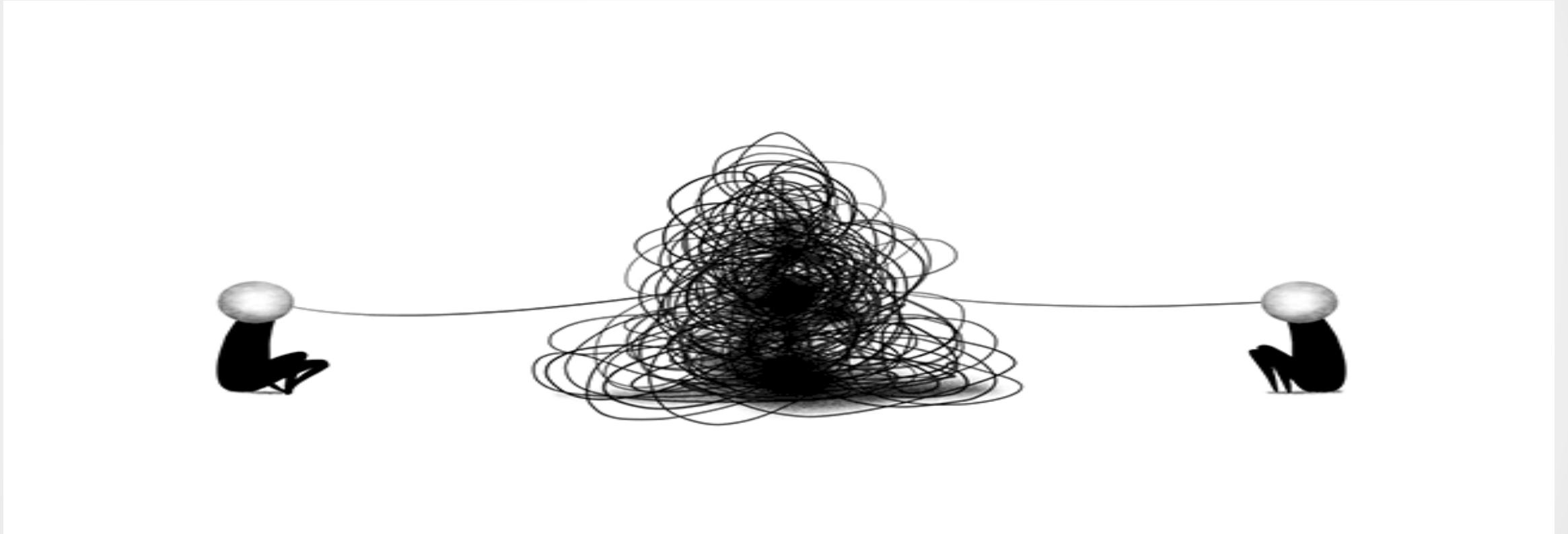


Occupational Therapy at home: palliative care approach

24th ENOTHE Annual Meeting 2018, ESSA Alcoitão

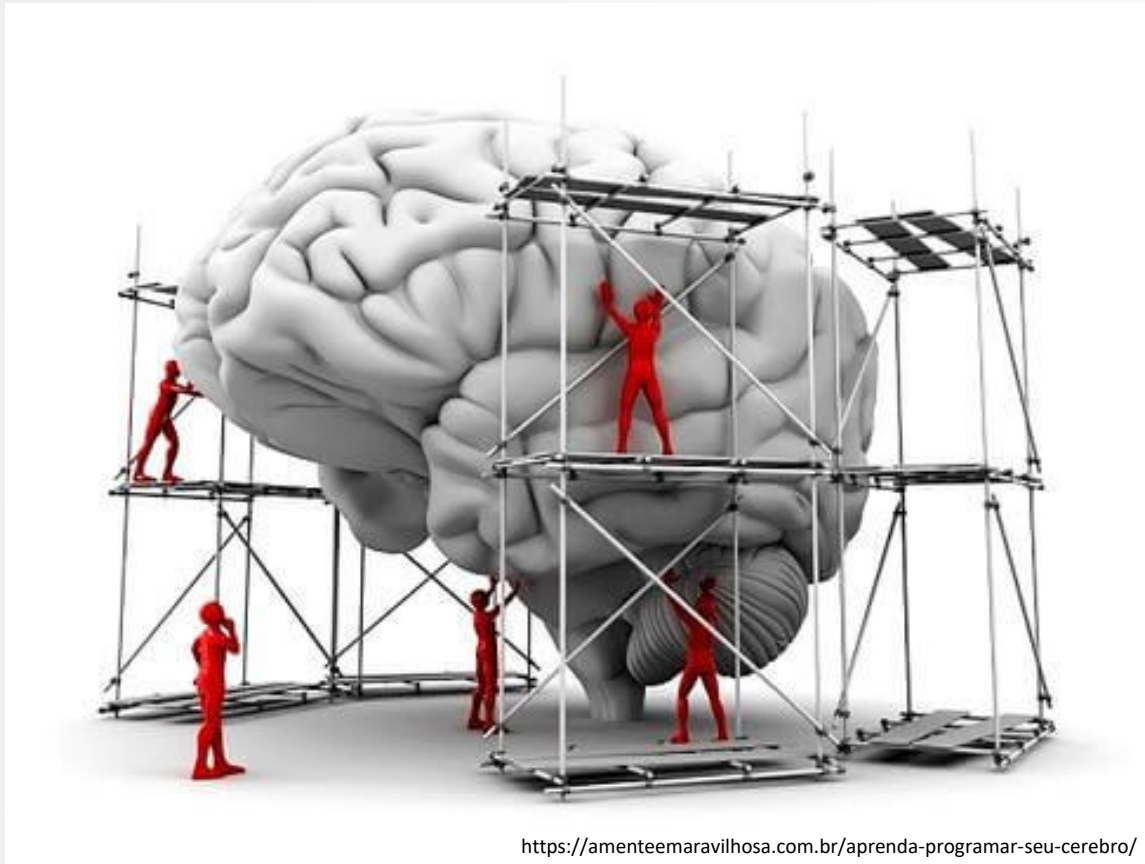


5 outubro 2018

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Occupational Therapy_(OT) at home: palliative care approach

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Workshop 90´

Objective is to reflect on OT role in PC approach at Home, within the scope of Portuguese Primary Health Care

Occupational Therapy

Palliative Care(learning & teaching)

Home

Health Context/Primary Care

OT at home: palliative care approach

01

**Refleting know-how
OT in Palliative Care
approach, specially at
Home**

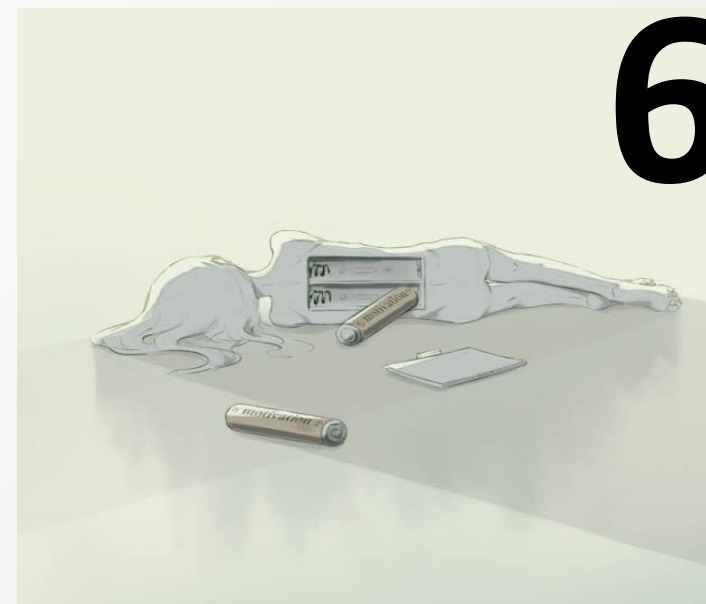
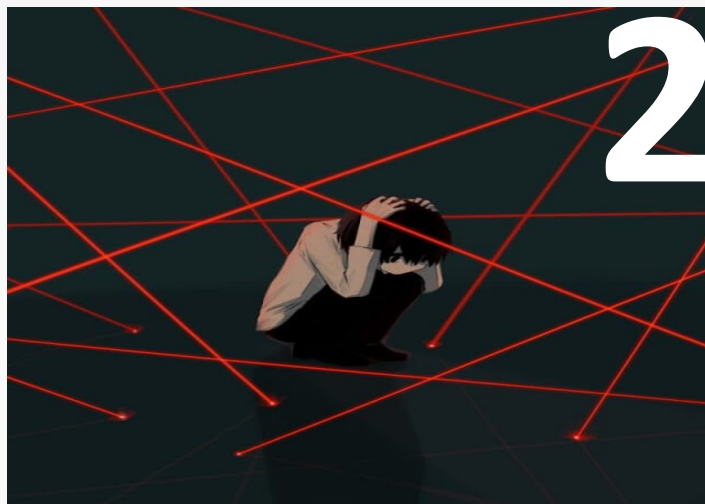


02

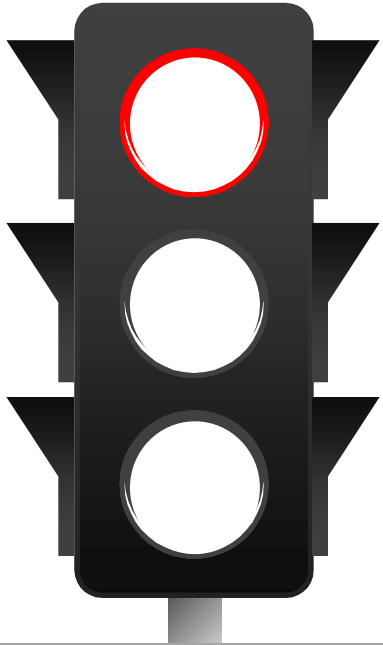
**Refleting about
learning & teaching
Palliative Care
approach in OT**

00

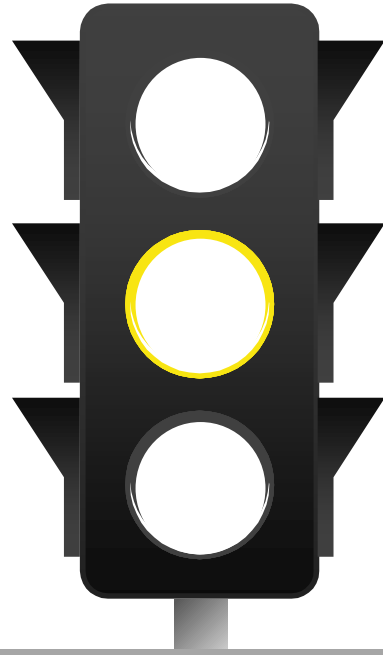
your opinion? the image best describes Pain (1)?



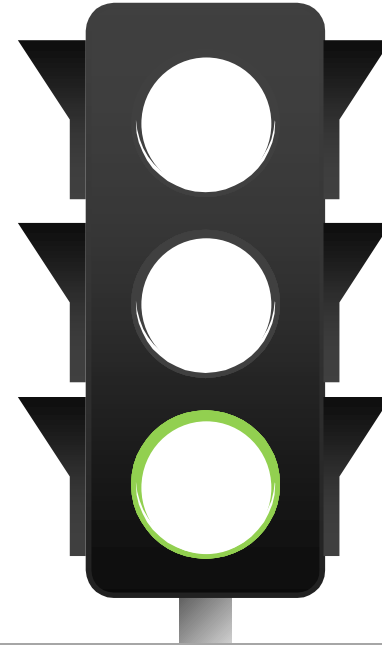
00 How do you **feel**, when **thinking** about Palliative Care ?



