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Living well with kidney disease by patient and care-partner empowerment: Kidney health for everyone everywhere.

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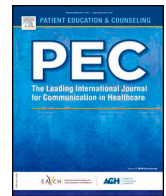
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## Correspondence

## Living well with kidney disease by patient and care-partner empowerment: Kidney health for everyone everywhere



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Living with chronic kidney disease (CKD) is associated with hardships for patients and their care-partners. Empowering patients and their care-partners, including family members or friends involved in their care, may help minimize the burden and consequences of CKD related symptoms to enable life participation. *Life participation* was established as a critically important outcome across all treatment stages of CKD [1,2]. The quotations from patients with kidney disease provided in [Box 1](#) demonstrates how life participation reflects the ability to live well with CKD [3]. There is a need to broaden the focus on living well with kidney disease and re-engagement in life, including an emphasis on patients being in control [4]. The World Kidney Day (WKD) Joint Steering Committee has declared 2021 the year of “Living Well with Kidney Disease” in an effort to increase education and awareness on the important goal of patient empowerment and life participation. Irrespective of the type of kidney disease or treatment stage, patients wanted to be able to live well, maintain their role and social functioning, protect some semblance of normality, and have a sense of control over their health and wellbeing. The patient-prioritized outcomes are shown in [Fig. 1](#). We urge for greater emphasis on a strengths-based approach as outlined in [Table 1](#), which encompasses strategies to support patient resilience, harness social connections, build patient awareness and knowledge, facilitate access to support, and establish confidence and control in self-management.

The 2021 WKD theme calls for the development and implementation of validated patient-reported outcome measures to assess and address areas of life participation in routine care. It could be supported by regulatory agencies as a metric for quality care or to support labelling claims for medicines and devices. Funding agencies could establish targeted calls for research that address the priorities of patients. Patients with kidney disease and their care-partners should feel supported to live well through concerted efforts by kidney care communities including during pandemics. In the overall wellness program for kidney

disease patients, the need for prevention should be reiterated. Early detection with a prolonged course of wellness despite kidney disease, after effective secondary and tertiary prevention programs, should be promoted. World Kidney Day 2021 continues to call for increased awareness of the importance of preventive measures throughout populations, professionals, and policy makers, applicable to both developed and developing countries.

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. Whereas World Kidney Day continues to emphasize the importance of effective measures to prevent kidney disease and its progression [5], 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 even during a world-shattering pandemic that may drain many resources [6]. 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.

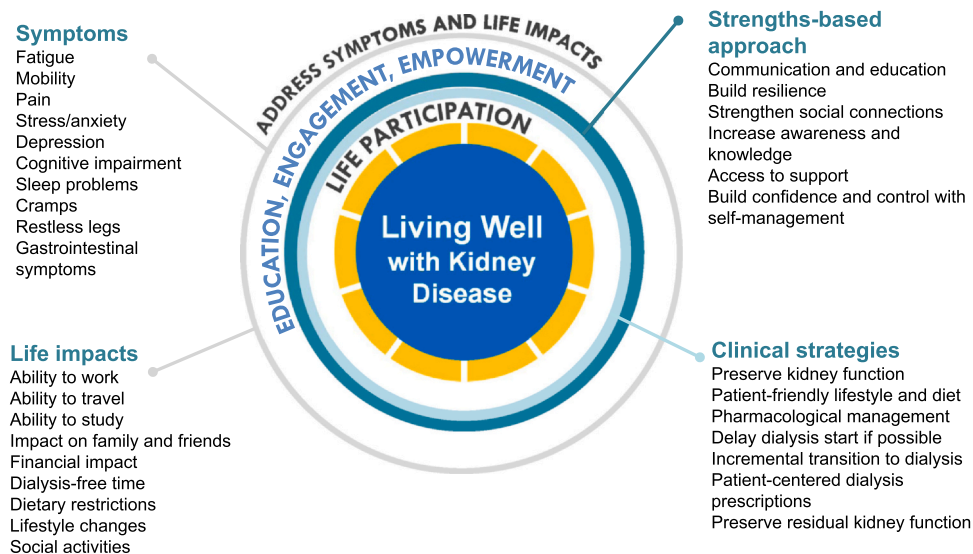
## Publication information

This article is being published in *Kidney International* and reprinted concurrently in several journals. The articles cover identical concepts and wording, but vary in minor stylistic and spelling changes, detail, and length of manuscript in keeping with each journal's style. Note that all authors contributed equally to the conception, preparation, and editing of the manuscript.

**Box 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 communication; quotations are identified by name with permission.



**Fig. 1.** Conceptual framework of “Living Well with Kidney Disease”.

**Table 1**  
Suggested strategies for “living well with kidney disease” 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, 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, conservative or non-dialytic 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>

## Declaration of Competing Interest

K.K.-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 Schaer, Sandoz, Sanofi, Shire, Vifor, UpToDate, and ZS-Pharma. P.K.T.L. reports personal fees from Fibrogen and Astra-Zeneca. G.S. reports personal fees from Multicare, Novartis, Sandoz, and Astra-Zeneca. V.L. reports nonfinancial support from Genesis Pharma. ET, LK, SL, IU, SA, AB, SD, TH, AH, RK, SK, MN, AP, and AT have declared that no conflict of interest exists.

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