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Emotional Wellness Is a Key to Renal Rehabilitation

There is no question that life after kidney failure can be challenging, both physically and emotionally. But, for many people on dialysis, it is the hope of a fulfilling life that makes the journey to overcoming these challenges worth the effort.

While people with ESRD face many physical and emotional changes related to their disease and its treatments, strategies for coping do exist. The basis for successful adjustment includes two key elements: optimal clinical care to improve how patients feel, and rehabilitation management to improve their ability to function.

Without these elements, good long-term outcomes are not possible. In essence, patients *can* live long, enjoy a high quality of life, and live independently and productively—*if* they are first able to function, both physically and mentally.

THE IMPACT OF EMOTIONS

While the physical effects of renal disease are often apparent, the emotional effects may not be. Their impact and importance, however, cannot be overlooked. From the start, people on dialysis are confronted with a number of powerful emotions. Among

the most common are fear—what does the future hold? Anger—why me? And loss of control—will I be dependent on others?

These emotions can be triggered by several factors. Lack of information plays a major part. For example, a 1998 Life Options Patient Opinion Study showed that, at the start of dialysis, many patients don't know what to expect—and they often fear the worst.

According to the study, many new patients believed death was imminent and began preparing for it, both psychologically and practically.¹ Said one patient, "I didn't know people could live as long on dialysis. I thought if I didn't get a kidney within so many years, that that was going to be it, that dialysis wasn't a long-term thing."

LIFE CHANGES

After the initial adjustment to kidney failure, people on dialysis continue to have many life changes. Quality of life is often compromised, for example, by fatigue, and challenges in planning meals and limiting fluids. For many patients, this may be compounded by the time and energy required of dialysis treatment. In addition, patients' social and role responsibilities

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Focus on Emotional Well-being

For people on dialysis, living long and well is a very real possibility—a possibility that relies on a combination of important factors. Among these factors are optimal clinical care and rehabilitation, which work together to promote patients' physical and emotional well-being. In turn, physical and emotional well-being are prerequisites to adherence, self-care, exercise, and other activities of patient self-management.

All of these elements—from clinical care to self-management—are inter-dependent and must be addressed together to promote the long-term goals of

survival, wellness, productive activity, and quality of life for people on dialysis.

This issue of the *Renal Rehabilitation Report* (RRR) focuses on one aspect of this complex of factors—emotional well-being—and how it fits into the overall dialysis care equation. It also offers a look at causes, effects, and strategies for overcoming depression—an emotionally debilitating condition that affects many people on dialysis. For more information on helpful resources, contact the Life Options Rehabilitation Resource Center (RRC) at (800)468-7777. ♦

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From Adaptation to Advocacy

Overcoming the Emotional Challenges of Kidney Failure



Michelle Horn. "But, just because your kidneys stop working, that doesn't mean you have to stop living."

Horn has adopted this outlook on her own journey of acceptance and adjustment to kidney failure and its treatments—a journey that has seen her through many medical, physical, and emotional challenges.

"A lot of people think that once you start dialysis, everything else is supposed to stop," says 27-year-old hemodialysis patient

angry. I would ask myself, 'Why me?' This was supposed to be a happy time in my life."

For Horn, losing a sense of independence was also difficult. "I've always been an independent person," she says. "And, for the first time, I had to depend on someone else for just about everything. I felt as if I had control of nothing in my life."

These feelings affected Horn's outlook on dialysis and on life in general. "I remember thinking, 'How do people survive for 20 years on dialysis if this is how it is?'" she recalls.

EMERGENCY DIALYSIS

In January of 1995, Horn's kidneys began to fail. At the time, she was 24 weeks pregnant and was hospitalized with pre-eclampsia and a rare blood disorder called hemolytic uremic syndrome (HUS).

Just 1 week later, when Horn's condition could no longer be medically controlled, her daughter Anna Kate was delivered by C-section. "She only weighed 1.7 pounds," Horn recalls. "The doctors gave her a 50/50 chance for survival."

