MANIFESTO

EUROPEAN KIDNEY PATIENTS` FEDERATION

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CEAPIR



The European Kidney Patients Federation represents over 75 million of people with kidney health conditions across Europe

PATIENTS MUST BE INVOLVED IN KIDNEY HEALTH POLICY

We strongly believe that our Manifesto will have a huge impact on the quality of health care received by all kidney patients and their families living across Europe.

Better information and resources for kidney patients to be effective partners in determine their care.

01

RAISE AWARENESS OF KIDNEY DISEASE

Kidney disease is a silent killer. Prevention and early detection are crucial in general population, so we need to address CKD in EU policy, promoting knowledge and healthy habits through educational programs.





INCREASE ACCESS TO TRASPLANTATION

Promoting access to kidney transplant in all countries, reducing the waiting list and overcoming living and deceased donations barriers with solidarity.

CHOICE OF TREATMENT

Information of all possible kidney replacement therapies, including conservative management. Shared decision making ensures kidney patients are choosing freely the best option of treatment for their lives.



VOICE



INVOLVEMENT

02

SELF-CARING AND EMPOWERMENT

The key to empower people is education, so we need to promote access in all countries to reliable sources of information about kidney disease, healthy habits and best practices.



SOCIAL IMPERATIVES AND PROTECTION

Improving and increasing social services. Inclusive approach for kidney recipients and living donors, with social protection in any KRT. Ensure equitable access to any KRT.

JOINT RESPONSIBILITY

Working together for the co-creation and co-design of materials, strategies and guidelines that serve as a reference for kidney patients.





SAFETY

03

COVID-19

Kidney patients in dialysis and using immunosuppression should be regarded as a high-risk group. Many of them are elderly and have impaired kidney function and other co-morbidities that increase the risk of adverse outcome of COVID-19 infection.



HOME THERAPIES

Across the world, the COVID-19 pandemic has made clear the urgency of ensuring equitable access to home dialysis so that kidney patients can stay safe at home.



ANTIMICROBIAL RESISTANCE (AMR)

AMR is an increasingly serious public threat, risking the effective protection and treatment of infections. Appropriate use and abuse of anti-infectives by kidney patients requires concerted efforts by us.





AUTONOMY

04

UNIVERSAL ACCESS

Kidney Replacements Therapies (KRT) universal coverage for all kidney patients. Adequate reimbursement policies and strategies must cover all KRT.

MOBILITY

Facilitate mobility of people with kidney disease across Europe in any KRT, even in dialysis and/or waiting list for kidney transplant. Holiday dialysis programs should allow kidney patients free movement in and out Europe area.

EMPLOYMENT

Working is profoundly important to many people who have kidney failure. It can help them to have a feeling of value to society and themselves. Facilitate access to employment in any stage of kidney disease and kidney transplant.



