

Developing a regional networked approach to care in Integrated Care Boards for Myasthenia Gravis

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Background

- Currently complex myasthenia gravis (MG) care is often not delivered close to home but in specialised regional centres leading to inequitable care and inefficiencies.
- This centralised model can lead to sidelining of referring centres from the decision-making process and disjointed ongoing patient care.
- Delegated budgets for integrated care boards (ICBs) and the NHS England neurology transformation agenda now open up new opportunities to neurology services to move to a multidisciplinary networked approach that will improve the delivery of integrated health and care services.

Aims

We brought together multi-disciplinary MG care teams across ICB areas that utilise the Sheffield and Birmingham regional MG services as exemplars to map current care delivery. This was carried out in 3 steps: development of an integrated care pathway for MG, systematically identifying the network of care, connect with commissioners in the ICB's to plan how multi ICB MG services will be delivered.

Methods

Using the model developed by the South West London and Surrey Heartlands Pathfinder NHS England neurology transformation pilot¹, neurology teams from the ICB areas met to discuss their individual services. The tasks of this workshop included:

1. Identify existing service components to plot how care is currently delivered locally (including workforce capacity, patient flows, areas for improvement) and to map the geographic footprint.
2. MG care pathway development for the whole footprint, modelled on the new three-tier system for neurology care and using a network approach coordinated around the specialist regional centre.
3. Explore how the regional centre could support networked MG care to improve patient outcomes by linking the MG networks with their ICB commissioners.

The Sheffield regional centre provides MG care for a population of ~ 9 million people across a footprint of three ICBs (Fig 1). Care is provided across 20 hospitals including 3 N1, 5 N2, 3 N3 and 11 N4 sites. There are 3 ICBs South Yorkshire, West Yorkshire and Humber and North Yorkshire.

In the West Midlands the regional centre provides MG care for a population of 6 million (~ 4.6 million adults) (Fig 1). Neurology services are provided across 12 NHS Trusts, 20 hospitals including 3 N1, 0 N2, 7 N3 and 10 N4. There are 6 ICBs Birmingham and Solihull, Black Country, Coventry and Warwickshire, Hereford and Worcestershire, Shropshire, Telford and Wrekin, Staffordshire and Stoke on Trent.

Current MG care in the UK:

MG patient population ²	22,855
Regional MG services ³	25
Specialist MG neurologists	43
Specialist MG nurses	6
Integrated care services	42

