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Let’s Influence!

Educational resources to promote knowledge and leadership in palliative care

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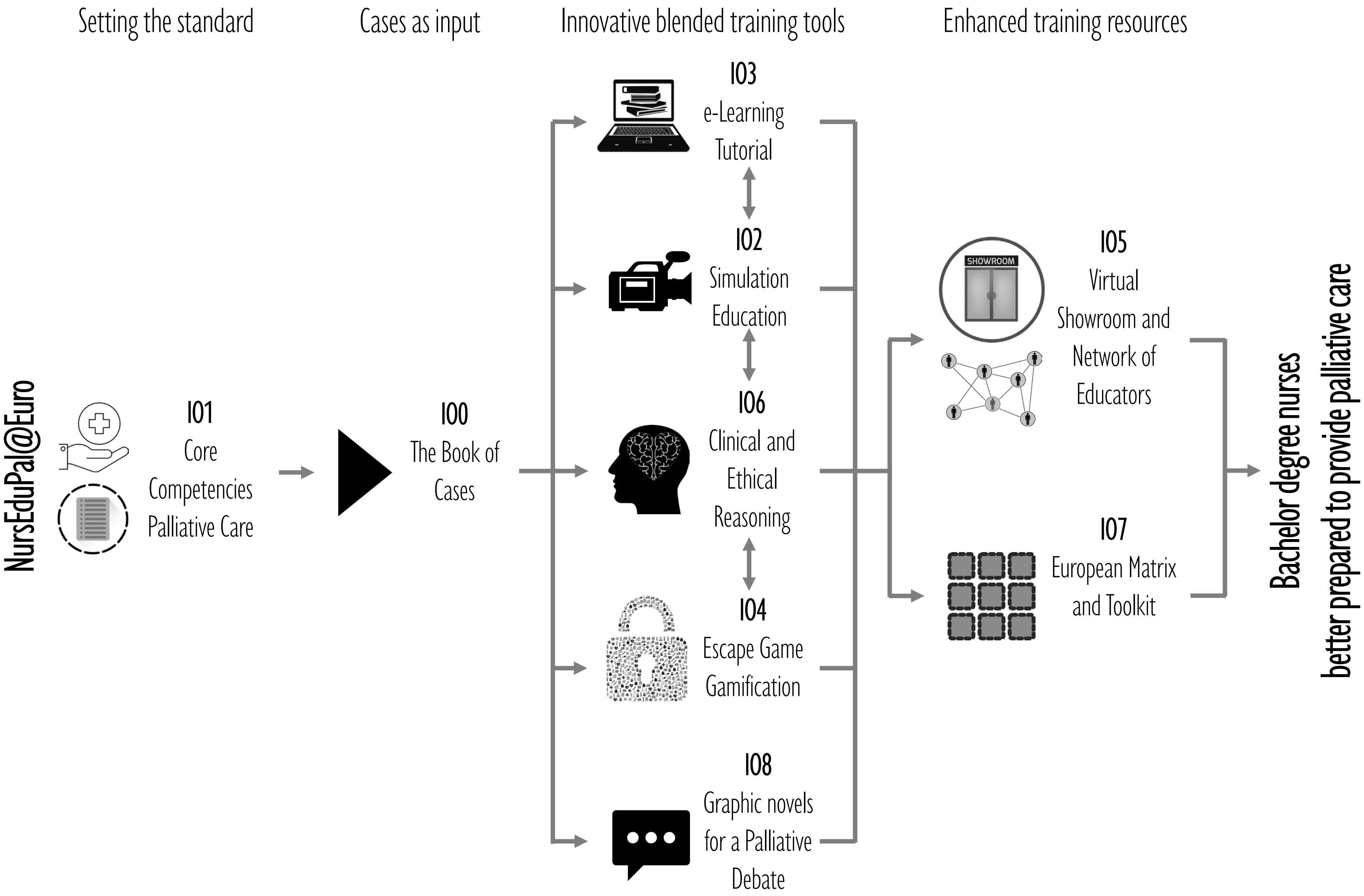
https://eapcnet.wordpress.com/2021/05/17/how-a-dinner-in-bruges-led-to-nursedupaleuro-an-erasmus-funded-ka203-project-to-improve-palliative-care-education-for-nurses/

NursEduPal@Euro: a strategic partnership for the improvement of palliative care education



Setting the standard

Cases as input

Innovative blended training tools

Enhanced training resources

NursEduPal@Euro

IO1
Core
Competencies
Palliative Care

IO0
The Book of
Cases

IO3
e-Learning
Tutorial

IO2
Simulation
Education

IO6
Clinical and
Ethical
Reasoning

IO4
Escape Game
Gamification

IO8
Graphic novels
for a Palliative
Debate

IO5
Virtual
Showroom and
Network of
Educators

IO7
European Matrix
and Toolkit

Bachelor degree nurses
better prepared to provide palliative care

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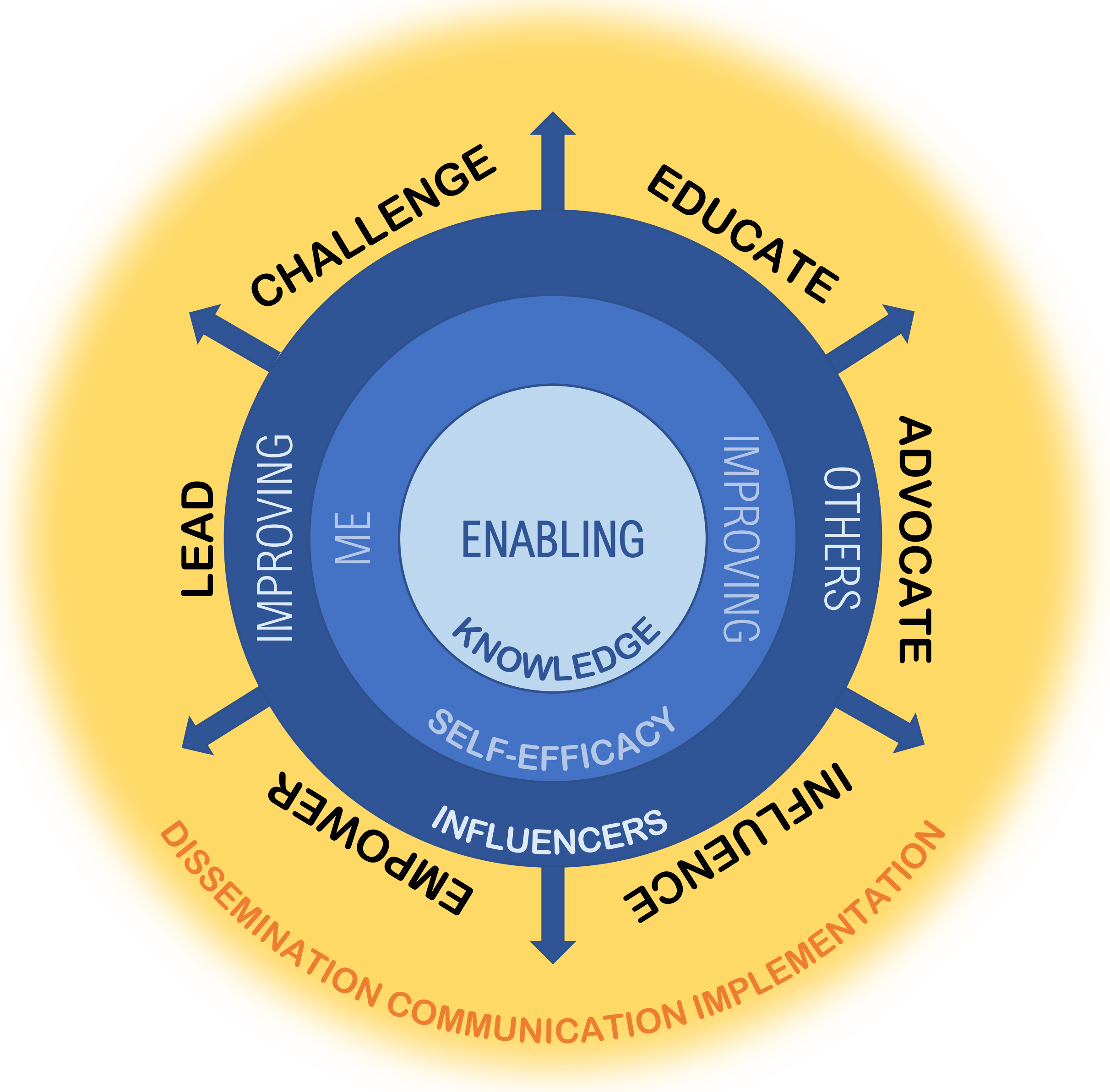