Horn's own medical situation was just as critical. She was placed in intensive care and began hemodialysis 6 days later. Over the next 11 weeks, she also underwent more than 30 blood transfusions and chemotherapy to treat her HUS, which is now in remission.

After nearly 3 months, Horn was released from the hospital. Her daughter came home just 1 day later. "She weighed only 3 pounds," Horn recalls. "But, Medicaid could no longer pay for her to stay in the hospital."

"Being involved in your treatment makes you responsible for what happens in your life. It motivates you to do what has to be done—you have nobody else to blame."

—Michelle Horn

TURNING THINGS AROUND

In time, Horn was able to absorb all of the changes in her life, and she then began the process of adjustment by focusing outside herself. "It just took some time," she says. "It would have been very easy to sit back and have a pity party, but I had more than just myself to think about. I had a baby who depended on me."

Horn also had a strong network of family and friends to help her get through the most difficult times. "I had a lot of support from my family, friends, and church community," she says. "In the beginning, my mom had to miss a lot of work to help me out."

Horn's adjustment process was further aided when her access problems were resolved. "At first, having a working access was so final," she explains. "But, in the end, it helped me to accept things a bit more—it helped me to get rid of the denial. I started thinking, 'Maybe this is okay, maybe it's not so bad.'"

EMOTIONAL STRUGGLES

For Horn, who was dealing with extreme fatigue and ongoing access problems, adjusting to kidney failure and a premature baby was overwhelming at times. "My body was pretty weak," she says. "And, when you're not feeling well physically, it's hard to feel well emotionally."

Horn soon found herself battling fear, anger, and a variety of other emotions that eventually led to depression. "I was afraid of dying—especially since I had a new baby to think of," she says. "And, I remember being

SELF-MANAGEMENT

Horn also feels that things became easier as she learned more about kidney disease and its treatments. "Because I began dialysis on an emergency basis, there really wasn't time for anyone to explain what was happening to me. I had no idea what was going on," she explains. "So, when I was able, I began looking for information—on the Internet, in books, and from my care team."

As a result, Horn switched to CCPD for a short period of time. "PD just worked out better for me then," she

explains. “It gave me more flexibility, and it allowed me to be home more with my daughter.”

This type of decision-making has been a key to success for Horn. “Being involved in your treatment makes you responsible for what happens in your life,” she explains. “It motivates you to do what has to be done—you have nobody else to blame.”

BECOMING INVOLVED

Horn feels that having outside goals, interests, and activities helps emotional wellness. “A lot of people on dialysis are very apathetic,” she says. “They come and dialyze, then they go home and sleep.”

For Horn, a strong sense of purpose comes from raising her daughter, who is now a healthy, active 5-year-old. With help from vocational rehabilitation, Horn also began taking college courses 4 years ago. A Dean’s list student, Horn now dialyzes at 5:30 am to fit school into her schedule. “School is really good for me,” she says. “It helps my feelings of self-worth—I feel that I’m really *doing* something.”

Horn also feels that it is important for her to pass along all she has learned to other patients. She is president of her unit’s patient advocacy group, and she volunteers for the Alabama Kidney Foundation.

LOOKING TO THE FUTURE

Though Horn is back on hemodialysis after a failed transplant 2 years ago, her outlook remains positive. She feels strong, both physically and emotionally, and she plans to graduate from college in October. After that, she would like to become a Medical Assistant or go on to medical school.

Though she knows how difficult it can be to adjust to kidney failure and dialysis, Horn feels the keys to success ultimately lie within each individual patient. “Your doctor can tell you what to do, but he can’t force you to do it,” she says. “You are the only one who can make things better—or make things worse.” And she is living proof of this. ♦

“Your doctor can tell you what to do, but he can’t force you to do it. You are the only one who can make things better—or make things worse.”

