengths and your feelings about some of the sacrifices you will have to make. This discussion will help your health care provider understand where you are in the change process, giving you a better chance of moving closer to the day where you will be ready, willing and able to change your behavior and start to feel better.

Robert Scales, Ph.D. is an experienced trainer in motivational counseling and teaches workshops to help health care professionals improve their communication skills with patients.



Drug Treatment for Emotional Problems...

Continued from page 5

through the dialysis treatment, it still does a good job of treating bipolar disorder in people on dialysis. The drug level test should be done before a dialysis session. While lithium has bad effects on the kidneys when taken over many years, this is not a concern for people on dialysis. However, too much lithium in the blood can be dangerous to dialysis patients also because it accumulates and can cause seizures and brain damage. You should discuss this with your physician if you are taking lithium.

All individuals who are taking any medicines for depression and other mental health problems should have regularly scheduled appointments with their doctor to discuss ongoing care and treatment. Any changes in medication, amount of medication and its effect on blood pressure or

other medicines used in your treatment should be carefully followed by your doctor.

SUMMARY

Depression, anxiety and other mental illnesses can be safely treated in people on dialysis. When starting treatment, the individual should review all of the medications he or she is taking with his or her nephrologist, including prescribed and over-the-counter drugs, to make sure there are no bad effects between the medicines. The rule of thumb is "go low and go slow." You should tell your doctor about new symptoms as soon as you notice them. With care, most emotional problems can be treated successfully.

William M. Bennett, MD, is a transplant physician at the Legacy Good Samaritan Hospital in Portland, OR.



“OKAY, SO YOU ARE SAYING I SHOULD EAT MORE MEAT, drink less milk, avoid canned soups, lunch meats, hot dogs, pickles and olives and limit oranges, bananas, potatoes and tomatoes. I need to increase the number of binders I take: three after each meal and two after each snack. Is that it?”

Does this sound familiar?

Month after month, you are counseled by your dietitian to achieve lab results within the desirable ranges. Due to the limitations of the kidney diet, you may find it difficult, or even depressing, to follow such a diet. “Sometimes I just want to give up eating. By the time I figure out something to eat, I am not even hungry anymore,” commented one person on dialysis. “Or I want to eat everything in my kitchen to rebel against the diet!” she added.

Dealing with the complexities of the kidney diet and other lifestyle changes may contribute to feelings of hopelessness, pessimism, sadness and other symptoms of depression, which can make you apathetic and less likely to care for your own physical needs.

Depression is not a weakness or a character flaw; it, too, is a medical illness. Depression can affect your ability to sleep, work and get along with others. People who are depressed may find daily tasks such as meal planning, shopping, food preparation and even eating to be a big struggle. As a result of poor eating due to depression, you may lose weight, have a low protein (albumin) level, or, in some cases, you may overeat and have unplanned or unwanted weight gain.

Psychological counseling and sometimes antidepressant medications can be helpful in treating depression. Medication can give relatively quick symptom relief for some individuals and counseling helps one learn more

Don't Let Your Diet Get You Down!

By Cathy Keller, RD, LDN

Taking control of your kidney diet could reduce your chances of feeling depressed.

effective ways to deal with life's problems. Ask your social worker to refer you to a mental health professional if you feel you need help with depression.

In the past few years, there has been much interest in the use of herbs to treat depression. St. John's Wort (*hypericum perforatum*) is becoming popular in the United States as an alternative to prescription medication to treat depression. In general, the use of herbs to treat depression or other medical condi-

tions can be dangerous and is not advised for people with CKD. Specifically, research has shown that St. John's Wort may interact with anti-rejection drugs, may be a source of hidden potassium[1] and may also interfere with iron absorption and cause gastrointestinal irritation[2]. The use of any type of herbal or over-the-counter depression “remedy” should always be discussed with your nephrologist (kidney doctor) and other members of your health care team.

If you think you might be depressed over your diet, talk to your dietitian about how you are feeling. Together you can develop ideas about how to help you stay positive about your diet. These could include:

■ Setting short-term goals for your lab values.

Perhaps the idea of eating more protein, eating less potassium and phosphorus and drinking less fluid is overwhelming. Work with your health care team to decide where to prioritize. It may be easier for you to choose one lab value that is

not within goal range and take steps to improve it. For example, you may decide to work on reducing your phosphorus level first. Try substituting one low phosphorus food item for one higher in phosphorus (try sherbet or sorbet instead of ice cream.) Achieving a series of small, easy goals helps build your confidence and improve your health.

■ Looking through kidney cookbooks at your local library or bookstore for menu ideas.

There are also Web sites that offer many kidney-friendly recipes. Try www.kidney.org/patients/cookbook, www.culinarykidneycooks.com or www.ikidney.com. Decide to try a new recipe once per week and share your favorites with other people who are on dialysis and your dietitian. You will also be helping others who are dealing with the same challenges of the kidney diet.

■ **Preparing larger quantities of food and freezing leftovers.** Quickly reheating is a breeze when you are feeling too tired to cook from scratch. Some people find they are worn out after their treatment, causing them to skip meals. Enjoying leftovers after treatment can be a quick and easy way to improve nutrition and boost your energy level.

■ **Buying frozen dinners that are lower in sodium, potassium and phosphorus.** Some nutrition labels

now also list the food's potassium content. If you find one you like without nutrient information, see your dietitian for guidance.

