Report and Recommendations to Jane Hutt, Minister for Health, and to the National Assembly for Wales from the National Epilepsy Workshop 2003
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Feedback from Workshops and individual participants

Paediatric submission (RCPCH document and document on managed clinical network)
Report on Epilepsy Workshop

The aim of the epilepsy workshop was to inform a report to Jane Hutt, the Minister for Health, and the Welsh Assembly Government with recommendations for a future epilepsy strategy for Wales.

The format of the one-day workshop was to:

- Highlight the issues raised in the National Audit of Epilepsy-Deaths
- Hear a range of expert perspectives on the way forward
- Facilitate 5 workshop discussions of stakeholders
- Receive feedback of consensus statements from each workshop
- Receive feedback from individuals attending the workshop

The workshop was organised by Epilepsy Bereaved with sponsorship from the National Assembly for Wales and working in partnership with Epilepsy Wales, Epilepsy Action and Epilepsy Gwent. The report is authored by Jane Hanna, Director of Epilepsy Bereaved, but is endorsed by the All Wales Epilepsy Forum (Epilepsy Wales, Epilepsy Action, Epilepsy Bereaved and Epilepsy Gwent) and the expert clinicians who participated in the Workshop. The All Wales Forum was established as a result of the joint working between organisations during and after the workshop.

The issues highlighted in the Audit Report

The National Sentinel Clinical Audit of Epilepsy Related Deaths is the last in a series of six national reports on epilepsy since 1953 (Ministry of Health 1953; Cohen Report 1956; Reid Report 1969; Winterton Report 1986 and CSAG 2000) drawing attention to very serious deficiencies in epilepsy services provision. Although 7/10 people with epilepsy and their families should be seizure free with modern drug treatments of epilepsy there is a significant treatment gap. There is a known misdiagnosis rate of about 20% and recent high profile inquiries e.g. Holton Inquiry, Leicester (misdiagnosis of children) and the Findlay Inquiry (judicial determination on a sudden death of a 16 year old in Glasgow) have highlighted the high medico-legal risks in relation to current epilepsy management.

The audit report highlighted shortfalls in services, care and support for people with epilepsy. Some of the key issues identified were:

- Lack of management plans or structured review for people with epilepsy.
- Lack of re-referral to a specialist by the general practitioner for individuals needing reassessment.
- Lack of discussion with patients and families of the fatality risk of seizures.
- Deficiencies in the overall quality of epilepsy care in general practice and hospitals, on a range of issues. (54% of adults and 77% of children, received inadequate care, and 42% of epilepsy deaths annually were potentially avoidable).

College of Health research into the experiences of bereaved families in parallel with the National Audit mirrored these findings, but also highlighted
Inadequacies in the system for the investigation of death
Lack of contact, information and support to families after a death

**Expert Perspectives**

Presentations were given at the workshop by:

- Leads on the National Audit of Epilepsy Deaths
  
  Dr Richard Appleton, Professor Stephen Brown, Professor David Fish, Ms Jane Hanna, Dr Henry Smithson

- Francis Daw, (Epilepsy voluntary sector)
- Dr Ajay Thapar (Primary Care)
- Dr Dave Smith (Epilepsy services, North Wales)
- Dr Phil Smith (Epilepsy services, South Wales)
- Dr Richard Appleton (Children)
- Professor Mike Kerr (Learning disability services)
- Ms Vicki Myson (Nursing services)

Material from the presentations has been included in the background to the recommendations to this report.

**Workshops**

Workshops were set up to answer the following four questions:

1. What should be the main objectives of any epilepsy strategy
2. What short-term measures should be recommended
3. What medium to long term measures should be recommended
4. What should be the role of the Welsh Assembly

Workshops reported back to the main meeting, but the results were written up and are attached as the appendix to this report.

80 Participants at the one-day workshop were divided into 5 workshops led by the following facilitators:

Workshop 1 - Mike Kerr
Workshop 2 - Phil Smith
Workshop 3 - Dave Smith
Workshop 4 - Jane Hanna (patients, carers and bereaved relatives)
Workshop 5 - Cathy White (Children)
Recommendations

The recommendations for an epilepsy strategy in this report are made by the All Wales Epilepsy Forum after consultation with the expert speakers and workshop facilitators participating at the conference.

We recommend that the Welsh Assembly should produce an epilepsy strategy and action plan with measurable objectives and formal monitoring aimed at delivering the series of action points recommended by this report.

