Chapter 5

Various Systems and Social Resources for Supporting Persons with Dementia and Their Families

A | Various Systems and Social Resources for Supporting Medical and Long-term Care for Persons with Dementia

CQ 5A-1

What are the functions and roles of the medical center for dementia?

Answer

The Medical Center for Dementia is required to provide two key functions: specialized medical functions (specialized medical consultation, differential diagnosis of dementia and initial response, and emergent responses for behavioral/psychological symptoms of dementia and physical comorbidities) and community liaison hub functions (establishment and operation of the Local Liaison Council for Dementia Care, and organizing workshops). In each prefecture, the Medical Center for Dementia is expected to design the hub function, deployment, and method of liaison, which match the characteristics of local communities, and to manage the quality of the activities.

Comments and evidence

The objective of the Medical Center for Dementia is "to build a functional system for people with dementia, which can provide comprehensive health care services in the community ranging from prevention of disease progression to support for community living. Specifically, the Medical Center for Dementia supports differential diagnosis for dementia-related diseases and initial response; emergent responses for acute treatments of behavioral/psychological symptoms, and physical comorbidities; and specialized medical consultations, while also conducts training for community health and nursing care personnel". Currently, there are three types of Medical Center for Dementia: "core type", "regional type", and "liaison type".

The functions required of the Medical Center for Dementia include (1) specialized medical services (1. differential diagnosis of dementia and initial response, 2. emergent response for behavioral/psychological symptoms and physical comorbidities, 3. specialized medical consultations) and (2) community liaison hub functions (1. establishment and operation of Local Liaison Council for Dementia Care, 2. organizing workshops).

Specialized medical consultations take place in a medical consultation room staffed with psychiatric social worker, public health nurse, and other personnel. In response to telephone or face-to-face consultations from persons with dementia, their families or related organizations, the staff of the medical consultation room makes medical appointments or arranges for referral to medical institutions ¹⁾. Following the diagnosis, staff of the medical consultation room provides information to the persons with dementia and their families, liaises and coordinates with relevant organizations, and supports them in using the services they need ¹⁾. The medical consultation room plays an important role in improving the functions of the Medical Center for Dementia ²⁾. To support differential diagnosis and initial response, the medical consultation room is staffed with specialized doctors and equipped with testing facilities. The staff also provides information to persons with dementia and their families after the diagnosis, and liaises with primary care physicians to secure continuous medical care. To support emergent response for behavioral/psychological symptoms and physical comorbidities, the medical consultation room responds to emergent cases by coordinating with hospitals with general or psychiatric beds, as well as with psychiatric and general emergency systems.

The Local Liaison Council for Dementia Care is a council formed and operated by local health and medical professionals, the Community General Support Center, long-term care insurance personnel, and experts related to dementia medical care. The aim is to promote the establishment of a community-based dementia support system. Workshops are organized for training local professionals as well as families and community residents. Training of medical specialists and specialized staff knowledgeable in a wide range of activities stipulated by the Medical Center for Dementia is an important responsibility of the core-type Medical Center for Dementia³⁾. In addition, organization of regular training programs including case studies with active participation by primary care physicians and certified dementia support doctors will contribute to maintain a high level of dementia medical care in the region ⁴⁾.

■ References

- 1) Awata S. Roles of Medical Center for Dementia in the community. Japanese Journal of Geriatrics. (Nihon Ronen Igakkai Zasshi) 2009; 46(3): 203-206. (In Japanese)
- 2) Awata S. New national health program against dementia in Japan: the medical center for dementia. Psychogeriatrics, 2010; 10(2): 102-106.
- 3) Ikeda M, Kojima S, Tomioka O. Roles of Medical Center for Dementia and future direction: Focusing on Kumamoto model. Japanese Journal of Geriatric Psychiatry (Ronen Seishin Igaku Zasshi) 2010; 21(11): 1189-1192. (In Japanese)
- 4) Kojima S, Ikeda M. Roles of Core Medical Center for Dementia in dementia medical care and issues. Japanese Journal of Geriatric Psychiatry (Ronen Seishin Igaku Zasshi) 2014; 25(7): 738-743. (In Japanese)

■ Search formula

PubMed search: July 14, 2015 (Tuesday)

#1 ("Dementia/therapy" [Majr] OR (dementia [TI] AND (therapy [TI] OR therapeutic [TI] OR treatment [TI])) OR "Cognition Disorders/ therapy" [Majr] OR (cognition disorder* [TI] AND (therapy [TI] OR therapeutic [TI] OR treatment [TI]))) AND ("Health Services for the Aged" [Mesh] OR "Community Health Services" [Mesh] OR "Community Health Centers" [Mesh])

Ichushi search: July 14, 2015 (Tuesday)

#1 Medical Center for Dementia/TH OR Medical Center for Dementia/TI



What are the roles of certified dementia support doctors?

Answer

The roles of certified dementia support doctors (dementia support doctor hereinafter) are: (1) to support primary care doctors and care professionals involved in medical and long-term care for people with dementia; (2) to facilitate multidisciplinary liaison mainly at the Community General Support Center; and (3) to train primary care doctors aiming to improve dementia managing skills and to educate residents of the community. Dementia support doctors are expected to promote collaboration between different medical disciplines and between medical care and long-term care in the community.

Comments and evidence

Accompanying aging of the population, the number of people with dementia has increased rapidly, and dementia is now considered a common disease. Under such circumstances, there is an urgent need to establish a support system for older people from the early stage of dementia with the participation of primary care doctors, and to educate doctors and care staff. By the end of 2015, a total of 5,085 dementia support doctors were certified. The roles of dementia support doctors are as follows: (1) to support primary care doctors and care professionals involved in medical and long-term care for persons with dementia; (2) to facilitate multidisciplinary liaison mainly at the Community General Support Center; and (3) to serve as lecturers in training of primary care doctors aiming to improve dementia managing skills and to educate residents of the community ¹⁾. Compared with general primary care doctors, dementia support doctors possess superior capabilities in differential diagnosis of dementia, management of behavioral and psychological symptoms of dementia (BPSD) in outpatient setting, and community liaison and long-term care ²⁾. In a survey of dementia support doctors, 84% are engaged in liaison and 64% in training and educational activities ³⁾.

■ References

- 1) Washimi Y, Horibe K, Takeda A, et al. Educational program in Japan for Dementia Support Doctors who support medical and care systems as liaisons for demented older adults in the community. Geriatr Gerontol Int. 2014; 14(Suppl 2): 11-16.
- 2) Awata S. Consideration of National Policies to Support the Development of Medical Services for Dementia. Psychiatria et Neurologia Japonica (Seishin Shinkeigaku Zasshi) 2014; 116(5): 378-387. (In Japanese)
- 3) NLI Research Institute. FY 2012 Ministry of Health, Welfare and Labour Health Project Promotion Grant: Report of study on the functions of dementia support doctor and training system and teaching materials. Tokyo: NLI Research Institute; 2013.

■ Search formula

PubMed search: June 17, 2015 (Wednesday)

#1 ("Dementia" [Majr] OR dementia [TI] OR "Cognition Disorders" [Majr] OR "cognition disorder*" [TI]) AND "Japan" [Mesh] AND (doctor OR doctors)

Ichushi search: June 17, 2015 (Wednesday) #1 Dementia support doctor/AL



What are the roles of long-term care insurance system for persons with dementia and their caregivers?

