UNDERSTAND IT IN 3 STEPS

Dementia

Consultation and support points

大阪府

Osaka Prefectural Government, Japan

Supervised by Graduate School of Human Sciences, Osaka University
OSJ Training and Research Center, Osaka Social Welfare Corporation

Supervision
Shinichi Sato
(Professor, Graduate School of Human Sciences, Osaka University)

Collaborators
Hikaru Oba
Yoshiko Nitta
(Graduate School of Human Sciences, Osaka University)

INTRODUCTION

Traditional care focuses on physical assistance through “on-hand nursing.” The goal is to enable people to live their daily lives by helping them with things that they cannot do by themselves. However, caring for people with dementia demands a new way to think, named “person-centered care,” which clarifies the nature of a problem, responds to mental changes, and aims to increase autonomy. This leaflet uses examples of Alzheimer’s dementia to introduce the “person-centered” way to think about personal care, which is based on behavioral science regarding elders.

WHAT IS PERSONAL CARE?

We define “personal care” in the sense of traditional “on-hand nursing” to support people by understanding that “daily life is defined by the individual’s personal history, and nursing care [is concerned with anything] that makes that difficult.” Therefore, understanding existing problems does not begin from the perspective of the person doing the caregiving, but from the perspective of the person who needs nursing care, and solving problems is about problems of everyday life. For better caregiving, we must not only consider physical care, but caring for the “heart” of the person receiving care. For that reason, it is necessary to consider “autonomy” as well as “independence.” “Independence” is a person’s ability to support her or his home life without outside help. However, “autonomy” refers to the ability to make choices and decisions about how to live. “Autonomy” might be improved even when a person is not receiving assistance or nursing care. Personal care attaches importance to supporting “autonomy” so that people who need care can choose their personal lifestyles and make personal decisions, even when it is difficult for them to live “independent” lives.

PERSONAL CARE POINTS

Personal care attaches importance to “increasing a person’s autonomy.” For that reason, we understand caregiving as following the three steps shown on the right. We explain these steps starting on the next page.

Analyze the problem

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Identify the problem and guess the causes

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Implement care to solve the problem

STEP 1 ANALYZE THE PROBLEM

Problem analysis points

1. What is the problem?
2. Who is affected by it?
3. When did the problem start?
4. What caused the problem?
5. Where did the problem occur?
6. What should be done about it?
7. What type of person is affected?
8. What can that person do?
9. How would that person like the situation to change?

Sato (2005)

Gather information about the following points regarding the problem. It is always important to remember these points when you analyze problems.

STEP 1 EXPLANATION

When you analyze the problems that affect people with dementia, you need to take a multifaceted point of view, and not see the problem from just one side.

Asking, "What is the problem?" is connected to asking, "Who is affected by it?" Usually, the person who is affected is the caregiver, but, often, when you try to take the point of view of the person being cared for, it is possible to think, for example, that "the person is refusing care because he or she is troubled." If the nature of the problem is different for the caregiver than it is for the person being cared for, it might be difficult to solve the problem.

If the answer to the question "When did the problem start?" is not clear, there might be reasons from the past to consider when asking "What caused the problem?" Also, the environmental factors that produced the cause might become clear by considering "Where did the problem occur?"

"What should be done about it?" considers the purpose of caregiving. For example, if the ADLs of a person receiving care have declined, and there is no hope of improving the ADLs, it is necessary to consider other goals, such as increasing QOLs with the idea of maintaining or reducing a further decline in ADLs. For that reason, it is necessary to know "What type of person is affected." By understanding the person's family history, educational history, personality, emotional tendencies, and interpersonal skills, things that you did not notice before might become obvious.

Based on this information, you might get some clues about "What that person can do." Also, whether they know it or not, and whether they can verbalize it or not, guessing "How would this person like the situation to change?" facilitates support of an autonomous lifestyle from that person's standpoint.

STEP 2 GUESS THE CAUSES

People have different problems, with different causes, and their emotional triggers are different, even when they have similar behaviors. Also, there might be more than one cause. Following the plan below is useful for organizing problems and guessing their causes.