■ **Eating with others if possible.** Pleasant conversation leads to a relaxed environment. If you live alone, consider inviting an understanding friend, relative or even another person who is on dialysis over for companionship during mealtime. Do not be afraid to ask them to bring a dish to share. You may find that many people want to lend a helping hand.

■ **Eating several small meals throughout the day** may help increase the amount you eat, making sure that you take in enough calories during times you may have a smaller appetite or might not feel so hungry. Try a mid-morning and/or mid-afternoon snack.

Many factors come into play with both the causes and the solutions for depression, including nutrition and diet. Having a positive attitude toward your kidney diet, while forming new eating habits (what, where, when and with whom you eat) can play a role in improving your physical health and your mental outlook.

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Cathy Keller, RD, LDN is a dietitian at Renal Care Group-South Suburban Dialysis in Olympia Fields, IL. 

“Sometimes I just want to give up eating. By the time I figure out something to eat, I am not even hungry anymore.”

DEPRESSION IS COMMON AMONG PEOPLE WHO ARE ON DIALYSIS.

NKF is currently sponsoring two studies of depression conducted by members of the Council of Nephrology Social Workers.

The goal of these investigations is to provide information that will help to improve the treatment and outlook for those on dialysis who suffer from depression.

Evaluation of Group Cognitive Behavioral Intervention on Depression, Social Support and Quality of Life for Patients on Hemodialysis

Estimates of depression among people on hemodialysis range from 25 percent in some centers to 100 percent in other centers.[1,2] Research has also shown that depression is associated with increased risk of death and hospitalization among individuals on hemodialysis [1,3,4] No large surveys have been conducted on the prevalence of depression in people on peritoneal dialysis.



Jessica Cabness, DSW

This study aims to determine whether a cognitive-behavioral intervention administered to small groups of individuals on dialysis would make a difference in their emotional health. The project team headed by Jessica Cabness, DSW, assistant professor at the University of South Florida (USF) in St. Petersburg, includes Cindy Miller, LCSW, nephrology social worker; Kia Flowers,

Two NKF-Sponsored Research Projects Study Depression in Dialysis Patients

By Jessica Cabness, DSW, Amy Freeman, LMSW and Laura Root, LCSW

MSW, Intern; and Stephanie Johnstone, LCSW, who has consulted on the research. The study duplicates earlier National Kidney Foundation-funded research by Johnstone, which provided data in support of the current study. “We know that end of stage renal disease is a life-altering condition and, under the circumstances, it is normal for people to experience situational depression which, if left untreated, is potentially dangerous,” says Dr. Cabness.

At USF Dialysis Center in Tampa, 23 people from each shift participated in the study. The intervention, designed by Stephanie Johnstone for a previous NKF-funded research project, lasts for six weeks with the individuals meeting weekly in a structured module. The intervention involves them talking about their hopes and fears in the safety and privacy of a small group of people facing similar issues. The aim is for individuals with chronic kidney disease to learn new ways to regain control over their lives.

After giving informed consent, they were given several short questionnaires including a depression screen for medical patients, a widely used health outcomes survey and a screen measuring social support. Some information was collected to see if there were any differences by age, gender, ethnicity or length of time on dialysis. Cabness reports that “preliminary findings look very promising and suggest empirical evidence of the effectiveness of nephrology social work intervention in dialysis

centers.” The project team is hopeful that social work interventions with people on hemodialysis will ultimately demonstrate a clear relationship between what social workers do in dialysis centers, lower rates of hospital readmission and higher quality of life for those on dialysis. Before the project ends in September 2005, Cabness hopes to recruit a second center for comparative research.

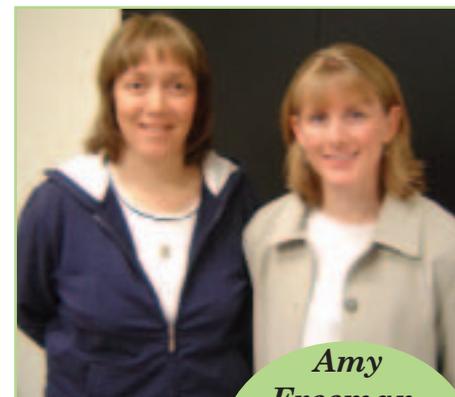
“We’re hoping that more social workers will replicate the study—the more data we have, the better we are able to draw conclusions about the generalizability of the study,” Cabness says. The study will be published in the *Journal of Nephrology Social Work* by 2006.

Psychosocial Risk Factors for Depression in New Hemodialysis Patients

DIALYSIS SOCIAL WORKERS AIM TO MAXIMIZE THE FUNCTIONING and well-being of people on hemodialysis. However, with the growth of dialysis facilities and increasing social work caseloads, many social workers find themselves in the role of financial counselor and transportation/travel expert, leaving them less time to function in their intended role of providing psychological counseling and emotional support to individuals on dialysis and their families.

The purpose of this research project, conducted by Amy Freeman, LMSW, and Laura Root, LCSW, of Saint Alphonsus Nephrology Center

in Boise, Idaho, is to examine the relationship between six psychosocial risk factors and level of depression in people new to hemodialysis. The six psychosocial risk factors are: gender, age, level of education, ethnicity, possession of medical insurance and amount of time individuals



Amy Freeman, LMSW and Laura Root, LCSW

knew they would be starting dialysis prior to their first treatment. The study period began in July 2004 and ended June 2005. The study included approximately 60 participants. In order to gather the necessary information, the researchers used two questionnaires with each person. One questionnaire contained information including questions about the six psychosocial risk factors. The other questionnaire used was the Beck Depression Inventory-Fast Screen for medical patients to measure depression level. The final results of this research study are expected to be published in the *Journal of Nephrology Social Work* in April 2006.

