

Intellectual Output 0

The Book of Cases



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ABOUT THE PROJECT

THE TEAM

The NursEduPal@Euro strategic partnership is an international consortium collaborating on innovation in palliative care education for undergraduate nurses.

THE GOAL

The Erasmus+ project aims to improve the quality of palliative care nursing education by enabling, supporting and empowering nurse educators to use a range of innovative teaching resources to ensure palliative care is included in their undergraduate nursing curriculum.

The project has developed a competence-based European matrix including innovative blended training tools for educators. This enhanced training resource aims to enable nursing students to achieve core competencies in palliative care so they are better equipped to contribute to palliative care in clinical practice.

THE APPROACH

The project consists of four phases in which nine Intellectual Outputs are realised:

1. Defining the core competencies to be acquired in palliative care (IO1);
2. Developing innovative teaching methods on palliative care topics and providing teaching materials (IO0, IO2, IO3, IO4, IO6, IO8);
3. Creating a European matrix for curriculum development and training educators in its use (IO7);
4. Facilitating a European network of palliative care educators (IO5).

The project has developed teaching materials to support nurse educators in achieving the appropriate knowledge, skills and attitudes to deliver palliative care education to their undergraduate nursing students in an innovative and engaging way. By implementing gamification, clinical and moral-ethical reasoning, and simulation as experiential and immersive teaching methods in nursing curricula, the consortium anticipates having a positive impact on the development of palliative care knowledge and skills of the future nursing workforce.



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**Transilvania
University
of Braşov**



HOSPICE CASA SPERANȚEI
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Preface

As nurse educators we are very aware of the challenges faced by nursing students as they realise the uncertainty and complexities of providing care to patients in a palliative care setting. Competing demands, contrasting priorities and diagnostic doubts, together with the personal, social and cultural characteristics of the patient and their family and the dynamics between them may lead to the nursing student experiencing an information overload and a strong sense of overwhelm.

The team at the University of Transilvania from Braşov (UnitBv) has developed the cases that are part of Intellectual Output 0, by working in collaboration with the staff of Hospice Casa Sperantei (HCS) – the centre for excellence in clinical practice, education and advocacy in Palliative Care in Romania. In HCS, nursing students are exposed to different clinical scenarios, many of which present ethical dilemmas that require a holistic, multidisciplinary approach. Mentors support the students with direct patient care and clinical interventions and facilitate discussions and reflection on how clinical reasoning and ethical deliberation contribute to the management of care of the patient and family.

To allow for a selection of cases, focus groups were organised involving palliative care experts from UnitBv and HCS to review the available literature and discuss how such situations can support the development of clinical reasoning and ethical deliberation skills for nursing students. From this, 20 clinical situations were developed as case vignettes, and together with the project consortium, 10 cases were eventually selected for this intellectual output. The selected cases are representative situations that nurses may encounter when working with patients and families affected by serious, chronic progressive illness and/or end-of-life situations. All cases are based on real people and real situations. They have a high level of detail and complexity and can therefore serve as a source of inspiration for all student levels. Additionally, they are adaptable to a variety of European cultural contexts.

The 10 clinical case vignettes have subsequently been translated into patient stories, both at the advanced and novice level. The vignettes together with the stories make the *Book of Cases*. It serves as a starting point for building content with all other intellectual outputs of the NursEduPal@Euro project. The *Book of Cases* is a unique and wonderful resource with information to present to your students for completing a clinical reasoning procedure, for doing a moral case deliberation session, or for making a simulation or an escape game.

We hope that the *Book of Cases* will inspire you, our colleagues in nurse education, to create new stories, that will further support palliative care education depending on the unique learning needs of nursing students from different parts of Europe and of the world.

We invite you to be creative and innovative with the *Book of Cases* and to share your case stories with the NursEduPal@Euro community. You can do this by joining our interactive forum which you can access from our website: <https://nursedupal.eu/>

Acknowledgements

The NursEduPal@Euro team would like to express their gratitude to the staff from Hospice Casa Sperantei and the nursing students at the University of Transilvania from Braşov that have courageously shared their experiences and their perspectives on the cases and the clinical situations encountered with the researchers of the UnitBv team.

We would like also to express our gratitude to the people that are presented here as cases/vignettes. It has been an honour and a privilege supporting and walking alongside these patients and their families on their journeys.

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										

The case of Lukas

1. Vignette

General information	
Patient Demographic data:	L.D male, 65 years old, married, 2 children, 2 grandchildren, retired
Underlying disease and treatment	Right axillary sarcoma, chemotherapy, radiotherapy, right upper limb amputation
Medication	
Comorbidities	Type II Diabetes, hypertension
More detailed description: Medical history	<p>2018 - biopsy, diagnosis, surgery – commence chemotherapy, lymphoedema occurs in the right upper limb</p> <p>2019 - local recurrence – surgery + chemotherapy - significant lymphoedema - high intensity pain requiring analgesia step III on the WHO ladder</p> <p>04.2019 - starts Radiotherapy + kineto-therapy + orthopaedic consult</p> <p>08.2019 – Major surgery - amputation of right upper limb</p> <p>Post-operative - phantom limb pain - treatment with Amitriptyline with some effect</p> <p>09.2019 - general condition improved – morphine no longer used – moves to treatment with step II on the WHO ladder (tramadol)</p> <p>12.2019 - Chemotherapy for pulmonary metastasis</p> <p>01.2020 – Displays anxiety + depression-psychological consultation</p> <p>04.2020 - Severe pain – recommences morphine</p> <p>02.2021 – Disease progression – decision to discontinue curative treatment</p> <p>03.2021 - General physical condition deteriorates patient has severe dyspnoea</p> <p>patient admitted to hospital via ambulance</p> <p>Thoracocentesis is performed - patient goes into cardio-respiratory arrest - is intubated and dies 24 hours later</p>
More detailed description: Issues identified: Physical Psychological Social Spiritual	<p>Physical - pain, functional impotence, dyspnoea, fatigue</p> <p>Psychological - anxiety, depression</p> <p>Social – no disability grade - gets assistance with the help of the social worker</p> <p>Spiritual – Nominally religious but does attend church regularly</p> <p>The patient knew he had a serious illness but his wife did not want the patient to know that he had a poor prognosis. The family and patient were keen to seek a second opinion in another country in the hope of a potential cure</p> <p>Unrealistic hope of cure - the patient had ordered a prosthesis and wanted to modify his car so that he could drive. During every visit, when we tried to talk about his prognosis, his wife always reassured him that he would be alright. The patient, now an amputee, was dependent on his wife for care. Whilst his care was exemplary, his wife was a barrier to telling the truth</p> <p>The patient, who was not fully informed about his condition and prognosis, expressed concerns that not enough was being done for him and that he would like a second opinion, he also requested a referral to a respiratory physician for review and treatment</p>

Care and treatment to date	Physical, Symptom control (lymphoedema, pressure sores wound care, postoperative wound management, Pain control (route of administration: syringe driver, Fentanyl patches), family involvement and education on how to care for their father/husband, psychological support on the course and prognosis of the disease
Particular details of the difficult situation	
Description of the challenging situation from an ethical-moral perspective	<p>Conspiracy of silence - the wife gives unrealistic hopes to the patient, does not want the patient to know the prognosis, Indications that the patient has unrealistic expectations (orders a prosthesis and wants to modify his car so he can drive even though the prognosis is limited) what does he understand about his condition and prognosis.</p> <p>The patient doesn't believe that everything has been done for his illness or thinks that there may be more that can be done, he requested a second medical opinion.</p> <p>Therapeutical decisions are difficult to make as long as the patient has unrealistic hopes.</p> <p>Involvement of patient and family in decision making</p> <p>Communication</p> <p>Hope</p>
What was the strategy used to approach the case?	<p>Communicating with the patient/wife about the evolution of the disease, but the wife was always present and created barriers to communication – but does this always stop good communication?</p> <p>Involvement of other members of the interdisciplinary team for the patient and his family aimed at providing information about diagnosis and prognosis and to provide psychological support to both spouses. They refused this intervention. Patient received psychological support following his arm amputation but refused any further support. Prescribed anxiolytic and antidepressant medication. The wife said she could not focus enough to get through the counselling process as she was very involved in caring for her husband.</p> <p>Family meeting</p> <p>The wife was invited to the office for discussions about the importance of truth telling but when the team visited the patient at home, she had the same attitude of putting up barriers.</p>
Which of the ethical - moral principles do you consider to have been undermined / ignored / neglected in this case?	<p>Challenges around truth telling and provision of information aimed at helping the patient make choices about his care.</p> <p>We don't know if the end-of-life care was what the patient wanted.</p> <p>Conspiracy of silence from the wife.</p>
Describe your personal perspective (values, feelings, emotions) on the case and how it was resolved	<p>I felt unable to do all I can to help the patient due to the conspiracy of silence. We, as professionals, felt powerless because we couldn't tell the patient the truth because his wife wouldn't let us. She was always there and when we tried to discuss the prognosis and the evolution of the disease, she would tell him that he would get better.</p> <p>Communicating with the wife, who finally accepted the prognosis. She has mixed feelings about her husband getting admitted (she regrets she's not there with him, but she's afraid he would die at home)</p>
What recommendations do you have for a better handling of the case, one	<p>Communication with patient first.</p> <p>Involvement of patient in their treatment decisions and enable advance care planning.</p>

<p>that respects both the patient's and professional values?</p>	<p>More frequent family meetings if the family would agree to it.</p> <p>Family support is very important. Pace of information giving and communication with the patient and family should be dictated by them.</p> <p>Challenging for the patient to have unrealistic expectations.</p> <p>These unrealistic expectations prevent open communication and the opportunity to establish the patient's wishes. The collusion between the patient and his wife hindered the team's ability to provide psychological, social and spiritual care.</p> <p>Although not talking about his diagnosis and prognosis, it is possible that the patient was aware of both but chose to not talk about these to protect his family.</p> <p>Support for the team to better handle such situations.</p> <p>Early referral and integration of palliative care for patients and the time to create a trusting relationship between patient, family and the professional team would provide the opportunity to address issues and communicate effectively.</p>
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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 and considered herself to be his advocate. Lukas suspected his condition was serious, however Anne was adamant that he was going to be ok, and she would distract him from discussing anything other than a positive outlook. At hospital appointments, she would immediately close down any conversation that veered towards the prognosis or outlook for Lukas, insisting instead that discussions should be about options for cure, perhaps from 'second opinions' from experts in other countries. Lukas suspected his condition was serious, but not wanting to cause additional distress to his wife, he agreed with her completely, and went down the route of looking for a cure. Neither of them would entertain the idea that this situation would end in Lukas' death.

Four months after the amputation, a CT lung scan showed the presence of pulmonary metastases and commenced further chemotherapy. This was a devastating blow to Lukas. He became withdrawn and depressed. His pain escalated and he required morphine to give him relief. Despite the obvious progression of the disease, he continued with his search for a cure, and asked to be referred to a specialist respiratory physician for assessment of his lung function.

At this stage the clinical team were quite concerned about the unrealistic expectations that Lukas had. They invited Anne to meet them to discuss the benefits of having open and honest conversations, particularly as this would help with future care planning for Lukas, who was coming towards the end-of-life. Anne however continued to create obstacles and barriers to any communication that addressed the future.

Considerations/discussion points:

- Communication with the patient and family.
- Acceptance and realistic expectation, yet not to lose hope.
- Collusion and truth telling and the implications of this on future care planning.
- Empowering, enabling, and supporting Lukas to live well until he dies, when it is not explicitly acknowledged that he is dying.
- Pain and symptom management (physical, psychosocial and spiritual), and how collusion may hinder a holistic approach to addressing needs.
- Support for the family around the time of and after death.

3. The story of Lukas – Novice level

Lukas is a 65-year-old man living with his wife Anne. They have two children and two grandchildren. They live in a two-story, 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 was diagnosed with Chronic Obstructive Pulmonary Disease (COPD). He had presented to his doctor with a persistent cough and shortness of breath and after a series of investigations the diagnosis of COPD was made.

Soon after his diagnosis, Lukas underwent a course of pulmonary rehabilitation led by the physiotherapist at his local hospital. This course gave Lukas the knowledge and confidence he needed to enable him to enjoy physical activity as part of his daily life, as he tended to his garden and vegetable plot. He was able to manage his symptoms using only his inhalers (preventer and reliever) and by monitoring and modifying the balance between activity and rest.

