



National Kidney Foundation™

# PEER Support

- Helps kidney patients adjust to living with a chronic illness
- Improves well-being and survival
- Decreases feelings of isolation and depression
- Leads to better self-management
- Improves the health of the helper

# Benefits of Peer Support

**IN PEOPLE WITH CHRONIC KIDNEY DISEASE**

Studies show that peer support is effective for patients with kidney disease and in long-term dialysis therapy. Peer support has also been shown to be effective for patients with cancer, diabetes, heart disease, depression, HIV/AIDS, multiple sclerosis, brain injury, burns, amputation, and numerous other health conditions.

*The National Kidney Foundation (NKF) has a new program that matches patients in need of support with peer mentors who are positive role models.*

Supported by the Amgen Foundation



# Benefits of Peer Support

Living with a chronic illness requires education and emotional support to help make the necessary changes to cope and adapt. Yet in today's world, meeting these needs is a challenge for both patient and clinician alike. There is limited time during office visits for clinicians and their staff to alleviate all the fears or answer all the questions a patient might have, especially if the patient is newly diagnosed or is having trouble coming to terms with the disease. In addition, clinicians cannot provide the perspective of shared experience and common concerns.

Programs that mobilize peer support can help. They are effective and economical. Peer support programs use laypeople – often someone who is living with the same disease – to assist other patients in managing their own health.

Peer support is reported to be beneficial to patients with kidney disease and in long-term dialysis therapy.<sup>1-7</sup> It has also been shown to be effective in patients with cancer,<sup>8-16</sup> diabetes,<sup>17-19</sup> heart disease,<sup>20-23</sup> depression,<sup>24, 25</sup> HIV/AIDS (human immunodeficiency virus and acquired immune deficiency syndrome),<sup>26-32</sup> multiple sclerosis,<sup>33</sup> brain injury,<sup>34</sup> burns,<sup>35</sup> amputation,<sup>36</sup> and numerous other health conditions.

## SOCIAL SUPPORT IMPROVES SURVIVAL

Patients who are living with chronic kidney disease or starting treatment for kidney failure face many challenges. The emotional and economic stresses can feel overwhelming to patients and their families. This can have a profound effect on their quality of life and response to treatment. It can lead to depression and anxiety due to factors that include:<sup>37</sup>

- feeling poorly
- the need to make significant changes in lifestyle
- functional limitations and the need to adhere to treatment regimens (including dialysis schedules, diet prescription, and water restriction)
- comorbidities and related hospitalizations
- symptoms caused by advanced kidney disease or kidney failure
- fears and uncertainty about death, disability, and sexual decline
- loss of one's role and identity (including loss of employment)

Studies show that depression in patients with chronic disease is common. Feroze and colleagues report that it is 3 times higher in patients with kidney failure than in the general population.<sup>37</sup> It is also an independent risk factor for mortality and morbidity.<sup>37-41</sup> According to Drayer and colleagues, depressed patients with kidney failure have 4.1 times the mortality rate of nondepressed patients (see Figure 1).<sup>42</sup> Moreover, there is a strong

association between suicide and a depressed state of mind.<sup>43, 44</sup> Depression is estimated to account for a death rate of 0.2% per 1000 dialysis patient-years at risk.<sup>45</sup>

Feeling socially isolated is another problem for patients who are starting or living with dialysis. Kidney failure and its treatments can restrict daily activities, employment, family life, and social relationships. This can lead to feelings of isolation. Feeling socially isolated can be stressful and anxiety-provoking. This, in turn, can produce physiologic changes that affect the immune system<sup>46</sup> which, if prolonged, can lead to higher rates of illness and death.<sup>47, 48</sup>

