



ECARIS PROJECT

KICK-OFF MEETING

Athens

10 MARCH 2020

With the support of the
Erasmus+ Programme
of the European Union



PROJECT PARTNERS



EPIONI
GREEK CARERS NETWORK



ANS

Anziani e non solo
società cooperativa sociale



ALCER
Federación Nacional



SARONIC
NEPHROLOGICAL
CENTER



Danish Committee for Health Education
Komiteen for Sundhedsoplysning



MEETING EXPECTED RESULTS

01

To familiarize ourselves with the project

02

To adopt the work plan, evaluation strategy and dissemination plan

03

To establish the communication, monitoring and reporting procedures

04

To understand the financial and contractual rules

05

To agree on the web and social media presence of the project

PROJECT'S IMPLEMENTATION ORGANS



01

PAB

Patient
Advisory
Board



02

MB

Management
Board



03

SC

Steering
Committee

INTELLECTUAL OUTPUTS

INTELLECTUAL
OUTPUT

01

IO 01

ME AND MY
CARER

03

IO 03

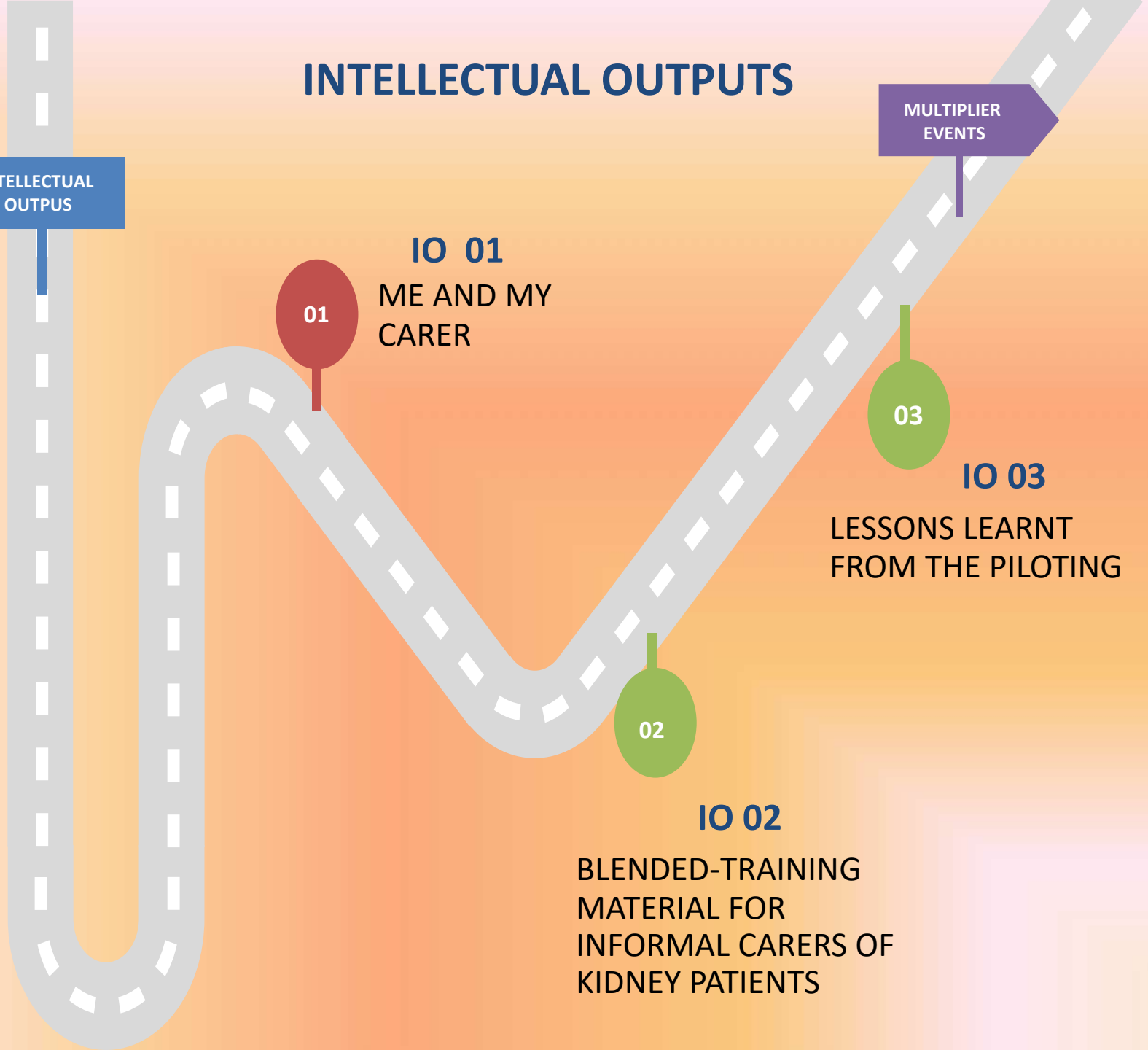
LESSONS LEARNT
FROM THE PILOTING

02

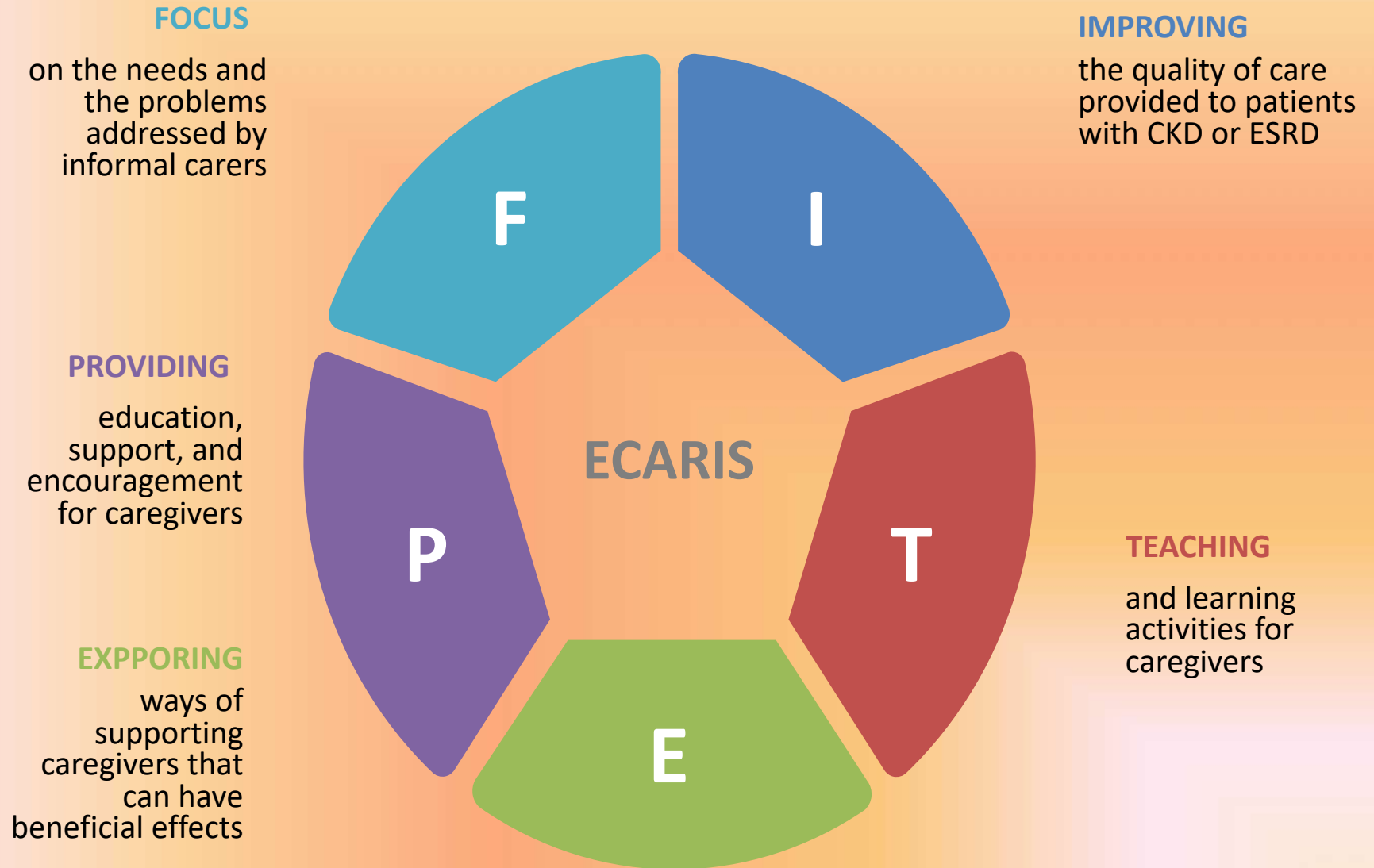
IO 02

BLENDED-TRAINING
MATERIAL FOR
INFORMAL CARERS OF
KIDNEY PATIENTS

MULTIPLIER
EVENTS



PROJECT GOALS





Co-funded by the
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ECARIS

Educating CARegivers of Kidney Patients

Greek Carers Network - EPIONI

Greek Carers Network

www.epioni.gr



Our association is a non-profit NGO established in 2017

- Contributes to the recognition of informal (i.e. family) carers in Greece. The term caregiver is not officially recognized in Greece.
- Advocates for carers in Greece by organizing relevant events



Co-funded by the
Erasmus+ Programme
of the European Union

Greek Carers Network



Involvement in EU projects targeting carers:

Linking Partners, Learn4Carers, Share4Carers, Share4Brain, ADHD-CARE, EIC



Annual Caring for Carers event at the office of the European Parliament in Athens



Co-funded by the