18 months ago, Lukas was admitted to hospital with a severe chest infection. He was extremely short of breath and required supplemental oxygen, intravenous antibiotics, and steroids. His symptoms were so severe that he needed full support with transferring out of bed, and he was unable to walk. Recovery from the chest infection was slow and protracted. Lukas spent 8 weeks in hospital, working on regaining his mobility so that he could achieve his goal of being discharged home, physically able to mobilise independently and able to go up and down stairs to sleep in his own bed.

10 months ago, Lukas was hospitalised again. Another chest infection had caused a further exacerbation of his symptoms. Physically, his level of function had been in gradual decline for the past few months, and during this admission his medical team had prescribed theophylline and mucolytics. The physiotherapist had conducted a 6-minute walk test with Lukas using ambulatory oxygen. He didn't perform very well, only able to cover a very short distance before his shortness of breath became too much to continue. He was prescribed home oxygen with a concentrator as he need to use it continually.

Lukas was no longer able to go upstairs to sleep. He had a hospital bed in the living room and he had become dependent on Anne for all daily activities, and personal care needs.

Anne became his main carer and considered herself to be his advocate. Lukas felt that his health was deteriorating and that this was serious, however Anne would immediately close down any conversation that veered towards a negative outlook, insisting instead that 'he was going to be ok, he just needed to get his strength back'. Lukas not wanting to cause additional distress to his wife, would agree with her completely, neither of them would entertain the idea that this situation would end in Lukas' death.

The clinical team are quite concerned about the unrealistic expectations that Lukas and Anne have. They have invited Anne to meet them to discuss the benefits of having open and honest conversations, particularly as this would help with future care planning for Lukas, who is coming towards the end-of-



life. Anne however continues to create obstacles and barriers to any communication that addresses the future. She continually asks, 'What else can you do for him? How can you help him? How can you ease his breathing and make him better?'

Considerations/discussion points:

- Communication with the patient and family.
- Acceptance and realistic expectation, yet not to lose hope.
- Collusion and truth telling and the implications of this on future care planning.
- Empowering, enabling, and supporting Lukas to live well until he dies, when it is not explicitly acknowledged that he is dying.
- Symptom management (physical, psychosocial and spiritual), and how collusion may hinder a holistic approach to addressing needs.
- Support for the family around the time of and after death

The case of Elena

1. Vignette

General information	
Patient Demographic data:	Patient 42 years old, married to 4 years younger woman, former artist, small pension, no children
Underlying disease	Ovarian cancer, multiple metastases
Co-morbidities	Covid 19
More detailed description: Medical history	Patient diagnosed in March 2019 with ovarian cancer, operated on, chemo-treated. In early 2020, patient has medical investigations because she is not feeling well and is diagnosed with liver and peritoneal metastases. In June 2020 she is also diagnosed with Covid 19 and is transferred from the emergency unit to the former PC ward of the county hospital, which is now the COVID ward. At the time of transfer, the patient is suffering from severe anaemia, oxygen saturation 90, bedridden, ECOG (functionality scale developed by Eastern Cooperative Oncology Group) = 4, lower limb oedema and ascites fluid. She is transferred and one of the recommendations is transfusion.
More detailed description: Issues identified: Physical Psycho-emotional Social Spiritual	Physical-abdominal pain, dyspnoea, astheno-fatigability, inappetence, oedema, ascites, severe anaemia Haemoglobin 6mg/dl Emotional: anxiety due to COVID infection, fears that it will cause her death Social: Patient's partner has no income, but is involved in care. Both live on small pension of the patient. Spiritual: Does not believe in God, but while in hospital wants a visit from a chaplain.
Care and treatment to date	After stopping chemotherapy, symptom control was initiated, the family was involved and taught how to take care of the patient. Counselling on the evolution and prognosis of the disease.
Particular details of the difficult situation	
Description of the difficult situation from an ethical-moral perspective	Due to the severe anaemia, the issue of transfusion administration arises. The dilemma is whether transfusion will be effective in this patient because several factors have been identified in the evaluation that show a limited prognosis of 2-3 weeks.
What was the strategy used to approach the case?	The team aimed to comfort the patient and relieve symptoms. Communicating with the patient about the prognosis, involving other members of the interdisciplinary team to accept the prognosis. Patient is cooperative and understands possible advantages and disadvantages of transfusion. She wishes to be pain-free, to improve dyspnoea. The partner claims that the patient needs the transfusion to feel better. She does not understand that it is a burden for the patient, that she does not want this treatment and that it is important to respect the patient's decision. However, the partner wants any treatment that can prolong the patient's life.
Which of the ethical - moral principles do you consider to have been undermined /	Making a medical decision, benefit vs burden of transfusion administration. The partner ignores and does not respect the informed therapeutical decision made by the patient.

ignored / neglected in this case?	
Describe your personal perspective (values, feelings, emotions) on the case and how it was resolved	I had a feeling of helplessness in communicating with the partner. As she did not have access to the hospital it was difficult to talk on the phone and not observe her non-verbal language. The inability to hold family meetings led to misunderstandings with the partner who verbally accused us of not doing everything we could for their mother.
What recommendations do you have for a better handling of the case, one that respects both the patient's and professional values?	<p>Family meeting online on a tablet or phone?</p> <p>The team has done well respecting the patient's wishes, we are given the opportunity to help the person as long as they want that. The important thing is to understand what the patient wants and to accompany and support them.</p> <p>The decision to provide symptom control and comfort to the patient was correct because this is a patient with ecog 4, ovarian cancer, multiple metastases, ascites fluid which indicates a limited prognosis. COVID 19 infection may further limit the prognosis and then the aim of care is to provide dignity and comfort, symptom control.</p> <p>Life belongs to the individual, not to the family.</p> <p>Involve all team members in discussions with the family, perhaps online discussions with patient and family at the same time. The message of all team members needs to be the same.</p>

2. The story of Elena – Advanced level

Elena is 42 years old and married to Sophie. They live together in a house that has an art studio, where Elena used to design and create her own sculptures. Elena made a good living from her work until about two years ago when she was forced to stop work as she was diagnosed with locally invasive ovarian cancer. When she started working in her late teens, she started to make payments into a pension scheme, and it was now the return on that pension that financially supported Elena and Sophie.

A year after her initial diagnosis Elena became acutely unwell and subsequent investigations showed that the cancer had spread to her liver and throughout her abdomen. Elena, Sophie and the care team had discussed and agreed that management of symptoms and maintaining comfort where now the most important goals of care.

A few short months later, Elena became acutely unwell again. She was extremely short of breath with an oxygen saturation of 90. She had extensive ascites and lower limb swelling and was anaemic. She was completely confined to bed, having lost the little mobility she had.

Elena was diagnosed with COVID-19 and transferred to the COVID ward of the local hospital. Where she was supported with oxygen and a transfusion was recommended. This diagnosis came as a shock to Elena. She was scared that the virus would kill her, as she had seen and heard so much on the news about its damaging impact, especially in clinically vulnerable people, which she was. Exacerbating Elena's fear and anxiety was the fact that now she was prevented from physically seeing the person whom she loved and relied on the most – her wife Sophie as the public health restrictions prevented hospital visitors. Elena struggled with the physical isolation, and although she was atheist, she agreed to a visit from the hospital chaplain, and enjoyed having a real conversation with a real person, even though the chaplain wore full PPE (personal protective equipment) and stood at the end of the bed. Elena missed physical touch and just wanted someone to give her a hug.

The clinical team discussed the advantages and disadvantages of the transfusion with Elena, and she reiterates that her main goal is the relief of symptoms and to be comfortable and above all, to maintain her dignity. She chooses to decline the transfusion and a video call is set up for her to speak to Sophie. Sophie becomes quite upset at hearing that the transfusion will not go ahead and pleads with Elena to reconsider her decision. She demands to speak to the medical team and is adamant in her view that Elena needs to have the transfusion or she will die. Sophie is visibly upset on the screen and accuses the clinical team of abandoning her wife. Elena tries to calm Sophie, but Sophie continues to demand that Elena change her mind because if she doesn't, she will die. Elena tries to tell Sophie that she is going to die soon anyway. Sophie switches off the call.



Considerations/discussion points:

- Patient autonomy.
- Benefit versus harm in the administration of transfusion.
- Communication with patient and family.
- The roles and responsibilities of family members.
- Symptom monitoring and management.
- Psychosocial needs.
- Communication.
- Advance care planning.
- Preferred place of care, preferred place of death.
- Provision of palliative/end-of-life care within public health restrictions and the challenges these create.

3. The story of Elena – Novice level

Elena is 42 years old and married to Sophie. They live together in a house that has an art studio, where Elena used to design and create her own sculptures. Elena made a good living from her work until about two years ago when she was forced to stop work as she was diagnosed with locally invasive ovarian cancer. When she started working in her late teens, she started to make payments into a pension scheme, and it was now the return on that pension that financially supported Elena and Sophie.

A year after her initial diagnosis Elena became acutely unwell and subsequent investigations showed that the cancer had spread to her liver and throughout her abdomen. Elena, Sophie and the care team had discussed and agreed that management of symptoms and maintaining comfort were now the most important goals of care.

A few short months later, Elena became acutely unwell again. She was extremely short of breath with an oxygen saturation of 90. She had extensive ascites and lower limb swelling and was anaemic. She was completely confined to bed, having lost the little mobility she had.

The clinical team discussed the advantages and disadvantages of the transfusion with Elena, and she reiterates that her main goal is the relief of symptoms and to be comfortable and above all, to maintain her dignity. She chooses to decline the transfusion and discussed this with Sophie. Sophie becomes quite upset at hearing that the transfusion will not go ahead and pleads with Elena to reconsider her decision. She demands to speak to the medical team and is adamant in her view that Elena needs to have the transfusion or she will die. Sophie is visibly upset and accuses the clinical team of abandoning her wife. Elena tries to calm Sophie, but Sophie continues to demand that Elena change her mind because if she doesn't she will die. Elena tries to tell Sophie that she is going to die soon anyway.

Considerations/discussion points:

- Patient autonomy.
- Benefit versus harm in the administration of transfusion.
- Communication with patient and family.
- The roles and responsibilities of family members.
- Symptom monitoring and management.
- Psychosocial needs.
- Communication.
- Advance care planning.
- Preferred place of care, preferred place of death.



The case of John

1. Case vignette

General information	
Patient Demographic data:	Male patient, 66 years old, married, 2 children, retired, lives in an urban area
Underlying disease	Liposarcoma
Co-morbidities	no comorbidities
More detailed description: Medical history	<p>In 2016, lump on the left lower limb is discovered. Investigations and then surgery follows. Biopsy shows no evidence of oncological disease. After 6 months another nodule appears. Re-investigation and diagnosis of liposarcoma is made. Patient starts chemotherapy and radiotherapy but during them his general condition deteriorates. Chemotherapy has to be stopped, local necrosis occurs and the lower limb is amputated. Until 2020 good general condition, in Dec 2020 - syncope, seizure, left hemiparesis. Investigations (Computer Tomography, Magnetic Resonance Imaging) show diagnosis of hemi-cranial tumour, 10 radiotherapy sessions, marked weight loss (20kg in 10 days).</p> <p>In January 2021, a nodule appears at the level of the coxo-femoral joint, exulcerated with a voluminous adenopathy block, biopsy is done and the diagnosis of metastasis is issued. Chemotherapy is resumed January 2021 but the general condition progressively deteriorates, the patient has trouble moving around, displays balance disorders, headaches, asthenia, temporo-spatial disorientation, confusion.</p>
More detailed description: Issues identified: Physical Psycho-emotional Social Spiritual	<p>Physical - symptoms: pain, constipation, disorientation, confusion, occasional nausea</p> <p>Care - local dressing at the level of the fungating tumor.</p> <p>Assisted movement due to amputation</p> <p>Psycho-emotional - anxiety due to deterioration and lack of prognostic knowledge</p> <p>Social - change in disability grade</p> <p>Spiritual – believer, non-practitioner</p>
Care and treatment to date	<p>Symptom control</p> <p>Local wound dressing</p> <p>Medication: Tramadol 200mg / 12 hours, non-steroidal anti-inflammatory, Metoclopramide, Lactulose</p>
Particular details of the difficult situation	
Description of the difficult situation from an ethical-moral perspective	<p>Conspiracy of silence - family opposes discussing diagnosis and prognosis with patient</p> <p>Our services also cared for the patient's father-in-law who died. In this situation, too, the family objects to the patient knowing what happened to the relative.</p> <p>The wife is in denial, refuses to accept the evolution of the disease and does not want support from the psychologist, she is very spiritual.</p>
What was the strategy used to approach the case?	Family meeting with the patient's wife and daughter so they can integrate the evolution of the disease. They claim they agree and they say they understand that the patient needs to know the diagnosis but during the