Fig 1. Myasthenia Care Pathway

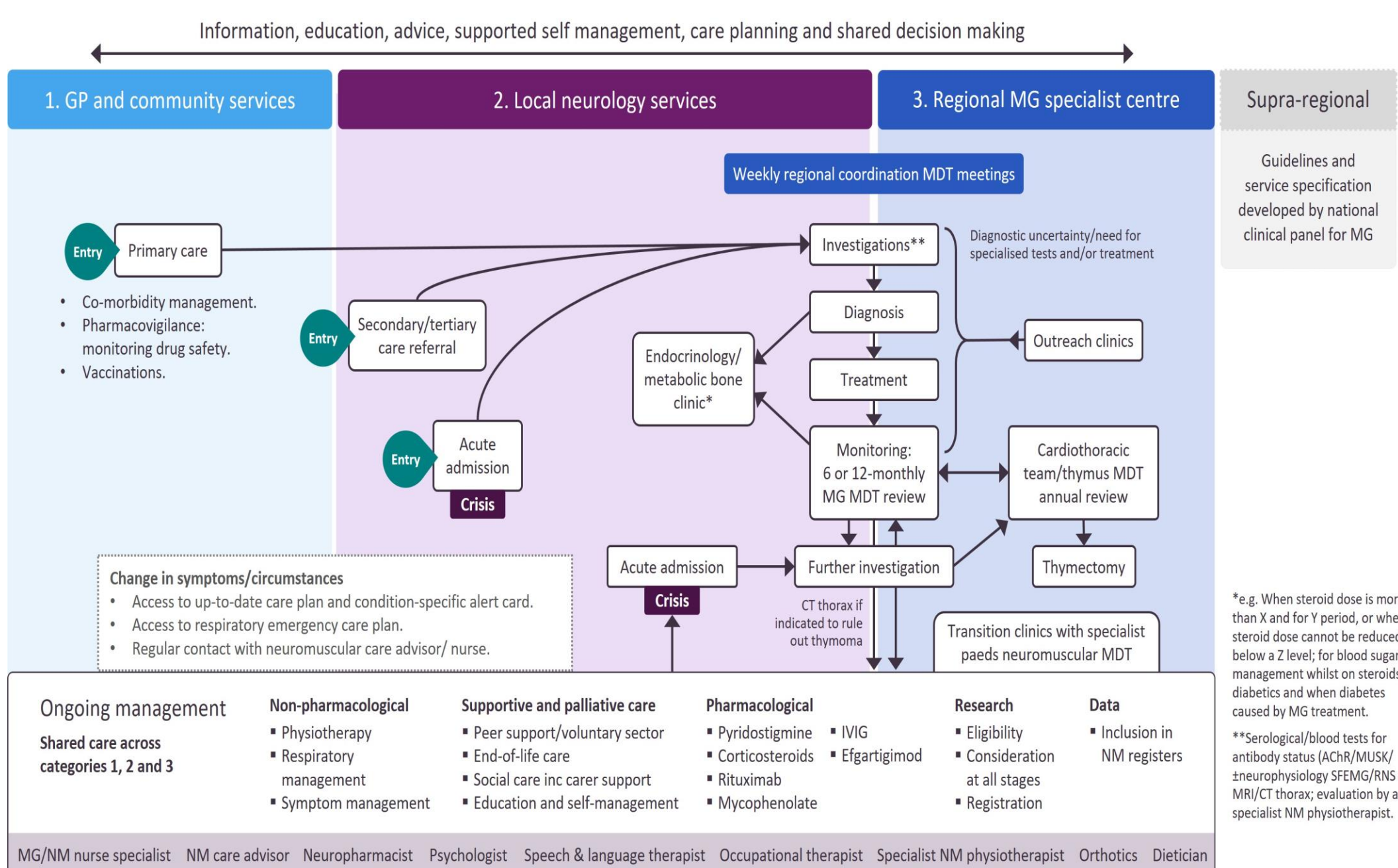


Fig 2. Multi-ICB footprint of Sheffield