CHALLENGE
EDUCATE
LEAD
ADVOCATE
IMPROVING
ME
ENABLING
KNOWLEDGE
IMPROVING
OTHERS
SELF-EFFICACY
INFLUENCERS
EMPOWER
INFLUENCE
DISSEMINATION COMMUNICATION IMPLEMENTATION

The European palliative care matrix

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Analytical themes	Descriptive themes*
Competence in the holistic nature of palliative care	The philosophy of palliative care The purpose of palliative care Epidemiology in palliative care Quality of life in palliative care Death and dying as a topic in palliative care Palliative care in different patient groups
Competence in organising palliative care	Organising palliative care Critical evidence-based thinking and decision-making in palliative care Advanced care planning in palliative care Advocacy in palliative care Palliative care services
Competence in pain management in palliative care	The multidimensional aspects of pain in palliative care/Total pain Pain assessment in palliative care context Pain management in palliative care
Competence in symptom management in palliative care	Identifying and assessing symptoms in the context of palliative care Principles of symptom control in palliative care Symptom management in palliative care Non-pharmacological symptom management in palliative care Pharmacological symptom management in palliative care
Competence in holistic support in palliative care	Responsiveness and supportiveness to psychosocial needs in palliative care Person-centred supporting when working with palliative patients and those most important to them Culturally sensitive supporting in palliative care Maintenance of hope in palliative care Grief and supporting in bereavement during the different phases of the palliative care process
Holistic communication, encounter, and interaction competence in palliative care	Open and active verbal and non-verbal communication in palliative care Open and active listening in palliative care Discussion of difficult topics in palliative care The importance of being present in palliative care Open-minded and dignified encountering in palliative care Responsive appropriate interaction in palliative care Encounters with the closest ones to patients in palliative care Communication, and interaction with those most important to patients' in palliative care

*Themes in blue colour have emerged from the literature

Analytical themes	Descriptive themes*
Competence in empathy in palliative care	Empathy in palliative care Empathic communication in palliative care
Spiritual competence in palliative care	Meaning of spirituality in the context of palliative care and its importance to patients Assessment of the spiritual needs of the patients in palliative care Support patients with spiritual needs in the context of palliative care Openness and confidence towards spiritual, religious and existential issues in palliative care
Competence in ethical and legal issues in palliative care	Ethical issues in palliative care and end of life situations Working according to moral and ethical values in palliative care Legislation in palliative care Awareness of euthanasia (or assisted dying) and the wish of hastened death
Teamwork competence in palliative care	Interdisciplinarity in palliative care Cooperation in interdisciplinary palliative care team Active, pro-active and confident communication with other disciplines involved in palliative care Teamwork in palliative care
Self-awareness and self-reflection competence in palliative care	Recognising and dealing with own emotions arising in palliative care Reflecting own emotions of death and loss Self-reflection concerning values and own actions in palliative care Openness to personal and professional growth
Competence in end-of-life care	Identifying and anticipating the dying phase of life End of life symptom management Psychological and spiritual supporting of the dying patient and family Care after death Knowledge and supporting in grief and mourning in dying phase

*Themes in blue colour have emerged from the literature

IO0 Book of cases

IO2 Simulation

IO3 E-learning

IO4 Escape game

IO6-1 Clinical reasoning

IO6-2 Ethical reasoning

IO8 Palliative Debate

IO1 - Core competencies
IO7 - EU Matrix

Analytical themes	Descriptive themes	IO0 Book of cases	IO2 Simulations	IO4 Escape game	IO6 Clinical & ethical reasoning	IO8 Palliative debate
Competence in the holistic nature of palliative care	The philosophy of palliative care The purpose of palliative care Epidemiology in palliative care Quality of life in palliative care Death and dying as a topic in palliative care Palliative care in different patient groups	✓	✓	✓	✓	✓
Competence in organising palliative care	Organising palliative care Critical evidence-based thinking and decision-making in palliative care Advanced care planning in palliative care Advocacy in palliative care Palliative care services	✓	✓		✓	✓
Competence in pain management in palliative care	The multidimensional aspects of pain in palliative care/Total pain Pain assessment in palliative care context Pain management in palliative care	✓	✓	✓	✓	✓
Competence in symptom management in palliative care	Identifying and assessing symptoms in the context of palliative care Principles of symptom control in palliative care Symptom management in palliative care Non-pharmacological symptom management in palliative care Pharmacological symptom management in palliative care	✓	✓	✓	✓	✓
Competence in holistic support in palliative care	Responsiveness and supportiveness to psychosocial needs in palliative care Person-centred supporting when working with palliative patients and those most important to them Culturally sensitive supporting in palliative care Maintenance of hope in palliative care Grief and supporting in bereavement during the different phases of the palliative care process	✓	✓	✓	✓	✓
Holistic communication, encounter, and interaction competence in palliative care	Open and active verbal and non-verbal communication in palliative care Open and active listening in palliative care Discussion of difficult topics in palliative care The importance of being present in palliative care Open-minded and dignified encountering in palliative care Responsive appropriate interaction in palliative care Encounters with the closest ones to patients in palliative care Communication, and interaction with those most important to patients' in palliative care	✓	✓	✓	✓	✓

Box 1. Suggested examples of possible learning objectives for the *Competence in the holistic nature of Palliative Care* (PC) and corresponding descriptive themes