“We hope to use the results of this research to assist in promptly identifying which people who are new to hemodialysis to be at higher risk for depression,” says Root. This would allow dialysis social workers to more quickly assess for depression and provide the needed intervention/

Continued on page 11

It Is Okay To Ask For Help

By David Jones



David Jones

WHEN IT COMES TO CHRONIC KIDNEY DISEASE (CKD) we routinely expect doctors and other health care providers to help solve medical complications such as high blood pressure, anemia or bone disease. On the other hand, when mental health problems arise, we often ignore them despite how these problems can directly impact the medical challenges of CKD and dialysis. You do not need to be a social worker or psychologist or even spend much time with people like me who have CKD to understand how widely depression and other emotional problems can occur with chronic illnesses such as CKD.

Although having CKD does not mean a person will be unable to work, it is a reality that CKD often magnifies the fear of losing a job and income source. In addition, we can have a loss of self-worth and feelings of anger surface as the question “Why me?” arises. We often have less energy to tackle issues that would normally not seem so difficult. Where normally we have had self-confidence about the future, suddenly it feels like we have lost control over large parts of our daily lives. I have felt these feelings.

The effects of CKD are not always obvious to others.

Although I may be having a terrible day in terms of energy, pain and uremia side effects, there is no sign on my forehead that tells everyone how I feel. I did not want to always complain, especially at my job. While my family was generally supportive and sympathetic, they had needs of their own and I was embarrassed to lean too heavily on them. Recognizing all these conflicting feelings, it is not surprising that individuals with CKD and their families may benefit from professional help when dealing with emotional and social problems. This is particularly true during the first months of dialysis when new experiences, demands and fears come from all directions.

Unfortunately, people who experience depression or other mental health challenges often struggle along and deny the need for help even though many valuable support resources are available—all they need to do is ask for the help. Perhaps individuals have difficulty seeing how emotional problems interfere with getting back on track. It is also likely most of us are afraid to share our deepest thoughts and feelings with family and outsiders to avoid the vulnerability created by such openness. Like most, I was reluctant to discuss my darkest thoughts with friends or family members. Who would want to expose such unacceptable thinking? It took several years before I could even admit help was needed. Finally, I recognized I could not rebuild my past sense of

self-confidence without help, and the desire to move ahead became stronger than a tendency to stand still. Relief came when I discovered the benefit of being able to express my fears with a trained professional without worry of being judged or lectured! Knowing the relief I felt, my hope is that others will become conscious of their emotional problems and act more quickly to get help than I did.

Often, the hardest first step is speaking with someone who can show you the way to find

and support you need to help you get started on addressing your emotional concerns. In some cases, the social worker may refer you to a mental health professional in your community. Fortunately, Medicare and many other insurance programs may pay for professional counseling. Be sure to check with your insurance provider in advance.

While mental health professionals cannot create instant solutions for your problems, my experiences showed me that working with them in an



Support is available from the social worker at your dialysis unit.

help. First, we often question whether life can get better. Second, trying to change our way of thinking and being open about our inner thoughts is not easy. My message for fellow patients and families is that it is okay to openly admit that you need help coping with emotional problems. After all, CKD is a tough burden! One excellent place for advice on where to find help is right in your dialysis unit with the social workers and the nephrologists. Social workers are generally able to provide the professional counseling

open and sincere manner helped me to find ways of coping, allowing me to move on to a better quality of life. Sure, it can be painful to expose personal doubts and fears that we try to deny. The first step begins the healing process. Surprisingly, as you begin each step, the process of healing becomes easier as your life begins to take on more meaning. Your family, too, can share in that healing and optimism.



Surviving the Wait

By Nancy Swick, RN, BSN, CCTC

How can you cope with the wait for your transplant? Gary knows from first-hand experience.

IT IS EASY TO WATCH THE CLOCK when you are waiting for something to happen. When it comes to waiting for a transplant, it is a calendar that is ticking away the months and not a clock with minutes or hours! The months and years may go by, and it feels as if the waiting will never end. How can you be patient when the wait is so long?



Nancy Swick and Gary Costly

Waiting times for a kidney transplant average between three and five years depending on your blood type and antibody level. Yet enduring the wait and being called for a transplant may not mean the final wait is over. You may be called to the transplant center for a possible transplant, then sent home if the kidney is found not to be suitable for transplant or does not match you. And sometimes the kidney does not work right away and you may need to continue dialysis while waiting for the transplanted kidney to begin to work. Waiting for something you want so badly is always hard and often emotionally draining. You may even wonder if transplantation is worth all of this.

Gary Costly from Santa Rosa, California received a living related kidney transplant in 1989 from his brother. The transplant lasted until February 2000 when it failed due to reoccurrence of the original disease that had affected Gary's kidneys. His first transplant had required that he wait

only a few months for his brother to donate a kidney. The wait for the second transplant was very different from his first transplant experience. He found himself waiting his turn for a transplant in a long line of others who were in need of a kidney. He knew how good he could feel with a successful transplant, which made the wait even harder. After the first months on the waiting list, though, he realized he must continue with his life and

not put everything on hold while waiting for another transplant. He continued to plan vacations with his family and work as a chemist while awaiting the call from the transplant center.

