

Peer Support Workers as an Innovative force in Advocacy in dementia care



2021-1-NO01-KA220-ADU-000026860





- 1) Introduction in dementia (general definition and prevalence)
- 2) 5 keys to have in mind about dementia (dementia friends' program)
- 3) The role of PSW in dementia care -Countries specific issues4) Significant issues for people
- living with dementia e.g. legal pending issues, human rights, and practical activities (reflective techniques, active listening, role playing)

Agenda

■ Objectives_Module 1:

- Basic information about dementia
- Recognize its different types
- **Early symptoms**
- Risk factors
- Progression to dementia and dementia stages

Learning material

Introduction to Dementia

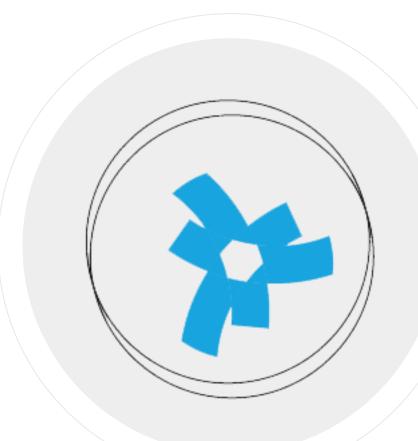
Dementia prevalence

Risk factors to Dementia

Dementia early symptoms

Different types of Dementia

Progression to Dementia- Different stages

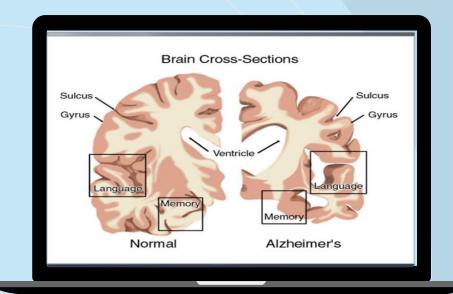




Dementia Definition

The term dementia refers to an acquired deficit of cognitive function(s), which may include complex attention, executive ability, learning and memory, language, visuospatial-perceptual ability, praxis and social cognition.

The cognitive deficits may or may not be accompanied by behavioral disorders and must be sufficient to interfere with functional independence.



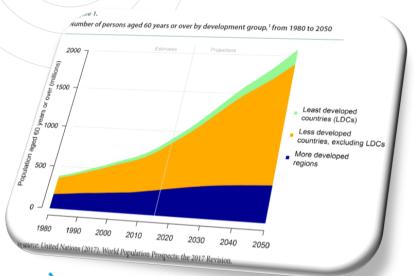
Dementia can affect

- Memory/Attention
- Insight and awareness
- Ability to plan and make decisions
- Information processing, comprehension
- Learning ability
- Language skills
- Independent living

- Inhibition and organisation skills
- Orientation and visuospatial skills
- Recognition and perception
- Behaviour/Mood/Stress
- Control mechanisms including emotions
- Motivation/Initiation



Dementia prevalence







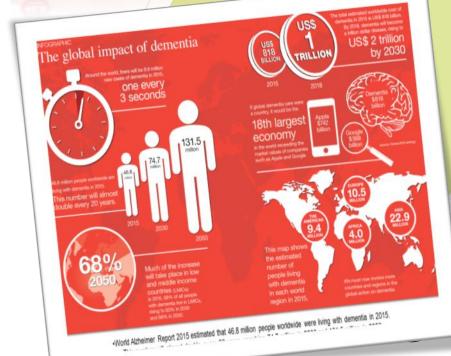


-012

430

120

STAT



Dementia now

Dementia affects 5,4% of people 65

WHO 2015

50.000.000 PwD worldwide

ADI World Alzheimer Report 2015

• 10.500.000 PwD in Europe

ADI World Alzheimer Report 2015

200,000 PwD in Greece

ADI Dementia Greece Report 2012

It is estimated that in 2030 it will reach 276,000 people and in 2050 365,000 people











