



# Support for a Patient's Family Member Acting as Key Person in a Patient's Discharge Procedure

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## Abstract

**Objective:** To clarify the support practices for a patient's family member who assumes the role of key person in decision-making regarding the post-discharge housing of a patient with terminal cancer.

**Methods:** The research was conducted as a case study. Data were collected by reviewing and chronologically organizing the nursing records and practice notes of the discharge support nurses responsible for the patient. The analysis summarized the patient's progress and the nursing practices of the discharge nurses and family support nurses. This included responsibilities related to the patient's symptoms, care, and family members' situations and assessments, as well as nursing support for the family members from admission to discharge. It also involved reviewing the questions, thoughts, and intentions that led to decisions at that time, based on the patient's progress chart. Ethical considerations were approved by the institutional review board.

**Results:** This case study concerned a patient with terminal kidney cancer whose discharge destination from the hospital was difficult to determine because his family could not decide who would serve as the key person. The discharge support nurse and the family support nurse worked together to gather information about the family structure and relationships and to assess the family situation. This revealed a pattern in which the patient had no family member to consult, and had, until then, held the sole authority to make decisions. The discharge support nurse attempted to determine how to resolve the family's problems based on the family structure and internal relationships, and attempted to intervene. As a result, the second son became the new key person. With psychological support from the discharge support nurse, the family bonds were strengthened, leading to a satisfactory discharge for both the patient and his family.

**Discussion:** We believe that healthcare providers should not choose a surrogate-decision maker to be the key person based on their own values, but should rather guide the patient and their family toward discharge based on the family's characteristics and relationships.

## Introduction

Recently, the number of nuclear families and single-person households has been increasing in Japan, resulting in the shrinking of the family structure. In medical care, family members of patients are required to make various decisions, such as choosing a treatment plan and deciding where to receive care, as medical care becomes increasingly sophisticated. However, patients with cognitive decline due to aging or impaired daily activities due to illness are more likely to have difficulty making decisions on their own. In 2021, the Ministry of Health, Labour and Welfare (MHLW) developed a guideline for decision support, which states that appropriate information and explanations from healthcare professionals should be repeatedly discussed with patients and their family members as time passes and their physical and mental conditions change [1]. Acute care hospitals in Japan encourage discharge to home or to an institution to reduce the length of stay, and according to a 2024 MHLW survey, the establishment of discharge support departments in hospitals has effectively reduced the average length of stay and promoted discharge to home [2].

Normally, discharge support in Japanese hospitals begins with the selection of a key person within the family charged with making decisions. However, some families cannot decide due to inconsistent communication among the family members, which often results in prolonged hospitalization. The most important thing in supporting the transition to home is knowing the family's true intentions. For this purpose, it is important to build relationships between the family and the medical staff; however, this can make communication challenging [3].

## Publication History:

Received: January 12, 2025

Accepted: February 04, 2025

Published: February 06, 2025

## Keywords:

Family nursing, Key person, Discharge support, Decision-making

In this case, a patient with kidney cancer and lower limb paralysis due to spinal cord metastasis needed to be discharged home to continue to receive chemotherapy treatment at home. However, it was proving difficult to discharge the patient from the hospital due to problems relating to the family's ability to care for the patient, as well as discordant relationships among the family members. Especially in elderly households, as in this case, it often takes time to decide on the patient's discharge destination because the patient would be even more dependent on social support resources at home. Therefore, the Discharge Support Nurse (DSN) and the Certified Nurse Specialist in Family Health Nursing (CNSF) of the Discharge Support Unit worked together to encourage the patient and his family, thereby facilitating the discharge home.

In this paper, we discuss family nursing from the perspective of the supporting family member, who became the new key decision-maker in deciding the patient's discharge destination.

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**Citation:** Toda M, Gungi S (2025) Support for a Patient's Family Member Acting as Key Person in a Patient's Discharge Procedure. Int J Nurs Clin Pract 12: 404. doi: <https://doi.org/10.15344/2394-4978/2025/404>

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**Objective**

To elucidate support for a family member who has newly assumed the roles of key decision-maker in deciding the discharge destination of a terminally ill cancer patient.

