



Study on the maintaining employment of persons with early onset dementia

[Research Reports No.96] Summary

【Keywords】

Early onset dementia, Employment support, Higher brain dysfunctions, Job coach support

【Points for using the findings】

First of all, we clarified the use of the word “early onset dementia” and overviewed the findings of the preceding research studies. Then, we interviewed the specialists for the purpose of revealing the present conditions of the support for persons with early onset dementia. To reveal the current status of employment of persons with early onset dementia, we made a survey of Early onset dementia Family Group. We also made a survey of vocational counsellors to understand the utilization status of Vocational Rehabilitation Centers for Persons with Disabilities and to clarify the current situations and problems of the employment support. Although there were few cases in which persons continued working after the onset of dementia, we conducted an interview survey on the cases. In the study, several issues that should be addressed are suggested.

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2. Period

Fiscal 2008 to 2009

3. Composition of the research report

Overview

Chapter 1 Early onset dementia

Chapter 2 Specialist interview

Chapter 3 Survey on current status of employment of persons with early onset dementia (Survey of Early Onset Dementia Family Group)

Chapter 4 Survey on the utilization status of Vocational Rehabilitation Centers for Persons with Disabilities

Chapter 5 Cases in which persons continued working after the onset of dementia

Chapter 6 Summary

Documents

4. Background and Purpose

In 2008, the Ministry of Health, Labour and Welfare mentioned the necessity of taking measures for early onset dementia in its report titled "Urgent Project for Enhancement of Medical Treatment of Dementia and Improvement of Life Quality." It aims to build a system to provide comprehensive support including "consultation," "medical treatment," "welfare," and "employment." In the process of the current status of persons with early onset dementia being revealed through diversified studies, the problem of the maintenance of their employment, in addition to financial problems, has come to be recognized as an urgent issue to be addressed, in light of the quality of life of the patients themselves.

Various activities for assisting the vocational rehabilitation of persons with disabilities have been fruitful, but the efforts for employment assistance for persons with early onset dementia just started recently. This is the field in which further positive efforts need to be made.

In light of such trends, this study clarifies advanced efforts on early onset dementia, and the current status of employment and utilization of Vocational Rehabilitation Centers for Persons with Disabilities so as to review problems in assisting the maintenance of employment of persons with early onset dementia, and further considers the issues to be addressed in continuing to provide support in the future.

5. Method

Chapter 1 clarifies the official name and definition of early onset dementia, compiles the findings of the preceding research studies, and shows the purpose of this survey.

Chapter 2 shows the knowledge obtained through the interviews of eight specialists who have made advanced efforts in the field of early onset dementia: the physician in charge at the "Memory Clinic" at a public general hospital, the vice-president of the "Early Onset Dementia Support Center," the president of the "IKI IKI Welfare Network," the physician in charge at the "Outpatient Department for Early Onset Alzheimer's Dementia" at a university hospital, the representative of Early Onset Dementia Family Group "Hoshinokai," the director of Early Onset Dementia Support Group "Artnokai," the director of Family Group, and the district leader of Family Group.

The interviews covered the developments of their efforts, the current status of providing support and problems therein, and any advice and comments on the survey on the current status of employment. Contents obtained on specific cases are omitted here from the viewpoint of personal information protection.

Chapter 3 compiles and shows the results of the survey on the current status of employment of persons with early onset dementia.

The questionnaire survey was conducted at the end of March 2009 by sending questionnaires to 355 members of the Early Onset Dementia Family Group. Valid answers were obtained from 81 members, out of which the analysis was made for 57 persons (45 males and 12 females) who meet the requirements of having obtained income through employment.

Chapter 4 shows the results of the survey on the utilization status of Vocational Rehabilitation Centers for Persons with Disabilities. The number of users of centers for the past ten years, the characteristics of the users, and the results of the attitude survey of chief counsellors and the like are shown.

Chapter 5 shows three sample cases of persons who continue working after the onset of dementia, with their consent in the survey on the current status of employment in Chapter 3 and the survey on the utilization status of regional centers in Chapter 4. We visited their workplaces and interviewed on i) the mode of their employment, ii) efforts and accommodation being made at workplaces, and problems and countermeasures, and iii) the effectiveness of Vocational Rehabilitation Centers for Persons with Disabilities and job coach support services.

