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MY NEEDS NOW—OUTCOMES OF INNOVATIVE COUNTY-WIDE COMMUNITY NEURO-PALLIATIVE COORDINATOR POST

Carol Scholes, Liz Garrood. *Herts Community NHS Trust, Hemel Hempstead, England*

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Introduction Following 4 years of community neuro-palliative multidisciplinary teams in Hertfordshire, the gap of a community co-ordinator for newly diagnosed patients with rapidly progressive neurological conditions emerged as a priority.

Aims To assess the impact of an innovative co-ordinator role assessing community neurology and palliative care needs at diagnosis of five rapidly progressive neurological conditions. To examine impact on patient experience, non-elective hospital admissions and place of death.

Method A pathway was developed direct from neurological diagnosis of five rare conditions-Motor Neurone Disease (MND), Progressive Supranuclear Palsy (PSP), Huntingtons Disease (HD), Cortico-basal degeneration (CBD), Multisystem atrophy (MSA). The community co-ordinator assessed their neuro-palliative needs soon after diagnosis, gave information, referred to appropriate community services, and then acted in a clinical consultancy role to staff and patients.

Results Total number of patients referred and assessed during January 2012 – May 2013=139

The most frequent onward referral was to specialist palliative care=75 (54%).

31 (22%) have died, 27 (87%) in their preferred place.

Eastern Region Public Health Observatory data showed reduction in elective and non-elective hospital admissions for people with these diagnoses by over 50% in 1 year. Cost of the co-ordinator post and administrative support is 60k per annum.

Patient experience –a baseline questionnaire revealed gaps in current service. Comparison after 1 year of the service will be presented. Anecdotally it has made huge improvements to many patients' lives and improved knowledge and skills of community staff, which can be applied in managing patients outside this project.

Conclusions The model appears to have been successful providing improved quality of co-ordinated community clinical care while reducing hospital costs. It is cost-effective and provides timely specialist support, working through existing workforce. It could be a model for managing other rare long term conditions, and to increase access to palliative care for other non-malignant conditions.

MND	71
HD	30
PSP	22
MSA	12
CBD	4