"The one thing I tried to do while on dialysis was lead as normal a life as possible and not let kidney failure or dialysis consume me. But, knowing the call could come at any time brought a little anxiety to the mix. When I was called to the hospital for a transplant and then sent home after being told the kidney was going to go to another person, I was extremely disappointed. That was short lived, though, as I soon began to feel happy for the person who received the kidney. As I reflected on the process I realized that getting called for a possible transplant, even though I ended up without it, meant I must be closer to actually getting a transplant!"

About two months later, Gary received another call from the transplant center and was suc-

cessfully transplanted. "My family is happy, and I am elated," says Gary. "The biggest challenge for me while I was awaiting a transplant was keeping a positive attitude."

Besides waiting, it can also be difficult watching others leave the dialysis unit when they are called for a transplant while you continue to wait. Although you are happy for them, you most likely will find it hard to keep from asking yourself, "When am I going to get my chance for a kidney transplant?" Waiting time varies for individuals due to the degree of difficulty in matching. Some may have a high antibody level (percent reactive antibody level, commonly referred to as PRA). Although some new therapies can remove these antibodies, the waiting time is generally longer due to difficulty finding a compatible match.

There are sources for support while waiting. One will be your transplant center staff. Call

them to check on your status. Make sure you are active on the list and that there is nothing more they or you need to do to keep your status active. Check for local support groups. Talking with others who are also waiting or who have endured the wait can be helpful both to you and your family. Get a copy of *Waiting for a Transplant*, published by the National Kidney Foundation. *Waiting for a Transplant* is full of ideas and insights from transplant recipients across the country on how to keep "living life" while waiting for a transplant. The goal while waiting is to stay as mentally and physically healthy as possible so that when the wait is finally over you will enhance your chances for a successful transplant.



Additional information on the Internet is available at: www.transplantrecipients.org, sponsored by the National Kidney Foundation, and www.transplantliving.org, sponsored by the United Network of Organ Sharing. 

My Cycler and I

By Cynthia D. Miller

My Cycler and I, we have become one
 Nine hours of therapy, by morning I'm done.
 Sometimes I get up, sometimes I lay still,
 All depending on how I feel.
 Sometimes I feel bad, sometimes I feel good,
 Sometimes I feel happy, sometimes I feel blue.
 But most of all I feel blessed, when I open my eyes,
 With the help of my Cycler, another morning I'm alive.
 As my day goes on, I do what I can
 To make myself feel better and chase away the blues.
 I thank everyone who truly helps me,
 But next to GOD I thank "CAPD!"

Cynthia D. Miller receives her CAPD in New Haven, CT.

MANY PEOPLE WITH CHRONIC KIDNEY DISEASE (CKD) and their family members wonder about Medicare coverage for health care. If you have kidney failure and receive Medicare because of your ESRD (End Stage Renal Disease), you are entitled to the full range of coverage allowed under Medicare Parts A (hospital care) and B (outpatient care). It is important to know that Medicare helps not just with payment for your physical health needs, such as dialysis treatment or transplantation, but also for some of the costs for mental health care. Taking care of your mental health needs is an important part of adjusting to life with CKD. As with most Medicare coverage, there are certain deductibles and co-payments, in addition to the monthly premium for Part B benefits.

Medicare covers mental health care given by a doctor or a qualified mental health professional, such as licensed social workers, physicians and psychologists. Before a patient

Medicare Coverage for Mental Health Services

By Roberta Bachelder, MA

Medicare covers portions of mental health services, just as it does for hospital and patient care.

gets treatment, he or she should ask the doctor, psychologist, social worker or other health professional if he or she accepts Medicare payment (sometimes referred to as Medicare "assignment"). Medicare assignment means that the doctor or professional delivering the care has a certified Medicare provider number and has agreed to accept the amount that Medicare reimburses for that particular service.

Medicare requires an annual deductible of \$100.00 for outpatient mental health care. This means that you have to pay \$100.00 of your mental health care expenses before Medicare starts to pay. Once you have paid \$100.00 under Part B during a calendar year

for this particular service, Medicare pays the rest of its coordinated portion. Once the deductible is met, Medicare covers 50 percent of the Medicare-approved amount for the mental health professional.

Either the patient, Medicaid or another source of insurance pays the remaining cost. If an individual wishes to use the services of a doctor or mental health professional who does not accept Medicare assignment, then the costs are likely to be more. Check with your supplemental health insurance plan to find out about mental health coverage with that plan. For mental health care in a general hospital or psychiatric hospital, Medicare pays for services in the same way that it pays for all other inpa-

tient hospital care. If an individual with kidney failure receives mental health care in a psychiatric hospital, there is a lifetime limit of 190 days of inpatient care covered by Medicare. In any type of hospital, the patient pays the same co-payments and deductibles as with all other hospital services.

Consider mental health treatment as a natural part of an overall healthy adjustment to the increased emotional demands of dialysis or transplantation. Medicare can help you by sharing the costs, as described above. For more information or help in finding mental health resources in your community, consult your dialysis or transplant social worker. Take care of yourself, your kidneys and your mental health!