	Descriptive themes	Learning objectives		
		Cognitive **Knowledge & Understanding**	**Skills** **Practical abilities**	**Attitude** **Personal competencies**
Competence in the holistic nature of palliative care	The philosophy of PC	Knows the WHO definition of PC Defines philosophy and values of PC Details important moments (milestones) from the history of the PC movement development	Recognises the challenges/misconceptions about PC	Addresses the challenges/misconceptions about PC
	The purpose of PC	Explains the holistic principles of practice for PC Explains the place of PC in medicine, nursing and public health Knowledge about the benefits of timely PC for patients, their close ones and society		Acknowledges and advocates for the integration of PC within health care systems
	Epidemiology in PC	Enumerates the categories of illnesses for which PC has addressability (adult/paediatrics; life-threatening/life-limiting conditions; the 4 categories of chronic progressive diseases) Discusses illness trajectories		Acknowledges and advocates for the integration of PC within the care for patients with different chronic conditions and throughout the entire lifespan
	Quality of life in PC	Explains the concept of quality of life and its value in PC as the goal of care		Demonstrates understanding of the impact of the gap between reality and expectations on the quality of life of people with chronic progressive diseases
	Individualized patient- and family-centred PC	Describes the nurse's role in providing individualised person-centred PC Describes the role of the other health care professions in delivering PC: physician, physiotherapy; occupational therapy; social work; psychology; and spiritual counselling/pastoral care in providing individualised person-centred PC	Recognises the professional responsibility to care for people with life-limiting conditions, and their families, to ensure comfort and dignity across the entire lifespan	Respects the professional responsibility to care for people with life-limiting conditions, and their families, to ensure comfort and dignity across the entire lifespan
	Death and dying as a topic in PC	Understands the impact for patients and their families of living with a life-limiting condition Understands the concepts of multi-morbidity, frailty and polypharmacy and their impact of patients' quality of life and families' dynamics Understands the taboos related to death and dying		
	PC in different patient groups	Explains particularities in PC delivered to specific patient groups		

NursEduPal resources

https://palliativeprojects.eu/nursedupal/

The book of cases

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Content

2. The story of Lukas – Advanced level

Lukas is a 65-year-old man living with his wife Anne. They have two children and two grandchildren. They live in a three-bedroom house in the city. Lukas was a self-employed painter and decorator he retired 5 years ago when the physicality of the job got too demanding for him. Financially, they owned their own home and still had an income coming in from Anne's job as a teacher. So, Lukas made the decision to retire, and to focus his time and attention on looking after his garden and vegetable plot, which he has a great passion for.

3 years ago, Lukas found a lump in his right armpit. He thought it nothing to worry about, and assumed it was probably a side effect of 40-plus years of manual work and demand on his right, dominant arm. He did go to his doctor to get it checked out, and after a series of investigations, the lump was discovered to be a sarcoma.

In 2018, Lukas underwent surgery and chemotherapy. The treatment was tough, and severely impacted psychological health and his quality of life at the time; however, he considered this a small price to pay for his survival. The only residual effect he had was a slight swelling of his right arm, although this wasn't painful, more an inconvenience that he had to be conscious of monitoring it and not letting it get any worse.

Less than a year after his initial diagnosis, a local recurrence of the sarcoma was detected after the arm lymphoedema increased massively in size and became associated with severe pain. He commenced a course of radiotherapy, and soon after that, his right arm was amputated. Lukas became quite dependent on Anne for daily activities, and personal care needs as he adapted to life as an amputee.

Himself and Anne attended every hospital appointment together, and Anne became his main caregiver

The core competencies and their representation in the novice stories

In Intellectual Output 1 of the NursEduPal@Euro project, 12 core competence categories have been defined that nursing students need to acquire during their studies in order to be ready to provide generalist palliative care once they go into practice. You can read all about the path towards these competence categories and their detailed description in the IO1 Report which you can download from the project website.

One of the aims of the project is to provide innovative teaching tools and resources to acquire and/or train these competencies. Therefore, we've indicated in the scheme below how the competence categories map on the novice level stories of the *Book of Cases*.

Competence category	Lukas	Elena	John	Patricia	Suzanna	Amy	David	Maria	Gabriella	Bruno
Competence in the holistic nature of palliative care		■	■		■			■	■	■
Holistic communication, encounter, and interaction competence in palliative care	■	■	■	■		■		■	■	■
Teamwork competence in palliative care				■	■		■			■
Spiritual competence in palliative care				■	■		■	■	■	
Competence in symptom management in palliative care	■	■	■			■	■		■	
Competence in pain management in palliative care	■	■	■			■	■		■	
Self-awareness and self-reflection competence in palliative care			■			■	■			■
Competence in ethical and legal issues in palliative care		■	■					■	■	
Competence in organising palliative care				■	■	■	■	■		
Competence in holistic support in palliative care	■	■	■			■			■	■
Competence in empathy in palliative care		■	■		■	■	■		■	■
Competence in end-of-life care		■					■			

Simulations

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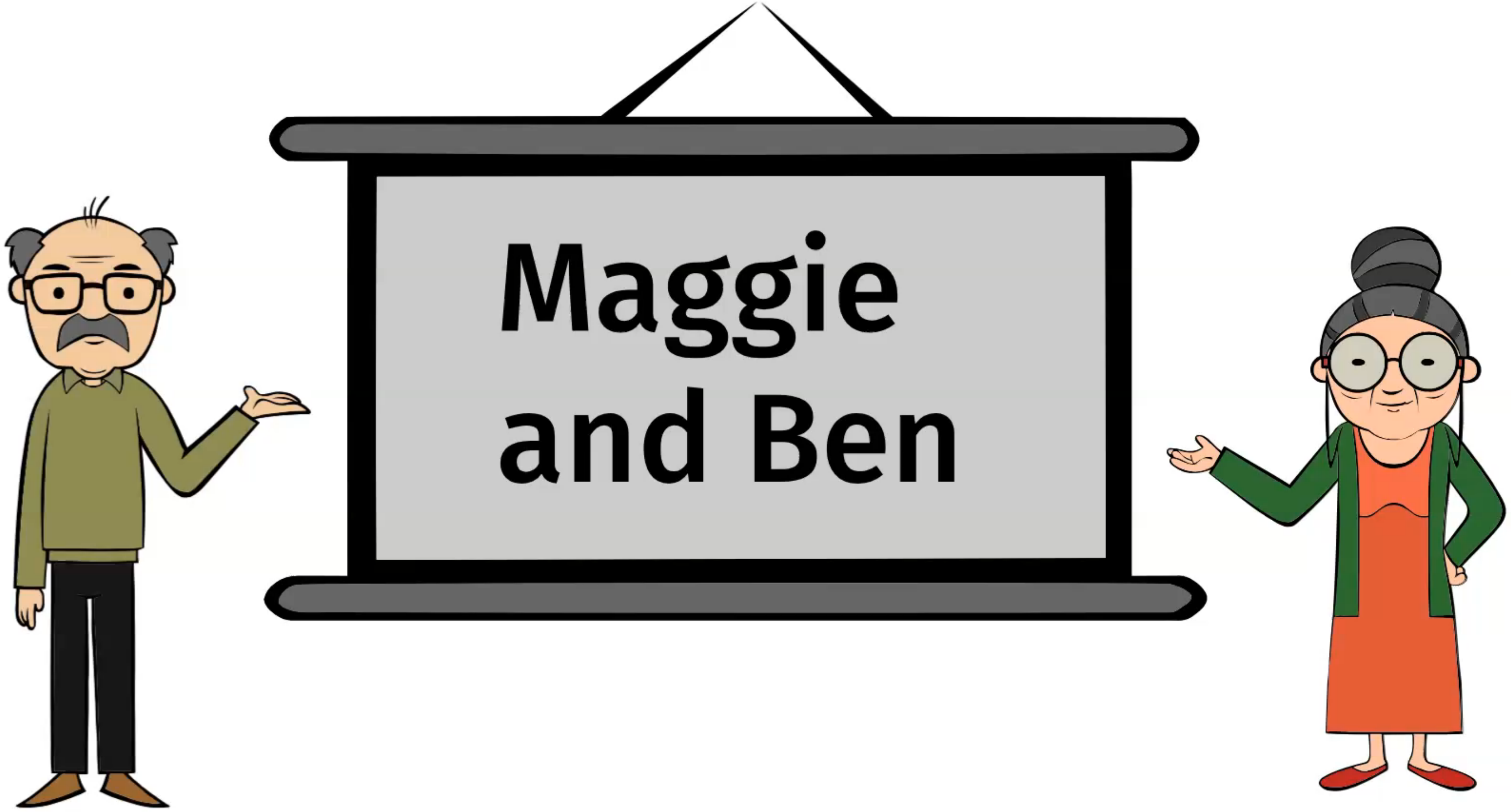