Chapter 6 is the summary of each Chapter.

6. Summarized Results of the Study

Chapter 1 Early onset dementia

Before the term "Dementia (*Chihou*)" became common, the symptom was described as "mental deterioration." However, the expression was criticized as not matching with the idea of respecting human dignity and was replaced with the term "Dementia (*Ninchishou*)". "Dementia" came to be used widely not only as an administrative or legal term but as a medical term by 2005.

"Early onset dementia (EOD)" refers to dementia developed early at the age of 18 or older but younger than 65, combining early dementia developed at an earlier age between 18 and 39 and presenile dementia developed at an age between 40 and 64.

The term "early dementia" is often used, but in this survey report, the term "early onset dementia" is used as

in the "Urgent Project for Enhancement of Medical Treatment of Dementia and Improvement of Life Quality" by the Ministry of Health, Labour and Welfare.

Chapter 2 Specialist interview

We obtained knowledge from eight specialists, but omitted part of the contents from the viewpoint of personal information protection, and compiled the results of the interviews from six specialists.

Multiple specialists agree that working at an early stage of the disease has positive rehabilitation effects and recommend the maintenance of employment. In most cases, persons with early onset dementia do not lose their overall cognitive functions rapidly as the disease progresses. Rather they lose part of their functions gradually. Therefore, considering the way of working in a broader sense, they have a chance to continue working even after the onset of dementia. The specialists point out the necessity to widen the meaning of "quality of labor" to include social activities and social participation, and the importance of providing support in a staged manner in accordance with the progress of the disease and taking measures based on a long-range outlook.

Chapter 3 Survey on current status of employment of persons with early onset dementia

(1) Causative diseases

The most common causative diseases of the analysis targets (57 persons) was Alzheimer's disease (31 persons), followed by frontotemporal lobar degeneration (17 persons), and cerebral vascular disturbance (one person). Causative diseases of four persons were unknown. 80% of them had degenerative diseases.

Table 1. Causative diseases of the analysis targets

Causative diseases	Number of people
Alzheimer's disease	31
Frontotemporal lobar degeneration (including Pick's disease)	17
Unknown	4
Cerebral vascular disturbance	1
Mixed diseases	1
Other diseases	1
No answer	2
Total	57

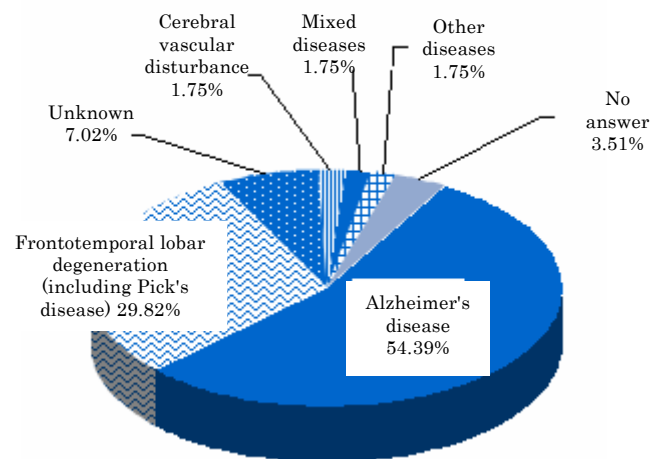


Figure 1. Causative diseases of the analysis targets

(2) Status of employment and reasons for retirement

At the time of the survey, nine were in employment or on a leave (only one person actually commuted to

work), and 48 persons had retired (84.2%).

Reasons for retirement were "out of own will" (15 persons), "persuaded by the company" (six persons), "age-limit retirement" (eight persons), "fired" (10 persons), and "others" (nine persons).