The short-term objectives should be achieved within two years with medium to longer term objectives delivered within ten years.

The factual background to the recommendations is taken directly from the evidence presented to the workshop by expert speakers.

The recommendations themselves are based on the level of consensus that emerged from both the workshop sessions and individual feedback following the workshop.

The recommendations are based upon the following principles:

- There should be equity of services across Wales, so that there should be no difference in the care received in the different health economies of Wales.
- There should be integration of the existing services.
- There ought to be information on epilepsy more freely available and better integration between NHS services and the voluntary sector.
- The needs of children with epilepsy should be recognized in any strategy. They should have their own Strategy with links to the strategies for adults and those with learning difficulties.

The results of the 5 workshops and individual feedback from people attending the workshops are in the Appendix to this Report.
Recommendations: Adults

Ten Objectives for the short-term

The measures listed below are suggested because they aim to make best use of existing resources and to harness the expertise and resources currently available within Wales. Pump-priming and support of these initiatives is however essential from health or education budgets relating to development of the voluntary sector in Wales:

To promote education and awareness on epilepsy

1. Education of Health Professionals.

Devise and implement an education plan aimed at all health professionals managing people with epilepsy. To include education about the risks of epilepsy for patients with ongoing seizures, including sudden unexpected death in epilepsy (SUDEP) and on communication about risk. Information about risk should be available as part of information on epilepsy.

2. Education of the general public, employers and others

Support a positive high profile campaign spear-headed by the All Wales Epilepsy Forum targeted at health professionals, managers, media, schools and employers

To promote local integration of epilepsy services

3. Development of local action plans

There should be a national requirement on all local NHS organizations to develop a 3 - 5 year action plan and to review their policies and practices for the management of epilepsy and epilepsy-related death in the light of the audit findings and the NICE epilepsy guidelines (once published) and to address any shortfalls in services as part of local planning arrangements and priorities.

National Support for local NHS organizations and clinicians to support this is suggested through the following initiatives:

(i) Welsh Assembly sponsorship for a National Welsh Epilepsy Forum to bring key stakeholders together.

- To give leadership and promote awareness of epilepsy
- To foster partnership working
- To support local development of services
- To hold a register of health professionals with an interest in epilepsy in W ales
- To maintain a Directory of Voluntary Services for Epilepsy in W ales
- A central national contact for resource and support tools for local development of services. The Forum could identify example good practice tools e.g. GP templates for
the GP contract, epilepsy register template, Epilepsy Care Pathway, Clinical Audit, Protocols listed under iv below.

(ii) Local Epilepsy Steering Groups to champion epilepsy and engage Trusts, Health Boards, Social Services, Clinicians, Voluntary Sector in the development of a care pathway for epilepsy and development of integrated services through informal/formal managed networks

- To ensure the best use of existing resources
- To promote the inclusion of the voluntary sector and other non-clinical stakeholders
- To include specialist sub-groups - children, learning disability, women and young people.

(iii) National and local promotion of the Action Plan with support to Primary Care Development with a view to ensuring there is an epilepsy register and structured annual review

This could be achieved making use of the existing expertise in the Welsh Epilepsy Forum

- Pro-active promotion of epilepsy quality marker to GPs with support materials
- Free national leaflet for people with epilepsy and carers giving essential information and signposting to all epilepsy voluntary sector services in Wales to be widely available in GP surgeries and hospital departments
- Access to resources and tools for the primary care team/Local Health Boards
- Primary Care Collaborative Project aimed at supporting local learning by addressing good and bad practice (using user and clinical feedback) and tailored support e.g. if poor educational input to clinicians with protected time and/or liaison nurse support

(iv) Protocol development

The development of appropriately managed shared care protocols between GPs and hospital specialists to help to reduce treatment failures.

Epilepsy Protocols should be developed for:

- essential record-keeping
- Annual Review
- copy of letters to patients
- A&E and other departments that may see ‘first-seizures’
- Triage to ensure fast-track of new patients and established patients needing priority
- discharge and re-referral
- ensuring results of investigations available before consultations
- women with epilepsy
- management of SUDEP.
To promote timely access to services

4. On-going National review of workforce requirements for epilepsy

Mapping exercise of existing resources and acceleration of number of posts. Research and Development function to review needs of and resources available to epilepsy and outline the actions needed to increase in the medium term the number of specialist posts (including neuro-surgery) to achieve one consultant with an interest in epilepsy, one epilepsy specialist nurse and one GP with a specialist interest in epilepsy per 100,000 population.

