

## Case Report

**Anticipatory Care Plan for End-Stage Chronic Kidney Patients – Case Report**

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**Abstract**

Chronic Kidney Disease is characterized by progressive, persistent, and irreversible loss of kidney function, with a high prevalence and increasing trend in the population. An important observation, common to all recent studies, is the constant changes experienced by these individuals. Analytical changes, health status and the patient's preferences should be



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considered when planning anticipatory care at any phase of the disease. To comprehend the significance of the Anticipatory Care Plan for Patients with End-Stage Chronic Kidney Disease, a descriptive case report was conducted following the Case Report (CARE) guidelines. This case involves an 87-year-old male undergoing hemodialysis since 2020. His medical history includes diabetes, chronic wounds in the lower limbs, and frequent emergency room visits due to severe dyspnea and worsening of wound conditions. Upon observation, the patient appeared to be in significant distress, with generalized edema, skin the presence of respiratory noises and dyspnea, dry skin, and complaining of grade 7 pain in the lower limbs. The family had limited information about the situation. Symptomatic management of pain and dyspnea became imperative, alongside the determination of an appropriate anticipatory care plan. The case report highlights the necessity and importance of implementing an anticipatory care plan so that, even at the end of life, the wishes of the patient and their family are fulfilled, improving the quality of life for both. Developing the anticipatory care plan at an earlier stage, with the involvement of the patient, family, and healthcare professionals, is associated with improved patient comfort outcomes.

### **Keywords**

Palliative care; case study; chronic kidney disease; anticipatory care planning; shared decision-making

## **1. Introduction**

Chronic kidney Disease (CKD) is a pathology characterized by a progressive and irreversible loss of kidney function [1]. The prevalence of CKD is high in the population. Approximately 10% of the adult population worldwide is estimated to be affected by some stage of CKD. In 2017, CKD led to about 1.2 million deaths and about 36 million years of life lost adjusted for disability, an estimated 2.2 million deaths in 2040 [2]. Portugal is one of the countries in the world with the highest prevalence of CKD, ranking first at the European level. There are several factors that contribute to these data, namely population aging and the high prevalence of Diabetes Mellitus and Hypertension [2].

When patients reach stage 5 of the disease, also known as end-stage CKD, treatment options include Renal Replacement Therapy, such as dialysis (peritoneal or hemodialysis), kidney transplant, or conservative treatment [2]. Patients with end-stage CKD on hemodialysis experience a series of changes and limitations that affect biological, psychological, and social aspects of their lives. The routine imposed by the treatment is exhaustive, as patients go to dialysis clinics twice or three times a week for three to four hours/session. This routine significantly disrupts their daily and work activities, generating financial dependence in addition to negatively impacting their quality of life [3-6].

Contemporary models show that most healthcare provided to people with chronic diseases is based on the principles and philosophies of Palliative Care (PC) [7]. CKD is a progressive and debilitating disease that makes patients extremely vulnerable, interfering with their concept of quality of life and personal identity. Therefore, there must be tools available that allow us to monitor

the impact of this disease in different areas, facilitating a better understanding and planning of the work of all professionals [7]. In addition, this monitoring can ensure and justify, in a more secure and evidence-based manner, the need for any adjustments, changes, or suspensions to be made throughout the disease process [8]. The introduction of PC in the nephrology curriculum should include not only symptom relief and spiritual and psychosocial support but also the Anticipatory Care Plan (ACP) (which sometimes involves ethical aspects in decision-making) [9].

The ACP is a process of discussions between healthcare professionals and patients/families. This allows for shared decision-making regarding current and/or future healthcare goals based on the patient's wishes and values, including technical aspects of care [10-13]. Furthermore, implementing ACP should be considered a priority in healthcare practices, as recommended by the European Association for Palliative Care [14].

## **2. Materials and Methods**

### **2.1 Case Report**

This is a case report developed by the CARE guidelines [15]. It covers a research methodology that explains the importance of implementing an ACP in all patients with end-stage CKD. The case report presented here concerns an individual who, after being hospitalized for about two months in the surgery department and undergoing hemodialysis, was discharged home, where he eventually passed away. Therefore, considering comfort should be a priority in any stage of the disease, this case report is based on Katharine Kolcaba's comfort theory [16].