	<p>next visit they behave the same as before and erect barriers to communication with the patient.</p> <p>Discussing with the children and trying to make them understand that they should learn from the previous death in the family they had to deal with, so as to avoid further contrition.</p>
Which of the ethical - moral principles do you consider to have been undermined / ignored / neglected in this case	<p>patient autonomy</p> <p>loyalty - tell the patient the truth about his situation. From the beginning I promised the patient that I would be honest with him and that whenever he has a question, I would tell him the truth.</p>
Describe your personal perspective (values, feelings, emotions) on the case and how it was resolved	<p>Failure to stay loyal to the patient</p> <p>Failure to do more for the patient</p>
What recommendations do you have for a better handling of the case, one that respects both the patient's and professional values?	<p>Family meeting</p> <p>Being realistic, getting to know each other and accepting our limits. The patient is confused, disoriented because of brain metastases and it is unlikely that we can discuss the diagnosis of metastases and prognosis with him. The objective remains to provide comfort and dignity to the patient.</p> <p>We all experience these feelings in patient care. It is difficult in-home care where the family is present during every visit and is our partner in the care process. It takes balance and patience with each party involved in care. In this patient's case, care is more important than discussing relapse.</p> <p>During every family discussion, we could ask "Do you think about what you're losing if you don't tell him the truth?"</p> <p>Involve all members of the interdisciplinary team.</p>

2. The story of John – Advanced and Novice level

John is a retired school headmaster of 66 years. He lives with his wife in a spacious flat by the sea. Together they have two sons. With five grandchildren they form a close family. The children live in a neighbouring community. He has one younger sister and one younger brother with whom he keeps in touch on a weekly basis. John still tries to be socially active. For example, he is a committed chairman of the local drama association and a member of the association of retired teachers. It is important to John to stay mentally active. He likes to read a lot, solve sudokus and think and organize in the drama association. He calls this 'brain gymnastics', because he is afraid of getting dementia (his father got dementia at the age of 80).



He has suffered from arthritis for several years, especially in his hands. This limits his self-care, especially when it comes to hygiene. A home care nurse visits him every day to help him with hygiene tasks and to help him get dressed; he takes a bath every week.

In terms of mobility, walking and cycling are no problem. Driving a car is no longer possible because of the arthritis in his hands (with all those little buttons/hand levers). He finds it difficult to cope with the physical deterioration and the restrictions on his activities. The 'mind' is still willing, but the 'body' doesn't always want to go along anymore.

He has had moderate hypertension for several years, for which he takes Catapresan® 0.15mg, 1x day. Every week, the nurse checks his blood pressure, which remains stable under medication. If he has too much pain from his osteoarthritis, he takes Paracetamol 500mg. Occasionally, John asks the nurse to rub his hands with Voltaren Emulgel®.

In 2019, the nurse discovered a lump in John's left lower leg. Several examinations and an operation follow. The biopsy showed no indications for further concern, however another lump appeared 6 months later. After further examination, the diagnosis of liposarcoma was made. John started chemotherapy and radiotherapy, but during these treatments his general condition worsened. The chemotherapy had to be stopped, local necrosis occurred and the lower limb was amputated.

John maintained well until the autumn of 2020. In December 2020 John's condition began to deteriorate. He developed frequent syncope, seizures and left hemiparesis and a CT and MRI scan revealed that John had a brain tumour. He received 10 sessions of radiotherapy and had further deterioration in his general condition, losing 20kg in weight over 10 days.

Throughout all the time, the family are close to John. The children and grandchildren visit often and John's wife feels supported by the home care nurse and the extra cleaning help that has been called in. John regularly has friends over and continues to do his "brain gymnastics". He is a social man, very interested in others and always ready for a chat.

In mid-January 2021, John was admitted to hospital because a new nodule was discovered at the hip joint. Metastases were diagnosed after a biopsy. Chemotherapy was resumed, but his general condition gradually worsened. John has difficulty moving around, exhibits disturbances in balance, headaches, asthenia, temporo-spatial disorientation and confusion. Added to this are the further aggravating symptoms of joint pain, constipation and occasional nausea.

John's son talks to the head nurse in the corridor, they would like to discuss the prognosis. They wonder if the chemotherapy is still providing quality of life. They are concerned that John is in pain. They also wonder whether it is good to keep discussing the diagnosis with John. Due to his confusion, he always forgets recent information and discussing his situation with him each time is very stressful.

Considerations/discussion points:

- Pain and symptom management.
- Communication with patient and family.
- The roles and responsibilities of family members.
- Psychosocial needs.
- Advance care planning.

The case of Patricia

1. Vignette

General information	
Patient Demographic data:	Woman, 96 years old, widow, 2 children, retired, lives in urban area alone in an apartment
Underlying disease	Neo mammary, chemo-threatened, radiotherapy-treated, lymph node secondary determinations in 2017, breast ulcerated tumour 2020
Co-morbidities	Pulmonary fibrosis, hypertension
More detailed description: Medical history	Insidious onset in 2010 a lump in the right breast, discovered by the family doctor during a routine check-up. He sends her for a breast ultrasound and other investigations after which she is diagnosed with breast cancer. She undergoes chemotherapy and radiotherapy then begins hormone therapy. Since January 2020 an fungating tumour appears in the breast, the patient dresses herself or with the help of a friend and then comes to the Hospice for a home care service appointment. Before coming to the Hospice, the patient attended a day centre in the city.
More detailed description: Issues identified: Physical Psycho-emotional Social Spiritual	Physical - symptoms: bone pain, dizziness, constipation, fatigue, dyspnoea, insomnia Care - local dressing at the level of the fungating tumour Active mobilisation around the house. Sometimes forgets to take medication. Psycho-emotional - anxiety due to disease progression and loneliness. She has fears, worries, fears because she is alone in the house and she may get sick and there is nobody to find her. Social: Patient lives alone, she had only one daughter who died at the age of 33. After the death of the daughter, she raised her grandson since he was 10 years old. The grandson now lives in Bucharest with his family, calls her daily and rarely visits his grandmother. The patient lives alone and a neighbour shop for her. She lives in a large house with several apartments, but is the only tenant in the building. She does not a disability grade because the patient does not want one. I called the nephew and he answered that it is not necessary to give her a disability grade, as the patient needs materials for dressings and other needs. Spiritually: Orthodox Christian, reads prayer books, keeps fasting, is sometimes visited by priest. Patient states that it is her faith that sustains her.
Care and treatment to date	Symptom control Topical dressing several times a week Emotional support Social support - patient alone, nephew is not involved but does not want anyone else to help the patient. Only a neighbour is accepted who does shopping and sometimes dresses the patient. Whenever he comes to Brasov, the grandson does not contact us and we cannot have a discussion to establish care goals and to understand what his

	expectations are about his grandmother's illness. Social department involvement
Particular details of the difficult situation	
Description of the difficult situation from an ethical-moral perspective	<p>Failure to understand the prognosis - the lady partially knows the diagnosis and prognosis. We discuss her understanding with her but she won't accept it. Because in the past she has had drips that "got her back on her feet", now, even though she is deteriorating, she hopes those same drips will make her feel better.</p> <p>We can't plan the patient's care in advance, which is important because she's alone.</p> <p>Lack of family - non-involvement of grandchild.</p>
What was the strategy used to approach the case?	<p>Involvement of the neighbour in the care including doing the dressing on weekend days</p> <p>I suggested that she be admitted to the hospice unit with beds but she refuses</p> <p>Social department involvement</p>
Which of the ethical - moral principles do you consider to have been undermined / ignored / neglected in this case?	<p>Patient has unrealistic hopes and is waiting to regain full independence</p> <p>Telling the truth</p>
Describe your personal perspective (values, feelings, emotions) on the case and how it was resolved	<p>Overwhelmed, burdened, at every visit I hear the same complaint from the patient that the grandchild doesn't have time to talk or spend more time with her.</p> <p>Powerless to do more for the patient</p> <p>Fear - if I visit her and find her fallen in the house or deceased, what do I do?</p>
What recommendations do you have for a better handling of the case, one that respects both the patient's and professional values?	<p>We can't take away the family's responsibility to help the patient</p> <p>Discuss the limited prognosis again with grandchild</p> <p>Nephew manipulates relationship with care providers, relies on hospice help because he gets it easily and does not waste time trying to get other help for patient</p> <p>The grandchild should be faced with a choice that is decisive regarding involvement in the grandmother's care, which may include termination of the care contract.</p> <p>Limits must be imposed and the care contract renegotiated</p> <p>Visits to the patient along with colleagues from the social department</p>

2. The story of Patricia – Advanced level

Patricia is 96 years old and lives alone in an apartment building close to the centre of the city. She is quite frail, but also quite independent and she depends on a neighbour who goes into the town to do the shopping for her.

Patricia's husband died some years ago. Her closest relative is her grandson Karl, who lives in another city and rarely visits her, although he does call her daily on the phone to see how she is. Karl was raised by his grandmother following the tragic premature death of his mother, Patricia's daughter when she was 33 years of age. Karl was 10 at the time. After attending college and university he moved away to another city and he maintains a long-distance relationship with his grandmother.



Patricia had been attending a day care centre on a weekly basis, where one day she mentioned to the care assistant that she had a 'sore' on her breast. The sore was examined and found to be recurrence of breast cancer that had now ulcerated through the skin. She had been diagnosed in 2010, over 10 years ago. At the time she underwent surgery, chemotherapy and radiotherapy and commenced hormonal therapy. She had believed that her cancer had been cured and was shocked to learn that this sore was in fact a recurrence.

Patricia received regular visits from the hospice home care nurse, who dresses her breast wound is dressed and monitors her condition. She complains of generalised pain, occasional dizziness, shortness of breath and constipation. She is also unable to sleep at night, feeling tired and lethargic throughout the day.

She is anxious and worried about what the future holds for her. She is very aware of her lonely, isolated life. Her grandson is many miles away and he is busy with his own life. Her neighbour is very good to her, but she doesn't see him every day. He and her home care nurse are the only people that visit her home regularly. She does get a visit from the priest sometimes, Patricia has a strong faith, and believes this is what sustains her and gives her strength.

The clinical team want to talk to Patricia about future care planning. This is challenging, as Patricia is under the impression that she will be 'back on her feet again' soon. At the same time, she does state that she is worried about being on her own and worried that she is alone with no-one to look after her, or help her if she gets sick. She refers to her grandson as her main person for the healthcare staff to contact regarding her condition, but it is difficult to engage him in conversation, partly because he lives away, and partly because he refuses to engage with the clinical team. Patricia has been offered the opportunity to attend the hospice as an inpatient, but she refused, wishing to stay at home instead.

The social work department have been involved in Patricia's care, but without the full cooperation of Karl, they have struggled to secure the services and benefits that she needs to enable her to live supported in her home.

Considerations/Discussion points:

- Patient autonomy.
- The roles and responsibilities of family members.
- Symptom monitoring and management.
- Psychosocial needs.
- Communication with patient and family.
- Advance care planning.
- Preferred place of care, preferred place of death.

3. The story of Patricia – Novice level

Patricia is 96 years old and lives alone in an apartment building close to the centre of the city. She is physically quite frail, but at the same time, she maintains her independence, able to perform all her personal activities of daily living (PADLS) and she gets help from a neighbour who goes into the town to do her shopping.

Patricia's husband died some years ago. Her closest relative is her grandson Karl, who lives in another city and rarely visits her, although he does call her daily on the phone to see how she is. Karl was raised by his grandmother following the tragic premature death of his mother, Patricia's daughter, when she was 33 years of age. Karl was 10 at the time. After attending college and university he moved away to another city and he maintains a long-distance relationship with his grandmother.



Patricia has been attending a day care centre on a weekly basis. She arrived earlier this morning with a large bruise on the left side of her face and her left forearm and hand. The care staff have been discussing the bruising with Patricia and they have discovered that the bruise is because of a fall she had a few days ago. On further questioning Patricia tells them that she has had several 'slips and trips' over the past months, and that she is finding it increasingly difficult to get up off the floor. After this last fall, she knew that her neighbour would be calling with her shopping soon, so she lay on the floor until he arrived and was able to help her up. He wanted to call an ambulance, but she was adamant that wasn't necessary, and that she would be seeing a nurse today at the centre, who she would tell all about the fall and get checked out.

