

UNITED SPINAL_{NOW}

Spinal Cord Injury Rehab Delayed and Denied

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United Spinal Association has discovered a recurring problem for people with spinal cord injuries (SCI).

This problem is so insidious that, upon reflection it is rooted in disability discrimination, even though it is about rehabilitation. United Spinal Association, which has fifty chapters throughout the U.S. and 53,000 members, has determined that those who incur spinal cord injuries — even some who go to SCI model centers — are not rehabilitated appropriately and are not reentering the community but remaining in institutions or reentering the community without appropriate skills or knowledge.

Even worse, some with high level spinal cord injuries are denied rehabilitation altogether.

Recently, we have been dealing with a case in New England regarding an individual who dove into a shallow swimming pool and broke his neck. He also sustained a head injury.

Since his injury ten months ago, he has been “maintained” in an intensive care unit on mechanical ventilation. He is dependent on a machine for breathing.

People with his level of injury can be weaned from the ventilator, but no attempt has been made to wean this individual. In this state, there is only one vent weaning facility, but it refused this patient because they have no SCI experience.

They also said there is disharmony in the family regarding future treatment, so they are reluctant to accept him. The injured individual is 43 years old and has a child and wants to live.

One of his parents contacted us asking for help. The other parent apparently feels he’d be better off dead.

However, parents’ opinions shouldn’t matter if you want to live and you’re 43. Hospital personnel have tried to pressure the mother and the patient to allow hospice to take over his care and remove him from life support.

After successful intervention by United Spinal, the patient will be transferred to an appropriate out-of-state facility, which will attempt ventilator weaning and then get him to an appropriate rehabilitation facility. None of this would have happened without intervention, despite everyone involved on the “denial of care” side having a medical degree.

Less egregious than letting someone die unnecessarily is releasing newly injured patients without appropriate rehabilitation or the skills to live successfully in the community. The primary problems associated with abbreviated SCI rehabilitation include the lack of health insurance or insufficient health insurance.

Many private health insurance policies consider SCI model centers “out-of-network.” Moreover, many hospitals — even top-tier rehabilitation facilities — state that they have no “Medicaid beds” available.

Individuals are, all too often, released to nursing homes, where they are isolated and unlikely to reenter the community without intervention by third parties like United Spinal Association.

Lastly, eligibility for rehabilitation can be jeopardized by collateral injuries and issues, including broken bones, vent weaning, pressure sores or head injuries.

These collateral matters indefinitely delay rehab or result in a lack of SCI-specific rehabilitation.

For the past eight years, United Spinal has brought a group of wheelchair users from all over the U.S. to Washington, D.C. for our Roll on Capitol Hill. One of the themes of the lobbying efforts of the hundred or so wheelchair users that will join us in June, is that we need legislation guaranteeing the right to appropriate rehabilitation for those with spinal cord injuries.

We need to have awareness in the medical community and the population at large of the fact that life is beautiful, even after SCI.