**Methods**

**Data collection**

This study comprised a case study. Therefore, data were collected from the DSN's nursing and discharge coordination records, including the patient's medical history, progress, symptoms, nursing care, and family composition and relationships, from admission to discharge. In addition, family assessment and nursing practice for the family members were compiled into a progress chart (table 1) by the DSN and the CNSF, and used as data for the study.

**Data analysis**

The analysis was based on material compiled in the progress notes. After discussion among the researchers about assessment, practice, and evaluation, the researchers summarized the purpose of the DSN's and the CNSF's interventions for patients and their families, and the progress made after the interventions, as nursing practice. Veracity was ensured by sharing the progress notes among the unit staff.

**Ethical consideration**

Approval for publication was obtained from the ethical review committee of the researcher's institution. Anonymity was ensured to prevent the identification of the family members of the research subject.

**Case Study**

**Facility**

The subject facility serves as a disaster base hospital and a core hospital in western Tokyo, providing high-acuity care. It also functions as a regional cancer treatment base hospital, a perinatal collaborative hospital, and a combined psychiatric hospital, and offers other policy-based medical services. In addition, the hospital

has been designated as a community medical support hospital. It has established an inpatient and outpatient support center, contributing to the community's comprehensive care system, thereby allowing patients and their families to live a life of recovery in their own familiar neighborhood.

**Case overview (Figure 1)**

Mr. A is a man in his 70s in the terminal stage of kidney cancer, multiple bone metastases (thoracic and sacral vertebrae), and lung metastases.

He lives with his wife (also in her 70s) and his eldest son (in his 40s, single). His second son (in his 30s) and third son are married and living with their wives and children in other prefectures. His daughter (in her 40s) lives separately from the rest of the family, having little interaction with the patient.

**Nursing Practices**

**Patient's progress**

The patient had been experiencing right knee pain since around May 202X, and was urgently transferred to the hospital in early August of the same year due to the onset of weakness in his lower limbs. Upon further examination, he was diagnosed with spinal cord injury and paraplegia due to a metastatic spinal dural tumor from renal cancer. Emergency thoracic decompression surgery was performed to remove part of the tumor, but the patient was still left with lower limb paralysis, bladder and rectal dysfunction, and other severe disabilities. One week later, the patient was able to undergo excision of the remaining tumor and was scheduled to be discharged from the hospital for outpatient chemotherapy. However, due to the structure of his home and his family's limited ability to care for him, discharging him from the hospital remained difficult. Unable to decide on the patient's discharge destination, the DSN and the CNSF intervened, and the patient was discharged to his home one month later.

**Family progress**

Mr. A's wife was suffering from an incurable disease and had difficulty coming to the hospital due to her poor health. His eldest