All nursing interventions, whether pharmacological or non-pharmacological, and the collaborative efforts of multidisciplinary teams share a common goal: to address the three types of comfort outlined in Comfort Theory, precisely relief (symptom control), tranquility (satisfaction and calm), and transcendence (overcoming problems). The main objective of nursing interventions is to contribute to the maintenance and promotion of health, defining that those who receive comfort care may be patients, families or communities [17]. Kolcaba, in her Comfort Theory, emphasizes that comfort needs can be experienced in four domains: physical, environmental, psychosocial, and sociocultural [17].

It should be noted that in this case, confidentiality and safety in approaching the individual, as well as permission to disclose the data presented in this study, were always guaranteed.

The selection criteria for this case report were: hemodialysis as the current therapy for renal replacement; Palliative Performance Scale (PPS) [18] 30-20%; Karnofsky Performance Scale [19] <40%; Charlson comorbidity index [20] >8; the answer "no" to the surprise question "Would you be surprised if this patient died in the next six months?" [21]; Integrated Palliative Care Outcome Scale – Renal (IPOS RENAL) [2] with at least one symptom and with the presence of pain according to the numerical pain scale [22].

### **2.2 Description of the Case**

This is a case report of a male individual, 87 years old, of Portuguese nationality. He presented with the following comorbidities: hypertension, diabetes, ischemic heart disease and end-stage CKD.

In February 2020, this patient entered the emergency room with dyspnea, serum albumin of 3.5 g/dL and creatinine clearance <15 mL/min. Already being followed by the nephrology team at the

hospital, he had just entered the last stage of CKD. He underwent hemodialysis at a private clinic until the end of January 2024. Even though at that time, the medical team was willing to continue hemodialysis treatment at the hospital for his better comfort and maximum surveillance, the patient and his family, whenever possible, refused. At that time, the Karnofsky Performance Scale was 60% and the Charlson comorbidity index was already greater than 8.

He underwent several rounds of antibiotics because of the negative evolution of wounds in the lower limbs and began periods of confusion and agitation that worsened during hemodialysis. Due to all this and the constant discomfort during the 4 hours of hemodialysis treatment, in early March, the medical team, together with the family, adjusted the care plan and reduced the time of each dialysis session. The increase in fragility and the worsening of diabetic wounds in the lower limbs were factors that led to the decision to proceed with the transfer of hemodialysis from the clinic to the hospital setting.

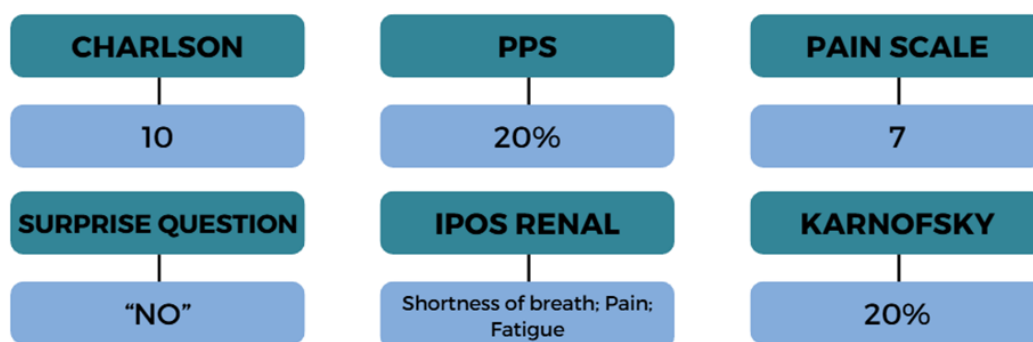
During hospitalization, two attempts were made to refer the patient to PC, which never materialized due to the family's refusal. The family, actively involved in the patient's care, comprised the wife, two daughters and several granddaughters. Regarding this family, and according to the nursing records, one of the daughters presents a discourse that creates unrealistic expectations for her mother about her father's general condition, showing herself to be out of sync with the situation. After the PCR values improved and 90% of the wounds had already been mummified, the family was called to the surgery department, and the possibility of discharge was discussed. At this stage, the family was aware of the scheduling of a family conference to plan their hospital discharge adequately. Several health specialties would be present.