Erasmus+ Programme
of the European Union

ECARIS - Kick off meeting - Athens, 2020

Next Meeting at the office of the European Parliament in Athens

Caring for Carers

Monday 28 and Tuesday 29.9.2020



Co-funded by the
Erasmus+ Programme
of the European Union

EPIONI's online presence



Website: www.epioni.gr

Social media presence:

- Facebook: <https://www.facebook.com/epioni/> (2.165 followers)
- Twitter: <https://twitter.com/ngoepioni> (450 followers)
- LinkedIn: <https://www.linkedin.com/company/epioni> (51 followers)
- Instagram: https://www.instagram.com/greek_carers_network/ (208 followers)

EPIONI'S INVOLVEMENT IN ECARIS

EPIONI will be involved in the project through participating in the production, together with the other partners, of the three intellectual outputs:

1. Me and my carer
2. Blended training material for informal carers of kidney patients
3. Lessons learnt from the piloting

Additionally EPIONI will undertake the social media presence of the project with the help of all the partners

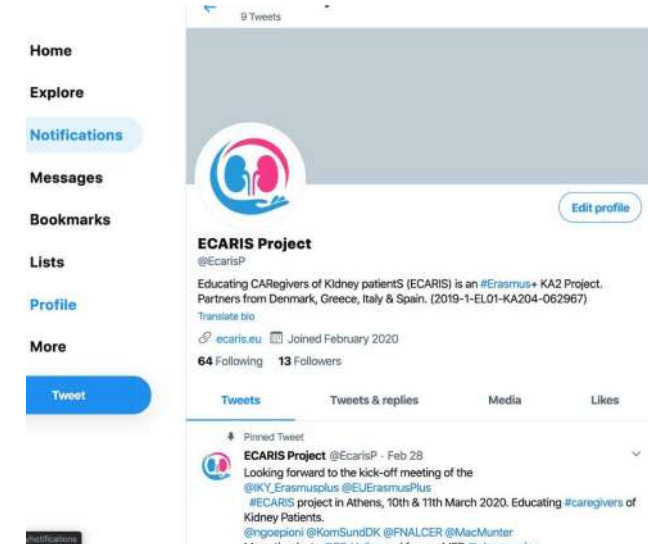


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Social Media Campaign

Will Create and update:

- ECARIS LinkedIn page:
- Facebook Page: /
- Twitter: <https://twitter.com/EcarisP>



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of the European Union

Steering Committee

- The Steering committee will be established in Athens to take the appropriate decisions consistent with the objectives of the project and to ensure implementation of the work plan.
- EPIONI will be represented in the Steering committee by Spyridon Zormpas.



Co-funded by the
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website: www.ecaris.eu

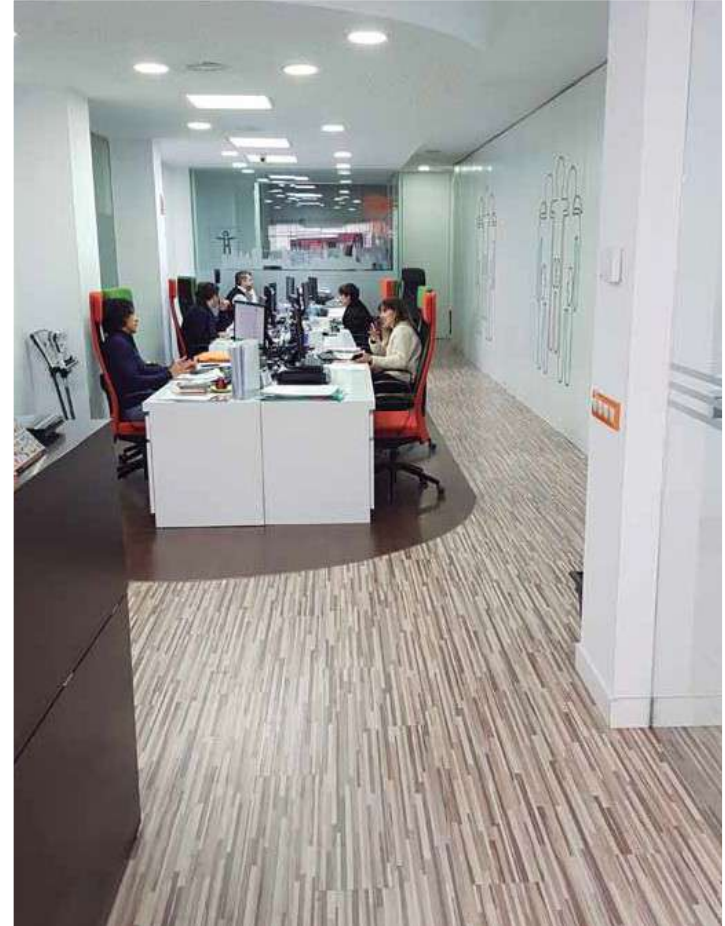
- The official domain of the project website will be maintained for a period of five years, thus ensuring that outcomes can be accessed after the project comes to an end.