and Birmingham MG regional centres

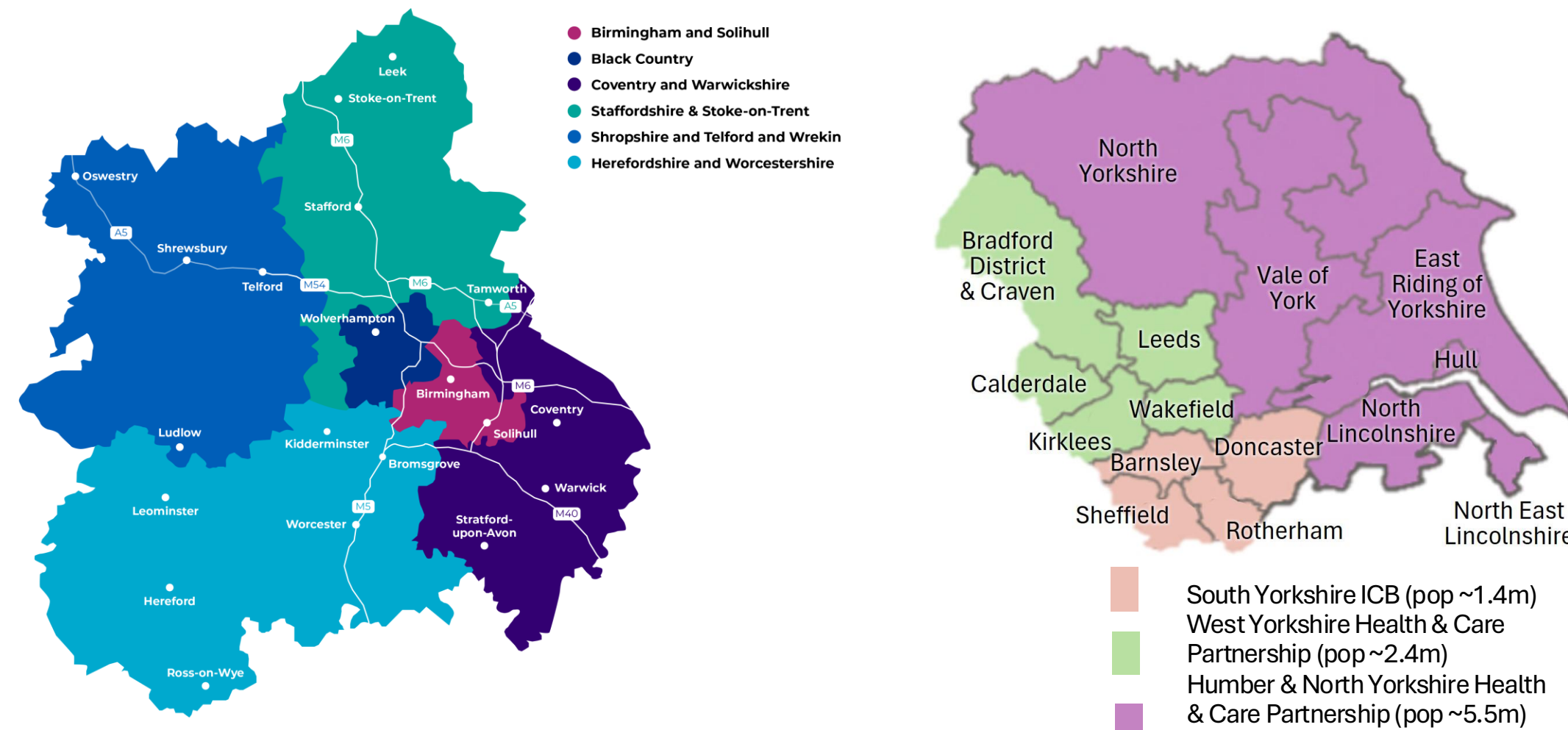


Fig 3 Referral flows within