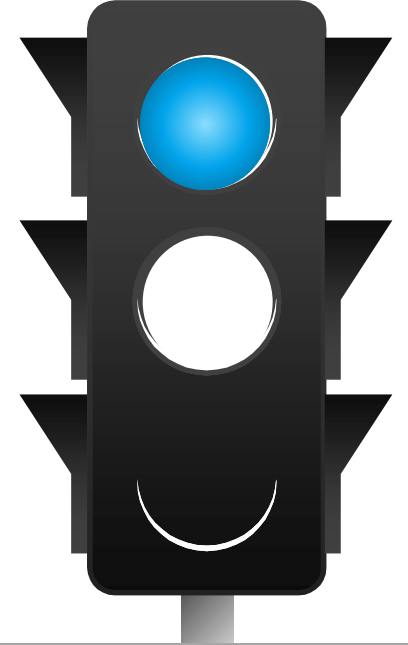
Aggressiveness
Anger



Joy
Optimism



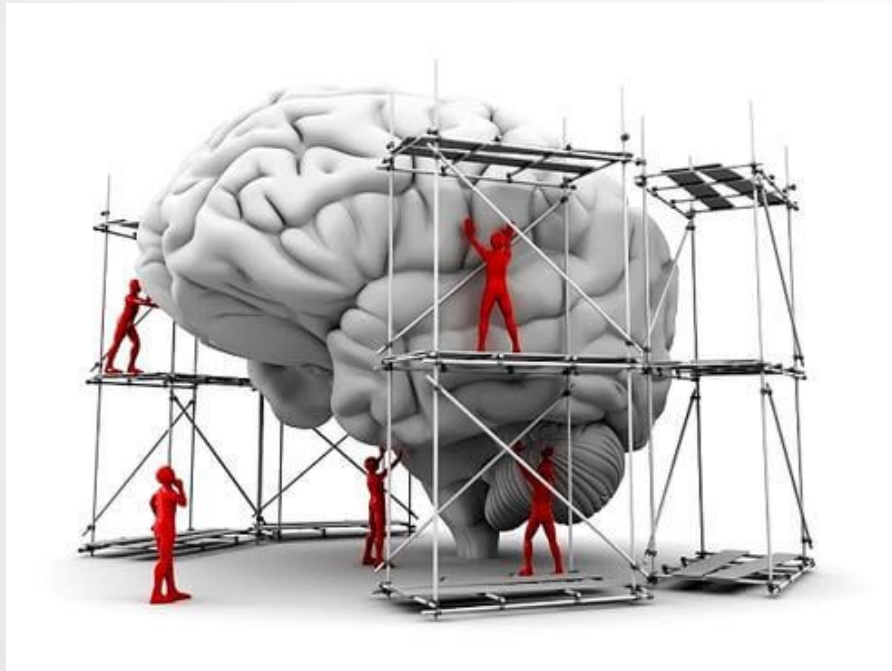
Calm
Tranquility



Inaction
Sadness

Occupational Therapy_(OT) at home: palliative care approach

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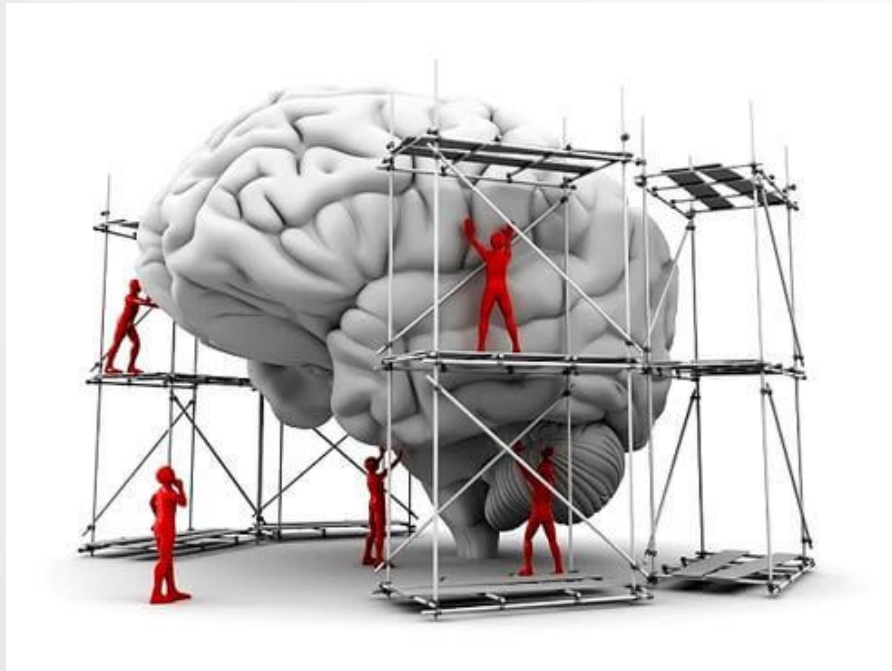
<https://amenteemaravilhosa.com.br/aprenda-programar-seu-cerebro/>

The Occupational Therapy (OT) in the Palliative Care (PC) can contribute, in a valuable way to preserve independence, comfort and quality of life, effectively during illness and even death.

Home, is the holistic and multiprofessional intersection of doing with the **person,**
the caregivers,
in their environment,
the place where the OT can play a very relevant role in the place, facilitating the improvement of the quality of life especially when we speak of intervention in PC

Occupational Therapy_(OT) at home: palliative care approach

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Health care save lives, but its main mission is to improve people's quality of life, reduce symptoms: a chest pain; incontinence; help people walk better or open a jug of water on their own.

The PC scenario worldwide is changing. In Portugal this Vision is materialized in the Strategic Plan Development Palliative Care in progress

According to the World Health Organization, PC improve the quality of life of patients and families, prevent and alleviate suffering in incurable health situations, identifying early pain and problems: physical, psychological, social and spiritual.

OT in Palliative Care Approach at Home



Principles in Palliative Care(PC)

PC Context at Home

OT, PC at Home

Changes OT in PC

Take Away Message



- a. **Definition PC**
- b. **Who needs PC**
- c. **Holistic Approach PC**
- d. **Total Pain in PC**
- e. **PC & Quality Life, in the proper/desired location**



a. Definition PC

All forms of caring for people with incurable diseases, problems linked to life threatening diseases, out of healing

Centered Person, always supporting it, especially critical periods

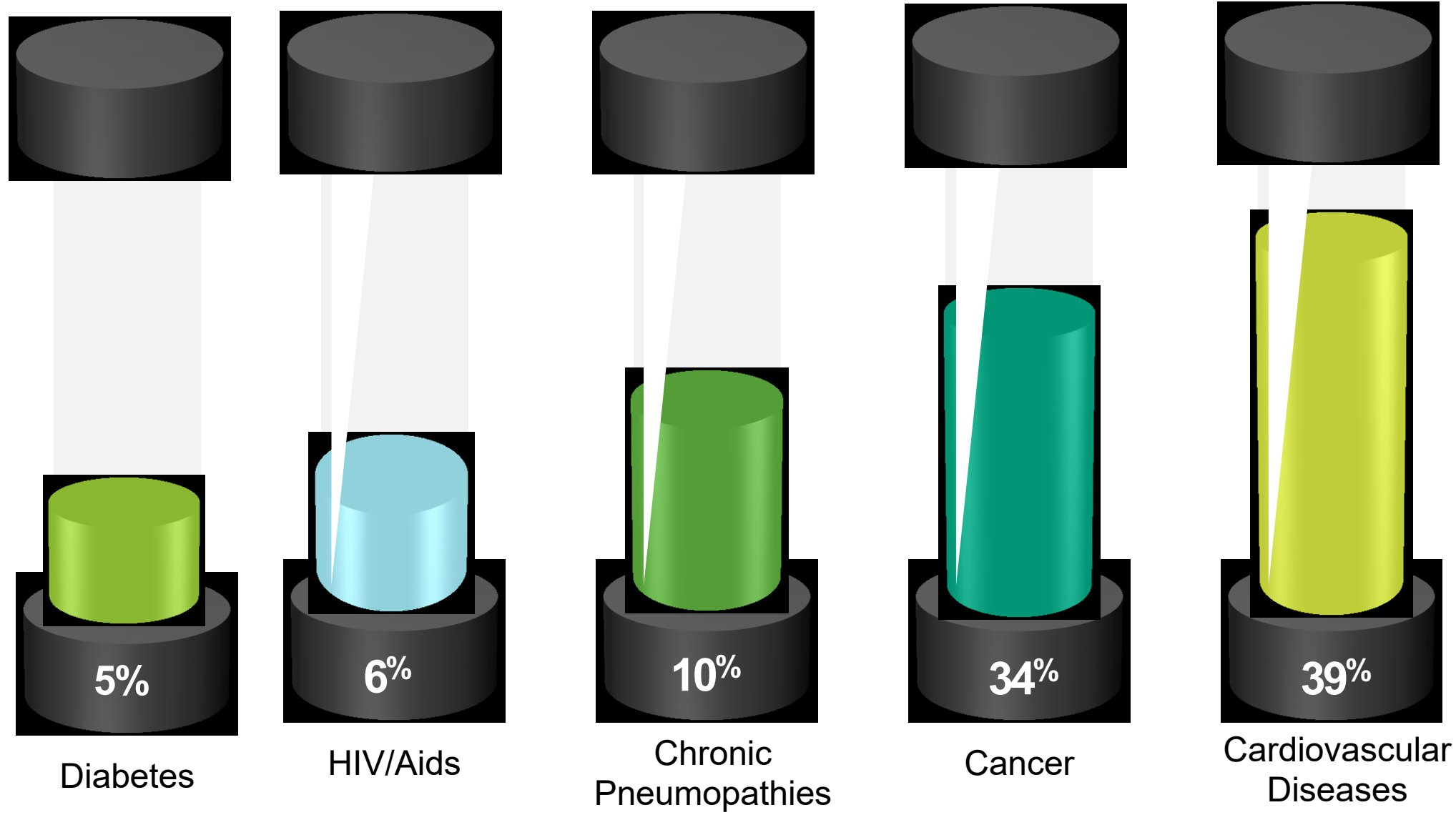
Prevent/alleviate suffering, at all levels health care