The long-term care insurance is the foundation that supports the living of people with dementia and their families. The long-term care insurance provides diverse services including consultation support services mainly at the Community General Support Center; home-visit services such as home help service, home-visit bathing, and home-visit nursing; and facility services such as day care and day rehabilitation service; as well as community-based services such as group home for older people with dementia and small-scale multifunctional in-home care.

Comments and evidence

1. Outline of long-term care insurance system

a. Basic design of the system

Based on the Long-term Care Insurance Act enacted in 1997, the long-term care insurance system was started in 2000 as the fifth social insurance system. The insured persons are those aged 40 years and above (65 years and above: primary insured persons, 40-64 years: secondary insured persons), and the insurer is a municipality. The insured persons can receive insurance benefits (use of services) if they are judged as requiring long-term care or requiring support, after going through a screening/ evaluation process of "whether or not they are in a state of needing long-term care". The screening/evaluation process is called "certification of long-term care need". The process consists of (1) application submitted by the insured person to the insurer; (2) investigation of physical condition (primary screening by computer); (3) report written by the family doctor from the medical viewpoint [secondary screening, considering also (2)]. There are seven levels of certification, ranging from mild to severe: "support needed" levels 1-2 to "care needed" levels 1-5. Those certified as "support needed" can use the preventive care services, and those certified as "care needed" can utilize the care services.

b. Long-term care insurance services

Over 20 services are provided by the long-term care insurance, and they are broadly classified as follows: (1) home services, (2) facility services, and (3) community-based services that utilize multiple home services in a package 1). (1) Home services and (3) community-based services, with some exceptions, are provided based on a monthly service utilization plan (care plan). The care plan is basically prepared by a care support specialist (care manager). In principle, the plan is prepared by combining services within the monthly payment limit (use limit) which is determined depending on the level of care needed. Although the usefulness of all these services has not been verified, disappearance or reduction of behavioral and psychological symptoms was observed by using day care for dementia, which is a facility service for dementia 2).

2. System reform in 2015 and fee revision 3)

The long-term care insurance system is operated based on a project plan developed by the insurer every three years, and insurance premiums and care fees (unit price for service) are revised every three years. In addition, if necessary, the system will be reformed accompanying revision of the Act. In fiscal year 2015, the system was reformed in response to the Act for Securing Comprehensive Medical and Long-term Care (Tax and Social Security Integrated Reform), and the fees were also revised following the usual 3-year schedule.

References

- 1) Awata S. Therapeutic approach for dementia in long-term care insurance. Japanese Journal of Psychiatric Treatment (Seishinka Chiryogaku) 2014; 29(8): 1051-1057. (In Japanese)
- 2) Social Welfare Corporation Yokufukai Dementia Care Research & Training Tokyo Center. A study on the approach of day services for persons with dementia. Surveys related to verification of the effects of long-term care fees and research in FY 2013 (FY 2013 survey), 2014. (In Japanese)
- 3) Ministry of Health, Labour and Welfare. Outline of the long-term care insurance system reform: revision of the Long-term Care Insurance Act and revision of long-term care fees. 2006 . http://www.mhlw.go.jp/topics/kaigo/topics/0603/dl/data.pdf (In Japanese)

■ Search formula

PubMed search: June 17, 2015 (Wednesday)

#1 ("Dementia" [Majr] OR dementia [TI] OR "Cognition Disorders" [Majr] OR cognition disorder* [TI]) AND ("Insurance, Long-Term Care" [Mesh] OR "long-term care insurance" [TI])

Ichushi search: June 17, 2015 (Wednesday)

#1 (Dementia/TH OR Dementia/TI OR Cognitive impairment/TH OR Cognitive impairment/TI) AND (Long-term care insurance/TH OR Long-term care insurance/TI)



What are the functions and roles of Community General Support Center?

Answer

The Community General Support Center was established in 2006. The contents of operation for dementia are not necessarily clearly defined so far, but the Center has played an important role as the core facility to provide support for persons with dementia in the following work areas: (1) general consultation/support, (2) protection of patients' rights, (3) comprehensive and continuous case management support, and (4) preventive benefits and preventive care management. In the future, its importance will increase as a core organization for the community-based comprehensive care system.

Comments and evidence

With the revision of the Long-term Care Insurance Act in 2006, Community General Support Center was established in each municipality as a base for promoting comprehensive community care. The center is mandated as a facility that "aims to comprehensively support the improvement of health care and promotion of welfare by providing assistance necessary for maintaining physical and mental health and stabilizing lives of residents living in the community". Specifically, a team consisting of three professionals: social worker, chief care manager, and public health nurse or nurse with experience in community care, is responsible for the following work areas: (1) general consultation/support, (2) protection of patients' rights, (3) comprehensive and continuous case management support, and (4) preventive benefits and preventive care management. However, some problems have been identified 1), which include 1) issue of support for households without family care capability, 2) issue related to daily life support with the rapid increase in households of single persons without relatives, 3) issue related to certification of long-term care need for dementia, and 4) issue of medical collaboration in community care for dementia 2-5). As indicated in another section, the installation of an initial-phase intensive support team for dementia in the Community General Support Center is expected to be one solution to these issues.

■ References

- 1) Yamamoto S. The future of community general support center: focusing on various issues in community care for dementia. Japanese Journal of Geriatric Psychiatry (Ronen Seishin Igaku Zasshi) 2012; 23(Suppl. 1): 126-131. (In Japanese)
- 2) Awata S, Sano Y, Fukumoto M. Status of works related to dementia in community general support center of suburban city, especially from the perspectives of medical resources and collaboration. Japanese Journal of Geriatric Psychiatry (Ronen Seishin Igaku Zasshi) 2010; 21(3): 356-363. (In Japanese)
- 3) Konagaya Y. Status and issues of consultations related to dementia in community general support center. Japan Medical Journal (Nihon Iji Shinpo) 2012; (4610): 84-88. (In Japanese)
- 4) Kikuchi K, Sato S, Yamaguchi K, et al. Functions of community general support center: present status and issues. Japanese Journal of Geriatric Psychiatry (Ronen Seishin Igaku Zasshi) 2012; 23(3): 299-304. (In Japanese)
- 5) Takeda A. Evaluation of the usefulness of building community support system. Proceedings of the 54th Annual Meeting of Japan Geriatric Society. Japanese Journal of Geriatrics. (Nihon Ronen Igakkai Zasshi) 2013; 50(2): 197-199. (In Japanese)

■ Search formula

PubMed search: June 17, 2015 (Wednesday)

#1 ("Dementia" [Majr] OR dementia [TI] OR "Cognition Disorders" [Majr] OR cognition disorder* [TI]) AND ("Comprehensive Health Care" [Mesh] OR "integrated care") AND ("Community Health Centers" [Mesh] OR "community based")

Ichushi search: June 17, 2015 (Wednesday), July 7, 2015 (Tuesday)

#1 (Dementia/TH OR Dementia/TI OR Cognitive impairment/TH OR Cognitive impairment/TI) AND (Community general care center/AL OR Community General Support Center/TH OR Community General Support Center/TI OR Community general center/AL OR (Community/TI AND Comprehensive/TI AND Center/TI))



What are the functions and roles of the initial-phase intensive support team for dementia?