Birmingham Regional Network

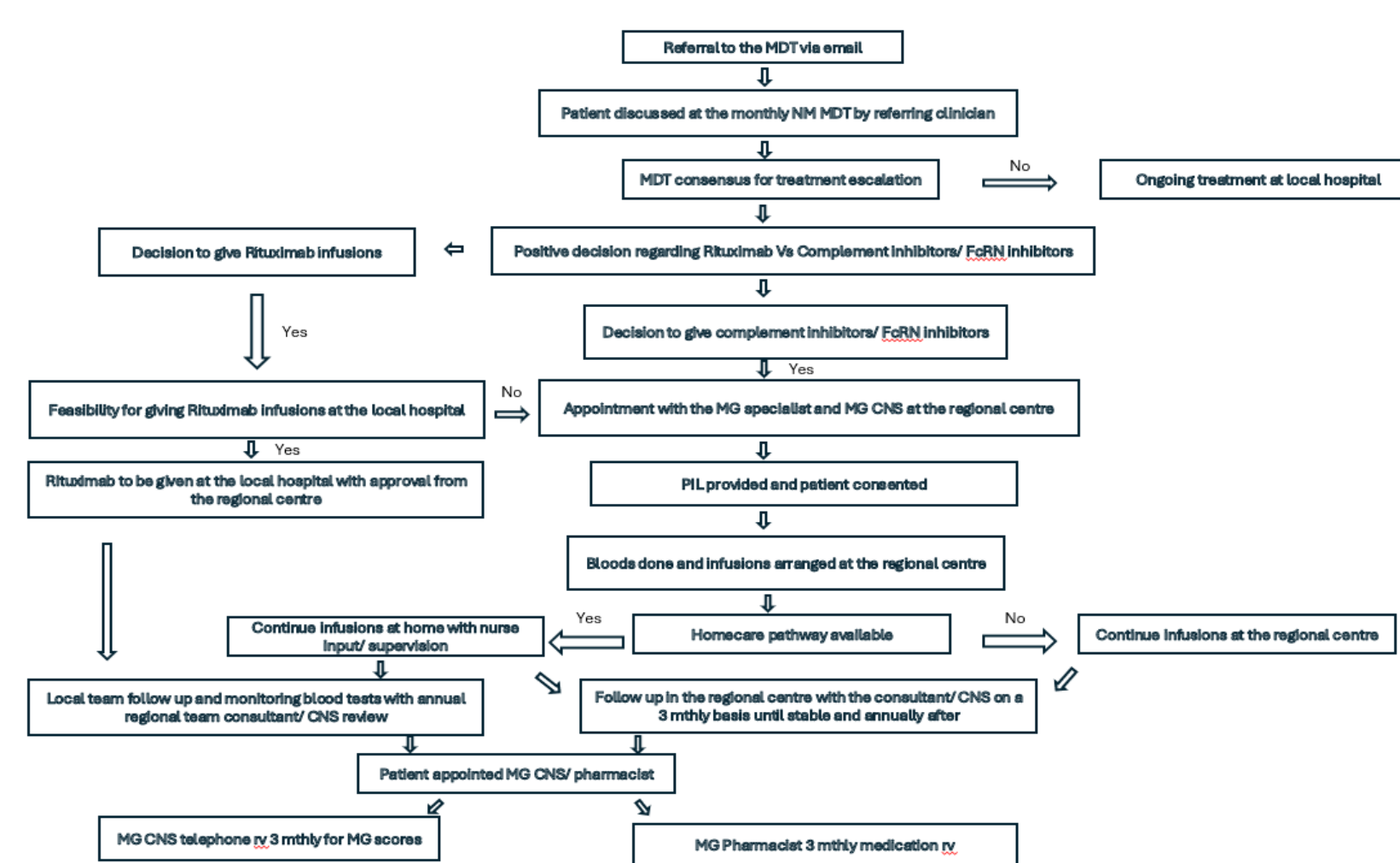
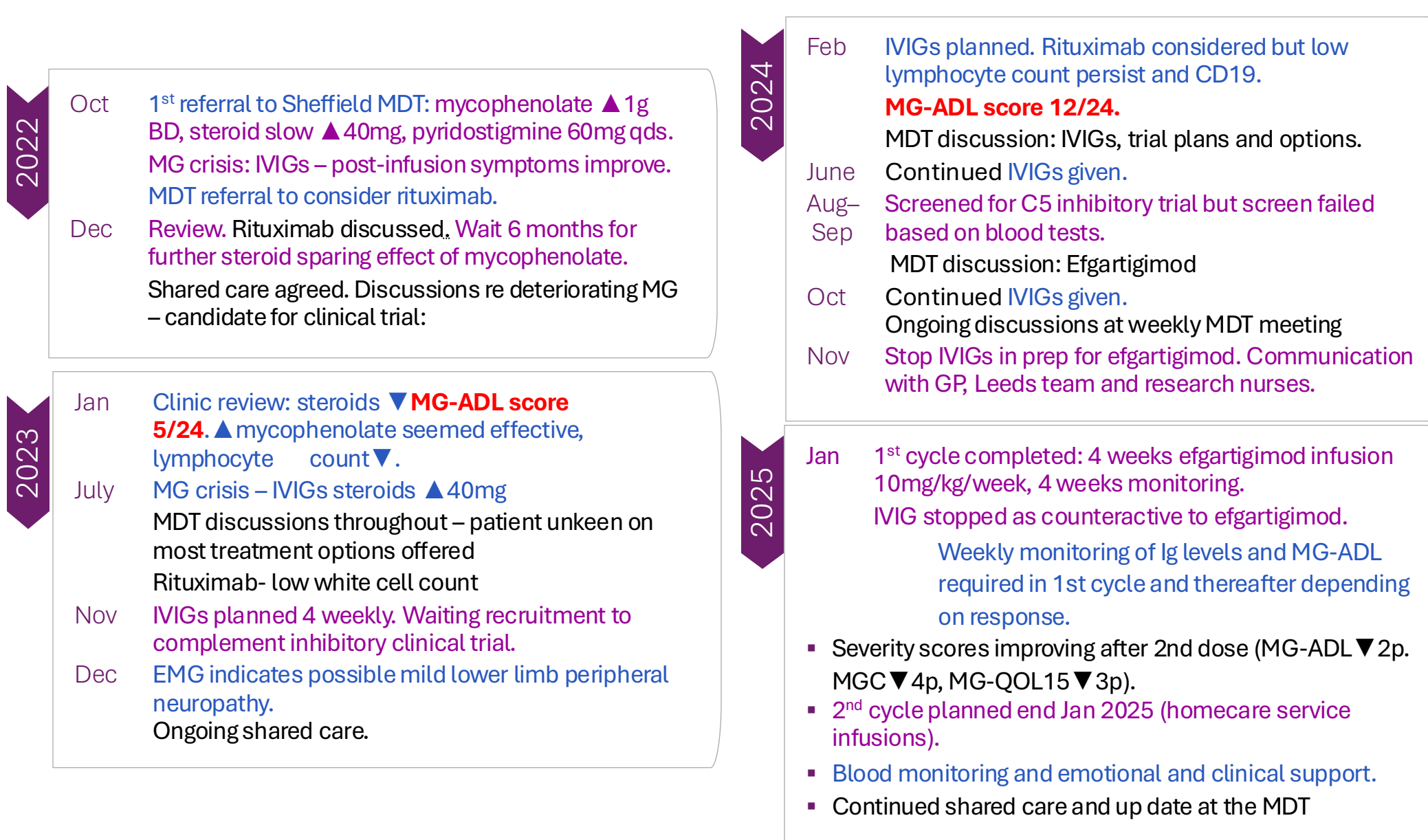


