# Severe and Persistent Mental Illness and Palliative Care Community of Practice

## How do we Move Forward? Models and Future Directions

Project ECHO
Palliative Care - Canada
BY
Pallium Canada

**Facilitator**: Kathleen Willison
**Presenters:** Dr. Loïc Moureau
**Date:** April 25th 2023

# Territorial Honouring

# The Palliative Care ECHO Project

The Palliative Care ECHO Project is a 5-year national initiative to cultivate communities of practice and establish continuous professional development among health care providers across Canada who care for patients with life-limiting illness and their families.

**Stay connected: www.echopalliative.com**

The Palliative Care ECHO Project is supported by a financial contribution from Health Canada. The views expressed herein do not necessarily represent the views of Health Canada.

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# LEAP Core

- Interprofessional course that focuses on the essential competencies to provide a palliative care approach.
- Taught by local experts who are experienced palliative care clinicians and educators.
- Delivered online or in-person.
- Ideal for any health care professional (e.g., physician, nurse, pharmacist, social worker, etc.) who provides care for patients with life-threatening and progressive life-limiting illnesses.
- Accredited by the CFPC and Royal College.

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LEAP CORE

Learn more about the course and topics covered by visiting

**www.pallium.ca/course/leap-core**

# Overview of Sessions

| Session # | Session Title | Date/ Time |
|---|---|---|
| Session 1 | What is Severe and Persistent Mental Illness? | January 17, 2023 from 12-1pm ET |
| Session 2 | What can Palliative Care offer to people with SPMI? | February 21, 2023 from 12-1pm ET |
| Session 3 | What is Palliative Psychiatry? | March 21, 2023 from 12-1pm ET |
| Session 4 | How do we move forward? Models and Future Directions | April 25, 2023 from 12-1pm ET |

# Welcome & Reminders

- Please introduce yourself in the chat! Let us know what province you are joining us from, your role and your work setting
- Your microphones are muted. There will be time during this session when you can unmute yourself for questions and discussion.
- You are welcome to use the chat function to ask questions and add comments throughout the session
- This session is being recorded and will be emailed to registrants within the next week.
- Remember not to disclose any Personal Health Information (PHI) during the session
- This 1-credit-per-hour Group Learning program has been certified by the College of Family Physicians of Canada for up to **4 Mainpro+** credits.

# Disclosure

Relationship with Financial Sponsors:

**Pallium Canada**

- Not-for-profit
- Funded by Health Canada

**This program has received financial support from:**

- Health Canada in the form of a contribution program
- Generates funds to support operations and R&D from Pallium Pocketbook sales and course registration Fees

# Disclosure

## Mitigating Potential Biases:

- The scientific planning committee had complete independent control over the development of course content

## Facilitator/ Presenter/ Panelists:

- Dr. Loïc Moureau: Has received grants from Bijzonder Onderzoeksfonds KU Leuven (BOF) related to research regarding ethics, palliative care and psychiatry
- Daniel Buchman PhD: Has received grants from Canadian Institutes of Health Research (CIHR) related to research and practice in palliative psychiatry
- Dr. Anne Woods: Nothing to disclose.
- Dr. Sarah Levitt: Has received grants from Canadian Institutes of Health Research (CIHR) related to research and practice in palliative psychiatry
- Dr. Alexandra Farag: Nothing to disclose.
- Kathleen Willison: Nothing to disclose

# Introductions

**Facilitator:**

**Kathleen Willison, RN MSc CHPCN©**
Assistant Clinical Professor, School of Nursing,
Associate Member and Continuing Education Lead,
Division of Palliative Care, Department of Family Medicine, McMaster University, Hamilton, Ontario
Clinical Nurse Specialist, Palliative Care,
St. Joseph's Healthcare Hamilton

**Presenter:**

**Dr. Loïc Moureau**
PhD student, RUPET, KU Leuven (Belgium)
Ethicist, VZW Gezondheidszorg Bermhertigheid Jesu (Belgium)

**Panelists:**

**Dr. Alexandra Farag, MD CCFP (PC)**
Assistant Clinical Professor, Division of Palliative Care, Department of Family MedicineMcMaster University
Palliative Care Physician, St Joseph's Healthcare Hamilton and Hamilton Health Sciences.

