

# Living Well With Kidney Disease by Patient and Care Partner Empowerment: Kidney Health for Everyone Everywhere



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treatment satisfaction and clinical outcomes.<sup>1</sup> To advance research, practice, and policy, there is increasing recognition of the need to identify and address patient priorities, values, and goals.<sup>1</sup>

Several efforts have addressed these important questions including the Standardised Outcomes in Nephrology initiative, which includes more than 9000 patients, family members, and health professionals from over 70 countries.<sup>2,3</sup> Children and adults with CKD have consistently given higher priority to symptoms and life impacts,<sup>2,3</sup> whereas health care professionals gave higher priority to mortality and hospitalization. The patient-prioritized outcomes are shown in [Figure 1](#).

Life participation, defined as the ability to do meaningful activities of life including, but not limited to, work, study, family responsibilities, travel, sport, social, and recreational activities, was established as a critically important outcome across all treatment stages of CKD.<sup>1,2</sup> Patients wanted to be able to live well, maintain their role and social functioning, protect some semblance of normality, have a sense of control over their health and well-being, and be at the center of decision making. The quotations from patients with kidney disease provided in [Table 1](#) demonstrate how life participation reflects the ability to live well with CKD. The World Health Organization specifically defines participation as

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## Patient Priorities for Living Well: a Focus on Life Participation

**C**hronic kidney disease (CKD) and its associated symptoms

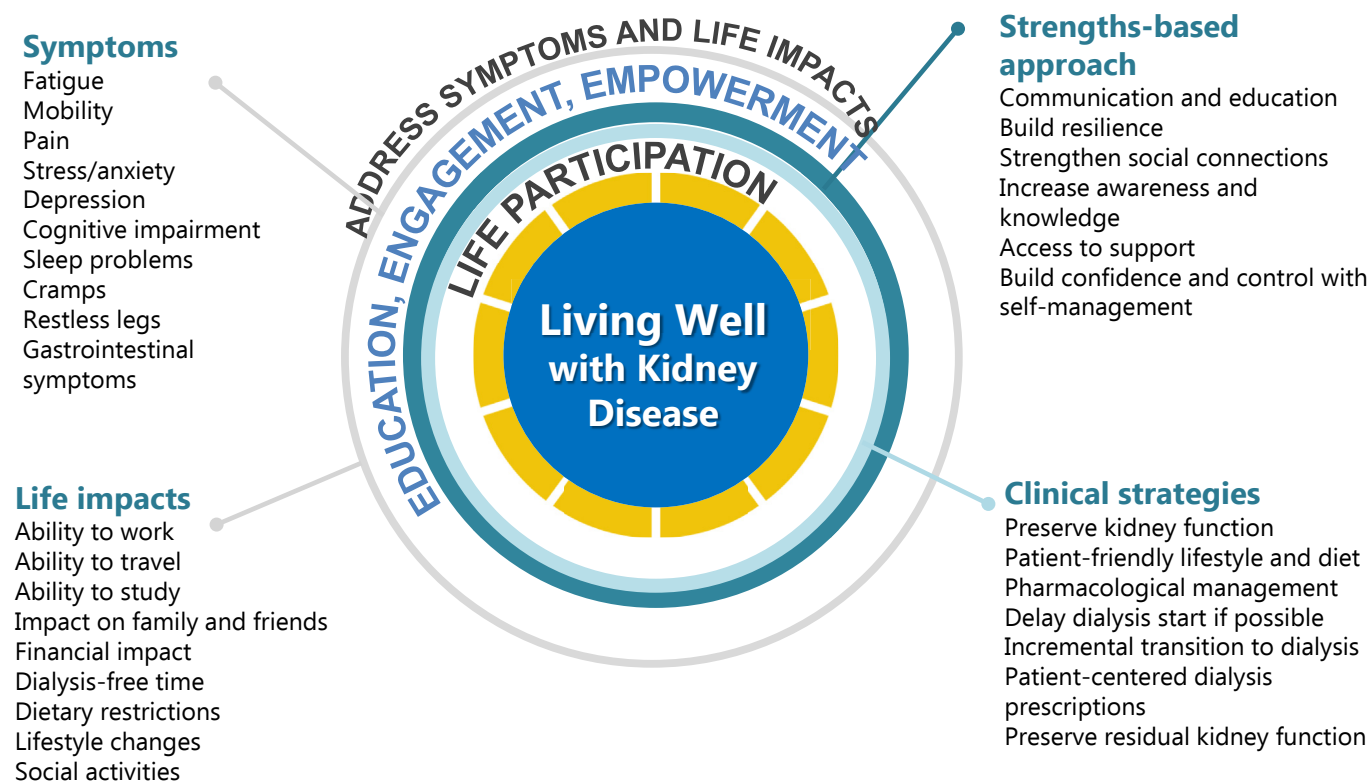
and treatment can disrupt daily living and impair the quality of life of patients and their family members. Consequently, this impacts