Portions of this article are taken from CMS Publications' "Your Medicare Benefits" # 10116 and "Medicare and Your Mental Health Benefits" CMS # 10148. To download a copy, visit the Medicare Web site, www.medicare.gov 

Two NKF-Sponsored Research Projects...

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monitoring for the people identified. This is not intended to replace the social worker's clinical assessment for depression. It is intended to provide a means for early detection of depression risk factors in new individuals on hemodialysis. "Hopefully, this will enable dialysis social workers to be more effective and efficient as we strive to meet the psychosocial needs of those in our dialysis centers," Root adds.

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Laura Root, LCSW, has been a social worker for 10 years. She is a member of NKF's Council of Nephrology Social Workers. 



WHY IS PARENTAL MENTAL HEALTH IMPORTANT?

While many parents make the job look easy, taking care of a child with kidney problems is actually very demanding. It takes dozens of hours each month to go to doctor's appointments, supervise medical care and take in information. It is very important for parents to stay in touch with the amount of stress they are feeling and to take steps to lower their stress before it gets too high. For parents to take the best care of their child, they first need to make sure that their own mental health needs are being met.

WHAT IS MENTAL HEALTH?

Mental health is more than just the absence of a mental disorder. Mental health is a state of well-being in which an individual is aware of his or her own abilities and can manage the stresses that come along with life. Getting and keeping good mental health, like good physical health, takes attention and work.

MONITORING STRESS TAKES PRACTICE

Unfortunately, no one has invented a device that can tell you if your stress is dangerously high. Sometimes we recognize stress only when there are negative consequences. Some warning signs of high stress levels include: more trouble than usual making decisions; difficulty managing anger; less patience with family, friends and health care providers; increased trouble with time management; sadness over little disappointments; changes in sleeping habits, such as insomnia (trouble falling asleep or staying asleep) or too much sleeping; and changes in eating habits (eating too much or too little).

PROBLEMS ASSOCIATED WITH HIGH LEVELS OF STRESS

High levels of stress that last for many weeks and/or months

MONITORING AND MANAGING STRESS: The Importance of Good Parental Mental Health for Children with Kidney Disease

By Arlene C. Gerson, PhD and Barbara A. Fivush, MD

Taking care of yourself is just as important as taking care of your child with CKD.

can lead to serious physical health issues including heart, stomach, bowel and/or bladder problems. Mental health problems such as depression and anxiety with panic attacks can also be caused by high stress. High parental stress can also cause more stress in children.

HOW TO LOWER YOUR STRESS LEVELS

Develop a support system of people who can help you.

Although it is sometimes hard to ask others for help, many people find great joy in helping others. Make a list of the kind of things people in your support system could do to help you so that when someone asks, you will be ready with an answer. If people do not ask about how they can be supportive, let them know!

Get enough sleep. You need to feel rested to be able to deal with parenting challenges. Work out a bedtime routine that allows you to have some time to "put to rest" the day's finished and unfinished tasks before you physically get into bed.

Take time for yourself. Do something for yourself each day that is unrelated to what your child needs and to what other people expect from you. For some parents, exercise is an essential component to managing stress. Once you get in the habit of taking a brief break each day for yourself you will see the value this has for everyone around you!

Enjoy your child. Take pleasure in spending time with your child each week doing something that is not related to his or her kidney problems. Even though it might seem like there are not enough hours in a day to take time just for play, playing is a valuable activity with both short- and long-term benefits for you and your child. Board games, card games, throwing a ball, reading a book, coloring a picture or playing a video game are examples of some playtime activities that most kids enjoy doing with a parent.

GETTING PROFESSIONAL HELP

If parenting stress causes you to have physical or emotional problems that interfere with taking care of your daily responsibilities, you should call a professional for help. Your child's doctor or social worker can direct you to mental health resources in your community. Your minister or rabbi may also offer advice about what kind of treatment and support is available. It is absolutely normal for parents of children with kidney problems to become overwhelmed with stress from time to time and it is important not to feel embarrassed to ask for help. Many parents get support from a counselor or psychotherapist (psychologist, social worker, or psychiatrist) experienced in working with parents who have medically ill children. Be sure to check

with your health insurance provider to find out about your policy's coverage for mental health services.

Internet resources about emotional stress and the importance of good mental health:

www.cdc.gov/niosh/stresswk.html: The National Institute for Occupational Safety and Health (NIOSH)

www.surgeongeneral.gov/library/mentalhealth/: Reports of the Surgeon General on Mental Health

www.who.int/mediacentre/factsheets/fs220/en/print.html: World Health Organization (WHO) fact sheet on mental health

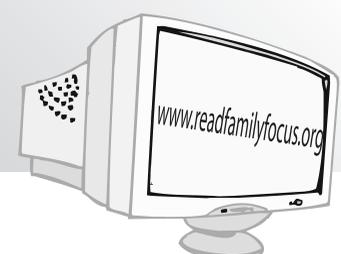
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ADJUSTING TO A DIAGNOSIS of chronic kidney disease (CKD) can be an overwhelming experience. Though all people with CKD are certainly not the same, and individuals respond to the diagnosis in different ways, it is common for people to have strong emotions when faced with the reality of needing to start dialysis. You may feel anger, guilt and shock. You may notice changes in your ability to work, your role in your family or your social life—all of these add to the confusion and upset that most people report feeling as they learn to cope with CKD. For some, both physical and emotional treatment and rehabilitation is necessary.