Treatment of pain-physical, psychosocial, spiritual, social problems

Early identification/correct evaluation

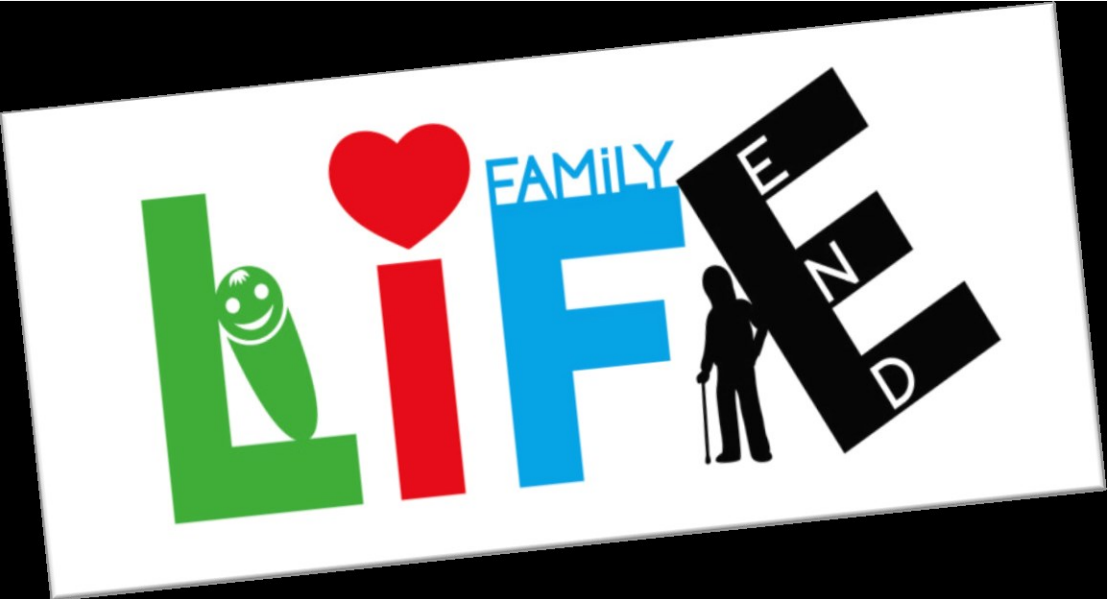
Improve patient's quality life (adults and children) and families

b. Who needc PC? (40 millions need PC)



b. **Who needs PC?**

Cancer
Cancer
Cancer
Cancer
Cancer
Cancer
Cancer
Cancer
Cancer
Cancer



Chronic Diseases
Progressive neurological diseases
Severe cardiac/renal insufficiencies
Organs Collapse
Pulmonary Diseases
HIV/Aids
Resistent Tuberculosis
Extreme Premature Birth
Fragility in old age (...)

c. Holistic Approach Problems (one list)

Can't sleep

Prayers that are not heard

Lack of money

Fear of death

Isolation & Family distant

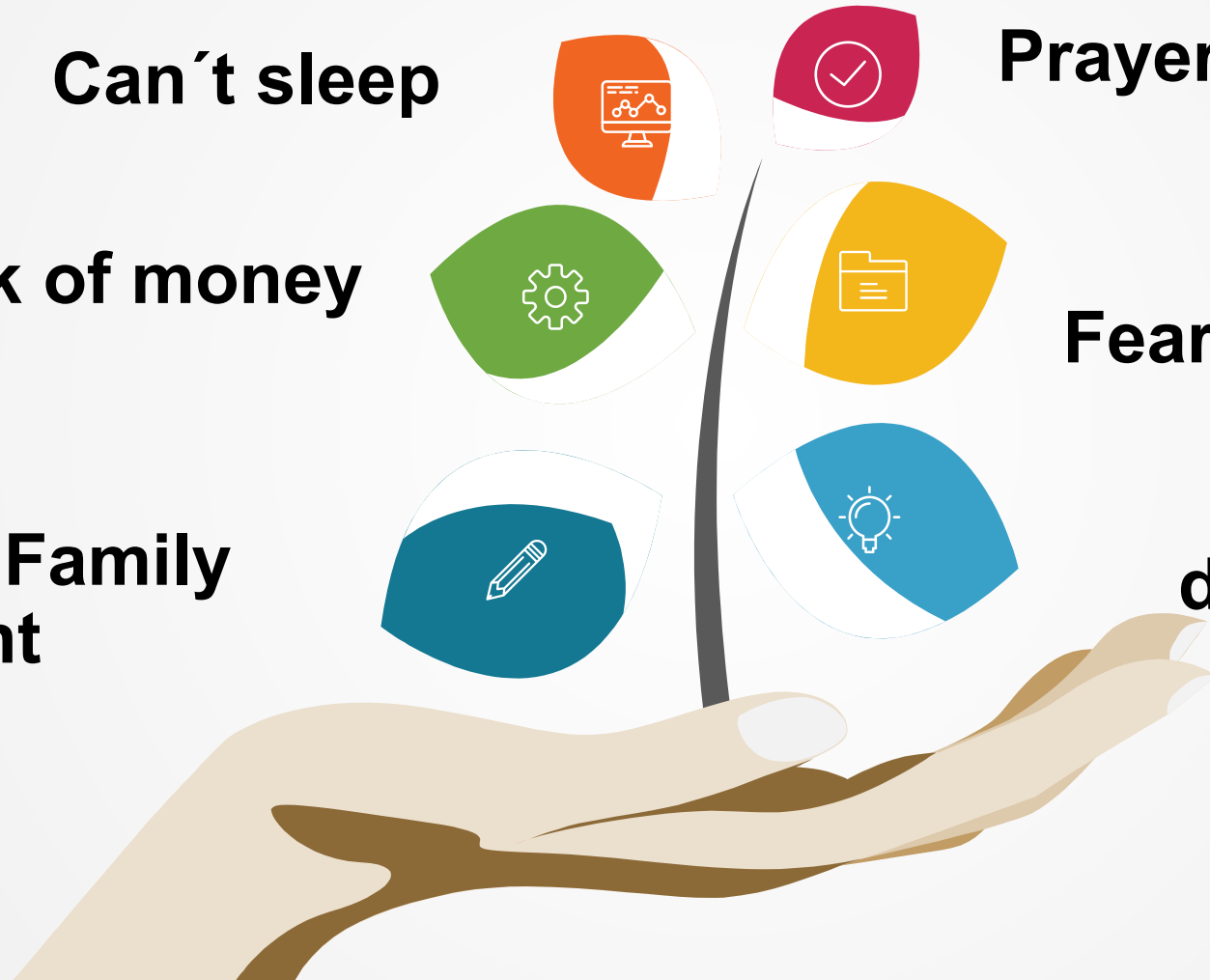
Feeling grief death husband

Physical

Psychological

Spiritual

Social



d. Total Pain Concept



The concept of **total pain** indicates that the four areas contribute to the increase or decrease of pain and other physical symptoms

Problems in one area can affect/problems in other areas

PC have a **person-centered approach** to problems that cause greater concern

e. PC & Quality of Life

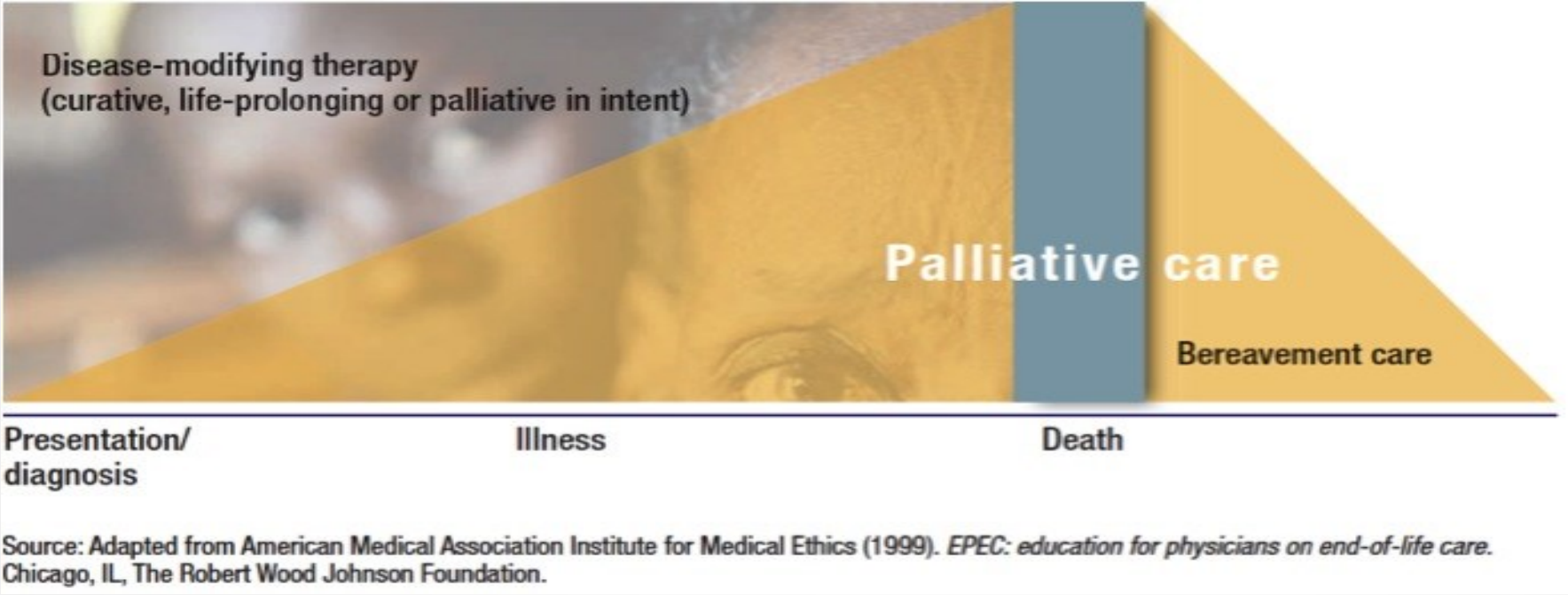
Quality of life? Physical and emotional well-being; comfort and inner peace. Not just absence of disease

So, PC begins in the moment Diagnostic for an incurable disease and not only at the end of life

Do not prologue or shorten life, promote quality of life in time remains, complementing other programs

Keeps focus on realistic, caring + holistic, based on important goals

e. PC & Quality of Life/Location?