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**Figure 1.** Conceptual framework of “Living Well with Kidney Disease” based on patient centeredness and empowering patients with a focus on effective symptom management and life participation.

“involvement in a life situation.” The 2021 World Kidney Day (WKD) Steering Committee calls for the inclusion of life participation, a key focus in the care of patients with CKD, to achieve the ultimate goal of living well with kidney disease. This calls for the development and implementation of validated patient-reported outcome measures that could be used to assess and address areas of life participation in routine care. Monitoring of life participation could be supported by regulatory agencies as a metric for quality care or to support labeling claims for medicines and devices. Funding agencies could establish targeted calls for research that address the priorities of patients, including life participation.

### Patient Empowerment, Partnership, and a Paradigm Shift Toward a Strengths-based Approach to Care

Patients with CKD and care partners should be empowered to

achieve the health outcomes and life goals. The World Health Organization defines patient empowerment as “a process through which people gain greater control over decisions or actions affecting their health.”<sup>4</sup> Understanding the rationale for a lifestyle change, having access to practical assistance, and family support promoted patient empowerment, whereas feeling limited in life participation undermined their sense of empowerment.<sup>5</sup>

The 2021 WKD Steering Committee advocates for strengthened partnership with patients in the development, implementation, and evaluation of interventions for practice and policy settings. We urge for greater emphasis on a strengths-based approach as outlined in Table 2. Different from the medical model, the strengths-based approach acknowledges that each individual has strengths and abilities to overcome the problems and challenges faced and requires

collaboration and cultivation of the patient’s hopes, aspirations, interests, and values. Structural biases, discrimination, and disparities in the health care system need to be identified.

### The Role of Care Partner

A care partner is often an informal caregiver who is also a family member of the CKD patient.<sup>6</sup> Care partners may take on a wide range of responsibilities and become more important in CKD care given the heightened complexity in communicative and therapeutic options. They may experience a substantial burden, which may impact family dynamics. Hence, the previously mentioned principles of life participation need to equally apply to care partners involved in CKD care.

### Living With Kidney Disease in Low-income Regions

In low- and lower-middle-income countries, patient care may often be influenced by internal factors

**Table 1.** Quotations from patients with CKD related to priorities for living well

"I don't want to think about dying from my disease. I want to be able to live well with my disease."—Patient with CKD
"Life participation is most important because without it, you can't do anything."—Child with CKD
"Maybe it's as simple as asking patients whether, how well they are able to participate in the life that they want to lead because it's going to be different for different people."—Kidney transplant recipient
"Everyone has to face death, what I would like to have is a good quality of life rather than to face death."—Kidney transplant recipient
"So, it doesn't actually really matter what the numbers say, and some of my numbers should have suggested that I should be feeling a lot worse than what I actually was, it's about how much I feel I can do and participate in my life and feel normal."—Patient with CKD
"I'm still living. I get out of bed, and I'm still living and still breathing. As long as I can do that, I'm going to carry on and be positive because life is short."—Patient with CKD
"I put life participation because I know that looking from the outside, I know [his kidney disease] stops [him] from thinking bigger . . . Although that's really big, there's this life that has to happen at the same time."—Family member
"Amazed at comments from professional(sic) about travel, free time, etc they seem to think the mechanics of dialysis far more important. Dialysis is a treatment which keeps us alive to live a life, not just to wait for death."—Patient receiving dialysis
"I prefer to be above ground, then below ground. So why not enjoy life whilst being above ground."—Adam Martin
"Over the years, I have learned to worry less, control my emotions, and not fear death. I keep my mind active. I follow the advice of the philosopher-emperor Marcus Aurelius to 'love the hand that fate (has dealt me) and play it as (my) own'. Living well with CKD means to live the best life I can in the time I have available . . . Living well with CKD is the same as living well."—Tess Harris
"While CKD brings me some limitations, I can maximize the possibility to live well. I kept working when I was doing hemodialysis. After transplant, I could live: study, work, travel, marry, have children, and service the community."—Maggie Ng