Most people are able to adjust and return to many of the activities that were present in their lives before CKD, including family, travel, leisure and work. To live well with kidney disease, it is important to care for both the physical and emotional issues that you may experience. Talking with someone about these changes and how they affect you can help you manage your feelings and lower your chances of becoming depressed or anxious, while increasing your chances of making a positive adjustment to living with CKD.

KNOWING WHEN TO GET HELP

Statistics show that up to 40 percent of people with CKD experience depression at some time [1] [2]. Signs of depression include trouble enjoying things that used to be fun, staying away from social situations such as time with family and friends, having a hard time concentrating and feeling sad or down most of the time. If you have one or more of these symptoms it does not always mean that you are suffering from depression, but it is important to discuss your symptoms with a professional

Emotional Rehabilitation After the Diagnosis of CKD

By Megan Prescott, MSW, FMC-NA

Adjusting to a new life with CKD can be difficult. But there are resources available.

who can help you. Other symptoms commonly experienced by people suffering from depression, such as difficulty sleeping and low appetite, can also be symptoms of uremia.

Usually, depression is easily treated. Many people find that talking about their feelings with the dialysis unit social worker or doctor, taking antidepressant medication or seeing a counselor on a regular basis can make a big difference. Usually, a combination of counseling and medication is most effective in preventing or managing depression.



Most people are able to adjust and return to many of the activities that were present in their lives before CKD.

Some people living with a chronic illness have a great deal of anxiety or nervousness. People who have an anxious emotional response to a diagnosis or treatment of CKD can sometimes have trouble sleeping and feel nervous and worried much of the time, often over things that they normally would not worry about. Anxiety can be quite disruptive to people's lives, making it difficult to relax, concentrate and become involved in everyday activities. Some symptoms of depression and anxiety are similar, and anxiety itself is sometimes a sign of depression, so a proper evaluation

by your medical team is important. Anxiety is also treatable with counseling and medication.

THE ROLE OF THE DIALYSIS SOCIAL WORKER

Every dialysis center has a team on site to handle the range of challenges that those people on dialysis or with a kidney transplant face. It is important for you to partner with the members of your dialysis team to make use of the skills that each has to offer. Fortunately, to find out about social support, professional counseling and to learn more about a variety of treatment options for depression, anxiety or difficulty adjusting to dialysis and CKD management, you need look no further than your dialysis social worker. The dialysis social worker is the one member of the health care team with training and experience in dealing with mental health issues. His or her main role is to counsel people with CKD and their family members to help them adjust to the changes and challenges. Social workers can give brief therapy in the dialysis unit to help people better understand and manage some of the feelings and thoughts that can lead to depression or anxiety. The social worker can partner with individuals to identify and solve problems that often come along with the changes of living with CKD and help them develop better coping strategies.

TREATMENT OPTIONS

There are a variety of treatment options available to help with the emotional reactions to a CKD diagnosis. First, you

should talk to your social worker about how you are feeling. In addition to helping you understand your feelings, your social worker may be able to help you learn the best treatment options for your unique experiences.

Among the treatment options available for depression and anxiety are individual and family counseling offered through many counseling centers in the community. Social workers can give you resources for group counseling and support groups for people facing similar challenges. There are a growing number of books, magazines, Web sites and other materials from organizations like the National Kidney Foundation (NKF) which offer educational and emotional support, inspirational materials and information about living with CKD. *Coping Effectively: A Guide for Patients and Their Families* is one brochure available through the NKF by calling 800-622-9010 or visiting www.kidney.org

Dialysis social workers can help you find these resources and taking advantage of them can help you feel less alone and more like an important part of the large network of people living well with CKD.

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CONGRESS AND MEDICARE STAFF are paying more attention to the mental health of Medicare beneficiaries these days. This is clear in the Medicare Prescription Drug, Improvement and Modernization Act of 2003, and in two draft regulations published on February 4, 2005 by the Centers for Medicare and Medicare Services (CMS).

The Medicare Prescription Drug, Improvement and Modernization Act of 2003 makes many changes in Medicare. Notably it provides that new beneficiaries are entitled to a "Welcome to Medicare" initial preventive examination. (In the past, Medicare has paid for a doctor's office visit only if a beneficiary was sick.) Beneficiaries who get their first preventive examination within six

One of the Proposed Rules concerns dialysis clinics and the other relates to transplant centers.

months after the effective date of their Medicare Part B coverage period are eligible for this service. Not only is the preventive examination a welcome advance in the Medicare program but the rules that carry out this law state that the first preventive examination should include a review of the beneficiary's risk factors for depression (including past history of depression or other mood disorders) based on the use of an appropriate screening instrument, which the doctor or other qualified non-physician health care professional may select from various available screening tests for this purpose. Medicare will not pay for a

Legislative and Regulatory Developments Affecting the Mental Health of People with CKD

By Dolph Chianchiano, JD, MPH

An update on Congress and Medicare.

visit to both a doctor and a non-physician health care professional, however, for this screening.

One of the Proposed Rules concerns dialysis clinics and the other relates to transplant centers. Both recognize the need to evaluate the psychosocial issues faced by individuals who are served by these facilities.

The first reference to psychosocial concerns in the Proposed Rule, "Conditions for Coverage for End Stage Renal Disease Facilities" would make dialysis facilities: (a) inform people on dialysis of their right to be treated with respect and dignity, and (b) recognize each person's individuality and personal requirements, as well as alert staff to be sensitive to the individuals' psychosocial needs and ability to cope with end stage renal disease (ESRD).