Cause	Trigger	Effect
Location of problem	Emotional change	Behavior
Physical problems Emotional problems Cognitive functions Living environment Individual traits and so on	Loneliness Anxiety Fear Depression Irritation and so on	Rejection Wandering Violence Excitement Lying and so on

Based on Sato (2005)

STEP 2 EXPLANATION

The difficult problems in caregiving might be the result of many kinds of causes. Therefore, to understand a problem, you must be certain about its cause and effect. However, it is likely that there will not be just one cause and effect.

The location (cause) of a problem might be "physical problems," such as bodily functions or an adverse reaction to medication; "emotional problems," such as depression or psychological disorders; "cognitive functions," such as memory loss or disorientation; "living environment," including the physical or interpersonal environment; and/or "individual traits," such as personality or emotional tendencies.

These causes might trigger behaviors (effects) that become direct problems, but that is not always the outcome because one cause might lead to problem behaviors for some, but not other, people. In many cases, these causes provoke emotional changes (triggers), such as loneliness, anxiety, and depression, and, as a result, they might not manifest as problem behaviors.

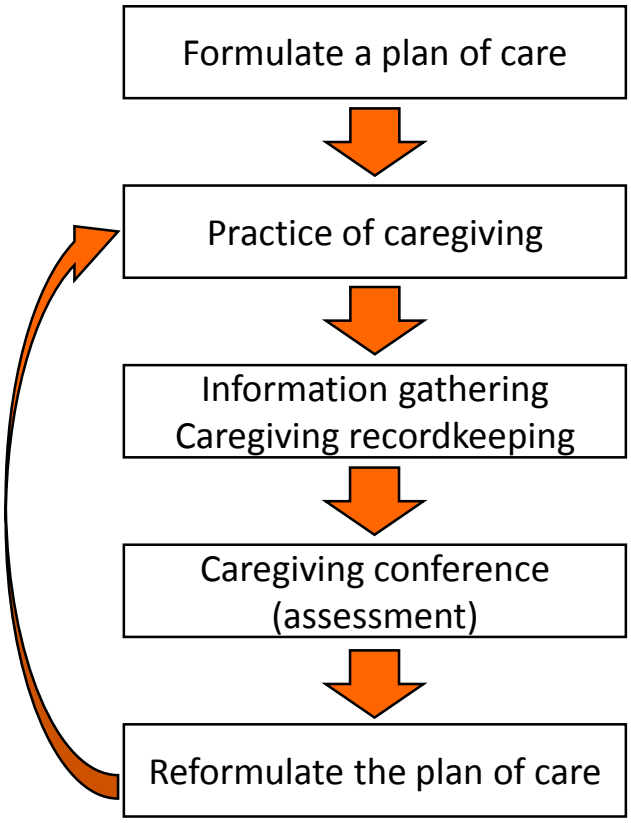
To find a solution, first consider the question "Can the cause be removed?" Although actions to remove causes are preferred whenever possible, when a cause is cognitive impairment, chronic illness, an environmental problem, or a personality trait that cannot be responded to, it will be difficult to remove it. In those cases, it is necessary to understand the triggering emotional change and respond to it.

STEP 3 THINK OF WAYS TO SOLVE THE PROBLEM

Based on your best guess about the cause of a problem, formulate a plan of care concerning the priorities, goals, and ways to solve the problem.

Assessment of the plan using records obtained during practice is comprehensively conducted regarding some points, such as whether it was put into practice, whether the content was appropriate, and whether the plan was excessive or deficient. If there is a need to change the plan, it is reformulated.

The foundation of personal care is support based on analysis and consideration of the problems through hypothesis, verification, and correction.



Based on Sato (2005)

STEP 3 EXPLANATION

A personal care plan is formulated based on the results of the analysis of the problem and your best guess of its cause. To assess the validity of caregiving, an objective point of view is essential, so factual observations must clearly be separated from the caregiver's opinions. When the plan of care is formulated, three points should be practically established to make objective information gathering possible: the priority of solving the problem, the goal of giving care, and the method of giving care.

