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## Books published by people with dementia in Japan - Are they important for us ?

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### Abstract

In these years, people with dementia had published many books by themselves in Japan. I found 15 books from year 2004 to 2017. This is a review article of those. I did content analysis. In early years, those books wanted to inform people about dementia and early-onset dementia and its 'reality'. And main messages were written by family caregivers. So most of them stressed the difficulties of family caregivers. And most proposals for policy and practices were the perspectives from family caregivers. In the next stage, people with dementia wrote main contents of their books with their real name. In many case, they described their own experiences of dementia, their daily life with many inventions developed by themselves. In the final stage, after 2014, 'dementia activists' wrote most of the materials in their book. In 2014, people with dementia established Japan Dementia Working Group (JDWG). Most authors of the books published after 2014 were written by core members of JDWG. They published books to change Japanese society. They wanted to change negative and wrong images of people with dementia. They disclosed the 'core problems' of dementia care in Japan, based on their own experience. All of their proposals were concrete. They had concrete proposals for reform of policy and practice. They stressed 'participation of the people with dementia in national and local decision making processes'. It is based on 'Nothing about us without us' idea which was influenced by disability people's movement. Most of their proposals were not 'reformist' ideas. Their proposals 'exceeded' current health and social services including Kaigo-hoken. They proposed their agenda not only to the government but also to professional bodies, family caregivers, private companies and ordinary citizen. Some of their proposals were similar to the core ideas of disability studies. These books I reviewed were useful for people with dementia, family caregivers, ordinary citizen, professionals, policy makers and researchers.

Key Words: people with dementia, publishing book, Japan, content analysis, dementia activist

### Introduction

In these years people who pay attentions to the voice of people with dementia are increasing. In mass media, in health and social services, in research and education of health and social services. Latest Japanese National Dementia Policy established in 2015 has a new chapter called 'Importance of perspectives of the person with dementia and their family'. This new chapter was introduced because influence of the people with dementia and their family was increased.

Iguchi (2007) analyzed the contexts and meaning of the ‘discovery of the real intentions of people with dementia’. Yoshihara (2016) pointed out that journal articles including the voices of people with dementia was increasing in these years. He insisted that those articles were very important.

Great journalist in Asahi Shinbun Ikui (2017) published a book titled ‘Historical Development of the Voice of People with Dementia : A Reportage’. Dementia and dementia care became her topic in 1994. She traced the history of the voice of people with dementia, from 2004 to 2016 in Japan. She did many interviews with people with dementia. Social movement of people with dementia is worldwide. Activists in Australia, US, Scotland and Japan met and discussed many times. They cooperated each other for many years.

Ikui’s book is exciting and fun to read. But this kind of work can only be done by experienced and knowledgeable journalist like Ikui. I cannot create this kinds of work.

In this paper I will analyze the books written by people with dementia in Japan. We have at least 15 of them from year 2004 to 2017. This is what social scientist can do. I think books written by people with dementia are most important material for dementia research.

### **Materials I Analyzed in This Article**

Some dementia activists published books in these 20 years. Christine Bryden (former Christine Boden) is a famous activist with dementia. This Australian woman published at least 4 books. And all of them were translated in Japanese and published in Japan. They are Boden (1998), Bryden (2005), Bryden (2015) and Bryden (2016). Another Australian activist Kate Swaffer (2016) also published a book and it was also translated and published in Japan.

But in Japan, books written by people with dementia are rather recent phenomena, some 13 years. I analyzed 15 books written and published by people with dementia, from year 2004 to summer of 2017. All of them are published by publishing companies. People can buy these in bookshops. In this paper I omitted research monographs published by research bodies. Those documents are for researchers and experts. People can not buy those in the bookshops in the town.

I omitted three important books. Those are Nagata (2015), DIPEX Japan (2016) and People with dementia and NHK (2017). Nagata (2015) edited a book, consisted of 45 brief comments of people with dementia. Materials were collected from families of people with dementia and care worker, nurse and social worker. These brief comments were unforgettable for them. So they have 45 episodes in this book. One phrase of people with dementia. Then in the next page, family or care worker explained the contexts and meaning of this phrase. This is a great book but it is not published by people with dementia, it is edited and published by Nagata.

I also omitted DIPEX Japan (2016) which also consisted of 200 episodes of people with dementia. But most of the materials were collected from families, not people with dementia. I omitted other important book, published by People with dementia and NHK (2017). NHK (Japan Broadcasting Corporation) broadcasted a TV program titled ‘Messages from people with dementia’ in December 2015. After this program, journalists in NHK collected additional materials from people with dementia. In this book we can enjoy over 50 messages of people with dementia. So you can say that this book is written by people with

dementia. But I think this book is edited and published by journalists in NHK.

In the following chapters I will explain 15 books I collected. In some book, people with dementia wrote only several pages. So I will point out which parts were written by people with dementia. And I want to inform you about WHY they wrote and published that book. For What, for Whom and so on.

### **Alzheimer's Association Japan (2004) Words of People with Dementia and Reflection by Family**

Alzheimer's Association Japan was established in 1980. It is a family (family caregiver) organization of people with dementia. Now it is the most powerful 'citizen' group in dementia policy making in Japan. They had 11,000 members in 2014. In year 2002, this organization decided to investigate about real feelings of people with dementia. Organization asked members to send unforgettable episode of people with dementia, with some words of them and its context. Organization got 600 replies. The organization decided to publish a book based on these materials. The investigation committee of this organization edited this book. Some 150 episodes were selected. All episodes were anonymous. They divided them into 14 categories. Most episode is written in one page, some are two pages. In total, this book has 183 pages.

Most episodes implied that people with dementia recognized their own sick. Many disappointed because they suffered dementia. Some of them wanted to die soon. Some wanted to understand their disease. Rather many were afraid that they would be thrown away to the hospital or nursing home.

Most of them worried about their family caregiver. Some of them said thanks to the family. Others wanted to contribute to the family. Some got upset to the family and regretted after those accidents. Some said that 'I should not be here, because I am disturbing you so much all the time'.

Some 14 episodes implied that quality of health and social services for people with dementia was not good. They criticized day care, home help, medical doctor, care worker, hospital, nursing home and group home.

So this is the first important milestone, which insisted that people with dementia had their own views and opinions. They are not 'crazy people' nor 'stranger with damaged brain'. Chairman of this organization stated in this book that people with dementia had heart as same as co-called 'ordinary' or healthy people. This organization presented this idea in year 1997 for the first time. And this book published in 2004 showed the firm and impressive evidence of this idea. But all materials of this book was contributed by family caregiver. Not people with dementia themselves.

### **Kaiji Ichinoseki (2005) My Memories are Disappearing : An Alzheimer's Disease Patient Speaks**

Kaiji Ichinoseki was an elected Mayor of Hokuryu Cho, populated about 2300. In the winter of 2003, he was diagnosed as Alzheimer's disease. He was 53 at that time. He had many memory troubles in the begging of 2003. In the year 2004 he quitted Mayor, announcing that he got Alzheimer's disease. He announced it in the official meeting, so newspaper reported this fact. After that some TV broadcasted documentary program about him, because he and his family agreed. Kaiji was relaxed at home some months after retirement. After that he and his wife started new local life. He took walk in neighborhood, enjoyed local hot spring, visit some friends nearby, with his mobile phone. Most residents in Hokuryu Cho welcomed his new life, they support him in the street and in local shops for example. Residents wanted to

talk to him because he was loved and respected Mayor, a popular man. Of course in his daily life, he was supported by his wife and son very much. In year 2004, he was sorry for his dementia, he lost memories and faced many difficulties but he lived a new life and felt happy. He said that people with dementia can manage many tasks.

