

Why support groups provide help and hope

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Receiving a diagnosis of chronic kidney disease and understanding the need for transplantation or dialysis in order to survive strikes at the very core of your being. I was diagnosed with CKD in 1968 when I was two years old and have learned how to cope with the many challenges presented to me—from years of dialysis to multiple transplants. Support from “someone who has been there” can be an emotional lifesaver.

I have run a local support group for years and started the Renal Support Network (RSN) to provide a place where patients and family members could share their experiences, strength, and hope. In 1993, I produced a local directory in which patients agreed to list their first name, treatment modality, languages spoken, and city of residence. This directory was extremely popular and eventually morphed into the RSN HOPEline, which is a toll-free number that patients and family members can call to talk to a person who has kidney disease and has learned how to navigate it.

Support groups are very important because they allow patients to connect with others who have experienced similar emotions and problems. The feeling that “I am not alone” can have a powerful healing effect. Telling your story can be a significant part of the healing process, and hearing someone speak about how he or she has survived can provide the hope that another person desperately needs.

The most important element of a successful support group is making sure that people leave feeling better than they did when they arrived. Support groups too often turn into “bitch” sessions of the “I have suffered more than you have” type, and if more of the people in attendance are in crisis rather than able to provide support, the group does not survive or thrive. In my support group, I am fortunate to have several people who attend every meeting just to help me provide support to others. Some people attend once, share their story, get all the information they can, and never come back. Support groups need a strong leader or facilitator who will ensure that one person does not dominate the meeting, that it stays solution based, that there is minimal cross-talk, and that attendees share only their experiences, strength, and hope. I always ask at the begin-

ning of a meeting whether there are any serious issues that we need to discuss. If so, we try to address them. If not, I always come up with a theme such as how to navigate the renal diet, deal with anger, or find coping strategies; share a short personal story about the topic; and then encourage others to share their stories. This keeps the group focused.

I also receive numerous calls from people who want to start a support group. I first ask them why they would like to do this. I typically get two responses: either they need support, or they want to help others. Needing support is usually a temporary thing, and I have found that this sort of group never takes off or is short-lived. The person who wants to help others and is motivated to take the necessary steps can be very beneficial to his or her peers.

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Health care professionals have expressed concerns about support groups because they fear that patients will get together to share information on what they find wrong with the facility or staff. This concern can be eliminated if a strong leader (preferably a patient to make it a peer support group) emerges and if the meeting is held at a location other than the dialysis facility or hospital.

Psychological adaptation to CKD is crucial to ensuring optimal long-term outcomes. Patients with CKD tend to have higher levels of anxiety and depression than the general population, and it is vital that they be offered appropriate resources to help them develop active coping strategies and feel that they are in control. Hope has emerged as a significant predictor of a patient’s ability to adjust to a wide range of chronic disorders, including pain, traumatic physical disability, visual impairment, and burns.¹⁻⁴ In a cross-sectional study of 103 patients on dialysis, the 12-item Trait Hope Scale was used to assess the relationship between hope and adjustment to CKD. Hope emerged as an independent and significant predictor in five multiple regression analyses: anxiety, depression, effects and symptoms of kidney disease, and mental health quality of

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Patients participating in the Zumba class.

continuing during future treatments. In the first session an arterial alarm was triggered for one patient that was quickly resolved by a position change. Apart from this, there were no adverse events noted during the exercises and the activities did not interfere with the treatments or functioning of the unit. Participants became increasingly active and engaged as the sessions progressed, and the instructor adjusted movements accordingly. Several staff and other dialysis patients spontane-

ously participated in the exercises.

Conclusion

This study has found that an intradialytic, modified form of Zumba Gold is a safe and feasible option for people receiving hemodialysis. The intervention was acceptable to patients, was cheap, and did not adversely impact on the hemodialysis treatment. It was fun and encouraged staff and other patients to join the exercises. Further research to determine the impact on

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life. These results showed that hope is a significant predictor of a patient's adjustment to CKD.⁵

Conclusion

The research confirming the vital role that hope plays in improving patient outcomes is not surprising to those of us who live with CKD. RSN was founded on the principle that "one friend can make a difference" and the conviction that people with CKD can help one another find the support and empowerment necessary to take charge of the course and management of their disease. The tagline that we

have used for the past 15 years—"An illness is too demanding if you don't have hope"—highlights our personal experience that hope is a vital component of the ability to live and thrive with CKD and that support groups play a vital role in this effort. *NN&I*

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patient empowerment, quality of life, biochemistry parameters and physical function using a larger number of participants is recommended. *NN&I*

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