QUALITY OF LIFE

05

MEASURING QUALITY OF LIFE

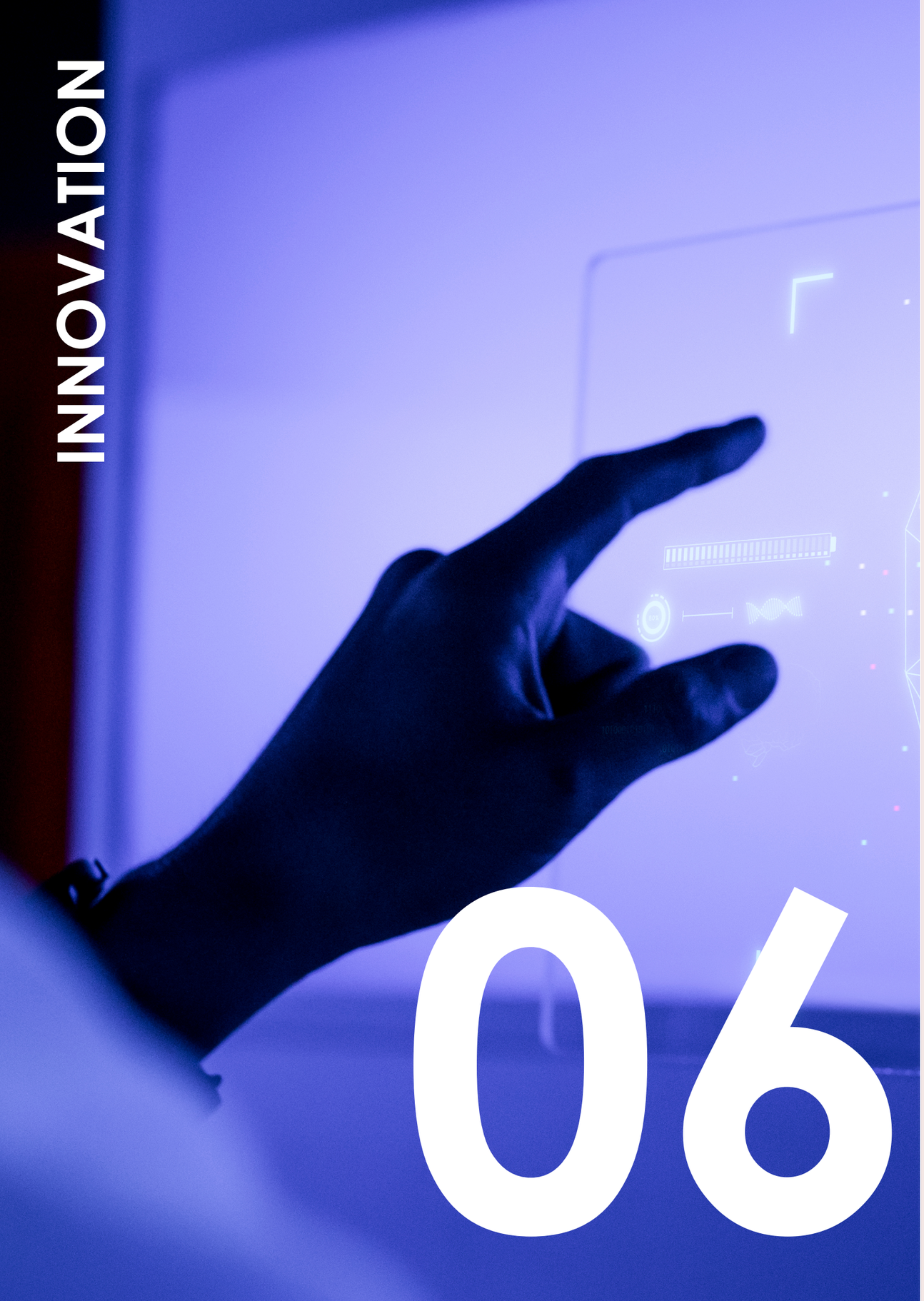
Health-related quality of life is an important outcome measure that is increasingly used in patients with chronic kidney disease. Quality of life declines in kidney patients in the early stages of the disease, but especially in advanced CKD and kidney replacement therapies such as dialysis.

UNMET NEEDS

The goal should be to address the humanistic burden of kidney disease, addressing unmet needs to improve the quality of care and the lives of people living with kidney disease, families, and caregivers.

UNPLEASANT SYMPTOMS

The unpleasant symptoms of the disease interfere with patients' quality of life. Therefore, it is necessary to give them importance and address them.



INNOVATION

06

NEW TECHNOLOGIES

Innovation isn't just possible, it's imperative.
New technologies for the treatment of chronic kidney disease (CKD) are opening up possibilities for improving patients' quality of life.

EASY TO TRANSPORT

One of the main priorities identified by the renal community for the treatment of kidney disease is the development of dialysis systems that are simpler, cheaper and easier to transport.

OVERCOMING CHALLENGES

Innovation outlines considerations for overcoming technical an market challenges to improve dialysis and transplant outcomes.



