

New Medicine in the Market for Amyotrophic Lateral Sclerosis; Accessibility Problems of Edaravone

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Received: July 16, 2019; **Published:** August 13, 2019

The moments of talking to a patient about the diagnosis of amyotrophic lateral sclerosis (ALS) are probably the most difficult minutes of neurologists. This means that we have to tell the patient is going to suffer progressive weakness and wasting in extremities, difficulties in swallowing and speech, and will eventually die due to respiratory deficiency within almost five years. Actually, all the information about the progress could easily be obtained from the internet including unpleasant photographs about parenteral gastrostomy and tracheostomy. The patients understand that they will face additional problems leading to several visits to emergency ward or ICU during this hard process.

Although ALS is known to be a middle-old age disease (usually the onset is over 50 years of age), we saw many patients in a range between 30 - 40 years in the last decade. It is hard to predict the background of this situation. One reason could be the increased awareness of neurologists and other physicians from all specialities, including GPs. Also, the current Awaji criteria help the clinical neurophysiologists to verify the diagnosis of ALS patients easier than before. Consequently, the patients are mostly diagnosed in early phase of the process.

Until the last two years, we had very few options to offer the patients in management of ALS. Conventionally, all neurologists are used to initiate Rilusole at the moment of the diagnosis, support nutrition until swallowing problems appear, and eventually administer parenteral gastrostomy and tracheostomy. In 2017, a new medicine Edaravone, was approved by FDA after waiting for 22 years following the approval of Rilusole. In Japan, Edaravone was already approved for treatment of acute cerebral infarction in 2001 and for ALS in 2015. It is a free radical scavenger, administered intravenously for 14 days at the beginning and then repeated in 10 day cycles with two week intervals. Edaravone was shown to slow down the disease progression if started in early phase ALS patients.

Ideally, a patient has to take Edaravone in approximately 25 cycles in a year. The US brand, Radicava costs 1480 United States Dollars (USD) for one box which seems to eventually cost more than 150000 USD per year. On the other hand cheaper, but still expensive, forms are also available e.g., Japanese brands Radicut (costs almost 15000 USD), and Kyorin (costs almost 4000 USD per year).

For the ALS patients coming from non US, non EU, or non-Japanese countries, accessibility to even the cheapest form of the drug is a big problem due to several reasons. First of all, all patients cannot afford such a financial burden, including the price of medicine, flights, and accommodation in Japan or US. The swift changes in currencies against USD usually force the patients to discontinuation of the medicine. In 2018 and 2019, some of my patients experienced this problem due to sharp value loss of Turkish Lira against USD. Secondly, even though the Japanese colleagues are absolutely helpful to overwhelm the local difficulties, a patient (or his representative) has to travel to Japan (e.g., a Turkish patient has to travel the world from one end to another) to define the situation, obtain the medicine and bring it to

the hospital. And lastly, the Edaravone boxes should to be passed from the US or Japanese customs. If the representatives of the patients transporting the medicine have difficulties in speaking or understanding English, they may have serious problems in explaining their situation to local authorities.

I am sure that many other neurologists from other countries can add other problems they experienced in the last two years. There is no doubt the manufacturers have right to claim the price in return of their investments and expenses to put Edaravone in the market. However, the situation of ALS patients is exceptional due to limitation of time determined by the catastrophic nature of the disease. The additional benefits that the medicine would provide could be something important for both ALS patients and their families.

Therefore, I suggest that pharmaceutical companies, international organizations should gather in a meeting to handle the marketing and accessibility problems. Organizing the distribution of the medicine via continental or regional sub divisions could help both ALS patients and their physicians to access the medicine more efficiently than the last two years.

Volume 11 Issue 9 September 2019

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