The patient exhibited signs of significant discomfort, reporting grade 7 pain on the numerical pain scale, despite limited verbal communication. Stiff, using oxygen and with edema, we were dealing with a weak patient and with palliative needs.

After the family accepted the family conference, the nephrology team contacted the PC team and requested a preliminary patient observation to obtain assistance in the therapeutic decision-making process, particularly regarding hemodialysis treatments. The meeting included the patient's wife and granddaughter, nephrologist, surgeon, PC physician, social worker, and a master's degree student in medical surgery - a person in a PC situation.

### 2.2.1 Assessment

Considering the inclusion criteria mentioned above, Figure 1 outlines the assessment measures after this observation by the PC team of the patient.



**Figure 1** Assessment measures.

In terms of analytical values, we were dealing with an anemic patient (8.4 g/dL), uremic (90 mg/dL), with a creatinine of 4.78 mg/dL, and with hypoalbuminemia (31 g/L).

### 2.2.2 Assessment of the Patient According to Kolcaba's Domains

Still regarding the assessment carried out by the team during the first approach to the patient in this study, the nurse considered the Kolcaba domains, with the aim of identifying the patient's evidence and concerns at that stage of their disease (Figure 2).

Physical	- Pain from fistula puncture; - Altered image;
Environmental	- Noise in the hospital; - Lack of privacy; - Cold in the ward
Psycho-spiritual	- Suffering; - Fear, - Frustration
Sociocultural	- Restrictions on fluids and food

**Figure 2** Initial assessment of the patient according to Kolcaba's domains.

### 2.2.3 Timeline

After all these procedures, a family conference was scheduled for April 2024, with the primary objective of discussing the ACP—Figure 3 shows, schematically, the progression of events and critical moments of this case over time.