RESEARCH

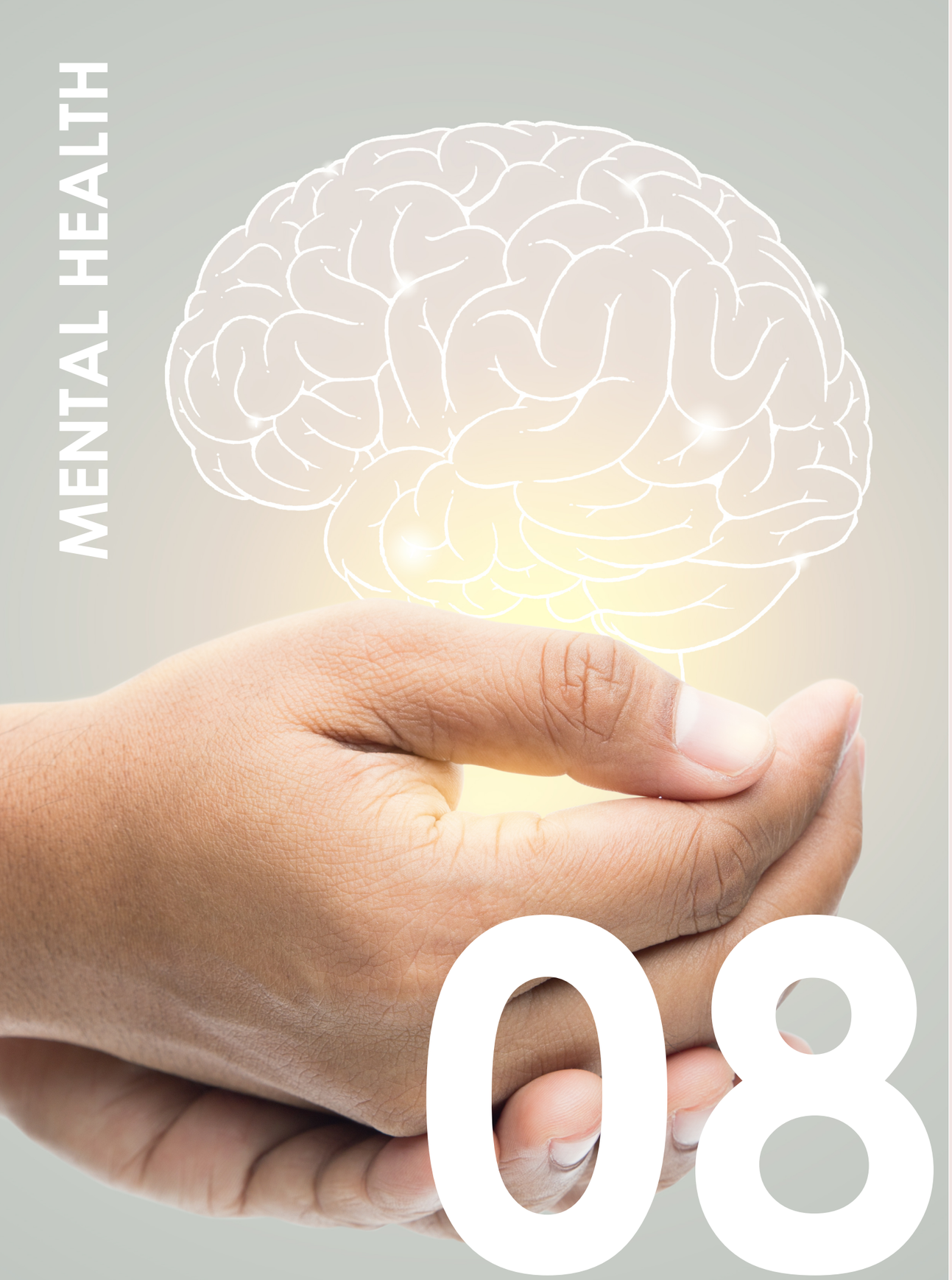
07

INCREASE KNOWLEDGE

Research and clinical trials allow kidney patients to participate in research that helps advance knowledge about chronic kidney disease, treatments and patient outcomes.

PROGRESS

The research that we are involved in is making significant progress in maintaining retrieved kidneys for longer, improving access and availability to increase transplantation and better kidney replacement therapies and treatments.



