

Intellectual Output 0

The Book of Cases

Patient stories – Advanced level



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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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Content

Preface	1
Acknowledgements	2
The story of Lukas – Advanced level	4
The story of Elena – Advanced level.....	6
The story of John – Advanced level.....	8
The story of Patricia – Advanced level	10
The story of Suzanna – Advanced level.....	12
The story of Amy – Advanced level	14
The story of David – Advanced level	15
The story of Maria – Advanced level.....	17
The story of Gabriella – Advanced level.....	19
The story of Bruno – Advanced level.....	21

Preface

This document is part of the *Book of Cases*: it only contains the advance level patient stories. The entire *Book of Cases* can be downloaded from the project website.

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 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.

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 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.

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.

The story of John – Advanced 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 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.

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 cause 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.

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.

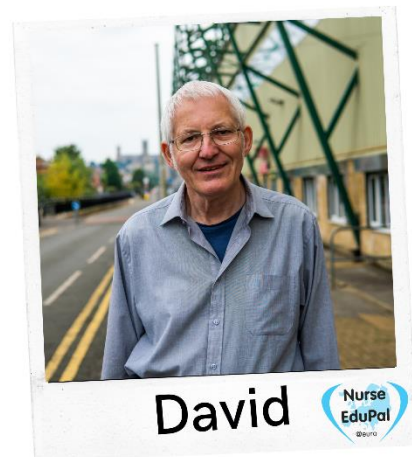
Considerations/discussion points:

- 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.

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?

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.

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.

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.