Co-funded by the
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of the European Union



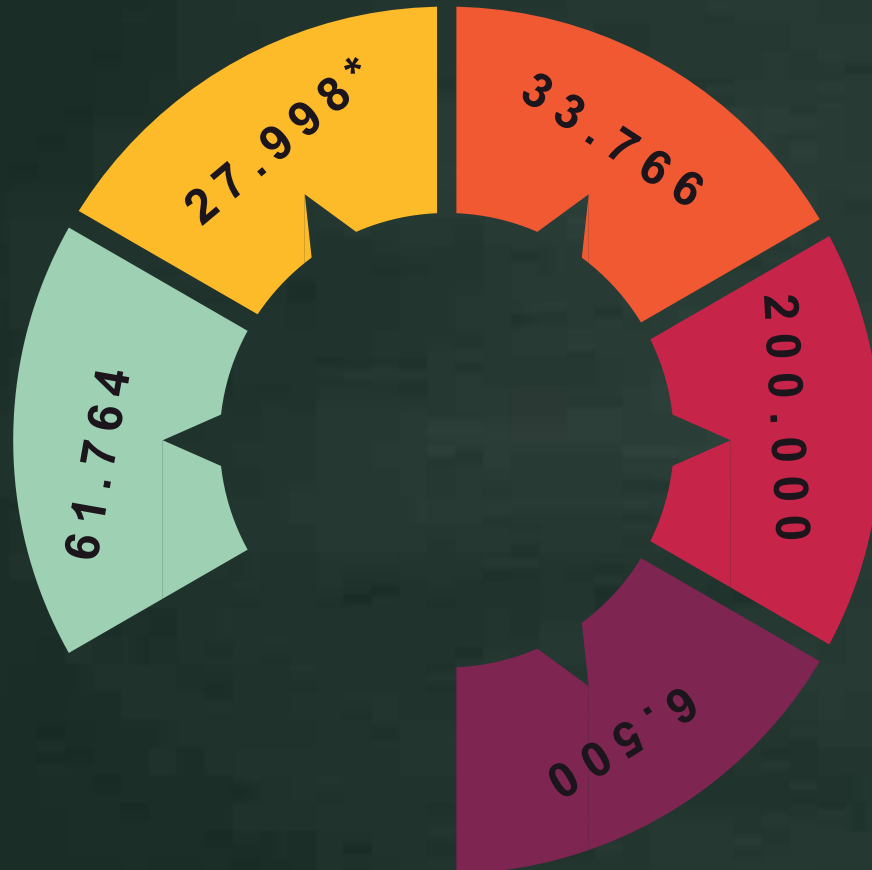
DOSSIER 2020



4



RENAL DISEASE IN FIGURES



PEOPLE IN RENAL
SUBSTITUTE TREATMENTS

PEOPLE IN DIALYSIS
TREATMENTS

* 242 PEOPLE IN HOUSEHOLD HD TREATMENT
* 3098 PEOPLE IN TREATMENT OF PERITONEAL
DIALYSIS

RENAL TRANSPLANTED PEOPLE

PEOPLE WITH ADVANCED
CHRONIC RENAL DISEASE

PEOPLE DIAGNOSIS OF RENAL CANCER
EVERY YEAR

ALCER

The National Federation of Associations ALCER (Association for the Fight Against Kidney Diseases), was created in 1981.

It currently has a total of 51 federated associations and 2 affiliated entities, distributed throughout the national territory representing the nearly 60,000 people in renal therapy and those who have a chronic kidney disease in Spain.

MISSION

To improve the quality of life of people with kidney disease in all its aspects, promoting the prevention and investigation of chronic kidney disease, as well as raising awareness about the donation of organs for transplantation.



EMPOWERMENT ACTIVITIES



SUMMER CAMP CRECE

Boys and girls with kidney disease aged 8 to 17 years, enjoy an educational summer vacation. With this experience it is sought that children learn to become aware and take responsibility for the general aspects of CKD.



RENAL PEOPLE MEETING

People with kidney disease and companions meet during a weekend to receive health education that allows them to learn to live better with their pathology and exchange experiences and share moments of leisure.



RENAL FAMILIES MEETING

Families with children with kidney disease live together during a weekend in which apart from carrying out organized activities, they exchange all their stories, in which they feel identified.





RIGHT PROMOTION



LEGAL CLINIC

The Legal Clinic is a service of great help for those groups that are in a special situation of vulnerability because they obtain a free legal advice from students who are tutored by teachers.



STUDIES

Studies concerning the investigation of psychosocial situations in people with CKD. These studies take special relevance on issues related to employment, women with kidney disease, girls and boys and young people.



LEGAL ADVICE

La Federación Nacional ALCER y Fidelity Consulting firmaron un convenio de colaboración en 2019, por la que esta empresa de asesoramiento jurídico prestará Asesoría GRATUITA durante todo el proceso. Todas las consultas que se realicen no conllevarán NINGÚN COSTE. La asistencia legal estará remunerada pero siempre se pactará A ÉXITO.

INFORME MUJER Y ENFERMEDAD RENAL 2019

GRUPO MUJER
FEDERACION
NACIONAL ALCER



GOBIERNO
DE ESPAÑA

MINISTERIO
DE SANIDAD, CONSUMO
Y BIENESTAR SOCIAL



POR SOLIDARIDAD
OTROS FINES DE INTERÉS SOCIAL



The Legal Clinic is a great help for those groups that are in a special situation of vulnerability





COMMUNICATION



KIDNEY WORLD DAY (Second Thursday of March)

This year it was celebrated on March 12 under the motto “Renal Health for everyone everywhere: from prevention to early detection”, calls everyone to advocate for concrete measures to promote and advance the prevention of the disease renal.



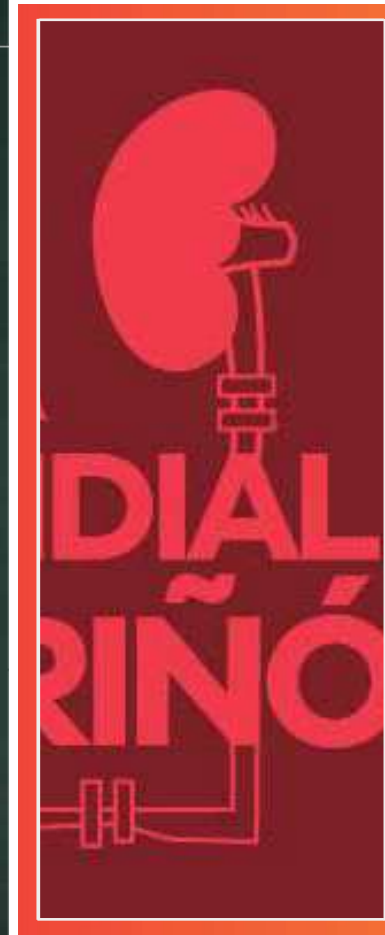
NATIONAL DAY OF THE DONOR OF ORGANS (First Wednesday of June)

Day set up to honor all anonymous donors who, with their altruistic gesture, have improved the quality of life of many people through a transplant and thanked their families for this decision. This year will be held on June 3.



WORLD DAY OF RENAL CANCER

Kidney cancer is one of the ten most common cancers in the world and rates are rising rapidly. Therefore, this day focuses on preventing this disease and improving the quality of life of people affected by kidney cancer.



Donor Day is an established day to honor all anonymous donors who, with their altruistic gesture, improve the quality of life of many people





COMMUNICATION



NATIONAL DAY OF THE ORGAN TRANSPLANTATION (Last Wednesday of March)

Campaign to promote this therapy and thanks to the professionals who make it possible. It will be held on March 25.



CAMPAIGN ABOUT KIDNEY STONES

Campaign to inform about the prevention of kidney stones. This campaign allows queries to users who wish to do so through a digital office. These questions are answered by a urologist specialized in kidney stones.



INTERNATIONAL SHUA DAY (24th September)

International Day of Atypical Hemolytic Uremic Syndrome (SHUa), a pathology that mainly affects the kidneys but also other organs such as the brain, liver, heart, lungs and gastrointestinal system.



Campaign to inform about the prevention of kidney stones. This campaign allows queries to users who wish to do so through a digital office.