Table 2. Status of employment and reasons for retirement

Status of employment and reasons for retirement	Number of people
In employment or on a leave	9
Early retirement out of own will	15
Early retirement by being persuaded by the company	6
Age-limit retirement	8
Being fired	10
Others	9
Total	57

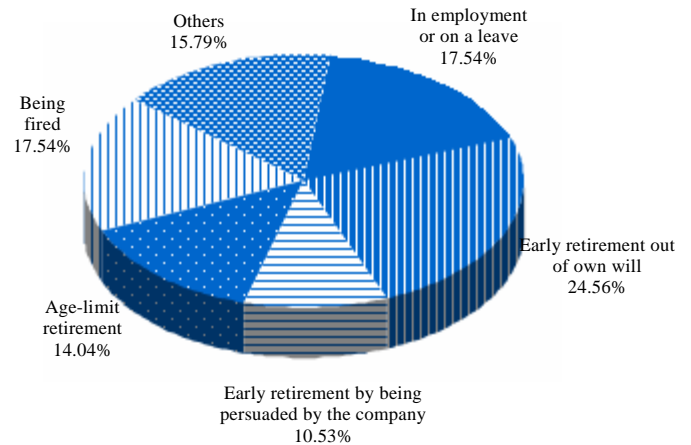


Figure 2. Status of employment and reasons for retirement

(3) Desire for employment

Out of 57 analysis targets, nine persons wished either for "engaging in the same work at the same workplace," "engaging in different work at the same workplace," or "engaging in new work at a different workplace," and 21 persons did not wish to work.

Table 3. Person's own desire for employment

Person's own desire for employment	Number of people
Engaging in the same work at the same workplace	2
Engaging in different work at the same workplace	2
Engaging in new work at a different workplace	5
Do not wish to work	21
Unconfirmed	15
Others	6
Unknown	6
Total	57

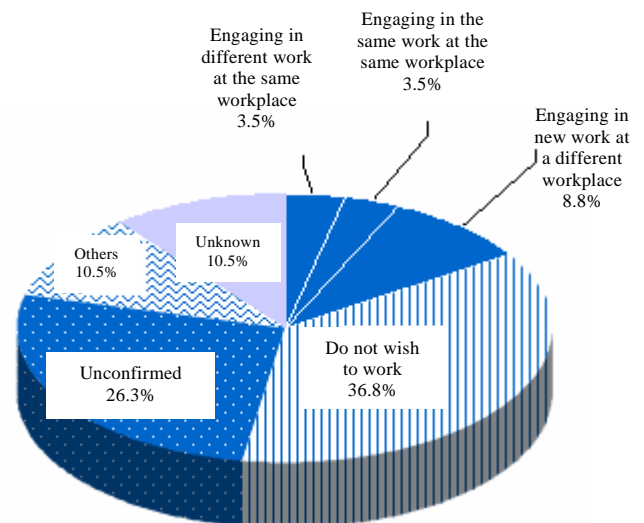


Figure 3. Person's own desire for employment

In the meantime, out of all of the respondents (family members living with the analysis targets), 30 wished for "employment" of the person and 27 did not, which indicates that a higher percentage of family members wish for the person to work. The most common reason for this was to "secure a place for the person to belong to" (13 respondents).

Table 4. Family member's desire for the person's employment

Family member's desire for the person's employment	Number of people
Wishing for employment	30
Do not wish the employment	27
Total	57

