People with ALS may soon be able to receive much of their clinical care in their own homes, delivered via video conference. That prospect was described by James Berry, M.D., M.P.H., of Massachusetts General Hospital in Boston, in a recent webinar hosted by Kim Maginnis, Chief Care Services Officer for The ALS Association.

Dr. Berry is about to begin a pilot program, supported by The ALS Association, to test the feasibility of a “telemedicine” program for people with ALS. He plans to enroll 20 people with Lou Gehrig’s Disease in Massachusetts and Maine for the initial trial.

Telemedicine is already in widespread use for delivery of acute stroke care. Hundreds of emergency rooms across the country are linked to hubs staffed by stroke experts, who can quickly evaluate patients and read brain scans to determine if they should receive time-sensitive, life-saving “clot buster” medicine.

For those with ALS, the needs being studied are not for rapid emergency care, but for the specialized services of an ALS multidisciplinary clinic. Currently, a person with ALS and their caregiver typically must set aside an entire day to attend such a clinic, including travel, evaluation, and time between specialists.

Dr. Berry’s hope is that by using telemedicine, it may be possible to have fewer visits to the clinic and more in-home evaluations, saving time and avoiding the stress of a day-long ordeal. Additionally, telemedicine may bring top-quality care to people who currently live too far to regularly travel to an ALS clinic.

The in-home visit probably can’t replace every feature of the clinical visit. In particular, respiratory evaluation may be problematic. But it may be possible to have that evaluation done by home-care nursing professionals, in consultation with the ALS clinical staff on the other end of the videoconference.

Other services of the clinic, including patient education, weight maintenance counseling, and talking with the patient and caregiver about what to expect in the near future, “are slam dunks” for telemedicine, Dr. Berry said. Many other aspects of the clinical visit are also likely to be amenable to remote evaluation and instruction, as well.

One likely advantage to telemedicine is that the clinical team can see the patient in their home environment, where many issues of accessibility, activities, and challenges for daily living
become obvious, unlike a clinical interview to assess the same aspects. “This can be an opportunity to provide better care,” he said.

The trial is slated to begin later this year. “I think we will learn important lessons from the pilot trial,” he said. The computer-based video system being used is fairly simple, and doesn’t require much technical knowledge to set up or use. In addition, telemedicine can allow multiple people in different sites to confer, so that community physicians or nurses, for example, could join the conference.

Unlike the clinic visit, in which the patient goes from one team member to another over the course of a very long day, Dr. Berry anticipates spreading out those consultations over a week. An initial conversation with a nurse will bring out the problems and concerns the patient is experiencing, followed by conferences later in the day or the week with appropriate specialists. “We have a lot of flexibility,” Dr. Berry said.

Dr. Berry will be measuring feasibility, patient satisfaction, and resource utilization. “The bottom line will be, is this a good care delivery method?”

Hurdles remain, he cautioned, since currently telemedicine is not reimbursed by Medicare or most insurance companies. State-by-state medical licensing requirements also hinder interstate conferences. But, he said, those barriers are likely to come down as more experience is gained with telemedicine, and as it proves its value in terms of patient care and cost savings. Many states are already making provisions for telemedicine licenses, recognizing the value to patients. “This is the wave of the future,” Dr. Berry said.

The full webinar may be viewed by clicking on this link: https://alsa.webex.com/alsa/ldr.php?AT=pb&SP=MC&rID=66427022&rKey=bf3ada811403e94c