In England, the NHS has an ‘internal market’. That means that some NHS organisations decide what services should exist, and pay for them – this is called commissioning, and they are commissioners. The parts of the NHS that actually offer the services are called providers. They may be hospitals, GPs or other community services. This factsheet highlights some of the key bodies locally that make important decisions for people living with motor neurone disease (MND).
Before making approaches, it is important to contact your Regional Care Development Adviser (RCDA), to find out what their current relationships and projects are with healthcare commissioners and providers in order to ensure joined-up working. If in doubt as to who your local RCDA is, please visit our website: www.mndassociation.org/staff-contacts

Hospitals play an important role in the care of people living with MND. Initial diagnosis will usually be confirmed in a hospital. If there is a care centre or other MND clinic in the hospital, some or all of the person’s care may be co-ordinated from there. You can raise awareness and knowledge of care issues relating to MND at your local hospital by making contact with the senior management team. Your hospital trust will have a website that provides information on key contacts such as:

1. Head of Engagement and Community – their job is to provide opportunities for service users, voluntary groups and members of staff to work together
2. Medical Director for Urgent Care and Long Term Conditions
3. Head of Nursing
4. Chief Executive
5. Governors of the hospital

Clinical Commissioning Groups (CCGs) are NHS organisations set up to organise the delivery of NHS services in England. Officially, they are run by GPs. In practice, most of the work is done by professional NHS managers, not GPs. Not all services are commissioned by CCGs – some regional or specialist services are commissioned centrally by the NHS.

Health and Wellbeing Boards – Each county or unitary council area will have its own Health and Wellbeing Board. They are a forum where key local leaders from the health and care system work together to improve health and wellbeing for the local population, and reduce health inequalities.

Healthwatch takes the views of local people to make recommendations and report on services provided, and how they can be improved. Sign up to your local Healthwatch for online newsletters:
www.healthwatch.co.uk/find-local-healthwatch - Look out for opportunities to get MND or wider issues like neurology on to their agenda.

TOP TIPS
Be confident – you probably know more about MND than the person/people you are speaking to, and will be able to offer a unique insight. If in doubt, keep it simple, and speak from the heart.