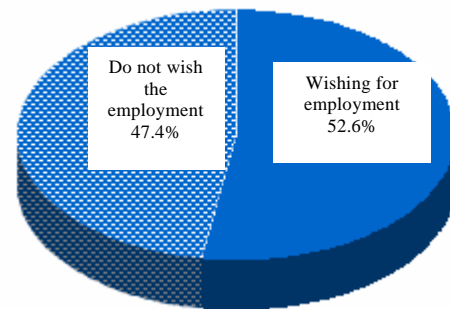


Figure 4. Family member's desire for the person's employment

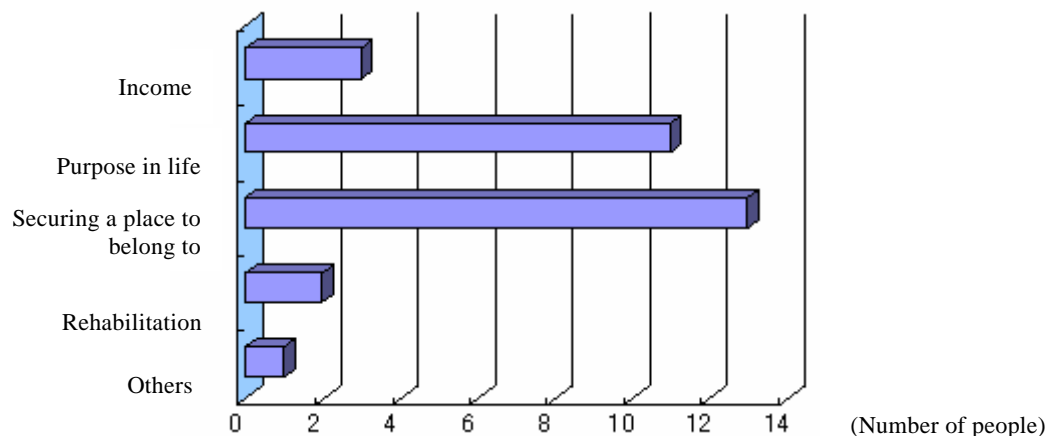


Figure 5. Reasons for a family member to wish for employment of the person

(4) Developments after the onset of the disease

As developments after the onset of the disease, the average ages when "a family member noticed a sign of the person's disorder," "the person was diagnosed," and "the person got retired" were 53.58 ± 4.16 , 55.24 ± 4.33 , and 55.64 ± 3.59 , respectively. In some cases, troubles were observed at workplaces before a family member noticed any sign of a disorder in the person. The exact time of the onset of the disease is difficult to identify, mostly depending on the circumstances in each case. However, it is estimated to be around five years from the onset of the disease to the time when the person becomes unable to continue working and retires.

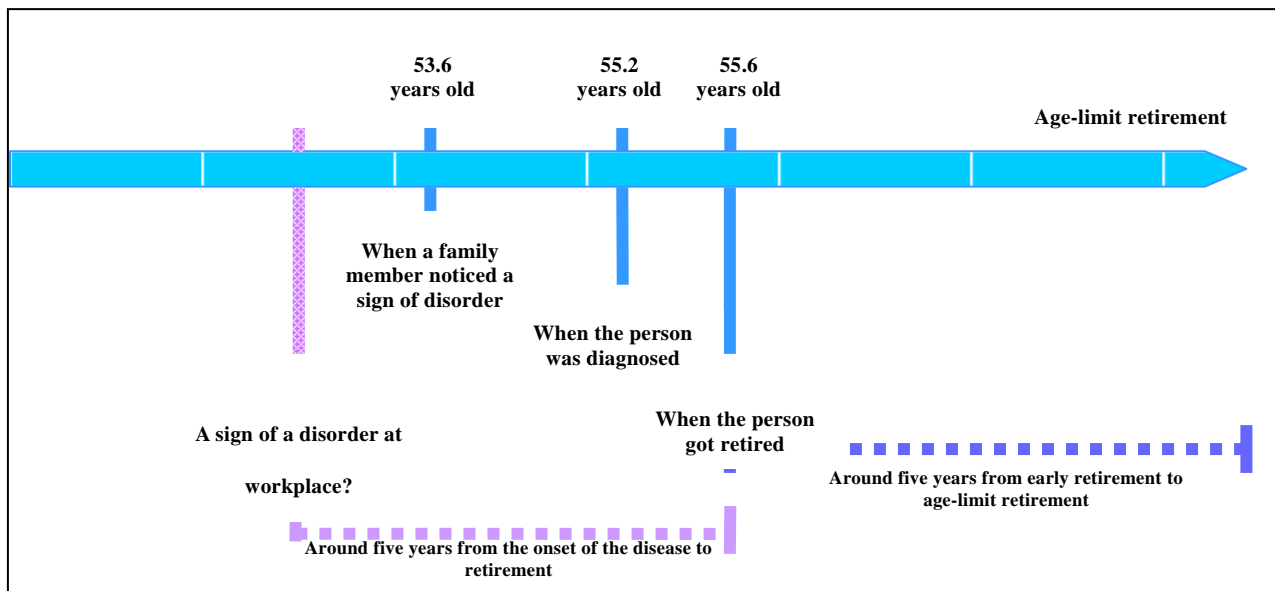


Figure 6. Developments after the onset of the disease at work by average

Looking at the average age of the person when a family member noticed his/her disorder (assuming it to be the age at which the person developed the disease) by reason for retirement, the age was 54.0 ± 3.03 for "early retirement out of own will," 49.8 ± 5.07 for "early retirement by being persuaded by the company," 56.43 ± 3.82 for "age-limit retirement," and 53.63 ± 3.02 for "being fired," respectively. When persons develop the disease at earlier age, they are apt to be persuaded to quit their jobs and face financial difficulties more seriously, as pointed out by Asada and others (2009). Such tendency was also observed in this survey. It is urgently needed to deepen the general understanding of early onset dementia, and for patients, who develop this disease in their working age, support for workplaces, as well as for individual patients, is indispensable, as the fate of whether or not they can continue working fully depends on the understanding and attitude of their workplaces.

