

"The Outreach Dystonia Nurse Practitioner"

In 1988, I assisted Professor Barnes in our first botulinum clinic with a handful of clients at the Regional Neurological Rehabilitation Unit in Newcastle-upon-Tyne, UK. Initially a three monthly clinic, within two years it quickly grew to become a weekly session. There was a slow but steady trickle of dystonia referrals but this increased dramatically when Dr Butler's epidemiological survey began to produce new clients.

The clinic numbers increased rapidly therefore other doctors were brought in to assist, unfortunately they changed frequently and the client may have seen a different clinician at each visit, directly affecting the quality of the treatment. The situation came to a head in 1994 when a new clinic had to commence, however it was obvious by examining the rate of new referrals that this would be only a temporary measure. Professor Barnes had a number of discussions with staff, management and the local dystonia support group and the outcome was that I should start to give the botulinum treatment.

The post began as a research project, using a grant from the Northern Region Health Authority, the hypothesis being, could a Nurse Practitioner deliver the care and treatment as effectively for quality and cost as the doctors in the clinic. The project consisted of an initial total of one hundred and twenty people with dystonia, split randomly into two groups. One group had treatment at the outpatient clinic by medical staff and the other received their care at home by the nurse practitioner who had undergone a six month training period. The clients in each group were assessed for clinical efficacy, i.e. response to treatment and side effects, using dystonia rating scales. Quality of life issues were recorded by an independent assessor (Dr A G Butler). Every conceivable cost to the NHS and the state was counted.

There was a number of variables which biased the project against the nurse practitioner; first the medical staff already had a number of years experience giving the treatment prior to the project, whereas the nurse had none; clients in the clinic group sought advice from the nurse which he was obliged to give, however this should have been given during the doctors consultations; as the project ran it became obvious that certain practices were improving the quality of care, for example the efficacy of treatment was improved when given by the same clinician, shown in the home group and caused the medical staff to change their practice before the completion of the research; finally the clients already had confidence in the doctors but the nurse was an unknown entity. In spite of these biases the final result still fell in favour of the nurse practitioner.

The findings showed that the care given by the nurse practitioner was as good and in many instances better than that given by the clinic. The side effects were fewer and less severe in the home group, also the clients preferred the home option, bearing in mind they already had experience of the clinic. Finally on cost; the expense was the same to the hospital trust for both groups, however the cost to the "State" was half for the home group compared to treatment given at the clinic.

The results were so successful that the trust immediately funded the outreach nurse practitioner post. I now have a caseload of over one hundred and fifty clients and run a number of outreach satellite clinics. The rehabilitation unit now also has two other nurse practitioners giving botulinum treatment and there are plans to set up a team of outreach nurses to make the dystonia clients treatment community based. There are now a number of nurse practitioners working in other trusts in the UK and we have set up a "Dystonia Nurse Network" to assist with advice, support and education. The Dystonia Nurse Practitioner has been proved to be the most effective method of providing care to this client group and is generally preferred by those who use this service.