After implementing personal care, a conference should be held to assess the effectiveness of the care. In the care conference, assessment is performed on four points: (1) "assessment of the method (was it implemented as planned and was the plan reasonable)," (2) "assessment of the care (how much was the problem solved and were there mistakes made when the problem was considered)," (3) "assessment of the plan (what else is needed and what is not needed)," and (4) "overall assessment (appearance of symptoms and things that were not in the initial plan)."

Based on the assessment, a new personal care plan is formulated, and the flow of "plan formulation – care practice – information gathering – care assessment – plan reformulation" is repeated. However, the status of the care receiver and caregiver evolve, and the same things are not always repeated. The fluidity of changing situations is a characteristic of caregiving, and, therefore, care has no endpoint. The caregivers' cumulative considerations are essential to achieve meaningful care.

OBSERVABLE BEHAVIORAL AND PSYCHOLOGICAL SYMPTOMS IN DEMENTIA (BPSD)

Dementia can be organized by the core symptoms that occur because of direct reduction in brain functions and the behaviors or mental states (BPSD) that occur in addition to the core symptoms caused by mental, physical, or environmental conditions. The table below shows the characteristics of BPSD by the severity of the dementia.

Extent of dementia	Behavioral and psychological symptoms
Mild	•Asking the same thing many times •Noticeable misplacing of objects and forgetting to finish things •Showing little interest in things •No longer goes shopping •Stops engaging in hobbies •Loss of cooking skills and unusual tastes •Becomes lethargic, apathetic, and/or loses ambition •Develops depressive tendencies •Frequently signs agreements or becomes a guarantor (cannot refuse people) •Others
Moderate	•Lack of awareness •Hallucinations •Delusions •Wandering •Night delirium •Abusive language, violence, and/or aggressive behavior •Emotional incontinence •Mania for collecting •Others
Severe	•Pica •Coprophilia •Others

Based on Sato (2012)

Starting on the next page, we provide examples to help you to understand dementia from the personal care perspective. We include examples from people's homes as well as from institutions. The decision reached in Step 3 of each example was arrived at based on the considerations of Step 1 and Step 2. It is important to think about Step 1 and Step 2.

CASE 1　WHY IS SHE SO DOWN?

I went to the hospital with my mother because her forgetfulness became severe, and she was diagnosed with "mild dementia." Recently, she often seems to feel sad, and she has stopped engaging in her hobby of making dolls. What should I do?

STEP 1 ANALYZE THE PROBLEM

To consider why the mother has become so sad, it is important to understand her circumstances because she has entered a phase where her forgetfulness is more noticeable. How often has her forgetfulness been observed? What was she like during those events? We also need to understand how the daughter deals with her mother when she notices her forgetfulness.

STEP 2 GUESS THE CAUSE

The daughter has probably repeatedly pointed out her mother's forgetfulness to her. By repeatedly pointing it out, the mother might have starting thinking "I have become weird." However, she also might want her daughter to recognize that she "is still not senile." Receiving a diagnosis of "mild dementia" while experiencing this conflict might have led her to think that "I have become weird," and it might have been a big emotional shock.

STEP 3 THINK OF WAYS TO SOLVE IT

In cases of mild dementia, cognitive impairments, such as forgetfulness, stand out more than they normally might; however, this is not as case of [full] dementia, and major barriers are not noticeable in everyday life. That is, a person might be able to do many things. So, consider talking with the daughter about "what her mother can still do." It might be important to build up successes [moments] when "I can do this" happened by casually supporting the mother in the things that she cannot do.

CASE 2　WHY ISN'T HE DOING ANYTHING?

My husband, who was always active, has been skipping neighborhood association meetings. He stopped engaging in his hobby of going to the go-parlor. He spends his time at home doing nothing. What should I do?

STEP 1 ANALYZE THE PROBLEM

First, we need to understand the changes that have occurred in the husband. When was the change first noticed? What are the behaviors that changed? Perhaps the wife's friends in the neighborhood association were asking her about it. By understanding the situation when he stopped attending the meetings and go-parlor when the change was noticed, we might be able to guess the reasons that the husband no longer wants to do things.