Maggie and Ben

Simulation exercise 1: Focus on advance care planning (ACP)

Simulation exercise 2: Focus on the roles of the informal caregiver

Simulation exercise 3: Focus on pain management

Simulation exercise 4: Focus on recognising the dying phase

Palliative debate

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STORY LINE 1/ **Andy** - 17 - *Suffers from a rare adrenal tumour*

This is Andy. He is 17 years old and he likes school very much. He likes playing football and being a scout, he goes to the youth club and sometimes he gets into a slap fight with his sister and brother.

In March, Andy falls ill: tired, not hungry, fever, joint pain.

Shortly afterwards, he is diagnosed with neuroblastoma with metastases. His chances of survival are estimated at 50% or less. Andy is treated in the university hospital, 40 km from his home.

Two operations, chemotherapy, radiotherapy and a stem cell transplant follow in nine months.

The doctors can never predict the effect of the treatments, nor the unpleasant symptoms that the disease and its treatments will bring.

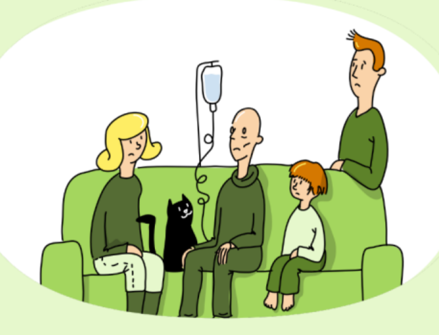
What is clear is that pain control will be a major concern because of the metastases.

Andy prefers to be at home. There is also little reason for him to stay permanently in the university hospital. However, organising palliative care at home (especially pain control) turns out to be a nearly impossible task.

The home nurses are not very familiar with it. The GP is not called in by Andy's mother because she does not know that this is possible.

When the pain is unbearable - and it often comes at night - his mother takes him to the local hospital. As a result, Andy is cared for in two places: the local hospital and the university hospital. Communication between the two hospitals is difficult.

In December, Andy and his family are told that there is no point in treating him any further and the doctors give him three months to live. Andy has to accept his fate.

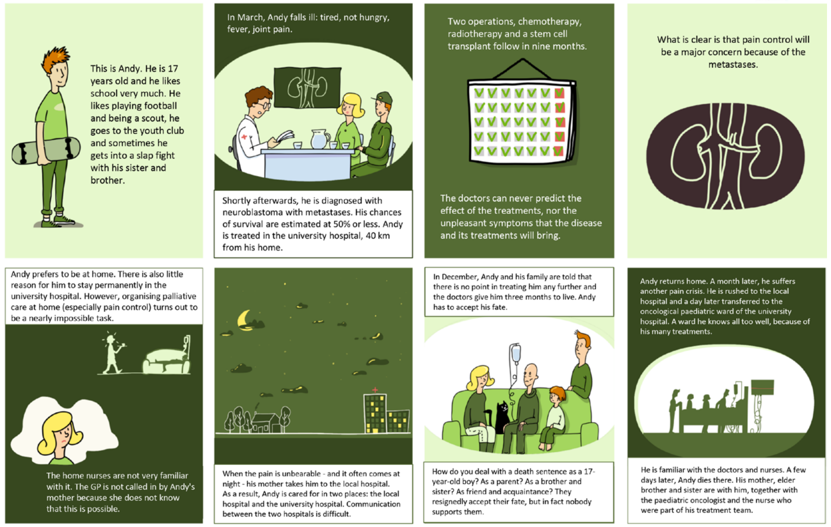


How do you deal with a death sentence as a 17-year-old boy? As a parent? As a brother and sister? As friend and acquaintance? They resignedly accept their fate, but in fact nobody supports them.

Andy returns home. A month later, he suffers another pain crisis. He is rushed to the local hospital and a day later transferred to the oncological paediatric ward of the university hospital. A ward he knows all too well, because of his many treatments.

He is familiar with the doctors and nurses. A few days later, Andy dies there. His mother, elder brother and sister are with him, together with the paediatric oncologist and the nurse who were part of his treatment team.

STORY LINE 1/ **Andy** - 17 - *Suffers from a rare adrenal tumour*



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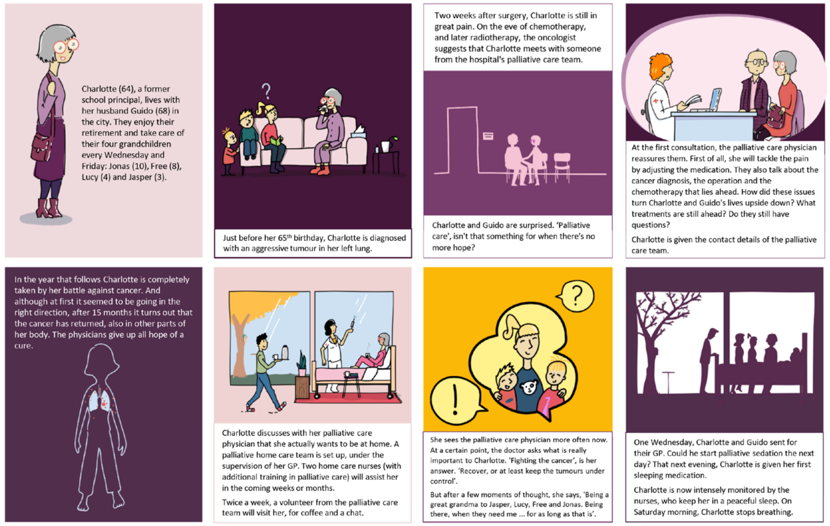
STORYLINE 2/ **CHARLOTTE** - *64 - Has an aggressive lung tumour*



Charlotte (64), a former school principal, lives with her husband Guido (68) in the city. They enjoy their retirement and take care of their four grandchildren every Wednesday and Friday: Jonas (10), Free (8), Lucy (4) and Jasper (3).

Just before her 65th birthday, Charlotte is diagnosed with an aggressive tumour in her left lung.

Two weeks after surgery, Charlotte is still in great pain. On the eve of chemotherapy, and later radiotherapy, the oncologist suggests that Charlotte meets with someone from the hospital's palliative care team.

