Epilepsy Services in South East Wales

Gwent Healthcare NHS Trust provides epilepsy services for adults and children across Gwent. The adult and children’s services are separate. There are also some differences between the services available in North and South Gwent. Both services are aiming to meet the standards set out in the NICE guidelines (2004).

Children’s Services

Medical Staff

- The Royal Gwent Hospital (RGH) has 2 full-time general paediatricians with an interest in epilepsy. They see many children in (mainly South) Gwent with epilepsy, each holding a weekly epilepsy clinic, one at the RGH and one in Cwmbran. Some children with epilepsy are seen by a paediatrician in a general clinic, but will be referred on if they have complex epilepsy.
- For complex cases, referral is made to tertiary services, i.e. paediatric neurologist at University Hospital of Wales in Cardiff, who holds a monthly clinic at both the Royal Gwent Hospital (RGH) Newport and Nevill Hall Hospital (NHH) in Abergavenny.
- At NHH in the North of the County there is no paediatrician with an interest in epilepsy, although a need has been identified for such a post, there is currently no funding. Children newly referred with epilepsy will be booked into the next available clinic appointment with one of the general paediatricians.
- Children with disability may have their epilepsy managed as part of their overall condition by a community paediatrician.

Current clinic waiting list times

- Epilepsy clinic RGH – new referral 3 weeks, follow-up 3 months
Nursing staff

There are 2.2 WTE Children’s Epilepsy Specialist Nurses, covering the whole of Gwent. Services provided include:

- Training for parents/carers in the administration of emergency medication either prior to discharge from hospital or in their own homes
- Training for school/nursery staff in epilepsy awareness and administration of emergency medication
- Support and information for all newly diagnosed children and their families in the form of home visits or via telephone.
- Ongoing support for all families with a child with epilepsy in the form of home visits or telephone counselling as needed.
- A source of information for all those involved in the care of children with epilepsy, provision of information leaflets, books and videos/DVDs, and details of voluntary organisations.
- A point of liaison for those involved in the care of children with epilepsy.

Child and Adolescent Mental Health Services

There is a higher than average incidence of mental health problems, in particular depression, suicide and behavioural problems, in children and adolescents with epilepsy. Psychology involvement is also helpful for children and adults with non-epileptic seizures. The NICE guideline recommends that the multidisciplinary team involved in managing complex epilepsy should include psychology and psychiatry. These services are available to children in Gwent, but are very limited. There is a waiting list of approximately 6 months for an appointment with a child psychologist and of 3-12 months for a psychiatry appointment depending on the borough.

Adults’ Services

Medical staff

- 1 Consultant Neurologist and 1 Senior Lecturer in Neurology in South Gwent, based at Royal Gwent Hospital, running outpatient clinics at Royal Gwent, St Woolos and Chepstow Hospitals.
- 1 Consultant Neurologist in North Gwent, based at Nevill Hall Hospital, running outpatient clinics at Nevill Hall and County Hospitals.
- Awaiting new appointment of Consultant Neurologist via SIFT funding, with the aim of providing teaching for Cardiff medical students within Gwent. Therefore this post will have limited benefit in terms of increasing existing service provision.

Waiting times – NHH
- Epilepsy clinics held twice a month
- New patient: ‘Urgent’ - 4 months / ‘routine’ – 5-7 months
- Follow Up patients – 3-4 months

Waiting times – RGH

- General Neurology waiting list, new patient: ‘Urgent’ – 4 months / ‘Routine’ – 8 months
- Follow Up patients - 4 months

Nursing

- One full-time Epilepsy Specialist Nurse, based at Royal Gwent Hospital, running outpatient clinics at Royal Gwent, Nevill Hall, County and Chepstow hospitals

The adult Epilepsy Specialist Nurse offers a ‘Whole of Gwent’ service that includes the following:

- Nurse led epilepsy clinics for new and follow-up patients, including epilepsy/pregnancy clinics held monthly in Antenatal Departments of both Nevill Hall and Royal Gwent Hospitals.
- Offer home visits to limited number of patients meeting established criteria, i.e. newly diagnosed and patients with profound/multiple learning/physical disabilities where appropriate.
- Provides training and education to patients and their carers. Acts as an information resource to other professionals as required. Has established a training/education schedule to ‘frontline’ nursing staff within A&E and MAU departments in both Royal Gwent and Nevill Hall Hospitals. Several ‘Neurology’ sessions have been provided for GP’s organised by Local Health Boards. These sessions included presentations on epilepsy.
- Maintain links with local Epilepsy services run by the Voluntary sector such as Gwent Epilepsy Group, as well as regional and national epilepsy organisations.