08

OVERCOMING BARRIERS

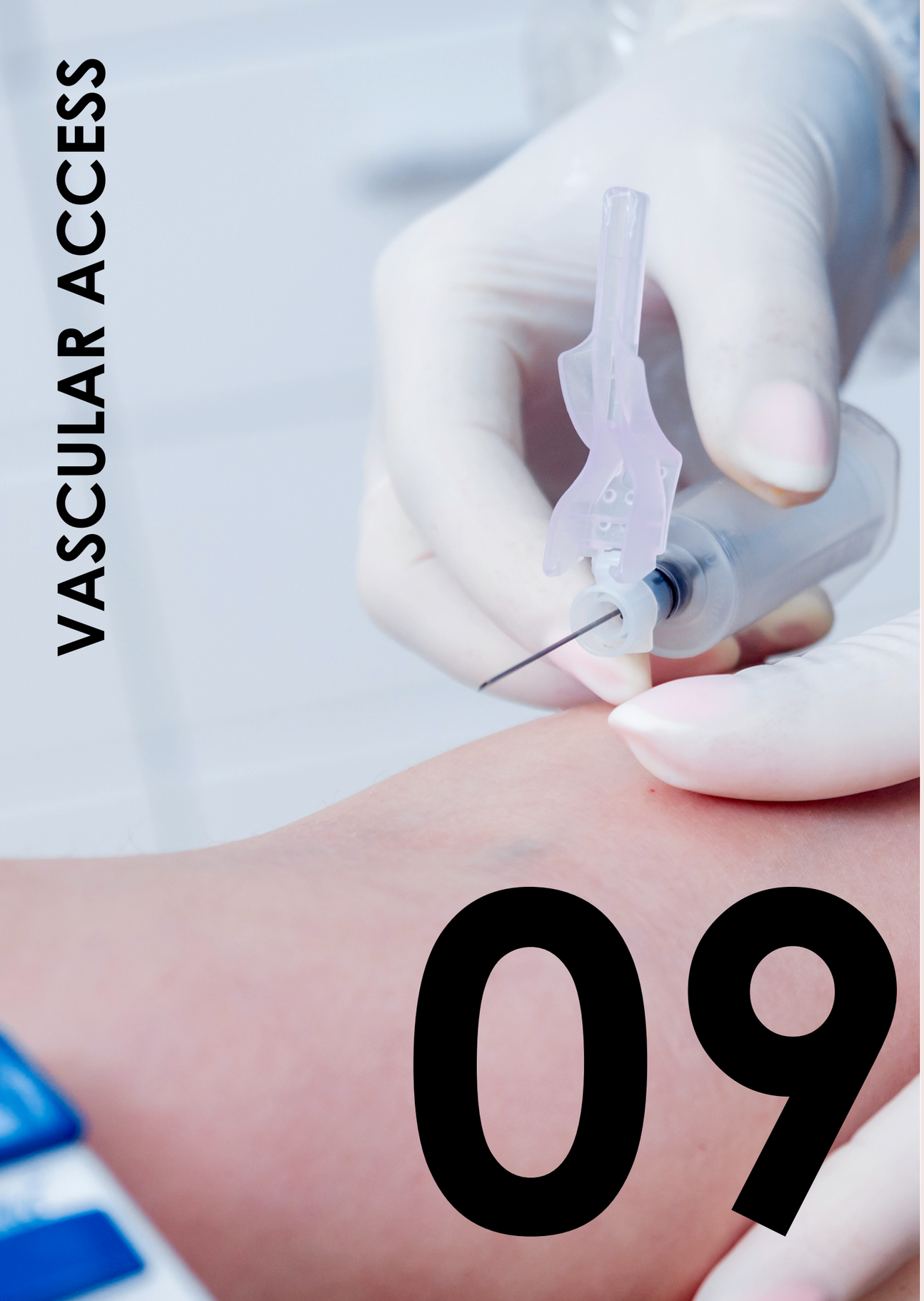
Maintaining good mental health is a struggle for most people, but it can be even more difficult if you have kidney disease. Depending on the stage of your kidney disease, you may have to deal with additional stressors in your life that affect your mental health. You may feel that there are many things you are being asked to change or give up, which can be overwhelming.

ACCEPTANCE

Health systems and professionals need to address the mental health conditions of people living with kidney disease, addressing acceptance of the disease throughout the lifelong condition, and feelings such as guilt, helplessness or depression.

MENTAL HEALTH

VASCULAR ACCESS



09

PROPER MANAGEMENT

It is crucial to promote and inform about the importance and proper management of vascular access for haemodialysis, in order to optimise the care of the person living with kidney disease.





FOCUS ON THE PERSON

The focus should not only be on the vascular access itself, but on the person with kidney disease who has a vascular access.

EDUCATION

It is important to involve the patient in surveillance and care to maintain and extend the life of the vascular access.





MAKING GOOD CHOICES

Nutrition is the key to managing kidney disease and your overall health. Making healthy food choices is important for all of us, but it is even more essential if you have kidney disease.





NUTRITIONAL PROGRAMS

Nutritional programs and strategies should be included in health systems to support and highlight the importance of food, healthy choices and habits in chronic kidney disease.

EMPOWERMENT

Education and empowerment of patients by giving them resources and tools to manage their nutrition in the bestpossible way.





PLANET-FRIENDLY MEASURES

With the majority of kidney failure patients on dialysis, ecological optimisation is imperative and must be pursued from production to delivery and waste management. Several industry stakeholders are taking planet-friendly measures to reduce climate change.

REDUCTION OF POLLUTANT PRODUCTION

Energy consumption is multifaceted and includes the manufacture of filters, machines and other consumables and the dialysis itself. It also includes dialysate production and heating, monitoring, lighting and climatization of the unit and the transport of material and patients, which contribute to extensive production of greenhouse gases and pollutants.



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