ALCER APP



Alcerapp

COMMUNICATION



AMAGAZINE ALCER

Most important and most historical means of communication of the ALCER National Federation and its entities. Currently, the ALCER magazine, with a quarterly periodicity, can be found in paper or digital format, through our website: alcer.org



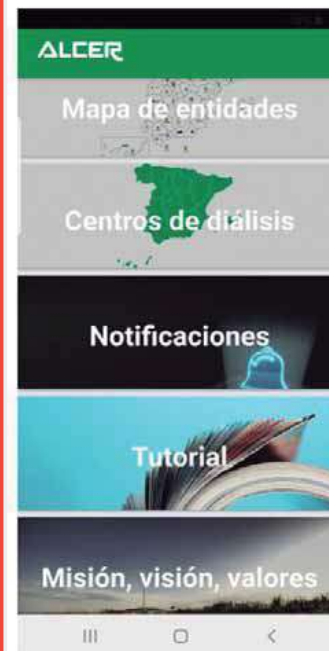
PERSONASRENALES.ORG

Information Center on kidney diseases. Everything you need to know about kidney disease and from reputable sources. You can access all the information through personarenales.org



APP FOR MOBILE DEVICES

Tool to provide electronic support to all those interested in kidney diseases. You can download "AlcerApp" in PLAYSTORE and APPLE STORE completely free of charge.



The ALCER magazine is the most important and most historical means of communication of the ALCER National Federation and its entities





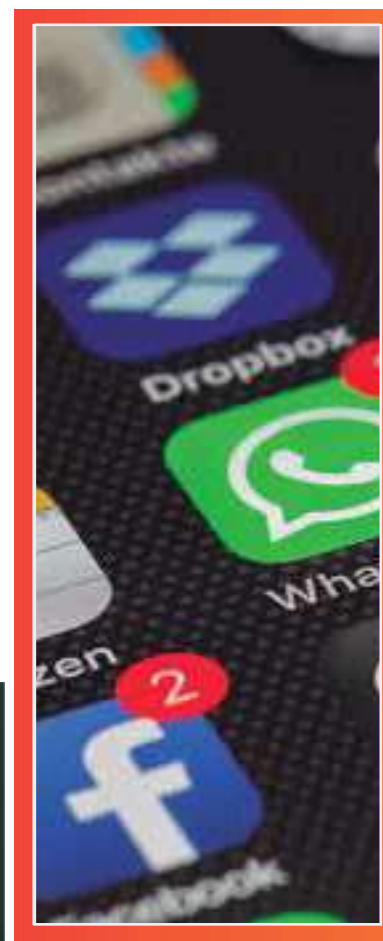
PANORAMA ALCER

It is the means of digital dissemination that supports the information related to the activities of the ALCER entities and the actuality of renal treatments in their health, social, labor, legal, etc.



SOCIAL NETWORKS

Daily, news related mainly to renal disease is published as well as to disseminate the activities of the ALCER entities. You can follow ALCER National Federation in any of its social networks.



PANORAMA ALCER

Panorama ALCER Es el medio de difusión digital que da soporte a la información relativa a las actividades de las entidades ALCER



TRAINING, EMPLOYMENT AND EDUCATION



CONTINUOUS TRAINING PLAN

Continuous training sessions for managers and technicians of the ALCER provincial entities. There are two sessions a year.



SMALL AND MEDIUM COMPANY ADVICE SERVICE

Free advice service to companies on aid, subsidies and technical adaptations to accommodate workers with disabilities, establishing relationships with the business world to facilitate access for the disabled to the labor market.



INTEGRAL EMPLOYMENT SERVICE: ALCER.ORG/SIE

Página web del Servicio Integral de Empleo de Federación Nacional ALCER. Portal dotado de información sobre noticias de actualidad, ayudas al estudio, eventos y publicaciones. Además el/la usuario/a podrá ver e inscribirse en las ofertas de empleo que el servicio dispone para personas con discapacidad.



Servicio de asesoramiento gratuita a empresas sobre ayudas, subvenciones y adaptaciones técnicas para acoger a trabajadores/as con discapacidad





FEDERACIÓN NACIONAL ALCER

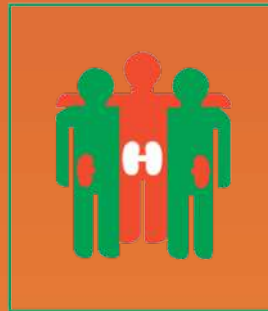
Calle Constancia 35 - Local 2

28002 - Madrid

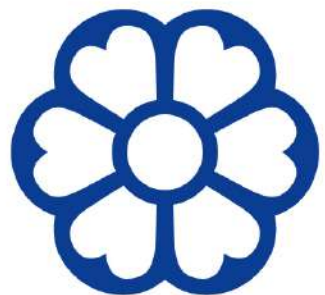
Teléfono: 915 610 837

federacion@alcer.org

www.alcer.org



ALCER
Federación Nacional



Danish Committee for Health Education

Komiteen for Sundhedsoplysning

Presentation for Kick-off meeting for Erasmus+ project

Educating caregivers of kidney patients - ECARIS

About the organization

The Danish Committee for Health Education (DHCE) is a nonprofit NGO that has been working in the field of health promotion since 1964. DHCE works within a broad scope of activities aimed at health promotion specifically through communication and education.

Activities carried out by Komiteen for Sundhedsoplysning concerns:

- Patient empowerment
- Implementing and evaluating patient education activities
- Developing methods and educating health care professionals on breastfeeding
- Developing and implementing digital evaluation tools used to measure well-being in children and adolescents
- Coordinating projects aimed at strengthening mental health in the workplace
- Developing children's cookbooks, and thereby promoting healthy habits at a young age
- Publishing health promotion material

Our areas of competence are:

- Project development, management and coordination
- Research
- Pilot project development
- Health education and training through information and events aimed at both health professionals and non-professionals
- International project development



CV

Lars Münter
Head of International Projects Unit

Experience in developing and leveraging interdisciplinary and cross-sectoral platforms, nationally and internationally – and creating joint communication results and political ambitions based on those platforms.

Dalia Bramming
Project Coordinator

Experience in pilot project and campaign development, and qualitative research methods.





ANZIANI E NON SOLO (IT)

ECARIS project

Kick off meeting – 10th March 2020

ANS PRESENTATION

Description of the organisation / 1

- **Anziani e non solo (ANS)** is an NGO funded in 2004 **active in pilot and research projects and realization of services and products** on the topics of:

- social innovation
- welfare
- social inclusion
- equal opportunities
- antidiscrimination
- training and educational programmes addressed to vulnerable target groups and professionals working in the social sector

- **ANS is registered as a social research institution and a member of relevant networks**, such as:

- **Eurocarers** – the European Network of Carers Organizations
- **COFACE** – the European Network of Family Associations
- **AGE Platform** – the leading umbrella organization of Older Persons
- **CAR.ER.** - Emilia Romagna umbrella association of carers organizations

Description of the organisation / 2

- ANS has an **extensive experience in management of EU-funded projects**, having been involved so far in over 40 projects
- ANS has a Memorandum of Understanding with **Modena University – CRID (Interdepartmental Research Center on Discriminations and Vulnerabilities)** and **Department of Psychology of Bologna University**, that support us in the development of Erasmus+ projects

ANS EXPERIENCE

Past experience in the area / PROJECTS

ANS projects linked with the topic of ECARIS are:

- **SINCALA** developing and piloting a model of pedagogical interventions for family caregivers
- **APPs for Carers** aims contribute to the wellbeing of informal carers by overcoming barriers through the use of mobile solutions
- **Care2work** addressed to young informal carers aiming at supporting their smooth transition from caring to adulthood
- **Care4Dem** aims to develop a new and innovative model of mutual aid groups which promotes caregivers involvement by introducing web based tools and integrating it with other type of interventions, in order to enhance caregivers satisfaction with care and reduce burnout

Past experience in the area / OTHER ACTIVITIES

Among the target groups of the various activities developed by ANS, **formal and informal carers hold a relevant position:**

- Has developed the **first e-learning course for family carers** available in Italy (including specific modules on Dementia and Alzheimer diseases)
- **Every year trains approximately 150 carers** across Italy
- Periodically **holds classes for informal carers** focused on health-related issues
- **Advocacy activities** (led to the approval of a new law in the region of Emilia Romagna regarding recognition of the role of carers)
- **Runs peer-support groups for carers**
- Organizes, every May, the **Carers Days** in the Carpi District (in 2012 the event became regional)

ANS RESPONSIBILITIES

- Leader of IO1 – ME AND MY CAREERS, with the input from all partners, which will be involved in the collection of interviews as well as in the analysis of results, in order to make sure that the material corresponds to different cultural backgrounds

- Task 1.1 Ans has drafted a document *Protocol Research_Focus group themes_IO1* including interviews themes and based on literature. **DONE.**
- Task 1.2 All partners will carry out Focus Group based on *Protocol Research*, in order to identify and collect needs and expectations. Each partners will summarize the results in English. **M5-M6 – April May 20**
- Task 1.3 ANS will make a draft analyses and report of the focus group. All partners will have a draft peer reviewed after a round table with at least 5 professionals and stakeholders **M7-M8– June-July 20**

- Task 1.4 The lead Partner will draft final version of the report, with specification for the training, material and MOOC. **M9-M10-Sep-October 20**

ANS as co-leader IO 2.4 will be responsible for the creation of the multimedia course (instructional design a& LMS version of training material, creation of different version of the training, alpha test of the LMS ecc)

THANK YOU!!