**Daniel Buchman, PhD RSW**
CAMH
Bioethicist and Independent Scientist, Centre for Addiction and Mental Health, Assistant Professor, Dalla Lana School of Public Health, Joint Centre for Bioethics. University of Toronto

**Dr. Sarah Levitt MSc MD FRCPC**
Associate Director, Brain Medicine Fellowship, Department of Psychiatry, University of Toronto
Assistant Professor, Department of Psychiatry, University of Toronto UHN
Co-Medical Director, IMPACT Program, University Health Network
Staff Psychiatrist, Inpatient Program, University Health Network

# Introductions

**Panelists:**

**Kelli Staiduhar RN PhD FCAHS FCAN**
Professor & Canada Research Chair (Tier 1)
in Palliative Approaches to Care in Aging & Community Health
School of Nursing and Institute on Aging & Lifelong Health
University of Victoria

**Dr. Anne Woods, BA RN MDiv MD CCFP(PC) FCFP**
Assistant Clinical Professor, Division of Palliative Care, Department of Family Medicine, McMaster University.
Co-Head of Service and Palliative Care Physician, Palliative Medicine Service, St. Joseph's Healthcare Hamilton

**Support Team**

**Aliya Mamdeen**
Program Delivery Officer, Pallium Canada

**Diana Vincze**
Palliative Care ECHO Project Manager, Pallium Canada

# Session Learning Objectives

**Upon completing the session, participants will be able to:**

- Articulate principles behind developing models of care.
- Describe a couple of examples of models that have been developed to address palliative care for individuals with SPMI.
- Engage with colleagues about how we can move forward.
- Build connections for future collaboration.

# Principles Behind Models of Care Development (Compared to Change Theory -> PDCA)

- From planning stages – include patient/family, stakeholders, researchers/evaluators: what data, how to collect
- Identify target population – patient-centered (not homogeneous)
- Location of care – which sector (not always conventional/accessible)
- Care providers – discipline/interprofessional (expertise/education)
- Intervention – What? How? Resources? (collaborative)
- Outcome measures – patient-focused, qualitative (outcome = death?)
- Economic evaluation – identify the impacts (LOS, # staff)
- Satisfaction – patient/family/care provider

# Models of Care: Integrated MH & PC Task Study

- 2 Studies utilizing PC & MH NP in joint collaboration and cross-training
- 2 workshops – 1 on PC -> MH and 1 on MH -> PC; plus skills modeling and self-directed learning modules
- Patients seen by:
  - both MH & PC NPs in case conference
  - as well as in independent visits
  - and joint follow up visits
- Data:  Qualitative interviews - +ve feedback from staff

(Picot et al, 2015; Taylor et al, 2012)

# Models of Care: “Do It Your Way” Demonstration Project

- $1^0$ objective – develop ACP tools for people with SPMI
- Stakeholder collaboration between PC and MH
- Cross-training – 1 day workshop, PC -> MH and MH -> PC
  - Characteristics of the illnesses & their trajectories
  - Symptoms and how to manage
- Discussion of cases
- Discussion of the systems context
  - Legal guidelines
  - Referral processes to other services

(Foti, 2003)

# Recommendations from the literature

- Partner & collaborate with colleagues across the table
- Make use of existing relationships -> allows continuity for patients
- Reduce silos to ensure that care is provided wherever needed & in collaboration with existing services
- Recognize heterogeneity in the population
- Include the voices of the patients/families
- Cross-training = respectful and builds relationships
- Share resources and each others' tools across the disciplines

(Woods, 2008; Donald, 2019)

# References


- Donald, E.E.,and Stajduhar, K.(2019). A Scoping Review of Palliative Care For Persons With Severe Persistent Mental Illness. *Palliative and Supportive Care*. **17**, 479-487. https://doi.org/10.1017/S1478951519000089
- Foti,M.E. (2003). “Do it your way”: A demonstration project in end-of-life care for persons with serious mental illness. *Journal of Palliative Medicine*. **6(4)**, 661-119.
- Jessup, R., Putrik, P., Buchbinder, R., et.al. (2020). Identifying alternative models of healthcare service delivery to inform health system improvement: scoping review of systematic reviews.*BMJ Open.* **10:**e036112.doi:10.1136/bmjopen-2019-036112.
- Picot, S.A., Glaetzer, K.M., and Myhill, K.J. (2015). Coordinating end-of-life care for individuals with a mental illness: A nurse practitioners’ collaboration. *Collegian.* **22**(1), 143-149.
- Taylor, J., Swatman, K., Myhill, K., et. al.(2012). IMhPaCT: An education strategy for cross-training palliative care and mental health clinicians. *Int J of Pall Nursing*. **18**(6), 290-294.
- Woods, A., Willison, K., Kington, C., Gavin, A. (2008). Palliative Care for People with Severe Persistent Mental Illness: A review of the literature. *Can J of Psychiatry*. **53**(11), 725-736.