—Michelle Horn



LIFE OPTIONS UPDATES

Life Options Website Highlights New Initiatives

Life Options offers many programs and publications that focus on all aspects of renal rehabilitation, including emotional well-being. On the Life Options website at www.lifeoptions.org, several resources for patients and professionals have recently been added.

- Download and photocopy the *Keys to a Long Life* educational tools. These include easy-to-read fact sheets for people on dialysis that cover vascular access, the dialysis machine, fluid and dialysis, hemodialysis adequacy, anemia, and rehabilitation. Patient Interest Checklists and Goal-setting Worksheets are also included.
- Read the newly-launched *Rehab Digest for Nephrologists*. This publication includes current

dialysis- and rehabilitation-related abstracts from peer-reviewed journals. Don’t miss the editorial by John Sadler, MD, who asks other nephrologists, “Are You Part of the Silent Majority?”

- See the updated *5 E’s Bibliography* for renal professionals, which includes a host of new citations from a variety of journals, and can be useful in education, research, and article development.

The *Keys* materials and the *Rehab Digest* are also available in print versions. For more information, contact the Life Options Rehabilitation Resource Center (RRC) at (800)468-7777 or send an e-mail to us at lifeoptions@medmed.com ♦

*ESRD and Emotional Health***Taking a Closer Look at Dialysis and Depression**

Depression is a “whole body” illness—one that affects the body, mood, and thoughts.

Emotional well-being, like physical functioning, is basic to good quality of life.¹ However, maintaining emotional health can be a challenge for people on dialysis. Most renal patients experience a wide range of feelings as they adjust to the realities of kidney failure and dialysis. If these emotions become overwhelming, they can create barriers to living long and living well.

For people on dialysis, the emotion that causes the “most common and significant clinical problem” is depression.² There is widespread agreement that “a high frequency of debilitating depression exists in patients with renal disease.”³ A 1999 report on the Dialysis Outcomes and Practice Patterns Study (DOPPS) showed that 21.2% of 8,601 U.S. hemodialysis patients in the study were diagnosed with depression.⁴

DEFINING DEPRESSION

While many people experience occasional sadness caused by life’s disappointments, this is not the same as clinical depression. According to the National Institute of Mental Health (NIMH), depression is a “whole body” illness—one that affects the body, mood, and thoughts.”⁵ Depression impairs a person’s ability to function in everyday situations.

It is a chronic “state of feeling sad or blue,” often paired with a sense of hopelessness, and changes in appetite and sleeping patterns.⁶ NIMH describes three types of clinical depression:

- **Major depression** involves a combination of symptoms (see *Recognizing the Symptoms of Depression*, at left) that interfere with the ability to work, sleep, eat, and enjoy pleasurable activities. Unless treated, these symptoms may last for weeks, months, or even years, and can increase the risk of suicide. Episodes of major depression may occur once, twice, or several times in a person’s lifetime.
- **Dysthymia** is a less severe form of depression involving long-lasting, persistent symptoms that may not be disabling, but can keep people from feeling good and functioning at “full steam.”
- **Bipolar disorder** (manic-depression) is less common and exhibited by severe mood swings—from extreme “lows” (depression) to extreme “highs” (mania). Mania is characterized by symptoms such as excessive elation, unbounded energy, severe insomnia, and impulsive, even dangerous, behavior.

CAUSES OF DEPRESSION

For people on dialysis, the onset of depression often involves a combination of factors. In addition to renal failure, people on dialysis often have decreased strength and energy; loss of independence, mobility and leisure time; and changes in workplace and family roles and relationships. If patients do not have the emotional skills or support to come to terms with these changes, depression may result.