Problems keeping track of things







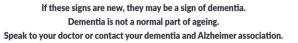






Early signs of Dementia Symptoms

World Alzheimer's Month 2021





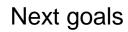




prescription

Nutrition, health indexes, physical status, natural products

B amyloid, neurotrophical factors



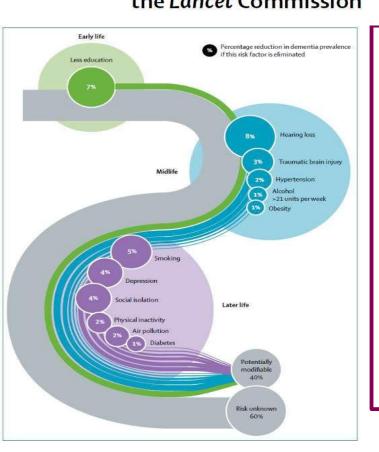


Risk factors' reduction Nonpharmacological interventions

Risk factors are like a cocktail!

Dementia prevention, intervention, and care: 2020 report of @ 🔭 📵 the Lancet Commission





Prevention potential ≈ 40% 12 modifiable risk factors

- 1.Diabetes
- 2. Hypertension
- 3.Obesity
- 4.Lack of physical exercise
- 5.Depression
- 6.Smoking
- 7.Low education
- 8. Hearing loss
- 9. Traumatic brain injury
- 10. Alcohol consumption
- 11.Social isolation
- 12. Air pollution

Modifiable risk factors

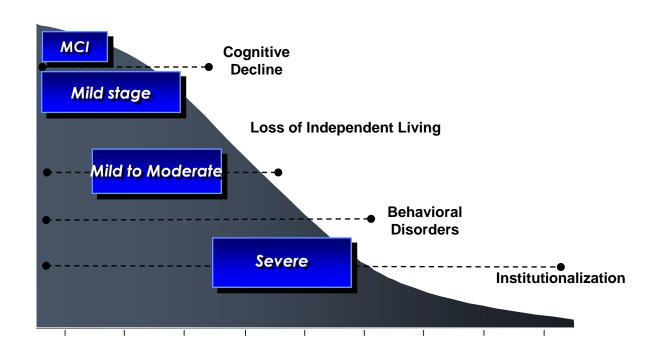
Nutrition

Education

Physical exercise

Cognitive training Social activity

Livingston et al., Lancet 2020



Years

REVERSIBLE DEMENTIAS

D Drugs, Delirium
E Emotions and Endocrine Disorders
M Metabolic Disturbances
E Eye and Ear Impairments
N Nutritional Disorders
T Tumors, Toxicity, Trauma to Head
I Infectious Disorders

Alcohol, Arteriosclerosis



Care team

_ PSW



Neurologist

(Neuro)psy chologist

Nurse

Physiotherapist

Social worker

Physical therapist

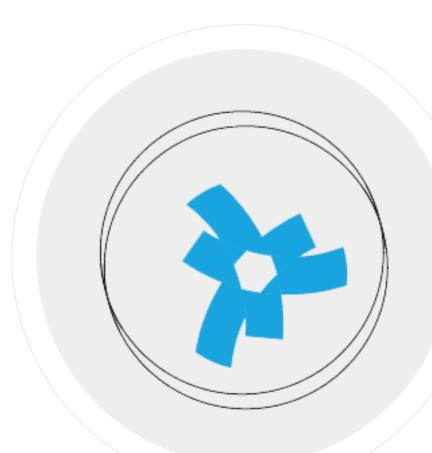




Care planning
Nonpharmacological interventions
Life changes (nutrition, physical exercise)
Quality of life modifications
Social support
Institutionalization delay
Reduction in dementia /care costs

The economist 27.08.2020

No country has found a sustainable way to finance dementia care







Holistic treatment in dementia care

Biological-Genetic domains (risk factors' control, medication, prescription)

Cognitive (cognitive training) and mood (psychotherapeutic techniques)

Social domain (dementia awareness, education, caregivers' support) – Dementia Friendly communities- The role of PSW

Who are the informal caregivers?

An informal carer is a person who - usually - provides unpaid care to people with chronic illness, disability or other long-term health or care needs, outside of a professional or formal setting.

(Definition from Eurocarers)

The carer is a special figure who often stays discreetly in the shadow, who is organized to meet the care needs of loved ones, who are no longer autonomous and who experience a very significant emotional and psychosomatic burden that inevitably affects all dimensions of life.