THE RESEARCH PROTOCOL

Background

The majority of patients with Chronic Kidney Disease (CKD) and patients with kidneys insufficiency rely on their family members for their daily activities and medical care, since the family is the best source for providing care to these patients. Studies have shown that good family support has a positive effect on successful patients' adaptation to dialysis treatment and compliance with a dietary regimen. However, sometimes patients do not follow the dialysis treatment' restrictions due to their perception that they have become a 'burden' to their family. Thus, family caregivers play an important role in the provision of effective communication to dialysis patients when it is appropriate. However, caregiving is regarded as a chronic stressor due to the demanding activities and the emotional burden of caring.

However, sometimes family caregivers have to take difficult decisions, such as interruption of dialysis therapy or referring their patients to hospice services.

Identifying family, professionals or individuals 'caregiver burden' early will optimize the well-being of the caregiver. Therefore, the evaluation of caregiver's status and determination of their needs are very important.

Discussing coping skills can improve the caregiver quality of life even in the difficult environment of end-of-life care. Psychosocial intervention can have significant, positive effects on caregivers' burden and improve their satisfaction with their role.

The benefits of informing/learning/teaching caregivers are numerous and include issues such as illness education, medication concordance improvements, explanation of prognostic expectations, and various other psychosocial and practical inputs.

The ECARIS project aims to improve the quality of care provided to patients with CKD or ESRD, to ease the burden on informal, family or professional caregivers and family-employed care assistants, and finally improve the QoL of both groups (caregivers and patients). Partners and associated partners are about to establish communication's channels for exchanging and developing existing

successful for the caregivers' support methods.

Research Team (local)

Each partner decides on this (preferably include persons with experience in focus groups e.g. as moderators, data analysis, bilingual translators).

Study design

A qualitative approach will be utilized for this study. The **focus group method** has been selected as a way of collecting qualitative data, but also as a technique for gaining a large amount of data regarding opinions and attitudes in the shortest amount of time. It relies on group processes and encourages interaction between group members, resulting in deeper exploration of the subject under study (Bowling 2014). Focus group, through focused discussions, enable the researchers to study a topic of interest in depth by composing teams (purposively chosen according to the study's aim) in which participants discuss similar experiences and share common characteristics. Participants are encouraged to freely express their feelings, ideas, agreements or disagreements in a non-threatening environment. Furthermore, discussions stimulate memories and facilitate the exchange of ideas and opinions, leading to a more in-depth study of the research topic.

The moderator will use a semi-structured interview guide during the focus group.

Participants

At least 5 couples of informal carers and patients from each country, will be consulted through 1 focus group.

Each partner will be responsible to recruit the required sample according to the pre-specified criteria.

The purposive sampling technique will be used so that the desired homogeneity and heterogeneity of the group are achieved.

All discussions will be held in the partner's local language.

Goals of IO1 – to explore how caring can have a different **impact** on carers of different countries, the types of support available, the role of education in wellbeing and coping. The report, while providing new qualitative inputs to the research on family relationships **coping strategies** and **educational needs** in families with a caring role for kidney patients will also contribute to informing the structure of the training material and curriculum.

Proposal for themes to be explored (from the perspective of the carer and the care recipient, in two separate interviews / focus groups, with the exception of topics identified with * which refers only to the caregiver): following literature review, the following main topics were identified:

Introductory topics

- Persons cared for / that cares for you
- Reasons for caring / to be cared for (what is the main kidney-disease [KD], are there any co-morbidities)
- Care needs (describe what care you need to provide / to receive in everyday tasks)

Support networks

- Support network (describe your support network / on how many persons you can count in case of needs / who are they – include professionals and non-professionals)
- Evaluation of the support received by professionals and non-professionals

Impact on practical life

- Impact of KD on life dimensions, such as: employment, education, house-hold care, finance

Impact on emotional life

- Impact of KD on physical and emotional life, such as: fatigue, anger, depression, feeling of uncertainty...

Impact on family and social life

- Impact of KD on family and friends relationships: which changes have been noticed in relation to support received; neglect of other family responsibilities; disruption of family life; intimacy between caregiver and care recipient; restriction to social life...

Coping strategies*

Introduce this topic explaining what the coping strategies are (definition, example ecc)

- Coping strategies implemented: strategies to improve communication, anger management, stress management, self-care, information seeking...

Educational needs

- Topics on which they would like to learn more – examples: information about the disease, available supports, nutrition and diet, treatments and therapies, providing emotional support, self-care...

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Promoting the needs and added value of informal carers across the EU

Time for a comprehensive EU Carer's Strategy

Stecy Yghemonos - Eurocarers

Kickoff meeting of the ECARIS Project

Athens, 10th March 2020

The Eurocarers Network



European network of carers' organisations and relevant research & development organisations

70 member organisations in 26 countries

Who are the (informal) carers?

A carer is any person who provides care - usually unpaid - to someone with a chronic illness, a disability or any other long-lasting care needs, outside a professional or formal framework.

The Situation of carers in Europe



The Personal is Political

According to research:

- Informal carers are **largest providers of health and social care support**
- Make up about **10-25% of the total EU population**
- **Women** provide 2/3 of care mainly as daughters (in law) and spouses/partners.
- Usually **between 45 and 75 years**

