

Intellectual Output 0

The Book of Cases

Patient stories – Novice level



Co-funded by the
Erasmus+ Programme
of the European Union



This project has received funding from the European Union's ERASMUS+ programme KA203 – Strategic Partnerships for higher education – under grant agreement number 2020-1-BE02-KA203-074740

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 core competencies and their representation in the novice stories	3
The story of Lukas – Novice level	4
The story of Elena – Novice level	6
The story of John – Novice level.....	7
The story of Patricia – Novice level	9
The story of Suzanna – Novice level.....	11
The story of Amy – Novice level	12
The story of David – Novice level	13
The story of Maria – Novice level.....	15
The story of Gabriella – Novice level.....	16
The story of Bruno – Novice level	18

Preface

This document is part of the *Book of Cases*: it only contains the novice 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 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 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 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 story of John – 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 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 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.

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 on the course of treatment, Suzanna was delighted to be told by her oncologist that she was cancer free.



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 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 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 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 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 – 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 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?