Fig 4. Case study: value of MDT shared care approach in MG Yorkshire Network

Background

- 74 yr female, diagnosed in Leeds in 1989 with generalised MG.
- AChR +ve, moderately affected (MG-ADL 10/24), thymectomy 1989.
- Symptom control difficult.
- Complications with azathioprine and methotrexate.

Key for activity carried out by:
 • Leeds neuromuscular MDT
 • Sheffield specialist MG MDT
 • Shared care between teams



Results

- By mapping services and linking the regional networks of neurologists and the multidisciplinary MG care team services can reduce unwarranted variation in care delivery and improve multiple aspects of patient outcomes in MG.
- The model can increase capacity within specialist MG services and overall reduce economic burden by providing prompt care closer to home.
- An integrated MG network can be the basis to improve diagnosis and care for people with MG and is a transferable model of care other regional services could adopt.

Acknowledgement

With thanks to Dr Priya Shanmugarajah neurologist, Gio De Guzman, Clinical nurse specialist for neuromuscular disease and Lisa Cutsey Roald Dahl Transition Neuromuscular Nurse Specialist, Leeds Teaching Hospitals NHS Trust for their help in developing this case study.

References

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The integrated MG care pathway has been financially funded by sponsorship from argenx UK Ltd. argenx UK Ltd has had no input into the pathway other than a factual accuracy check.

▲=increase, ▼=decrease, AChR=acetylcholine receptor, BD=twice daily, EMG=electromyography, ICB=Integrated Care Board, IG=immunoglobulin, IVIG=intravenous immunoglobulin, MDT=multidisciplinary team, MG=Myasthenia Gravis, MG-ADL=MG activities of daily living (scale), MGC=MG composite (scale), MGNS=MG nurse specialist, MG-QOL15=MG quality of life scale 15, MGII=MG impairment index, NM=neuromuscular, NMNS=neuromuscular nurse specialist, p=point, pt=patient, qds=4 times a day.

N1 Neuroscience Centre, N2 Neurology Centre with in patients N3 DGH Neurology centre without inpatients, N4 Visiting neurologist only