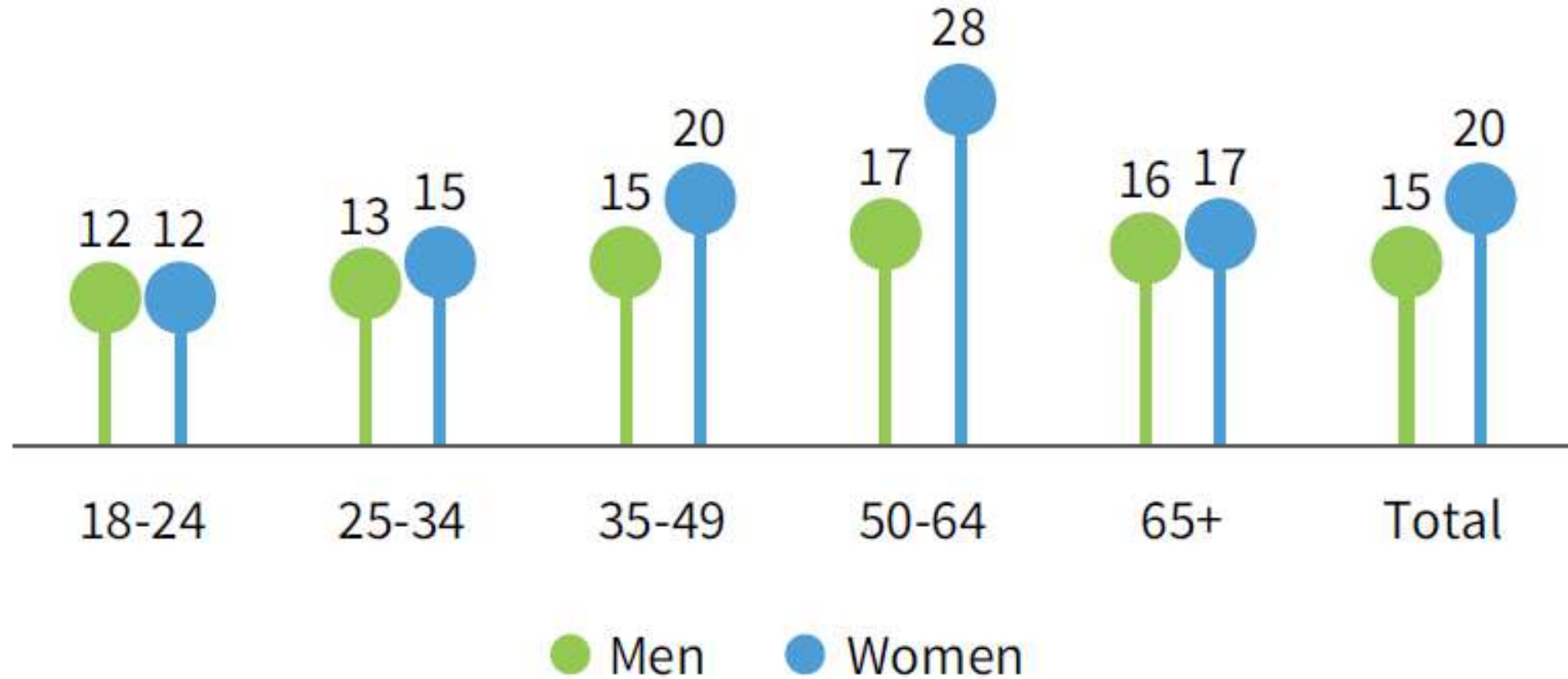
The “economic” value of informal care

Estimates of the value of unpaid informal care in EU Member States between 50 and 90 % of the overall costs of “formal” LTC provision

Budgetary impact of progressive shift from informal to formal care by 2070 would mean an increase by 130% in share of GDP devoted to LTC on average for the EU

→ No universal long-term care without informal carers !

Caring for disabled/infirm relative or friend



Proportion of men and women in different age groups providing care (at least once a week) – EQLS 2016

Regular carers of people with a disability or infirmity, among people of working age (18–64 years), by country (%)

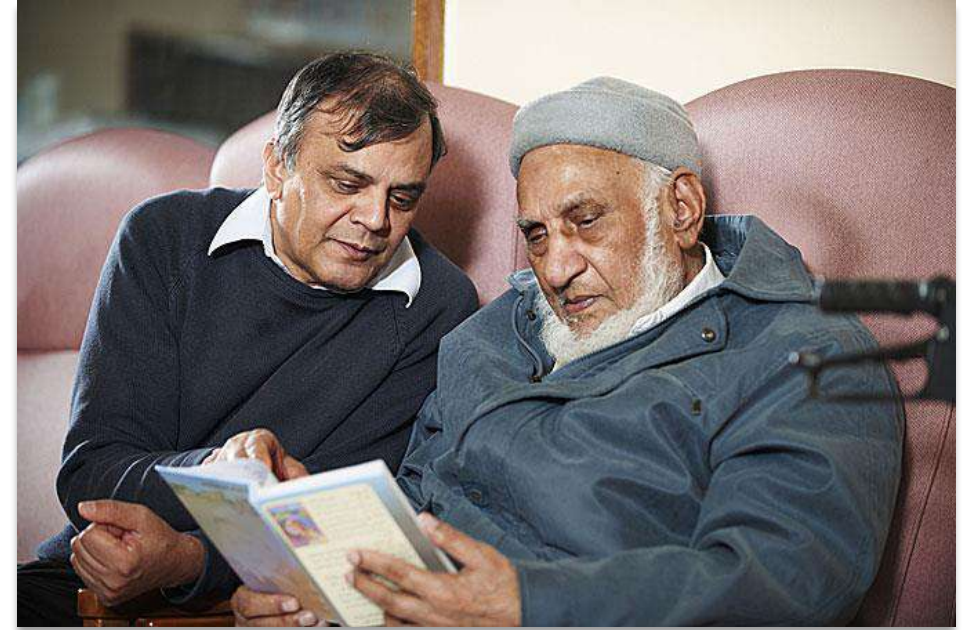
	Non-carers	Working carers	Carers not in employment
Austria	95	3	2
Belgium	81	11	8
Bulgaria	92	3	5
Croatia	87	7	6
Cyprus	89	5	6
Czech Republic	91	4	5
Denmark	93	5	2
Estonia	88	7	5
Finland	90	7	3
France	74	18	8
Germany	94	4	2
Greece	90	3	6
Hungary	92	4	3
Ireland	86	6	7

Italy	90	6	5
Latvia	78	15	7
Lithuania	86	10	5
Luxembourg	85	11	3
Malta	86	5	9
Netherlands	91	6	3
Poland	89	5	6
Portugal	93	4	3
Romania	84	10	6
Slovakia	91	5	3
Slovenia	87	8	5
Spain	88	7	6
Sweden	96	4	1
United Kingdom	86	9	5
EU28	88	7	5

Impact of caring

Clear correlation between caring and:

- Work-life/care balance
- Social exclusion and poverty
- Health and well-being



"As a carer, you have no social life whatsoever. I have been an unpaid carer for 20 years. I do not feel part of society at all. I feel a complete outsider"

Social and economic situation of regular carers of working age (18–64)

	Non-carers	Working carers	Other carers
In fair or bad health	22	27	41
Having difficulties making ends meet	38	44	54
In lowest income quartile	25	26	45
Feel lonely more than half of the time (in previous two weeks)	10	14	17
Feel the value of what they do is not recognised by others	19	26	28
Social Exclusion Index	2.1	2.2	2.4
Life satisfaction	7.2	7.1	6.5

Regular carers' refers to those providing care to someone with a disability or infirmity several days a week or every day - Eurofound 2018

What do carers want?



Financial support: income based on a minimum wage

Employment: flexible working, paid and/or unpaid leave

Pension credits for care time

Regular breaks from caring

Training

Caregiving is not the source of my stress and exhaustion, the constant battle for services is!

EU Pillar of Social Rights

Chapter 1: Equal opportunities & access to the labour market

1. Education, training and lifelong learning
2. Gender equality
3. Equal opportunities
4. Active support to employment

Chapter 2: Fair working conditions

5. Secure & adaptable employment
6. Wages
7. Information about employment conditions
& protection in case of dismissal
5. Social dialogue & involvement of workers
6. Work-life balance
7. Healthy, safe & well-adapted work environment & data protection

Chapter 3 : Social protection and inclusion

11. Childcare and support to children
12. Social protection
13. Unemployment benefits
14. Minimum income
15. Old age income and pensions
16. Health care
17. Inclusion of people with disabilities
18. Long-term care
19. Housing and assistance for the homeless
20. Access to essential services



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EC Directive on WLB for parents and Carers

WHAT WILL THE NEW DIRECTIVE IMPROVE?