PC Units

Hospital Teams
CP support

Community Teams PC support



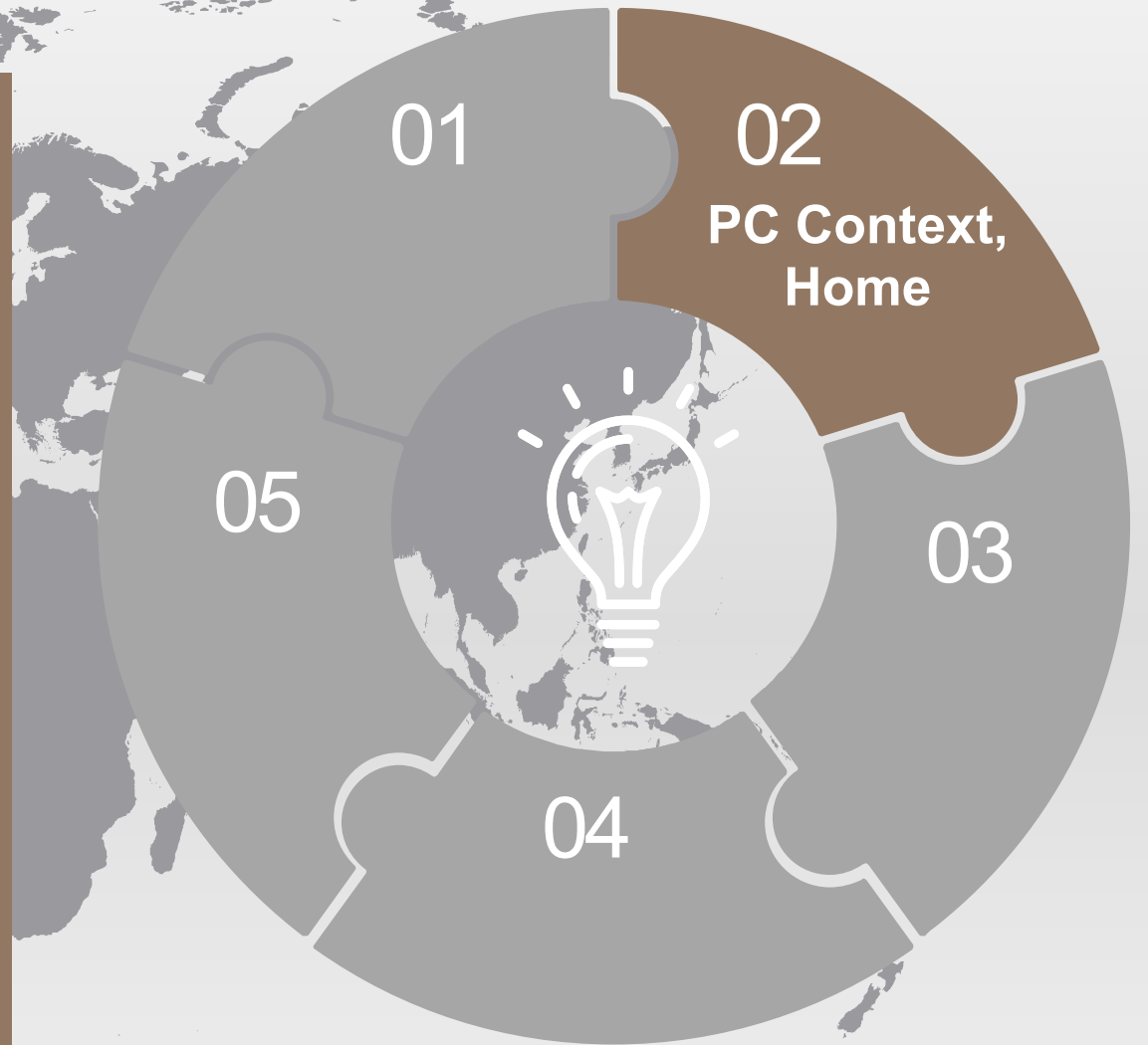
a. Importance PC Home

b. Strengths/Opportunities PC Home

c. Weaknesses/Threats PC Home

d. National Context PC

e. National Context PC in Primary Care



a. Importance PC at Home

International Perspective



National Perspective

World Health Organization
European Association
Palliative Care
Professional Association
Ireland, Australia, Canada,
United Kingdom, Spain (...)

National Boarder PC
National Association PC
Portuguese Association
APTO

a. Importance PC at Home (international)

01

There is a lot of information, so much has never been said about CP

04

Never been so necessary, children with less access

02

Development depends political and strategic encouragement

05

Majority People who need are at home

03

Large disparities

06

CP They find several home-made benefits, Primary Health Care (CSP)



a. Importance PC at Home (international)

01

Integrated CSP potential/privileged position for CP efficacy

02

They are able to accompany patients in all life-threatening diseases, from inception/evolution

03

Domicile, home host, family home, day center (...)

04

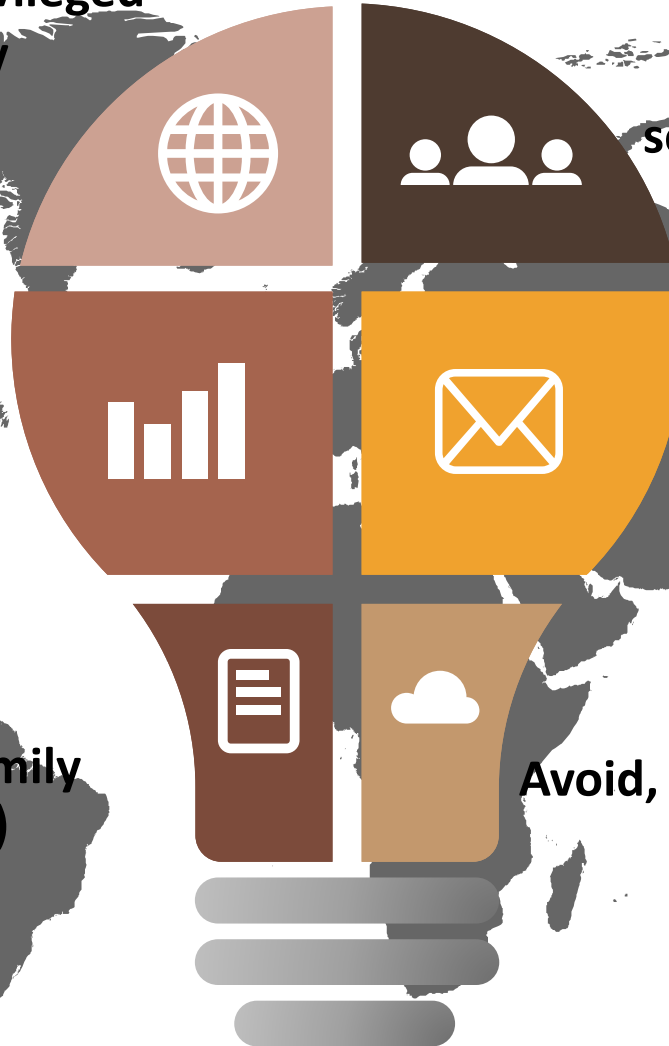
Facilitates Knowledge all dimensions of need: physical, social, psychological and spiritual

05

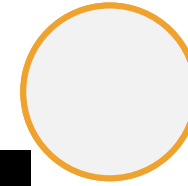
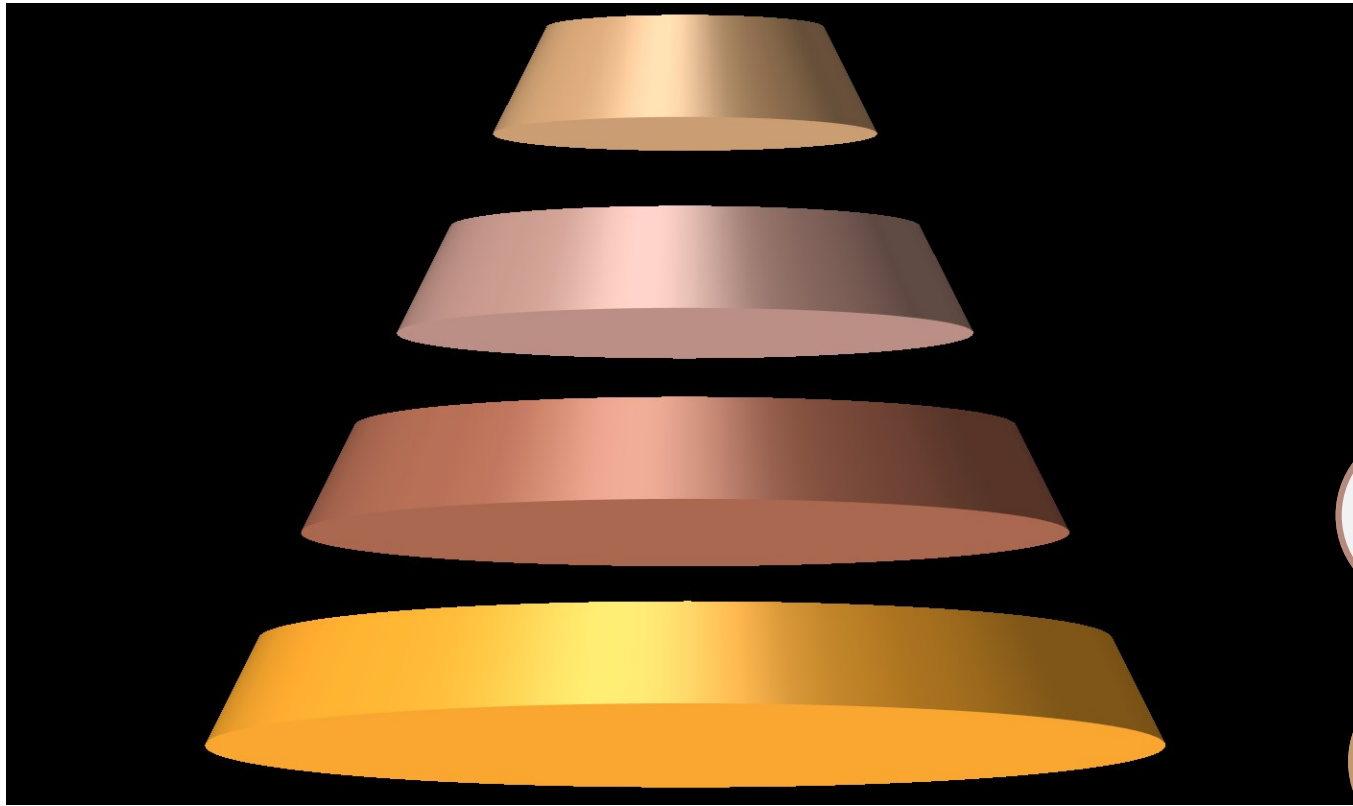
Facilitate follow-up on grieving and support for family/caregivers

06

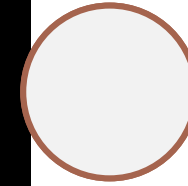
Avoid, seek to avoid unnecessary hospital admissions



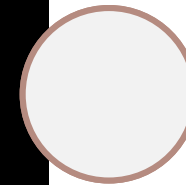
b. Strengths/Opportunities PC Home (International)



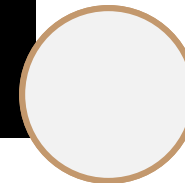
Possibilities specific training (facilitator) available in some countries



All patients access CSP, greater accessibility of people CP/End of life if there are infrastructures

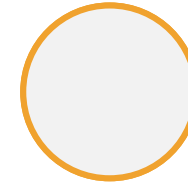
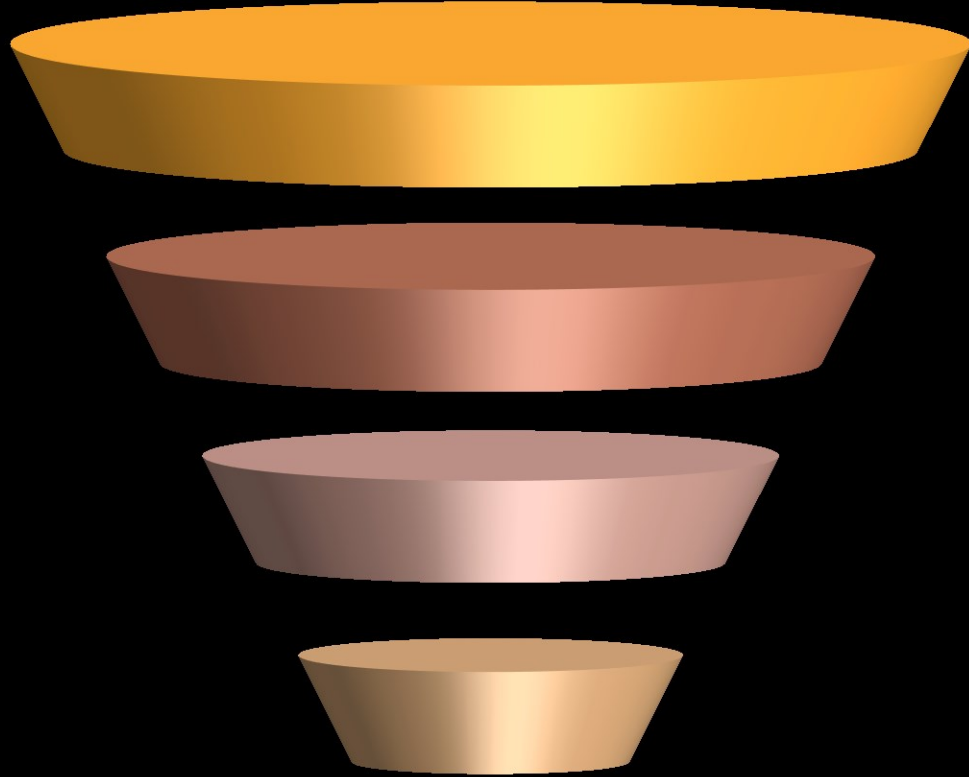