Charlotte and Guido are surprised. 'Palliative care', isn't that something for when there's no more hope?

At the first consultation, the palliative care physician reassures them. First of all, she will tackle the pain by adjusting the medication. They also talk about the cancer diagnosis, the operation and the chemotherapy that lies ahead. How did these issues turn Charlotte and Guido's lives upside down? What treatments are still ahead? Do they still have questions?

Charlotte is given the contact details of the palliative care team.

In the year that follows Charlotte is completely taken by her battle against cancer. And although at first it seemed to be going in the right direction, after 15 months it turns out that the cancer has returned, also in other parts of her body. The physicians give up all hope of a cure.

Charlotte discusses with her palliative care physician that she actually wants to be at home. A palliative home care team is set up, under the supervision of her GP. Two home care nurses (with additional training in palliative care) will assist her in the coming weeks or months.

Twice a week, a volunteer from the palliative care team will visit her, for coffee and a chat.

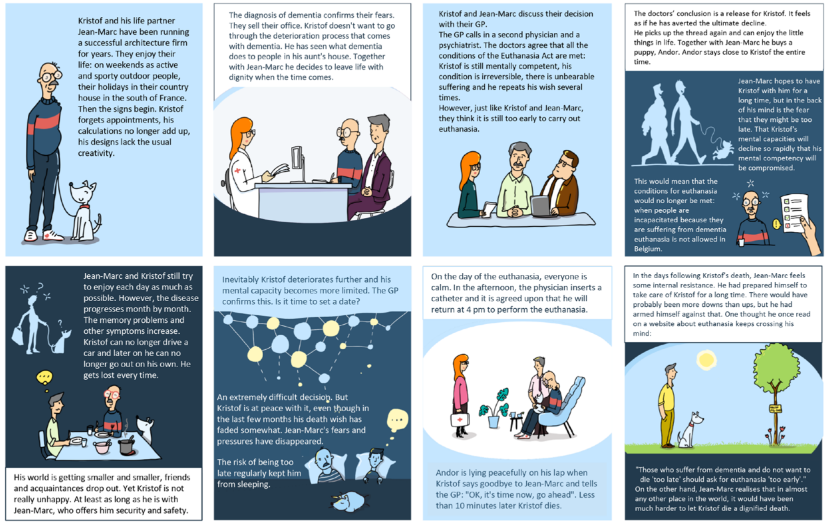
She sees the palliative care physician more often now. At a certain point, the doctor asks what is really important to Charlotte. 'Fighting the cancer', is her answer. 'Recover, or at least keep the tumours under control'.

But after a few moments of thought, she says, 'Being a great grandma to Jasper, Lucy, Free and Jonas. Being there, when they need me ... for as long as that is'.

One Wednesday, Charlotte and Guido sent for their GP. Could he start palliative sedation the next day? That next evening, Charlotte is given her first sleeping medication.

Charlotte is now intensely monitored by the nurses, who keep her in a peaceful sleep. On Saturday morning, Charlotte stops breathing.

STORY LINE 3/ **KRISTOF** - *60 - Has young dementia*



Kristof and his life partner Jean-Marc have been running a successful architecture firm for years. They enjoy their life: on weekends as active and sporty outdoor people, their holidays in their country house in the south of France. Then the signs begin. Kristof forgets appointments, his calculations no longer add up, his designs lack the usual creativity.

The diagnosis of dementia confirms their fears. They sell their office. Kristof doesn't want to go through the deterioration process that comes with dementia. He has seen what dementia does to people in his aunt's house. Together with Jean-Marc he decides to leave life with dignity when the time comes.

Kristof and Jean-Marc discuss their decision with their GP.
The GP calls in a second physician and a psychiatrist. The doctors agree that all the conditions of the Euthanasia Act are met: Kristof is still mentally competent, his condition is irreversible, there is unbearable suffering and he repeats his wish several times.
However, just like Kristof and Jean-Marc, they think it is still too early to carry out euthanasia.

The doctors' conclusion is a release for Kristof. It feels as if he has averted the ultimate decline.
He picks up the thread again and can enjoy the little things in life. Together with Jean-Marc he buys a puppy, Andor. Andor stays close to Kristof the entire time.

Jean-Marc hopes to have Kristof with him for a long time, but in the back of his mind is the fear that they might be too late. That Kristof's mental capacities will decline so rapidly that his mental competency will be compromised.

This would mean that the conditions for euthanasia would no longer be met: when people are incapacitated because they are suffering from dementia euthanasia is not allowed in Belgium.

Jean-Marc and Kristof still try to enjoy each day as much as possible. However, the disease progresses month by month. The memory problems and other symptoms increase. Kristof can no longer drive a car and later on he can no longer go out on his own. He gets lost every time.

His world is getting smaller and smaller, friends and acquaintances drop out. Yet Kristof is not really unhappy. At least as long as he is with Jean-Marc, who offers him security and safety.

Inevitably Kristof deteriorates further and his mental capacity becomes more limited. The GP confirms this. Is it time to set a date?

An extremely difficult decision. But Kristof is at peace with it, even though in the last few months his death wish has faded somewhat. Jean-Marc's fears and pressures have disappeared.

The risk of being too late regularly kept him from sleeping.

On the day of the euthanasia, everyone is calm. In the afternoon, the physician inserts a catheter and it is agreed upon that he will return at 4 pm to perform the euthanasia.

Andor is lying peacefully on his lap when Kristof says goodbye to Jean-Marc and tells the GP: "OK, it's time now, go ahead". Less than 10 minutes later Kristof dies.

In the days following Kristof's death, Jean-Marc feels some internal resistance. He had prepared himself to take care of Kristof for a long time. There would have probably been more downs than ups, but he had armed himself against that. One thought he once read on a website about euthanasia keeps crossing his mind:

"Those who suffer from dementia and do not want to die 'too late' should ask for euthanasia 'too early'." On the other hand, Jean-Marc realises that in almost any other place in the world, it would have been much harder to let Kristof die a dignified death.

STORY LINE 4/ **KEREM** - *53 - Suffers from a serious lung disease (COPD)*

Kerem is from Turkey. He has been living with his family - four children and his wife - in England for twenty years. He is an industrial painter in his older brother's company. He has been coughing for a long time. He thinks it's from smoking. One and a half packs a day.

Kerem and his wife speak very little English. At home they always speak Turkish with their family and friends.
Recently he became so short of breath that he went to the emergency service. He was admitted.
Final diagnosis: advanced COPD (lung failure due to a severe, chronic and irreversible inflammation of the alveoli).

The diagnosis is not explained properly. Or they don't understand it very well. What should they expect? They do not know. A lot of information is lost because there is no interpreter available.

Kerem doesn't want his children to come to the hospital. So Kerem goes home without much information. He continues to smoke, to the annoyance of his wife. He continues to paint; who else is going to make a living?

A year later, Kerem is admitted to the hospital again because of a COPD flare-up. Apart from his lungs, it turns out that his heart is also functioning less well now. He stays in the hospital for a week and is 'patched up'.

Back home, oxygen has to be brought in for the night. Additional costs. There is no consultation with the physicians in the hospital about the home situation. Moreover, Kerem does not have a GP. It is no longer possible to work. There is no contact with social services. Another serious bout of COPD. Kerem stays in the hospital for weeks and undergoes various interventions. He eventually regains some strength.

