



LYMPHEDEMA STAKEHOLDERS

Political Action Committee

The Medicare Crisis for Lymphedema Patients Occasioned by the Implementation of Section 230.5 “Physical Therapy, Occupational Therapy and Speech Language Pathology Services Provided Incident to the Services of Physicians”

1. According to a National Institutes of Health estimate, between 3 and 5 million individuals in the USA are afflicted with Lymphedema (LE) from all causes.
2. Because of medical and physiological reasons, the incidence of LE is skewed towards our older population. For example, much LE is the sequela of surgeries for cancer, circulatory problems and orthopedic conditions which tend to afflict older persons.
3. At present there are only about 4,400 adequate trained therapists treating LE patients in the USA. This number of therapist falls far short of the number required to treat the existing population afflicted with LE. For example, an early stage LE requires at least 10 treatments of one hour’s duration each to get the LE under control to the point where this incurable condition can be managed by the patient following clinical treatment. This means that a therapist can, at most, treat 200 patients a year – 4,400 therapists can therefore treat approximately 880,000 early stage patients a year. More advanced cases & bilateral limb cases require more than 10 treatments to get the condition to a self-manageable stage. Follow up clinical treatment is sometimes needed to treat flare-ups of LE resulting from episodic infections and other trauma which exacerbate the LE. Hence it is fair to say that a pool of 4,400 therapists falls far short of the required number to treat our citizens afflicted with LE. In fact, LE is an undertreated pathology and its victims are underserved.
4. LE is a chronic condition which, left untreated, tends to worsen, and predisposes the individual to life-threatening infections requiring costly hospitalizations for intensive intra-venous antibiotic therapy.
5. To be adequately trained to safely and effectively treat LE, a therapist should take at least 135 hours of special education and training to practice Complex Decongestive Therapy (CDT), the treatment of choice for LE. This education and training is in addition to the

basic education for their licensure as physical therapists (PTs and PTAs) occupational therapists (OTs and OTAs), licensed massage therapists (LMTs) and Nurses (RNs). This level of training has been established as the required standard by the National Lymphedema Network and the Lymphology Association of North America in consultation with the International Society of Lymphology. The approximate 4,400 adequately trained LE therapists have been educated and trained in several schools whose curricula meet that standard. It took approximately 15 years to build the pool of adequately trained therapists to its present level. And some of the schools which trained these therapists no longer exist.

6. The recently implemented Medicare rule has effectively eliminated approximately 1,500 adequately trained LMTs and RNs from the pool of therapists available to treat seniors afflicted with LE under Medicare. This represents approximately 34% of the existing pool of adequately trained LE therapists. (In the State of Florida with its heavy population of senior full time and part time residents, LMTs and RNs constitute 43% of the available pool of LE therapists.)
7. Some private carriers insuring non-seniors are beginning to adopt the Medicare rule excluding specially-trained LMTs and RNs from treating LE patients.
8. Elimination of 1,500 LMTs and RNs from the pool of eligible LE therapists, means that annually at least 300,000 LE patients are being deprived of medically necessary LE treatment.
9. In many instances, outpatient LE clinics under appropriate medical supervision are staffed entirely or predominantly by LMTs and RNs. Some of these clinics are having to close thereby depriving LE patients of reasonable geographic access to medically necessary treatment.
10. At present there are only 3 mainline schools in the USA whose curricula meet the 135 hour standard and which offer courses in CDT year round – typically 12 sessions a year. They have the capacity to train approximately 600 therapists a year if their courses are fully enrolled. If LMTs and RNs continue to be excluded by the Medicare rule, the courses will have to be filled with PTs and OTs, many of whom are not trained in or predisposed to undertake a career in which the therapy is one-on-one, labor-intensive and physically exhausting. PTs, especially, are used to treating multiple patients at one time. In addition, the services of PTs and OTs in their respective traditional fields of practice are now much in demand given the ever-increasing number of wounded from the ongoing Iraq conflict who will require intensive and extended rehabilitation. Therefore, it is likely to take more than 3 years to replace the LMTs and RNs excluded by the Medicare rule.
11. If the current Medicare rule is not promptly recinded, many of the LMTs and RNs who have been treating LE patients will have to relocate and/or return to their traditional fields of massage therapy and nursing to earn a livelihood.

12. In the intermediate and long term, the Medicare rule excluding specially trained LMTs and RNs from treating senior and non-senior patients afflicted with LE will prove to be more costly to the government and individuals because of the medical complications from untreated or delayed treatment LE.
13. The most frequent serious complication arising out of neglected LE are infections (cellulitis and lymphangitis) which exacerbate the LE and often result in life-threatening fevers requiring hospitalization for intensive intravenous antibiotic therapy. Of the 300,000 LE patients annually treated by LMTs and RNs, approximately 2/3rds or 200,000 are seniors on Medicare.
14. Given the shortage of qualified LE therapists which has been worsened by the exclusion of LMTs and RNs from the pool of therapists available to treat Medicare LE patients, it is likely that 75% of these patients or 150,000 will be unable to access treatment for a least a year because there are simply not enough PTs & OTs adequately trained to treat them.
15. If only 25% of these 150,000 neglected patients or 37,500 suffer an infection in the next 12 months requiring hospitalization for antibiotic therapy, given an minimum stay of 7 days to realize the full benefit from the intravenous administration of Vancomycin (the drug of choice for these infections) and a Medicare approved daily rate for hospitalization of just under \$1,100, of which Medicare pays 80% (which number does not cover the of cost of the Vancomycin and its administration and other possible therapy, for which Medicare also pays an approved amount) the annual cost to the government projects to be approximately 230 million dollars. This figure does not take into account multiple hospitalizations in one year which many untreated LE patients require for repeated infections.

Because the severity of LE progresses the longer that it goes untreated, the greater the likelihood of and frequency of infections. Given the fact that it will take an estimated 3 or more years to replace the LMTs and RNs with PTs and OTs adequately trained in CDT, it is not unreasonable to expect that the federal government (and indirectly the U.S. taxpayers) will be paying many additional hundreds of millions of dollars over the next few years in hospitalization costs as a direct result of the recently implemented CMS rule which deprives Seniors of medically necessary treatment that is covered by Medicare, subject obviously to the availability of Medicare approved and adequately trained therapists, which availability has been sharply curtailed as a result of the ill-conceived CMS rule.