National strategies and increased political support for PC's (substantial improvements)

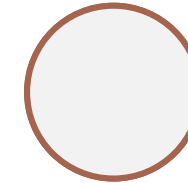


Development networking PC many countries

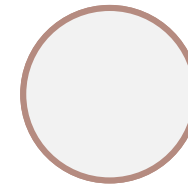
c. Weaknesses/Threats PC Home (international)



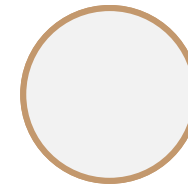
Lack of knowledge/skills medical, nursing, other health professionals (specialized professional support)



Financial systems that do not allow refunds for PC

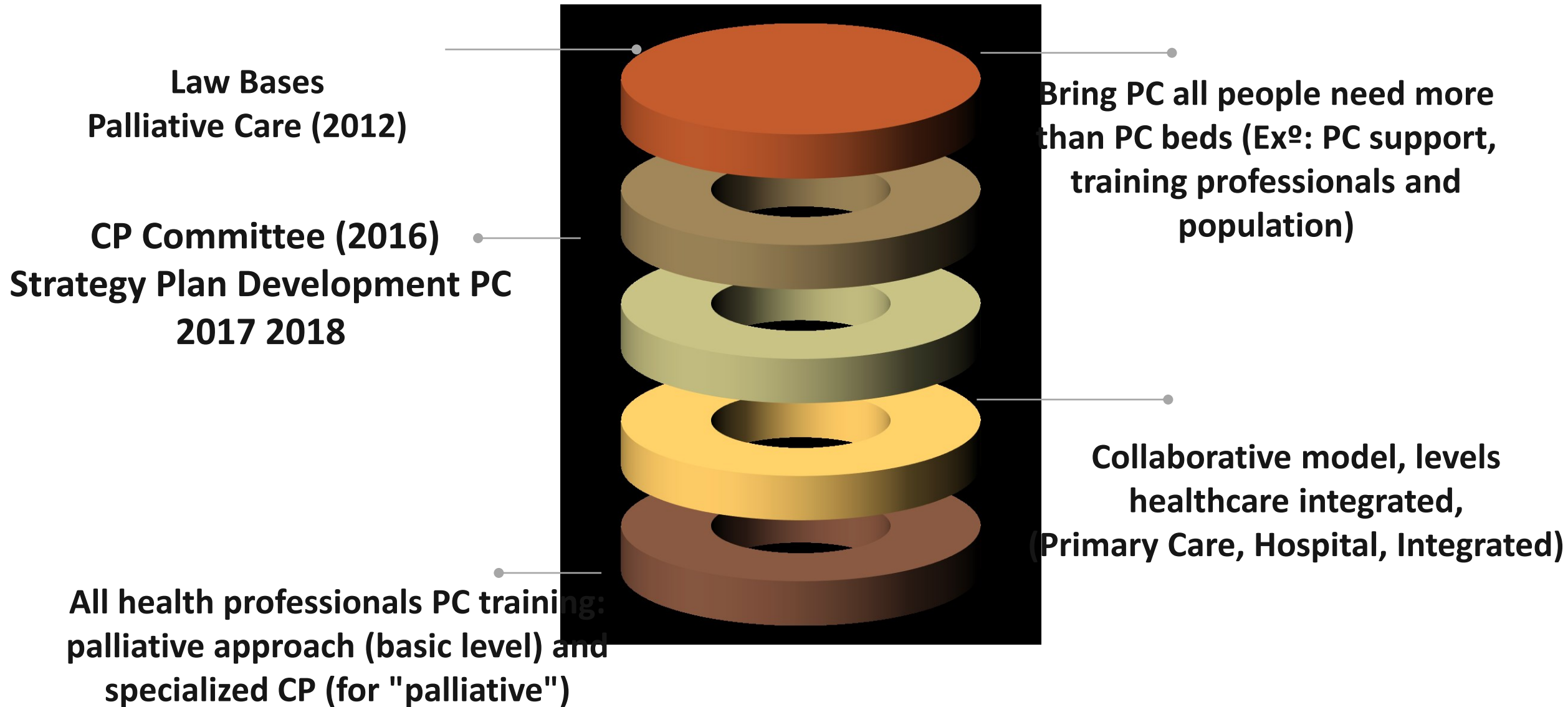


Problemas Opioid prescription, morphine suitability, time need/resources adequacy

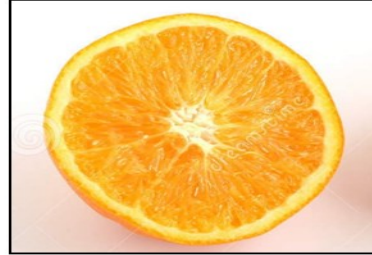
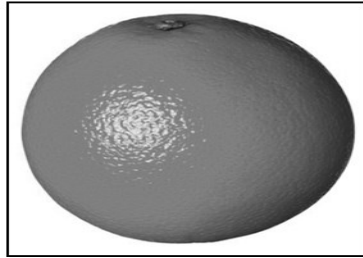
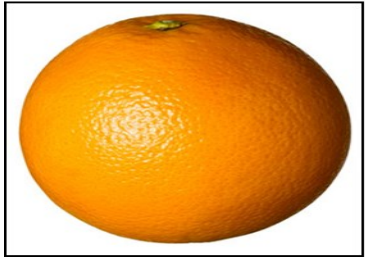


Poor identification patients need PC, public understanding limited, stigmatized PC

d. National Context PC



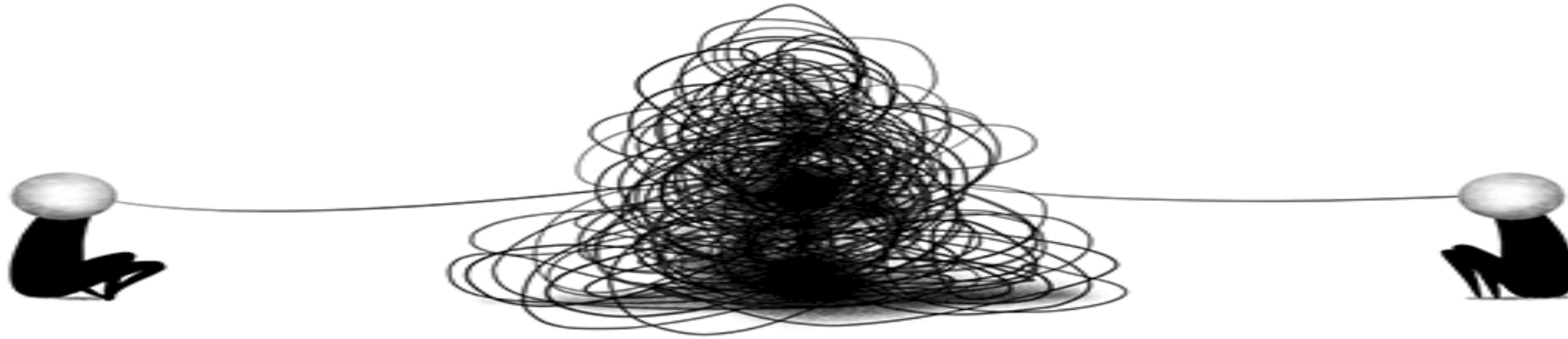
d. National Context PC *Vision & Improvement*



People with severe or incurable disease, advanced and progressive, residing national territory, quality PC access, regardless age, diagnosis, place/residence or socioeconomic level, from diagnosis to death

- (1) organizational definition, characterization of different PC teams
- (2) output National Integrated Continuing Care Network (RNCCI)
 - (3) definition of human resources of the teams
 - (4) referral criteria and registration rules care activity
 - (4) inclusion of PC in contractualisation 2017-2019
- (5) exemption from fees and access to non-urgent transportation
- (6) training, collaboration with higher education and team building

d. National Context PC *in Primary Care*



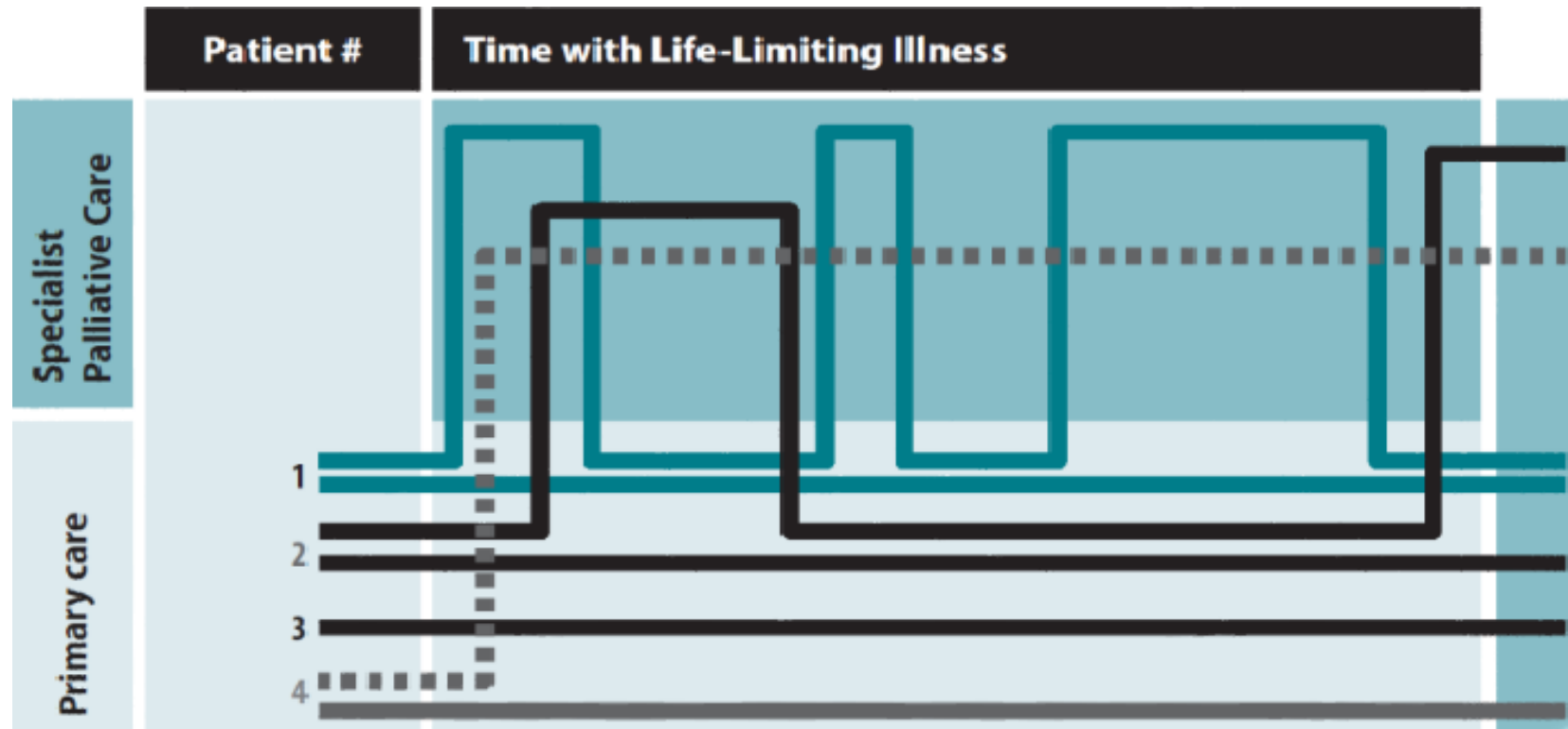
d. National Context PC *in Primary Care (trajectories)*

01

Primary care shared/collaborative model in the 3 specialized care episodes
Shared care model enforces in death, meeting the patient's primary level needs

02

Model of shared/collaborative care, 2 episodes
Specialized Care
Model of shared care enforces in death, satisfying the patient's specialized level needs



03 PC that only requires Primary Health Care Home

04 Collaborative Care Model with Care Needs Level Care Specialist
In death, needs require specialized care

00 PainConcern Breaking Barriers



<http://painconcern.org.uk/emotional-impact-of-chronic-pain/>

Learning Aim

To facilitate an empathetic understanding of what it is like to live with painful conditions and thus facilitate a therapeutic partnership.