Personal communications; quotations are identified by name with permission.

including spirituality, belief, and religiosity and external factors including disease knowledge, poverty, family support, and one's grit and social relations network. The support system comprising health care providers and caregivers plays a crucial role because most patients rely on them in making decisions and for the necessary adjustments in their

health behavior.<sup>7</sup> In low-income regions, where there are often a low number of kidney care providers per population, especially in rural areas, a stepwise approach can involve local and national stakeholders including both nongovernmental organizations and government agencies by (1) extending kidney patient education in rural areas, (2)

adapting telehealth technologies if feasible to educate patients and train local community kidney care providers, and (3) implementing effective retention strategies for rural kidney health providers including adapting career plans and competitive incentives.

### WKD 2021 Advocacy

The 2021 WKD theme on "Living Well with Kidney Disease" is deliberately chosen to redirect more focus on plans and actions toward achieving patient-centered wellness. "Kidney Health for Everyone, Everywhere" with emphasis on patient-centered wellness should be a policy imperative that can be successfully achieved if policy makers, nephrologists, health care professionals, patients, and care partners place this within the context of comprehensive care.

The 2021 WKD Steering Committee would like to promote to the policy makers increasing focus and resources that enable patients to live well with kidney disease. Home dialysis therapies have been consistently found to improve patient quality of life and enhance life participation, and it should be promoted in conjunction with appropriate "assisted dialysis" programs to reduce patient and care partner fatigue and burnout. The principle of equity recognizes that different people with different levels of disadvantage require different approaches and resources to achieve equitable health outcomes. The involvement of primary care physicians, especially in low- and lower-middle-income countries, would be useful in improving the affordability and access to services through the public sector in helping the symptom management of CKD patients and improve their wellness. Primary prevention should be

**Table 2.** Suggested strategies for "living well with CKD" using a strengths-based approach

Strengths-based approach	Suggested strategies
Build resilience	<ul style="list-style-type: none"> <li>Identify or provide strategies and resources to manage stress and functioning when encountering challenges, adversity, and trauma (e.g., commencement of dialysis).</li> </ul>
Harness social connections	<ul style="list-style-type: none"> <li>Facilitate connections with other patients to learn coping strategies and for support.</li> <li>Support family members/caregivers.</li> </ul>
Build awareness and knowledge	<ul style="list-style-type: none"> <li>Provide education (including practical advice) on diet and lifestyle modifications.</li> <li>Understand, identify, and address the potential impacts of CKD (e.g., cognitive function).</li> <li>Encourage patients to ask questions.</li> <li>Encourage the use of knowledge to empower and prepare for the future.</li> </ul>
Facilitate access to support	<ul style="list-style-type: none"> <li>Refer to allied health care professionals (e.g., dietitian, social worker, mental health professionals, and occupation therapists).</li> <li>Provide support that enables the patient to participate in important life activities (e.g., work).</li> </ul>
Establish confidence and control in self-management	<ul style="list-style-type: none"> <li>Support informed and shared decision making (including dialysis, kidney transplantation, and conservative or nondialytic care).</li> <li>Encourage patients to learn to "get in tune" with what works well for them and to voice any concerns, and work together to develop better management strategies to enable patients to feel better.</li> <li>Provide strategies to prevent or manage complications (e.g., infection).</li> <li>Support open communication regarding goals, concerns, and priorities.</li> </ul>

CKD, chronic kidney disease (not receiving kidney replacement therapy).

reiterated. Early detection with a prolonged course of wellness despite kidney disease, after an effective secondary prevention program, should be promoted.<sup>8</sup> Prevention of CKD progression can be attempted by lifestyle and diet modifications such as a plant-dominant low-protein diet and by means of effective pharmacotherapy including the administration of sodium-glucose transport protein 2 inhibitors.<sup>9</sup> The 2021 WKD campaign continues to call for increased awareness of the importance of preventive measures throughout populations, professionals, and policy makers, which is applicable to both developed and developing countries.<sup>8</sup>