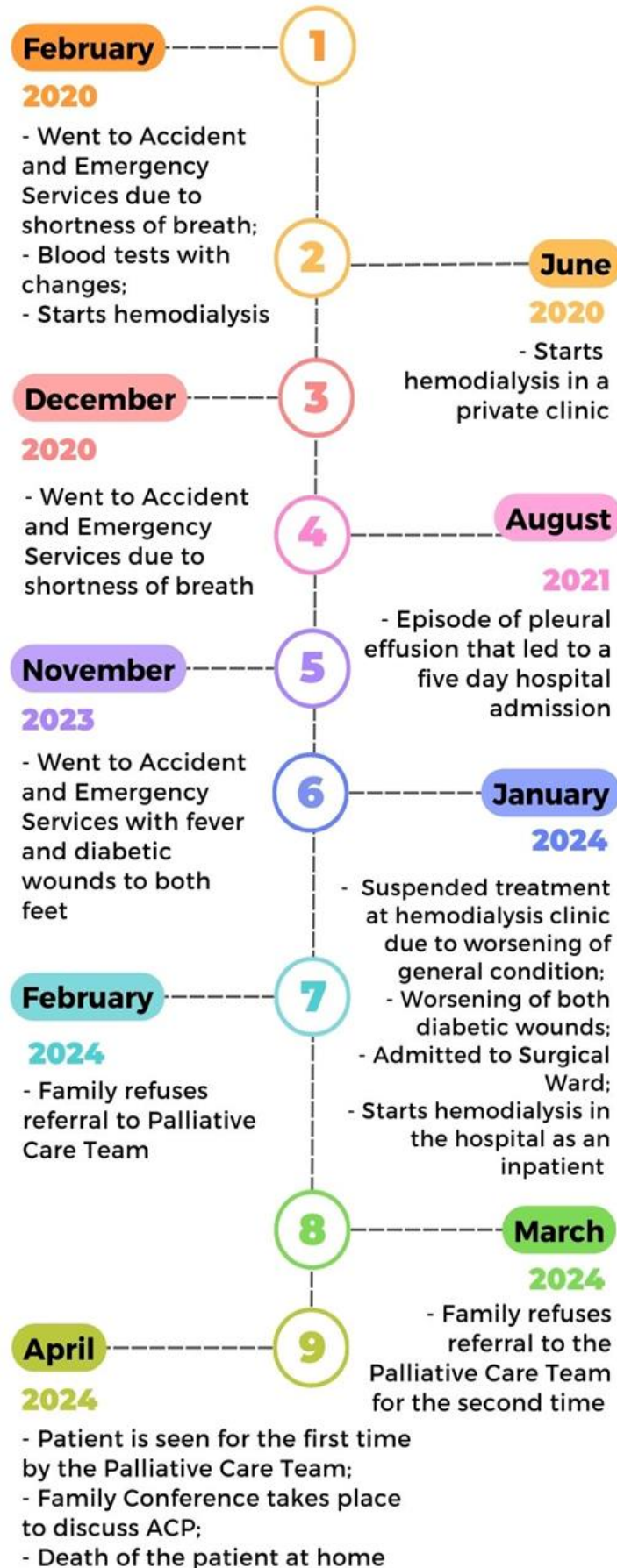


Figure 3 Timeline.

### 3. Clinical Findings

The PC interventions were carried out over approximately 15 days following the family conference. It is essential to understand how this process unfolded to appreciate its impact fully. Initially, it was observed that the family had limited knowledge about PC. To address this, introductory explanations were provided, an effective “icebreaker” to foster open communication and establish trust. The benefits of PC interventions for the patient at this stage were thoroughly explained, emphasizing the flexibility of anticipatory care, which could be adjusted at any time in response to changes in the patient’s condition.

Expectations were meticulously managed, and all participants were encouraged to express their thoughts and concerns regarding the patient’s well-being. Regarding surgical care, the physician highlighted the likely worsening of wounds if treated at home, ensuring that opioid medication would be available to address any resulting pain. Psychological support was also offered immediately to the family members present, assuring that this assistance could be extended to other relatives if needed. In addition, the PC physician addressed the eventual cessation of hemodialysis, explaining that there would come a point when the treatment would no longer benefit the patient. The physician reassured the family, emphasizing that, at this stage, the primary focus should be on the patient’s comfort and quality of life.

The nurse, based on the assessment tools used, reinforced the high burden of symptoms observed at this stage of the disease. Being the healthcare professional on the team who spends the most time with the patient, he emphasized, especially at this stage, that the main objective of care is to promote quality of life and comfort for the individual. Next, it was agreed that the patient would be discharged from the hospital, as this was the wish expressed by the patient several times. However, given that his health status was very fragile, it was decided to maintain hemodialysis at the hospital, despite the patient's preference for treatment at the clinic.

Several treatment hypotheses were considered about hemodialysis. Initially, a reduction in the number of sessions and the time per session was considered. It was even supposed to suspend hemodialysis, an option that the family did not accept immediately. Still, it remained a possibility should it be noticed that the journey from home to the hospital was very tiring and uncomfortable for the patient or if he was not hemodynamically stable during the dialysis session remains on dialysis treatment.

In addition to all these considerations, and as a result of the complex interactions during this period, it was revealed that the patient had been receiving physiotherapy and occupational therapy at home prior to hospitalization. However, it was determined that at this stage, the disadvantages of continuing these interventions outweighed the benefits, as they risked causing unnecessary fatigue and pain. Consequently, the care plan was adjusted. Initially, only the duration of each hemodialysis session was reduced, from 3.5 to 3 hours. After the first session under this revised schedule, during which the patient experienced hypotension, nausea, and significant weakness upon returning home, it was decided further to reduce the frequency to two sessions per week, each lasting 3 hours.

Under this modified regimen, the patient received comprehensive care for approximately two weeks, supported by a multidisciplinary team tailored to his needs. Symptoms were meticulously managed throughout all hemodialysis sessions, including pain and dyspnea, through a comprehensive approach involving pharmacological interventions (morphine) and non-

pharmacological measures, such as repositioning the patient in bed during treatment, alongside the provision of emotional and spiritual support. During the patient's final treatment, symptoms of shallow breathing, persistent vocal expressions of discomfort, and extensive edemas unresponsive to hemodialysis were noted. At this point, it was decided to discontinue treatment altogether, with the family being informed and actively involved in every step of the decision-making process.

The decision to suspend dialysis treatments was made collaboratively by the multidisciplinary team and the patient's family, following a thorough review of the ACP and the patient's clinical progression. Rather than an explicit choice by the patient to withdraw from dialysis, the decision was reached gradually, to taper the treatments as they became less effective.