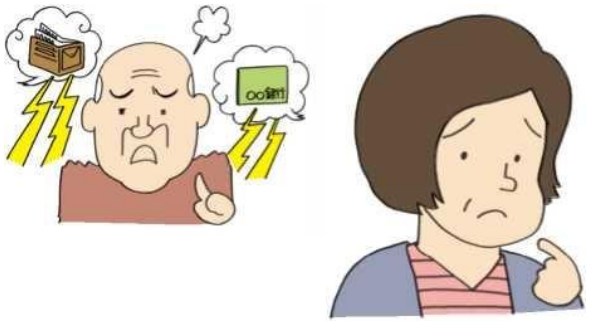
STEP 2 GUESS THE CAUSE

In this case, "loss of motivation," which often appears in the early stages of disease, might be one cause. The husband's loss of motivation might relate to, even if he goes to the meetings, an inability to follow the discussion, or he might not be able to think clearly about playing go. The meetings and go games that were once his *raison d'être* might be becoming a burden. His experiencing of this reversal might be causing him psychological pain regarding participation.

STEP 3 THINK OF WAYS TO SOLVE IT

The husband might be frequently experiencing "I can't do it properly" at meetings and in the go-parlor, and it is possible that the meetings and go-parlor, which previously motivated him, now have the opposite effect. Doing nothing would likely lower his ADLs and QOLs. In this case, he might need to find new hobbies that he can "do properly." Because he has lost motivation, perhaps activities that require low levels of responsibility, such as looking at beautiful scenery or playing music, should be encouraged.

CASE 3　WHY IS HE SUSPICIOUS?



About three months ago, my husband started telling me, “you’re stealing my money!” and “you have put my bank book somewhere!” When I deny it, he gets very upset. What should I do?

STEP 1 ANALYZE THE PROBLEM

In this case, the husband is having delusions that his wife is a thief. First, confirm that there were no previous examples of this before he became delusional. We also need to understand what kind of person he is when deciding how to respond. It is important to gather information on his personality and lifestyle, such as the type of job he had, and not just on the past or on physical factors, such as ADLs.

STEP 2 GUESS THE CAUSE

The husband is focusing on simple things when he says, “my wallet is gone and my wife has taken it.” He has confused the reality of “my wallet is gone” with his imagination when he thinks, “my wife has taken it.” We might guess that one reason for this delusion is a reduced ability to distinguish reality from imagination. In addition, he might be suspicious of his wife because dementia is associated with a loss of ability to control oneself and to guess the feelings of other people, even though she used to be someone he trusted more than anybody else.

STEP 3 THINK OF WAYS TO SOLVE IT

The wife denies her husband’s deluded statements, but the husband believes that his thoughts are valid, so denial would likely make him feel invalidated, and it might even cause him to get very agitated. Sometimes, it is effective to avoid refuting delusional people, and to sympathetically ask questions and help them to search for the lost item. However, this might be difficult for this wife because she is the target of the delusions. It is important to be positive with the wife, who is involved in these incidents because they are happening in her husband’s mind.

CASE 4　WHY IS HE TAKING OFF HIS DIAPER?

My husband takes off his diaper and urinates in the corridor and the living room. I try to put his diaper on him, but he violently resists, and I cannot do it. What should I do?

STEP 1 ANALYZE THE PROBLEM

In this case, it is important to understand the problem from the standpoint of the wife (caregiver) as well as the husband (recipient of care). From the wife's standpoint, the problem is "my husband's urination is troubling me," but, from the husband's standpoint, it might be that "something is troubling me, so I inappropriately urinate." To understand what might be troubling the husband, we must gather information about "what the husband can do."