Table 5. Average age when a family member noticed the person's disorder by reason for retirement

Reason for retirement	Average age when a family member noticed
Early retirement out of own will	54.0 ± 3.03
Early retirement by being persuaded by the company	49.8 ± 5.07
Age-limit retirement	56.43 ± 3.82
Being fired	53.63 ± 3.02

Chapter 4 Survey on the utilization status of Vocational Rehabilitation Centers for Persons with Disabilities

The survey on the utilization status was conducted for 47 Vocational Rehabilitation Centers and five

branches (52 facilities in total) nationwide, and valid answers were obtained from 44 facilities (84.6%). The results were as follows.

(1) Utilization status

Out of 44 facilities that gave valid answers, 15 facilities have been actually used by persons with early onset dementia in the past ten years.

A total of 22 persons have used these 15 facilities between 1999 and 2008. The first user was observed in FY2002, and the number of users increased gradually since FY2005 but decreased in FY2008. It is difficult to forecast the future trend.

Table 6. Number of users by year

Fiscal year	2002	2003	2004	2005	2006	2007	2008	Total
Number of users	1	0	1	5	6	8	1	22

(2) Characteristics of users

- (i) Regarding 22 persons with early onset dementia who utilized Vocational Rehabilitation Centers for Persons with Disabilities by FY2008, 95.5% were male and the average age was 52.1 ± 6.8 . 68.2% of them were in their fifties. Those who have a physical disability certificate were only 27.2%, and the most common certificate was a mental patient disability certificate.
- (ii) The most common causative disease was Alzheimer's disease (54.5%), and those with nonprogressive dementia, such as cerebral vascular disturbance, head injury, and brain tumor, were 31.8%.

Table 7. Causative diseases of users

Causative disease	Number of people	%
Alzheimer's disease	12	54.5
Cerebral vascular disturbance	4	18.2
Frontotemporal lobar degeneration	1	4.5
Head injury	1	4.5
Brain tumor	1	4.5
Encephalitis	1	4.5
Unknown	2	9.1
Total	22	100.0

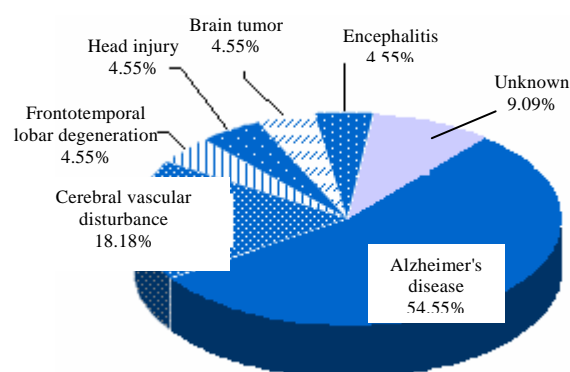


Figure 7. Causative diseases of users

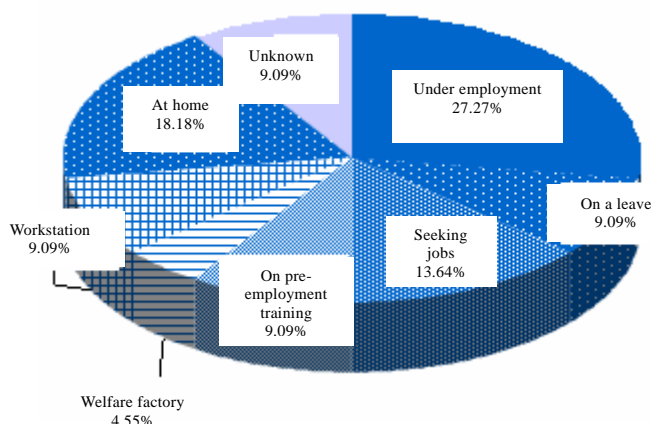
- (iii) In the case of degenerative disease, it is difficult to specify the onset of the disease. Assuming that the time when those around the person noticed any sign is the age at which the person developed the disease, the average age is 49.1 ± 8.1 . Compared with the preceding research studies, this survey shows that users of

Vocational Rehabilitation Centers generally developed the disease earlier.