# ‘Oyster Care’

A palliative care approach for people with a severe and persistent mental illness.

# On the crossroads of psychiatry and end-of-life care: 5 encounters

Patients in a palliative stage who develop psychiatric symptoms (anxiety, depression, delusions,...)

Psychiatric patients dealing with life-threatening conditions (e.g., cancer)

Patients with a psychiatric disorder who enter a terminal phase because of this specific disorder (e.g. refractory forms of anorexia nervosa or chronic suicidality)

Persons requesting euthanasia or other forms of medically assisted dying, due to unbearable and incurable mental suffering (Reakiro)

**Persons with severe, persistent psychiatric illness who have 'no treatment options left' (futility) and also enjoy little quality of life ('palliative care approach' – implementations of a 'palliative philosophy')**

# Origins of the concept ‘oyster care’

- **Dr. Ilse Decorte**, general practitioner, specialised in palliative care at the Public Psychiatric Hospital Geel
  - Target group: patients with a severe and persistent mental illness (SPMI), often with somatic comorbidity
- **Dr. Françoise Verfaillie**, psychiatrist
- **Forum ‘end-of-life and psychiatry**’ (Federation Palliative Care Flanders)

# Origins of the concept ‘oyster care’

Oyster care offers an answer to the care needs of patients with a serious psychiatric illness who appear ‘to have no more valid treatment options left’, who suffer from severe mental illness, for whom Recovery (as societal rehabilitation) is not feasible, who need permanent intensive treatment, and who are in danger of being forgotten by the government as within the healthcare system.

Parallel to the development of regular palliative care, there is also a place for 'palliative psychiatry’, alongside curative and recovery-oriented treatment.

# Meaning of the concept ‘oyster care’ (2)

'Crusta' means shell: “we **protect** these people with a shell in which they know themselves safe. At the same time, the term refers to the care-unit in the hospital, which, like an external skeleton, gives **meaning and structure** to these patients, who do not have sufficient strength for themselves "(Dr. Decorte)

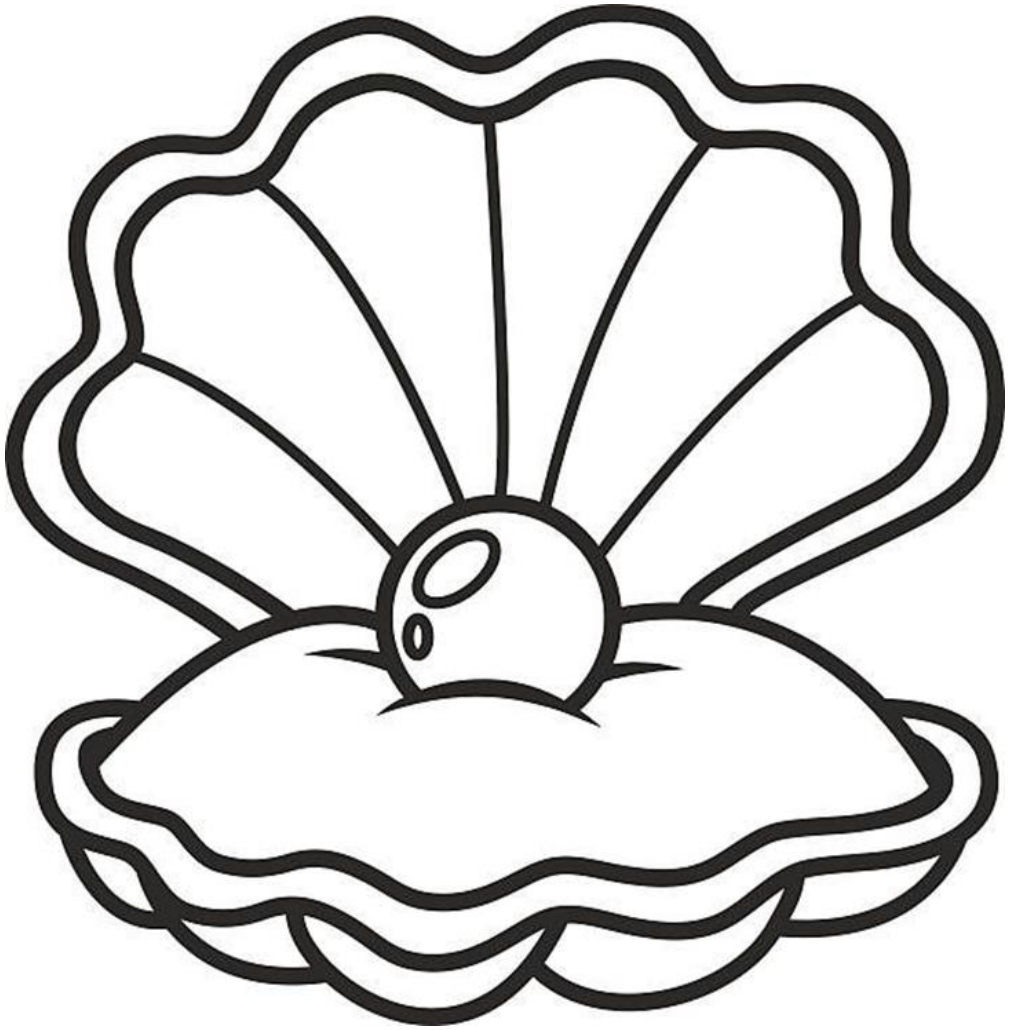
“Oyster care is a **dynamic approach** that responds to the needs, possibilities and pace of each patient: within the security of the shell, people can shelter, or take new steps: the shell can open itself a bit more or a bit less, depending on the current situation” (dr. Verfaillie)

