

Your Voice Matters - Raising the Profile of Neurological Conditions

There are many people across Gloucestershire who are affected by a neurological condition.

There are over 600 types of neurological conditions, which are broadly categorised:

- Sudden onset conditions (eg acquired brain injury, spinal cord injury, stroke, meningitis, Guillain-Barre Syndrome)
- Intermittent and unpredictable conditions (eg epilepsy, Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS), some long Covid, Post Viral Fatigue Syndrome, certain types of headache and the early stages of Multiple Sclerosis)
- Progressive conditions (eg motor neurone disease, Parkinson's disease, later stages of Multiple Sclerosis, Charcot Marie-Tooth disease, Huntingdon's disease)
- Stable neurological conditions (eg post-polio syndrome or cerebral palsy in adults)

All these conditions impact upon the nerve system of the body. Some may be life limiting conditions others may not be, but all will have an impact to some degree on the quality of life of the people effected.

Improving Outcomes

Gloucestershire Clinical Commissioning Group (GCCG), now the Integrated Care Board (ICB), recently established the Neurology Clinical Programme Group (CPG). The CPG will raise the profile of neurological conditions and try to bring together representatives of health, social care and voluntary and community organisations to encourage collaborative working and improve the health and social care pathway for the people who use their services. This is intended to improve outcomes for individuals living with neurological conditions.

Collaborative Partnerships

The Neurology Sub-Group currently provides a broad forum for agencies, voluntary groups and individuals who have experience of one of the many neurological conditions and the challenges of these conditions. The Sub-Group will provide input to the Neurology CPG providing examples of practice across the county which will assist the CPG in ensuring the neurological services delivered in Gloucestershire are to a consistent and high standard.

The Neurology Sub-Group will also feed into the Neurology CPG both as a collective voice and a reference group providing specialist expertise and insight into the current systems and pathways.

A similar link with the Physical Disability & Sensory Impairment (PDSI) Partnership Board will enable those issues, which crosscut other disabilities, to be shared where the PDSI Partnership Board can connect with a wider network.

Be a Part of the Neurology Sub-Group

We want to expand the membership of the Neurology Sub-Group further to get a wider representation and input from as many different neurological conditions as possible. In this way we hope to offer a forum to share experiences and challenges and look wherever possible to offer support and solutions, work towards identifying the similarities and differences between the various neurological conditions so that good practice can be identified and shared as widely as possible.

Membership of the group needs to include people both with a lived and learned experience of the condition, charities and organisations that focus on a particular condition and carers of people who have a condition and live independently in the community.

If we can work together to create that 2-way flow of information between those that set the policies and those the policies impact upon, this will help with co-producing services across the county to reflect priorities and needs of all those involved. Such an understanding will help improve mental, physical and social wellbeing outcomes for those living with and caring for people with a neurological condition.

Contact Us Now to Influence Future Neurology Services

If you would like the opportunity to influence future neurology services, please contact disabilitiescommissioning@gloucestershire.gov.uk for more information about how you can become part of the wider network to support and develop positive outcomes for people with a neurological condition.