This is very touching book, some 180 pages. But in fact this book is not written by Mr. Ichinoseki. Two professional writer and editor did lots of interviews with Kaiji, his wife and son, his former colleague, medical doctor, friends and neighbors. In my count, Kaiji's voices occupied some 20 to 30 % of this book. This is very well-edited book, the product of professional writer and editor.

Another impressing fact about this book is that they have two photos of Kaiji and his family. In the very last page of this book, they have a big photo of Ichinoseki family. Kaiji, wife and their son. And we can find another photo in inside of book cover of his book. Kaiji's solo photo and short introduction about him and his life.

When I read it through, this book was published to inform about early-onset dementia to the public. In 2005, early-onset dementia was not well-known in Japan. So Kaiji and his family wanted to inform about early-onset dementia by themselves, wrote about their real life. Even 53 years old professional politician suffered Alzheimer's disease. And it does not mean 'the end of his life'. He could manage many daily tasks by himself. And when he could get adequate support by family, neighbors and professionals, he could enjoy his life in the community.

### **Alzheimer's Association Japan (2005) Views and Opinions of People with Early-onset Dementia : Terumichi Matsumoto's Case**

In year 2005, Alzheimer's Association Japan prioritized the activities called 'We will present the views and opinions of people with dementia to the public'. They asked Terumichi Matsumoto to do a public speech at their annual national conference. Mr. Matsumoto aged 56, suffered early-onset dementia.

The main part of this book was the draft of his public speech, some 9 pages. This book has 180 pages. So Terumichi's words occupied only 5 % of this book. So beside Terumichi's words, it had another parts. Public speech of his wife and his medical doctor. Records of the symposium of Matsumoto family, his doctor, his care manager and four activists in Alzheimer's Association Japan. They talked about the voices and opinion of people with dementia. This book also included the records of the lecture by famous psychiatrist.

The main points of Mr. Matsumoto's words are as follows. He had memory troubles in his work some years. He was diagnosed as Alzheimer's disease, when he was 52. Then he was fired. His wife was a high school teacher so he did housework alone. After two years he had difficulties in doing housework. So he got new medical doctor and care manager. He started to participate day care and enjoyed it so much. He got new friends there. He was sorry for his wife. He wanted to serve other people. He had dementia but he could manage many tasks. He insisted that when he could get some support from family, friends, neighbors and health and social services, people with dementia could enjoy a happy life in the community.

When we read the materials written by his wife Kyoko, we can get another perspective of this case. Terumichi sometime got lost in the community, the other day he got mad to his wife and so on. Kyoko criticized their first medical doctor, who was not helpful for them. Kyoko wrote that day care for elderly

and elderly with dementia were not nice for early-onset dementia. They needed more individualized services. And in fact, Terumichi's draft for his public speech was edited by Kyoko.

When I read it through, this book was also published to inform about early-onset dementia to the public, as book by Ichinoseki (2005) I mentioned above. In this book we can enjoy many photos of Mr.Matsumoto, his daily life and his life history.

### **Masahiro Ohta and His Supporters (2006) I live with Dementia and I am Active**

Masahiro Ohta was an experienced social worker in local government. He had memory problems in his job when he was 51. At the same time his wife also recognized same issue at home. He was diagnosed as Alzheimer's disease when he was 55. He did early retirement some months later. At that time, he could speak in his pace and he liked to talk. So his medical doctor proposed him that Mr.Ohta, doctor and his occupational therapist will do some public lecture together. Mr.Ohta liked this idea. So this 'Unit' started lectures in many public meetings. In their session, Mr.Ohta started to talk, then doctor or therapist would ask some questions to Mr.Ohta, then he replied. Sometime doctor and therapist talked about his disease or additional information about Mr.Ohta. This group presentation was so fun to hear. And Mr.Ohta likes this group presentation. He talked about his experience and he was happy that he can contribute to the society.

So this book has 162 pages but main part of it is the record of this group presentation, some 111 pages, which occupied 69 % of this book. So when I count, Mr.Ohta's words occupies some 30 to 40 % of this book. When they made this book, Mr.Ohta was not good at writing. So this was the only way he could present his idea to the society.

He talked about his difficulties. He also insisted that he can manage many tasks, by himself. Sometime he did mistakes in the city. His main message was very clear. He need support when he cannot manage that task by himself. Ohta said 'Please do not command me something. I will make decisions about myself'.

He participated day care and he liked it. He got many friend there, they supported each other. In relaxed and comfortable atmosphere, they talked each other, enjoyed many jokes all the time. The staff of day care were professionals, they did individualized services for users. Here you can forget anything, when you did some mistakes, you would not be criticized.

The most impressive point of this book is its book cover. In the surface we will meet big smiling face of Mr.Ohta. He held microphone in his hand, it was the picture of their group presentation. In the surface of book cover, we can recognize the words 'I am dementia' and 'Author, Masahiro Ohta' and his big smiling face. It never happened in Japanese history I think. When I picked up this book, Mr.Ohta is smiling at me and start to talk, I feel. In fact they had over 15 pictures of Mr.Ohta in this book. Most of them, he was smiling.

### **Family Caregiver of the Early-onset Dementia (2006) Early-onset Dementia : 7 Stories told by People with Dementia and their Family**

Family caregivers of early-onset dementia established their organization in 2001 in Japan. They named it 'Hoshino-kai'. This organization is also active, they published some books. This is one of them. This has 267 pages, consists of 3 parts. In part 1, we can read 7 stories of early-onset dementia, case reports. In

these 7 cases, 2 were written by people with dementia, 5 were written by family. Part 2 explained the basic information about early-onset dementia, written by medical doctor. Part 3 described the good practices in the fields in Japan.

I should focus on the Part 1 of this book. The 7 case reports, half of them written in real name, the other in fictitious name. The volume of Part 1 was 108 pages, reports by people with dementia was about 27 pages, and by family was 80 pages. So materials contributed by people with dementia was 27 pages, only 10 % of this book. In fact, in some case report written by people with dementia, half of those document was written by family.

Case 1 was told by a man with dementia, aged 57. He got Alzheimer's disease when he was 50. Then he retired. At this moment he enjoyed his life, he participated day care and his mother and his sister helped him so much. He said he had not so much difficulties in his life at that day. He enjoyed day care. He thanked so much for his mother and sister.

But his mother and sister wrote bad experiences they suffered. When he worked with memory problems, he lost big money by fraud. His colleague did that. They could get very limited money back after the trial.

Case 2 was Nobuharu Nakamura, aged 56. He got Alzheimer's disease in the age of 45. After diagnosis, he was fired. It was a kind of abuse by his colleague and his boss. He stayed some months in the hospital. When he came home, he started to participate day care. He liked that day care. But he and his family faced economic difficulties after his retirement. So they moved to another city, where rents were low. Mr.Nakamura participated day care in this city, but it was not good for him. He was not happy with it. He wanted to work again, even a part-time job. His family hoped that, too.

When we read the case reports by family in this book, we can find rather many 'violence' episodes of people with dementia. In Part 2 of this book, Dr.Miyanaga analyzed another 8 cases of early-onset dementia. In Miyanaga's chapter, we can also find family troubles which included some violent episodes of people with dementia. Typical case was that some middle-aged man with early-onset dementia beat his wife and children.

So main messages of this book was that most family caregivers of early-onset dementia faced very difficult situation. Early retirement, unemployment, economic problem, difficulties in caregiving, lack of health and social services or low quality of them, troubles with neighbors and local shops, child care issues when they had children or youth. So they insisted that we needed more health and social services for early-onset dementia. And quality of services should be improved.