5. New Seizure Clinic in every hospital

Each hospital should have a rapid access new seizure clinic

6. Improved Access in areas without epilepsy specialist

Initiatives to improve access e.g. pilot of use of video-link referrals and telemedicine to increase access (as developed in Northern Ireland), initiative to improve access to speed of access to tests/results.

7 Structured Annual Review

Ensure all patients have a structured annual review of their epilepsy, their medication and other needs with either their GP or an epilepsy specialist as required

To develop support to people with epilepsy, carers and bereaved relatives

8. Access to Voluntary Sector

Support access to the voluntary sector by ensuring the Directory of Voluntary Agencies is disseminated to Primary Care and all front-line agencies (e.g. A&E)

9. Provide information to people with epilepsy

Ensure the production and circulation of a free leaflet for people with epilepsy and carers with signposting to epilepsy voluntary sector in Wales and to be made widely available in surgeries and hospital

10. Closer working with and support to the voluntary sector

Development and support to the voluntary sector in service planning and in delivery of information and support to patients/carers/bereaved families.
Ten Objectives for the medium to longer term

**Reduction in epilepsy-related deaths**

1. Achieve a 40% reduction in epilepsy-related deaths

**Education on epilepsy**

2. Embedded education on epilepsy (including SU DEP) for all health professionals at under-graduate and post-graduate levels

3. Inclusion of epilepsy in education and communications strategy and action plans to ensure awareness by non-medical professionals, the public and in community forums e.g. schools

**Timely access to care**

4. Increase number of specialist posts (including neuro-surgery) to achieve one consultant with an interest in epilepsy, one specialist nurse and one GP with a specialist interest in epilepsy per 100,000 of the population

**Integrated Services**

5. Ensure implementation of locally developed action plans to deliver services as outlined within the NICE clinical guidelines for the diagnosis and management of epilepsy

6. Creation of dedicated epilepsy clinics accessible to patients and carers, epilepsy services organized through a Managed Clinical Network with recognition of the needs of special groups

**Quality assurance**

7. Ensure there is an effective annual National and Local Audit of epilepsy services

8. Ensure there is an effective reporting structure and monitoring for epilepsy-related deaths

9. Ensure there is an on-going research and development strategy in to improving epilepsy services

**Support for people with epilepsy, carers and bereaved relatives**

10. Ensure access to voluntary sector support workers for people with epilepsy, carers and bereaved families
Recommendations: Children

These are supplementary to those for the adult services

Four Objectives for the short-term

To promote local integration of epilepsy services

1. Children's network

Develop a children's network as part of a South Wales Epilepsy Network/Forum - this would involve people with an interest in epilepsy in adults, children and those with a learning disability, and be a forum for communication and exchange of information and ideas on best practice and new developments. The children's section would develop audit tools and information resources.

2. Acute and community sectors

Better integration of services for children across the acute and community sectors, also including social services and the LEA, and including a smooth transition to services for adults with epilepsy, either within the neurology “set-up” or the Learning Disability “set-up”.

To promote education and awareness on epilepsy

3. Study days

Facilitate study days on paediatric epilepsy.

To promote timely access to services

4. On-going National review of paediatric workforce requirements for epilepsy

Mapping exercise of existing resources and acceleration of number of posts. Research and Development function to review needs and resources of paediatric epilepsy and outline the actions needed to increase in the medium term the number of specialist posts, epilepsy specialist nurses, and doctors with an interest, both at paediatric and paediatric neurologist level, to the levels in the RCPCH submission (see Appendix D)
Five Objectives for the medium to longer term

**Education on epilepsy**

1. Embedded education on paediatric epilepsy (including epilepsy-related deaths) for all health professionals at under-graduate and post-graduate levels

**Timely access to care**

2. To increase the number of specialist posts, epilepsy specialist nurses, and doctors with an interest, both at paediatric and paediatric neurologist level, to the levels in the RCPCH submission

**Integrated Services**

3. Formal managed paediatric clinical networks should be developed along the lines suggested by the RC PCH/BPNA in their advice to the Chief Medical Officer of England. This network will to be able to audit its practice and develop guidelines that would be owned by all the professionals.