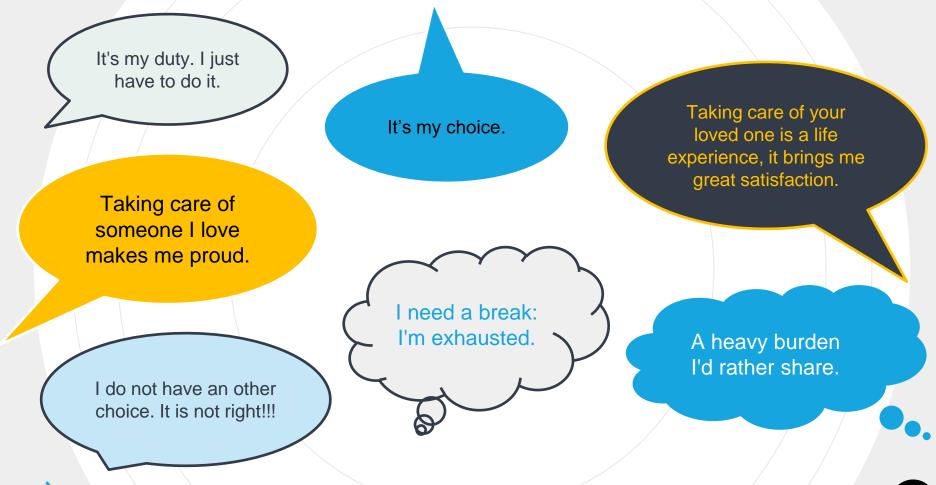
Who are the informal caregivers?

Family caregivers are an invisible resource, a silent army consisting of children, husbands, wives, parents or just friends who, free of charge and outside the professional sphere, care and help the elderly and disabled people who cannot live independently.

Informal carers in Europe provide more than 80% of all care and are twice as many as professional carers. The economic value of the informal unpaid caregiver ranges from 50% to 90% of the total cost of care provided by professionals.





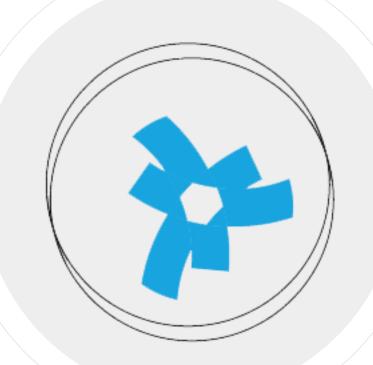




The value of experience

Experiential knowledge is the fundamental value of peer support practices such as:

- Ifruit of the experience of discomfort and its awareness.
- favors the personal, social and cultural development of those who know it.
- is the main tool for providing comparison and support to those living in a state of psychological distress.
- it is accompanied by other founding values such as empathy, listening, responsibility, competence, reliability.
- Improve communication skills with professionals, other family members and institutions.





■ Objectives_Module 2:

- Dementia Friends program
- Enroll in the Dementia Friends program

Learning material

Introduction in Dementia Friends program

5 key messages about Dementia Friends program

Activities concerning Dementia Friends





What is the first word that comes to mind when you hear the word "dementia"?

Are these words overwhelmingly positive or negative? :

- 1. The way society treats dementia
- 2. It is important to change these perceptions
- 3. Dealing with fear / stigma of dementia
- 4. Become Dementia Friends



A Panhellenic Federation of Alzheimer's Disease and Related Disorders Initiative





A Panhellenic Federation of Alzheimer's Disease and Related Disorders Initiative

Social action

Local
Alzheimer
association
agencies

Increasing Dementia awareness Support PwD in their local community

Creating
Dementia
friendly
communities

Become a Dementia Friend

Dementia friendly actions





1	Dementia is not	12	convert understanding to action
2	Dementia is caused by	1	part of normal ageing
3	A common type of dementia is	8	still communicate effectively
4	Dementia is progressive means that	4	the symptoms are gradually deteriorated
5	Alzheimer's disease early symptom is	7	humans' perception
6	Dementia is not only	11	beyond dementia diagnosis
7	Dementia can also affect	9	every three seconds
8	People living with dementia can	10	for someone who lives with dementia to live well
9	Someone in the world progress to Dementia	2	Diseases of the brain
10	It is possible	3	Alzheimer's Disease
11	Each person is	5	working memory decline
12	Dementia Friends program aim to	6	about losing your memory