The physicians try to start a discussion with the family about further care, but that discussion is difficult. Kerem's wife and children want everything to be done to save his life.

Various home care nurses come to his home, but all stop because of the language problems. In the region where he lives, there are no home care workers who speak Kerem's language.

The family receives no information about end-of-life care. They themselves do not look for support. Palliative is not started. They don't want to, because they remain focused on healing.

In the last two months of his life, Kerem is transferred to the emergency department four more times. On his last admission, he is transferred to the hospital's palliative care unit. Kerem is at peace with this.

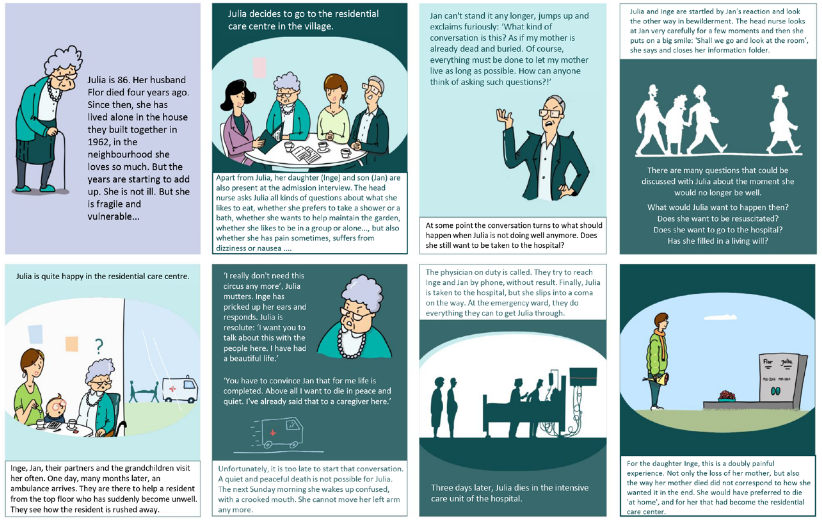
A physician and a nurse, appointed by the hospital as diversity counsellor, explain to Kerem why he is there and what he can expect.

He feels all too well that he is going to die. His body is finished. So is his mind.

His family finds it difficult to come to terms with his death. They are left with a nagging feeling that, medically speaking, so much more might have been possible.

They do not want to speak to anyone from the palliative care team because they feel that they left Kerem to die.

STORY LINE 5/ **JULIA** - 86 - *Being admitted to an residential care center*



Julia is 86. Her husband Flor died four years ago. Since then, she has lived alone in the house they built together in 1962, in the neighbourhood she loves so much. But the years are starting to add up. She is not ill. But she is fragile and vulnerable...

Julia decides to go to the residential care centre in the village.

Apart from Julia, her daughter (Inge) and son (Jan) are also present at the admission interview. The head nurse asks Julia all kinds of questions about what she likes to eat, whether she prefers to take a shower or a bath, whether she wants to help maintain the garden, whether she likes to be in a group or alone..., but also whether she has pain sometimes, suffers from dizziness or nausea ....

Jan can't stand it any longer, jumps up and exclaims furiously: 'What kind of conversation is this? As if my mother is already dead and buried. Of course, everything must be done to let my mother live as long as possible. How can anyone think of asking such questions?!'

At some point the conversation turns to what should happen when Julia is not doing well anymore. Does she still want to be taken to the hospital?

Julia and Inge are startled by Jan's reaction and look the other way in bewilderment. The head nurse looks at Jan very carefully for a few moments and then she puts on a big smile: 'Shall we go and look at the room', she says and closes her information folder.

There are many questions that could be discussed with Julia about the moment she would no longer be well.

What would Julia want to happen then?
Does she want to be resuscitated?
Does she want to go to the hospital?
Has she filled in a living will?

Julia is quite happy in the residential care centre.

Inge, Jan, their partners and the grandchildren visit her often. One day, many months later, an ambulance arrives. They are there to help a resident from the top floor who has suddenly become unwell. They see how the resident is rushed away.

'I really don't need this circus any more', Julia mutters. Inge has pricked up her ears and responds. Julia is resolute: 'I want you to talk about this with the people here. I have had a beautiful life.'

'You have to convince Jan that for me life is completed. Above all I want to die in peace and quiet. I've already said that to a caregiver here.'

Unfortunately, it is too late to start that conversation. A quiet and peaceful death is not possible for Julia. The next Sunday morning she wakes up confused, with a crooked mouth. She cannot move her left arm any more.

The physician on duty is called. They try to reach Inge and Jan by phone, without result. Finally, Julia is taken to the hospital, but she slips into a coma on the way. At the emergency ward, they do everything they can to get Julia through.

Three days later, Julia dies in the intensive care unit of the hospital.

For the daughter Inge, this is a doubly painful experience. Not only the loss of her mother, but also the way her mother died did not correspond to how she wanted it in the end. She would have preferred to die 'at home', and for her that had become the residential care center.

