During the first hundred years since the Meiji Restoration in 1868, the ratio of aged persons (above age 65) among the total population in Japan had been stable around 5%. However, once the ratio surpassed 7% in 1970, the ageing of the population proceeded with unprecedented speed, reaching 14% in 1994, and 25% (31.9 million) in 2013.

Along with the ageing of the population, the morbidity rate for dementia in Japan has risen to 15% in 2012, and 4.6 million people are now estimated to have dementia. Due to their deteriorating memory, patients with dementia have difficulty in understanding the surrounding situations and expressing their will and thus are at risk of abuse and negligence. Since behavioral psychological symptoms of dementia can be alleviated by appropriate care, it is crucial for people providing care to have a proper understanding of dementia.

More than half of the principal carers who are living with elders dependent on care are above the age of sixty, resulting in the so-called “Ro-Ro Kaigo (Elder-Caring-Elder)” situation. With a structural shift towards a nuclear family, and the rise of double-income working couples and single person households, caring of elders, especially of those with dementia, is becoming more and more difficult. Eldercare service today requires the collaboration between the public sector, local community and family members. Therefore, it is important for people to understand the anxiety and distress that most patients and family carers experience.

In order to promote awareness for dementia which may lead to early diagnosis, and to construct appropriate medical and nursing-care policies, DIPEx-Japan, a non-profit organization, has created an online database of narratives on dementia. The database is aimed to provide necessary information and psychological support to the patients diagnosed with the disease, and to enable friends and families to learn about the experience of having and caring for dementia. 35 carers and 7 patients were interviewed for the project.

In this database patients speak for themselves about having dementia. As they talk about “not feeling like oneself” or “not being able to see what is there,” they are in fact reversing the process of detachment by talking about the experience of detachment. In addition, by contributing to the narrative database, patients take up a new role as a witness giving testimonies to their experience for the good of the society. In other words, the DIPEx project contributes to the participants’ recapturing of the self as a social being.

(The database of narratives on dementia was created by the research group headed by Tomiko Takeuchi of University of Toyama funded by Grant-in-Aid for Scientific Research C No.25463542.)