EKPF
EUROPEAN KIDNEY PATIENTS' FEDERATION
CEAPIR

What does it mean: "Living well with kidney disease?"



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Health professionals point of view

Home treatment provides the patient with a higher quality of life but still is under represented in all countries.

There is a need for better education for patients. Better and more correct information about treatments. There is a lot of health illiteracy among kidney patients. The importance of receiving better information from professionals is key to improve the quality of life.



Raymond Vanholder
President of the European Kidney Health Alliance (EKHA)



Kamyar Kalantar-Zadeh
President of the International Federation of Kidney Foundations (IFKF)

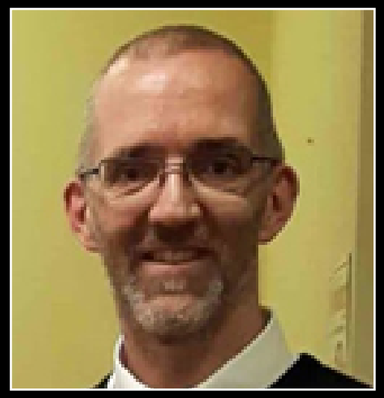
To advance research and practice, there is an increasing need to identify patient priorities, values and goals. We have to prioritise the person and find solutions with (not for) the patient.

There is a need to focus on what is working rather than on what needs fixing and to learn from past successes.

The most important outcomes for health professionals are cardiovascular disease, hospitalisation, mortality, target weight, blood pressure. Whereas for patients they are: ability to travel, dialysis-free time, fatigue, cognition, depression and ability to work.

For Health professionals, living well with Kidney disease means:

- To provide health education
- To achieve adequate nutrition
- To promote home dialysis and living donation for transplantation



Collin White
National Projects Manager in Irish Kidney Association

Mental health is a really important topic. There is a need for increasing psychological support for people overcoming the disease. There should be more money invested in that.

A problem is that many times the doctors themselves are not properly educated on peritoneal dialysis or transplantation, especially older generations. We need to educate younger doctors and nurses about this topic and give them the tools to understand this in a systematic way.



Paulo Zoio
Member of the Portuguese Kidney Patients Association (APIR)

Patients' point of view

The symptoms and treatment can disrupt daily living and quality of life, as well as affecting treatment satisfaction and clinical outcomes.

The challenge of promoting home therapies has become urgent in the wake of the COVID-19 pandemic.

We have to increase knowledge and support.



Jan van Cruchten
Secretary of the EKPF and former president of the Dutch Kidney Patients Association (NVN)



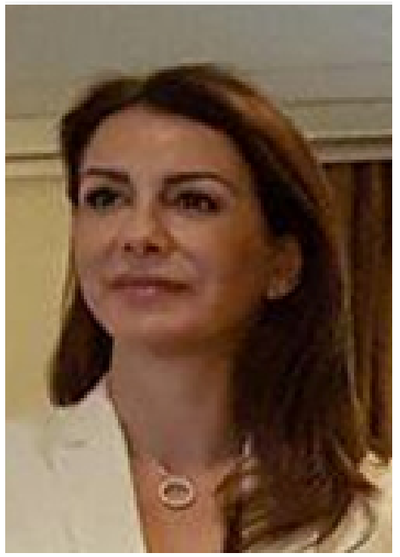
Fiona Loud
Policy Director in Kidney Care UK

There is a huge problem in how a patient receives information from a doctor

"When we are first told that we have kidney disease we are not often empowered to understand the impact of the disease and what would make you live a longer and better life. We are not being given the information."

Nutrition is a key fact regarding the quality of life and mental health of patients. Some people enter a depressive spiral which tends to make them eat the food they "should not eat". This is also part of education.

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Emily Groutidou- Petridou
Vice-president at EKPF and President of the Cyprus Kidney Patients Assocation

For patients, living well with Kidney disease means:

- ability to travel
- dialysis free-time
- ability to work
- participating in day life
- improvement of mental health





Patients gave higher priority to symptoms and life impacts than health professionals. Professionals gave higher priority to mortality and hospitalisation