Answer

Medical and general care for dementia in the future is expected to base on early and proactive response aiming to prevent crisis, and to be equipped with functions for early support and support to avoid crisis. The initial-phase intensive support team for dementia is a promising mechanism to fulfill these functions. An expert team visits persons with dementia and provides comprehensive support at an early stage to enable them to continue living in the community. The model project started in 2012, and activities in all municipalities were scheduled to begin by the end of 2017.

Comments and evidence

The mission of the initial-phase intensive support team for dementia is to visit persons with dementia and provide comprehensive support at the earliest possible stage to enable them to continue living in the community. "Initial" in this case does not necessarily denote the initial stage of the disease, but means "first touch". Furthermore, "intensive" refers to visiting the persons with dementia and their families, providing assessment and family support comprehensively and intensively (for approximately 6 months), and after providing support for independent living, referring them back to their usual medical and general care team. Persons who should be targeted are those who have not received medical services or long-term care services, or who have stopped receiving these services. Some examples of such cases are those (1) who have not received a clinical diagnosis of dementia-related disease; (2) who are not receiving continuous medical services; (3) who are not connected to long-term care insurance services, (4) who were diagnosed with dementia but have stopped receiving long-term care services, or those who despite receiving medical and long-term care services are struggling to cope with behavior and psychological symptoms of dementia (BPSD).

Model projects were conducted at 14 locations nationwide in 2013 ¹⁾, and at 41 locations nationwide in 2014 ²⁾. The results showed that persons targeted for visit and support were identified centrally through the Community General Support Centers, but details of the route of identification showed that consultations from the families and the patients accounted for 50%, indicating that the persons concerned requested consultation. In addition, 85-90% of the patients continued to live at home after receiving intervention from the team, showing that the team did not respond to difficult cases simply by hospitalization and admission to care facilities. Furthermore, improvement in the care burden scale has been reported ^{2, 3)}. From 2015, the initial-phase intensive support team was scheduled to start operation in all the municipalities in which this initiative was feasible as a community support project. By the end of 2017, the team was scheduled to start in all municipalities nationwide. Results of a study show that the initial-phase intensive support team for dementia is useful in enabling persons with dementia to continue living at home, and can be expected to be an attempt that improves the overall community care ⁴⁾. However, since this project has just been started, further verification is needed in the future.

References

- 1) National Center for Geriatrics and Gerontology. Grant-in-aid for the promotion of health services for the elderly 2013. Research project on the development of an initial-phase intensive support service model to achieve early diagnosis and early intervention for dementia: project report. 2014. (In Japanese)
- 2) National Center for Geriatrics and Gerontology. Grant-in-aid for the promotion of health services for the elderly 2014. Research project on the installation and operation of an initial-phase intensive support service model to achieve early diagnosis and early intervention for dementia: project report. 2015(2): 138-146. (In Japanese)
- 3) Washimi Y. Dementia and community collaboration: on the initial-phase intensive support team. Japanese Journal of Geriatrics. (Nihon Ronen Igakkai Zasshi) 2015; 52(2): 138-146. (In Japanese)
- 4) Awata S. Orange Plan and challenge from the community: initial-phase support for dementia: especially the outreach issues (home-visit care). Japanese Journal of Geriatric Psychiatry (Ronen Seishin Igaku Zasshi) 2013; 24(9): 883-889. (In Japanese)

■ Search formula

PubMed search: June 17, 2015 (Wednesday)

#1 ("Dementia" [Majr] OR dementia [TI] OR "Cognition Disorders" [Majr] OR cognition disorder* [TI]) AND "Patient Care Team" [Mesh] AND "Intensive Care" [Mesh]

Ichushi search: June 17, 2015 (Wednesday)

#1 Dementia initial-phase intensive support team/AL OR ((Dementia/TH OR Dementia/TI OR Cognitive impairment/TH OR Cognitive impairment/TI) AND Initial-phase intensive/AL AND (Support team/TI OR Team care/TH OR Team care/TI))

B | Advocacy for People with Dementia

CQ 5B-1

Is it possible to evaluate the abilities of judgment and decision-making in persons with dementia?

Answer

When obtaining consent for performing a medical action or considering the use of the adult guardianship system, doctors need to determine the mental capacity (abilities of judgement and decision-making) of a person with dementia. The mental capacity has a three-layer structure: (1) functional ability, (2) capacity, and (3) competence. Doctors are able to determine the mental capacity of an individual with dementia by assessing the cognitive function (functional ability) associated with a specified legal action and assessing the underlying clinical state (capacity).

Comments and evidence

Mental capacity is the ability to effectively express an intention and understand the result of one's actions (abilities of judgment and decision-making). Capacity to act refers to a legal status or legal qualification that a person can execute an effective legal act alone. In routine medical care for persons with dementia, it is necessary to evaluate the mental capacity of these individuals when obtaining consent for a medical action or when considering the use of the adult guardianship system.

1. Structure of assessment of mental capacity

The structure of assessing mental capacity has three levels: (1) functional ability, (2) capacity, and (3) competence.

Functional ability is the mental function required at each stage of the psychological process leading to decision-making, and is a phenomenon that can be measured as a continuous variable, as for cognitive function. Capacity is the clinical state judged by a doctor, and is a categorical phenomenon related to whether a person can make meaningful decision under the circumstances in which the person is placed. For example, a medical diagnosis of severe dementia state belongs to this category. Competence is a legal status which is judged by a legal personnel, especially a judge, and is a categorical phenomenon judged by the dichotomy of "yes" or "no" regarding whether a person possesses the ability required to execute a legal act alone.

2. Practical judgment of mental capacity

The conventional judgment of mental capacity used for determining capacity for criminal responsibility consists of the following procedures: (1) confirm the psychiatric diagnosis (biological factor), (2) determine whether or not the psychiatric disorder is severe enough to impede legal action (psychological factor), and (3) make a legal judgment based on the above. On the other hand, Igarashi ¹⁾ advocates that since not all the persons diagnosed with dementia lack mental capacity and ability to act, the following procedures are more appropriate in the era of normalization: (1) assess functional ability related to a specific legal action; (2) next, evaluate capacity as an underlying factor; and (3) entrust the judgment of competence to a judge.

There are various approaches to the assessment of the functional ability of a person with dementia: (1) an approach that focuses on cognitive function, (2) an approach that focuses on the ability to execute a specific action, and (3) an approach based on observation of daily actions ²⁾. The approach focusing on cognitive function employs Mini Mental State Examination (MMSE), but there is insufficient evidence regarding the relationship with mental capacity ³⁾. For the approach focusing on the ability to execute a specific action (related to consent to treatment), Applebaum et al. ⁴⁾ advocated a concept consisting of four steps: (1) understand the information related to decision making (understanding), (2) rationally process the information obtained (rational thinking), (3) recognize the situation in which decision is made and the result of decision-making (recognition), and (4) express the result of decision-making to others (statement of choice). Based on this concept, they developed a scale for measuring the ability to consent to treatment ⁵⁾. In addition, Marson et al. ⁶⁾ have developed the "Financial Capacity Instrument".