# Meaning of the concept ‘oyster care’

- Palliative care: ‘pallium’ (cloak)
- Crustatieve zorg: ‘crusta’ (shell)

- Similarities with ‘regular’ palliative care:
  - Futility, risking of both negligence or over-treatment
  - Focus on making suffering more tolerable & harm reduction
  - To improve the quality of life as the main focus of care
  - Helping to build/maintain a meaningful existence
  - Supporting the mourning processes
  - Highly complex and creative care
  - Holistic care
- Caveat: the word ‘palliative care’ has connotations ‘with giving’ up and the dying process

# How the shell became an oyster: an anecdote



# Pillars of Oyster Care

Oyster care or shell care is a form of psychiatric palliative care

It is a ‘total care’, based on 4 pillars:

- The somatic pillar
- The mental pillar
- The social pillar
- The existential pillar

# The Somatic Pillar

- **Shorter life expectancy** (10-20 years compared to general population).
- Somatic **comorbidity**, linked to psychopathology, its treatment and lifestyle.
- **Unhealthy lifestyle**, long-term neglect of self-care.
- Increased risk of choking or suffocation ('fast food syndrome’).
- **Limited access** to somatic treatment and follow-up treatment, due to psychiatric issues (stigma, siloing,…).

# The Somatic Pillar (2)

- **Physical signals are often not adequately interpreted by the patient himself or the caregivers.**
- Symptoms are more easily interpreted as behavioral problems or psychosomatic symptoms of psychiatric the patient.
- **Pain and physical complaints are expressed and experienced differently**, and often go not recognized and under-treated.

# The Somatic Pillar (3)

**Focus in oyster care:**

- Good somatic care and treatment, individually, tailored to the patient, e.g. close collaboration with **general practitioner.**
- In-time **recognition** of physical complaints the integration of somatic and psychiatric treatment in the treatment of ‘total’ pain.
- Care for meals (1 on 1 supervision).
- **Psycho-pharmacological therapy: continuous follow-up** and evaluation; maintain a good balance between treating symptoms and limiting side effects.

# Mental Pillar

- Major **psychological frailty** due to:
  - High sensitivity to stress
  - Serious information processing disorders (attention, thinking, memory) => strong hypersensitivity to overstimulation
  - Serious problems with the processing of stimuli and the regulation of stress
  - Serious discomfort because of delusions, hallucinations, agonizing thoughts, negative emotions
  - Limited illness insight

# Mental Pillar (2)

- Limited ability to introspection and mentalization
- Reduced problem-solving capacity
- Reduced emotion regulation and behavioral control
- Negative self-image and disturbed body experience

- Major psychological insecurity in contact with others (due to severe trauma, severe attachment problems) => serious difficulties to build up a relationship of trust.

