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INFORMATION AT DIAGNOSIS OF HUNTINGTON'S DISEASE (HD), MOTOR NEURONE DISEASE (MND) AND PROGRESSIVE SUPRANUCLEAR PALSY (PSP)

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Introduction People with a long term condition require information in order to self manage and make informed choices. Access to timely information can be challenging for people with rare conditions.

Aim To document information given at diagnosis of HD, MND and PSP and ask whether people can now make informed choices.

Method A postal questionnaire was sent to 150 people living with HD, MND and PSP in Hertfordshire regarding knowledge of their disease before diagnosis, information given at diagnosis including supporting services, and ability to make informed choices.

Results 62 (41%)–6 HD, 39 MND, 17 PSP- questionnaires were returned

1) *Did you know anything about your condition before you were diagnosed?*

Overall 19 (31%) Yes, 43 (69%) No

“Yes” by diagnosis—4 (66%) HD, 13 (33%) MND, 2 (12%) PSP

2) *At diagnosis were you given information about your condition?*

Overall 42 (66%) Yes, 16 (26%) No, 4 (7%) unsure.

“Yes” by diagnosis – 5 (83%) HD, 26 (67%) MND, 11 (65%) PSP

3) *Were you told about services that could support/help you and how to access them?*

Overall 40 (65%) Yes, 21 (33%) No, 1 (2%) unknown.

“Yes” by diagnosis – 6 (100%) HD, 28 (72%) MND, 6 (35%) PSP

Question breakdown revealed information on carer support/respite most frequently unavailable but needed (11 overall – 8 MND, 2 PSP, 1 HD)

4) *Do you feel enabled to make informed choices about living with your condition?*

Overall 41 (66%) Yes, 15 (24%) No, 6 (10%) unknown

“No” by diagnosis – 1 (17%) HD, 7 (18%) MND, 7 (41%) PSP

Conclusions At diagnosis, people with HD feel the most and PSP the least informed about their condition and local support available. Lack of information and local support may have affected ability to make informed choices. Service development should reflect these findings.