

Neurology You Said We Did

**Communication and information about local and national support including third sector
Ability to source own information easily and signposting**

A dedicated website is under development for the NHS WI Neurological Specialist Nurse Service. This will have links to our partners in NHS Greater Glasgow Neurological website which covers a wide range of Neurological services that are not supported locally.
There is also a Neurological Specialist Nurse Service leaflet and business card which is under development. An estimated completion date for these areas of work is December 2024.

Use of local hubs to host information

On completion of the website and leaflet a Poster will be developed and shared across local Hubs signposting to where information can be sourced

**Lack of support networks for families of people affected with a Neuro condition
A listening service as a safe space for people to share experiences one to one or in group**

There is a Community Chaplaincy Listening Service available in WI Hospitals and the community. Support is also available via Neuro Hebrides (which covers all neurological conditions) Long Term Conditions Hebrides and via Western Isles Parkinsons Group. In addition, there is a range of community supports for people with children who have a neurological condition via Action for Children. We also signpost to online supports such as Silver Cloud

Person specific and flexible reviews, not to be too reliant on self-referral needs to have flex in the system

Self-referrals are not available pre diagnosis, this is for patient safety reasons.
Self-referral is available for reviews under Patient Initiated Referral (PIR). Reviews are normally arranged at the previous appointment as part of a patients Care Plan. However, should a patient feel that they require a review either before or after this date, due to a change in their condition, this can be requested directly with the team.

Support for people to make first move to seek support re guidance and capacity, to do on own was considered the most difficult thing for people with a neurological condition

The newly developed webpages will contain links to both local and national organisations who can offer support.

Positive response to prospect of an assistance pathway and wondered what this would look like

The consideration of Assistance Pathways are part of the national review of Neurological Services. This area of development will be considered alongside all the recommendations from the national review.

Services join up to include active health for people with a neurological condition

Public Health are undertaking a Health Needs Assessment Survey on Health and Wellbeing.
Public Health have a range of programmes available that are advertised locally such as Walks for Health. In addition, the Neurological service works alongside partners such as Scottish Ballet re online activity support.

Transition between paediatric and neuro services needs improvement

Paediatric Neurological services are provided by NHS Greater Glasgow and are not part of NHS Western Isles Neurological Specialist Nurse Service.

Is there a contact number in case of an emergency out of hours who should I contact?	A Neurological Specialist Nurse Service leaflet and business card which is under development. An estimated completion date for these areas of work is December 2024. Out with office hours people should contact NHS24 which will direct you to the appropriate service.
Provide an answering machine to leave messages for a return call, what happens when the answering machine message box is full.	There is an answering service which is checked daily Monday to Friday (apart from Public Holidays) All calls are dealt with on a daily basis. There is also a generic email address which can be used for people who do not wish to leave a message on the answering machine
The website is confusing naming Gail Allan as contact for MS Nurse.	Gail Allan, as lead Nurse was named as the main contact as the service transitioned into the generic Neurological Specialist Nurse Service, updates to this information will form part of the newly developed webpages as outlined above
When medications are changed can there be additional follow up from MS Team	There is a template letter that explains medication changes. Patients can contact the Specialist Neurological service for a Patient Initiated Review if they have any concerns
Can review meetings alternate between face to face and telemedicine	Patients are given a choice in methods of attendance this information is documented in their records. For those that are unable to travel telemedicine via Near Me is available
Being advised to look on the internet for information does not feel good this is not accessible to everyone, no literature available	Clinicians can print information and provide to patients as required. Information is tailored to the patients' individual needs. Patients are also able to access information in an alternative format if they have accessibility requirements. This can be arranged via their clinician.
Video link consultations do not work for me due to difficulty with speech and communication, I am unable to travel how can this be improved	Clinicians can be available to provide support for appointments on request
Can information such as blood test results be sent out in letter format as information can be forgotten when given verbally when you have a neurological condition	Yes, this can be provided by the Western Isles Neurological specialist Nurse service, this will be flagged on patients notes. Test results provided by other teams such as NHS GGC should request that this is provided and that this is the patients preferred method of communication.
There should be a written statement showing names and roles of people involved and how to contact them, and a statement outlining what should be expected from the service	A dedicated website is under development for the NHS WI Neurological Specialist Nurse Service. There is also a Neurological Specialist Nurse Service leaflet and business card which is under development. An estimated completion date for these areas of work is December 2024.
Guidance on when it is a GP issue or a Neurological issue and when to seek support from the right person	If the patient is known to the Western Isles Neurological service guidance will be offered at review. Out of Hours advice should be sought from NHS 24 / 111 who will provide triage to refer to the appropriate person
More information /clarity re how to access the service. It is not easy to find information on the NHS Western Isles website	A dedicated website is under development for the NHS WI Neurological Specialist Nurse Service. An estimated completion date for these areas of work is December 2024.

Advice on Nutrition and timings of medication for people with a neurological condition	All medications come with an information leaflet; the prescribing clinician should provide information at time of prescribing as part of decisions on Realistic medicine. Additional information can also be sought from GPs and Pharmacy services. Should a patient require nutritional support a self-referral can be made to the Nutrition and Dietetic service.
A personal plan of action agreed with the Neurological Team would be really helpful	The western Isles Specialist Neurological Service has action plans for their patients which include goals of care as agreed with patients at their meetings and reviews
Is the standard of care and review the same in Uist and Barra as it is for those in Lewis	The standard of service for Parkinsons and MS is the same across all geographic areas of the western Isles. This has been a benefit of the review of the Neurological Specialist Nurse Service