

# Barriers and facilitators to health care for people from minority ethnic communities living with a neurodegenerative condition

People from minority ethnic backgrounds can face distinctive challenges in accessing appropriate care. To ensure equitable access, we need to understand the barriers and facilitators affecting service use. In this project we:

- Identified reviews that collated research on barriers and facilitators to service access for minority ethnic groups affected by neurodegenerative conditions.
- Consulted people from minority ethnic backgrounds with lived experience, family carers, practitioners, and other stakeholders about their views on improving access to services.
- Identified implications and recommendations for policy and practice.

## Key messages

Implementing a whole-systems approach can improve access to consistent, joined-up, and collaborative support for all families affected by neurodegenerative conditions and help reduce inequities for minority ethnic communities.

1. **Ensure continuity across the care pathway.** Develop systems that promote continuity of care by improving communication and coordination between specialist services, primary care, and social care. This helps families feel supported throughout every stage of the disease.
2. **Build trust and confidence through skilled professionals.** Trust in services encourages families to access and engage with support options. This can be supported through professionals who demonstrate expertise in specific neurodegenerative conditions.
3. **Where feasible, embed culturally responsive, person-centred care:** Actively identify opportunities to tailor care to peoples' cultural, religious, and dietary needs. Embedding this approach in daily practice, even through small actions, can enhance the quality of care and improve engagement from diverse communities.

## Background

Around 18% of the UK population is from a minority ethnic background (1). In the UK, approximately 50,000 people from minority ethnic communities live with dementia (2), 7,650 with Parkinson's disease (3), 1,440 with Huntington's disease (4) and 900 with motor neurone disease (5).

This review consolidates evidence on the barriers and facilitators influencing access to services among minority ethnic groups affected by neurodegenerative conditions. Beyond the key findings presented below, the research highlights wider systemic challenges in delivering specialised, person-centred care for affected individuals and families. Barriers to accessing timely and appropriate care can contribute to later presentation, fragmented support and increased reliance on crisis services. Addressing these barriers is central to the ambitions of the 10-Year Health Plan, particularly in relation to prevention, early intervention and the delivery of proactive, coordinated long-term condition management

## Key findings

### Evidence is dementia-focused

- Ten reviews addressed dementia, but none covered other neurodegenerative conditions of interest, highlighting the need for further research to understand condition specific barriers.

### Perceived personal relevance and benefit promotes engagement

- Awareness of available support, accessible information, and understanding potential benefits increased the likelihood of seeking help.

### Language influences access and engagement

- Language barriers hindered communication between people and professionals, limiting trust and rapport across the care pathway.

### Misconceptions limit awareness

- Misconceptions about symptoms and stigma reduced recognition of the need for care and support.

### Limited specialist provision for neurodegenerative conditions

- A shortage of support services and professionals with specialist knowledge undermined confidence and reduced motivation to engage.

### Inflexibility of services is off putting

- Services unable to adapt to cultural preferences and needs were seen as inappropriate.

## Policy implications

Inequities in accessing services exist throughout the care pathway for minority ethnic communities. Although it may not be feasible to meet every cultural need or match staff and patients by cultural background, we propose three recommendations to enhance the consistency, quality, and responsiveness of care.

### Policy recommendations

Key conditions for access	Recommendations
<p><b>Integrated services:</b> Strengthening integration between specialist services, primary care, and social care can promote coordinated care and increase trust in services.</p>	<p>Review how primary, community, and specialist services work together to support people who use services living with neurodegenerative conditions in each Integrated Care System (ICS). Highlight successful models that improve service coordination and access, focusing on approaches that can be scaled up in a sustainable and cost-effective way.</p>
<p><b>Culturally responsive, person-centred care:</b> Even small efforts to tailor care to religious, cultural, and dietary needs build confidence in care and encourage collaboration.</p>	<p>Review available resources supporting culturally responsive care to develop clear guidance for services. At the service level, evaluate mechanisms that help staff respond flexibly to diverse cultural needs in service design and delivery, for example, through language-sensitive communication and recognition of religious/cultural calendars (schedule appointments to avoid religious holidays or fasting periods).</p>
<p><b>Culturally aware workforce:</b> A culturally aware workforce is crucial for effective interactions.</p>	<p>Examine the cultural awareness training currently available and explore ways to develop a national training model, ensuring that each ICS has resources tailored to the ethnic diversity of its population. Additionally, assess and model the likely cost-benefit ratio of implementing this training at scale.</p>

## Conclusions

Implementing a whole-systems approach, underpinned by integrated services that provide consistent, skilled, and culturally responsive care, can improve access to support for all families affected by neurodegenerative conditions and help reduce inequities in service access for minority ethnic communities. The following actions should be considered:

Deliver culturally responsive, person-centred care

Build a culturally aware workforce

Develop integrated care pathways

## Contact details and where to find out more.

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