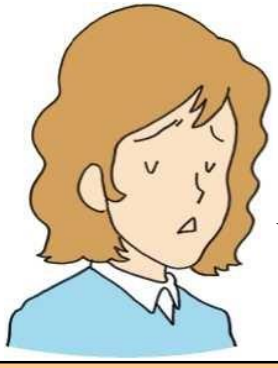
STEP 2 GUESS THE CAUSE

To understand the problem from the husband's perspective, which might be that "I am a person who can take off his diaper and pee," he might be thinking, "I don't like wearing a diaper," or "I don't need to wear a diaper." So, from the wife's perspective, the problem is that "my husband won't let me put his diaper on him" and, from the husband's standpoint, it is "my wife is forcing me to wear a diaper." That might be the reason that he resists his wife when she tries to put his diaper on him after he has removed it. He also might be using urination as means of self-expression.

STEP 3 THINK OF WAYS TO SOLVE IT

It is necessary to understand this problem not as "my husband won't wear his diaper at all," but as "what needs to be done so that the husband can live without a diaper?" Although it is not easy to have people with dementia out of diapers, it might be possible to accomplish, through a process of repeated trial and error, developing a daily routine, and knowing the husband's urination and defecation patterns. Fixing this problem might need the help of a professional to support the caregiver.

CASE 5　WHY IS SHE REFUSING?



This is about my mother: whenever I try to get her into the bath or change her diaper, she violently resists. She does not even seem to know me as her daughter. What should I do?

STEP 1 ANALYZE THE PROBLEM

First, we must gather specific information about "the types of situations in which the mother is violently resistant." However, it also is important to think about this from the perspective of "of situations in which she is calm" Some confusion might arise because she does not recognize her daughter, and an assessment of her natural language comprehension and other abilities might be necessary.

STEP 2 GUESS THE CAUSE

In this case, resistance has been observed during bath time and when toileting. What these two situations share is the "removal of clothing." Usually, when we become adults, other people do not remove our clothing. Because the mother is confused about people's identities, from her point of view, she might think, "someone I don't know is trying to take off my clothes." It is reasonable under that circumstance for her to resist and defend herself if she feels afraid that she might be injured or embarrassed.

STEP 3 THINK OF WAYS TO SOLVE IT

If the mother is refusing because she is afraid and confused that "I don't understand what is being done to me," then frequent reassurance would be key. For that reason, it is important to constantly talk to her while helping her, and take action only after confirming that she understands what is happening. If the mother's natural language comprehension is failing, it might take a long time for her to understand what is being said to her. However, taking your time and confirming her understanding might lead to smoother bathing and toileting.

CASE 6　WHY ARE RELATIONSHIPS BETWEEN CAREGIVERS DETERIORATING?

My father-in-law keeps asking me, “Isn’t it time to eat?” I am working hard to care for him, but my mother-in-law has started asking me, “Have you really not fed him yet?” Nobody understands my situation, so nursing him is becoming unbearably harsh for me. What should I do?

STEP 1 ANALYZE THE PROBLEM

Since the father-in-law is repeatedly asking, “Isn’t it time to eat?” his memory loss seems to have progressed quite far. Perhaps his questions are related to a persecution complex, such as “my daughter-in-law will not let me eat.” However, what is important in this case is “who the troubled person is” and “why is this person troubled?” When we understand the case from this perspective, a different problem emerges.

STEP 2 GUESS THE CAUSE

In this case, it might be that the daughter-in-law is the one who is troubled the most. When we think about why she is troubled, we might decide that it is because she is isolated, based on her sense that “my mother-in-law is taking my father-in-law’s side.” It is obvious that, if this continues, the daughter-in-law ultimately will be unable to function as a caregiver. The three relationships among the father-in-law, mother-in-law, and daughter-in-law might have stabilized such that the daughter-in-law is ostracized and the mother- and father-in-law are close. Intervention with all three people would be key to solving this problem.

STEP 3 THINK OF WAYS TO SOLVE IT

When intervening in these three relationships, it is preferable that no one is left out. Therefore, intervention should build satisfactory relationships for all of the parties. For that reason, the mother-in-law’s actions are key. She should not doubt the daughter-in-law regarding the father-in-law’s complaints, but she needs to support her. It also is important that she allows her relationship with the father-in-law to change by telling him, “our daughter-in-law is a good daughter-in-law.” This is a case in which it is important to intervene in the relationships that affect the person who is troubled by the problem.