Let’s try

The schemes

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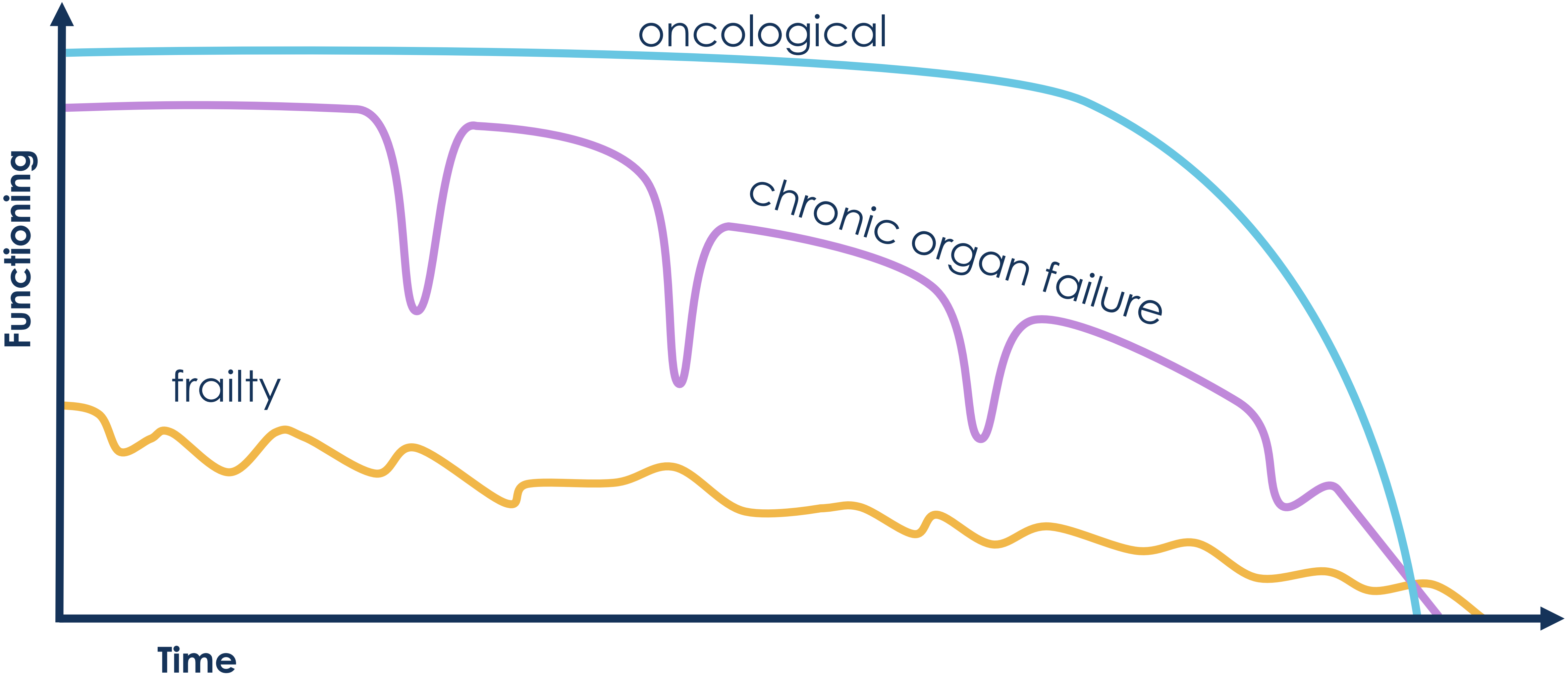
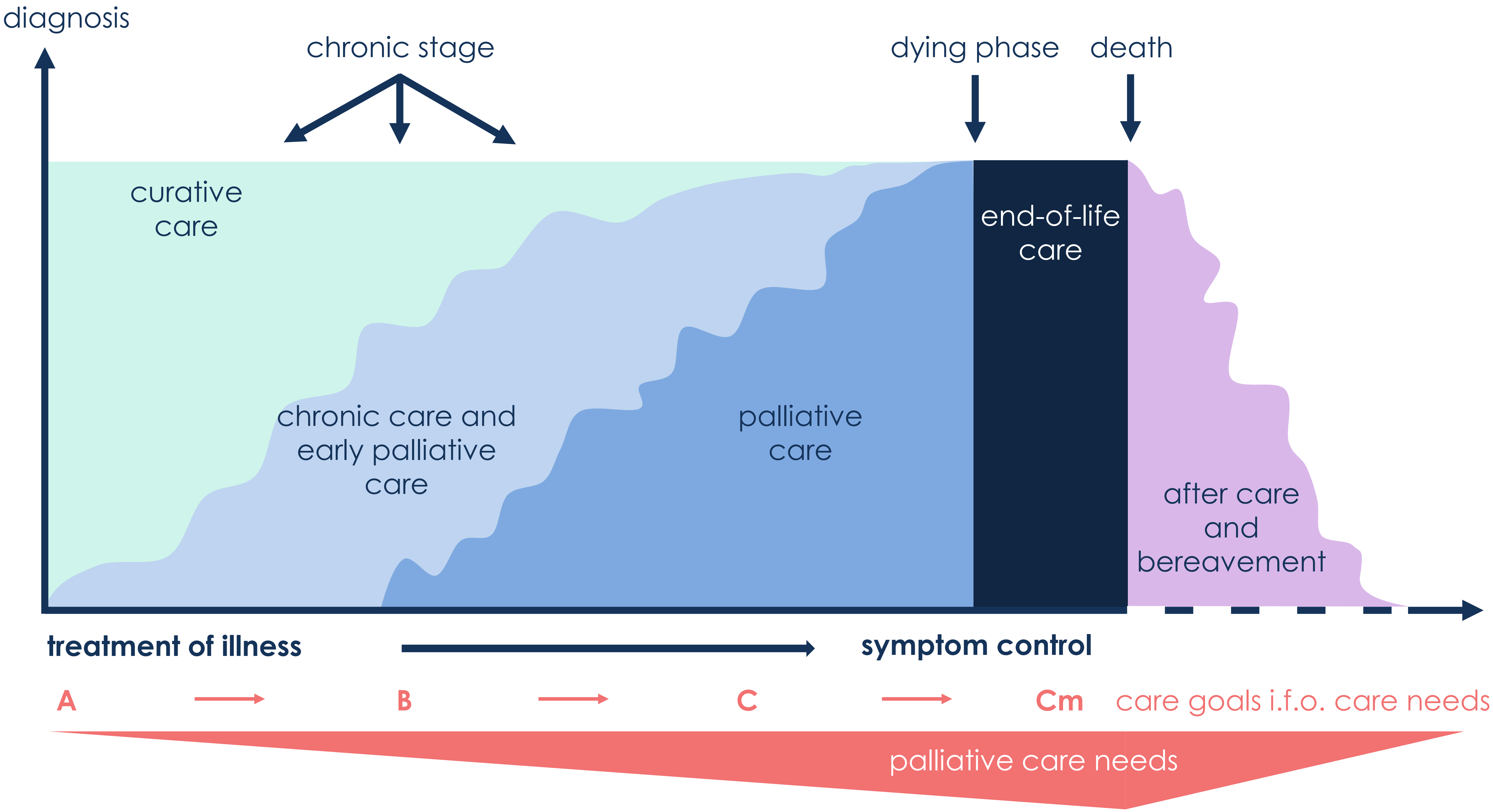
Meet John