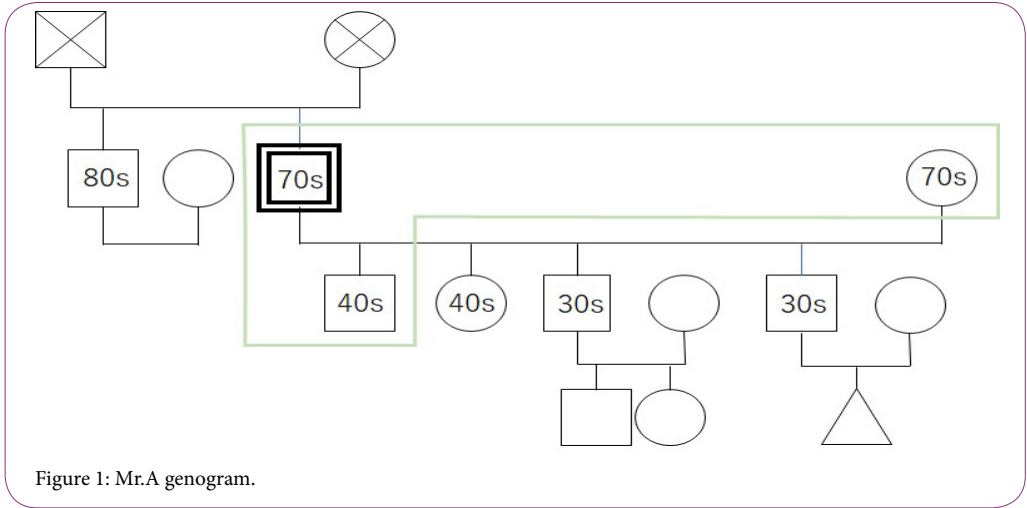


Figure 1: Mr. A genogram.

Supporters / Department	Days	Symptoms	Care	Family Situation & Assessment	Family Care & Practice
Ward in charge	Days 1–4	Diagnosis of spinal cord injury and paraplegia from a metastatic spinal dural tumor caused by renal cancer.  Requirement of emergency surgery  Pain and insomnia  Post-operative paralysis of lower limbs and cysto-rectal dysfunction  Mr. A wanted to explain the treatment plan.	Emergency surgery  Explanation & informed consent for surgery  Pain & insomnia management  Toileting & comfort care  Doctor's explanation & recommendation about the current condition and early start of outpatient chemotherapy according to the patient's request  Request to the Admission & Discharge Support Center	The family members came to the hospital, and we explained the emergency surgery to them and obtained their consent. However, the family did not ask any questions and listened quietly.  We told the doctor that the patient had asked for an explanation of his condition. We encouraged the family to be present, and they came to the hospital.	We tried to help the family accept the sudden progression of the patient's condition with as little anxiety as possible.  The ward nurse arranged a meeting with Mr. A and his family so that they could be present when the doctor explained his condition.  We noted a need for discharge support for the patient and his family.  The ward nurse consulted the DSN about discharge support for Mr. A.
DSN provided discharge support at the Admission & Discharge Support Center.  Multiple departments intervened	Days 5–13	Partly due to the residual tumor, the patient was suffering from back pain and progressive paralysis of the lower limbs.  Mr. A requested to be transferred to a hospital near his home for chemotherapy.  Re-operated on the 7th day.  Back pain decreased after surgery.  Continued to suffer from insomnia.  Residual paralysis of the lower limbs and cysto-rectal disorder were observed.	Reoperation was performed to remove the residual tumor from the spinal dura mater tumor.  The attending physician explained Mr. A's condition to him and his family.  The attending physician explained Mr. A's condition to him and his family.  The medical social worker began coordinating a transfer to a hospital near Mr. A's home.  Physical therapist intervention for rehabilitation  Palliative care team intervention	When the doctor explained his condition, Mr. A, his wife, third son, and third son's wife were present.  Mr. A. wanted to be discharged to his home.  The family was nervous when Mr. A was present, which perplexed us.  After Mr. A. left the room, the family expressed the following concerns:  Mr. A's wife was suffering from an incurable disease and severe hearing loss, and expressed concern about caring for him.  The third son lived far away, and his wife was in her final month of pregnancy, and therefore refused to care for Mr. A.  The family felt that the structure of the house (with dozens of stairs to the entrance) made it difficult for Mr. A to get to the hospital.  The DSN wondered why the eldest son and the second son, a keyperson in the family, were not present at the time of the interview.	The DSN was present when the doctor explained Mr. A's condition to him and his family.  The DSN listened to the family's concerns while respecting Mr. A's wishes.  We decided to support the family in collaboration with other professionals at the hospital to reduce the burden on the family.  We discussed with Mr. A. how to get up and down the stairs.  We recognized the need for family support.