- (iv) The average age at which they were diagnosed definitely was 49.7 ± 8.1 . The length from the onset to the definite diagnosis was one year or less for 36.4% and one year or more but two years or less for 36.4%, collectively accounting for over 70%. Users of Vocational Rehabilitation Centers generally visited a clinic relatively earlier after they noticed their disorder.
- (v) After the onset of the disease, only one person was in employment (within one year after developing a cerebral vascular disturbance). Two persons were on a leave (one person utilized the Vocational Rehabilitation Center within one year after he/she noticed a sign and was later diagnosed with Alzheimer's disease, and the other utilized the Vocational Rehabilitation Center four years later after noticing a sign and was diagnosed with dementia afterwards but had been diagnosed with mood disorder at the beginning). Except for these three persons, the other 19 persons all quit jobs after the onset of the disease.
- (vi) The average retirement age was 50.4 ± 8.5 , and the length from the onset to the retirement was 1.9 ± 2.3 years on average. Looking at individual cases, in nearly half of them, persons quit jobs within two years (within one year: 26.3%; one year or more but within two years: 21.1%). The length between the diagnosis to the retirement was 1.0 ± 1.7 years on average.
- (vii) Reasons for retirement were "out of own will" for six persons (31.6%) and "persuasion by company" for five persons (26.3%). One person was fired and another retired due to the age limit.
- (viii) Vocational Rehabilitation Centers have provided support for persons with early onset dementia, such as vocational assessment for 18 persons (81.8%) and interview for 15 persons (68.2%).
- (ix) After utilizing Vocational Rehabilitation Centers, six (27.3%) out of 22 persons were employed (one person maintained employment and five persons were newly employed), while two persons were on a leave, three persons were seeking jobs, two persons were in pre-employment training, two persons commuted to workstations, and four persons stayed at home. The survey revealed a lower employment rate of these persons compared with other persons with disabilities, such as those with higher brain dysfunction, developmental disability, and mental disorder.

Table 8. Outcomes after utilization

Developments after utilization	Number of people	%
Under employment	6	27.3
On a leave	2	9.1
Seeking jobs	3	13.6
On pre-employment training	2	9.1
Welfare factory	1	4.5
Workstation	2	9.1
At home	4	18.2
Unknown	2	9.1
Total	22	100.0

**Figure 8. Outcomes after utilization**

Chapter 5 Cases in which persons continued working after the onset of dementia

We reviewed three sample cases with different outcomes, with consent from the parties concerned for cooperation in the survey, and studied problems in providing support in each case.

(1) Case A: Case where the person wishes for employment extension

Mr. A (59 years old, male) was diagnosed with early onset Alzheimer's disease at the age of 58. He has such symptoms as disorder of memory and attention deficit, but continues working with cooperation and special consideration from his boss and co-workers. He is to retire at the age of 60, but wishes for employment extension. However, his symptoms have progressed and it seems difficult for him to continue working.

According to persons concerned, Mr. A is likely to have developed early onset dementia at the age of around 50. He could manage to continue working until age-limit retirement, in spite of his symptoms having progressed rather seriously, thanks to the utmost care and consideration of his boss and co-workers. The company has highly evaluated Mr. A's past contributions and this may be one of the reasons that Mr. A could continue working. Similar developments were observed in some other cases in the survey on current status of employment (see Chapter 3).

When these persons concerned came to notice a sign of a disorder in Mr. A, who was around 50 years old and had got promoted steadily due to his performance, he was diagnosed with depression and his family did not know that he was suffering from dementia. Therefore, if prompt measures are taken at an early stage of depression and other symptoms, keeping the possibility of early onset dementia in mind, support can be provided more properly with consideration to the future developments of the disease. For that purpose, it is important to spread the awareness that early onset dementia is to be treated as a "disease."