## Conclusions

Effective strategies to empower patients and their care partners strive to pursue the overarching goal of minimizing the burden of CKD-related symptoms in order to enhance patient satisfaction, health-related quality of life, and life participation. To increase education and awareness on the important goal of effective symptom management and patient empowerment, the 2021 WKD Steering Committee has declared 2021 the year of “Living Well with Kidney Disease” despite the coronavirus disease 2019 pandemic that had overshadowed many activities in 2020 and beyond. Although the 2021 WKD campaign continues to emphasize the importance of effective measures to prevent kidney disease and its progression,<sup>8</sup> patients with preexisting kidney disease and their care partners should feel supported to live well through concerted efforts by

kidney care communities and other stakeholders throughout the world.<sup>10</sup> Living well with kidney disease is an uncompromisable goal of all kidney foundations, patient groups, and professional societies alike to which the International Society of Nephrology and the International Federation of Kidney Foundation World Kidney Alliance are committed at all times.

## APPENDIX

### List of the World Kidney Day Steering Committee

Philip Kam Tao Li, Kamyar Kalantar-Zadeh, Sharon Andreoli, Alessandro Balducci, Sophie Dupuis, Latha Kumaraswami, Vasilios Liakopoulos, Siu-Fai Lui, Gamal Saadi, and Ifeoma Ulasi

## DISCLOSURE

KK-Z reports honoraria from Abbott, Abbvie, ACI Clinical, Akebia, Alexion, Amgen, Ardelyx, Astra-Zeneca, Aveo, BBraun, Cara Therapeutics, Chugai, Cytokinetics, Daiichi, DaVita, Fresenius, Genentech, Haymarket Media, Hospira, Kabi, Keryx, Kissei, Novartis, Pfizer, Regulus, Relypsa, Resverlogix, Dr Schaefer, Sandoz, Sanofi, Shire, Vifor, UpToDate, and ZS-Pharma. PK-TL reports personal fees from Fibrogen and Astra-Zeneca. GS reports personal fees from Multicare, Novartis, Sandoz, and Astra-Zeneca. VL reports nonfinancial support from Genesis Pharma.

## REFERENCES

1. Tong A, Manns B, Wang AYM, et al. Implementing core outcomes in kidney disease: report of the Standardized Outcomes in Nephrology (SONG) implementation workshop. *Kidney Int.* 2018;94:1053–1068.

2. Carter SA, Gutman T, Logeman C, et al. Identifying outcomes important to patients with glomerular disease and their caregivers. *Clin J Am Soc Nephrol.* 2020;15:673–684.
3. Hanson CS, Craig JC, Logeman C, et al. Establishing core outcome domains in pediatric kidney disease: report of the Standardized Outcomes in Nephrology-Children and Adolescents (SONG-KIDS) consensus workshops. *Kidney Int.* 2020;98:553–565.
4. World Health Organization. Health promotion glossary. 1998. Available at <https://www.who.int/healthpromotion/about/HPR%20Glossary%201998.pdf>. Accessed February 25, 2021.
5. Baumgart A, Manera KE, Johnson DW, et al. Meaning of empowerment in peritoneal dialysis: focus groups with patients and caregivers. *Nephrol Dial Transplant.* 2020;35:1949–1958.
6. Parham R, Jacyna N, Hothi D, Marks SD, Holtum S, Camic P. Development of a measure of caregiver burden in paediatric chronic kidney disease: The Paediatric Renal Caregiver Burden Scale. *J Health Psychol.* 2016;21:193–205.
7. Angwenyi V, Aantjes C, Kajumi M, De Man J, Criel B, Bunders-Aelen J. Patients experiences of self-management and strategies for dealing with chronic conditions in rural Malawi. *PLoS One.* 2018;13, e0199977.
8. Li PK, Garcia-Garcia G, Lui SF, et al. Kidney health for everyone everywhere—from prevention to detection and equitable access to care. *Kidney Int.* 2020;97:226–232.
9. Kalantar-Zadeh K, Li PK. Strategies to prevent kidney disease and its progression. *Nat Rev Nephrol.* 2020;16:129–130.
10. Kalantar-Zadeh K, Wightman A, Liao S. Ensuring choice for people with kidney failure - dialysis, supportive care, and hope. *N Engl J Med.* 2020;383:99–101.