It is a while since the medical team have fully assessed Patricia and so a doctor is called to see her. She tells the doctor she is also unable to sleep at night, feeling tired and lethargic throughout the day. She also complains of generalised pain, occasional dizziness, shortness of breath and constipation.

She is anxious and worried about what the future holds for her. She is very aware of her lonely, isolated life. Her grandson is many miles away and he is busy with his own life. Her neighbour is very good to her, but she doesn't see him every day. He and her home care nurse are the only people that visit her home regularly. She does get a visit from the priest sometimes, Patricia has a strong faith, and believes this is what sustains her and gives her strength.

The clinical team want to talk to Patricia about future care planning. This is challenging, as Patricia is under the impression that she will be 'back on her feet again' soon. At the same time, she does state that she is worried about being on her own and worried that she is alone with no-one to look after her, or help her if she gets sick. She refers to her grandson as her main person for the healthcare staff to contact regarding her condition, but it is difficult to engage him in conversation, partly because he lives away, and partly because he refuses to engage with the clinical team. Patricia has been offered the opportunity to attend the hospice as an inpatient, but she refused, wishing to stay at home instead.

The social work department have been involved in Patricia's care, but without the full cooperation of Karl, they have struggled to secure the services and benefits that she needs to enable her to live supported in her home.

Considerations/discussion points:

- Patient autonomy.
- The roles and responsibilities of family members.
- Symptom monitoring and management.
- Psychosocial needs.
- Communication with patient and family.
- Advance care planning.
- Preferred place of care, preferred place of death.

The case of Suzanna

1. Vignette

General information	
Patient Demographic data:	Patient aged 53, married, sickness pension, 3 adult children living in other towns.
Underlying disease	Right breast tumour
Co-morbidities	no comorbidities
More detailed description: Medical history	Patient diagnosed in 2017, undergoing surgery, chemotherapy and radiotherapy. Under treatment the tumour does not have a favourable evolution and ulcerates, the biggest problem being the haemorrhage in the tumour. She is admitted to the bed unit for symptom control and because the husband feels exhausted due to care, especially dressing the ulcerated tumour.
More detailed description: Issues identified: Physical Psycho-emotional Social Spiritual	<p>Physical - symptoms: pain in the anterior thorax and right upper limb, constipation, insomnia, anxiety</p> <p>Care - specific for a bedridden patient and local dressing at the level of the exulcerated tumour</p> <p>Psycho-emotional – the internalization of the patient, she doesn't want to communicate with her family, she doesn't want her children to know how damaged she is</p> <p>Social - financial problems, she lives with her husband who is overwhelmed by the care needs of the patient in the process of getting a disability grade</p> <p>Spiritual - religious, non-practitioner</p>
Care and treatment to date	<p>Symptom control - Morphine 60mg/24h, Gabaran, Anxiar</p> <p>Local dressing is done as needed</p> <p>Psycho-emotional and spiritual counselling. While she was hospitalized, she was visited by the priest and counselled by the psychologist</p>
Particular details of the difficult situation	
Description of the difficult situation from an ethical-moral perspective	<p>There is no consensus between the spouses as to where the patient should be cared for - after she has been admitted for a few days and the symptoms have started to be controlled, the patient wants to go home. She is deteriorating and says she wants to die in her bed. Her husband feels overwhelmed by all the care issues and does not want to take her home.</p> <p>The children don't know what the patient's situation is and he won't tell them.</p>
What was the strategy used to approach the case?	<p>The team discussed with the patient the advantages and disadvantages of each place of care, but she wants to go home. The need to discuss with the children about her health and the involvement of the children in the care was also discussed, but the patient refuses.</p> <p>Discussions were also held with the husband about the patient's wish to be cared for at home, he was told that he would be helped by the home care team but he is afraid to take her home because he does not know how to care for her.</p> <p>Discussion of the case in the interdisciplinary meeting</p>
Which of the ethical - moral principles do you consider	<p>Confidentiality - we cannot tell children without the patient's consent</p> <p>Patient care where she wishes to be cared for</p>

to have been undermined / ignored / neglected in this case?	Benevolent/non-maleficent Quality of care at home vs. quality of care in bed unit, she is a patient with complex care issues, at risk of massive bleeding at the level of ulcerated tumour
Describe your personal perspective (values, feelings, emotions) on the case and how it was resolved	Both patient and caregiver are members of the care team. When there are different opinions between them and each is right from their own point of view (the patient's desire to be cared for at home vs. the husband's fear that he won't be able to provide quality care) it puts you in a difficult situation and you can't help them both. You choose to help the patient and respect her wishes even though you doubt she will be better cared for at home.
What recommendations do you have for a better handling of the case, one that respects both the patient's and professional values?	Meeting with the family, with the patient, husband and team members attending. Discuss the patient's and husband's fears about the care process and the evolution of the disease Discuss with the patient the reasons why she does not want to tell her children about her situation. During the period of hospitalization involving and educating the husband when dressing, mobilizing, toileting the patient. It can be a method of gaining confidence. Discussions between the patient's husband and the home care team to get to know each other and start building a relationship based on trust.

2. The story of Suzanna – Advanced level

Suzanna is 53 years old. She is married to Martin and has three grown up children, two girls and one boy. Her children and grandchildren all live quite far from Suzanna and Martin, and although she sees them very infrequently, she thinks about them often. Suzanna doesn't work. She used to work as an administrator but has been in receipt of sickness benefit for the last year, due to deteriorating health. Martin works in a bakery. He often works the early morning shift, and leaves the house at 3.30am, returning by 11am where he then goes on to provide care for his wife.

Suzanna's mother died of breast cancer aged 41 and her sister was diagnosed with Ovarian cancer a year ago.

Aged 49, Suzanna discovered a small lump in her right breast as she examined herself in the shower. She immediately contacted her doctor and was sent for a fine needle biopsy. The doctor reassured her that it was unlikely to be anything serious but biopsy revealed a small malignant stage III breast tumour, 2cm in size.

Having known survivors of breast cancer, Suzanna positively and enthusiastically embarked on a course of treatment. As well as being cared for by her oncologist, Suzanna was also referred to a Specialist Breast Cancer Nurse. A lumpectomy (breast conserving surgery) and axillary node sampling was performed and 3 axillary nodes tested positive indicating some spread of the cancer from the breast. Suzanna was prescribed a course of adjuvant treatment including hormone therapy. She underwent 3 weeks of radiotherapy followed by six cycles of chemotherapy. This was administered via a specially inserted central line. Suzanna found the chemotherapy induced several difficult side effects including nausea, loss of appetite and weight, fatigue, and hair loss. During her treatment there were times when her white cell count was low, treatment was delayed. This worried Suzanna, she was concerned that the delay would mean that her chemotherapy would not be as effective. On completion of the course of treatment, Suzanna was delighted to be told by her oncologist that she was cancer free.

15 months after completing her treatment, Suzanna noticed a new red area on her right breast. She visited her doctor who examined her and then, just to be sure, referred her back to her oncologist. A series of further investigations revealed recurrence of the breast tumour, and the presence of metastases in her liver. Suzanna was devastated by the news. She commenced a further course of chemotherapy. Unfortunately, due to her falling white cell count, and her inability to tolerate the nausea and vomiting, the chemotherapy was stopped after cycle three.

8 months ago, Suzanna presented to her oncology team with a persistent, increasing pain in her shoulders and upper back. An MRI scan of her spine revealed that she had bone metastases at several levels, and she received a course of palliative whole-spine radiotherapy. After completing the radiotherapy, Suzanna's physical health continued to deteriorate. Her mobility worsened, and she quite quickly became restricted to transferring only from her bed to a wheelchair. For the past 6 weeks, Suzanna has been completely confined to the bed, with Martin having to perform all her personal care.

The tumour in the right breast has invaded the skin and is ulcerative and fungating and requires daily dressing changes, which both Suzanna and Martin find deeply distressing. The two of them are really struggling to cope with the situation they find themselves in. Martin had taken some unpaid leave from his job to focus on caring for Suzanna, but this did cause some financial difficulties, so he had to return to work. He is exhausted and overwhelmed.



When you meet Suzanna, she has been admitted to the hospital for a full review of her condition and symptom management. She presents with intractable pain in her right thorax and upper limb. She is constipated and struggles to get a good night's sleep. The fungating lesion on her breast creates an extremely unpleasant odour, which causes embarrassment to Suzanna. She has become withdrawn. She feels guilty that she is a burden, that she is unwell and causing so much anguish to Martin whom she loves dearly. Suzanna has religious faith, but she has never been an active practitioner. She reflects on this and struggles to find a sense of meaning and purpose in what is happening to her. She is incredibly sad that her life is coming to an end. She knows she is dying, and she wants to die at home.

She is referred to the palliative care team who assess her physical, psychosocial, and spiritual needs. Her pain and other symptoms are addressed, but these are impacted by her psychosocial distress. The team are aware of her wish to die at home but are concerned this might not be the best option for her. They have approached the idea of Suzanna staying in the hospital, where she can have all her physical needs addressed by the staff, and Martin can be her husband, not her caregiver, explaining that this option would reduce the stress and anxiety for Martin too. Suzanna is adamant she wants to go home.

The next option discussed is that she could contact her adult children, and that they could be more involved in her life at this stage and provide support for Suzanna and Martin at home. Suzanna flatly refuses, she does not want her children to know how sick she is.

She wants to go home to die in her own bed. The home care team are available to provide support at home, however the clinical team feel that Suzanna would be better cared for, and Martin better supported if she remains in the hospital.

Considerations/discussion points:

- Patient autonomy and her wish to die at home versus clinical judgement and the opinion she would be better cared for in hospital.
- Care and dressing of the fungating lesion and the risk of haemorrhage.
- Physical care needs of a person confined to bed, including management of constipation, skin integrity etc.
- Pain management and the risk of escalation of the pain.
- Addressing Suzanna's spiritual needs, both religious and other.
- Support for Martin - Martin's fear about being able to cope and his reluctance to take Suzanna home.
- Patient confidentiality - Suzanna has stipulated that her children are not told – what implication might this decision have for the future (Bereavement care for Martin, and bereavement experience of the children).
- Communication at the end-of-life.
- Is there a genetic component – will her daughters also have the gene. Her sister had ovarian cancer. Is this related.
- Bereavement care and support.

3. The story of Suzanna – Novice level

Suzanna is 53 years old. She is married to Martin and has three grown up children, two girls and one boy. Her children and grandchildren all live quite far from Suzanna and Martin, and although she sees them very infrequently, she thinks about them often. Suzanna doesn't work. She used to work as an administrator but has been in receipt of sickness benefit for the last year, due to deteriorating health. Martin works in a bakery. He often works the early morning shift, and leaves the house at 3.30am, returning by 11am where he then goes on to provide care for his wife.

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Considerations/discussion points:

- In the communication process with Suzanna, do you notice any points where misunderstandings might have occurred.
- If early integration of Palliative Care interventions were to be included in the plan of care for Suzanna, what will those be? Be specific.
- In what will consist the care of her arm affected by lymphedema?
- What nutritious advices will you give to this patient?
- What about the hair loss?
- How will you advice this patient to avoid social isolation due to fatigue, change in her body image, nausea?