This activity focuses on understanding the emotional impact of chronic pain

00 PainConcern Breaking Barriers Palliative Approach

1. Watch Pain Concern's film



<http://painconcern.org.uk/emotional-impact-of-chronic-pain/>

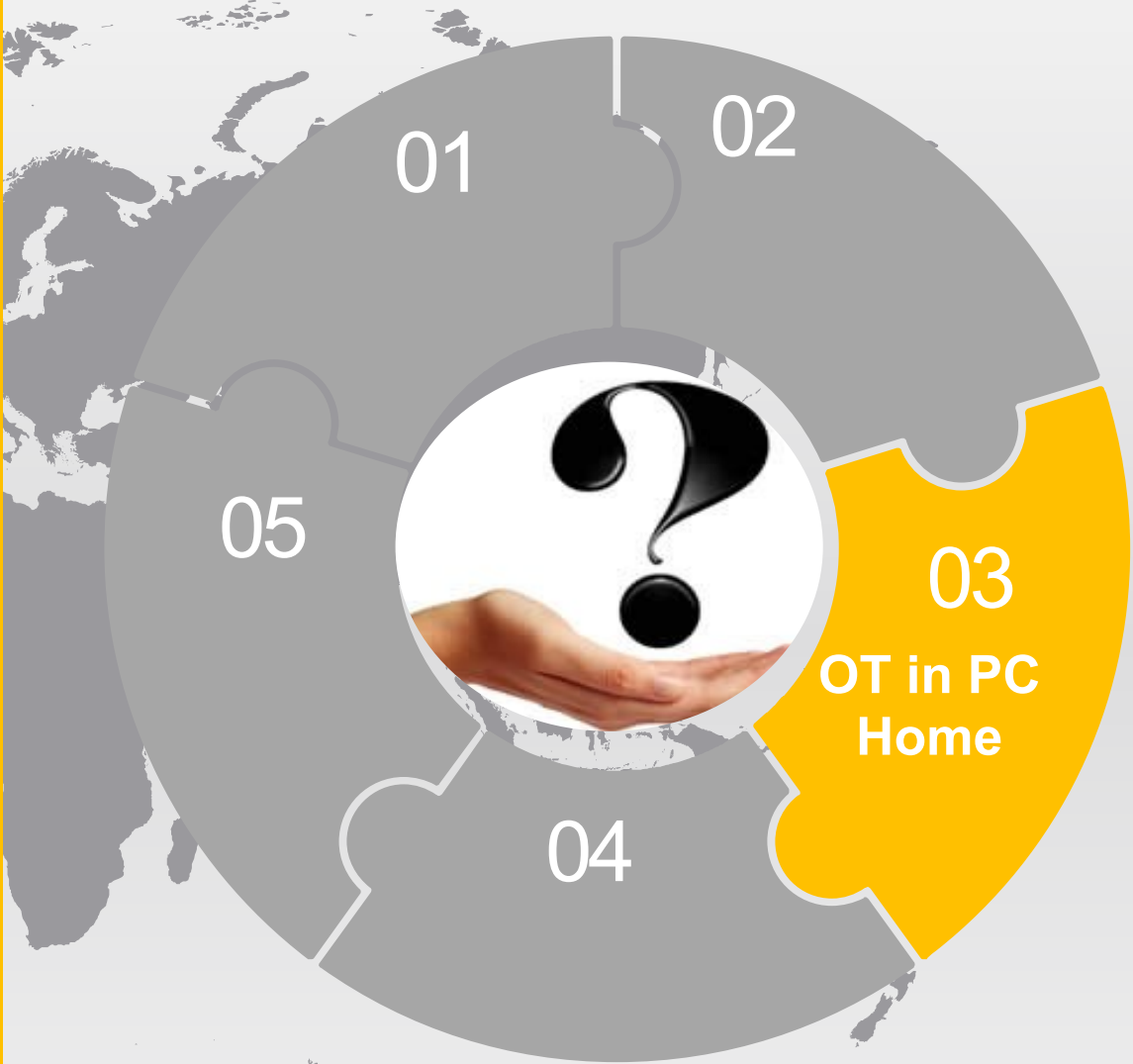
2. Consider and discuss the following questions:

- How did it make you feel?
- Describe the impact of the film on you? Surprises?
- What can we do to improve healthcare for people in pain?

3. Discuss your ideas group (number?)



OT in PC at Home, in Primary Care



a. OT in PC in Primary Care/Home

The abrupt or progressive loss of functionality affects and distress people with diseases out of cure (trajectory disease)

Especially in their living environment (home) (odd benefits/ more sensitive context), Needs change constantly,

They lack continuous action in order to Maximize every moment the occupational performance of each situation, in all ages, life span (**OT GAP**)

It refers to the therapeutic use of habitual activities (occupations) by facilitating life to the maximum, promoting health, preventing or living better with injury, illness, disability. Facilitates lively, continuous, optimized role participation, symptom management (disease course to death)

In a palliative philosophy, the home (single context) allows personalization, safety, productivity, close relationship caregivers

a. OT in PC in Primary Care/Home (our Mission)

Occupational Therapy is a "specialist" in facilitating the choices that involve the intersection daily activities (daily), lifestyle, better management of chronic diseases

The OT is a professional (health education /proactive control/energy conservation) "Observe" /intervenes based on self-management of disease, adaptation and overcoming barriers in daily life. Has a crucial role in education.

1. overcoming barriers that impede meaningful activities;
2. helping the person to make the most of life;
3. recognize and prepare the course of sickness and death;
4. carry out meaningful, meaningful activities: day-to-day activities, occupations that give us identity (make us who we are)

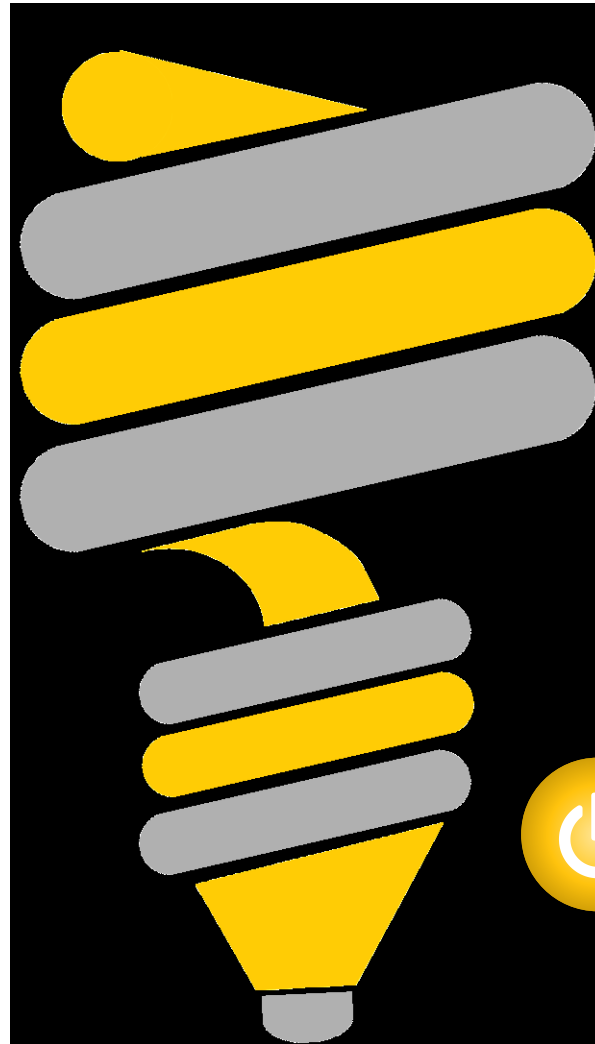
a. OT in PC in Primary Care/Home (diferente teams)



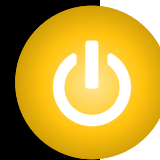
*Community
Care Unit*



*Shared
Assistance
Resources
Unit*



*Integrated
Continuing Home
Care Team*



*Community Support
Palliative Care*

a. OT in PC in Primary Care/Home *Principles*



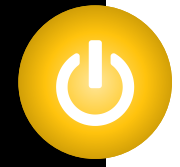
**Respect interests/
priorities
Holistic Perspective**



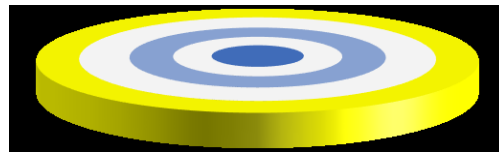
**Non-pharmacological side
in oncological situations
& non-cancerous (outside cure)**



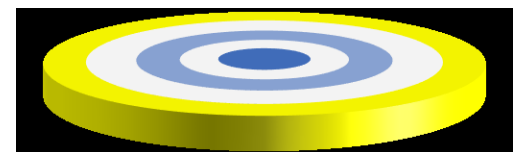
**Person-Centered and
Life-Cycle**



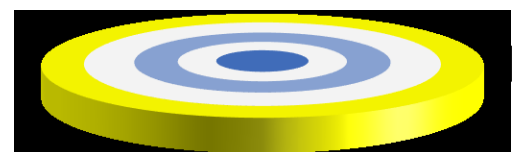
**Focusing on the
Person's Life Context**