# Mental Pillar (3)

**Focus in oyster care**:

- **Being patient and persistent** in finding ways to build a positive relationship with the patient
- Continue to offer the patient the chance to attach himself to the caregivers at his own pace
- Persevere in assisting the patient in a **creative** way that is unique to each patient
- Striving for an optimal supply of contact and stimulus level
- Striving to maintain a good **balance between distance** (letting go, giving space, self determination) **and proximity** (structuring, holding, limiting)

# Mental Pillar (4)

**Focus in oyster(2)**:

- Being present (attention, dedication) (*Andries Baert*).
- Having a good view of the patient's way of communicating and the meaning of often non-verbal signals.
- Trying to sense and understand what can not be said or experienced, but is expressed in ‘strange’ or ‘unwanted’ behavior.
- **Role of the care provider**: the care provider offers ‘from his person’ (emotional) safety and structure that makes connection with the patient possible *(remark: risk of transgression of boundaries from both sides!).*
- The importance of a good therapeutic attitude.

# Mental Pillar (5)

- Importance of a good therapeutic attitude: keywords are ‘holding’ and ‘containment’= supporting, providing support, being emotionally available, being reassuring in combination with setting protective limits.
- ‘P**ositive risk taking**’: maximizing shared responsibility, applying coercion as a last resort.

# Social Pillar

- **Limited social network**, isolation
- Hospital = home; important and meaningful bond with caregivers
- Serious communicative and social difficulties
- ‘Mourning processes’ regarding close relatives
- The contact with society is interrupted: “they stay inside because it is hurts outside” (Doortje Kal)

# Social Pillar (2)

**Focus in oyster care**

- Helping patients reconnect with others
- Creating a reliable environment or ‘exoskeleton’
- Creating opportunities to meet other people
- Recognizing, respecting and enduring being alienated and being different (as long as it remains safe)

- **Role of the care provider**: ensuring recognisability and predictability (daytime program) and being available in a sensitive and respectful way; continue to invest in being a ‘social role model’; investing in the care for relatives and friends; to recognize lifelong commitment and emotional support

# Social Pillar (3)

**Focus in oyster care (2):**

- Social rehabilitation not as a goal in itself
- Support patients in their desire to belong and to be of significance
- Against exclusion, stigma and marginalization: in the care unit, in the hospital, in society; working towards a place of their own
- **Role of the care provider**: **bridge-builder** between the patient and the world around him

# Existential Pillar

- Confrontation with **many loss-experiences.**
- **Suffering from, and under the effects of the disease.**
- Confrontation with the frailty and the brokenness of life.
- Feelings of hopelessness, injustice, senselessness; explicit (words) and implicit (e.g. inactivity).
- Feelings of **powerlessness** (both in patients, family and caregivers).