The case of Amy

1. Vignette

General information	
Patient Demographic data:	3-year-old patient, only child with very young parents
Underlying disease	Agenesis of corpus callosum and palatoschisis
Co-morbidities	Epilepsy
More detailed description: Medical history	<p>Taken in the paediatric hospice service two years ago when the little girl was almost a year old. Until then the child stayed in the paediatric hospital, there were a few attempts to go home but they all failed due to severe symptoms. Then the paediatric team from the hospital sent the child to palliative care for symptom control. The patient is being fed via a nasogastric tube; it is desired to correct the palatoschisis so that feeding tube is not used.</p> <p>On admission, the mother was asked what she expected from our service and her answer was to be helped heal her child.</p>
More detailed description: Issues identified: Physical Psycho-emotional Social Spiritual	<p>Physical - symptoms: convulsions, agitation, feeding on a nasogastric tube, fever due to disturbances in the thermoregulatory centre</p> <p>Psycho-emotional - family support, the mother is very tired and anxious, her mood changes according to the child's condition</p> <p>Social – the mother is taking care of the child, she is unemployed, she is alone with the child for many hours a day and does the same thing every day</p> <p>Spiritual – parents feel that their child's disease is a punishment</p>
Care and treatment to date	<p>Symptom control</p> <p>Educating the mother about nutrition and non-pharmacological symptom control</p> <p>Change nasogastric tube every 2 weeks, sometimes I extend my visits because the baby has seizures and I have to wait for her to calm down and then make the manoeuvre</p> <p>Psycho-emotional support for parents</p>
Particular details of the difficult situation	
Description of the difficult situation from an ethical-moral perspective	<p>Mother does not accept the diagnosis, is in a continuous search for healing solutions</p> <p>Family wants correction of cleft palate but there is a benefit vs burden dilemma</p> <p>Patient's quality of life</p> <p>Mother's exhaustion</p>
What was the strategy used to approach the case?	<p>Communication with the family about prognosis</p> <p>Explaining the advantages and disadvantages of surgery</p> <p>Involvement of interdisciplinary team members</p> <p>Psycho-emotional support for mother and father</p>
Which of the ethical - moral principles do you consider to have been undermined / ignored / neglected in this case?	Benevolence/non-malevolence of surgery

Describe your personal perspective (values, feelings, emotions) on the case and how it was resolved	Frustration because no matter what we do as a medical team, it is hard for a mother to accept what is happening to her child Fatigue, the family trusts me and hardly accepts another member of the team
What recommendations do you have for a better handling of the case, one that respects both the patient's and professional values?	Admitting the patient to the bed unit to give the mother a period of respite Help the mother meet other parents who have children with the same problems

2. The story of Amy – Advanced level

Amy is 3-years-old and the only child of Sam and Karim a young couple both in their late teens. Amy was born after an uneventful pregnancy and delivery. She was born with a cleft palate and when she later developed epilepsy at a few months old, was diagnosed with agenesis of the corpus callosum. Amy exhibits signs of developmental delay. She was slow to achieve full head control and independent sitting, and hasn't walked yet or made any attempt to verbalise words.

Amy has spent much of her young life in hospital. Her seizures are poorly controlled and she has febrile episodes, which are associated with her brain abnormality. She receives all her nutrition via a naso-gastric (NG) tube which requires replacing every two weeks. As Amy has become more alert and aware of her surroundings, she has also become increasingly agitated and distressed by the constant physical examinations, and particularly the changing of the NG tube. She often shows non-verbal signs that she is in pain.

The possibility of a surgical correction of the cleft palate has been discussed with Sam and Karim, however the medical team fear that at the present time, the risks involved in performing the surgery would far outweigh any benefit for Amy and so have told the parents that this discussion needs to be placed on hold for the foreseeable future. Sam and Karim are desperate for their little girl to have a 'normal' life and want surgery performed as soon as possible. They want Amy to be healed.

Amy is now at home with her parents. Her dad works as a warehouse operative and Sam is unemployed, she takes care of Amy around the clock.

The palliative home care nurse visits the house every 2 weeks. She replaces the NG tube, monitors Amy's symptoms and provides support for Sam. Sometimes the visits run over in time considerably as Amy may have been unwell with a seizure and the feeding tube change procedure must be delayed. The nurse uses this time to provide support for Sam, talking to her about how the use of play, gentle massage and singing nursery rhymes can all help to alleviate distressing symptoms.

Sam is exhausted. She receives little support from her husband who is out at work all day, financially they depend on his income. Sam feels abandoned, and that her little girl has been abandoned. She feels that if Amy gets the corrective surgery, then everything will be ok and all their current problems will be solved.



Considerations/discussion points:

- Symptom management. (Including non-pharmacological management).
- Involvement of the MDT to address Amy's needs.
- Support for the parents to understand the prognosis.
- Communication of sensitive issues.
- Harm versus benefits of corrective surgery.
- Parents as carers versus parents as parents.
- Respite care for family.
- Peer support for parents.

3. The story of Amy – Novice level

Amy is 3-years-old and the only child of Sam and Karim. Amy was born after an uneventful pregnancy and delivery. She was born with a cleft palate and when she later developed epilepsy at a few months old, was diagnosed with agenesis of the corpus callosum. Amy exhibits signs of developmental delay. She was slow to achieve full head control and independent sitting, and hasn't walked yet or made any attempt to verbalise words.

Amy has spent much of her young life in hospital. Her seizures are poorly controlled and she has febrile episodes, which are associated with her brain abnormality. She receives all her nutrition via a naso-gastric (NG) tube which requires replacing every two weeks. As Amy has become more alert and aware of her surroundings, she has also become increasingly agitated and distressed by the constant physical examinations, and particularly the changing of the NG tube. She often shows non-verbal signs that she is in pain.



The possibility of a surgical correction of the cleft palate has been discussed with Sam and Karim, however the medical team fear that at the present time, the risks involved in performing the surgery would far outweigh any benefit for Amy and so have told the parents that this discussion needs to be placed on hold for the foreseeable future. Sam and Karim are desperate for their little girl to have a 'normal' life and want surgery performed as soon as possible. They want Amy to be healed.

Amy is now at home with her parents, Karim works and Sam is home with Amy all the time. The palliative home care nurse visits the house every 2 weeks. She replaces the NG tube, monitors Amy's symptoms and provides support for the parents. Sometimes the visits run over in time considerably as Amy may have been unwell with a seizure and the feeding tube change procedure must be delayed. The nurse uses this time to provide support for Sam, talking to her about how the use of play, gentle massage and singing nursery rhymes can all help to alleviate distressing symptoms.

Sam and Karim feel that their little girl has been abandoned. They believe that if Amy gets the corrective surgery then everything will be ok and all their current problems will be solved.

Considerations/discussion points:

- Symptom management. (including non-pharmacological management).
- Involvement of the MDT to address Amy's needs.
- Support for the parents to understand the prognosis.
- Communication of sensitive issues.
- Harm versus benefits of corrective surgery.
- Parents as carers versus parents as parents.
- Respite care for family.
- Peer support for parents.

The case of David

1. Vignette

General Information	
Patient demographic data:	D.G., male, 54 years old, retired, divorced, rural background, smoker
Underlying disease	Bronchopulmonary neoplasm, stage 4 (neuroendocrine), brain metastases, irradiated, right hemi-body motor deficit, lung metastases, lymph metastases, mediastinal metastases, bone metastases, axillary metastases, latero-cervical metastases, supraclavicular metastases, abdominal metastases, irreducible chronic pain, secondary epileptic seizures (petit mal), right adrenal metastases.
Co-morbidities	none
More detailed description: - Medical History	Clinical onset two years ago with shortness of breath and a spastic cough with white aerated sputum, sometimes bloody. He is transferred from a penitentiary to a specialist hospital for investigations where a crude diagnosis is made and chemotherapy is indicated. He is admitted to the oncology ward for chemotherapy. Sindaxel 240 mg and Cisplatin 120 mg are well-tolerated under haematological and biochemical control.
More detailed description: - Issues identified: o Physical o Psycho-emotional o Social o Spiritual	Patient with stage 4 left bronchopulmonary neoplasm (neuroendocrine) with right hemi-body motor deficit and secondary epileptic seizures. Recently released from prison for aggravated murder, having served 20 years in prison. No social life, left by his wife and daughter many years ago. Admitted to the Palliative Care ward for pain and symptom control. Relatively good general condition, chronic pain, dysphagia, altered physical integrity, changes in skin appearance, anxiety, temporal-spatial disorientation, fatigability, spastic cough, dyspnoea, hypotension, oedema. Behavioural disorders, uncontrolled reactions, verbal and physical violence. In addition to how his physical needs have been affected, the patient's need for socialization is also affected. Spiritual: He is anxious, depressed, turned against formal religious traditions. He completely refuses the idea of confession and communion. He refuses meetings with the unit's psychologist and refuses to give the contact details of his ex-wife and daughter or close acquaintances.
Care and treatment to date	Analgesics, co-analgesics and opioids, management of associated symptoms, namely prevention of seizures, cessation of vomiting, cough relief, preservation of mucosal and skin integrity. Antibiotics, corticosteroids, antitussives, anticonvulsants and analgesics were administered only with the patient's consent following discussions about the beneficial effects of these on his state of health.
Particular details regarding the difficult situation	
Description/definition of the difficult situation from an ethical/moral perspective	Ethical issues increase as the patient's health deteriorates. There is no family and no relatives. Communication with the patient becomes increasingly difficult due to brain damage and dysphonia.

	<p>He is not willing under any circumstances to give up cigarettes, becomes recalcitrant when he does not smoke.</p> <p>The case is very delicate, requiring a lot of physical and emotional involvement, with the period of hospitalization being very long - about 6 months - and the general condition of the patient being in a progressive deterioration.</p> <p>Symptom management: during hospitalization the patient is treated with non-steroidal anti-inflammatory drugs, gastric protectant, analgesics, a diuretic depletive, anticonvulsants, anxiolytics. He adapts to the hospital and ward rules for a while and accepts treatment. The treatment scheme is modified according to pain and symptoms. The first epileptic seizures appear.</p>
What strategy was used to resolve the case	<p>In the case of patient D.G, all necessary measures were taken to ensure the comfort of the patient, both physically and mentally. He was accommodated in a room with a private bathroom, a TV and a refrigerator. We were aware that he did not accept to be looked at with pity, he did not want to be seen by other patients as dependent. We observed during his hospitalization all 5 emotional reactions to death, namely: denial (minimizing reality through ignorance and to hide his fear), anger (directed at family members, he always maintained that he had been abandoned, that he had endured torment in prison and that no one had looked for him for 20 years; at us, the medical professionals, for not giving him enough attention and not curing him, even though he was aware of the seriousness of the situation and the impossibility of curing him; at his own person, he always accused himself of not taking enough care of himself and that this was the reason why he had acquired the disease, and at God. Each time we gave him the opportunity to express his outrage); negotiation (accepting the idea of death, but negotiating to live a little longer); depression (the patient was withdrawn, isolated, with feelings of helplessness and inferiority, eating alone, eating slowly and coughing in the process of swallowing) and acceptance.</p> <p>The patient D.G. presented throughout the hospitalization a maladaptive behaviour, namely: guilt, pathological denial, anger against those who help him, anxiety, depression, unrealistic hopes, despair, manipulation.</p> <ul style="list-style-type: none"> - non-maleficence: no treatments with uncertain benefits or unacceptable side-effects for the patient were administered. - the principle of autonomy: the patient participated in making therapeutic decisions and treatment planning in full knowledge of the facts. - the principle of justice and utility: the right to equal access to care and resources, i.e., getting the maximum benefit for the maximum possible number with limited resources.
Which of the ethical/moral principles do you consider to have been undermined/ignored/neglected in this case?	<p>I believe that in the case of terminally ill patients the following essential rights should be guaranteed:</p> <ul style="list-style-type: none"> - the right to be treated as a living person until the end of life - the right to have hope - the right to be cared for by people capable of maintaining my hope - to express my feelings and emotions about death - I have the right to participate in decisions - to receive care, even if healing is not possible

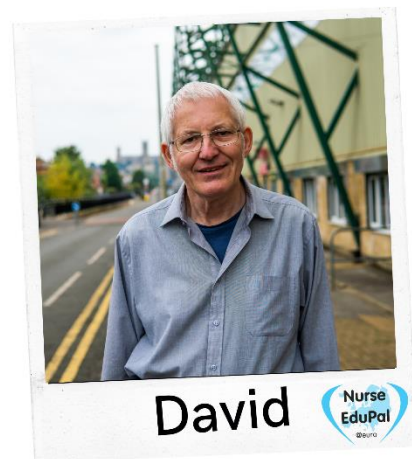
	<ul style="list-style-type: none"> - I have the right not to die alone - I have the right not to suffer - I have the right to receive honest answers to questions - I have the right not to be lied to - I have the right to die in peace and dignity - I have the right to hold and express my religious beliefs and opinions without being judged, regardless. - I have the right to be cared for by capable people who understand my needs, people who have the satisfaction of helping me through this stage of life. - the sanctity of a person to be respected even after death.
Describe your personal perspective (values, feelings, emotions) about the case and how it was resolved	<p>During the first months of hospitalization, life was supported at all cost and by all means - biological samples were taken, antibiotic therapy was carried out, treatment schedules with oral and parenteral medication were discussed in advance with the patient. The anxiety and depression issues he was experiencing were eliminated with the passage of time and interpersonal relationships were improved. He was informed and counselled at the occurrence of each change in his general condition and the appearance of symptoms associated with the disease. His rights and needs were respected. He was given mental, emotional and physical support in times of distress. Doors were opened for him, through which he found understanding and empathy. He was not judged for his past and his secrets were kept. His fears were listened to, and also his desires. He was assisted spiritually and also educated in this respect. He was assured that he would have a Christian burial and that he had served his punishment on earth and would be received into heaven with human wrongs acknowledged and forgiven.</p> <p>For 6 months we were his family. We were the people he learned to trust. We ensured he came to a dignified end, as every person deserves. We stood by his side in his last moments and eased his suffering.</p> <p>On 21 June, after approximately 6 months of hospitalization, two weeks of immobilization and a severely comatose general condition, the patient's death was recorded in the observation sheet.</p>
What recommendations would you have for a better handling of the case, which respect the values of the patient and the professional?	<p>"If the time comes that I can no longer take part in decisions concerning my own future, let this statement be regarded as a testament to my wishes:</p> <p>If there is no reasonable hope for my recovery from a physical or mental illness, I,, ask to be allowed to die and not to be kept alive by artificial means or heroic measures. Death is as real as birth, growing up, maturing and aging - that is a certainty.</p> <p>I am not afraid of death as much as I am afraid of the indignity of degradation, dependence and pain without hope. I ask that medication be administered out of pity for my terminal suffering, even if it will hasten my death.</p> <p>This request is made after careful deliberation. Although this document has no legal force, you, who I hope care about me, will feel morally obliged to proceed according to this mandate. I recognise that it places a great burden of responsibility on you, but I make this statement with the intention of sharing that responsibility and lessening any sense of guilt."</p>