Nurse led clinics

- At Royal Gwent and Nevill Hall Hospitals the nurse led epilepsy clinics are mostly overbooked and there are no available appointments for approximately 4-5 months.

Investigations

There is no definitive test for epilepsy. Diagnosis is made following a detailed and time-consuming patient history and clinical examination. Hence outpatient appointments for new referrals are very lengthy, compared to those for other medical conditions. There are some tests which may aid diagnosis. These include magnetic resonance imaging (MRI) and computerised tomography (CT) scans as well as electroencephalograms (EEGs). The approximate waiting times for a routine referral are shown below. Urgent referrals are seen sooner dependant on need. The current EEG waiting time is very good and meets the NICE recommendation.
<table>
<thead>
<tr>
<th>Test</th>
<th>Where available</th>
<th>Routine waiting time</th>
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<tbody>
<tr>
<td>CT scan</td>
<td>RGH</td>
<td>4 weeks child</td>
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<tr>
<td></td>
<td>NHH</td>
<td>5 months adult</td>
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<tr>
<td></td>
<td></td>
<td>6 weeks</td>
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<tr>
<td>CT scan (under general anaesthetic)</td>
<td>RGH children only</td>
<td>2-4 weeks</td>
</tr>
<tr>
<td>MRI scan</td>
<td>RGH</td>
<td>Data unavailable</td>
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<tr>
<td></td>
<td>NHH</td>
<td>4 months</td>
</tr>
<tr>
<td>MRI scan (under general anaesthetic)</td>
<td>UHW (Cardiff) children only</td>
<td>4 months</td>
</tr>
<tr>
<td>Standard EEG</td>
<td>RGH</td>
<td>2 weeks</td>
</tr>
<tr>
<td></td>
<td>NHH (limited service)</td>
<td>2 weeks</td>
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<tr>
<td>Sleep EEG</td>
<td>RGH</td>
<td>Data unavailable</td>
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<tr>
<td>Ambulatory EEG</td>
<td>RGH</td>
<td>Data unavailable</td>
</tr>
<tr>
<td>Video telemetry</td>
<td>UHW (Cardiff) adults only</td>
<td>Data unavailable</td>
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</tbody>
</table>

Due to the need for patients to lie very still during an MRI or CT scan children and some adults with learning difficulties may not be able to cooperate and therefore need the procedure to be done under general anaesthetic (GA). CT scans for children are done under GA at the RGH, but this is not funded for adult patients. Those children requiring MRI scan must travel to Cardiff – there is no funding for adults to have scans under GA.

There is no EEG department at Nevill Hall Hospital in the North of Gwent, however a once weekly EEG clinic is held there. In Newport the EEG department is at St. Woolos Hospital.
A standard EEG gives limited information and often a more prolonged recording of electrical activity in the brain is called for. Ambulatory and sleep deprived EEG are available within Gwent, however the more useful video telemetry where a patient is videoed during a more prolonged EEG recording (24-48 hours) is only available for adults in Cardiff and is not available at all for children in Wales. Children in Gwent requiring video telemetry are usually referred to Oxford.

The Future

- It is hoped that funding will become available for a third general paediatrician with an interest in epilepsy, to be based at NHH in Abergavenny.
- The current Children’s Epilepsy Team in South Gwent are planning to set up a clinic for teenagers with epilepsy, to run after school.
- It is hoped that a ‘transition clinic can be set up to allow smooth handover of patients from the children’s to the adults’ service. This will however require extra funding.
- MRI scans under general anaesthetic need to be made available in Gwent to both children and adults who need this service. This requires funding.
- Video telemetry needs to be made available to children across South Wales.
- The adult epilepsy nurse has highlighted the need for a second adult epilepsy specialist nurse, due to the large numbers on her case load and the large geographical area covered. A large part of this role would be to liaise with primary care. There is currently no funding available for this post.
- Further psychology/psychiatry services are needed, preferably with expertise in epilepsy.
- The All Wales Standards for Paediatric Neuroscience Services are currently being developed by the Welsh Assembly. This will have implications for future development of services for children with neurological conditions including epilepsy.

Diane Flower, Lead Children’s Epilepsy Specialist Nurse
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