# Existential Pillar (2)

**Focus in oyster care**

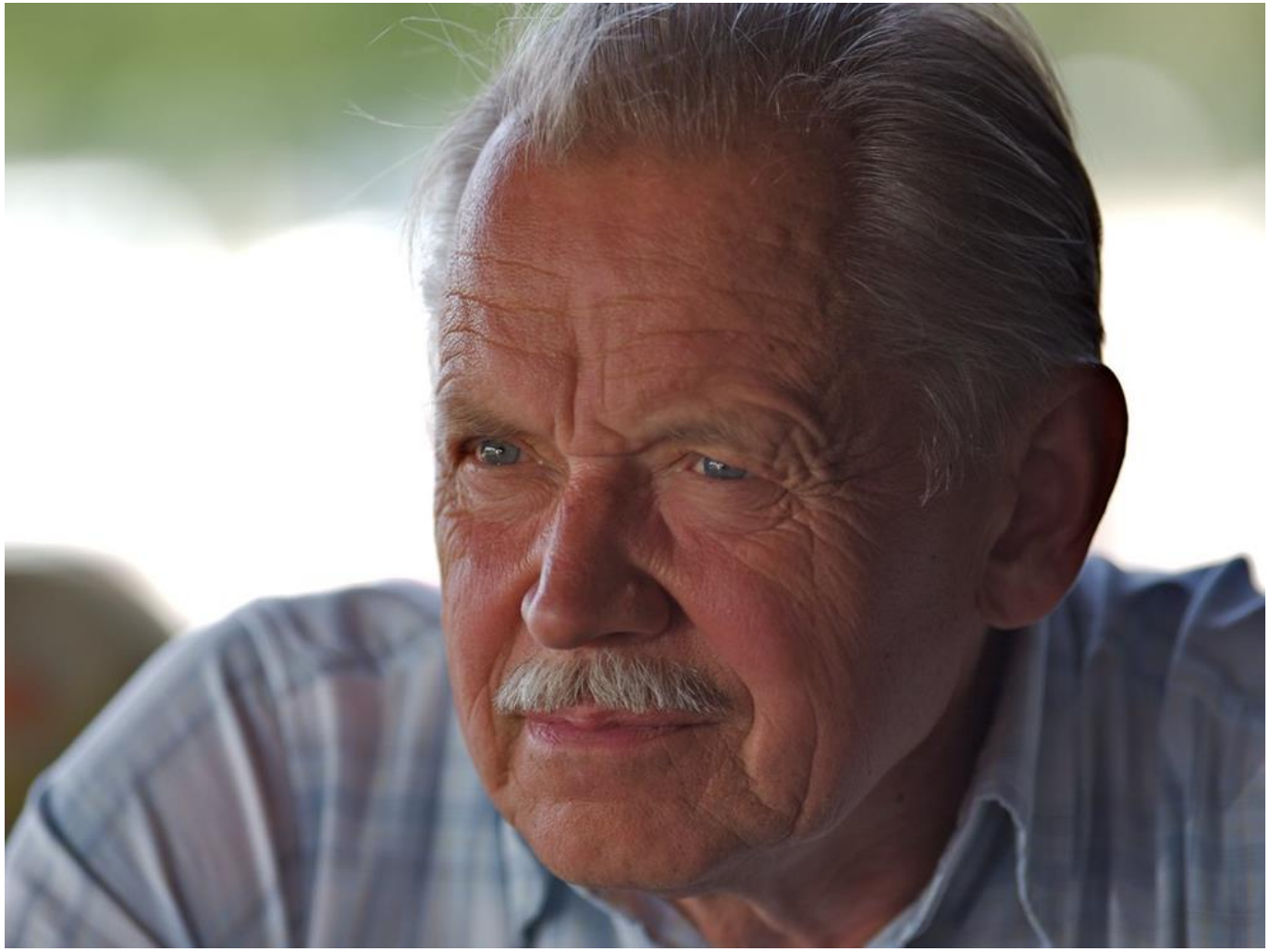
- Being sensitive and open to existential themes (death, the meaning of life, freedom and autonomy).
- Daring to deal with and being able to deal with statements of meaning(lessness).
- **Remaining present, even when powerless.**
- Addressing power sources, such as the (often remarkable!) will to live.

# Existential Pillar (3)

**Focus in oyster care (2):**

- Helping patients connect with themselves, the others, nature and the sacred in their lives, through meaningful and well-being activities.
- Searching in word and deed  for the ‘essence of the person’, for a  remaining seed of meaning and self-esteem &  stimulation to let it grow.
- Care for caregivers (understanding and supporting each other from apposition of not-knowing, not-judging).