### **Masahiro Ohta and His Supporters (2007) Enjoy Happy Life with Dementia : My Way**

Mr.Ohta published another book in March 2007. A big publishing company wanted to make a new book with him. Ohta wanted to inform more about early-onset dementia to people all over Japan. And he wanted to present his daily life as an example. He lived his life, did what he want and did what he can do, with many inventions by himself, because he had memory problems. He could enjoy happy life, because many people supported him every day. So this was his way of life, the title of this book was 'My Way'. He was not good at writing at that day, so professional writers and editors did many interviews with him, his wife, his former colleague, medical doctor, staff of day care and so on. They quoted Ohta's diary in some

pages, in some part they quoted the records of group presentation by Ohta, his doctor and his occupational therapist (the Unit).

So this was 205 pages, well-edited, fun to read book. The source of documents was coming from various places. He talked about his life in 'one day' base, with many inventions by himself and support by family, friends and professionals. He told his life history. The first stage of memory problems when he was a social worker, diagnosis, early retirement, treatment and training, participating day care, started new activity 'the presentation by Unit'.

He explained all inventions in his daily life, developed by himself. He had many difficulties but he created new coping strategies. I think Ohta reported these inventions in this book, to contribute to other people with dementia and their family. These coping strategies would be hints to them for their life and difficulties.

In the surface of the book cover, you can recognize Ohta's smiling face. They had over 38 photos of Mr.Ohta. With these photos, you can understand his daily life. He enjoyed his life. You can understand his 'environment' by many photos in this book. Like calendar which he used in his house, community he walked every day, his bicycle, mobile phone, wallet, day care notebook, his key ring which he made by himself and so on.

#### **Osamu Mizuki (2007) A Blog Daily of a Man with Dementia : Once-in-a-lifetime Chance**

Osamu Mizuki was diagnosed as Alzheimer's disease when he was 67, in year 2005. After diagnosis, he read Bryden (2005) in Japanese. He joined Alzheimer's Association Japan. Then he started his blog and start to write diary in his blog, real life experiences of a man with dementia and his opinions and views. Osamu Mizuki was his 'Pen Name' in internet world. He was an active man in internet, some years he runs 3 sites, his blog diary, reading (book) circle in internet base, chat or free discussion site (he named it 'Net Café').

Experts said that this was the first blog diary of people with dementia in Japan. After diagnosis, he felt isolated. But Alzheimer's Association Japan reported his blog in their newsletter. So his blog became so popular, many people with dementia and their family and others contributed comments on his sites. He wrote that he was empowered by those internet friends all over Japan. And his internet friends were empowered by his blog.

Alzheimer's Association Japan and Mr.Mizuki discussed some years. In 2007, Mizuki decided to do a public speech in the annual conference of Alzheimer's Association Japan. He completed it. After that, Alzheimer's Association Japan did interview with him and his wife two times. Mizuki decided to publish his book, and Alzheimer's Association Japan supported him. Before Mizuki, books were published by people with early-onset dementia. Mr.Mizuki was 69 when he published his book. Mizuki thought that people in Japan need a real (insider) information about 'elderly' with dementia, too. So he wanted to publish his experiences.

So he published a book with 174 pages. Professional editors helped him very much. He and editors selected about 100 blog diary from November 2005 to May 2007, in total 135 pages. They divided them into 6 parts, based on the topic. They have a draft of Mizuki's public speech in 2007 conference in this book. And they have the records of the interviews of Mizuki and his wife, by Alzheimer's Association Japan in



the summer of 2007.

Contents of the diary had great variety. His memory problem before diagnosis, long process of diagnosis, his difficulties in everyday life, medicine he took every day and his reflection upon it, regular reassessment by medical doctor and psychologist, books and TV programs he enjoyed and his reflection to them, play game with grandchildren, foods and drinks of his family, about his friends, shopping, thanks for his wife and so on.

It is so interesting that people with dementia got new friends based on his internet sites. His sites became some kinds of 'community' for the participants. They supported each other. Other important thing in this book was that it described diagnosis process and regular re-assessment process from patient's side. And for me it is also very interesting that he wrote about his incontinence accidents several time in his book. He was a brave person. It was a difficult task. He placed some of his photos in his book. But not in the book cover, nor in the surface.

### **Sumiko and Shunji Ochi (2009) What I Got After my Husband was Diagnosed as Dementia**

Shunji Ochi was one of most famous people with dementia in Japan. In October 2004, they had Alzheimer's Disease International Conference in Kyoto. Shunji did a public speech with his real name. Most researchers wrote that this was the first public presentation of people with dementia in real name. He got memory problems when he was 47, and was diagnosed as Alzheimer's disease when he was 53, in year 2000. Sumiko was his wife, family caregiver. Sumiko published the book about the life of this Ochi family.

This is a chronological episodes book, started from Shunji's birth to year 2009. Most pages were written by Sumiko, because when they prepared this book, Shunji could not write an essay. But in the middle of the book, we can enjoy Shunji's draft of public speech in 2004 in Kyoto, some 8 pages. This book has 180 pages.

Shunji's public speech was also chronological. First memory trouble in his job, increasing of difficulties, early retirement, diagnosis, participating day care and he enjoyed it. He thanked for his wife and three daughters. He wanted to recover from this disease and work again. He advised people with dementia to smile, make new friends, and not be isolated. He insisted that although he had memory problem, he could think and could manage many tasks.

His presentation in 2004 impressed many Japanese. And most mass media reported it many times. NHK broadcasted a documentary program about the life of Ochi couple. A movie was made and screened in Japan, based on the stories of Ochi's family (it was a fiction one).

He loved his day care, because he got new friends there. And he did many creative activities, there. Drawing, pottery, calligraphy and make poem for example. In 2008, Ochi couple and his supporters did an exhibition called 'The World of Shunji Ochi'. Many of his work was presented, poems, potteries, drawings and calligraphy. Many visitors came from all over Japan and most participants were impressed.

But his physical and brain condition was getting worse in years. He moved to nursing home. He passed away in the summer of 2009 by pneumonia, just before publication of his book. He was 62. They put some 37 photos in this book. We can understand the progress of Shunji's disease by those photos.

In her essay, Sumiko wrote the difficulties of family caregivers of early-onset dementia. Economic

difficulties, denial by staff in health and social services, low quality of health and social services for early-onset dementia. And she quoted many words of Shunji in this book. For example 'I am finished', 'Please kill me now'. Sometime Sumiko wrote 'unspoken' words of Shunji.

In total, this moving book informed us three themes. 'Realities' of a man who suffered early-onset dementia. Difficult realities of family caregivers. We should improve health and social services for early-onset dementia in many aspects.

### **Shigenobu Nakamura (2011) Go Ahead with Frontotemporal Dementia**

Shigenobu Nakamura and his supporters decided to publish a book about themselves. Shigenobu was diagnosed as Frontotemporal Dementia in 2006. Frontotemporal Dementia was not well-known in Japan. Shigenobu and his family faced many difficulties, which was so different from people with Alzheimer's disease. When they prepared this book, they asked help for the professional editor and writer. Editor and writer did many interviews with Shigenobu, his wife, his brother and sister, professionals and citizen activists who supported him and his family.

So they published a book with 215 pages. In my count, Shigenobu's words was documented in some 71 pages, one third of this book. They put basic information about Frontotemporal Dementia, based on the materials provided by medical doctors.

Shigenobu was arrested by police officer, because he did shoplifting (chocolates, noodles and so on) in supermarket in 2006. He denied that definitely. But some shop clerks said they witnessed his actions. And Shigenobu's memory about shopping of this day was so unclear for him. He was middle management in local government (city), and city fired him after this event (disciplinary dismissal). His family talked with him and send him to the hospital. He was diagnosed as Frontotemporal Dementia, which all of them did not know about. Shigenobu was 56 at that time.