	CURRENT EU LAW	IMPACT OF THE NEW DIRECTIVE
Paternity Leave 	No minimum standards for paternity leave at EU level.	Working fathers will be able to take at least 10 working days of paternity leave around the time of birth of the child. Paternity leave will be compensated at least at the level of sick pay.
Parental Leave 	At least 4 months per parent, out of which 1 month is non-transferable between parents. No minimum rules on allowance/payment.	At least 4 months per parent, out of which 2 months are non-transferable between parents. Parents can request to take the leave in flexible forms (full-time, part-time or in a piecemeal way). The 2 non-transferable months of parental leave will be compensated at a level set by Member States.
Carers' Leave 	No minimum standards for carers at EU level (except "force majeure" allowing to take short time off for imperative and unexpected family reasons).	All workers will have the right to 5 working days of carers' leave per year.
Flexible Working Arrangements 	Right to request reduced and flexible working hours upon return from parental leave. Right to request part-time work for all workers.	All working parents with children up to at least 8 years old and all carers will have the right to request the following flexible working arrangements: 1. reduced working hours 2. flexible working hours 3. flexibility on the place of work

The rationale for an EU-wide Strategy on Carers



Thank you

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CHRONIC KIDNEY DISEASE



Numbers in Greece (2019)

- 12.318 patients with Chronic Kidney Disease Stage 5
 - 11.634 in dialysis
 - 684 in peritoneal dialysis
- 2691 people live with kidney graft

Although kidneys are relatively small (each one is about the size of your fist), when they are healthy, they process 100% of the body's blood supply about every 5 minutes.

- ✓ clean waste from the blood
- ✓ manage fluid in the body
- ✓ control blood pressure
- ✓ make red blood cells
- ✓ balance acidity and mineral composition

What is chronic kidney disease (CKD)?

Chronic kidney disease (CKD) occurs when kidneys are no longer able to clean toxins and waste product from the blood and perform their functions to full capacity. This can happen all of a sudden or over time (acute or chronic)

Symptoms: *changes in urination (more or less urine, feeling pressure when urinating, changes in the colour, foamy or bubbly urine, getting up at night to urinate), swelling of the feet, fatigue, weakness, shortness of breath, ammonia breath or an ammonia or metal taste in the mouth, back or flank pain, itching, loss of appetite, nausea, vomiting, more hypoglycemic episodes if diabetic*

- There are five stages of kidney disease
- Your glomerular filtration rate (GFR)-considered by medical professionals to be the best measure of kidney function-lets kidney care experts figure out your stage of kidney disease
- Understanding it can help you learn how to take control and slow the progression of your condition
- Determining your GFR levels requires a simple blood test
- Use this GFR Calculator tool to help you determine which stage of kidney disease you are in currently.

What Your GFR Result Means

Completely healthy kidney function is measured at a glomerular filtration rate (GFR) of around 100, which means that the kidneys are working at 100 percent. Your kidney function is still considered normal if the GFR number is 90 or greater. If your GFR is 45, you know that your kidneys are working at approximately 45 percent of the normal rate.

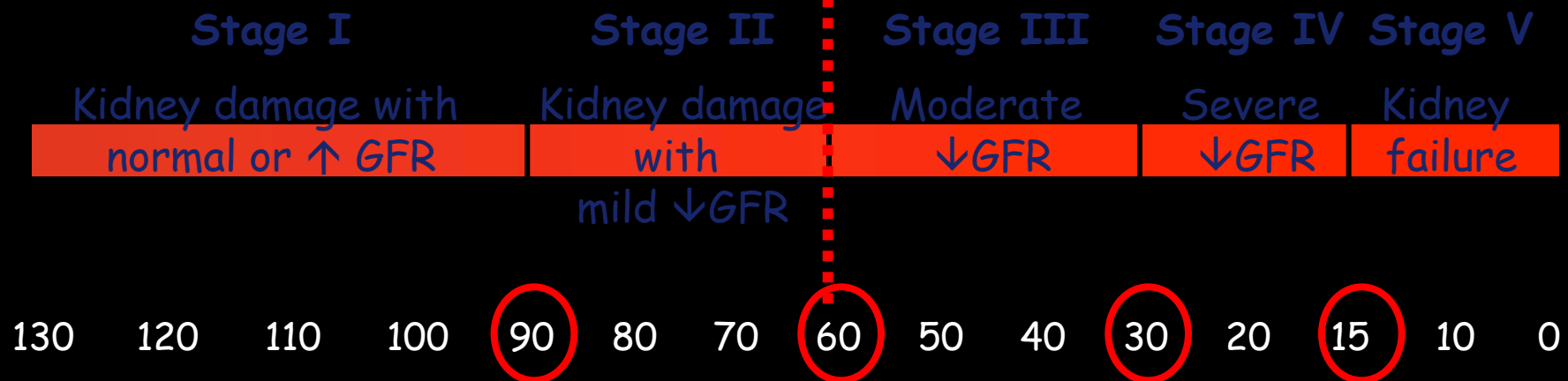
COCROFT AND GAULD CALCULATOR

$(140 - \text{age}) \times \text{weight in Kg}$

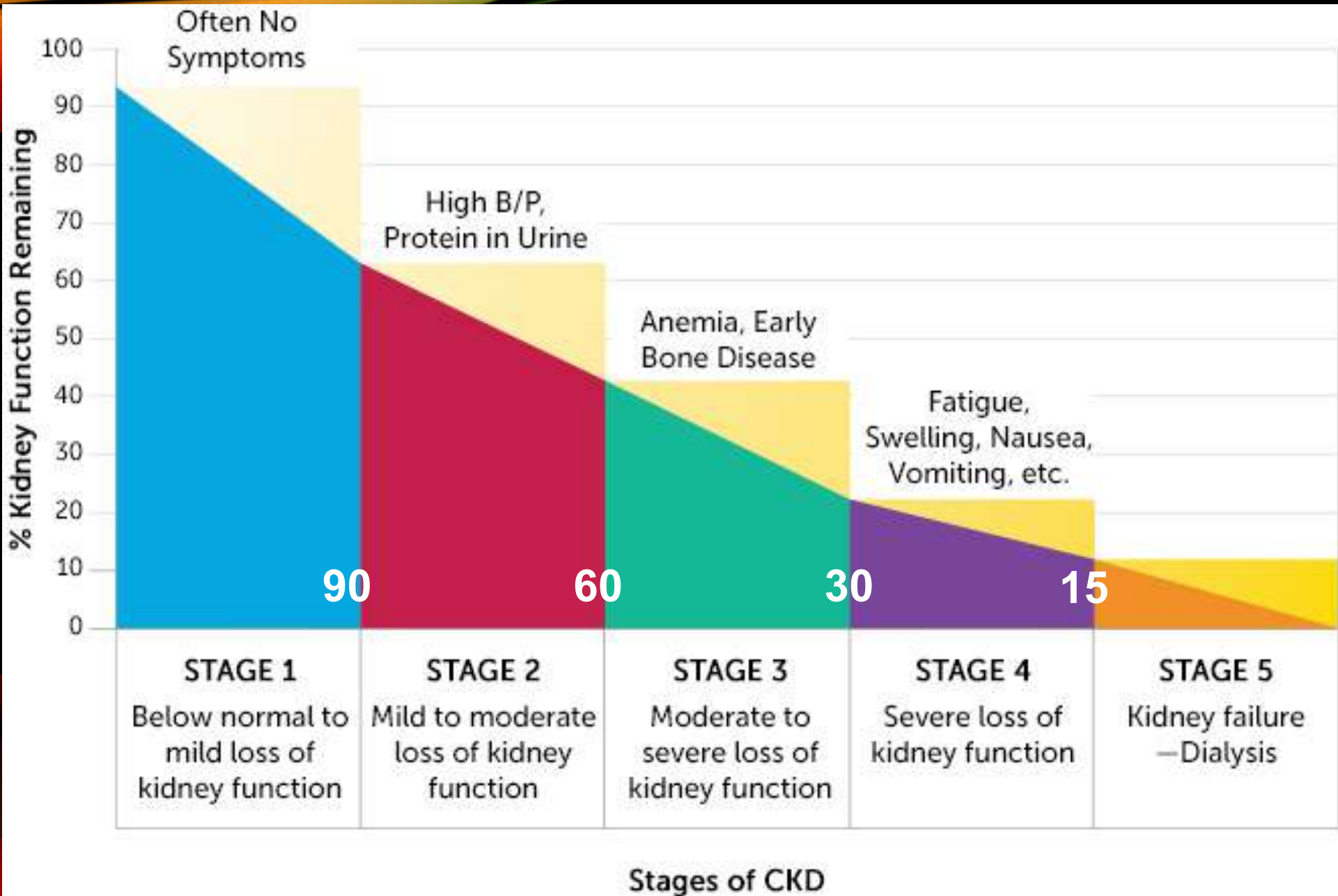
$(72 - 85) \times \text{creatinine}$



≤60 ml/min for > 3 months



Glomerular filtration rate (mL/min/1.73m²)