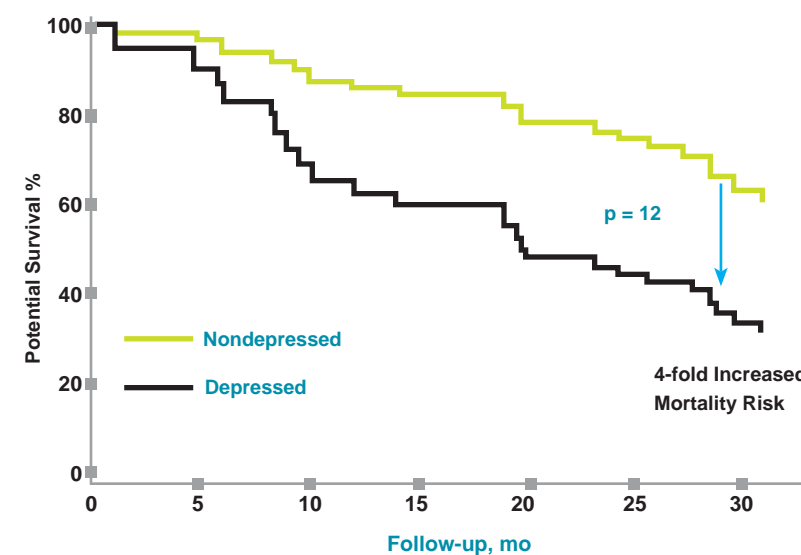
Social support helps. It has been shown to improve survival and quality of life in dialysis patients.<sup>48</sup> Systimer and Friend report that optimism and self-esteem in patients with kidney failure increases with social support, which in turn decreases depression.<sup>37, 49</sup> Moreover, having social support has been consistently linked to better health outcomes in patients with cancer,<sup>9, 12</sup> diabetes,<sup>17</sup> heart disease,<sup>22</sup> and other conditions.

## PEER SUPPORT IS EFFECTIVE BECAUSE IT IS A SHARED EXPERIENCE

Peer support works because patients are able to give each other something the clinician does not have – shared life experience. It is support from the perspective of someone who has “been there.” Research shows that people often cope better when they interact with peers with whom they identify and share common experiences. In this way, feelings are validated, social isolation and stigma are reduced, hope for the future and optimism grows, and experiences are normalized.<sup>12</sup>

Peer mentoring has been shown to be highly effective in helping kidney patients adjust to dialysis and approach end-of-life planning, and in alleviating fears about kidney transplantation.<sup>1-6</sup> It also improves depression, social isolation, self-esteem, and self-management. This, in turn, leads to better health and survival.

Figure 1 Effect of depression on survival rates in hemodialysis patients



Reprinted with permission from Kopple and colleagues.<sup>37</sup>

## Kidney patients face many challenges

- Complex medical management for complications like hypertension, dyslipidemia, anemia, poor nutrition, mineral and bone disorder
- Risk for adverse outcomes like cardiovascular disease and kidney failure
- Adjustment to dietary prescription and reduced fluid intake when on maintenance dialysis
- Maintaining important roles relative to jobs, family, and friends
- Confronting their own mortality and potentially shortened life span
- Disruption of their activities due to complex medical plan and/or dialysis treatment schedule
- Coping with the anger, fear, anxiety, frustration, and sadness of having a chronic illness
- Recurrent hospitalizations and the discomfort of dialysis and other medical treatments
- Adjusting to “wellness” after a kidney transplant

Patients with kidney disease, kidney failure, or a kidney transplant can call

**855.653.7337 (855-NKF-PEER)**

to become a mentor or mentee. To learn more about the NKF's Peer Support program see back cover.

# Can chronically ill patients mentor others?

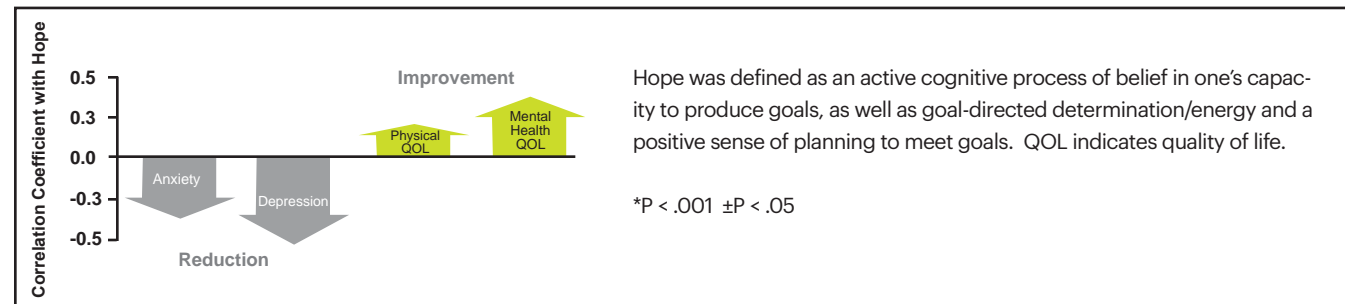


Healthcare professionals may wonder whether chronically ill patients with limited training can mentor other patients. Research shows they can. In numerous studies, healthcare professionals have successfully used the skills of volunteer patients who were elderly, disadvantaged, or chronically ill. Peer mentoring works because it is a mutual relationship that involves sharing real-life experiences with others who are facing similar challenges. Peer mentors do not offer medical advice. They are trained to refer patients back to the healthcare team if medical questions arise. Peer mentors provide:

- Empathy and understanding
- Confirmation that one is not alone in suffering
- Positive role models of coping
- Hope for the future

Furthermore, it is easier for many people to discuss a problem or concern with someone of their own age, background, or with similar health problems. Having support from someone who has 'been there, too' gives patients hope. It provides what the clinician cannot give – a shared experience with the potency of common concerns.