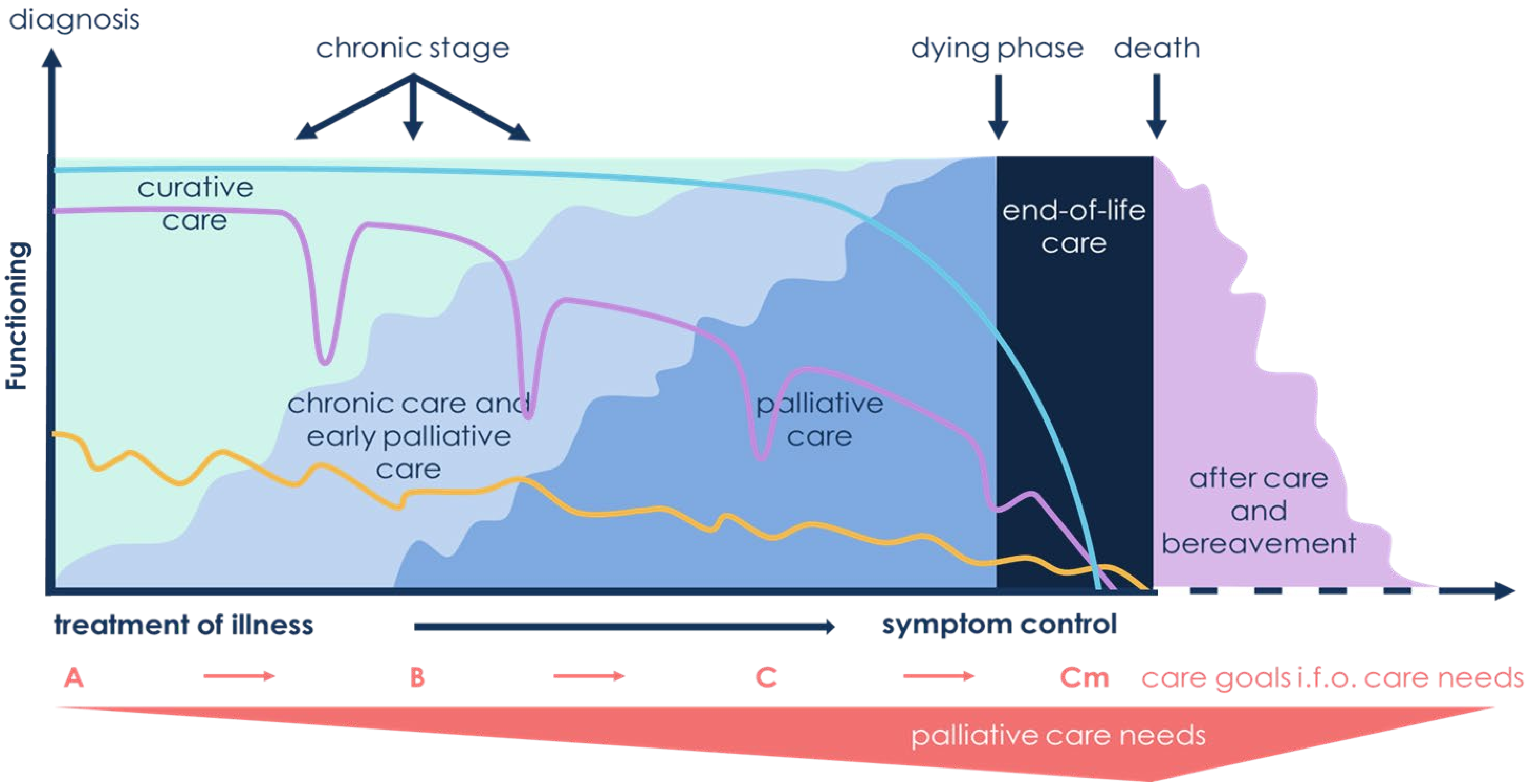
- 66 years
- early last year: lump in lower leg ➔ liposarcoma
  - chemotherapy + radiotherapy
  - amputation
- end of last year: brain tumour ➔ radiotherapy
- last month: metastases in hip ➔ chemotherapy

Illness trajectories




diagnosis
chronic stage
dying phase
death
curative care
chronic care and early palliative care
palliative care
end-of-life care
after care and bereavement
treatment of illness
symptom control
A
B
C
Cm
care goals i.f.o. care needs
palliative care needs

Illness trajectories and cure-care scheme



Escape game

NursEduPal
@
IMPACT

Find the 4 themes!

Each theme is described by 3 terms

from diagnosis	week or days	decisional capacity
end of life phase	natural dying process	active ending of life
quality of life	choice of the patient	maximal comfort
decision of a physician	can last years	refractory symptoms

1:........................

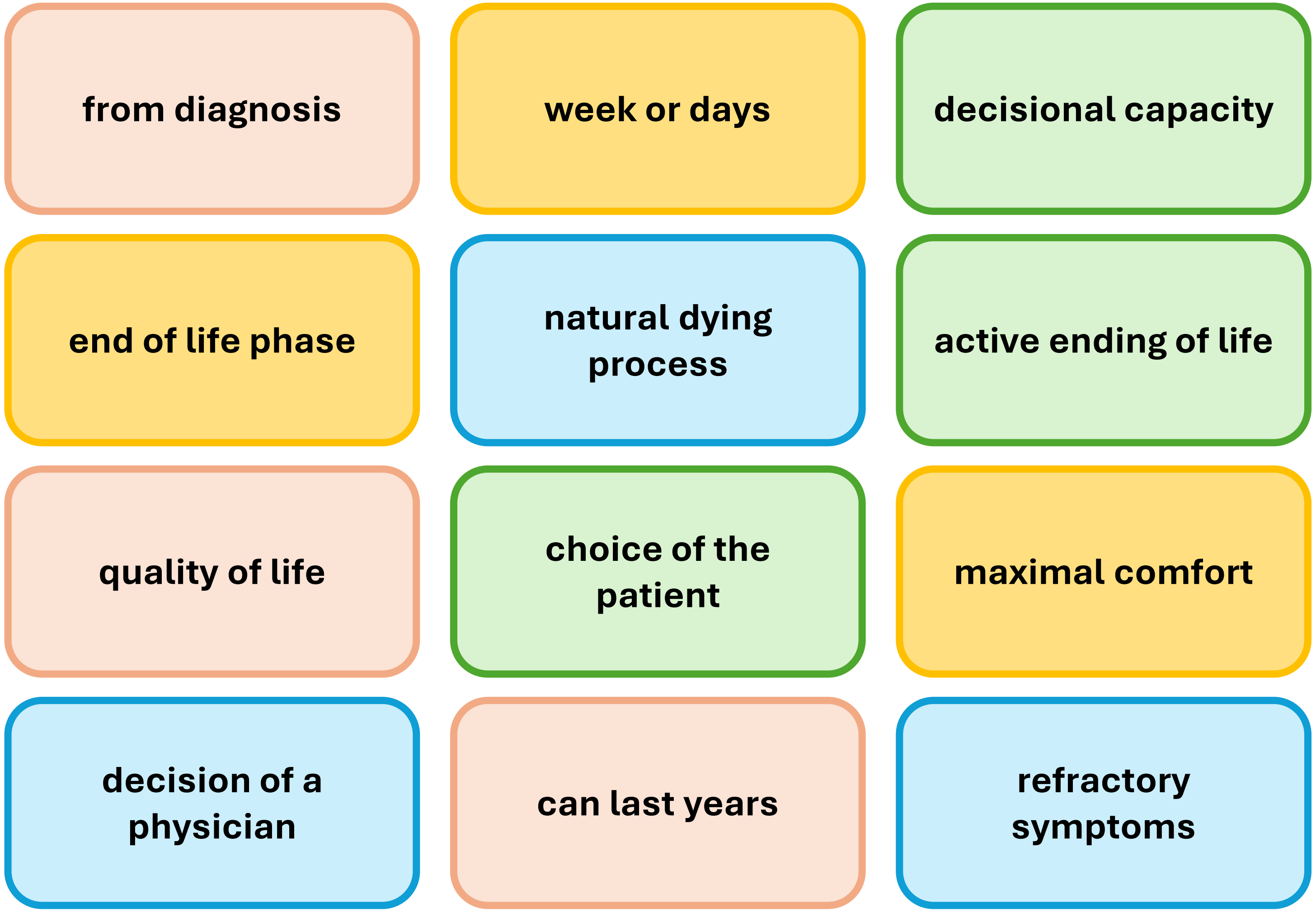
2:........................

3:........................

4:........................

Find the 4 themes!

Each theme is described by 3 terms



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1:……………………… **3:………………………**

2:……………………… **4:………………………**

Palliative care indicators

The indicator BINGO!

PALLIATIVE CARE AND ADVANCE CARE PLANNING INDICATORS

- ✓ Any change (suspicion of)
- Difficulty in swallowing
- Recurring infections
- Refusal (care, food)
- ✓ New severe pathology
- ✓ Weight loss (>5% at 6m)
- ✓ Change of care need
- End-of-life question
- After hospitalisation
- Repeated falling
- Dementia
- …

ASSESS AND ACT

- Surprise Question
- Use the SPICT
- Talk about it!

Questions or reflections?

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