3. Issues related to informed consent and medical consent for persons with dementia

Individuals who receive medical care have the right to make decisions about receiving the medical care. A doctor must obtain the patient's consent before performing the medical action, and as a premise, the doctor should give an explanation necessary for obtaining the consent. In other words, medical actions must be performed based on informed consent.

From this perspective, a person who has been diagnosed with dementia is entitled to receive explanations including the diagnosis (name of disease), symptoms, predicted clinical course, treatments, and systems and services available. In addition, as a premise of such explanations, the patient has the right of self-determination about receiving (or rejecting) the medical action.

If a person with dementia lacks the ability to consent to medical care, the health care personnel customarily obtains consent from the family or relatives, and then conducts the medical practice. However, if there are no family members or relatives who can cooperate with consent to medical care, medical decision for a person with dementia who lacks the ability to consent to medical care becomes a difficult problem. In Japan, there is currently no legislation on medical consent for adults who lack the ability to consent.

In Japan, from the legal side, the Japan Federation of Bar Associations has published "Outline of the act on proxy medical consent for persons lacking medical consent ability" (2011), and the Legal-Support Adult Guardianship Center has published the "Interim report on consent to medical action" (2009). From the medical side, the Japan Geriatrics Society has issued a "Position Statement" on "End-of-life medical and general care for the elderly" (2012). From the administration side, the "Guidelines on the decision-making process of medical care at the end of life" (2015) has been published. In addition, the method of (written) advance healthcare directive is increasingly being used to decide in advance the contents of medical care that one wishes to receive (or not to receive).

■ References

- 1) Igarashi Y. Adult guardianship system and structure of judging mental capacity. Japanese Journal of Geriatric Psychiatry (Ronen Seishin Igaku Zasshi) 2003; 14(10): 1228-1239. (In Japanese)
- 2) Matsuda O. Aspects of aging society (9) Aging society and judgment ability; evaluation of normal aging and pathological aging. Japanese Journal of Geriatric Psychiatry (Ronen Seishin Igaku Zasshi) 2009; 20(6): 681-687. (In Japanese)
- 3) Matsuda O, Saito M. Protection of rights and ability assessment of elderly people with dementia: study of the degree of agreement between the results of intelligence tests and cognitive function tests and the execution of daily living activities including financial capacity. Japanese Journal of Geriatric Psychiatry (Ronen Seishin Igaku Zasshi) 2011; 22: 723-733. (In Japanese)
- 4) Applebaum PS, Grisso T. Assessing patients' capacities to consent to treatment. N Engl J Med. 1988; 319(25): 1635-1638.
- 5) Grisso T, Appelbaum PS. The MacArthur Treatment Competence Study. III: Abilities of patients to consent to psychiatric and medical treatments. Law Hum Behav. 1995; 19: 149-174.
- 6) Marson DC, Sawrie SM, Snyder S, et al. Assessing financial capacity in patients with Alzheimer disease: a conceptual model and prototype instrument. Arch Neurol. 2000; 57: 877-884.

■ Search formula

PubMed search: July 14, 2015 (Tuesday)

#1 ("Dementia/diagnosis" [Mesh] OR dementia [TI] OR "Cognition Disorders/diagnosis" [Mesh] OR cognition disorder* [TI] OR cognitive disorder* [TI] AND ("Neuropsychological Tests" [Majr] OR neuropsychological test* [TI] OR "Disability Evaluation" [Majr] OR disability evaluation* [TI] OR disability assessment* [TI]) AND ("Liability, Legal" [Mesh] OR legal liability* [TI] OR "Forensic Psychiatry" [Mesh] OR "Decision Making" [Mesh] OR decision making* [TI] OR "Executive Function" [Mesh] OR functional ability* [TI] OR "Mental Competency" [Mesh] OR competency* [TI] OR capacity* [TI])

Ichushi search: July 14, 2015 (Tuesday)

#1 (Dementia/TH OR Dementia/TI OR Cognitive impairment/TH OR Cognitive impairment/TI) AND (Neuropsychological examination/TH OR Neuropsychological examination/TI OR Neuropsychological test/TI) AND (Legal responsibility/TH OR Legal responsibility/TI OR Legal ability to act/TI OR Decision making/TH OR Decision making/TI OR "Executive function (awareness process)"/TH OR Executive function/TI OR Functional ability/TI OR Mental ability/TH OR Mental ability/TI OR Judgment ability/TI OR competence/TI OR capacity/TI)

CQ 5B-2

How can the adult guardianship system be used to protect the rights of people with dementia?

Answer

Individuals with dementia are vulnerable to infringement of their rights due to decline of judging ability. The adult guardianship system is a system that supports all legal activities including asset management and contract related to personal custody for a person who lacks sufficient judgment ability, by appointing an assistant (such as adult guardian) who protects the rights of the persons with dementia. However, there are many issues in the current adult guardianship system including the following: the guardian does not have the right to consent to medical actions; there are insufficient measures against asset embezzlement by the guardian; the utilization rate is low; and there is a shortage of persons willing to take on the role as guardian.

Comments and evidence

Persons with dementia are vulnerable to having their rights infringed due to decline in judgment ability ^{1, 2)}. In order to prevent such infringement of rights, persons with dementia can utilize the programs for supporting independence in daily living and the adult guardianship systems. In both systems, the crucial point is to support daily living while respecting the person's self-determination ³⁾.

1. Outline of the program for supporting independence in daily living

For persons whose ability of judgment is impaired due to dementia, intellectual disability, mental disability, and other causes, and who experience difficulties in managing the contracts of utilizing welfare services by themselves, these persons can utilize the "Program for supporting independence in daily living (former: Community welfare rights protection project)" that provides assistance for using welfare services, management of everyday finance, custody of important documents, and other services based on the contract signed with the person with dementia. However, in order to use this project, there is a condition that "the person himself/herself has the ability to understand the contents of the program and sign a contract".

2. Outline of the adult guardianship system

The adult guardianship system is a system that supports all legal activities including contracts related to asset management and personal custody (taking care of personal affairs) for a person who lacks sufficient judgment ability, by selecting an assistant (such as a guardian) who protects the rights of the person with dementia. There are two systems: a statutory guardianship system and a voluntary guardianship system. The statutory guardianship system is a system that protects and assists the person with dementia (hereinafter referred to as the person) by the following framework: an adult guardian appointed by the family court (adult guardian, curator, or assistant), while considering the interests of the person, acts on behalf of the person to execute legal acts such as contracts (proxy right), give consent when the person conducts legal acts by himself/herself (consent right), or cancel a legal act after the person has committed an unbeneficial legal act without consent from the adult guardian (right to rescind). On the other hand, the voluntary guardianship system operates as follows: to prepare for the future when judgment ability becomes inadequate, the person while still having adequate judgment ability selects a proxy (voluntary guardian), and concludes a contract granting proxy right for legal acts related to the person's own asset management and personal custody (voluntary guardianship contract), which is a notarized document prepared by a notary.