CASE 7　WHY IS HE EATING HIS STOOLS?

My husband has taken to picking up beads and stones and eating them. Last month, he removed the stool from his diaper and began rubbing it on the floor and walls and eating it. At night, he moves around and makes strange sounds with his voice. What should I do?

STEP 1 ANALYZE THE PROBLEM

Pica and coprophilia are symptoms that present during severe dementia. The mental impairment has a major effect, so, when thinking about this problem, it is important to ask whether "the triggers of the pica and coprophilia could be eliminated." To do so, it is important to gather information about "when it occurs" and "the types of situations when it occurs." This also is true regarding the strange vocalization.

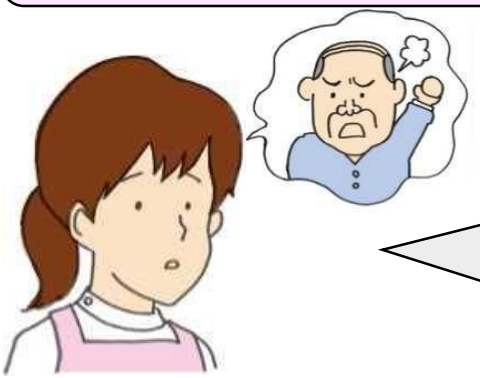
STEP 2 GUESS THE CAUSE

In this case, the husband has likely lost his senses of smell and taste because of his mental impairment, and he might not recognize that his stool is excreta when he looks at it. Additionally, because of the pica, he is putting things into his mouth immediately without identifying them, which might be related to eating his stool. Regarding the strange vocalization, night wandering behavior also has been observed, and it might be that, in his delirium, he is hallucinating, which is stimulating him to make these sounds.

STEP 3 THINK OF WAYS TO SOLVE IT

Pica and coprophilia are difficult symptoms, which cannot be controlled, regardless of how much you try to do so. Therefore, it is important to respond preventatively by, regarding pica, removing all dangerous objects that might be eaten from places where he might see them. Regarding coprophilia, it is important to understand his defecation patterns and reduce his opportunities to access his stools. The strange sounds he makes also cannot be stopped, and it might be a good idea to adjust the environment so that he feels safe by holding his hand and staying near him. It also is important to remove all triggers that might cause delirium.

CASE 8　WHY IS HE CURSING?



One resident of a long-term care facility has had mood swings since moving in six months ago, and he has started cursing at the other residents. He was prescribed psychiatric drugs, but, since then, he has been violent. What should be done?

STEP 1 ANALYZE THE PROBLEM

First, regarding the mood swings, cursing, and violent behavior, we must know "when it started," "when it happens," and "where it happens." Perhaps, expressing these behaviors is a type of manifestation of intent by the person. Considered this way, it might be necessary to reconsider "what type of person" he is.

STEP 2 GUESS THE CAUSE

Life in an institutional setting is not like life at home because you must live with many unfamiliar people. When this man first moved to the home, he might have been anxious about this sudden change to an environment that was new, but, after settling in, he might have considered his new life and had a rush of feeling "why do I have to be in a place like this." Also, his violent behavior was observed after he was prescribed psychiatric drugs. Drug metabolism and defecation functions decline with old age, so side effects are common. It might be necessary to discuss his prescriptions with his doctor.

STEP 3 THINK OF WAYS TO SOLVE IT

To understand how this man might be feeling about moving to an institution, we should know the history of how he previously lived. It would be helpful to gather information, such as the type of house he grew up in, his previous occupation, and what sort of father he was to his children. In this way, by understanding "what type of person" he is, we could sympathetically listen. Also, by recording his reactions in social interactions, we could refer to other staff. Regarding the side effects of his drugs, it would be necessary to discuss his situation with his doctor based on objective records of the situation after the drugs were prescribed as well as observations of his behavior.

CASE 9　WHY DOES SHE WANT TO GO HOME?

In the evenings, a resident of a long-term care facility for the elderly asks, “When will I go home?” She says, “I should phone my husband.” When we explain where she is, it reassures her temporarily, but, then, she immediately asks again. What should we do?