EFFECTS OF DEPRESSION

Depression affects people on dialysis in many ways. Left untreated, it can cause unnecessary pain and suffering for dialysis patients and their families, and can greatly reduce quality of life.⁷ Depression has also been associated with a higher risk for hospitalization and lower rates of survival among people on dialysis.^{3,4}

Depression can also have a negative impact on renal rehabilitation efforts. It can, for example, interfere with proper nutrition, adequate dialysis, and control of fatigue— aspects of clinical management that form the foundation for emotional and physical functioning. It can keep patients

Recognizing the Symptoms of Depression

Talk with your patients about the symptoms listed below. If five or more of the symptoms are present for 2 weeks, or if they interfere with work or family life, treatment for depression should be considered.

Symptoms of Depression

- Depressed mood—feeling sad, empty, or tearful
- Little or no interest/pleasure in doing activities
- Insomnia (can’t sleep) or hypersomnia (excessive sleep)
- Slowed or restless movements
- Persistent fatigue or loss of energy
- Feelings of worthlessness or excessive/inappropriate guilt
- Difficulty concentrating or making decisions
- Significant weight gain or weight loss when not dieting
- Recurrent thoughts of death or suicide (not fear of dying)

Adapted from the American Psychiatric Association’s *Diagnostic and Statistical Manual of Mental Disorders* (DSM-IV), 1994

from participating in rehabilitation activities, including education, exercise, and employment or hobbies.

DIAGNOSING AND TREATING DEPRESSION

Most people with clinical depression—even the most serious cases—*can* be treated successfully through medications, psychotherapy (also called talk therapy), or a combination of both. In recent years, advances in pharmacology have greatly increased the use of antidepressant medications for people on dialysis. Talk therapy may also be used to help patients learn new coping behaviors or change negative styles of thinking. With proper treatment, improvement can often be seen in a matter of weeks.

Assessment and treatment of depression in people on dialysis has the potential to improve outcomes and enhance quality of life.⁶ The first step in treating depression is to recognize the potential for its development.⁷ Recognizing and diagnosing depression can be difficult, however, since many of its symptoms are similar to those of uremia or other conditions associated with kidney failure.²

Aside from clinical depression, for example, “depressed” mood has been associated with many physical conditions, including imbalances of calcium, sodium, and parathyroid hormone. Anemia can cause lack of pleasure and low energy levels, as can depression. Weight changes may be caused by fluid gains or loss of appetite caused by uremia—or they may result from depression. Problems with concentration may be the result of depression or of sleep disorders, which are common among people on dialysis.⁸

Accurate diagnosis may also be complicated by the fact that depression can be very unpredictable. “Depression can affect a patient at any time during the course of dialysis,” explains dialysis social worker Wendy Funk Schrag, LMSW. “Because there is no predictable pattern, I watch for signs of depression all the time—particularly after hospitalizations or other major life changes.”

THE ROLE OF THE SOCIAL WORKER

Dialysis social workers can play a critical role in helping people on dialysis adapt to the emotional challenges of kidney failure through encouragement and counseling. Master’s level dialysis social workers with clinical training are qualified to assist patients and families with the

psychosocial aspects of kidney failure, including the assessment and treatment of depression.

Social worker Mary Beth Callahan, ACSW/LMSW-ACP, makes an effort to informally screen dialysis patients for depression during each contact, which is at least weekly. Every 6 months, she administers the Medical Outcomes Study Short Form 36 (see *Assessing Emotional and Mental Health*, below). Many psychosocial issues are considered during assessment for depression, including risk factors such as a patient’s coping style, previous history of mental illness, the availability of social support,⁹ marital status, living arrangements, and employment status.

For continued or severe depression, the dialysis social worker can determine if a referral to an outside professional is needed—preferably someone who is both trained in the treatment of depression, and who understands the needs/experience of ESRD patients.

FAMILY SUPPORT

In addition to professional counseling, there is strong evidence that social support, particularly from family members, can influence survival, wellness, and outcomes in chronic

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Assessing Emotional and Mental Health

The BDI-II (see below) is a valuable tool for assessing depression. The ECB Questionnaire is used to assess the need for immediate social work intervention. The KDQOL and SF-36 are self-report instruments often used with ESRD patients to assess health-related quality of life, including physical, emotional, and mental health.