Five key messages

1 Dementia is not part of normal ageing

2. Dementia is caused by diseases of the brain



3. Dementia is not just a lack of memory

4. It is possible to live well with dementia

5. The individual is more than the diagnosis of dementia



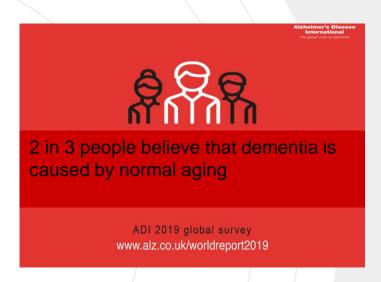
If we live many years will we all get dementia?

From what age is it "normal" to forget?



Do all seniors forget?

62% of health professionals still believe that dementia is part of normal aging



1ST key message: Dementia is not part of normal ageing



Dementia

Description of symptoms of a large group of diseases

They cause a gradual decline in a person's general mental function

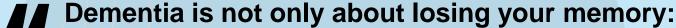
It affects the daily functionality of the individual





They vary from day to day

2nd key message:



- Memory
- Concentration / planning / decision making / problem solving
- Language
- Orientation/ visuospatial skills
- Mood/ Behavior



3RD KEY MESSAGE: DEMENTIA IS CAUSED BY BRAIN DISEASES

Alzheimer's disease Lewy body spectrum Vascular **Fronto-temporal** Korsakoff's psychosis **Down Syndrome** Huntington's Creutzfeldt-Jakob's **Progressive supra-nuclear Palsy AIDS**



4TH key message: It's possible to live well with dementia

Ability for work / social contacts It depends on the circumstances of the individual's condition Living well means different things to different people Dementia brings challenges Despite all the challenges

The person beyond the diagnosis The diagnosis does not take the place of the person with dementia Just as we would look at a person with cancer or diabetes and see the person first, the same is for dementia What does one look like with

5TH key message The person is beyond dementia diagnosis



dementia?



Principles of creating environments that are friendly to dementia

Use strategies to compensate for disability Maximize independence, strengthen personal identity and self-esteem

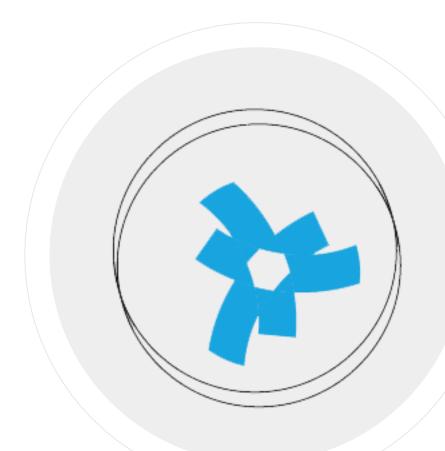
Take care of caregivers / caregivers as well Be problem-oriented and understanding Welcome caregivers to the local community

■ Objectives_Module 3:

The role of PSW in dementia care

Learning material

- Peer Support Workers' characteristics
- Roles
- Characteristics
- Why become a PSW
- Countries specific issues





Is someone who provides support, both social as well as emotional, to People living with dementia (PwD). However, PSW can also be involved in various health care settings.

This kind of support is **delivered through various ways** e.g direct communication and immediate care provision, participating in home care needs, providing practical assistance in various dementia services, and/or organizing various dementia awareness activities, and social events, such as Alzheimer cafes etc

The PSW aims to promote and increase a sense of optimism, solidarity, hope and mutuality with the PwD.

Who is a Peer Support Worker (PSW)?



Information provided by the NIHS



They can use their own lived experience to connect with people and help them by giving them a sense of hope and wellbeing



They can support people to gain a sense of control over their lives



They can help people engage with, build connections, and feel a sense of belonging to their local communities



They can enable people to gain satisfaction in different parts of their lives.

ACCORDING TO NATIONAL HEALTH SYSTEM IN UK:

- A Peer Support Worker (PSW) is someone who has previously passed the dementia caregiving journey, and wants to share his/her personal experience through his/her role as a carer.
- The main purpose of a PSW is to share his/her lived experience, inspire, give hope, encourage, and provide information to other caregivers, as well as support them to find their own way to recovery.

