Kidney support groups empower and give strength to patients

Lana Schmidt ● Patty Purcell

Kidney support groups play a vital role in the lives of kidney patients, whether they are pre-dialysis patients, current dialysis patients, or caregivers. Kidney patients often hear a dietitian, nurse, or doctor advise them about reducing their fluid intake, cutting back on salt, or eating protein-rich foods to better their health. Yet talking to other patients who have experienced and gone through these things can certainly be the best medicine for kidney patients.

Kidney support groups are providing this support and help for patients, letting them know they are not alone and not the only ones coping with this challenging, life-changing disease. They empower patients to take charge of their health and be knowledgeable and confident about their choices and decisions. Getting together with other kidney patients provides a lot of emotional support, hope and comfort and inspires patients and families to stay strong and not to give up.

When kidney patients share their real life situations and the challenges they are facing with each other, it brings encouragement and gives a safe outlet to discuss the initial shock, anger and helplessness of kidney disease. A wealth of relevant, practical information is exchanged between the patients that can be applied in their daily lives, making a huge difference in their outlook and quality of life.

Comments heard in co-author Lana Schmidt’s Kidney Patients Support Groups: “... just being there and hearing everyone’s story of their kidney problems and knowing I’m not alone any more, meant more than I can tell you...” and “I cannot tell you how much you all lifted my spirits. “I felt great after the meeting yesterday! I can hardly wait until our next get together.”

Medical professionals see benefit

Medical professionals are also seeing the benefits of kidney support groups. They compliment their efforts in providing the best quality of care and equips the patients with practical life skills in dealing with the disease. Doctors have their role to play in the patients’ care that a support group cannot offer, and support groups do a part of the job that the doctor and the renal team cannot provide. “The journey with kidney disease is physically and emotionally challenging,” said nephrologist Anu Wadhwa, MD, assistant professor of medicine in the division of renal disease and hypertension, Loyola University Medical Center, in Chicago. “I have seen that it makes a world of difference in the lives of kidney disease patients when they talk to others who are in the same boat. Sharing experiences or just talking helps patients make connections with others facing the same situations and alleviates fear and isolation. While support groups do not replace the care the medical team provides, they are a valuable resource to help cope with the disease. Hence, I am actively talking to my patients to get together and start a support group in our area.”

Once someone goes on dialysis they are inundated with a wealth of information, way too much to comprehend when they are in the process of making huge life changes. Many pre-dialysis patients (stage 2, 3 and 4) attend the kidney support group and really benefit from it because at that stage, there is not a lot of education or information that is provided to them about kidney disease by their nurse or doctor. Having this information early on in their disease process gives them time to comprehend the kidney disease information and treatment modalities options, and, should they need to go on dialysis, it makes the therapy not so shocking for them. People already on dialysis, and caregivers too, benefit greatly from the support group also, as they share thoughts and ideas about shortcuts, and other ways to do things to make treatment a little less stressful.

“As a kidney nurse for many years, I have seen how much patients have benefitted from sharing with each other in the group, the strength they receive from one another, the empowerment, and the motivation to not throw in the towel,” said Charlene Vollmer, RN, who heads the Springfield, Ill. Kidney Support Group.

Ms. Schmidt is co-leader and Ms. Purcell is a board member of the Kidney Patients Support Group of Quincy, Ill., and Hannibal, Mo. Ms. Schmidt has been on dialysis for 11 years and Ms. Purcell is a home hemodialysis personal assistant.
Tips for starting a kidney support group

You don’t have to be a trained professional to run a support group, just have the heart! Gather up a couple individuals to help get things started. It can be kidney patients, may include a social worker, nurse, etc., anyone who has the passion to help the support group. Having more than one person involved along with patients in organizing helps, so that it is not seen as a medical meeting.

Many groups meet once a month, every other month or a few times a year with a speaker on a specific topic or have a sharing and caring time. There are many free meeting spaces available, such as hospitals, medical centers, libraries, community colleges, hotels, community centers, etc. If you are interested in finding out more information about starting up a support group, contact author Lana Schmidt at lanasch@yahoo.com.

Other resources
- American Association of Kidney Patients: www.aakp.org/support-group-resources.html

In addition, there are numerous kidney disease face book pages and yahoo groups online.

—L.S., P.P.