STEP 1 ANALYZE THE PROBLEM

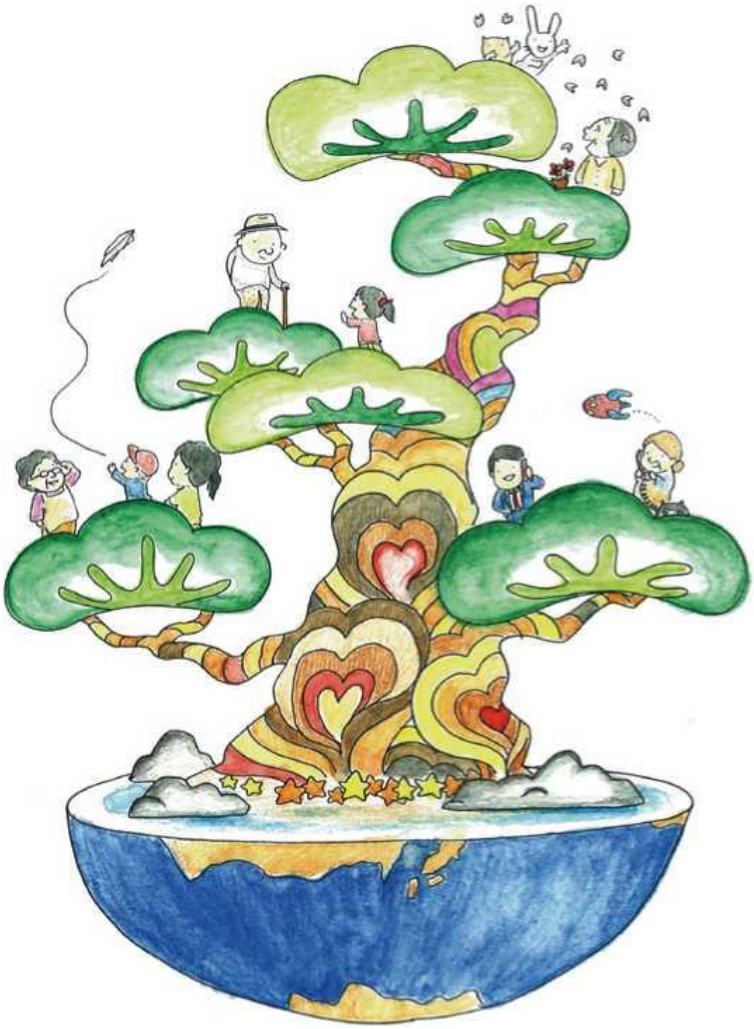
It is clear that this woman’s behavior occurs in the evenings, but do any events trigger this problem? It might be necessary to know “in what type of circumstances it occurs” as well as “when it occurs.” There might be hints to solving this problem in the circumstances of her everyday life, such as how she spends her time with staff and the other residents.

STEP 2 GUESS THE CAUSE

Wanting to go home at night is a phenomenon often observed among institutionalized residents. One reason for this might be disorientation. The resident might think that she needs to go home because her awareness that she is living in an institution is impaired. She might have weak relationships with the other residents, and, if they have no roles in her life, it might be easy for her to turn her attention inward. She might easily become trapped into thinking that she must go home.

STEP 3 THINK OF WAYS TO SOLVE IT

In this case, the solution to the problem might relate to giving her a role to play and building her relationships with the people around her, such as staff and other residents. However, if she has a lot to do, this approach could have an adverse effect and cause her to feel distressed. For this reason, it is important to know “what the person can do.” It also might be good to have the staff talk with her whenever they encounter her, even if they only say a word or two. It is easy to leave an impression on a person by gradually building up frequent, short interactions.



大阪府
Osaka Prefectural Government

Osaka Prefectural Government, Department of Welfare Services, Senior Citizens Care Office, Care Support Division
Otemae nichome, Chuo-ku, Osaka-shi, Japan ZIP 590-8570
TEL +81-6-6941-0351 (switchboard number)
Email: koreikaigo@sbox.pref.osaka.lg.jp