	<p>The last moments of patient D.G. were peaceful, with serenity of mind, reconciliation with people and God, without pain, surrounded by people who offered him support. He had a "Christian end of life, without pain, in unopposed peace."</p> <p>I conclude by saying that each patient, each with their own story behind them, is a life lesson for us medical professionals, and palliative care is a never-ending wellspring of knowledge for professional and emotional self-development.</p>
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2. The story of David – Advanced level

David is a 54-year-old divorced man. His wife left him, and took full custody of their 7-year-old daughter many years ago. This happened shortly after David was sentenced to a lengthy prison sentence for the crime of aggravated murder. David has no other living relatives, and very few people whom he would call friends. David lives in a small house on the outskirts of a town. He was recently given compassionate release from prison due to deteriorating health.

David has been a smoker since he was 13 years old. For the last 30 years he has smoked 20-30 cigarettes a day. He has tried a few times in the past to stop, but he found it too difficult and only ever managed a few days off the cigarettes, becoming miserable, irritable and moody without them. A long time ago, he gave up trying to give up.



2 years ago, David presented with a new onset, persistent cough and shortness of breath. He was transferred from the prison to a specialist hospital where investigations revealed he had a stage 4 non-small cell lung tumour. On diagnosis the cancer was at an advance stage with extensive lymph node involvement and multiple metastatic deposits throughout his body. He was treated with chemotherapy in the hospital, and his prison release on compassionate grounds followed shortly after. He received whole brain radiotherapy for symptomatic relief of brain metastases, which caused him to have a slight right sided weakness, affecting his mobility and fine motor function.

6 months ago, David presented with an epileptic seizure and was admitted to the palliative care unit for a full review of his condition. At that time, he was able to walk very short distances, however he was quite ataxic and presented an increased risk of falling. He was extremely short of breath on exertion and tired quickly. His non-verbal body language suggested he was experiencing a high level of pain. He had a persistent cough and he also experienced some swallowing difficulties.

Communicating with David was very challenging. In addition to some of the cognitive and speech difficulties caused by the brain metastases, he was aloof and detached, and was prone to outbursts of verbal and physical anger and rage when any of the clinical team asked him questions. David was accommodated in his own room where he could be in his own private space, away from the gaze of other patients. David refused all options that were presented to him, among these were the use of medication for relief of his symptoms, the opportunity to speak to a priest and the opportunity to talk to the unit's psychologist. David refused to talk about his wife, daughter and family, or his life before and during prison.

As the days progressed, David began to open up very slightly to conversation with the staff. After a conversation about the benefits of commencing various medications, that would relieve the seizures, reduce his pain levels, lessen the cough and stop his vomiting he gave his consent for those to be administered. He still however refused to talk to the psychologist and the priest, and he reverted to his anger and rage when it was suggested he stop smoking.

During the lengthy hospital admission, David's health deteriorated, however the use of anxiolytics did appear to improve his mood, and gradually he began to develop trusting relationships with the staff who cared for him. He was able to talk more about himself, his fears and his wants, and the staff, who showed him kindness, care and empathy were able to support him and address all his needs as he approached the end of his life.

Considerations/discussion points:

- How a person's previous history can impact on their current circumstances
- Non-judgemental approach to care.
- Dealing with challenging communication difficulties.
- Using non-verbal ways signs to assess symptoms.
- Empowering, enabling, and supporting David to live well until he dies.
- Patient autonomy and the right to be involved in decision making about their care.
- Advance care planning and advance healthcare directives.
- Pain and symptom management (physical, psychosocial and spiritual). Involvement of the multidisciplinary team to address total pain.
- Support for colleagues working within the situation, bereavement care for staff?
- Smoking as a stress reliever – should David be encouraged to stop?

3. The story of David – Novice level

David is a 54-year-old divorced man. His wife left him and took full custody of their 7-year-old daughter many years ago. David has no other living relatives, and very few people whom he would call friends. David lives in a small house on the outskirts of a town.

A few years after the divorce, David was diagnosed with Schizophrenia following a severe psychotic episode. Since that time, he has been involved with the community mental health team, who monitor his condition and provide support as needed.

David has been a smoker since he was 13 years old. For the last 30 years he has smoked 20-30 cigarettes a day. He has tried a few times in the past to stop, but he found it too difficult and only ever managed a few days off the cigarettes. Each time he tried; his mental health deteriorated. A long time ago, he gave up trying to give up.

2 years ago, David presented with a new onset, persistent cough and shortness of breath. Investigations revealed he had a stage 4 non-small cell lung tumour. On diagnosis the cancer was at an advance stage with extensive lymph node involvement and multiple metastatic deposits throughout his body. He was treated with chemotherapy and received whole brain radiotherapy for symptomatic relief of brain metastases, which caused him to have a slight right sided weakness, affecting his mobility and fine motor function. The mental health team have been providing support to the oncology team with David's care planning, and monitoring David's mental health as he went through the cancer treatment.

6 months ago, David presented with an epileptic seizure and was admitted to the palliative care unit for a full review of his condition. At that time, he was able to walk very short distances, however he was quite ataxic and presented an increased risk of falling. He was extremely short of breath on exertion and tired quickly. His non-verbal body language suggested he was experiencing a high level of pain. He had a persistent cough and he also experienced some swallowing difficulties. He also exhibited signs of deteriorating mental health with delusions and hallucinations.

Communicating with David was very challenging. In addition to some of the cognitive and speech difficulties caused by the brain metastases, he was aloof and detached, and was prone to outbursts of verbal and physical anger and rage when any of the clinical team asked him questions. David was accommodated in his own room where he could be in his own private space, away from the gaze of other patients. David refused all options that were presented to him, among these were the use of medication for relief of his symptoms, the opportunity to speak to a priest and the opportunity to talk to the unit's psychologist. David refused to talk about his wife, daughter and family.

As the days progressed, David began to open up very slightly to conversation with the staff. After a conversation about the benefits of commencing various medications, that would relieve the seizures, reduce his pain levels, lessen the cough and stop his vomiting he gave his consent for those to be administered. He still however refused to talk to the psychologist and the priest, and he reverted to his anger and rage when it was suggested he stop smoking.



David's health has deteriorated; however, the use of anxiolytics and neuroleptics do appear to improve his mood, and gradually he has begun to develop a trusting relationship with the staff who care for him.

Considerations/discussion points:

- How a person's previous history can impact on their current circumstances.
- Non-judgemental approach to care.
- The impact of mental health and wellbeing.
- Dealing with challenging communication difficulties.
- Using non-verbal ways signs to assess symptoms.
- Empowering, enabling, and supporting David to live well until he dies.
- Patient autonomy and the right to be involved in decision making about their care.
- Advance care planning and advance healthcare directives.
- Pain and symptom management (physical, psychosocial and spiritual). Involvement of the multidisciplinary team to address total pain.
- Support for colleagues working within the situation, bereavement care for staff?
- Smoking as a stress reliever – should David be encouraged to stop?

The case of Maria

1. Vignette

General Information	
Patient demographic data:	P.M., female, 61 years old, unmarried, unemployed, Orthodox Christian, urban background, lives alone in a 2-room house with high hygiene conditions. Biographical elements related to health: mother/father - deceased (of old age), one sister - aged 57, apparently healthy.
Underlying disease	Cancer of the gallbladder
Co-morbidities	none
More detailed description: Medical History	<p>The patient, aged 61, is admitted, through the emergency department, 4 days after the onset of superior digestive tract haemorrhagic episode, externalized by melena stools (4 stools) and vomiting. The medical history shows a marked weight loss for several months (10-15kg) with decreased appetite.</p> <p>Clinical: on admission the patient shows signs of haemorrhagic shock (blood pressure), grade 2 malnutrition, melting of muscle masses. Local examination of the abdomen shows grade 1 hepatomegaly, mild painful tenderness in the right hypochondrium. Rectal exam confirms melena.</p> <p>Personal pathological history: chronic hepatitis B virus for 20 years, ultra-sonographically confirmed biliary lithiasis and operated appendiceal peritonitis. Biological investigations at admission showed severe anaemia Haemoglobin=12%, Haematocrit=26%, Leucocytes = 8700/mm, Glutamic Oxalic Transaminase = 36UI/1, Glutamic/Glutamate Pyruvic Transaminase =22UI/1, urea=88mg, total bilirubin = 0.6mg. Electrocardiogram and cardiological examination showed myocardial ischemia secondary to anaemia. The patient responds favourably to volemic rebalancing therapy and drug haemostasis.</p> <p>Imagistic investigations:</p> <p>Upper digestive endoscopy performed in the first 24 hours reveals a 4cm hiatal hernia, without haemorrhagic stigmata in the oesophagus, stomach or duodenum.</p> <p>Abdominal ultrasound: liver with 16cm right lobe, 8.4cm left lobe, in segment VII there is an image of a 39mm isechogenic nodule having the appearance of a metastatic tumour. An 11,5cm transonic image of the gallbladder shows it with a thick wall, anfractuous, with vegetation inside and a 3cm gallstone.</p> <p>Computerised tomography: hypodense images with appearance of metastases in segments VIII (18mm) and VI (34mm), gallbladder very distended, thick-walled, irregular, focalised parietal thickening, with tissular structure, iodophilic, 2cm diameter gallstone.</p>
More detailed description: - Issues identified: Physical Psycho-emotional Social o Spiritual	<p>The patient's state at the time when the home palliative care service took over:</p> <p>Physical state: high intensity pain (VAS – visual analogue scale 9/10) in the abdomen, postprandial vomiting about 15-20 minutes after eating, marked weight loss in recent months, melanic stools, difficulty moving around the house.</p> <p>Psycho-emotional state: marked anxiety, panic attacks, melancholic mood and marked sadness at the thought that she has no one to care for her and</p>

	<p>"will die alone, like an abandoned dog". Under no circumstances does she agree to leave her home.</p> <p>Social: single. Has a sister who tries to help her. The sister has a family and is currently caught up in helping her daughter who recently gave birth.</p> <p>Spiritual: she expresses regrets about some choices she made in life, the fact that she did not start a family "at the right time" and now she is alone without support.</p>
Care and treatment to date	Mild analgesics - as needed, antiemetics, Anxiar (Lorazepam).
Particular details regarding the difficult situation	
Description/definition of the difficult situation from an ethical/moral perspective	<p>Autonomy - the patient wants her wish to be cared for at home to be respected.</p> <p>Beneficence - home care would be the most beneficial option for the patient, according to her wishes.</p> <p>Non-maleficence - inability to properly organise and control her own treatment plan and implementation of interventional care - dependent on the presence of a caregiver.</p> <p>Utility - Justice: although it is the ideal service to provide for this patient - the palliative home care offered by our specialist service - it does not provide 24/7 care, only consultative service, in order, on the one hand, to keep costs as low as possible, and on the other hand, to be able to help as many patients/families as possible.</p>
What strategy was used to resolve the case	<p>The burden of care, which is most often carried by family members is, in this case, impossible to take over by the care team.</p> <p>Contacting partner institutions to take over the burden of ongoing care of the case.</p> <p>Meeting with the family</p>
Which of the ethical/moral principles do you consider to have been undermined/ignored/neglected in this case?	Autonomy - it is difficult to maintain the dignity of the patient when the patient's number one priority is to be cared for (with all that this entails) at home, and we cannot respect this, limited as we are by financial resources and the lack of organisation of the health service system adapted to needs.
Describe your personal perspective (values, feelings, emotions) about the case and how it was resolved	<p>Frustration</p> <p>Job dissatisfaction</p> <p>Non-concurrence between what should be done and what is realistically possible to offer this patient in terms of palliative home care services</p>
What recommendations would you have for a better handling of the case, which respect the values of the patient and the professional?	<p>Allocation of financial resources to develop a network of home caregivers</p> <p>Transfer of roles and responsibilities from doctor to nurse in order to streamline care delivery and to implement appropriate interventions in this case</p>

2. The story of Maria – Advanced level

Maria is a 61-year-old lady who up until very recently had always enjoyed good health. She was an active member of her local church and a devout Orthodox Christian. Maria was a biochemist and worked in the regional cancer research institute, her career mission being to find a cure for cancer.