Shigenobu and his supporters tried official complain procedure about his disciplinary dismissal. After long discussions, the board accepted his appeal and cancelled his disciplinary dismissal in 2009. Nakamura family had very hard time from 2006 to 2009. Economic difficulties, Shigenobu made trouble with his family frequently, his wife was diagnosed as depression and so on.

Shigenobu started to use Kaigohoken services in 2006, for example day care for elderly, which he did not satisfied. Then he enjoyed services for the handicapped, some kinds of vocational training, he liked it. In 2007, his life story was reported in Asahi Shinbun, one of the biggest newspaper in Japan. After this article, his supporters started to increase in his community. He got part-time job in day care for elderly, very near to his house. He found his new day care for himself, he satisfied with it and he participated it regularly as a user. Beside these, he enjoyed sports with his old friends in the community. And he got new hobby, (digital) photo taking after retirement. He got new friend and supporter with this new hobby. He did exhibition of his photo in 2010 in local café.

Shigenobu, his wife and his doctor thought that stress management was very important for his daily life. When they prepared this book, his daily life was meaningful for him and it had some order, it had a nice balance. He wanted to contribute to others more, so he started new activity, doing public speech about his life. Early-onset dementia especially Frontotemporal Dementia was not well-known even in 2010.

So he wanted to present his active life for many people. That was why he published this book. People with Frontotemporal Dementia could enjoy meaningful and active life, Shigenobu was an example. Presenting his life story would help other people with Frontotemporal Dementia, he thought. He wanted to inform about Frontotemporal Dementia to the public, because many of them lived in the disadvantaged situation. Main reason of this problem was the lack of information and attention, he thought. So he put his photo in the book cover and its surface. He lived his life.

### **Masahiko Sato (2014) My Messages to All of You : From a Man with Dementia**

Masahiko Sato is a one of outstanding leader of the people with dementia in Japan today. He wanted to publish a book about his life and his opinions, because he wanted to overcome misunderstanding, prejudice and false information about people with dementia. He wanted to change Japanese society. He published his first book in 2014, when he was 60. This book has 207 pages and Mr. Sato wrote most of them, 186 pages. Besides Sato, researcher Kumiko Nagata wrote an explanatory article about Mr. Sato, some 21 pages. Nagata wrote that she and a professional editor helped Sato to edit this book. All of his essay was written by himself. To overcome misunderstanding and prejudice, Sato put photo of his face in the surface of book cover. His face was very serious and thoughtful. He put over 19 photos of him in this book, life history, daily life, his 'activist' life and so on.

He had memory problems in his job and was diagnosed as Alzheimer's disease when he was 51. At that time he wanted to get information about this disease, but he found no positive and useful information for him, he found only negative ones. So he suffered depression. Later, he found that most people had negative image about people with dementia and people with dementia shared those image, so they became powerless and many of them suffered depression.

He recovered from depression little by little. He participated meetings of Hoshino-kai, where he got positive and useful information for his daily life. He got some friends with dementia. He met Kumiko Nagata and got important advice. He decided 'I will not give up my life, although I live with dementia'.

So he listed up what he had difficulties in his daily life. He had long lists, he lived alone. Then he invented his solutions for those lists one by one. He utilized computer, smart phone and mobile phone. He asked help to others in some tasks. In this book, he explained his daily life in weekly base. He had dementia over 10 years, so he proposed his idea about how to cope with the progress of disease in this book. He also proposed what you should do after you would be diagnosed dementia.

To overcome prejudice for dementia, Sato started to do public presentations or lectures in various kinds of meeting. He insisted that these activities could change the perspectives and attitudes of the participants. These meetings would be a small step for better society.

In 2009, Ministry of Health, Labor and Welfare held an open discussion day for national dementia policy. Mr. Sato and his friends with dementia presented their opinion actively in that day. Sato and other people with dementia had participated many research projects which emphasized 'the views and opinions of people with dementia'. In many projects, Sato widened the participation of people with dementia. Sato called for the public many times, 'We need more views and opinions of people with dementia, about this issue. Please express your idea now, to change our situation'.

In 2012, Sato and others established 'Organization of people with dementia' for the first time. It is a non-profit organization. This organization emphasized three tasks. To Inform Public, To Create What We Need and We Work Together (Solidarity). In 2013, National Police Agency asked public comment about the reform of Road Traffic Law. A point at issue of this reform was driving license of people with dementia. So Sato and his friends proposed their views. He stressed that government should decide this issue based on the views of people with dementia. Participation is so important in this process. He had 'Nothing about us without us' idea.

In 2014, Sato and others established Japan Dementia Working Group (JDWG). Core members of this organization had a lot of contacts with Scottish Dementia Working Group (SDWG) for many years. This organization had 3 co-chairpersons, Masahiko Sato, Shigenobu Nakamura and Kazuko Fujita when they established it. Their goal was 'Living well with dementia, holding hope and dignity'. They were action group, initiating social change.

They emphasized that early diagnosis of dementia created new social problem in Japan, today. Many people got early diagnosis and got no support at that time. When diagnosed earlier, they did not need Kaigohoken services immediately. So most of them 'left alone' for many years, so they named this stage 'blank period'. But many of them were shocked by diagnosis and had no idea about how to live with dementia. Many of them suffered depression. They can not find someone to talk about their new situation. They had great anxiety about their future and many of them were isolated. In this stage, family caregivers were also in the crisis situation. They insisted we should develop new scheme for 'blank period' problem.

Sato was one of the founder of JDWG, so he quoted basic information of this organization in this book. Its mission statement, description about main activities (or action plan) and important principles of their activities. You can get information about this organization by internet, they have official web site now, both in Japanese and in English. In October 2014, JDWG handed over their first requests to the Ministry of Health, Labor and Welfare. They emphasized 3 requests as follows at that day. (1) Participation of people with dementia in policy making, (2) Develop new scheme for 'blank period' problem, (3) Government should start new campaign about people with dementia, positive and happy life.

In the final part of this book, he send messages to 7 actors in our society, as follows.

To people with dementia. We should focus on our positive sides. Get friend with dementia. Present your opinion to others. Do not give up your own life.

To family caregiver. Listen to our voice, we have our view, wait for a while, and do not hurry. Do not take away the tasks I can do. You should live your own life, take rests sometime. Enjoy meetings of family caregiver organization.

To medical doctor. Be careful when you do disease notification. Inform your patients about social service or social worker. Explain about diagnosis and treatment to the people with dementia. Hand out some document and send it by e-mail is recommended.

To nurse and care worker. Focus on my positive sides. Support us to enjoy our life, meaningful life. Propose us alternatives. Face us with respect, we are human being with dignity. Recall 'bad way' lists invented by Tom Kitwood, sometime.

To neighbors. Recognize and reply us as ordinary residents. We want to live as ordinary citizen in the

community. Please understand our weak points. Wait, do not be hurry. Support us when we made mistake or in trouble.

To government. Please listen to our voice. Nothing about us without us. Policy should focus on people with dementia not family caregiver.

To all of you. People with dementia can manage many tasks. We feel sorry for dementia, but we are NOT unhappy. We are not mere health and social service users. We live our lives, we are individuals. We have dreams and want to contribute to others.

This is a very comprehensive book. When you read it, you would be surprised many times and impressed. It is not only a book about dementia and services. He wrote about the values of human being, he was searching the meaning of life time in this book, deep and philosophical.