- **Beck Depression Inventory-II (BDI-II)**
The Psychological Corporation, (800)211-8378
- **ECB Renal Patient Questionnaire**
National Kidney Foundation, Inc., (800)622-9010
- **Kidney Disease Quality of Life (KDQOL)**
RAND, (202)296-5000, ext. 5611
- **Medical Outcomes Study Short Form 36 (SF-36)**
QualityMetric, Inc., (888)947-9800

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illness.¹⁰ For this reason, social workers often enlist the help of family members. Social workers may also conduct education and therapy sessions for patients' families in an effort to improve coping skills and understanding.

Family and friends can do several things to help their loved ones conquer depression:

- Encourage the person to seek treatment
- Support adherence to the treatment plan, including medications
- Offer emotional support by listening
- Try to include the person in activities, but do not expect too much too soon

THE ROLE OF THE PATIENT

While dialysis patients with depression cannot simply “pull themselves together,” and get over their illness, there are things they themselves *can* do to overcome its effects:⁵

- **Ask for help.** Seeking help is nothing to be ashamed of. The dialysis social worker is an excellent resource for mental health counseling options.
- **Stay connected to people.** Try not to spend too much time alone. Peer support groups can be very helpful.
- **Stay physically active.** Exercise and activity promote mental health.
- **Set realistic goals.** Don't take on too much responsibility right away. Focus on your own health until you feel better.
- **Break large tasks into small ones.** Tackle them as you are able.
- **Make decisions with care.** Consult those who know you well—or wait until depression has lifted—before making major life decisions.
- **Do not expect too much too soon.** Overcoming depression takes time.

Coping with Renal Disease

Below are resources that can help people on dialysis cope with depression and other emotions related to kidney failure and its treatments.

Life Options Materials (single copies free)

(800)468-7777, www.lifeoptions.org

- *Bridging the Barriers: For Patients and Their Families*
- *New Life, New Hope: For Families & Friends of Renal Patients*

American Association of Kidney Patients (AAKP)*

(800)749-2257, www.aakp.org

- *aakpRENALIFE* (for AAKP members—includes inspiring patient stories)

National Kidney Foundation (NKF)*

(800)622-9010, www.kidney.org

- *Coping Effectively: A Guide for Patients and Their Families*
- *Coping* (video, available to professionals only; call 1-800-28-AMGEN)

National Mental Health Association*

(800)969-6642, www.nmha.org

- *Clinical depression: www.depression-screening.org*

National Institute of Mental Health

(800)421-4211, www.nimh.nih.gov

- *Depression*, publication no. NIH-00-3561

* Ask about local chapters or affiliates, support groups, and free educational materials.

A HOPEFUL OUTLOOK

For those who suffer from depression, the effects can be physically draining and emotionally and socially debilitating. Fortunately, with the right resources and support, depression is a condition that people on dialysis *can* overcome.¹ ♦

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*Adapting to ESRD and Dialysis***Emotional Wellness Is a Key to Renal Rehabilitation** *(continued from page 1)*

may be altered due to such issues as problems with travel, impotence, and changes in body image.

Such changes are almost certain to have an emotional impact. “Fatigue, weakness, nausea, physical limitations, loss of functioning, changes in bodily appearance, and the cumulative impact of struggling with a life-threatening illness will inevitably affect the patient’s feelings,” explains Laurie Rosen, MSW, in a recent article on psychological factors in ESRD.²

FINDING SOLUTIONS

Fortunately, there are ways to manage the ongoing emotional effects of kidney disease. For example, education, social support, and self-care have been shown to foster coping skills among people on dialysis.³ Patients themselves have cited additional strategies for emotional adjustment, including adherence to prescribed treatments, positive attitude, exercise, and engagement in life.¹

EDUCATION

Research has shown that early education—about renal disease, its treatments, and the potential to live long and productively—can aid in overall adjustment and decision making for people on dialysis. More specifically, learning about topics including kidney failure, treatment choices, medications, and the renal diet can help dialysis patients maintain a sense of control—a factor linked to improved adherence⁴ and life satisfaction.