The DSN and the CNSF collaborated at the Admission & Discharge Support Center to intervene in discharge support.  Multiple departments intervened within and outside of the hospital.	Day 14–38	Mr. A was adamant about being discharged home and forced his family to accept this request.  Mr. A began calling his second son to discuss future hospital visits and the home environment.  Mr. A began to depend on his second son.  The second son's story showed signs that Mr. A's discharge home was becoming a realistic possibility.  Mr. A's facial expression brightened, and he began to sleep more soundly.  Mr. A got into a care cart arranged by his second son and left the hospital with a smile on his face.  It was decided that chemotherapy would be administered at a medical facility near his home.	The DSN listened to Mr. A's thoughts and wishes.  The DSN listened to Mr. A's past involvement with his family and the role he had played in their lives.  The medical social worker coordinated with a medical facility near Mr. A's home and arranged for chemotherapy to be administered immediately upon discharge.  Transition to Home Care:  The DSN and the second son worked with the care support specialist to arrange a care cart that could go up and down dozens of steps for Mr. A to go to the hospital.  The DSN and the second son worked together to arrange a medical care system to enable Mr. A to begin to receive home care from the day he was discharged.  The DSN followed up with Mr. A's home healthcare providers on the progress of his post-discharge care.	The DSN gathered information from the second son by telephone.  The DSN learned about the eldest son's mental disorder and the relationship between the daughter and Mr. A (they did not get along and had lost contact). The DSN and the CNSF confirmed that the second son lived far away from the home with his wife and children, that his relationship with Mr. A had originally been bad, that Mr. A had absolute authority over him, and that he had told himself that if Mr. A wanted to be discharged home, he (the second son) would have no choice but to accept the fact.  The DSN and the CNSF analyzed that the second son felt a strong burden in dealing with Mr. A, but he could not ask for help from the other family members and was struggling alone. Therefore, the DSN and the CNSF analyzed the need for a support person for the second son, and decided to proceed with preparations for his discharge from the hospital.  As part of the DSN's support, the CNSF analyzed that Mr. A's leadership role in his family was not functioning, and that there was a lack of emotional interaction between the second son and Mr. A.  The DSN's involvement motivated the second son to take the lead in assigning roles to other the family members. It facilitated the preparation of Mr. A's home care system in collaboration with related professionals in the community.  The second son was able to take on a leadership role, Mr. A's wife adjusted to the home environment, and Mr. A's eldest son was able to accept the role of caring for Mr. A.  The second son and his co-resident family established Mr. A's care system.	The DSN consulted with the CNSF about supporting Mr. A's family.  The DSN and the CNSF worked together to provide support for the family.  (The CNSF supported the DSN-led family support and provided logistical support.  The following were carried out mainly by the DSN:  Gathering information about the family, including Mr. A, while listening to the second son's story  Building a partnership with the second son  Supporting the second son in his role as the key person  Facilitating a heart-to-heart exchange between Mr. A and the second son and his family  Arranging a pre-discharge conference in collaboration with the second son and related professionals in the community  Intervention ended when stable post-discharge progress was confirmed.