### **Naomi Higuchi (2015) Recovery from Dementia with Lewy Bodies**

Naomi Higuchi suffered various kinds of sleep disorder for many years and was diagnosed as depression in 2004. Her doctor gave her medicines. It was a misdiagnosis. So she had very bad condition for 6 years because of the medicine she took. She fainted sometime. In 2012 she was diagnosed Hashimoto's thyroiditis. It was also a misdiagnosis. In 2013, she was diagnosed Dementia with Lewy Bodies (DLB) for the first time.

Ms.Higuchi was asked to publish her book by a publishing company. She thought she might be DLB for many years. But it was not easy for her to get useful information about DLB. She decided to publish a book because she wanted to contribute to others with DLB. And she wanted to change the situation of DLB in Japan. For example, frequent misdiagnosis, serious outcomes of wrong medication, most professional staff in health and social service know nothing about DLB and so on. In her experience, DLB and Alzheimer's disease was completely different. We had growing concerns about dementia. But for many people, dementia equal Alzheimer's disease. In reality, it was not true. Experts insisted that DLB occupies 20 % of dementia patients. So people with DLB were in the disadvantaged situation in Japan.

This book has 255 pages. An expert medical doctor contributed his comment on this book, some 4 pages. Beside this Higuchi described all material in this book. She accepted a proposal of publishing company, she selected chapters from her diary from 2012 to 2014, which occupied 220 pages. She selected and edited her diaries. Beside this she put drafts of her public speech in January 2015, some 22 pages. She did a lecture in Lewy Forum in Japan, titled 'DLB from the viewpoints of patient'.

She emphasized that her main difficulty was autonomic disorder and sleep disorder. She had difficulties to cope with climate changes. She had consciousness disorder, felt very tired, very sleepy suddenly. She insisted that her blood pressure, heart rate and body temperature were so unstable and she could not control them at all. Related to this, she had headache, neck ache and back ache frequently.

She emphasized that the biggest risk she had was that she was so sensitive with medical pills. She experienced heavy side effects many times. Most experts wrote that this was the most important issues for DLB patients. Another difficulty she had was visual hallucination, auditory hallucination and olfactory hallucination. She saw insects or people, which did not exist. She did not suffered memory problems much. When she was in worst condition, she forgot some job routine. And she had difficulties in calculation sometime. In that period, she could not manage two tasks at the same time. So she quitted her job when

her brain was in the worst condition.

After diagnosed DLB, she had changed her medical doctor. And treatment was effective with her new doctor. In 2014 her condition became better and better. She experienced no visual hallucination. Condition of her brain became good. In those months, she experienced that meet old friends, enjoy talking with some foods, enjoy travel with friends were effective than any medical treatment, for example medical pills. It was some kinds of miracle that she overcame unpleasant symptoms.

She insisted that people with DLB were not good at cope with stress. In her case, hiding her disease to others itself was strong stress. When she started to explain her disease to others, her condition became better and better. And in 2014, she decided to live as DLB activist, with her real name. After this decision, her condition improved significantly. She wanted to live as herself. She wanted to change Japanese society. She described that Japan was a ‘dementia phobia’ society.

### **Masahiko Sato (2016) 20 Messages to All of You : From a Man with Dementia**

This is the second book written by Masahiko Sato. This book had 61 pages. A medical doctor contributed an essay, which was 4 pages. Beside this, Mr.Sato wrote all the materials.

Sato published this book for ‘just diagnosed’ person. Many of them were shocked and had no idea about how to live with dementia. So Sato explained his experience and advised for them.

This book is a short, easy to read version of Sato (2014). All essays were short. Sato wanted to provide advices to the people with dementia. So he wrote 20 short essays. I will quote some of them as follows.

We can enjoy our life, when we can get some support. For example we can go out, enjoy shopping, and eat out.

We should try what we WANT to do, not we can do. Let’s try new thing.

I am a man living with dementia. Not demented man, not dementia patient. We are individuals. We all differ.

I prefer to have more ‘partners’ for me, not ‘helpers’. Partner is enjoying something together with me. For example, enjoy a concert together. I like ‘equal status’, not ‘helper and service user’ relationship.

I am an activist with my real name. It is very tough task in fact. But I believe our voices will change our society. And we activists need lots of supporters. Please walk with us.

In this book, we can find new activity of Mr.Sato. In 2016, he established a new organization. Its name is ‘Organization of people living with dementia in Kawaguchi City’. You can understand this is a local group.

This book is so beautiful and artistic one. Mr.Sato has many hobbies. Taking digital photo is one of them. Sato selected some 20 photos he took and put them in this book. Flowers, walk path, beach, park, sunrise in the city, houses covered by snow, cake, dishes in the party and so on. All of them are color photos. This book is very well organized. His essays and photos he took and one sentence explanation of those photos. In the book cover, we can meet Sato with smiling face. We can enjoy some photos of Sato in this book. A professional photographer took several photos of him, presenting daily life of Sato.

### **Kazuko Fujita (2017) I Want to Create Society Where People with Dementia Can Enjoy Meaningful Life**

Kazuko Fujita was an experienced nurse. She was diagnosed as Alzheimer’s disease in 2007 when she

was 45. Now Ms.Fujita is a one of leading activist of people with dementia in Japan. As I mentioned earlier, Fujita is a co-chairperson of Japan Dementia Working Group, together with Masahiko Sato and Shigenobu Nakamura.

This is her first book with 194 pages. She wrote 155 pages, and her 6 partners contributed some 39 pages. A publisher asked her to publish a book, because she was so impressed by her public lectures. She had some drafts for her lectures. And she had enjoyed Facebook for some years, so she wrote many messages there. Her editor proposed that she can publish her book based on her Facebook materials. Fujita welcomed this idea and struggled another 6 months with editor. She added many new sentences on her past ones, and finished her book.

She wanted to present her experiences and ideas to the people who would suffer dementia in the future and their partners. She wanted to provide some 'hints' for them. She put her smiling photo in the surface of book cover. And she put many photos of her daily life and 'activist' life in this book. It is a lovely book.

Her book started with very impressive paragraph. A famous expert doctor wrote a series of column about people with dementia in the newspaper for some years. She read that and felt so sad. That doctor wrote person with dementia as a person driven by emotion only, with NO RATIONAL MIND. His essay included nothing about perspectives of people with dementia. Fujita wondered that if this doctor tried to hear the voice of people with dementia in his job. Fujita thought that this doctor had talked to person with dementia as they were empty, had no view and opinion. Some famous expert medical doctor's image about people with dementia was those. For ordinary people, they had worse images like 'they understand nothing' or 'they had lost themselves'. People in general has such 'the end of life' images for dementia. In this society, one who diagnosed dementia would be struck by these bad images at once and many of them became powerless.

But she was positive about social change in these years. More and more people with dementia presented their views and opinions to the society. She thought that all people with dementia could enjoy happy life. They can live in secure environment, with hope and dignity. To realize this, we should make use of the voices of people with dementia.

She described her life story and daily life at that days. She worked as nurse for many years. She got married and got 3 daughters. Some years she took care of her mother and father in law, her mother in law suffered dementia. And she was involved in local 'human rights' movement, when she took care of her children. Then her mother got dementia. Her mother lived with her brother and Fujita sometime took care of her. Then she had several memory troubles in her house. She had sleep disorder and headache, too. So she visited expert doctor and was diagnosed as dementia. She quitted her job. All of her family understand her situation and supported her. So she continued cooking, shopping, cleaning and other housework.