Person



Environment

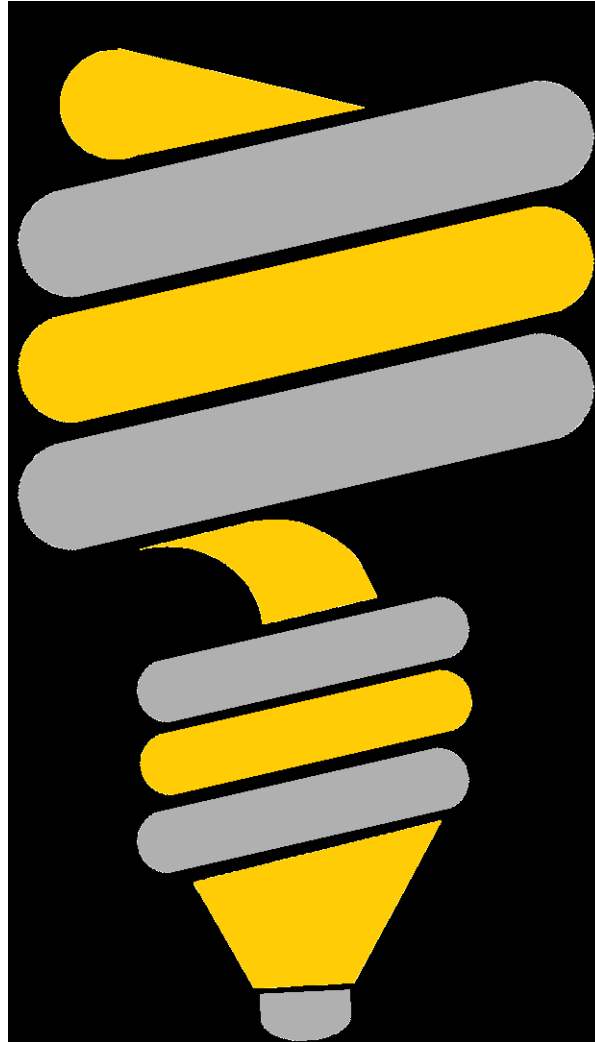


Caregivers

a. OT in PC, Primary Care/Home *Examples PC approach*



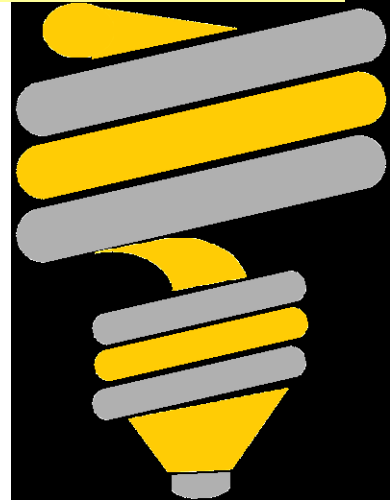
Twins Love



Lovely Girl

a. OT in PC, Primary Care/Home *Examples PC approach*

Approaches Occupation Different stages Cancer



Paquistan Man

Old Fellow

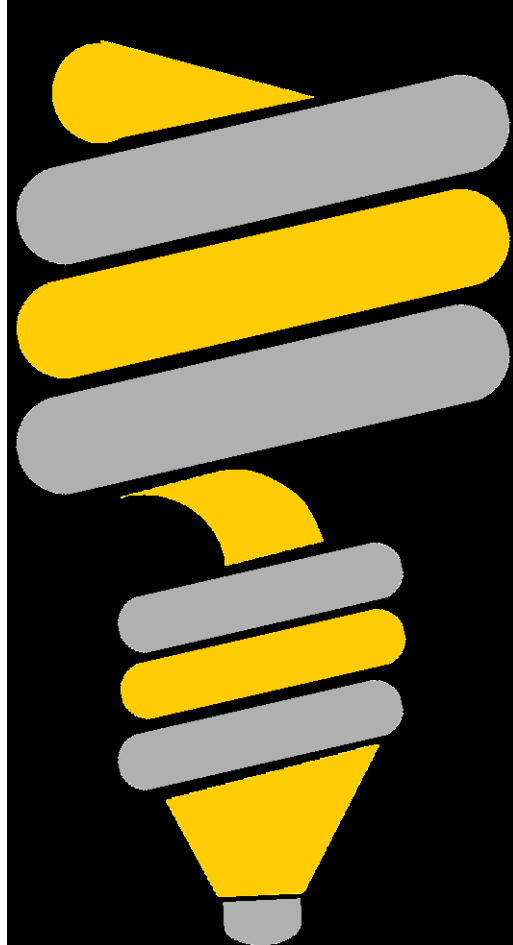
Restoration	Suport	Paliation	Prevention
It aims to recover as much as possible the residual person function	It aims to increase daily living and mobility, reducing difficulties and compensating permanent deficits	It aims to reduce symptoms such as pain, shortness of breath, improvement in positioning	Visa to maintain energy versus movement after treatments (balance)

a. OT in PC in Primary Care/Home (non oncologic)

Fibromialgia



Simon, A. U. & Collins, C. E. R. (2017). **Lifestyle Redesign[®] for Chronic Pain Management: A Retrospective Clinical Efficacy Study**. *American Journal Occupational Therapy*, *Maio 2017 (71)*, 7104190040p1-7104190040p7



Diabetes



Pyatak, E. A. *et al* (2018). **Occupational Therapy Intervention Improves Glycemic Control and Quality of Life Among Young Adults With Diabetes: the Resilient, Empowered, Active Living With Diabetes (Real Diabetes) Randomizes Controlled Trial**. *Diabetes Care*, *jan 19*, dc171624

a. OT in PC in Primary Care/Home (non oncologic)



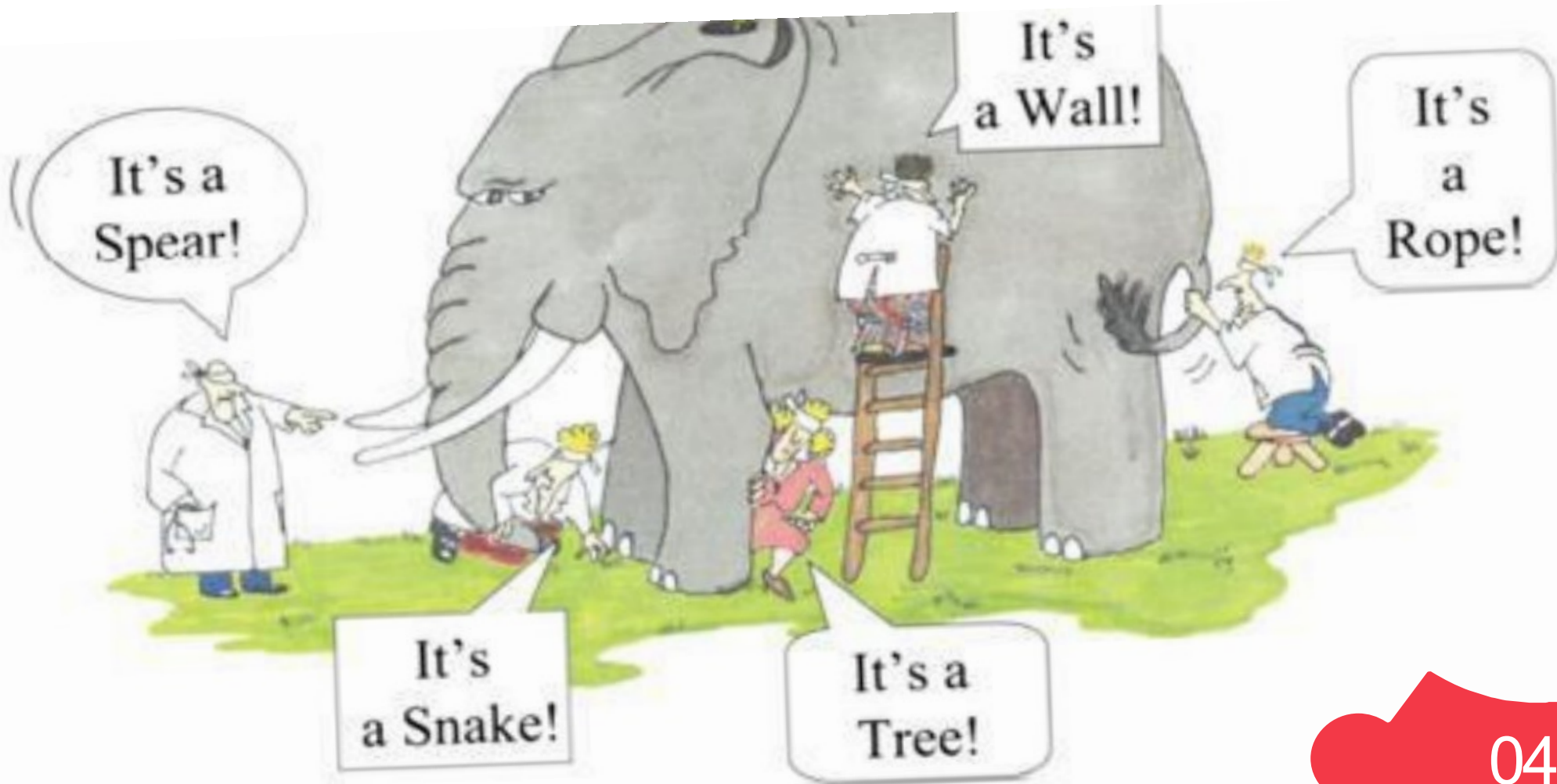
Fibromialgia



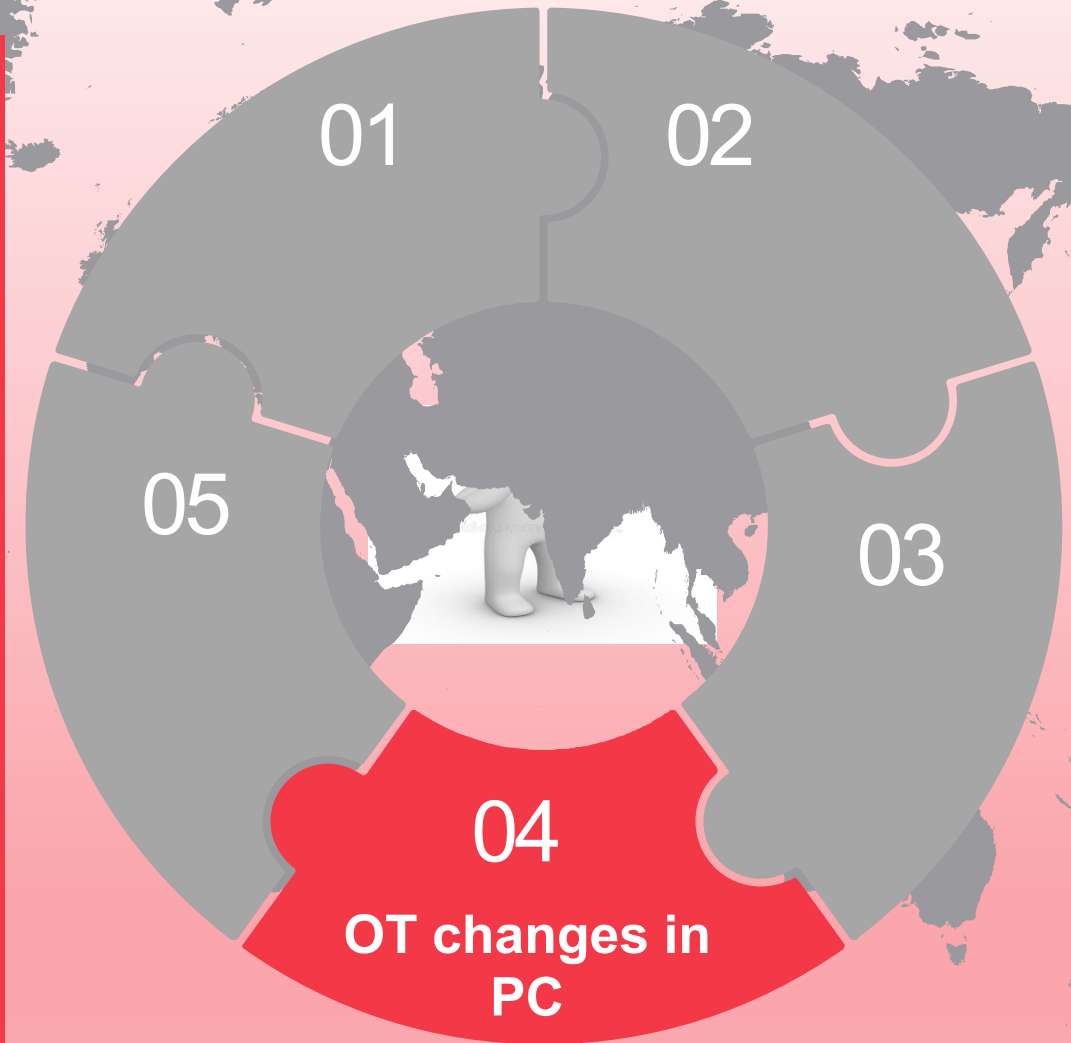
Diabetes

- They are huge annual costs pain management, direct medical expenses, loss of workforce
- OT can relieve "burden" (cost-effectiveness) by improving daily function and quality of life
- Stimulation to the patient in the sense of gaining motivations, identifying solutions and developing healthy habits