Information provided by the NHS



PSW in dementia care

Peer support is well established in areas such as the disability and mental health movement and is increasingly recognized as one way of providing support to and from people diagnosed with dementia and their carers.

Peer support had a positive emotional and social impact, rooted in identification with others, sharing of experiences and reciprocity of support. There was also a contrast between the quality of peer support and that of professionals, with advice from the former group being more effective than the latter.

This highlights the importance of lived experience and the promotion of a strengthsbased approach to interpersonal support that empowers and challenges an incomplete approach to understanding dementia.



What kind of support would you like to provide?

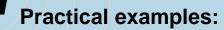


Despite the fact that there are various types of peer support services, all of them *involve giving and receiving support* as well as providing the PSWs' *valuable experience in dementia through their personal perspective*.

These types of peer support can involve: sharing knowledge, providing emotional support, social interaction and/or practical help.

Question to the audience: Do you have any ideas on how a PSW could provide practical assistance in PwD according to your personal experience?

PSW role: support the dementia services, health access, and availability in care settings (according to the different type of services),



- Supporting people in care facilities
- Helping people participating in various activities
- Support local care settings
- Engage in recovery plan with the guidance of experts
- Help health professionals accomplish the care plan (e.g provide valuable feedback with the direct contact with the PwD)
- Participate in social activities and organize awareness activities

Areas of activity:

The role of PSW

1. Formal and informal settings (NGOs, voluntary organizations, dementia cafes, day care centers, outpatient clinics etc)

Member of care team:

1. Collaboration with doctors, nurses, psychologists, social workers, family members, other members of health services

Prerequisites

- 1. Relevant experience with the care setting in which they will be employed
- 2. Receiving specific training
- 3. Communication –Social skills with health professionals and PwD



Financial status

1. Voluntarily or paid work



Caregivers skills

Through caring experience, carers acquire a range of knowledge, skills and abilities.

These include:

Health-related skills (medication administration, health procedures, symptom management, non-pharmacological approaches, health course ...)

Communication skills (with health and social professionals, with the person they care for, with other family members...)

Transversal skills (organization, coordination, time management)



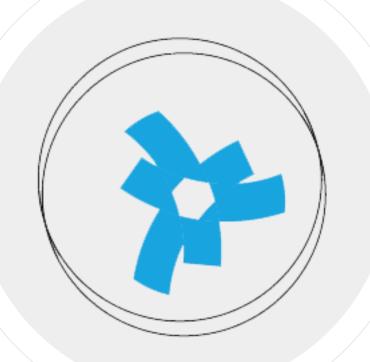
Why become a PSW in Dementia Services

Can **share** your own lived experiences of recovery from dementia challenges, **inspire hope** to caregivers and people living with dementia, give your **feedback to health professionals** well as **supporting service users** in finding their own path in living well with dementia.

PSW can share feelings of empathy, compassion and compassion with dementia stakeholders and help them understand they are not alone. Additionally, they can empower caregivers and PwD, and help them feel less isolated and rejected, provide opportunities for socialization and social inclusion.

Create trusting relationship





Why become a PSW in Dementia Services

Facilitating discharge from inpatient wards

Supporting PwD and caregivers in their homes, **providing practical support** (eg home visits, help them in outdoor activities, pending issues with various services etc.)

Providing their own experience to help stakeholders set priorities, planning process, problem solving, manage daily challenges, find new strategies to cope with significant issues, providing practical solutions to various dementia issues



Why become a PSW in Dementia Services

Personal benefits

self-confidence/ self esteem positive reflection of their own experience altruism provision social skills/ communication sense of feelings of being valued sense of personal activation/ empowerment fight against stigma positive feelings (empathy, compassion, etc) feelings of being included in a team feelings of finding a life purpose





Which of these could be useful as a peer support?



BENEFITS FOR PEOPLE USING

Greater sense of control
Reducing the feeling of isolation
Greater ability to see and analyze his
situation
Empowerment
Inspiration

hope

Benefits of peer support

BENEFITS FOR PSW

Personal development
More confidence in your own abilities
Greater sense of self-efficacy
Better self-esteem
Empowerment satisfaction

BENEFITS TO THE SERVICE SYSTEM AND SOCIETY

Greater and better access to services
More awareness for users of the offer
in the area
Dissemination of good practices
Greater sense of community and sense
of belonging



51

The Healtbridge study

In 2013, the Healthbridge study was conducted in England, which evaluated the inclusion of peer support for carers in dementia support services.