In one recent study, education was shown to be a positive predictor of physical *and* mental health for people on hemodialysis.⁵ Informed patients have also reported fewer symptoms,⁶ as well as more confidence in their ability to manage the symptoms they do have.

ENCOURAGEMENT AND SUPPORT

Supportive social environments have been shown to have a positive impact on adjustment for people with renal disease.⁷ Encouragement—especially from families and dialysis staff—can increase patients’ autonomy, control, and participation in treatment. Further, a number of studies show that patients who are encouraged to learn about their treatment have better outcomes and improved quality of life.^{5,8} Such patients may take more responsibility for things they can control, including exercise, remaining actively engaged in

life, and sticking to the renal meal plan. For example, one study⁹ showed that the support patients received from their families and dialysis staff was a major factor in promoting employment—an activity that contributes to emotional health.

SELF-MANAGEMENT

With education and support, people on dialysis can begin to make careful, informed decisions about their treatment. Self-management can help patients regain control over certain aspects of their lives and their health—a step that can directly influence emotional well-being and other important outcomes.

For people on dialysis, successful self-management begins with a positive attitude and a belief that living long and well is within their control. For example, in one study, “patients who saw their illness as an opportunity for personal growth were happier than those who reacted to it with blame and avoidance.”¹⁰

Several self-management activities noted below have been shown to contribute to patients’ emotional health.

Self-Care

Patients’ involvement in self-care can positively affect their adherence with treatment regimens.¹¹

Further, patients trained for self-care hemodialysis have reported better subjective quality of life—including social and role functioning, and emotional well-being.⁵

Exercise

Exercise can enhance the potential for physical activity and improved quality of life.¹² Exercise has been shown to help reduce fatigue, alleviate depression, improve social adjustment, and help patients feel more independent and in control of their lives and their health.¹²

Employment and Engagement

Employment and involvement in school have also been shown to promote greater acceptance of kidney failure¹⁰—and accepting and adjusting to illness positively influences quality of life. In addition, employment can increase self-esteem and provide a source of identity and a sense of contributing to society.¹³

THE ROLE OF DIALYSIS STAFF

People on dialysis can significantly influence their own long-term outcomes. However, dialysis professionals can

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*Adapting to ESRD and Dialysis***Emotional Wellness Is a Key to Renal Rehabilitation** *(continued from page 7)*

have a major impact—positive or negative—on how patients deal with the life changes caused by kidney failure and its treatments.

According to the authors of a recent study on adjustment and acceptance of ESRD, “The role of the healthcare professional is to encourage and, where possible, to enable patients to accept responsibility for their health and well-being and to fulfill their obligations within the family and society.”¹⁴

Prospects for renal rehabilitation increase if dialysis staff convey a positive attitude and show a belief in patients’ potential to live long and well on dialysis. In addition, staff encouragement toward rehabilitation goals helps patients form positive attitudes that will allow them to participate actively in life. Further, staff can provide valuable information on a wide range of topics—particularly things patients are able to control, like adherence, exercise, and self-care.

At the facility level, adjustment can be aided by offering flexible dialysis schedules, work-related goal-setting, and referral to vocational rehabilitation, as well as opportunities for patient-to-patient communication and meaningful staff interaction.

Overcoming the emotional challenges of kidney failure and dialysis is an important and necessary step toward renal rehabilitation. It is a step that is most effectively promoted by educating patients that they *can* achieve a long and full life on dialysis—and by providing the tools and support that will help them to do so. ♦

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