

The Japanese Ministry of Health's Patient Survey of ME/CFS Patients in Japan

In Japan, ME/CFS has been regarded as a fatigue illness triggered by stress, and after 20 years, research has continued in this vein. It was even reported in 2010 that 40% of patients recover fully and that many patients who have been ill for over five years are able to return to school or work. As a consequence, severely ill patients have not only been unable to access necessary public disability assistance, but have been ignored by medicine and by government. Thanks to persistent patient advocacy efforts under these circumstances, the Japanese Ministry of Health commissioned a national Patient Survey in 2014 that revealed for the first time the harsh reality of ME/CFS patients' daily living situations in Japan.

Because many severely ill patients are unable to travel to medical facilities to be examined by physicians, patient surveys that accurately grasp the state of severely ill ME/CFS patients are rare even internationally. This Patient Survey had a short timeframe that limited the time needed to disseminate information to achieve wider participation. Other issues included difficulty obtaining responses from severe patients via home visits, telephone calls, and having family members respond on behalf of patients. These limitations suggest that there are many severe patients who were unable to participate, and that there are many individual patients whose situations are worse than those captured by the Survey results. In order to accurately grasp the actual state of the disease, there is an urgent need to establish a system to assess ME/CFS patients' living situations on an ongoing basis.

The Survey revealed that many moderate and severe ME/CFS patients were dependent on family members for their daily living needs. Considering the dire situations of patients who live alone without support from family or other close relations, there is an urgent need to quickly establish a public assistance structure to provide necessary assistance.

While the disease may or may not be progressive, the fact that many patients become more severely ill over time suggests that environmental factors (such as daily living situations) contribute to the worsening of illness. Accordingly, providing support and intervention to moderately ill patients in addition to severely ill patients would be highly meaningful as a measure to prevent descent into severe ME/CFS.

Responses to the Survey revealed cases of a patient who obtained a Disability Certificate, but who only received one hour of home care per day even where the patient so severely ill she could not shift positions in bed on her own and was alone for most of the day, as well as a patient who was granted home nursing care, but barely received any actual care due to a purported shortage of caregivers. Such problems must be addressed immediately. We urgently seek relief for the day to day suffering of patients as well as advancement of medical research that will directly lead to concrete improvements in patients' quality of life.