Application to use the statutory guardianship system is filed by the person, spouse, relative within the fourth degree, public prosecutor, or (if there is no relative) the municipal mayor. There are three types of statutory guardianship: guardian, curator, and assistant. In the case of "a general state of lacking judgment capability", a guardian is appointed, and the guardian is able to exercise all proxy rights and rights to rescind. In the case of "markedly inadequate judgment capability", a curator is appointed. The curator is able to exercise rights to consent and rights to rescind on specific matters (debt, lawsuit, approval/waiver of inheritance, new construction/renovation, etc. listed in Civil Code Article 13). In addition, the curator may be granted proxy rights for certain legal acts (such as bank cash management, asset management, long-term care contract, hospitalization contract, etc.) according to the request of the person. In the case of "inadequate judgment capability", an assistant is appointed, and the assistant can exercise rights to consent or rights to rescind for a part of specific matters

according to the request of the person.

However, the proxy rights that a guardian can exercise are limited to asset management and personal custody. For example, the guardian cannot exercise proxy rights regarding divorce/marriage/adoption, consent to medical actions, surety, and guarantor. In addition, there are other issues such as insufficient measures against asset embezzlement by the guardian, low utilization rate per population compared to European and American countries, and shortage of persons willing to take on the role as guardian.

■ References

- 1) Ikeda E. To prevent economic damage: how to support elderly persons living alone. Japanese Journal of Geriatric Psychiatry (Ronen Seishin Igaku Zasshi) 2011; 22(7): 815-824. (In Japanese)
- 2) Akanuma Y. How to protect the rights of persons with dementia? Rights protection for dementia. Naika 2012; 109(5): 825-827. (In Japanese)
- 3) Arai M. Rights protection for patients with dementia. Roles of the adult guardianship system. The Journal of the Japanese Society of Internal Medicine (Nihon Naika Gakkai Zasshi) 2011; 100(8): 2195-2199. (In Japanese)

■ Search formula

PubMed search: July 14, 2015 (Tuesday)

#1 "Dementia" [Mesh] OR dementia [TI] OR "Cognition Disorders" [Mesh] OR cognition disorder* [TI] OR cognitive disorder* [TI] AND ("Legal Guardians" [Mesh] OR adult guardian* [TI]) AND ("Patient Advocacy" [Mesh] OR "Patient Rights" [Mesh] OR advocacy [TI] OR right* [TI])

Ichushi search: July 14, 2015 (Tuesday)

#1 (Dementia/TH OR Dementia/TI OR Cognitive impairment/TH OR Cognitive impairment/TI) AND (Adult guardianship system/TH or Adult guardianship system/TI) AND (Patients' rights protection/TH OR Rights protection/TI OR Patients' rights/TH)

CQ 5B-3

What role does the Prevention of Elder Abuse Act play in preventing abuse to persons with dementia?

Answer

The Prevention of Elder Abuse Act sets forth national responsibilities for preventing elder abuse, protection measures for older people who have been abused, and support measures to prevent abuse of older people by caregivers. Cognitive impairment is a major factor that increases the risk of abuse. Anyone finding an older person who appears to be abused has the obligation to report or the obligation to make efforts to report to the municipalities (Community General Support Centers), depending on the severity of abuse.

Comments and evidence

The "Act on the Prevention of Elder Abuse, Support for Caregivers of Elderly Persons and Other Related Matters" (hereinafter "Prevention of Elder Abuse Act") was approved in November 2005 and enforced in April 2006. To protect the rights of older people, this law sets forth the responsibilities of the country to prevent elder abuse, protection measures for older persons who have been abused, and support measures to prevent abuse of older persons by caregivers (such as by reducing caregiver burden) aiming to promote policies related to support for prevention of elder abuse and support for caregivers ¹⁾.

1. Outline of the law

In this law, an elderly person is defined as a person who is aged 65 years or older, and elder abuse is classified into "elder abuse by a caregiver" and "elder abuse by care facility staff". Caregivers are assumed to include family members, relatives, and persons living with the elderly person, who are taking care of the elderly person. Care facility staff is assumed to be employee working in a "care facility" or "care business".

Elder abuse is defined as "an elderly person placed in a state where his/her rights and interests are infringed, or in a state where his/her life, health, or living is impaired by inappropriate treatment from others".

A person finding an older person who appears to be abused has the obligation to report or the obligation to make efforts to report to the municipalities (Community General Support Centers), depending on the severity of abuse. In addition, municipalities are primarily responsible for the prevention of abuse, protection of the older persons, and support for the abuse perpetrators. Even if it is difficult to determine whether a case is abuse, the municipality should take necessary assistant measures according to the Prevention of Elder Abuse Act, when it is speculated that the rights of an older person may be infringed, or his/her life, health, or living may be impaired.

2. Factors for elder abuse

The risk factors for abuse in community-dwelling older persons include (1) factors related to the older person (75 years of age and older, female, ethnicity, poor economic or health status, cognitive impairment, behavioral problems such as aggression and care refusal, high level of dependence due to functional decline, psychiatric illness or psychological problems, poor physical health or frailty); (2) factors related to the perpetrator (psychiatric illness or psychological problems, care burden, and stress) (3) relationship (family disharmony, poor or conflictual relationship), and (4) environmental factors (poor social support, living with others) ²⁾.

3. Situation of response to the Prevention of Elder Abuse Act

Since 2007, the Ministry of Health, Labor and Welfare has reported the "Survey results on the status of responses based on the Act on the Prevention of Elder Abuse, Support for Caregivers of Elderly Persons and Other Related Matters".

4. Limitations of the Prevention of Elder Abuse Act

A survey of long-term care insurance facilities and daycare facilities for dementia finds that cases of suspected abuse constituted approximately 10 to 20%, but speculates that a considerable number of cases did not get notified ³. Although elder abuse is attracting attention because of the intent, there are many cases in the gray zone that are difficult to prove as

abuse. Also, there is no provision in the current law for self-neglect. The necessity of proposing a law that can deal with a wide range of infringements, including self-neglect, has been pointed out ⁴⁾. Regarding elder abuse by care facility staff and others, it is necessary to more clearly define the importance of efforts aiming to improve the quality of care, reduce the occupational stress on workers, and implement appropriate organizational management. On the other hand, dementia care workers need to detect signs of abuse by caregivers and provide appropriate care management and family support ⁵⁾.

■ References

- 1) Takizawa K. Outline of the Act on the Prevention of Elder Abuse. Japanese Journal of Geriatric Psychiatry (Ronen Seishin Igaku Zasshi) 2008; 19(12): 1301-1306. (in Japanese)
- 2) Johannesen M, LoGiudice D. Elder abuse: a systematic review of risk factors in community-dwelling elders. Age Ageing. 2013; 42(3): 292-298.
- 3) Yoshikawa Y. Elder abuse and physical restraint by care facility workers: 5 years after enactment of the law. Japanese Journal of Gerontology (Ronen Shakai Kagaku) 2012; 34(1): 71-76. (in Japanese)
- 4) Nomura S. A study of the legal system to prevent and support self-neglected elderly: Issues regarding enactment of law for elderly advocacy including self-neglect. Journal of the Japan Academy for the Prevention of Elder Abuse (Koreisha Gyakutai Boshi Gakkai) 2011; 7(1): 82-99. (in Japanese)
- 5) Yoshikawa Y. Prevention of elder abuse in dementia care: from the viewpoint of prevention before occurrence. Journal of Japanese Society for Dementia Care (Nihon Ninchishokea Gakkaishi) 2013; 11(4): 765-771. (in Japanese)

■ Search formula

PubMed search: July 14, 2015 (Tuesday)

#1 ("Dementia" [Mesh] OR dementia [TI] OR "Cognition Disorders" [Mesh] OR cognition disorder* [TI] OR cognitive disorder* [TI]) AND "Elder Abuse/prevention and control" [Mesh]

Ichushi search: July 14, 2015 (Tuesday)

#1 (Dementia/TH OR Dementia/TI OR Cognitive impairment/TH OR Cognitive impairment/TI) AND (Elder abuse prevention law/TH OR Elder abuse/TH OR Elder abuse/TI) AND ((SH = Prevention) OR Prevention/TI OR Prevention/TI))

C | Early-onset Dementia



What is early-onset dementia?