Table 1: Chronology from admission to discharge.

\*DSN: Discharge Support Nurse, CNSF: Certified Nurse Specialist in Family Health Nursing

son was struggling with mental withdrawal at home due to a panic disorder, and was unable to provide advice on Mr. A's discharge destination. Mr. A's daughter had a poor relationship with him and was estranged from the family home. The third son lived far away with his wife, who was in her final month of pregnancy, making it difficult for him to assume responsibility for Mr. A's care. Therefore, the second son became the contact person during Mr. A's hospitalization. The DSN noted from the doctor's interview that all of Mr. A's family members had negative feelings toward him and were uncooperative. The daughter and third son had both rejected Mr. A.

The second son was the only one who could play a key role with the support of the DSN.

### Family care planning and intervention

(1) Sharing of family issues by the DSN and the CNSF In August 202X, Mr. A had been living a normal life until he was hospitalized when his kidney cancer metastasized to his spinal cord, and he suddenly developed paralysis in his lower limbs, requiring emergency surgery and chemotherapy. Mr. A and his family were upset and anxious about the sudden discovery of his illness and the need for further outpatient treatment, so the DSN was assigned to work with the family.

The DSN asked the family how they felt about Mr. A's sudden disease progression, and arranged a meeting with the doctor to clarify his condition and provide support. Mr. A attended the meeting, and his wife, his third son, and his third son's wife, who was in her final month of pregnancy, came to the hospital. At that time, the DSN questioned why his eldest son, who lived with him, did not come to the hospital, and why his second son, who lived far away, had been made the key person. Mr. A strongly requested to be discharged to his home and to go to a hospital near his home, and the family members present listened to Mr. A's comments with stern expressions without speaking. Mr. A then left the room, and the family and medical staff discussed the matter again. Then, the third son revealed that Mr. A's wife had an incurable disease and could not come to the hospital due to her poor health, and that she also had difficulty talking on the phone due to her severe hearing loss. In addition, the third son's wife clearly stated that she was in her final month of pregnancy and could not care for her father-in-law. The DSN became concerned about the possibility of Mr. A being discharged to his own home, because the third son informed the DSN that Mr. A's home was on a hill and there were dozens of steps leading to the front door. The DSN began to suspect there might be issues within the family members' relationships. Therefore, the DSN consulted the CNSF, an Advanced Practice Nurse (APN), and decided to handle the discharge support for Mr. A's family collaboratively.

(2) Understanding the family, exploring good care for the family, and considering strategies for future support

Two weeks after Mr. A's admission, the CNSF decided to create a genogram based on the DSN's understanding of Mr. A's family, and analyze the family structure and relationships. The DSN told the CNSF that, although Mr. A's family structure at home comprised Mr. A, his wife, and his eldest son, it seemed unnatural that the eldest son had not participated in any interviews to date, and that the second son, who lived far away, was serving as the key person. The way Mr. A's family reacted during the interviews made it clear that the family

reacted differently when Mr. A was present and when he was not. The DSN and the CNSF assessed that none of the family members were able to say frankly what they thought was happening when Mr. A was present. The second son had assumed the role of key person, even though he lived three hours from Mr. A's home and the hospital. It was assumed that family problems lay behind this arrangement. Although the second son had been making decisions and carrying out procedures for Mr. A's treatment, it became increasingly clear that Mr. A had previously taken the lead in resolving problems that had arisen among the family members. However, when Mr. A suddenly became ill, there was no longer anyone with decision-making authority in the family. Therefore, the second son, who would not have played a leadership role under normal circumstances, had no choice but to become the key person. Therefore, the DSN decided to obtain information that would be useful for future support, while considering the difficulties the second son was experiencing.

(3) Helping the second son improve his coping skills

After Mr. A had been hospitalized for 16 days, the DSN established and implemented a care plan to first check on the second son's mental state by telephone, taking into account the fact that he lived far from the family home. The DSN called him at a time that was not too inconvenient for him and asked him about his family's situation, while informing him of Mr. A's situation. The second son expressed his gratitude for the DSN's thoughtful involvement and described the current chaotic situation within the family. He hesitantly disclosed that the Mr. A's eldest son was mentally distressed and withdrawn, and that Mr. A's daughter had run away from home several years ago due to her poor relationship with Mr. A. The DSN inferred that the second son must have been the key person in the situation by asking about the condition of Mr. A's family and children. The DSN then realized the second son was shouldering a heavy burden and encouraged him. The second son was speechless and burst into tears on the phone. He further revealed that Mr. A had absolute power in the family and that no one dared defy him. The DSN told the second son that the DSN would be his collaborator from then on, and would work together to find a place for Mr. A to be discharged and a direction for his medical treatment.

The CNSF heard from the DSN about the relationship issues within Mr. A's family, and supported the DSN's initiative in building trust with the second son and providing family nursing support. The two nurses also shared that they needed to continue to work in partnership with the second son and help him fulfill his role as the key person in Mr. A's family.

(4) Helping the second son become the key person in the family and determining the future direction

Three weeks from the start of Mr. A's hospitalization, the DSN continued to discuss his future medical care system, taking into account the second son's mental state. Although the second son seemed to be gaining confidence as the family leader, he expressed that he was at an impasse regarding Mr. A's discharge to his home. The CNSF suspected that Mr. A had been the family's decision-maker and recommended that the DSN ask Mr. A directly about this. The DSN asked Mr. A how he had dealt with family problems. Mr. A stated that he had solved all the problems himself and had acted as the family leader. However, Mr. A regretted that his illness had made it impossible for him to continue to solve the problems as before.