Stage 1 Kidney Disease

Healthy kidneys or kidney damage with normal or high GFR

GFR LEVEL: 90mL/min or more

Stage 1 CKD is diagnosed when a person has kidney damage and CKD risk factors with normal or high GFR. In Stage 1, there are often few to no symptoms. Management includes a healthy diet, blood pressure regulation and good glucose control in people with diabetes. Early CKD is usually diagnosed when there is:

- High blood pressure
- Higher than normal levels of creatinine or urea in the blood
- Blood or protein in the urine
- Evidence of kidney damage in an MRI, CT scan, ultrasound, or contrast X-ray
- A family history of polycystic kidney disease (PKD)

Stage 2 Kidney Disease

Kidney damage and mild decrease in GFR

GFR LEVEL: 60 TO 89 mL/min

In Stage 2 CKD, the GFR is mildly decreased between 60-89, indicating the person has kidney damage and mild loss of kidney function. Similar to Stage 1 CKD, following a healthy diet, controlling blood pressure and managing diabetes are key ways to slow the progression of CKD. Early CKD is usually diagnosed when there is:

- High blood pressure
- Higher than normal levels of creatinine or urea in the blood
- Blood or protein in the urine
- Evidence of kidney damage in an MRI, CT scan, ultrasound, or contrast X-ray
- A family history of polycystic kidney disease (PKD)

Stage 3A & 3B Kidney Disease

Moderate decrease in GFR

GFR LEVEL: 30 TO 59 mL/min

Stage 3 CKD, a moderate decrease in kidney function, is divided into 3A (GFR is 45 to 59) and 3B (GFR is 30 to 44). The following can occur when someone is in stage 3 of CKD:

- Waste products build up in the blood.
- Symptoms include fatigue, too much fluid, urination changes, sleep problems and kidney pain.

You can often manage stage 3 by changing to a kidney-friendly diet plan as well as managing high blood pressure and diabetes.

Visit your doctor or nephrologist to help manage kidney disease through kidney-friendly living habits and possibly with prescription medication.

Stage 4 Kidney Disease

Severe decrease in GFR

GFR LEVEL: 15 TO 29 mL/min

When CKD has progressed to Stage 4, it's time to begin preparing for dialysis and/or a kidney transplant. If GFR falls below 30, people need to find a kidney doctor (called a nephrologist) and talk about treatment options.

- People may develop complications, such as high blood pressure, anemia, bone disease and cardiovascular diseases.
- Symptoms include fatigue, back pain, nausea, taste changes, nerve problems and difficulty sleeping.

Seeing a kidney doctor will help a person manage their disease.

A dietitian is usually referred by a kidney doctor to help a person with kidney disease to learn more about the right kidney diet for them.

Stage 5 Kidney Disease

Kidney Failure

GFR LEVEL: Less than 15 mL/min or on dialysis

A person with Stage 5 CKD has end stage renal disease (ESRD) with a GFR less than 15 ml/min. At this advanced stage of kidney disease, the kidneys have lost nearly all their ability to do their job effectively, and eventually dialysis or a kidney transplant is needed to live.

- Symptoms include loss of appetite, nausea, itching, swelling and making little or no urine.

People with Stage 5 CKD will need to consider a couple of different treatment options, such as dialysis (a treatment that removes wastes and excess fluid from your body) or a kidney transplant.

CAREGIVERS

INSPIRED OR OVERWHELMED

Becoming a caregiver to a person with kidney disease can be a responsible obligation to put all your efforts, but also a stressful change, physically, emotionally, economically and also time consuming.

It is easy to feel overwhelmed and unable to cope.

While it may not be possible to avoid the stressful situation of being a caregiver to someone with renal disease, we can learn to cope with stress in a healthy way. All of us can learn to control the way we react to stress and change how stress affects us.

Warning signs of stress

It is important to recognize the physical, emotional and behavioral signs that our bodies send when we are in stressful situations, such as caring for someone with end stage renal disease (ESRD). If we recognize these signals early, we can take the action needed to minimize the harmful effects of prolonged stress.

Physical signals

- × Inability to sleep or sleeping too much
- × Weight gain or loss
- × Feeling tired all the time
- × Change in posture—walking with your head down or with a stooped posture
Chronic headaches, neck pain or back pain

Emotional signals

- x Anger
- x Frequent crying spellsInability to think clearly or concentrate
- x Excessive mood swings
- x Feelings of sadness that don't go away

Behavioral signals

- x Withdrawing from usual activities and relationships
- x Quitting or changing jobs frequently
- x Becoming more impulsive and over-reacting to things
- x Using alcohol or drugs to feel better

- ✓ **Modify your behavior patterns**
- ✓ Become more assertive—share your expectations with other caregivers, friends, family, etc.
- ✓ Seek out others for support and assistance—don't be afraid to ask for help from others, including DaVita team members
- ✓ Make time for, and focus on, your positive social and family relationships
- ✓ Continue physical activity—walking program or other activity as you are able
- ✓ Take time to reward yourself—have some fun.
- ✓ Laugh—it is the best medicine. Read the funny papers or a humor book, watch a comedy program or movie and look for humor in any situation.
- ✓ Be flexible—learn to prioritize and to let some things go.
- ✓ Eat healthy, avoid tobacco and excessive use of alcohol
- ✓ If something is wrong or overwhelming in your life, seek out the advice of others—family, trusted friends, clergy or social workers

RELAXATION TECHNIQUES

Two-minute relaxation

Concentrate on yourself and your breathing. Take a few deep breaths, exhaling slowly.

Mentally scan your body. Notice areas that feel tense or cramped. Quickly loosen up these areas and let go of as much tension as you can.

Rotate your head in a smooth, circular motion once or twice (STOP if any movements cause pain).

Roll your shoulders forward and backward several times.

Let all of your muscles completely relax - Recall a pleasant thought for a few seconds.

Take another deep breath and exhale slowly. You should feel relaxed.

Mind relaxation

Close your eyes. Breathe normally through your nose.

As you exhale, silently say to yourself the word "one," a short word such as "peaceful" or a short phrase like "I feel quiet."

Continue for 10 minutes - If your mind wanders, gently remind yourself to think about your breathing and your chosen word or phrase.

Let your breathing become slow and steady.

Deep breathing relaxation

Imagine that your abdomen is a balloon.

Inhale slowly and deeply imagining that you're blowing up the balloon, and then slowly exhale imagining you're deflating a balloon.

With every long, slow breath, you should feel more relaxed.

Guided imagery

Guided imagery is a technique that involves focusing on a particular visual image, sound, taste, touch or smell to create a specific physical reaction—in this case relaxation. Focus your mind on some sensory factor that pleases or relaxes you (the smell of baking cookies, petting a silky dog, the ocean at sunset) and try to recreate and enjoy that feeling.

Also called guided meditation, it is a form of mind-body therapy that can bring about deep relaxation and positive focus, the state of mind and body most conducive to healing.

Guided imagery can also be used to release tension, anxiety and stress.

Biofeedback

Biofeedback helps a person learn stress-reduction skills by providing precise, immediate information about muscle tension, heart rate and other vital signs.

It is used to learn total body relaxation and to gain control over certain physiological functions that cause tension and physical pain.

Talk to your doctor or social worker about biofeedback to find out if it will help you and ask for a referral to a qualified biofeedback therapist.