Figure 2 Correlation of hope with the quality of life in patients with kidney failure.



Reprinted with permission from Kopple and colleagues.<sup>37</sup>

# Peer support helps people adjust

As kidney disease progresses to kidney failure, patients must begin evaluating treatments to decide which is right for them—dialysis or transplantation. For many, this is a stressful time. Not only must they adjust to life with a chronic illness, but they must make difficult choices about treatments that will profoundly impact their lives. In one study, many patients “described the ‘shock’ of being told they must soon start treatment for kidney failure and said they had found it helpful to talk to other patients.” However, the conversations mostly happened by chance in clinic waiting rooms. The patients suggested creating a formal peer support system in which patients who are about to begin treatment can speak with others who have had experience with dialysis and transplantation.<sup>3</sup>

# Helping others improves the health of the helper

Providing social support to others can improve the health of the helper. Evidence shows that people who provide social support experience higher rates of physical health, life satisfaction, and lower rates of depression. They are more optimistic about their chances to live longer.<sup>50-55</sup>

## Sense of Purpose



One way in which volunteering improves well-being is through the sense of purpose it provides, especially in older adults. Kidney failure disproportionately affects older adults. Stevens and colleagues report that the median age of new dialysis patients is 65 years, and the fastest growing age group is over 75 years.<sup>56</sup> Recent data from the National Health and Nutrition Examination Study (NHANES) suggest that kidney disease is present in 38% of people over 65 years old compared with 13% in the overall US population.<sup>57</sup>

## Well Being



Social support has been shown to improve the well-being of people of all ages, including chronically-ill adolescents,<sup>58</sup> young people with anorexia<sup>59</sup> or HIV/AIDS,<sup>27,28,30</sup> and breast-feeding mothers.<sup>60</sup> It has been known to benefit survivors of breast cancer<sup>10,61</sup> and people with depression.<sup>24,25</sup> It helps those with or without a chronic illness. Simply put, the very act of helping others makes people feel good about themselves. It fosters a sense of accomplishment and competence.

## Knowledge Gain



Helping others can reinforce the self-health skills of mentors. Those who help others become more knowledgeable and confident in their skills. As a result, they become better at managing their own health. In studies of patients with diabetes, peer mentors found meaning and experienced positive reinforcement for their own self-care by supporting their partner's efforts to manage diabetes.<sup>17,18</sup> This benefit has also been noted in patients with cancer,<sup>61</sup> heart disease,<sup>22</sup> kidney disease,<sup>62</sup> physical disabilities,<sup>63</sup> chronic pain,<sup>64</sup> and other conditions.

## Acceptance

Mentoring others helps people in numerous ways. In one study, people with kidney failure came to terms with their own illness from helping others newly diagnosed with kidney failure.<sup>62</sup> In depressed patients, research shows that, in addition to receiving support, the act of helping others may be an important mechanism by which peer relationships improve depression.<sup>25,50,52-54,65</sup>

## Self Help

As people age, they experience important losses. Studies show that volunteering helps older adults compensate for critical losses incurred later in life, such as the loss of a spouse, job, or losing the role of being a parent.<sup>66,67</sup> By helping others, they help themselves. By supporting others, they protect themselves from social isolation and physical decline.

# Telephone-based peer support is effective

Peer support programs are implemented in many different ways — group settings or in one-on-one encounters. Interaction can be face-to-face, or by telephone, email, or internet. Telephone-based support has been studied in numerous patient populations, and it has been shown to be effective in patients with kidney failure,<sup>5</sup> cancer,<sup>8, 16</sup> diabetes,<sup>18, 19</sup> heart disease,<sup>20, 22</sup> depression,<sup>25</sup> HIV/AIDS,<sup>32</sup> osteoarthritis,<sup>68</sup> pain management,<sup>64</sup> and other conditions. Among other benefits, mentoring by telephone can increase the quality and quantity of support between clinic visits, leading to better self-management, improved well-being, and better health outcomes. This is especially useful to those who are tackling challenging medical tasks, such as adjusting to chronic kidney disease, kidney failure, kidney transplant, or insulin management.