The results of the study showed that:

Carers' awareness that there are also other people in a similar position increases, which could lead to friendship, a sense of belonging and social acceptance
Their sense of loneliness, isolation, loss and struggle has diminished
Participants learned new coping strategies by sharing information and advice

Peer-to-peer sharing of information, advice and coping strategies was important, as was being in an environment where dementia could be discussed without stigma, creating this 'space to create collaborative meanings about dementia away from imposing medical definitions of it' disease. characterized by an emphasis on deficit" (Ward et al, 2011).

Who provides diagnosis
Who provides educational training
Who provides care services
Who provides medical advice/counseling/therapy





Care certificate

It could include a title for example Dementia Challenge

Do you have any ideas about how a Care Certificate for PSW would look like?





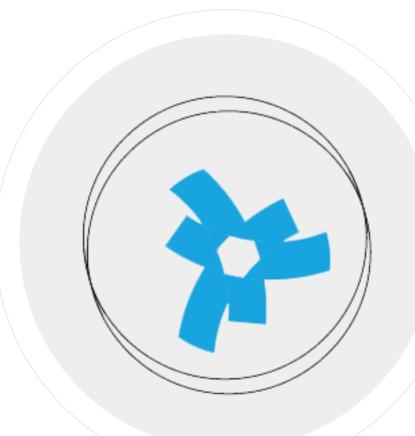
ending points comments questions sum up

Objectives_Module 4:

- Dementia Services in Greece
- Significant issues for people living with dementia e.g. legal pending issues, human rights, and practical activities (reflective techniques, active listening, role playing)

Learning material

- Dementia Services in Greece
 - What dementia friendly communities mean
- Significant issues (human rights, economic issues, communication techniques, exercises)





National dementia strategies



What is happening in Greece?





Could you provide any examples of these needs according to you experience?

Current needs

- Early detection
- Dementia awareness
- Equal access to diagnosis and treatment
- Respect to the human rights of PwD (legislative framework development)
- Involving PwD and carers in developing and/or improving dementia care services



- Memory Clinics in the Psychiatric or Neurological Departments of General Hospitals throughout Greek cities
 - Psychogeriatric clinics (in Clinics for chronic diseases)
- Private practice
- Alzheimer's Associations (non governmental organizations)
- Dementia Day Care Centers in big cities in collaboration with Municipalities
- Home care services in the Municipality
- Geriatric hospitals in private practice
- Hospices for dementia care

Dementia services in Greece



National campaigning activities I

The Annual Carer Day (16/3)

Which kind of activities you would use for the awareness carers campaign?







National Campaign Activities II

- Theater performance 'Caregiver's voice'
- Music Evenings
- Alzheimer café
- Art exhibitions
- TV and Radio programs every week
- Lectures in elementary/secondary schools
- Which is the PSW contribution in the aforementioned activities?



		SUFFICIENT	INSUFFICIENT	ABSENT
Exercise which are the CARE AVAILABILITY services according to your experience what kind of support would a PSW provide?	Care coordination/Case management			
	Home Help			
	Meals on Wheels			
	Incontinence help			
	Assistive technologies/ ICT solutions			
	Tele Alarm			
	Adaptations to the home			
	Homecare (Personal hygiene medication)			
	Counselling			
	Support groups for people with dementia			
	Support groups for carers			
	Respite care at home (sitting service etc.)			
	Holidays for carers			
	Carer training			
	Alzheimer Cafés			
	Day care			
	Residential/Nursing home care			
	Palliative care			