(2) Case B: Case where the person was hired by an agricultural company

Mr. B (53 years old, male) was diagnosed with early onset Alzheimer's disease. He commuted to a Type B Establishment for Support for Continuous Employment (a non-employment type establishment; hereinafter referred to as a "Type B Establishment") for support and was hired by an agricultural limited company. He suffered from disorder of memory, had difficulty in writing and calculation, and showed a decrease in motivation. He received job coach support and other services for maintaining employment.

There are various processes in agricultural production, and diversified jobs may be made available according to a person's ability. However, considering the progressive nature of the disease and the problems of securing quality of labor matching wages, it is difficult to maintain employment without limit. Therefore, in Case B, a system is maintained under which the person can continue to utilize the Type B Establishment when he can no longer work at the farm, providing him with flexible support in accordance with his circumstances. The survey showed that many request the enhancement of societal resources at the stage when patients' symptoms become too serious for them to continue working (see Chapter 3). Case B will be a hint to review an appropriate support system.

(3) Case C: Case of the person with nonprogressive dementia

Mr. C (41 years old, male) developed encephalitis at the age of 26, and was diagnosed with a mild degree of cognitive impairment. He went back to work afterwards, but had difficulties in performing his duties due to memory problems and lack of attention to his surroundings when focusing on one thing. Eventually, he resigned.

He then utilized a vocational aid center, Hello Work, a Vocational Rehabilitation Center, and other facilities to receive job coach support services and was newly employed.

The causative disease in this case was encephalitis, and no significant progress has been seen in Mr. C's symptoms. He is diagnosed with mild cognitive impairment (MCI). In the former two cases, the progress of the disease makes it difficult for Mr. A and Mr. B to perform their duties, while Mr. C can continue working, with his symptoms being unchanged, supported by the care and understanding of persons concerned. In some cases of dementia where symptoms are nonprogressive depending on causative diseases, measures for higher brain dysfunctions may also be effective.

Chapter 6 Summary

1. Problems directly related to patients' lives

Symptoms of early onset dementia are similar to those of senile dementia but the incidence is much lower. Patients develop the disease at their working age, and if they cannot continue working, they directly face financial problems and their situation is apt to be more serious.

2. Current status of employment

Out of 57 analysis targets in this survey, only one person was in employment. In the past ten years, 22

persons with early onset dementia utilized Vocational Rehabilitation Centers nationwide, but only six of them could be employed afterwards. Maintaining employment is extremely difficult at present.

3. Measures to be taken at an early stage of the disease

(1) Importance of early diagnosis

The most important thing is to start taking measures for early onset dementia at an early stage, and early diagnosis is indispensable for that purpose. It is urgently needed to enhance medical care quality so that doctors have the capacity to diagnose the disease at an earlier stage.

(2) Establishment of consultation service offices

A workplace preferably has a consultation service office where workers can have consultation promptly when they are suspected to have developed early onset dementia. If the consultation service office acquires some sort of information at an early stage, the chances may be greater that proper adjustment may be made at the workplace. For that purpose, a workplace needs to have a person with specialized knowledge in this field. Further efforts should be made to promote enlightenment and educational activities so as to realize prompt action upon the onset of the disease.

4. Measures to be taken in a staged manner

Patients may have difficulties in performing duties that require highly specialized technology or prompt judgment, but can engage in certain levels of jobs and activities according to their individual ability. As a means to provide support for realizing a flexible work style in accordance with the progress of the disease, job coach support services are available. Specialized services need to be provided in a staged manner to support employment in accordance with patients' progressive symptoms.

5. Development of a system to support workplaces

A long-term support system for workplaces needs to be developed so as to help them take proper measures for persons with early onset dementia based on full understanding on the characteristics of the disease. The system will be developed in a staged manner, such as through providing information and advice to workplaces, and making coordination with related organizations, from the viewpoint of vocational rehabilitation.

6. Methods of effective use of research achievements

This research aims to define the disease of early onset dementia, compile the findings of the preceding research studies, and clearly show advanced efforts, the current status of employment and the utilization status of Vocational Rehabilitation Centers. This will serve as basic data for ascertaining the current status when starting employment support services for persons with early onset dementia.