Maria lives alone in a 2-bedroom house with stairs, which she keeps in immaculate condition. She has a sister, Jane who lives 50 km away. Maria and Jane's relationship isn't a close one, but they contact each other regularly and keep up to date with events in each other's lives. Jane has recently become a grandmother, and is busy helping her daughter to adjust to motherhood.



Eight months ago, Maria was admitted to the emergency department of her local hospital after becoming very unwell, with a four-day history of complaining of severe abdominal cramping, vomiting and the presence of blood in her stool. On admission she was found to be hypotensive and anaemic. A physical examination of her abdomen revealed an enlarged liver. Melena was confirmed by a rectal exam. She appeared mal-nourished, showing signs of muscle wasting, poor skin tone and pallor.

As the nurse recorded Maria's history, Maria explained that she had 'let herself go' recently and had not been taking proper care of herself. She described how she had neglected her nutritional wellbeing, saying that she often didn't feel like eating, or when she did, she would feel sick or bloated soon after.

She had gone down 2 dress sizes in the past few months, but always being a bit on the heavier side, she felt this was a good thing and so didn't pay much attention to it. She attributed her recent health issues to that fact that her team in the research institute was low on staff and she was stressed, tired and exhausted by her work. In addition, Maria was diagnosed with Hepatitis B twenty years ago, and had been living with the virus for years. She assumed all her recent health problems were related to this.

Maria underwent several medical investigations which ultimately revealed she had a locally advanced gallbladder tumour with liver metastases. Maria fully understood the consequence of the diagnosis. She knew that her prognosis was poor and opted for palliative management only. When she was offered the opportunity to become a participant in a clinical trial, she turned it down. She wanted to go home as soon as possible, to be in her own home.

A referral had been made to the palliative home care team who visited Maria 2 weeks after she left the hospital.

During that first visit the team found Maria in severe, uncontrolled pain. She had continued to lose weight with a drop of 3 kg since she left the hospital. She told the team how she got sick after every meal, unable to keep anything down. Physically she had deteriorated, she was only able to move around the house using the furniture to steady herself. For the last 2 nights, she had been unable to get up the stairs and so had slept in an armchair in the living room. Luckily, she had a downstairs toilet.

Maria was also experiencing anxiety and panic attacks. She was low in mood, listless and had withdrawn from any previous social activities and networks that she used to enjoy, not that she had many. She had realised that her life revolved around her work and the only other people she engaged with were her sister and members of her church. Her sister was now too busy being a grandmother,

so she didn't want to bother her, and she was unable to get to church, although she did continue to observe and practice her faith daily. Maria felt alone in the world. The endless days of solitude had led to her reflecting on her life and questioning her choices. Should she have been less career driven? Should she have got married, had a family? She was tormented by the irony of her situation – a high-flying researcher who was going to cure cancer, now facing her impending death as a result of cancer. She felt she had failed, she felt her life had been a failure, and now, she had nothing. She did however have the presence of her own mind, and while she had that she was determined to die on her own terms, in her own home.

Considerations/ discussion points:

- Deterioration of Maria's physical condition and her symptoms, and the ability to manage this in the home setting.
- Patient autonomy and her right to choose to be at home, along with the challenge of ensuring the appropriate care be provided in the home.
- Maria has complex spiritual/existential needs, despite her strong religious faith. How can these needs be addresses?
- Resourcing of support, care, equipment in the community to enable Maria to stay at home.
- Advance care planning and preferred place of care.

3. The story of Maria – Novice level

Maria is a 61-year-old lady who has always enjoyed good health. She is an active member of her local church and a devout Orthodox Christian. Maria is a biochemist and works in the regional cancer research institute, her career mission being to find a cure for cancer.

Maria lives alone in a 2-bedroom house with stairs, which she keeps in immaculate condition. She has a sister, Jane who lives 50km away. Maria and Jane's relationship isn't a close one, but they contact each other regularly and keep up to date with events in each other's lives. Jane has recently become a grandmother, and is busy helping her daughter to adjust to motherhood.



Over the past year, Maria has been struggling at work. She has found her concentration capacity and attention span has been decreasing, with her often 'losing track' of what she is working on. She has completely forgotten several important meetings and events and lost her office and car keys frequently. Her colleagues have noticed her mood has become labile, and she has had heated disagreements with some of them over very trivial matters.

Maria, noticing something was wrong and being the scientist that she is had contacted her GP as she wanted to discuss her cognitive issues. Her doctor referred her to a memory clinic under the care of the psychology team, and over the course of a few weeks assessment they have diagnosed Maria with Early Onset Dementia (EOD).

Maria is meeting the EOD specialist nurse for the first time.

Maria has been devastated by the diagnosis. She feels that she has 'let herself go' recently and has not been taking proper care of herself. She describes how she has neglected her nutritional wellbeing, saying that she often didn't feel like eating, or when she did, she would feel sick soon after. She had gone down 2 dress sizes in the past few months, but always being a bit on the heavier side, she felt this was a good thing and so didn't pay much attention to it. She attributed her recent health issues to that fact that her team in the research institute was low on staff and she was stressed, tired and exhausted by her work.

Since the diagnosis, she has been reflecting on her life and questioning her choices. Should she have been less career driven? Should she have got married, had a family? She is tormented by the irony of her situation – a high-flying career researcher who was going to cure cancer, now facing life with dementia. One thing she is certain of is that she wants to maintain her independence and do things her way. Her biggest fear is losing control completely.

Considerations/ discussion points:

- Deterioration of Maria's condition and her symptoms, and the ability to manage this in the long term.
- Patient autonomy.
- Maria has complex spiritual/existential needs, despite her strong religious faith. How can these needs be addressed?
- Resourcing of support, care, equipment in the community to enable Maria to stay at home.
- Advance care planning and preferred place of care.

The case of Gabriella

1. Vignette

General information	
Patient Demographic data:	Patient G. F., Age: 44 years old, Gender: female, Marital status: married, has a 20-year-old son, Habits: smokes 6-8 cigarettes a day, has 2-3 coffees/day
Underlying disease	Stage III B cervical neoplasm
Co-morbidities	menarche at 14, normal flow menstrual cycle, 1 pregnancy, 6 miscarriages, operated ectopic pregnancy, gastritis.
More detailed description: Medical history	<p>Stage IIIB cervical neoplasm, confirmed by clinical examination and histopathological examination, showing large keratinized cell squamous cell carcinoma.</p> <p>Before the surgery the patient undergoes radiotherapy treatment via Uterovaginal Curie therapy.</p> <p>Before surgery the patient undergoes paraclinical examinations.</p> <p>The operation consists of: radical abdominal hysterectomy with bilateral adnexectomy.</p>
More detailed description: Issues identified: Physical Psycho-emotional Social Spiritual	<p>The patient has a free and intact upper airway, normal chest, lung sounds, vesicular murmur, normal, wide breathing, 18 breaths/minute. Respiratory mucosa is moist with reduced secretions. Heart sounds even, rhythmic, strong, 75 beats/minute, blood pressure is =130/80 mmHg. The skin is warm, pinkish in colour.</p> <p>The usually has her meals on a regular schedule. She has pinkish mucous membranes, no ulcerations, gums are adherent to teeth. Chewing is light, digestion slow and unhindered.</p> <p>Likes pastries, cookies and oranges, consumes about 1800-2000 ml of liquids daily, by drinking coffee, soups, mineral water, etc.</p> <p>The patient weighs 70 kg and is 1.62 m tall.</p> <p>The patient presents painless spontaneous urination with a frequency of 3-4 /day, having yellow colour with clear-transparent appearance and a diuresis of 1300-1400 ml per 24 hours.</p> <p>The intestinal transit is normal.</p> <p>The patient is a tranquil person, shows harmonious coordination of movements, is a polite person, likes to talk a lot.</p> <p>After the surgery she is adynamic, feels weaker, does not have full physical strength, stays in bed more and reads. She refuses to get out of bed, alone, for fear of falling.</p> <p>The patient sleeps well, sleep is restful, the problem is that she falls asleep with difficulty. She sleeps for 6-7 hours a day. The problem is that she has a harder time falling asleep in the hospital as well, showing signs of irritability.</p> <p>The patient states that she likes to wear elegant clothes, she wears make-up. She dresses appropriately to the environment. In the hospital she has her own clothes.</p> <p>She is a clean, neat person, showers daily, is very concerned about her physical appearance. Skin is clean, nails are clean.</p> <p>The patient has a warm complexion with minimal sweating. She states that she likes the summer season. Her normal temperature ranges between 36.2 - 36.9.</p> <p>She adapts to the environment in which she lives and works, knows how to avoid potential conflicts. Adapts easily to new situations.</p>

	<p>She knows little about her current state of health, about her illness, is worried and wants to know what to expect.</p> <p>Mrs. G. F. is an easily sociable person, she talks with pleasure about herself, her family, her job. She likes to talk about the Black Sea, Constanta being her hometown.</p> <p>She is not so easily persuaded to make decisions.</p> <p>She is Pentecostal, she believes in God. She prays daily for her and her family's health. Even if she is not healed, she knows she is "going to the Lord". She considers herself a sinner, now saved. The 6 abortions follow her like a shadow. She believes that through this suffering the Lord has "rewarded her" with redemption/salvation.</p> <p>According to her, she is satisfied with what she has achieved so far in life.</p> <p>The patient takes an interest in her illness, and confidently turns for information to the medical staff in charge of her care.</p>
Care and treatment to date	<p>Needs affected:</p> <ol style="list-style-type: none"> 1. Need to rest and sleep 2. Need to move and have good posture 3. The need to hydrate and feed oneself 4. The need to be clean, neat, to protect the skin and mucous membranes. <p>Addiction problems:</p> <ol style="list-style-type: none"> 1. Discomfort 2. Pain 3. Alteration of the skin and the furrows 4. Gastritis - nausea, vomiting, localized epigastric pain 5. Refusal to move
Particular details of the difficult situation	
Description of the difficult situation from an ethical-moral perspective	<p>Benevolence/non-maleficent</p> <p>Denial of pain control medication for religious reasons</p> <p>Pain versus quality of life</p> <p>Multidisciplinary team's limited willingness to understand, process and get over their own biases led to a limited capacity to provide care</p>
What was the strategy used to approach the case?	<p>The care provided by the multidisciplinary palliative care team was limited, on the one hand by the patient's choices, and on the other by the frustrations and lack of conformity of team members confronted with such spiritual and religious concepts of suffering.</p>
Which of the ethical - moral principles do you consider to have been undermined / ignored / neglected in this case?	<p>Benevolence/ Non-maleficent</p> <p>Autonomy</p> <p>Respect for dignity</p>
Describe your personal perspective (values, feelings, emotions) on the case and how it was resolved	<p>Frustration</p> <p>Helplessness</p> <p>Worry</p> <p>Guilt</p> <p>Professional dissatisfaction</p>
What recommendations do you have for a better handling of the case, one that respects both the patient's and professional values?	<p>Adequate additional training of professionals</p> <p>Assertive communication</p> <p>Moral debate/ deliberation of cases</p>

2. The story of Gabriella – Advanced level

Gabriella is 44 years old and married to Tom. They live with their 20-year-old son Robert in a two-story house in a friendly neighbourhood on the outskirts of the city. Gabriella worked as an interior designer and ran her own very successful business, providing her services to some of the most lucrative residential areas in the region. She enjoys going to the gym and swimming pool to keep herself fit and she is an active member of her local church.

Gabriella and Tom married when they were both 18 and were keen to start a family as soon as they could. They planned to fill their house with children, wanting at least 3. Gabriella however miscarried on six occasions before she was able to carry Robert to full term and deliver him safely. They had such a fear of experiencing more pregnancy loss, that together they decided to stop trying to conceive. They are thankful of Robert as a gift from God and Gabriella prayed daily for his health and that of herself and her husband.