The DSN told Mr. A that his second son was considering a support system for his discharge, and also encouraged a heart-to-heart exchange between Mr. A and the second son. The next day, Mr. A called his second son and told him that he really wanted to go home. Now that he knew Mr. A's true intentions, the second son coordinated with the other family members, and proceeded with the measures to put social resources in place during the transition to Mr. A's discharge home.

## Discussion

This study concerned an intervention in a case where Mr. A's inability to take a leadership role in solving family problems due to his illness made it difficult to persuade him to leave the hospital. The DSN and the CNSF worked together to help the second son become the key person, and the family found a new problem-solving pattern that facilitated discharge support.

Discharge support at the end of life can be seen as a process of envisioning life at home. Not only the patient and their family members but also the medical staff are often anxious about the patient's discharge from the hospital. In this case, Mr. A was suddenly diagnosed with stage IV kidney cancer, along with lower limb paralysis and bladder and rectal dysfunction, creating a situation that required a medical system and a high level of care. The CNSF and the DSN reviewed Mr. A's family structure and functioning based on the information they had received, and explored the family's past coping patterns. In the case of Mr. A's family, we had information that Mr. A wielded absolute power. It became clear that he always took the lead in solving family problems. However, once Mr. A himself became ill, he could no longer exercise his leadership.

When practicing family care, it is necessary to assess the family's capacity to cope. It is important to understand who in the family provides leadership, who is the key person with decision-making authority, and in what capacity [4]. In this case, the second son became the key person as a new leader, replacing Mr. A in the family. This can be described as a generational transfer of authority from parent to child. For Mr. A's family, the rise of a new leader, the second son, gave them the strength to deal with problems that might arise. When practicing family nursing, it is essential for the nurses to establish relationships with the patient and their family as partners in supporting their individual lives. The nurses must also observe and support the family as they reach their goals [5]. In this case, the DSN felt that supporting the family was important in realizing Mr. A's discharge from the hospital. The CNSF, as an APN, was also committed to providing logistical support, believing that a partnership between the DSN and the second son would help enhance Mr. A's family's resilience. The DSN observed Mr. A's family communication patterns and relationships with the other family members, and became involved to avoid overly burdening any of them. Gradually, the DSN and the second son developed a relationship of trust, and the second son became able to express his feelings of pain to the DSN. We believe that this kind of support from the DSN, which improved the second son's coping skills, helped him regain his mental stability. The key person is not the caregiver of the patient who needs help, but rather the person who works to meet the basic needs and desires of the patient and each family member [6], regardless of whether their efforts are appropriate. In family systems theory, a change in one family member affects the entire family [4]. In Mr. A's family, the stability of the family had been maintained by Mr. A, the patient, who

played the key role, but the family became unstable when Mr. A fell ill. However, the second son became the new leader and played the key role in stabilizing the family's overall functioning. Mr. A's family included his wife, their eldest son, their third son, and their daughter. Nevertheless, the decision for the second son to take over from Mr. A as the decision-maker was extremely important. It is up to the family to decide who the key person will be to work with the medical staff, and the medical staff should not impose their own values. The nurses must become involved to enable the key person chosen by the family to feel confident in their role. In this case, the DSN could help the second son by bringing him up to speed, and the CNSF could provide logistical support, which facilitated the second son's assumption of the new role.

## Conclusion

This case study summarizes the process of helping the DSN take on a new leadership role while working in partnership with the patient's second son. In recent years, due to the shrinking family structure, many patients do not have a family member who can make decisions on their behalf or play a central role in supporting their discharge, as in this case. However, it is suggested that it is important for us, as healthcare providers, to be flexible with each family member, to decide who the most important person for the patient is, and to support that person.

## Competing Interests

There are no conflicts of interest to disclose in this case study.

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This article was originally published in a special issue:

Case Studies of Family Nursing Practice

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