The medical team, including nephrologists, nurses, and social workers, worked closely with the family, considering not only the clinical aspects of the patient's condition but also the emotional well-being and quality of life of the patient. Throughout this process, the benefits and limitations of dialysis treatments were discussed, considering the patient's prognosis and health status. The conclusion was that the continuation of dialysis would, at a certain point, no longer be beneficial to the patient, both physically and emotionally. It was, therefore, agreed that the most appropriate approach would be to gradually reduce the frequency of dialysis sessions until the treatments were no longer technically feasible or beneficial, with constant monitoring of the patient's clinical progression and quality of life. This decision was based on a holistic analysis, involving the family in understanding the effects of withdrawing treatment, with the primary goal of ensuring that the patient received the most appropriate and compassionate care given their circumstances.

The patient's preferred place of death was respected, as they passed away surrounded by their family at home. The patient died the day after the last hemodialysis session, two weeks after the intervention of the specialized team.

#### **4. Discussion**

In Portugal, several studies indicate that the preferred place for patients to die is at home. Reasons such as representing a "haven", a place of familiar references, where dignity is maintained, autonomy is generally granted, and family relationships are maintained constantly and favorably, mark the moment of decision [23-25]. Prognostic assessment is a very relevant issue for decision-making for patients/families with end-stage CKD. Defining a prognosis helps to identify the patients with whom it is a priority to discuss goals in terms of treatment and the course of the disease [26]. However, the unpredictability of CKD makes creating tools for prognostic assessment challenging, often leaving healthcare professionals with limited options.

The 2015 KDIGO [27] recommends two valuable tools for CKD prognosis: the surprise question and the Modified Karnofsky activity scale. In this case report, both tools were applied effectively, particularly during the family conference, providing crucial information about the patient's worsening condition. While all patients with CKD would, to some extent, benefit from PC, especially those in advanced stages of the disease, discussions about PC are not always initiated promptly, regardless of whether patients are on dialysis [5, 28]. In this case, the PC team had already introduced the benefits of palliative care during hospitalization. Although initially met with resistance, this discussion proved instrumental in guiding the family throughout the process.

Despite the growing recognition of the need for PC among the broader population, misconceptions persist, such as the belief that PC is exclusively for terminally ill cancer patients [29,



30]. Research shows that patients with non-cancerous chronic diseases experience a comparable burden of symptoms and require PC to a similar extent as cancer patients. However, these patients are often referred for PC less frequently, highlighting a notable discrepancy in care [31-33]. Historically, integrated end-of-life follow-up was considered essential only for patients with short life expectancy, particularly cancer patients. This perspective has been shifting, with increasing acknowledgment of the need for PC in patients with non-cancerous chronic illnesses [33]. Expanding access to PCs and fostering discussions on topics such as advance directives can significantly enhance the quality of end-of-life care for patients with end-stage CKD [9].

In this case report, re-evaluating the care plan was essential as the patient's condition progressed. The PC team assumed a pivotal role, prioritizing the patient's comfort while effectively managing expectations for the family and the broader healthcare team. Although other medical specialties focus on curative interventions, in this particular case, the PC team in this case provided essential guidance to manage expectations. Their approach was centered on the patient's well-being and comfort, ensuring alignment between the family, the medical team, and the patient's condition while considering the relevant medical realities.

Managing expectations presents a wide range of complexities across various contexts. These include considerations of indispensable treatments, as well as clinical decisions that necessitate ongoing negotiation with the patient to ensure their expectations are realistic and aligned with the achievable outcomes of treatment [34].

In this case report, the patient's death aligned with the five dimensions of comfort:

1. **Physical comfort:** Pain and dyspnea were managed effectively, ensuring the patient experienced minimal physical distress in their final days.
2. **Psychological comfort:** The patient was supported emotionally, with clear and empathetic communication that helped reduce anxiety and foster a sense of peace.
3. **Social comfort:** The patient's desire to be surrounded by family was respected, reinforcing the importance of maintaining strong social bonds.
4. **Spiritual comfort:** The team ensured that the patient's values and beliefs were honored, providing a sense of meaning and dignity at the end of life.
5. **Environmental comfort:** The patient's wish to die at home, in a familiar and safe setting, was fulfilled, contributing to a sense of control and tranquility.