## o PROVIDES ANONYMITY

Participants appreciate the relative anonymity of the calling system. In one study of telephone-based mutual peer support for depression, participants reported that they found the calling system “more helpful than group therapy because it’s easier to be open and honest over the phone. You don’t feel as afraid of judgment, and you don’t have to censor yourself.”<sup>25</sup>

## o ELIMINATES DISTANCE BARRIERS

Telephone-based peer support can help bridge the isolation gap for many patients, especially those who are elderly, frail, or isolated due to geography. In some rural communities, for example, there is often a lack of services which, for many, can lead to a perception of ‘being

alone’ in the struggle to become better.<sup>8</sup> In a study of patients with hemophilia and HIV/AIDS, participants reported that the telephone-based support had decreased their feelings of isolation and loneliness.

## o A VALUED RESOURCE

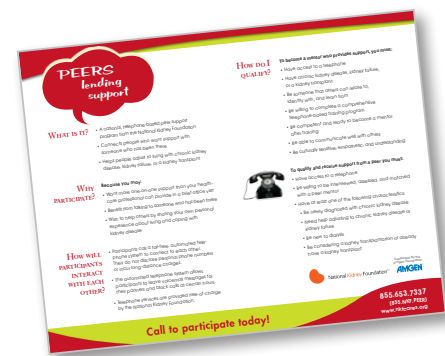
Telephone-based peer support is a valuable resource for patients who do not have internet access or email — which is common among patients with kidney disease or kidney failure.

## o IMPROVES POST-OPERATIVE CARE

In post-operative care where distance and geography restrict access, telephone-based peer support can help improve recovery outcomes after discharge. It has been shown to be beneficial for patients recovering from coronary by-pass surgery<sup>20</sup> and other health problems.

For many patients, telephone-based support is preferable to face-to-face support because it:

- o Provides participants with anonymity and privacy
- o Eliminates distance barriers and the difficulties of attending regular face-to-face meetings
- o Allows for frequent patient contacts at a low cost



## For your patients

A flyer describing the Peers program to patients can be downloaded free at: [www.nkcares.org](http://www.nkcares.org)

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# PEERS lending support

## What can you do?

- Tell patients who are interested in being a peer mentor or mentee to call: 855.653.7337 or email: [nkfpeers@kidney.org](mailto:nkfpeers@kidney.org)
- To learn more about NKF's Peers program, visit: [www.nkfcare.org](http://www.nkfcare.org)

## What is NKF's Peers Lending Support?

"Peers Lending Support (Peers)" is a new patient program from the National Kidney Foundation (NKF) that matches patients in need of support with peer mentors who are positive role models.

Mentoring takes place by telephone. Participants call a toll-free, automated telephone system to connect to each other. They do not disclose their personal phone number or incur long-distance charges. The automated telephone system allows participants to leave voicemail messages for their peer partners, and block calls at certain hours. Telephone services are provided free-of-charge by the NKF.

Potential peer partners are interviewed, screened, and appropriately matched. Guidance and oversight of the peer relationship is provided by an expert clinician from the NKF. Peer mentors complete a comprehensive telephone-based training program and post-training assessment before being matched with a mentee. Peers do not offer medical advice. They refer patients back to the healthcare team if medical questions arise. Access to an educational website specifically designed for patients and their families is also available.

## How do your patients qualify

### **To qualify as peer mentors, a patient must:**

- Have access to a telephone
- Have made a positive adjustment to living with chronic kidney disease, kidney failure, or a kidney transplant
- Be a positive role model that others can relate to, identify with, and learn from
- Be willing to complete a comprehensive telephone-based training program
- Be able to communicate well with others
- Be culturally sensitive, empathetic, and understanding
- Speak English to participate in training
- Be competent to serve as a mentor after training

### **To be matched with a peer mentor, a patient must:**

- Have access to a telephone
- Be willing to be interviewed, assessed, and matched with a peer mentor
- Have at least one of the following:
  - Be newly diagnosed with chronic kidney disease
  - Need help adjusting to chronic kidney disease or kidney failure
  - Be new to dialysis
  - Be considering a kidney transplantation or already have a kidney transplant



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