- Domain Principles CP
- Domain field PC Non-Pharmacological
- Training OT in CP (pre and post graduate)
- Integration Occupational Therapists in Palliative Care Primary Care namely in Community Teams Support Palliative Care (ECSCP)
- Integration Professional Models OT and PC
- Research on OT and PC, all patients (non-oncological)



04

Changes OT in
PC



Investigation

01	Non-Cancer patients
02	Education, training and curriculum development care providers
03	Organization, interdisciplinary PC approaches
04	Spirituality and existential questions
05	Family / caregiver needs, patient perspectives, culture, ethnicity
06	Symptom control
07	Decisions & communication

(.....) PECP (2017 2018)

00 Learning from Findings (cards exercise)

Learning Aim

To facilitate an empathetic understanding of what it is like to live with painful conditions and thus facilitate a therapeutic partnership.

This activity focuses on understanding the emotional impact of chronic pain

🔗 This activity can be done in groups or as individuals before or during the session depending on the time available.

🔗 Using all 100 cards will take a long time. Give students a limited number to work with, particularly if time is limited during a session. Give each group a random selection of cards (e.g. 20 cards).

🔗 Groups are likely to find common themes to discuss about what it is like to live with pain.

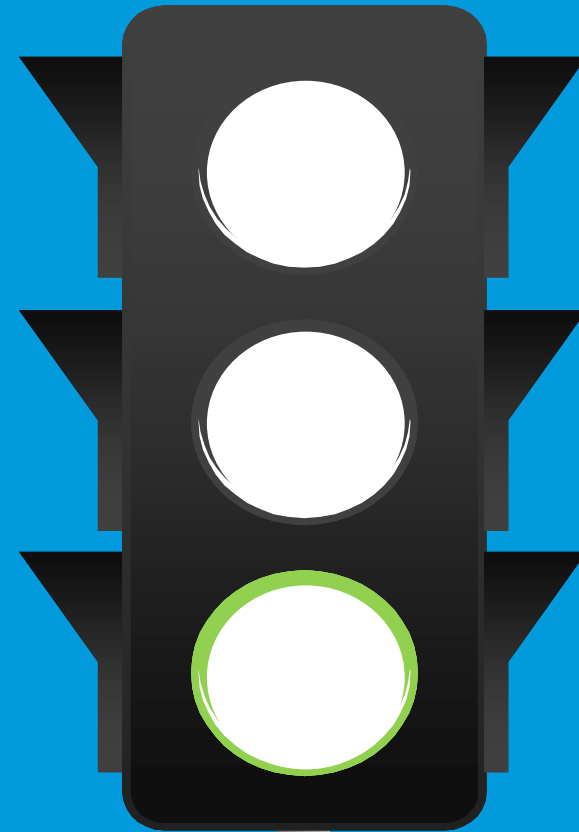
🔗 You could try this activity with any of the QES findings in appendices 2-10.

Cartões com descrições do que é viver com dor na comunidade, dor crónica que muitas vezes não acede CP



*Take away
Message*





**Calm
Tranquility**

TAKE AWAY MESSAGES



<https://www.facebook.com/photo.php?fbid=508832149560012&set=gm.10157648695392619&type=3&theater&ifg=1>

Abandon the thought that
CP are end-of-life care for
cancer patients

Anyone who becomes
fragile or faces a chronic
illness may have benefits

In Primary Care, PC asset
management chronic
disease throughout life

TAKE AWAY MESSAGES



<https://www.facebook.com/photo.php?fbid=508832149560012&set=gm.10157648695392619&type=3&theater&ifg=1>

An integrated palliative approach can start anywhere, especially at home, where the person problems/needs are not only physical

Pain control without holistic support CAN NOT be called PC
Psychosocial support without pain relief and symptom control will NOT be PC

TAKE AWAY MESAGES



<https://www.facebook.com/photo.php?fbid=508832149560012&set=gm.10157648695392619&type=3&theater&ifg=1>

It is crucial that the OT can
should be represented
different configurations/
units of Palliative Care

Desire for participation in
significant occupations
intensifies end life

OT recognizes two faces of
the same reality of the life
cycle (living and dying)

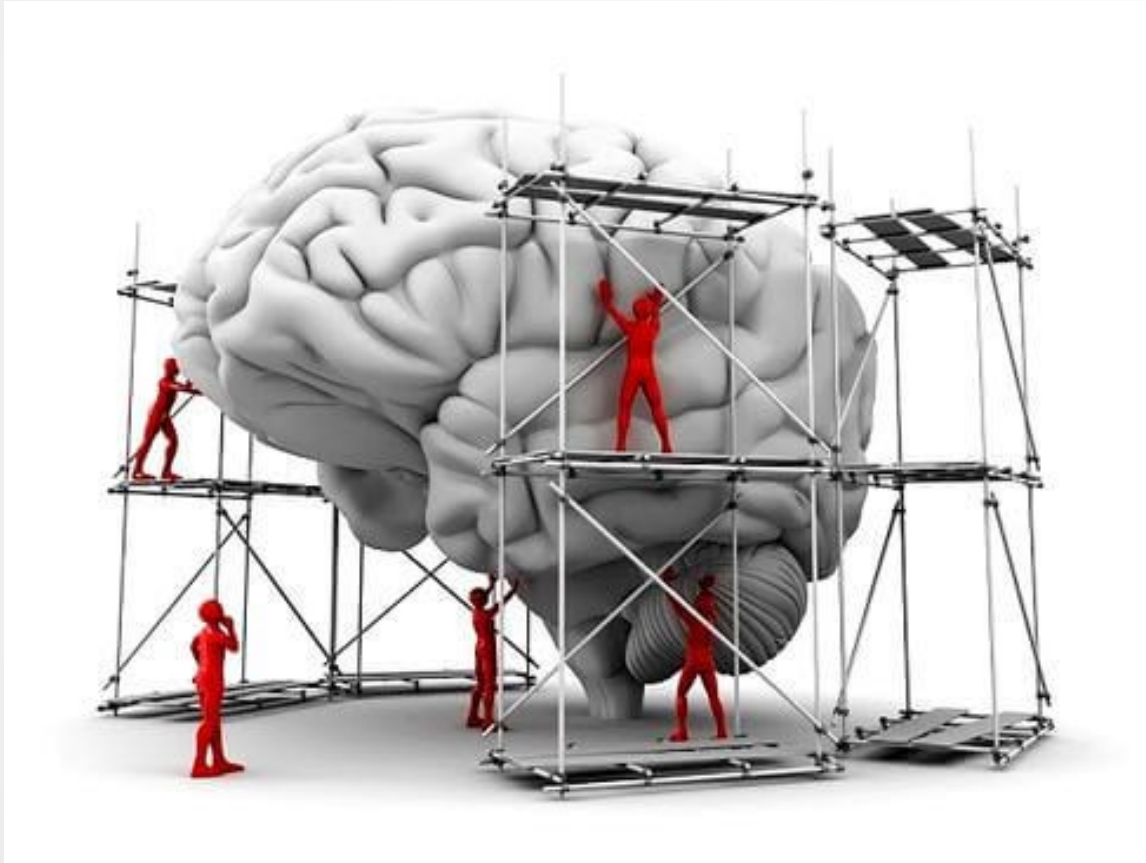
TAKE AWAY MESSAGES



<https://www.facebook.com/photo.php?fbid=508832149560012&set=gm.10157648695392619&type=3&theater&ifg=1>

The act of dying or living with an illness that is not curative should not limit the occupation whose priorities are defined by **the client, at home,** where it only makes sense **Don't forget Palliative Approach**

24th ENOTHE Annual Meeting 2018, ESSA Alcoitão



<https://amenteemaravilhosa.com.br/aprenda-programar-seu-cerebro/>

Thank you

Vanda Varela Pedrosa

Polytechnic of Leiria/ School of
Health Sciences, Portugal

vanda.varela@ipleiria.pt

Ver o que escrevi na submissão

Background: The Occupational Therapy (OT) in the Palliative Care (PC) can contribute, in a valuable way to preserve independence, comfort and quality of life, effectively during illness and even death. The PC scenario in the world and in Portugal is changing. According to the World Health Organization, PC improve the quality of life of patients and families, prevent and alleviate suffering in incurable health situations, identifying early pain and problems: physical, psychological, social and spiritual. In Portugal this Vision is materialized in the Strategic Plan Development Palliative Care in progress.

The objective is to reflect on the role of OT in PC approach at Home, within the scope of Portuguese Primary Health Care.

Methods: Comprehensive reading of the literature about the last 5 years: World Health Organization; European Palliative Care Association; National Association of Palliative Care, OT Associations, will support case studies to be discussed, in small/after large group.

Conclusions: The outcomes of workshop are in advice format, supporting the holistic, multiprofessional, non-pharmacological scope that the OT, a relevant professional area that acts on the loss of functionality that usually affects and anguish the client, being able at any moment to maximize their occupational performance, helping process and professional reasoning.

Ver o que escrevi na submissão

Comissão Nacional Cuidados Paliativos. Plano Estratégico Cuidados Paliativos 2017 2018. 2017 [cited 2018 27 janeiro]. Available from: https://www.sns.gov.pt/wp-content/uploads/2016/09/Plano-Estrat%C3%A9gico-CP_2017-2018-1.pdf

Direção Geral da Saúde. Plano Nacional de Saúde, Revisão e Extensão a 2020. Lisboa: Ministério da Saúde; 2015 [cited 2017 1 dezembro]. Available from: <http://www2.insa.pt/sites/INSA/Portugues/ComInf/Noticias/Documents/2015/Junho/PNS-2020.pdf>

Hart, E. C. & Parsons, H. Occupational Therapy: Cost-Effective Solutions for a Changing Health System. USA: The American Occupational Therapy Association; 2015 [cited 2017 29 novembro]. Available from: <https://www.aota.org/~media/Corporate/Files/Advocacy/Federal/Fact-Sheets/Cost-Effective-Solutions-for-a-Changing-Health-System.pdf>

Simon, A. U. & Collins, C. E. R. (2017). Lifestyle Redesign® for Chronic Pain Management: A Retrospective Clinical Efficacy Study. *American Journal Occupational Therapy, Maio 2017 (71), 7104190040p1-7104190040p7*

Pyatak, E. A. *et al* (2018). Occupational Therapy Intervention Improves Glycemic Control and Quality of Life Among Young Adults With Diabetes: the Resilient, Empowered, Active Living