These dimensions underline the importance of a holistic approach to care, ensuring that the patient's needs and preferences are prioritized throughout the process. In addition, the challenges faced by patients and their families often extend to bureaucratic matters, such as inheritance issues, as well as personal concerns that may significantly impact a patient's emotional state throughout the process. Regardless of the specific context or the difficulties encountered, it is during times of heightened suffering that the relationship between the patient and the healthcare professional must be further strengthened [34]. In these moments, it becomes essential to demonstrate honesty, respect, and empathy, fostering trust not only in the patient but also in their family. Such an approach helps to build a strong therapeutic bond, offering crucial support during periods of heightened anxiety and distress [35]. However, a recurring issue highlighted in the literature is the difficulty healthcare teams, particularly those not specialized in palliative care, face in delivering bad news [36].

How bad news is delivered has a lasting impact on the patient and/or family, affecting the expression of feelings, the adaptation process to the situation and satisfaction with the healthcare

service [37]. Doing so consciously and securely can bring benefits in the short term in helping the relationship established between peers. Practical, transparent and appropriate communication between patients, healthcare professionals, family members and caregivers, facilitating the decision-making process is one of the pillars of PC and plays a crucial role in this approach [38]. Communication becomes a significant tool that seeks to intervene in human relationships, promoting sustainability and consolidation of autonomy, always encouraging the individual to express their feelings, concerns and doubts, thus fostering a strong bond between the healthcare professional, the patient and the family, strengthening the interpersonal relationship, allowing the patient to feel cared for, supported, comforted and understood [36].

Thus, the ACP emerges as a component that combines all these concepts, aiming for the best for the patient. For the patient, the ACP allows for greater autonomy, ensuring respect for their dignity and privacy at the time of death, improving their quality of life, reducing their anxiety levels and reducing the need for hospitalization and eventual Continuous Care Units [38, 39]. For family members, it makes dealing with any decision-making processes they may be subject to if the patient cannot do so, reduces stress and anxiety associated with the situation, and makes the eventual grieving process easier [38]. For healthcare professionals, the ACP allows for prior knowledge of the patient's preferences and decisions, making it easier to manage costs and resources associated with healthcare [38].

In this case report, and because of the application of the ACP in this situation, it was possible to promote comfort for the patient, support for the family and also respect the patient's wishes in two ways: planning discharge and allowing the patient to die at home, with his family.

Finally, a significant challenge in this context is that, despite the recognized value of palliative care, healthcare professionals often report difficulties in its implementation. These challenges arise not only from uncertainty about the appropriate timing for initiation but also from a lack of adequate skills to engage in such discussions with patients [40]. Moreover, it would be far more effective, both in this case and for all patients with end-stage CKD, to implement an ACP proactively and promptly rather than delaying until the patient reaches a more terminal stage.

## **5. Conclusions**

The increasing involvement of PC teams for patients with end-stage CKD is understood. There is sufficient evidence that justifies the development of an ACP, as a key process aimed at improving end-of-life care, and, therefore, it should be routinely integrated into clinical practice by all the team that follows a patient with end-stage CKD.

The earlier these discussions are initiated, the greater the chances that the patient will receive treatment that meets his wishes and values, which will be reflected in a better quality of life. In addition, this allows for a lesser emotional burden on family members and a reduction in costs associated with disproportionate interventions.

## **Abbreviations**

CKD	Chronic kidney Disease
g/dL	grams per deciliter
IPOS-RENAL	Integrated Palliative Care Outcome Scale - Renal
mL/min	milliliters per minute

ACP	Anticipatory Care Plan
PC	Palliative Care
PPS	Palliative Performance Scale

### Author Contributions

The contribution of each author is as follows: Ana Marta Menezes, the identification of the person for case report and the writing of the article; Dalila Silva and Catarina Simões, the analysis and revision of the article; Rita Figueiredo the final revision of the article. All authors reviewed and approved the article before submission and provided final approval of the article.

### Competing Interests

The authors have declared that no competing interests exist.

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