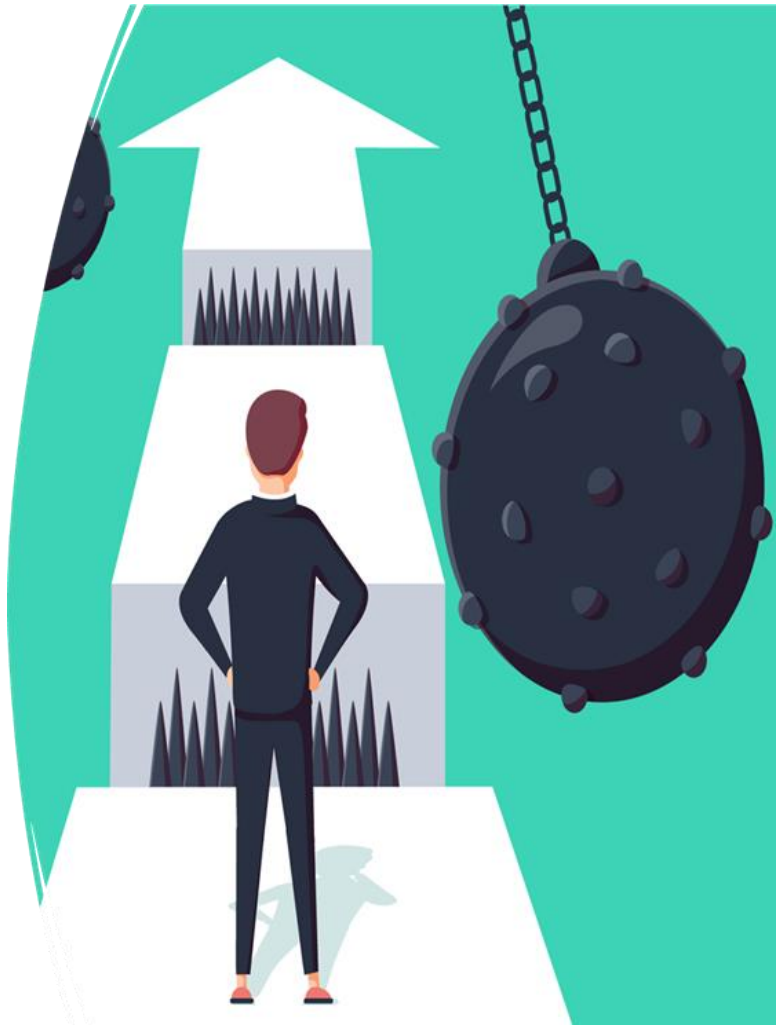
# Oyster Care In Practice: William



# The Continuous Development Of A New Care Model

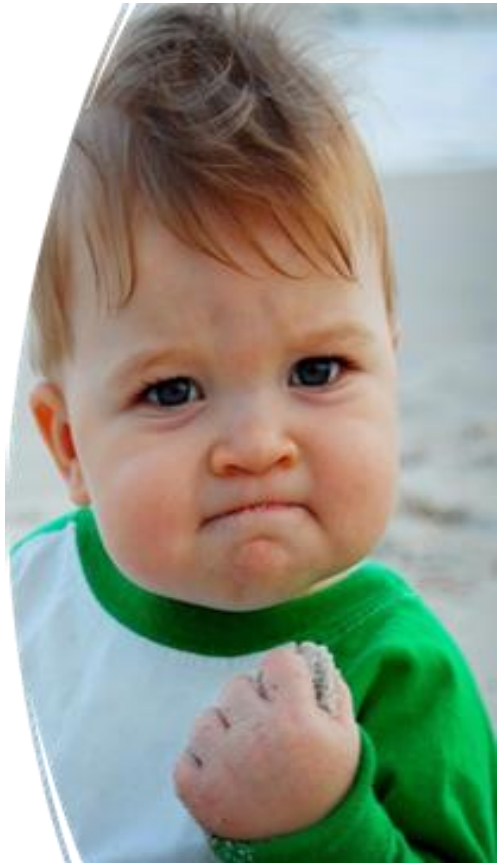
# Future Goals and Obstacles

- The structural recognition, expansion and implementation of oyster care units.
- Studies regarding care actual complexity.
- Oyster care as an alternative for people with a demand for euthanasia?
- Expansion and implementation scientific research.
- Training and recruitment.
- Continuous caution regarding ethical aspects of care (coercion, DMC,...).
- …



# Some Milestones and Achievements

- Publications in local and international literature.
- ‘Forum crustatieve zorg’ (consultation, intervision, logo, website, networking, awards, television series).
- ‘monitor crustative zorg’ (a working tool and quality indicator for caregivers).
- Intensification Scientific research regarding and with the target group.
- **Appreciation and recognition of the complexity of care and the role of caregivers!**



# Further Reading

- Website: https://www.crustatievezorg.be/
- Artikel Frontiers: https://www.frontiersin.org/articles/10.3389/fpsyt.2020.00509/full
- Artikel TvGG: https://tvgg.be/nl/artikels/schelpzorg-een-palliatief-zorgmodel-voor-pati-nten-met-een-ernstige-persisterende-psychiatrische-aandoening
- ART: http://art-psy.nl/het-model/
- Reakiro: https://reakiro.be/

# Q&A

# Discussion

# Session Wrap Up

- Please fill out our feedback survey, a link has been added into the chat.
- A recording of this session will be emailed to registrants within the next week.
- Thank you for your participation during this series!

# Thank You

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