She was experienced nurse, she helped elderly with dementia in her job for many years. And she took care of her mother and mother in law, both suffered dementia. But when Kazuko Fujita was diagnosed when she was 45, she realized 'the reality'. She was an active members of local human rights movement for many years. When she was diagnosed, they had lots of discussion about difficulties of caregivers of people with dementia. At that time, it was a 'caring' problem. But when Fujita was diagnosed, she had many difficulties. As I mentioned, people with dementia was struck by prejudice, flood of negative

information and bad image. And many of them felt that they were excluded from society and isolated. For Fujita, it was a human rights issue of people with dementia. We should change our perspectives about this issue. To realize this, people with dementia themselves should present their views to the society. So in 2010, she established a citizen group engaging this activities. The name of the group was ‘Citizen group tackling early-onset dementia issues : Clover’. Fujita was a first chair-person of this group. This group collected the voices of people suffered early-onset dementia and notified those messages to local government, medical doctor’s association, nurse association and social service providers. Meanwhile Masahiko Sato and Fujita got to know each other. They exchanged their opinions and established Japan Dementia Working Group (JDWG) in 2014.

In October 2014, Fujita started her Facebook. Her daughter recommended her to do it and helped her to start it. She put messages and photos there frequently. Her daily life, her ‘activist’ life and her opinions. Based on her message on Facebook, she described impressive episodes about her ‘child raising’ life in the past. When her youngest daughter was a high school student, Fujita was already diagnosed. In the final year of high school, they had many meetings between Fujita and teacher of her daughter. Fujita had difficulties in those meetings so she informed the teacher about her disease. That teacher visited Fujita at her home with papers with him. He handed out Fujita papers with big character and explain the important points of the meeting with those papers. Fujita and her daughter was so happy with these efforts that teacher did. It is one example that when people with early-onset dementia had some child raising tasks, professional could help parents and children in many ways.

Fujita proposed new ideas about private insurance for dementia in this book. In Japan, private insurance for the risk of dementia would pay benefits when insured had ‘considerable care needs’. Fujita proposed new type of insurance which will benefit insured ‘when she was diagnosed dementia’. Because she need lots of money to go to hospital and pay for treatments and pharmacy and so on. At the same time most patients would quit job or lose income. When we enjoy private insurance for the risk of cancer, we can get benefit when we are diagnosed in Japan. So Fujita wanted new items for dementia.

In this book Fujita wrote many aspects about dementia policy and practice in Japan. JDWG established in 2014 had proposed many proposals to Ministry of Health, Labor and Welfare. In 2015 Japanese government published new National Dementia Policy (so-called New Orange Plan). This document had 7 core programs. One of them were ‘We make use of perspectives of people with dementia and their family’. It was new idea and was what JDWG proposed to the government. They had another core program named ‘More services for early-onset dementia’. And in detail, the document included important words ‘We should pay attention to the needs of just-diagnosed patients and we should support their new life’. Fujita welcomed this new policy by national government. Fujita emphasized the importance of ‘Living well with dementia’ idea many times in this book. So she was not happy with too much attention on ‘prevention of dementia’ campaign. Instead, she hopes that all people with dementia can enjoy their own life in the community, as ordinary citizen. And she thinks it was possible to realize if we will step forward.

As she is an active co-chairperson of JDWG, she quoted some documents of JDWG in this book. This book was published in April 2017, so she quoted newest JDWG document, ‘Our proposal 2016’. It included (1) We want have ‘meeting of people with dementia’ in every municipality. (2) Do not stop or restrict



‘going out’ activities of people with dementia. (3) We hope that we can get support we need, just after diagnosis. (4) Quality of local consulting service for dementia was ‘very poor’. Lots of efforts should be done to improve them at once. (5) We want to participate and say our opinions when local government start new initiatives like ‘Creating local care-path for dementia’ and ‘Establishing local dementia-café’.

She pointed out more concrete problems in Japan. In medical, Kaigohoken and in social services, most professionals would talk to families of people with dementia, NOT PEOPLE WITH DEMENTIA. She experienced this problem so many times. For example, user of medical services was patient herself. And Kazuko Fujita herself wanted to know about her disease and its mechanism. And she want to choose her service and her life. She insisted that ‘Expert of dementia is the person living with dementia’. Because they are experiencing this disease. This statement is same as important thesis of disability studies.

She wrote that she welcomed policy and service development for dementia in these years and many professionals struggled to get solution for the difficulties which person with dementia experienced (and insisted) in everyday life. But people diagnosed dementia has ‘existential’ distress, for example ‘how to live (well) with dementia’ and ‘what I want to do in my life from now on, even though I live with dementia’. In Japan we cannot respond to these needs.

Fujita insisted that she can think as other people, even though she had Alzheimer’s disease. But she had difficulties to express her views, after she got this disease. And ‘main character’ of her life is herself. She is responsible for her life plan and everyday life. For example, only people with dementia can report the side effects of medicines to the doctor. People with dementia need some abilities to express their views and choose from the alternatives.

### **Katsushi Ohshiro (2017) Recording Is Important than Memorizing : My Life with Dementia**

Katsushi Ohshiro suffered headache, faint, sudden sleepiness and related disorder in his brain. He was examined in the hospital and diagnosed as Brain Inflammation (Limbic Encephalitis with Auto-immune Disease) in 2012 when he was 38. He got treatments but he experienced after effect, he was diagnosed as Higher Brain Dysfunction. After that he was diagnosed as Alzheimer’s disease in 2015, when he was 41.

So his life from age 35 to 43 were ‘hospital, rehabilitation, return to work, hospital, rehabilitation, return to work’ rounds many times. He repeated these process several times. He decided to publish his book and it was realized in 2017. He had three aims for this publication. (1) He has 3 children. He was sick and engaged in rehabilitation for many years. So he wanted to explain his struggles for his children. (2) He wanted to inform about Higher Brain Dysfunction and early-onset dementia to the public. (3) His most important supporter, Mr.N wanted to know about his views and distress he experienced in detail.

He published a book with 261 pages. He wrote 257 pages. And he put 4 pages summary of his ‘medical notes’ his medical doctor described, which included his clinical history after 2011. He put his big photos in both sides of book cover, he put another photos in his book. He had lots of documents in his PC, because he established his blog (weblog) in 2013. So he can edit his book. And he enjoyed ‘crowdfunding’ to publish this book. It went very well, he got over 505 contributors. This book was also organized in chronological way.

Before diagnosed dementia, he was a man with Higher Brain Dysfunction, he was registered as

‘handicapped adult’ in his local government. He enjoyed vocational training for Higher Brain Dysfunction in Chiba Prefecture, very far from his home town. He stayed that special training institution for 3 months. There he got many skills and most important one was called ‘Memory Note’. His memories were so limited so he use Memory Note in many occasions, in his job and in his daily life. He was an automobile retailer before sick. He came back to work and worked as car washer now. He works 4 days a week, he does his best.

When he was diagnosed as dementia, his social worker and the leader of local Alzheimer’s association and himself talked to the boss of the company he worked. The company coordinated his new duty, car washing in nearest shop from his house. This company held a seminar (study meeting) about dementia in the shop he worked. The leader of local Alzheimer’s association and Mr.Ohshiro talked to the colleague. Most of participants were positive about this meeting and they gave Ohshiro many supportive remarks. Ohshiro was very happy with them.

In 2016, Ohshiro started new activities. He started public speech and lectures about his experiences. He was asked this activity and he thought it was a nice way to inform people about dementia. When he would talk, he could change bad and negative images of people with dementia. He worked 4 days a week, he enjoyed his blog every day since 2013. He enjoyed his life with his wife and 3 children. Before he stepped forward, he talked to his family and his company about his new challenge. All of them were positive about his plan. He did many public lectures and got good reactions. Newspapers and TV broadcasted his activities and his life. Sometime he was greeted by people who recognized him in the community.

