GUILLAIN BARRÉ SYNDROME FROM THE INSIDE - A PATIENT'S PERSPECTIVE

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AIM

To present a unique personal experience of Guillain Barré Syndrome (GBS) by a Physical and Rehabilitation Medicine (PRM) specialist who previously treated patients with GBS.

BACKGROUND

The main focus is rehabilitation throughout the continuum of care from the acute illness to the community.

PRESENTATION

Febrile illness for 10 days prior to sudden onset of symmetrical sensory neuropathy of hands and feet, progressed to an ascending severe quadriplegia with cranial nerve involvement, associated dysesthesia and bladder and bowel dysfunction. It reached the 'nadir' in about two weeks. Intubation and ventilation required for 17 days. Lack of effective communication was a major issue. Six sessions of Plasmaphoresis with gradual improvement noted in specific muscles. Fantasy and reality occurred in ICU. Dysautonomia observed with fear of acute complications. Significant and prolonged neuropathic pain experienced mainly in hands and feet. The latter was aggravated by foot splints and intermittent compression calf pumps. Episodes of feeling cold with discomfort occurred. Aware of consequences of flaccid quadriplegia. Concerned about maintaining residual function and avoiding complications due to immobility.

REHABILITATION

Medical rehabilitation commenced in the acute phase but was insufficient. Transfer to specialised stand alone rehabilitation hospital was personally difficult. Pain management was crucial to comfort and participation in therapy. Simple remedies were important in facilitating recovery. Hydrotherapy greatly relieved pain and boosted confidence. Episodic sense of muscle tightning throughout the body during recovery. The physician-led multidisciplinary rehabilitation model of care was very effective. Institutionalization was a barrier to discharge where supports were much reduced. Family information and education was pivotal in the successful discharge process to the community. Phased return to normal activities was important. Residual symptoms and reduced level of fitness remain after 2 years. On-going hydrotherapy and fitness programme improves outcome.

CONCLUSION

Experience provided significant insights into the GBS recovery process. Energy, knowledge and emotions were channelled into improving physical status. Inadequate PRM occurred in the acute phase. The importance of a comprehensive, integrated, goal-oriented rehabilitation programme from acute to community-based on the ICF[1] model and supported by a PRM physician is essential to optimizing outcomes.

Reference:

1. WHO Geneva (2002).