Recently Gabriella has been diagnosed with stage IIIB cervical cancer. A cervical screen a year ago revealed abnormal cells, and a follow up last month resulted in the diagnosis and the start of a cancer treatment journey.

She received neo-adjuvant internal brachytherapy before undergoing a radical hysterectomy with bilateral pelvic lymphadenectomy.

Following the surgery, Gabriella was in good spirits mentally, but she was fatigued and physically deconditioned, finding activities of daily living exhausting. She is eating and drinking well. Her sleep cycle has been disturbed and although her sleep is of good quality when it comes, she struggles to fall asleep at night. She can and does fall asleep in the day, sometimes for up to 7 hours. When she is awake, she doesn't move around very much, afraid that she may fall and damage herself further, preferring to stay in bed and read her books. She frequently asked if she can be taken outside the building in a wheelchair so she can have a cigarette.

Gabriella feels like the diagnosis and treatment has all happened so fast, that she doesn't really fully understand what has happened to her, nor what lies ahead in the future. During the long sleepless nights, she ruminates on her life so far. She is proud of her son, and all she has achieved in her life, marriage and work. She is however tormented by the memory of her 6 pregnancy losses and wonders if her current suffering will result in her redemption and salvation with her Lord. Gabriella is evidently in pain; however, she refuses to admit this or to take the analgesia prescribed as to do so would be to relieve this suffering and risk her redemption.

Gabriella is confident in her clinical team and a meeting is scheduled, to include Gabriella, Tom and Robert to discuss future care planning.



Considerations/ discussion points:

- Potential significance of diagnosis on future independence and ability.
- Balancing rest and activity to address fatigue and physical condition.
- Symptom management.
- Denial of pain control.
- Spiritual needs around the meaning and significance Gabriella places on the experience of suffering versus the relief of pain/quality of life.
- Sleep cycle disturbance.
- Advance care planning and preferred place of care.
- Communicating sensitive issues.

3. The story of Gabriella – Novice level

Gabriella is 44 years old and married to Tom. They live with their 20-year-old son Robert in a two story house in a friendly neighbourhood on the outskirts of the city. Gabriella worked as an interior designer and ran her own very successful business, providing her services to some of the most lucrative residential areas in the region. She enjoys going to the gym and swimming pool to keep herself fit and she is an active member of her local church.

Gabriella and Tom married when they were both 18 and were keen to start a family as soon as they could. They planned to fill their house with children, wanting at least 3. Gabriella however miscarried on six occasions before she was able to carry Robert to full term and deliver him safely. They had such a fear of experiencing more pregnancy loss, that together they decided to stop trying to conceive. They are thankful of Robert as a gift from God and Gabriella prayed daily for his health and that of herself and her husband.

Recently Gabriella has been diagnosed with Amyotrophic Lateral Sclerosis (ALS).

Gabriella is in good spirits mentally, but she is fatigued and finding activities of daily living exhausting. She has weakness in both upper and lower limbs, her mobility is much reduced, and she needs help with many daily tasks. She has frequent muscle spasms and cramps which are painful. She is eating and drinking well. Her sleep cycle is disturbed and although her sleep is of good quality when it comes, she struggles to fall asleep at night. She can and does fall asleep in the day, sometimes for up to 7 hours. When she is awake, she doesn't move around very much, afraid that she may fall or trip preferring to stay in bed and read her books. She frequently asks if she can be taken outside the building in a wheelchair so she can have a cigarette.

Gabriella feels like the diagnosis and physical deterioration has all happened so fast, and she doesn't really fully understand what has happened to her, nor what lies ahead in the future. During the long sleepless nights, she ruminates on her life so far. She is proud of her son, and all she has achieved in her life, marriage and work. She is however tormented by the memory of her 6 pregnancy losses and wonders if her current suffering will result in her redemption and salvation with her Lord. Gabriella is evidently in pain; however, she refuses to admit this or to take the analgesia prescribed as to do so would be to relieve this suffering and risk her redemption.

Gabriella is confident in her clinical team and a meeting is scheduled, to include Gabriella, Tom and Robert to discuss future care planning.



Considerations/ discussion points:

- Potential significance of diagnosis on future independence and ability.
- Balancing rest and activity to address fatigue and physical condition.
- Symptom management.
- Denial of pain control.
- Spiritual needs around the meaning and significance Gabriella places on the experience of suffering versus the relief of pain/quality of life.
- Sleep cycle disturbance.
- Advance care planning and preferred place of care.
- Communicating sensitive issues.
- Grief.

The case of Bruno

1. Vignette

General information	
Patient Demographic data:	B.I. aged 53, single, unemployed He is accompanied to the hospital by his mother, in whose house he lives
Underlying disease	HIV infection AIDS stage
Co-morbidities	Diabetes mellitus, lower right limb amputated Mild heart attack
More detailed description: Medical history	<p>Tendency to isolate himself, refusal of food, refusal of personal hygiene, refusal of communication, psychomotor restlessness, decrease of initiative and interest in hobbies. He likes to consume alcoholic beverages even though the doctor explained the harmful effect on his health. He refuses to go on a diet so he reaches a weight of 104 kg with a height of 1.68 m. His B.A.=146/85 Unkempt clothing shows depressive moods, limited communication, low-pitch voice, depressive ideation, reduced gestures.</p> <p>The patient is uncooperative with marked anxiety and in moral distress. Does not look at the interlocutor, respects the reciprocity of the dialogue. Capacity of self-conduct and self-care partially disturbed. Dress attire is deficient. Has a sober look aimed downwards.</p> <p>Verbal discourse is difficult, there is a long delay between question and answer. He has a sad mood, rebellious insomnia, a negative opinion of himself and shows social isolation.</p> <p>The timing and context of HIV infection is unknown. The mother blames the lack of continuous supervision in the hospital for the HIV infection.</p>
More detailed description: Issues identified: Physical Psycho-emotional Social Spiritual	<p>Generalized neuropathic pain, VAS 10/10, alopecia, antalgic squatting position with knees to the chest</p> <p>The patient's mother is legally designated to make decisions for him because he is a non-communicative, introverted person, cannot make rational decisions and is always afraid that something bad will happen to him that he cannot cope with. He has a hard time adapting to new places (hospitalisation), and he manages to collaborate with and talk to few people.</p>
Care and treatment to date	Antiretrovirals Refuses food and hydration
Particular details of the difficult situation	
Description of the difficult situation from an ethical-moral perspective	<p>According to him, the patient says that if he is going to be a burden to his mother, then he wants to be euthanized. He has this idea in his mind and he repeats it over and over again not wanting to listen to the advice and opinions of other people or doctors. It is an idea that he repeats over and over again, obsessively. He says that he isn't a danger to himself and therefore, doesn't want his mother to take care of him, which would cause a lot of pain and suffering to both parties for many years to come. Thus, he would rather die. Euthanasia comes from the Greek word "eu", meaning "good", and "thanatos", meaning "death", meaning the voluntary induction of death in a person suffering from an incurable disease, with the intention of preventing suffering.</p>
What was the strategy used to approach the case?	<p>The patient was listened to, understood and valued for what he is, beyond the limits imposed by a strictly medical diagnosis. It is not often that we hear patients thanking staff for this attitude, as the hardest thing is to face prejudice and public ignominy</p>
Which of the ethical - moral principles do you consider to	<p>Providing care and treatment for patients with stigma: HIV infection/AIDS Euthanasia as the only possible alternative from a patient's point of view</p>

have been undermined / ignored / neglected in this case?	
Describe your personal perspective (values, feelings, emotions) on the case and how it was resolved	<p>As a nurse I aim to:</p> <p>a) Prevent suicidal risk</p> <ul style="list-style-type: none"> - establish a therapeutic relationship with the patient to meet his needs, to monitor suicidal risk - provide a warm and safe atmosphere - remove any dangerous objects, drugs or toxic substances that could harm him - supervise the patient closely - administer medically prescribed treatment - engage the patient in various activities such as reading, crossword puzzles, ward conversations - help the patient relieve discomfort by promoting emotional support - encourage the patient to open up, speak in a calm voice, use short, easy-to-understand sentences - show understanding, warmth and honesty <p>b) I help the patient to eat properly:</p> <ul style="list-style-type: none"> - with the help of the patient's mother, I provide him with his favourite foods - I encourage the patient to eat in the dining room <p>c) I create conditions for the patient to have a peaceful sleep:</p> <ul style="list-style-type: none"> - I provide the patient with a calm and safe environment - I provide the comfort of airy room and clean clothes - I talk to the patient and seek to identify the causes of sleep disturbance <p>d) I help them understand the need for personal hygiene:</p> <ul style="list-style-type: none"> - I make sure the patient has a towel, soap, shampoo, toothpaste, clean clothes - I remind him of the need to maintain his hygiene - I supervise the patient and encourage him to take care of his body and clothing. - I advise him to brush his teeth at least twice a day - I remind him that a warm bath before bedtime is beneficial <p>e) I talk to him and help him stop being socially isolated</p> <ul style="list-style-type: none"> - I adopt an attitude that encourages the patient to express his feelings and needs - I give the patient the opportunity to participate in different activities that have made him useful and valued - I explain to the patient that he does not have to dwell on past failures - I praise the patient's past achievements - I avoid criticism when discussing with the patient - Discussing with the patient, I establish a schedule of activities according to his possibilities
What recommendations do you have for a better handling of the case, one that respects both the patient's and professional values?	<p>Adequate additional training of palliative care professionals to deal with situations where euthanasia is requested</p> <p>Additional appropriate training of palliative care professionals to provide quality, non-judgmental and equitable care for all types of patients, regardless of their sexual preferences or medical conditions</p>

2. The story of Bruno – Advanced level

Bruno is 53 years old and lives with his mother Julia in a two-story house in the city. Bruno has recently been admitted to the hospital for a full assessment and has been referred to the palliative care team for support with symptom management.

Bruno has been diagnosed with HIV infection which has progressed to the AIDS stage. It is not known where or how Bruno contracted the virus. Some years ago, Bruno had his right lower limb amputated because of Diabetes Mellitus and he has also suffered a mild heart attack.

When he arrives at the hospital he is in poor physical state and unkempt in his appearance. He is non-communicative and avoids making eye contact with anyone, his gaze constantly averted towards the floor.



Julia has been legally appointed to be Bruno's designated decision maker, including for the purposes of making healthcare decisions. She has arranged his admission to hospital as she was becoming increasingly concerned about his low mood and self-neglect and his talk of 'ending it all'.

Bruno indicates on a visual analogue scale that he is experiencing pain at the level of 10/10. He adopts a crouched position, bringing his knees to his chest to relieve the pain. He appears to be in emotional distress and appears anxious in the hospital surroundings. He refuses to eat or drink any food or fluids that are provided to him. He makes no attempt to interact with the world around him.

The palliative care nurse has just been to visit Bruno. They spent nearly an hour in his room, and although most of the conversation was provided by the nurse, Bruno did mutter few words. He told the nurse that his wish was to be euthanized, that he was aware he was a burden and that he didn't want to cause any more pain or suffering to himself or his mother.

Considerations/discussion points:

- Symptom assessment and management.
- Provision of basic care and attention to basic care needs.
- Fears and concerns.
- Finding hope in the face of despair and hopelessness.
- Quality of life – what is Bruno willing to sacrifice, what is he not willing to sacrifice.
- Addressing of spiritual and existential needs.
- Assessment of mental health needs.
- Prognostic uncertainty.
- Patient autonomy.
- Decision making rights and responsibilities.
- Feelings of being a burden.
- Communication verbal and non-verbal.
- Support for Julia.

3. The story of Bruno – Novice level

Bruno is 53 years old and lives with his mother Julia in a two-story house in the city. Bruno has recently been admitted to the hospital for a full assessment and has been referred to the palliative care team for support with symptom management.

Bruno has been diagnosed with HIV infection which has progressed to the AIDS stage. It is not known where or how Bruno contracted the virus. Some years ago, Bruno had his right lower limb amputated because of Diabetes Mellitus and he has also suffered a mild heart attack.

When he arrives at the hospital he is in poor physical state and unkempt in his appearance. He is non-communicative and avoids making eye contact with anyone, his gaze constantly averted towards the floor.



Considerations/discussion points:

- How will you approach this patient and his mother in the communication process in order to make the tension of the situation less intense?
- What symptoms, in your professional opinion, will be more prevalent in this stage of the disease?
- In the plan of care, what will be the first three priorities that you will focus on as the case coordinator?