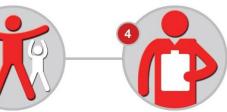
WHO's Global action plan on dementia







Dementia diagnosis, treatment, care and support



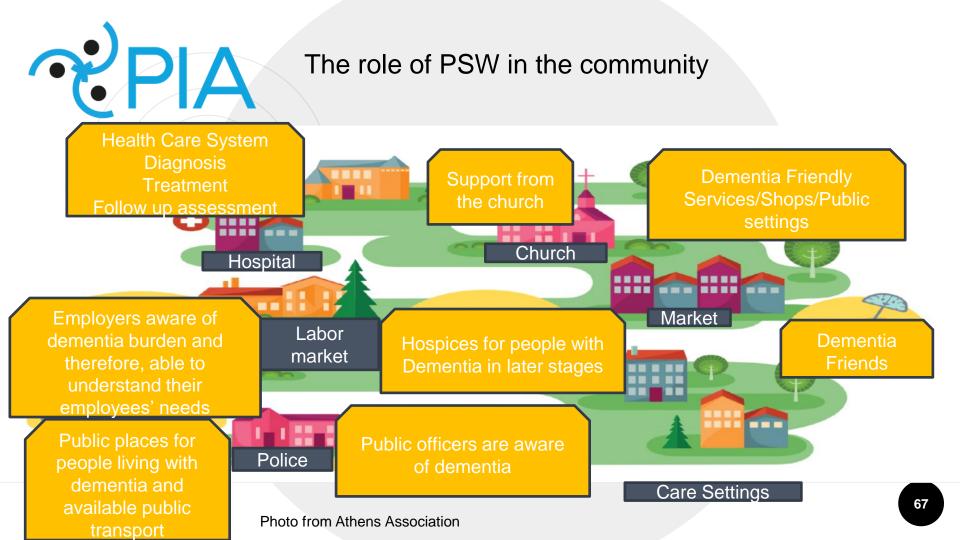




- -A community is the place where the life of each of us exists.
- -Being friendly to dementia means you are also friendly to the older adults (irrespective of their mental status)
- -Being dementia friendly means that dementia is not only treated by means of mental, medical, psychological and social care.
- -Being dementia friendly means that the treatment is not limited only by medical interventions, but it also involves everyone's autonomy, as well as the continuation of daily life and individual rights

We build together dementia friendly communities





Legal rights
Economic issues
Communication techniques
Exercises for PSW





Legal issues in dementia:

- Sense of personal freedom
 - Sense of personal safety
 - Physical integrity
 - Personal right to free mobility
 - The right to private and family life
 - The right to medical care
 - Personality and character, habits, interests
 - needs privacy, activities and socialization
 - has not given us the right to interfere in his life



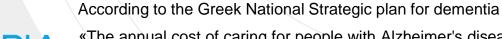
Insurance coverage

Actions for dementia (however they are not assumed as state's legislation)

Especially for PwD it is crucial to ensure:

economic issues in dementia

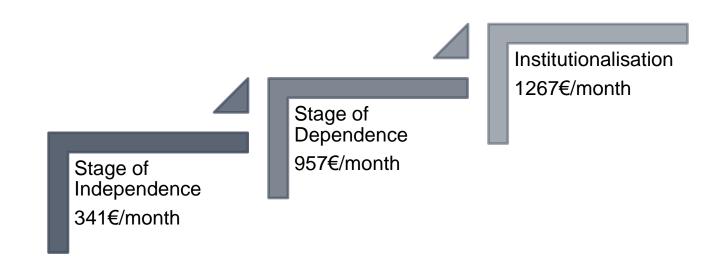
Immediate	Indirect		
Medical costs/ follow up	Consequences due to PwD progressive frailty		
Hospitalization	Caregivers' support and extra needs		
Daily care	Inability to work (PwD as well as his/her caregivers)/ time off work		





Annual dementia costs: 4092-15204€





Kaitelidou et al. (2013) (publication in Greek «Κοινωνικοοικονομικές επιπτώσεις της νόσου Alzheimer στην Ελλάδα: Πιλοτική μελέτη. Νοσηλεία και έρευνα. Απρ.2013»)

Kyriopoulos et al. (2005) (publication in Greek «Το κόστος της Ανοιας Τύπου Alzheimer στην Ελλάδα. Άνοια: Ιατρική και Κοινωνική πρόκληση. Τσολάκη Μ, Καζης Α (επιμ.) University studio press. Θεσσαλονίκη 2005»)

Confidence
Recognize feelings/needs
Respectful attitude for PwD
Understanding
Support emphatically by showing interest and compassion

Communication MODEL when discussing with PwD [CRRUS]



Try not to be offensive by saying difficult/complicated words

Give enough time for PwD in order to respond, Don't hurry.

