

The actions of the volunteer studio for muscular dystrophy

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In muscular dystrophy, respiratory failure and heart failure are the most common causes of death [1]. Artificial respiration therapy came to be provided for respiratory failure in national sanatoriums throughout the country from the late 1970s. The initial artificial respiration therapy used outside the body expression breathing. Intermittent positive pressure-style artificial respiration therapy (IPPV) began subsequently. NIPPV was performed as noninvasive artificial respiration therapy from about 1990. The average life span of patients with Duchenne muscular dystrophy was 20.4 years in the 1980s. In 2004, the average life span increased to 31.0 years in respirator-wearing patients [2]. The hospitalization of muscular dystrophy ward inpatients was therefore extended to approximately 25 years from approximately ten years [3]. The nursing guidance room of the Tokushima National Hospital plans nursing activities for hospitalized muscular dystrophy patients. As for the patients with Duchenne muscular dystrophy, the arm function that is necessary for hobby activities is lost at about 20 years old. Some kind of support apparatus is required so that they receive circle activity. However, it is difficult instrumental to use a lot that we is commercially available. A local volunteer established a volunteer studio for muscular dystrophy with the nursing guidance room staff in March 1998 to solve those problems.

Respirator deployment on electric wheelchairs.

For respiratory failure caused by muscular dystrophy, artificial respiration therapy came to be provided from the late 1970s. On the other hand, the patients who required a respirator were forced to the life in the bed in the management of the

respirator daylong. Therefore, installing respirators in electric wheelchairs was begun in 1995. In the Tokushima National Hospital, a method to carry a respirator on the backrest of the electric wheelchair was used. At the same time, the chair was remodeled so the battery could be exclusively used as an emergency power supply.



Figure 1. The respirator (LTV950) deployment on an electric wheelchair



Figure 2. The respirator (Trilogy1000) deployment on an electric wheelchair



Figure 4. The electric operation of the digital single-lens reflex camera



Figure 5. The fulcrum of the note PC



The electrical operation of the digital camera

The fictionization using the camera was performed increasingly at institutions where muscular dystrophy patients underwent medical treatment. However, it became difficult to continue the activity for physical reasons. In the Tokushima National Hospital, the electric operation of the digital camera was tried from 2008. In 2008, we wrestled with becoming electric motion of shutter operation and the gun elevation operation using a compact digital camera. In 2009, we attempted to improve angle of view operation and up and down operation using a digital single-lens reflex camera.

Fulcrum for a note PC

Muscular dystrophy patients conduct hobby activities or work activities with a PC. However, the use of the PC may be impaired when it becomes difficult to sit down. Therefore, a fulcrum for a note PC

was produced in order to use a note PC as posture of the decubitus.

The improvement of various controllers

When the muscular dystrophy patients use a wireless remote controller, they find some models difficult to use. Therefore, we produced a wireless remote controller that can be operated with a light touch.

References

1. Ishihara T. Management of Patients with Duchenne Muscular Dystrophy. *Brain and Development*. 2004; 36: 130-135.
2. Konagaya M. Muscular dystrophy. The present and the future. *Social medicine and a change of the quality of life. Clin Neurosci* 2008; 26: 200-2001.
3. Miyosi K. The outcome of the patients admitted to the muscular dystrophy ward 20 years ago. 2007; 61: 49-51,