In another draft section, CMS calls for a comprehensive assessment of all people who are new to dialysis and periodic re-assessment of those already on dialysis. CMS states that it is fitting and necessary for every assessment to focus not only on the person's medical needs, but also on his or her psychosocial and rehabilitation needs. In fact, evaluation of psychosocial needs is one of 13 assessment criteria that the agency proposes to require. Although the existing regulations require a patient care plan, they do not require a comprehensive assessment before the development of the care plan. The addition of an assessment is one of the major

improvements that would come from the Proposed Rule. Some of the other criteria include evaluation of family and other support systems and evaluation of vocational and physical rehabilitation status and potential.

Monthly re-assessment would be required if an individual experiences very long or frequent hospitalizations, a major setback in health status, a *significant change in psychosocial needs* or poor nutrition. Under the Proposed Rule, new patients have to have an assessment within 20 days and another assessment after three months. Stable patients have to be re-assessed annually thereafter. However, as per the Proposed Rule, patients who are not stable should be re-assessed on a monthly basis. CMS acknowledges that mental health should be taken into account when considering whether a person is stable.

A third section in the Proposed Rule for dialysis clinics would require that the plan of care for the person on dialysis include measurable and expected outcomes and estimated timetables to meet his or her medical and *psychosocial needs* as identified in the first and following assessments. When completed, this section would also state that the plan of care must outline all of the services that would be given to reach and keep up the expected outcomes of care.

The Proposed Rule would also require dialysis units to have a quality assessment and quality

improvement program. In its response to the draft regulation, the National Kidney Foundation insisted that such quality assessment and quality improvement programs include mental health.

The second Proposed Rule, "Requirements for Approval and Reapproval of Transplant Centers To Perform Organ Transplants" also addresses psychosocial concerns. It says that transplant centers must use a qualified social worker to evaluate a transplant recipient's psychosocial needs, participate in care planning for the transplant recipient and identify community resources to assist the person and his or her family.



Dolph Chianchiano, JD, MPH

A new provision in the Proposed Rule for transplant centers would require that a likely transplant candidate receive a psychosocial evaluation before being placed on the waitlist. In explaining this requirement, CMS states: "Although a person may be medically suitable for transplantation, he or she may have inadequate social support or coping abilities, or may be unable to demonstrate adequate adherence to a therapeutic regimen, which could then put the graft, and ultimately the transplant recipient, at risk."

Family Focus readers who would like more information about the Medicare issues discussed in this article can send an e-mail to:

info@kidney.org



FEELING WELL EMOTIONALLY may be challenging when coping with physical illness. For many people, how an illness will affect one's independence, family life, ability to work and financial picture becomes nearly as important as the physical symptoms or treatment of the illness. Poor physical health and the worries that go with either chronic kidney disease (CKD) or being on dialysis may bring about feelings of depression. Depression is not just feeling down in the dumps or blue now and again. And it does not affect only your mood, as it is a true medical disorder that may affect your thoughts, feelings, physical health and behaviors. It is common for people who have a chronic illness, such as CKD, to also experience depression. It is not a sign of weakness, nor is it something that you can will yourself to snap out of.

Understanding more about depression may be helpful in overcoming it. Here are some facts and figures that show how common depression is:

- Depression is the leading cause of disability in the United States.[1]
- Depression is now the leading cause of disability in the world.[2]
- Chronic illness increases one's chance for depression.[3]
- Some studies have shown that 20-25 percent of people on dialysis are depressed.[4,5]
- Depression is treatable and most people who are treated show improvement.[3]

Kidney disease experts think that depression among people on dialysis is both underdiagnosed and undertreated.[6,7] When untreated, depression can cause unnecessary pain and suffering for those on dialysis and their families and symptoms can last for weeks, months or even years. Among its many effects, depression can impact

Drive Out Depression and Feel Better

By Barbara K. Campbell, MSW, ACSW, LSW

Learning about depression can help you to overcome it.

your ability or desire to follow treatment recommendations, such as following a proper diet and getting adequate dialysis, and to take part in your overall plan of care. In addition, it has been shown that depression in people with kidney failure can lead to a higher chance of early death compared to people on dialysis who are not diagnosed with depression.[8]

Learning about the signs and symptoms of depression may be a good first step in the pursuit of feeling better. Here are some things to look for, especially if they have occurred nearly every day for at least two weeks:

- FEELING** sad or empty most of the day
- LOSS** of interest or pleasure in life
- DIFFICULTY** concentrating or inability to make decisions
- FEELING** worthless
- THOUGHTS** of suicide.

It is often useful to talk to family members or friends to see if they have noticed changes in your moods or behaviors that you may not have noticed.

If you are on dialysis, your facility health care team has resources and expertise to help you deal with your mental health issues and emotional wellness. In particular, there is a master's-prepared social worker who has the training and background to help you address the complex issues of adjusting to a chronic disease. The Medicare guidelines for dialysis and kidney transplant programs mandate the duties of licensed master's-prepared social workers in dialysis and transplant facilities to "support and maximize the social functioning and adjustment of the patient." The social worker can help you find ways to better cope with the challenges you may be facing. There are impor-

tant things you can do to help yourself when facing depression. (See sidebar: How to Help Yourself If You Are Depressed.)

