Results: 274 patients with neuromuscular diagnoses were referred to Martin House (MH) during this time period. This is 18% of total referrals during this time period.

70.1% (192) had a diagnosis of Duchenne Muscular Dystrophy (DMD) with a peak in referrals in the year after the opening of MH, 24.1% (66) Spinal Muscular Atrophy (SMA) and 5.8% (other neuromuscular diagnoses). The mean age at referral was 9.7 years (SD 5.2) but this was significantly higher in DMD (mean 11.6, SD 3.9) than the other two groups although age at referral of DMD patients has decreased from a mean of 16 to 10 years during this period.

The survival patterns differ significantly between the three groups with children with SMA having a steeper curve and therefore a significantly shorter survival time (mean 0.25 years) compared to DMD patients (mean 8.7 years).

Conclusions: Children and young people with neuromuscular diagnosis form a large proportion of the referrals to a children's hospice.

The survival patterns highlight the different palliative care needs of the children and young people with subgroups of neuromuscular disease.

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END OF LIFE CARE PLANS (ELCP) IN CHILDREN WITH LIFE LIMITING CONDITIONS

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Background and aim: Paediatricians face acute situations with children with life limiting illness, wherein resuscitative medical interventions should not be attempted. We aim to survey current prevailing practices on provision of ELCP in children who fulfil the criteria for life limiting illness in the London borough of Haringey, UK.

Methods: Survey was conducted in the last quarter of 2009. A list was compiled of medical conditions deemed as life-limiting in children. Medical notes of all children on the list were reviewed, directing attention to the specific points that were noted as relevant in the audit proforma. Ethical issues were discussed with the clinical governance department at Great Ormond Street Hospital, London, UK.

Results: 18 children with life limiting illness were resident in Haringey. 10 of the 18 (55.5%) children suffered from cerebral palsy. 13 of these children (72.2%) fulfilled criteria for the provision of an End of Life Care Plan (ELCP). 3 children of the 13 (23%) had an ELCP. Only one child had the ELCP documented and communicated to professionals appropriately.

Conclusions: National standards for delivering end of life care for children are currently not being met, and children with complex neurodisabilities are not usually being appropriately considered for ELCP discussion. Professionals are uncomfortable with approaching and addressing the issue of ELCP in eligible candidates. A programme for training and support at all levels of service delivery - consultants, registrars and nursing staff should be developed and implemented.

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NEONATAL POST-MORTEM RATES: A 10 YEAR EXPERIENCE AT A TERTIARY CENTRE IN THE UK

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Background: Post-mortem examination is important in determining cause of death and can add additional information even when the cause is felt to be apparent. The organ retention scandal in 1999 has changed the perception of post-mortems particularly in children.

Aims: To determine the post-mortem rates for babies who have died on our neonatal unit and to see if there are any differences between term and preterm babies.

Methods: All babies who died on our neonatal unit from January 2000 to December 2009 were identified using a combination of our neonatal databases, admissions book and death certificates. Post-mortem examinations were determined from our neonatal database and mortuary records.

Results: There were 329 deaths and 80 post-mortems performed during this period (24%). The yearly post-mortem rate for all babies varies from 13 to 39 percent. Over the 10 year period, rates