In conclusion Ohshiro insisted that he was a one of ‘lucky case’. Because most people with early-onset dementia would be fired or retired. He pointed out that collaboration between hospital, social worker, vocational training center and employer (company) was not good in practice. In his case the leader of local Alzheimer’s association coordinated many service providers and local government. But he did it AS A VOLUNTEER. In reality collaboration and coordination was not well developed, nor systematized at this moment. We have many things to do to support people with dementia to work after diagnosis. In 2017, National government introduced new system for this coordination. We would watch what happens with this.

His blog is titled ‘Recording is Important than Memorizing’. So he titled his book as this. With this blog, he could publish this great book. He got new friends and new views from this blog. And this blog was useful for his daily life and helped him to enjoy his meaningful life today.

### **Tomofumi Tanno (2017) Tanno Tomofumi, Smiling and Living with Dementia**

Tomofumi Tanno was diagnosed as Alzheimer’s disease in 2013 when he was 39. At that time he was an automobile retailer. He was shocked and got depression. He struggled some months and found his supporter. And he returned to work and was allocated new job in that company. Then he met an active man with dementia. Tanno was empowered by him and retrieved his own life. Now he is a youngest dementia activist in JDWG.

He wanted to publish his book. The aims or main messages of his book was as follows. (1) He hoped that more and more people with dementia retrieved their ‘positive life’. (2) He wanted that families and

professionals who helped people with dementia should recognize ‘too much protection leads bad results for that person’.

He had published a book with 317 pages. All materials were written by Tanno. A professional editor helped Tanno. He put a photo of him in the book cover, ‘the big smiling face’. He put many photos of him and supporters in his book.

He wrote his life history, his daily life today and his ‘return to work with dementia’ issues. But for me, most exiting parts of this book was his experiences and evaluation of dementia support in Japan. Main points were as follows.

1. Consulting services in municipality was ‘very poor’

Tanno visited municipality and asked for help and information. The personnel gave Tanno WRONG INFORMATION. They DID NOT give information which Tanno and his family need. One of them spat out abusive words to Tanno’s and hurt him. He was so disappointed and got mad with them.

2. Care managers and social workers did not talk to people with dementia, they talked to family caregiver only and decided important matters about people with dementia.

Based on his own experiences, care manager, social worker and other professionals talked to his wife, NOT Tanno himself. No professional talked to him ‘what do you want to do from now on?’ or ‘what is your wishes about new life with dementia?’. His care manager explained how to use Kaigohoken services only. Many of them talked person with dementia ‘hello, how are you today?’ in one second and then talked all important issues with family caregiver. Many of care managers including his care managers said ‘we are very busy everyday’ and talked to him one or two words in their visits. He did not understand that because when he was a car retailer, he had about 400 customers. In Kaigohoken, one care manager has some 10 to 20 users.

He explained another episode. His municipality Sendai city organized a committee which would develop new support system for dementia called ‘Care Path for People with Dementia’. Tanno was asked to join this committee. Besides him, he found many care manager and social worker members. In the meeting, Tanno insisted that we need Care Path which was easy to understand and useful for people with dementia. But care managers and social workers wanted Care Path which was good for care manager, social worker and family caregiver. Tanno was impressed by this big differences.

3. People with dementia was oppressed and controlled by family caregivers and care managers

He was empowered by an active man with dementia and retrieved his new life some years ago. Based on this experience, he and his supporters started new initiative named ‘Orange Door in Sendai’ in May 2015. They started new consulting services for people with dementia, once a month (2 hours a day). In Orange Door, people living with dementia (for example, Tomofumi Tanno himself) would hear the voices of the people with dementia. And the consultants, for example Tanno would talk his own experiences to ‘just diagnosed’ people. His depressed days in the past, his way of life today and so on.

He wrote that many visitors of Orange Door were people with dementia and family caregiver or care manager. When Tanno talked to people with dementia, family or care manager replied instantly. They respond ‘instead of’ people with dementia. They told Tanno that she/he CAN NOT speak. But when Tanno and she/he talked alone, she/he spoke many things. Many of them told him ‘I want to do X’. They

could talk and express their desire. When he feed backed these results to family or care manager, all of them were surprised. Family and care manager told Tanno that she/he never laughed. When she/he and Tanno had some conversation, she/he was relaxed and laughed. Tanno described that family and care manager ‘misunderstood’ the person with dementia. Tanno insisted that this kind of misconception ‘ruined’ the life of people with dementia. Tanno thought that family and care manager ‘helped’ the person with dementia in the way she/he WOULD NOT TALK, would not express their real needs. It was an oppression or control.

Tanno pointed out another examples of oppression. Some family caregiver ‘forced’ the activities which people with dementia did not like. Some people with dementia were forced to do calculation drills every day, to train their brain. But most of them did not like it. Tanno told them ‘Do what you want, Say NO what you do not like’. Tanno’s idea was very simple. Do what be ‘fun’ for you. Family and care manager may recommend you to participate day care, dementia café and meeting of local Alzheimer’s association. When you like to participate, you do. When you do not like them, just skip them. Tanno himself visited dementia café all over Japan. And he found no good ones. Important matter for the people with dementia was NOT participating day care, dementia café and meeting of local Alzheimer’s association. Just ‘Do what she/he liked to do in their community’.

Tanno’s conclusion in this book was also simple. We have very bad and negative images about people with dementia in Japan. Most of them are not true. Tanno insisted that he was ordinary citizen ‘with bad memory’. He hoped that everyone will interact with him ‘ordinarily (normally)’. Please help him when he failed and when he had difficulties to do something. Do not criticize him when he failed. Please do not take away what he can.

## **Analysis**

When we overviewed those 15 books, I can point out some findings.

1. Besides Mizuki (2007), most books had focused on early-onset dementia.
2. Besides Nakamura (2011) and Higuchi (2015), most books described about Alzheimer’s disease. Nakamura wrote about Frontotemporal Dementia he suffered. He wrote different stories and different difficulties he experienced. Higuchi stated about Dementia with Lewy Bodies (DLB), she experienced. She insisted that DLB and Alzheimer’s disease was completely different. Big difference in risks and difficulties.
3. In early years, Alzheimer’s Association Japan and other family caregiver’s organization published ‘the voice of people with dementia’. But in those books, most materials were contributed by family caregiver. In those books, person with dementia was anonymous. Ichinoseki (2005) had published his book with his real name for the first time. But most materials was written by professional editor and writer.
4. Ohta published two books in 2006 and in 2007. It was epoch-making ones. He put big photo of his face in the book cover with his real name. Titles of both book implied that ‘people with dementia described his own happy and active life’. Ohta did many lectures to the public at that time.
5. Before Sato (2014), most books were published ‘to inform realities of people with dementia and their family caregiver’ to the public. Many of them recognized their own disease, they could think, talk and manage many tasks, and they had their own views and feeling. Their life stories, their daily life, difficulties

and wishes. Ichinoseki, Ohta, Mizuki, Sumiko and Shunji Ochi, Nakamura and Higuchi were the examples of this category. And Alzheimer's Association Japan (2005), Family Caregiver of the Early-onset Dementia (2006), Ochi and Nakamura focused more on 'the difficulties of family caregivers of early-onset dementia'. They wrote many 'policy and practice' proposals about dementia care in Japan, from the family caregiver's position.

6. In my view, most 'common' remarks by people with dementia were 'Please help us when we failed and when we had difficulties to do something. Do not criticize us when we failed. Please do not take away what we can'. These messages were included almost all books I listed.