Answer

From the medical viewpoint, early-onset dementia refers to onset of dementia younger than 65 years of age. In terms of utilization of support system, the term refers to a person younger than 65 years of age at the time of utilization.

Comments and evidence

In Japan, various terms had been used to describe dementia depending on the time of onset, such as juvenile dementia, presenile dementia, and senile dementia. However, in several diseases such as juvenile Parkinson's disease, "juvenile" refers to onset age younger than 40 years. It was pointed out that since the same term "juvenile" may refer to different age groups depending on the disease, terms such as juvenile dementia and senile dementia perhaps should not be used to avoid confusion [Japan Society for Dementia Research (Ed.) Textbook of Dementia 2008]. Then, since launching of "Policies for early-onset dementia" in 2009 (http://www.mhlw.go.jp/topics/kaigo/dementia/e01.html), the term "early-onset dementia" was clearly described in the 5-year Plan for Promotion of Measures Against Dementia (the Orange Plan) in 2013 and the Comprehensive Strategy to Accelerate Dementia Measures (the New Orange Plan) in 2015. At present, the notation of early-onset dementia as onset of dementia younger than 65 years of age is commonly used at the administrative level.

According to the "Study report on the status of early-onset dementia and infrastructure development as control measures" (2009, Asada et al. 2), the number of persons with early-onset dementia per 100,000 population was 47.6 [95% confidence interval (CI) 45.5 to 49.7) in the 18-64 year-old population, 57.8 in men, 36.7 in women, and the total number of persons with early-onset dementia nationwide was estimated to be 37,800 (95% CI 36,100 to 39,500). The causative diseases were vascular dementia (39.8%), Alzheimer's disease dementia (25.4%), sequelae of head injury (7.7%), frontotemporal lobar degeneration (3.7%), alcoholic dementia (3.5%), and dementia with Lewy bodies (3.0%).

In addition to being younger, persons with early-onset dementia have life issues that are different from older persons with dementia: they are the main providers of family finance and childcare; the family may have children still attending school, etc. Therefore interventions should take these into consideration 4). In an environment where services are not fully utilized, active and comprehensive use of systems including informal services should be promoted 3).

Since 2016, early-onset dementia support coordinators have been deployed in each prefecture, who are available for consultation. The purpose of this service is to provide support that meets the needs of each person. In addition to providing consultation service, this office is expected to build a collaborating system with municipalities and related organizations, as well as to disseminate correct knowledge and conduct education activities about early-onset dementia 5).

References

- 1) Ministry of Health, Labour and Welfare. Summary of study results on the status of early-onset dementia and the Ministry of Health, Labour and Welfare policies for measures against early-onset dementia. 2009. http://www.mhlw.go.jp/houdou/2009/03/h0319-2.html (In Japanese)
- 2) Asada T. Study report on the status of early-onset dementia and infrastructure development as control measures. 2009. (In Japanese)
- 3) Dementia Care Research Training Obu Center. Handbook on early-onset dementia (revised edition). https://www.dcnet.gr.jp/support/research/ center/list.html?center=2 (In Japanese)
- 4) Dementia Care Research Training Obu Center. Handbook on support for early-onset dementia (revised edition). https://www.dcnet.gr.jp/support/research/center/list.html?center=2 (In Japanese)
- 5) Dementia Care Research Training Obu Center. Manual for placement of support coordinator for early-onset dementia (excerpt). https://www.dcnet.gr.jp/support/research/center/list.html?center=2 (In Japanese)

■ Search formula

PubMed search: June 27, 2015 (Saturday)

#1 "juvenile dementia" OR "early onset dementia" OR "young onset dementia" OR (("Dementia" [Mesh] OR dementia [TI]) AND (juvenile OR "early onset" OR "young onset" OR "Age Factors" [Mesh])) AND ("economics" [subheading] OR "Economics" [Mesh] OR economic* [TI]) AND ("Social Support" [Mesh] OR "Health Planning" [Mesh] OR "Delivery of Health Care" [Mesh])

Ichushi search: June 27, 2015 (Saturday)

#1 (Early-onset dementia/AL OR ((Dementia/TH OR Dementia/TI) AND Juvenile/AL)) AND (Economics/TH OR Economic/TI) AND (Social support/TH OR Social resource/TI OR Support system/TI OR Health care plan/TH OR Health service provision/TH)



What are the support systems to help persons with early-onset dementia with their economic challenges?

Answer

Public supports including medical payment for services and supports for persons with disabilities under the Services and Supports for Persons with Disabilities Act, accident and sickness benefits, and disability pension are available, but whether the patient is eligible to receive these supports depends on the disease condition, disease stage, and household income.

Comments and evidence

If a person is diagnosed with early-onset dementia while still in employment, the first financial support available is the reduction in copayment (portion paid by patient) of medical expenses under the System of Services and Supports for Persons with Disabilities. If the person takes leave of absence, he/she will receive accident and sickness benefits for a period of 1 year and 6 months. In addition, the person can apply for the Health and Welfare Certificate of Persons with Mental Disabilities from 6 months after the date of the first hospital visit, which allows him/her to benefit from deductions of service fees and taxes. After leaving employment, the person can apply for disability pension from 1 year and 6 months after the date of the first hospital visit. In addition, if the person continues to receive accident and sickness benefits after leaving employment, once he/she applies for extension of the employment insurance benefit (unemployment benefit), he/she will be able to use the disability welfare services. When the payment of accident and sickness benefits is stopped, those who have joined the employment insurance can also receive unemployment insurance benefits for a certain period.

The System of Services and Supports for Persons with Disabilities offers the following benefits. When a person is diagnosed with dementia and receives non-hospitalization-based medical care, by applying at the municipal office to utilize the above System, the copayment portion of medical expenses is reduced to 10% in principle. Accident and sickness benefit is a social security system for persons under medical treatment provided by the Health Insurance Law. When a person who is insured with a health insurance society is under medical treatment and cannot work for more than 3 consecutive days, then from the 4^{th} day at which he/she has not been paid a salary, he/she is entitled to receive a sum of two-thirds of the standard daily wage, for a period of 1 year and 6 months.