Discuss about PwD feelings and not trying to say who is right

Be focused and present

Notice your body language. Follow with faces, action and body position

Try to find the time of the day where the person will be more able to communicate. Understand the causes of their behavior and needs

See things in different ways and be open for creativity



Follow the CRRUS model

Speak clearly by using short and simple sentences

Avoid complicated questions

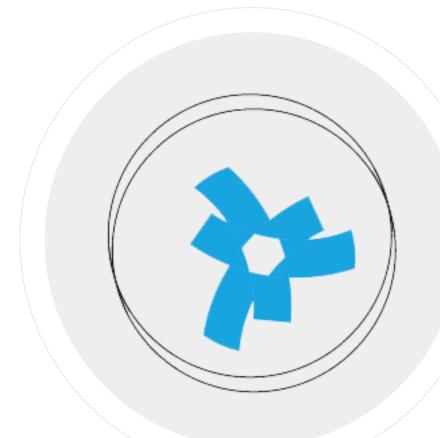
Stick to just one idea at the time, many options can be confusing

Use non-threatening words

Warm and safe tone

Assessment of the emotional state. Respect personal space. Accept particularity

Approach the person's with dementia "personal perspective"







Carl ROGER's three basic human steps for communication in daily life



Attention

Acceptance

Empathy

(Rogers, 1967)



Can you describe a personal experience In which you were in line with Roger's humanistic approach?

Exercise 1

Self Care



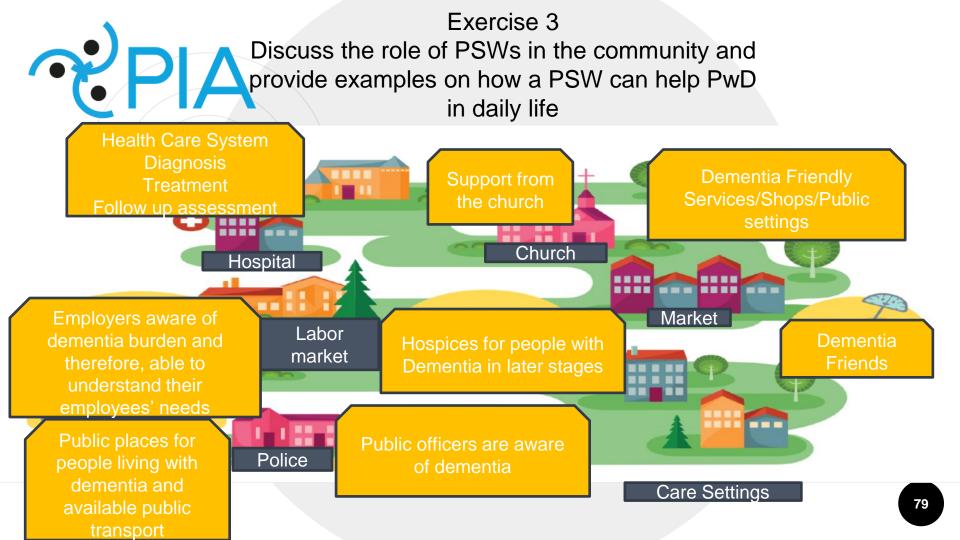
What type of self-care strategies are you using as a Peer Support Worker to maintain your wellbeing while helping others?

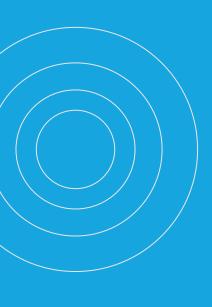
#peersupportcanada

Exercise 2

Stigma, Denial and lack of Financial resources are the main obstacles to provide complete medical care in dementia (Greek National Strategic plan)

What could be possible solutions against the aforementioned barriers?





Writing Exercises 4-5-6



Reflect your strongest emotions through the caregiving journey
What would you advice yourself at the beginning of the caregiving journey?
Provide a title/picture/moto/logo which described better you experience

Exercise 7:

A volunteer of the PSW group narrates a difficult situation when he/she was caregiver, and the other members of the group create a theater performance based on this experience, in order to help him/her evaluate this experience from another point of view







(Tsatali et al. (2022). Greek adaptation of the positive aspects of caregiving (PAC) scale in dementia caregivers. *Clinical Gerontologist*, *45*(3), 538-547.





"A good listener helps us to listen to ourselves". (Yahia Lababidi)