7. Sato, Higuchi, Fujita, Ohshiro and Tanno were local and national dementia activists, leaders of those activities today. At least Sato, Fujita and Tanno are the core-members of JDWG. All of these people could use personal computers. They had written many documents in their computers, blogs and Facebook, for many years. They were active and they took part these activities for a long time. They had lots of materials to publish. They had many concrete proposals to Japanese society. In short, they 'wanted to CHANGE Japanese society from the viewpoint of people living with dementia'. Proposals for change were as follows, for example.

(1) Consulting services for dementia in the municipality were low quality. National and local government should improve them at once. Especially, people suffered early-onset dementia and their family dissatisfied with them.

(2) Care manager, doctor, nurse, care worker and other professionals should talk to person with dementia first. NOT TO FAMILY CAREGIVERS. Many professionals underestimated the people with dementia or misunderstood them. Please interact with people with dementia, your most important client. Be careful about their voices.

(3) People with dementia wanted participation in policy making process in national and local government. Today we have many political agenda related to the life of people with dementia. So please listen to our voices. 'No thing about us without us' is our most important principle.

(4) Government should develop new scheme for the 'blank period' problems, which most people with dementia experienced. Social support for the patient should start in the 'diagnosed day'. They need information and social support for the new life with dementia. How to live with it. Medical doctor and nurse should give new diagnosed patient, basic information about social service and social support in the community.

(5) When diagnosed patient had a job, we need more systematic support for them to continue their working life. Most client needs medical, rehabilitation and social services. And we need many discussion with employers. At this moment, we do not have systematic approach for this task.

(6) Although we have some risks, we have rights to 'go out' and 'enjoy our community', because we are ordinary citizen. Do not restrict our activities in the community. We do not want be 'house-bound' nor 'nursing home bound' people. And do not 'force' us to participate day care nor dementia café. We would choose where we visit, how we enjoy every day.

(7) We want to have self-help group of people with dementia in every municipality in Japan. Or some regular meeting of people with dementia in every community. We need 'peer'. And we want to have a

group, where any people with dementia can participate and express their views, difficulties, opinions and proposals in relaxed atmosphere.

(8) Some people with early-onset dementia have young children. So they need some support and services to raise their children.

All of these proposals were emerged from the experiences of people with dementia. I was so surprised with the proposals (1) and (2). These two are ‘fundamental’ and ‘the first principle’ of dementia care. But the ‘reality’ which people with dementia disclosed was ‘terrible’. Tanno and others wrote about Type (1) experiences. Tanno’s Type (1) episodes were one of the worst social service practice I ever read. And Fujita, Tanno and others pointed out Type (2) episodes many times in their book<sup>1</sup>. I was so shocked that many care managers did ‘wrong’ practice. Care manager who practice this wrong way is NOT PROFESSIONAL, I think.

Proposals (4), (5), (6), (7) and (8) were also impressive for me. Without their proposals, I never recognized these important issues. The word ‘blank period’ problem was invented by Fujita. It is well-known concept today. Ohshiro described detail about proposal (5) in his book.

Most dementia authors insisted the ‘rights to go out’ issues. And Tanno stated ‘radical’ claim on this issue in his book clearly. He denied the ‘oppressions’ by family caregiver and professionals. And he found no nice dementia café nor day care in Japan at this moment. In this aspect, he did not like all menus provided by Kaigohoken nor social services. He just wanted to visit fun places for him. Or enjoy some sports or shopping someday. His claim ‘exceeded’ the support system for dementia we have today in Japan. But when we go back to 15 books written by people living with dementia, Tanno’s claim was not exceptional. At least Sato, Fujita, Higuchi and Ohshiro had similar ideas, I think. Matsumoto, Ohta, Ochi and Nakamura enjoyed ‘their’ day care. They loved ‘their’ day care. But others did not participate day care nor dementia café. Ohshiro and Tanno worked 4 or 5 days a week. Sato and Fujita enjoyed their life without Kaigohoken services. They did ‘what they want’ every day.

I have another impressive ‘radical’ remark in those 15 books, which was insisted by Fujita. She wrote ‘Expert of dementia is the person living with dementia’ in her book. I am not sure about this remark was influenced by disability studies. But its idea was same, I think. Expert of dementia is NOT medical doctor, nurse, care worker, rehabilitation staff, social worker nor family caregiver. Fujita’s book started from her criticism against expert medical doctor’s essay. In the middle of the book, she insisted that people living with dementia is the expert. In the final part of her book, she focused on the ‘responsibility’ of people with dementia. It was so logical and her book was consistent.

The proposals (2) and (3) were related to the ‘No thing about us without us’ idea. Many people think that this idea come from disability people’s movement. Or core ideas of democracy itself.

### **Concluding remarks**

Books written and published by people with dementia are useful for new dementia patients and their family. And it is also useful for people in general, especially for the people who are interested in dementia issues.

These books are also useful for researchers, health and social service professionals and policy makers

in national and local government and officers working there. When they read those books, they can understand the ‘reality’ of people with dementia and their needs and better ways to reply them.

In addition, some books confronted professionals with ‘bitter medicine’. They disclosed the realities of dementia care in Japan from the user’s perspective. Some of them proposed the ideas for reform or improvement in a concrete way. So these messages from people with dementia were valuable ‘presents’ from them. It is a bitter medicine, but professionals can use them as ‘check lists for your policy and practice’ or ‘to do list for your improving efforts in the future’. Books written by Sato, Higuchi, Fujita, Ohshiro and Tanno were the examples. All of these authors are dementia activists with their real name. And most of them are core members of JDWG.

### Note

1. This kinds of experiences were told by many people with dementia. For example, Tokyo Metropolitan Institute of Gerontology (2016). This research project was financed by Ministry of Health Labor and Welfare. Many people with dementia participated in this research project from all over Japan. They enjoyed the focus group discussion session. Most participant told that they experienced Type (2) episodes. They were so unhappy with these experiences. Sato, Fujita and Tanno also participated this project.

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## 日本における認知症の人々による出版物

### —15冊の内容と公刊意図に関する考察

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#### 要 旨

日本では近年、認知症の人が本を出版することが増えている。本論文は2004年から2017年までに出版された15冊をレビューし、内容分析を行った。最初の頃は、認知症や若年性認知症の存在と現実を社会に知らせることを目指す本が、多かった。この時期は、介護家族が執筆した部分も多かった。したがって、介護家族のたいへんさが多く述べられ、制度や実践の改善提案も、家族の視点からだった。その後、本人が実名で本の重要部分を執筆した作品が、何冊か登場した。これらは、認知症の現実を本人の側から述べたものである。彼らは、困難を抱えつつ、生活のなかで様々な工夫をして生活をしている。それらの具体例を、社会に知らせることを目指していた。認知症の人々は、2014年に「日本認知症ワーキンググループ（JDWG）」を創設した。これ以降の出版物は、この組織のコアメンバーが執筆したものが多く、彼らは「日本社会を変える」ために、自分たちの見解を出版した。彼らは、認知症に関する否定的で誤ったイメージを変えることを目指している。また、彼らは自分たちの経験をふまえて、日本の認知症ケアの「問題の核心部分」を、具体的に明らかにしている。政策や実践の改善案は、具体的である。また、政策決定過程への「認知症の人自身の参加」を強調している。これは、「私たち抜きで私たちに関することを決めるな」という障害者運動の中心概念に影響されている。彼らの提案は、現在の我が国の制度や政策の「改善案」を超えるものも多い。また、彼らは政府に改善提案をするだけでなく、専門職、介護家族、民間企業、一般市民にも、多くのことを具体的に提案している。提案の一部は、障害学の中心概念と同じである。この論文で取り上げた著書は、認知症の人々、介護家族、一般市民、医療福祉専門職、政策決定者、研究者など、いずれにも有用な内容である。

キーワード：認知症、社会運動、書籍の出版、日本、内容分析