Health and Welfare Certificate of Persons with Mental Disabilities under the Mental Health and Welfare Act allows a person with a certain degree of mental disability to receive various assistances, aiming to promote the person's independence and social participation. The Certificate entitles a person to receive two types of services: services that can be received nationwide, and services that can be received depending on region and employer. The former includes deductions in income tax, resident tax, inheritance tax; reduction in automobile tax and automobile acquisition tax; reduction or exemption of utility charges; and social welfare loan. The latter include discounts for railway, bus, taxi fares; discounts for mobile phone fee and water and sewage charges; discount for public facility admission fee; increases of welfare benefit and public assistance for persons with disabilities; and priority to be allocated public housing. The patient may apply for the Health and Welfare Certificate of Persons with Mental Disabilities at the municipal office after 6 months from the date of the first hospital visit. The Certificate is classified from grade 1 to grade 3 according to the degree of disability. Note that at this stage, it is also possible to apply simultaneously for medical payment subsidy under the System of Services and Supports for Persons with Disabilities.

Furthermore, persons who have joined the national or employee pension scheme can receive a disability pension after 1 year and 6 months from the date of the first hospital visit. An insured person of the national pension scheme receives a basic disability pension. An insured person of the employee pension scheme can receive the disability employee pension on top of the basic disability pension. If the disability grade is less than grade 3, the person cannot receive a disability pension, but can receive disability benefit as a lump sum.

In addition, in some cases, some patients are eligible for life insurance and other insurances, reduction or waiver of diaper charge, and childcare system (depending on the municipality).

Also, since July 1, 2015, frontotemporal dementia and semantic dementia have been designated as intractable diseases based on the Intractable/Rare Disease Act. Certain medical assistance is provided if the requirements are met.

Further reading

- 1) Awata S. Use medical care services, living support services, long-term care insurance services. Japanese Journal of Geriatric Psychiatry (Ronen Seishin Igaku Zasshi) 2015; 26(4): 398-405. (In Japanese)
- 2) Japan National Council of Social Welfare . Use of disability welfare services. April 2014 edition. http://www.shakyo.or.jp/business/pdf/pamphlet_h2604.pdf (In Japanese)
- 3) Nakanishi A, Tagawa R. Method of system utilization for diagnosing dementia: Method of using services of Health and Welfare Certificate of Persons with Mental Disabilities and Services and Supports for Persons with Disabilities Act. Japan Medical Journal (Nihon Iji Shinpo) 2015; (4769): 38-43. (In Japanese)
- 4) Ministry of Health, Labour and Welfare. Let's start from knowing: General site on mental health for everyone. http://www.mhlw.go.jp/kokoro/support/promotion_4.html (In Japanese)

■ Search formula

PubMed search: June 27, 2015 (Saturday)

#1 "juvenile dementia" OR "early onset dementia" OR "young onset dementia" OR (("Dementia" [Mesh] OR dementia [TI]) AND (juvenile OR "early onset" OR "young onset" OR "Age Factors" [Mesh])) AND ("Social Support" [Mesh] OR social support* [TI] OR life support* [TI] OR "Health Planning" [Mesh] OR "Delivery of Health Care" [Mesh])

Ichushi search: June 27, 2015 (Saturday)

#1 (early-onset dementia/AL OR ((Dementia/TH OR Dementia/TI) AND Juvenile/AL)) AND (Social support/TH OR Social resource/TI OR Support system/TI OR Health care plan/TH OR Health service provision/TH)



What are the systems that can be used to support the living of persons with early-onset dementia?

If a person is diagnosed with any of the 16 specified illnesses of early-onset dementia, he/she can utilize the long-term care insurance system from the age of 40 years. If younger than 40 years, the long-term care insurance system cannot be used. If the person is certified as a person with mental disorder, he/she can utilize facilities based on the Services and Supports for Persons with Disabilities Act.

Comments and evidence

If a person is diagnosed with any of the 16 specified illnesses* of early-onset dementia, he/she can utilize the long-term care insurance system from the age of 40 years. However, these services are difficult to use because most long-term care services are operated with the assumption that the users are older people. For persons of all ages having mental disorders, it is possible to use facilities for mentally disabled persons based on the Services and Supports for Persons with Disabilities Act. However, there is also a problem that these services may be difficult to use because they are not operated with the assumption that users have dementia.

<Specified diseases*>

The Ministry of Health, Labor and Welfare lists the specific diseases as described below, from the viewpoint of clarifying the scope of the diseases and facilitating certification of the level of care/support needed in the long-term care insurance system (Enforcement Order of Long-term Care Insurance Act, Article 2).

A specified disease is a disease that is considered to have a medical relationship with the psychosomatic pathological aging phenomenon. The disease should meet all the requirements listed below. Upon comprehensive consideration, the disease is recognized as one that causes psychosomatic changes with aging, leading to a state requiring long-term care.

- 1) The disease occurs frequently in older people aged 65 years and older, while it is also found in the age group from 40 to younger than 65 years. In this disease, a relationship of its incidence/prevalence (including similar indicators) with aging is observed, and the medical concept can be clearly defined.
- 2) A disease that is considered to have a high rate of needing care or support for 3 to 6 months or above.
 - 1. Cancer (terminal stage of cancer)* (limited to those judged by a doctor to have no prospect of recovery based on generally accepted medical knowledge.
 - 2. Rheumatoid arthritis*
 - 3. Amyotrophic lateral sclerosis
 - 4. Ossification of the posterior longitudinal ligament
 - 5. Osteoporosis with bone fracture
 - 6. Dementia in early old age
 - 7. Progressive supranuclear palsy, corticobasal degeneration, and Parkinson's disease* (Parkinson's disease-related diseases)
 - 8. Spinocerebellar degeneration
 - 9. Spinal canal stenosis
 - 10. Progeria
 - 11. Multiple system atrophy *
 - 12. Diabetic neuropathy, diabetic nephropathy, diabetic retinopathy
 - 13. Cerebrovascular disease
 - 14. Arteriosclerosis obliterans
 - 15. Chronic obstructive pulmonary disease
 - 16. Osteoarthritis with significant deformation in bilateral knee or hip joints (Asterisks denote diseases added in April 2006, after revision)

■ Further reading

- 1) Awata S. Use medical care services, living support services, long-term care insurance services. Japanese Journal of Geriatric Psychiatry (Ronen Seishin Igaku Zasshi) 2015; 26(4): 398-405. (In Japanese)
- 2) Ministry of Health, Labour and Welfare. Selection criteria for specified diseases. http://www.mhlw.go.jp/topics/kaigo/nintei/gaiyo3.html (In Japanese)
- 3) Ministry of Health, Labour and Welfare. Let's start from knowing: General site on mental health for everyone. http://www.mhlw.go.jp/kokoro/support/promotion_4.html (In Japanese)

■ Search formula

PubMed search: June 27, 2015 (Saturday)

#1 ("juvenile dementia" OR "early onset dementia" OR "young onset dementia" OR (("Dementia" [Mesh] OR dementia [TI]) AND (juvenile OR "early onset" OR "young onset" OR "Age Factors" [Mesh]))) AND ("Social Support" [Mesh] OR social support* [TI] life support* [TI] OR "Health Planning" [Mesh] OR "Delivery of Health Care" [Mesh])

Ichushi search: June 27, 2015 (Saturday)

#1 (early-onset dementia/AL OR ((Dementia/TH OR Dementia/TI) AND Juvenile/AL)) AND (Social support/TH OR Social resource/TI OR Support system/TI OR Health care plan/TH OR Health service provision/TH)



What kind of consultation support is available for persons with early-onset dementia?

