



## A qualitative generic study of the preparedness of generalist health and social care practitioners to provide palliative and end of life care for people living with motor neuron disease at home

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### Abstract

The symptoms of Motor Neurone Disease (MND) also known as Amyotrophic Lateral Sclerosis (ALS) result in disabilities impacting on most activities of daily living. This means that people diagnosed with MND will require care and support with their activities of daily living at some stage in the disease process. In the United Kingdom (UK), care for people with disabilities is usually provided informally by family members, friends, and significant others. Health and social care services also provide care for people at home. However, there is a paucity of evidence in available literature on how health and social care professionals who are not specialized in MND care are prepared to care for MND patients in their homes in palliative and end of life care (EOLC). The study aimed to explore the experiences of Generalist health and social care professionals on how they perceived they are prepared to care for people living with MND at home in palliative and EOLC. The Study questioned how are Generalist health and social care professionals prepared to care for people living with MND at home in palliative and EOLC? Ethical approval was gained from Edge Hill University Faculty of Health and Social Care Research Ethics Committee. Health Research Authority approval in England was also obtained. This study used a generic qualitative approach not guided by an explicit or established set of philosophic assumptions in the form of one of the known or more established qualitative methodologies e.g. grounded theory (GT), phenomenology or ethnography (Kahlke, 2014) to allow for a flexible, responsive research approach for the researcher to answer the study question. A generic qualitative approach was employed to meet research needs and to build new genres. The study found that generalist practitioners needed formal training when caring for people living with MND during palliative and EOLC at home. Support from the MDT including palliative care services was valued. Practitioners felt they needed to be updated about how to care for MND patients at home in palliative and in EOLC.

### Biography

Helen Brewah is currently studying PhD in Nursing having completed an MRes in clinical and Health Research. She has a background in general community nursing and practiced as a District Nurse, and Community Matron for many years. The main interest is on how health and social care workers care for people living with Motor Neurone Disease at Home. She has published two articles relating to this and one article relating to policy development by nurses. She is also a reviewer in publons and has reviewed 5 articles for peer reviewed journals.

### Publications

Brewah H. A qualitative study of the preparedness of practitioners to care for people with motor Neurone disease in their homes. 2019. Primary Health Care.



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