If you think you may be depressed, understand that depression is treatable. Talk to your doctor or social worker about your concerns, and to see if you could benefit from treatment for depression. Treatment options may include prescription antidepressant medication from your doctor, supportive counseling from your dialysis facility social worker or counseling from other professionals in your community. Depression is most effectively treated when you work with your care team to decide on the best treatment method for you and when you are committed to sticking with the treatment plan.

You CAN regain feelings of emotional well-being. Take action today to feel better.

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if you are depressed

DEPRESSIVE DISORDERS may make one feel exhausted, worthless, helpless and hopeless. Such negative thoughts and feelings make some people feel like giving up. It is important to realize that these negative views are part of the depression and typically do not accurately reflect the actual circumstances. Negative thinking fades as treatment begins to take effect. Some things you can do include:

- **SETTING** realistic goals in light of the depression and assume a reasonable amount of responsibility.
- **BREAKING** large tasks into small ones, setting priorities and doing what you can as you can.
- **TRYING** to be with other people and to confide in someone; it is usually better than being alone and isolated.
- **PARTICIPATING** in activities that make you feel better.
- **EXERCISING**, going to a movie, a ballgame, or participating in religious, social or other activities may help.
- **EXPECTING** your mood to improve gradually, not immediately. Feeling better takes time.

Taken from *Depression*, a 2002 brochure from the National Institute of Mental Health.

What You Should Know About Medicare's New Drug Coverage

YOU MAY ALREADY HAVE HEARD ABOUT THE NEW MEDICARE PRESCRIPTION DRUG COVERAGE (also called Medicare "Part D"). If you have Medicare, you can join a Part D plan. Your income, drugs you need and plan choice will affect how much you save with Part D. Sign up from November 15 to December 31, 2005 to get coverage as early as January 1, 2006. After May 15, 2006 you may have to pay a higher premium.

YOU MAY QUALIFY for extra help under a "limited income subsidy." If you are approved, your income will affect whether the subsidy pays all or part of your monthly Part D premium, your deductible and how much your co-pay will be. You could pay as little as \$1 to \$5 per drug. If you have both Medicare and Medicaid, SSI or get help from your state paying Medicare premiums and you got a letter from the Centers for Medicare and Medicaid Services (CMS), you do not need to apply for this extra help. Otherwise,

you can apply at your Social Security or Medicaid office.

MEDICARE PART D can work with or replace other drug coverage you have now. If you have both Medicare and Medicaid, Medicare Part D will replace Medicaid starting January 1, 2006. If you have a Medigap plan, union, employer, or retiree plan, your plan will let you know how it compares with Medicare Part D. If it is at least as good as Medicare Part D and you wait to sign up for Part D, you can join later without paying a higher premium. But if your current plan is not at least as good as Part D, you may pay more for Part D when you join.

IF YOU HAVE CHRONIC KIDNEY DISEASE (CKD), take the time you need to choose the best plan for you. Think about what drugs you take now. Ask your doctor what drugs you should take to keep you healthy and what drugs you may need if you change treatments or your health changes. You will save more money with a "kidney friendly" plan, one that covers

most of the drugs your doctor tells you. Some drugs covered by Medicare Part D that people with CKD often take include those for bone disease, high cholesterol, diabetes, heart problems, high blood pressure depression and anxiety.

STARTING OCTOBER 13, 2005, you will be able to call 800-MEDICARE or visit www.medicare.gov to see what Part D plans insurance companies offer in your area and what drugs they cover. You will have a choice of at least two plans.

You will have different deadlines to join Part D based on your income and assets.

→ Join between November 15, 2005 and December 31, 2005 to get coverage on January 1, 2006.

→ If you have Medicare and Medicaid, and do not sign up by December 31, 2005, Medicare will choose a plan for you. What Medicare chooses may not cover as many drugs as a plan you choose.

- If you do not have Medicaid, but have SSI or your state helps you pay your Medicare premium, you must sign up by May 15, 2006 or Medicare will choose a plan for you. Again, it is best to choose the plan that works best for you.
- Anyone else who has Medicare and other drug coverage that is not at least as good as Part D must join by May 15, 2006 to pay the lowest premium.
- If you get Medicare later and have drug coverage that is not at least as good as Part D, you will have six months to join Part D for the lowest premium.

THE NATIONAL KIDNEY FOUNDATION (NKF) wants to help people with CKD, like you, learn how Medicare Part D may affect their health care. Look for more on Part D in future issues of *Family Focus*. To find out more, call 800-MEDICARE (800-633-4227) or visit www.medicare.gov, www.medicarerights.org or www.kidneydrugcoverage.org

THERE'S ONLY ONE WAY TO FACE DIALYSIS. TOGETHER.

No one should have to face dialysis alone, and thanks to Amgen, no one has to. Because Amgen—the world's largest biotech company—is dedicated to helping you deal with the many issues that can go along with kidney failure and dialysis.

For example, many people with chronic kidney disease on dialysis develop *anemia*, a shortage of red blood cells. Anemia can make you very tired and unable to complete routine daily tasks. Anemia may also lead to more serious problems like heart disease.

An important gland called the *parathyroid* can also be affected by kidney disease, leading to a condition called *secondary hyperparathyroidism (secondary HPT, for short)*—which can cause serious problems in your bones and blood vessels.

Amgen offers an entire family of products and services to help support people on dialysis and the people who love them. Because we're not just dedicated to improving the lives of people with kidney failure, we're dedicated to protecting them.

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