There are family associations in various districts, counseling bodies commissioned by municipalities, and others. However, the actual situation varies depending on the region, so it is necessary to contact the municipalities.

Comments and evidence

From the disease characteristics of dementia and also from the viewpoint of information exchange and peer counseling, it is important to utilize the consultation counters, participate in family associations of caregiving families, use informal services, and utilize dementia cafes that have been set up in various places in recent years.

In 2009, Ministry of Health, Labour and Welfare set up a call center at the Dementia Care Research Training Obu Center (http://www.mhlw.go.jp/houdou/2009/09/h0930-6.html) as a free consultation telephone service for persons with earlyonset dementia.

- Early-onset dementia call center http://y-ninchisyotel.net/callcenter/new.html Some municipalities also set up independent support centers.
- Tokyo early-onset dementia support center http://www.fukushihoken.metro.tokyo.jp/zaishien/ninchishou_navi/kisochishiki/jakunensei/jakunen_center/

■ Further reading

- 1) Awata S. Use medical care services, living support services, long-term care insurance services. Japanese Journal of Geriatric Psychiatry (Ronen Seishin Igaku Zasshi) 2015; 26(4): 398-405. (In Japanese)
- 2) Ministry of Health, Labour and Welfare. Summary of the future policies for early-onset dementia. http://www.mhlw.go.jp/topics/kaigo/dementia/e01.html (In Japanese)

■ Search formula

PubMed search: June 27, 2015 (Saturday)

#1 ("juvenile dementia" OR "early onset dementia" OR "young onset dementia" OR (("Dementia" [Mesh] OR dementia [TI]) AND (juvenile OR "early onset" OR "young onset" OR "Age Factors" [Mesh]))) AND ("Referral and Consultation" [Mesh] OR consult [TI] OR consultation [TI] OR referral[TI])

Ichushi search: June 27, 2015 (Saturday)

#1 (early-onset dementia/AL OR ((Dementia/TH OR Dementia/TI) AND Juvenile/AL)) AND (Social support/TH OR Social resource/TI OR Support system/TI OR Health care plan/TH OR Health care service provision/TH) AND (Referral and consultation/TH OR Consultation/TI OR Consultant/TI OR Counseling/TH OR Counseling/TI)

D | Road Traffic Act

CQ 5D-1

What should be done if one finds that a person diagnosed with dementia holds a driver license and is still driving?

Answer

Since 2002, driving is not permitted if a person is diagnosed with dementia in Japan. From 2014, a voluntary reporting system has been started, and reporting to the Prefectural Public Safety Commission has been approved.

Comments and evidence

1. Comments

Various medical assessments of driving competency for people with dementia have been examined, but no testing methods have been established for determining and predicting driving ability and competency, with consideration of dementia as the underlying disease. No conclusions have been drawn regarding the conditions and the types of dementia that present danger when persons with dementia continue to drive. The reasons are that dementia has diverse underlying diseases, and that driving ability may be influenced by the severity of dementia. On the other hand, in Japan, the 2002 revision of the Road Traffic Act restricts driving related to dementia.

Currently, if a person aged 75 years or above applying for renewal of the driver license is suspected of dementia after taking the Cognitive Impairment Screening Test for Senior Drivers, and if that person has caused specific traffic violation called "standard actions" within one year, the Public Safety Commission will order the person to undergo a Special Driving Competency Test or to be examined by a family doctor for assessment of dementia. If the result determines that the person has dementia as provided by the Article 5-2 of Long-term Care Insurance Act, the driver license will be revoked.

Under the Revised Road Traffic Act enacted in March 2017, a special screening test is introduced for persons aged 75 years or above who have committed traffic violation of one or more of 18 items, and they are obliged to take the Cognitive Impairment Screening Test for Senior Drivers without waiting for the time of license renewal. And, if the person is assessed as category 1, he/she has to see a doctor for assessment for the presence or absence of dementia. The "Guide for family doctors on writing medical certificate related to renewal of driver's license for older people with dementia" produced by Japan Medical Association was released on March 8, 2017 (http://www.med.or.jp/doctor/report/004984.html). Doctors may refer to this guide when writing a medical certificate.

Furthermore, the voluntary reporting system was started in June 2014. Doctors who are engaged in medical care for dementia can report to the Public Safety Commission when dementia is suspected or when dementia is diagnosed, but they should first of all diagnose appropriately regarding whether or not the person has dementia. When dementia is diagnosed based on evidence, after disclosing the diagnosis of dementia to the patient and the family, the doctor should explain carefully all the details about the patient's need to give up driving, and record in the medical record the patient's and the family's reactions to the explanations. In addition, the doctor should keep in mind to provide guidance to the patient and family on daily living, including the effect of giving up driving on the patient's treatment and daily life, not only just once after notifying the patient to give up driving but to repeat thereafter. Five medical societies related to dementia have jointly released a guideline for using the voluntary reporting system. Doctors may refer to these guidelines (http://dementia.umin. jp/GL_2014.pdf).

Further reading

- 1) Martin AJ, Marottoli R, O'Neill D. Driving assessment for maintaining mobility and safety in drivers with dementia. Cochrane Database Syst Rev. 2013; (5): CD006222.
- 2) Martin AJ, Marottoli R, O'Neill D. Driving assessment for maintaining mobility and safety in drivers with dementia. Cochrane Database Syst Rev. 2009; (1): CD006222.
- 3) Dawson JD, Anderson SW, Uc EY, et al. Predictors of driving safety in early Alzheimer disease. Neurology. 2009; 72(6): 521-527.

■ Search formula

PubMed search: July 14, 2015 (Tuesday)

#1 ("Dementia" [Mesh] OR dementia [TI] OR "Cognition Disorders" [Mesh] OR cognition disorder* [TI] OR cognitive disorder* [TI]) AND "Automobile Driving" [Mesh] AND ("Decision Support Techniques" [Mesh] OR decision support* [TI] OR "Health Education" [Mesh] OR education [TI] OR "Law Enforcement" [Mesh] OR law enforcement" [TI] OR "Safety Management" [Mesh] OR safety [TI] OR "Physician's Role" [Mesh] OR physician's role* [TI] OR ("Accidents, Trac" [Mesh] OR trac accident* [TI]) AND (risk [Mesh] OR risk [TI])) OR "Dangerous Behavior" [Mesh] OR dangerous behavior* [TI] OR dangerous action* [TI])

Ichushi search: July 14, 2015 (Tuesday)

#1 (Dementia/TH OR Dementia/TI OR Cognitive impairment/TH OR Cognitive impairment/TI) AND (Automobile driving/TH OR Automobile driving/TI OR Driver license/TI) AND (Patient education/TH OR Education/TI OR Law enforcement/TH OR Road Traffic Act/TI OR Safety management/TH OR Safety management/TI OR Doctor's role/TH OR Doctor's role/TI OR ((Traffic accident/TH OR Traffic accident/ TI OR Traffic violation/TI) AND (Risk/TH OR Risk/TI)) OR Risky actions/TH OR Risky actions/TI OR Risky behavior/TI)