4. Improved access to investigation services

**Quality assurance**

5. Create a database of all children with epilepsy
Identification of Major obstacles to system-wide improvement

- Scarcity of clinicians interested in epilepsy and workforce issues
- Scarcity of professionals in other sectors with an understanding of epilepsy
- Existing management performance measures exclude epilepsy and emphasis on access targets distort clinical priorities
- Many people with epilepsy and families disengaged from services
- Rural services

1. Scarcity of Trained Professionals workforce issues

Existing national guidance indicates waiting times of 4 weeks for new patients. This is essential because ‘first seizures’ are a medical and social emergency. Correct diagnosis and treatment is essential for continuation of normal family life but also because seizures are potentially fatal. Suspected new epilepsy accounts for 24.3% of neurology referrals and of these 28% will have epilepsy. This means that any first seizure service must have capacity to see four times the predicted incidence of new patients within its catchment.

Existing national guidance also indicates a 12 monthly annual review. Within the prevalent population there are many people who have been misdiagnosed while those with epilepsy are often sub-optimally treated, ill informed and neglected. Research also showed that most established patients not under shared care merited specialist review as 25% with active epilepsy achieved a one year remission after being treated in a specialist clinic.

The resources required to provide a service are recommended as 1 Consultant with a special interest in epilepsy and one epilepsy specialist nurse per 100,000 population.

Existing Capacity:

There are over 20,000 people in Wales who have epilepsy. It is more than 2 times more likely in the poorest groups in society (BMJ October 2002).

There is an acute shortage of neurologists in Wales. There are only 11 neurology consultants in Wales amounting to the worst patient/specialist ratio in Europe (1:1,800 epilepsy sufferers and 1:270,000 head of population). With a population of 2 million South Wales has only 1 neurologist per 200,000 (the 2nd lowest in the UK).

In South Wales more than 90% of the people diagnosed with epilepsy (14,000) have not had any specialist contact in the last 12 months. Current waiting times are over 18 months for routine appointments, 12 months for ‘soon’ and 2 months for ‘urgent’. There is a serious inequity here between North and South Wales because the North gets its epilepsy service from England where the maximum wait allowed is 6 months compared with a maximum waiting time of 18 months allowed in South Wales. Neurology Clinics, however, currently do not have the capacity to process an unplanned avalanche of referrals and it is therefore important that there are plans for managing demand and increasing capacity in the short-longer term.
There is an acute shortage of epilepsy specialist nurses in Wales. There are only 7 epilepsy specialist nurses (adult and paediatric) for all of Wales. This compares with 15 nurses dedicated to diabetes in Cardiff alone.

Epilepsy management is undeveloped in primary care relative to other chronic conditions with a similar prevalence e.g. insulin dependent diabetes. The Focus Group Study – Wales 2003 found that although half of GPs accepted responsibility for epilepsy care many worried about their lack of knowledge. The use of an opportunistic prompt and reminder card was an example of a simple strategy that improved process measures of care. Patient satisfaction however required understanding by GPs of the importance of patient concerns and access to better information and advice to empower their own choices.

There are specific learning disability clinics in Cardiff, Carmarthen and Brecon but from August 2003 there will be no epilepsy specialist learning disability nurse in Wales.

There is also an acute shortage of trained and knowledgeable staff in the public sector able to respond to epilepsy seizures making this a high risk area in terms of health and safety.

2. Distortions from targets

Focus on waiting times for elective surgery and A&E are obscuring the needs of the large part of the population suffering from long-term chronic conditions. 60% of GP consultations and use of hospital beds are related to chronic disease yet there is a relatively low recognition of this within health care debate and decisions on priority in the allocation of resources.

Within the neglected area of chronic disease management, epilepsy is particularly neglected with lack of development of initiatives or services compared with conditions with a similar prevalence e.g. insulin dependent diabetes.

To move epilepsy services forward in this context requires national and local targeting or an abandonment of targets in other areas so that there is a level playing field for epilepsy.

Priority should be accorded to epilepsy because of

- Inequity in the treatment of this condition
- Some quick (and cost-effective) wins are possible for this condition
- Premature avoidable deaths with 2/3 of these under 50 years

3. Patients and Carers disengaged

Most people with epilepsy and their families have a negative attitude to the level of service being provided and many are disengaged from the service. The most common problems experienced by patients and families are waiting times; lack of basic information and support and ignorance of employers, families and associates.
Obstacles to change in children’s services

Obstacles to change in children’s services mirror those in adult services.

Children’s services are, however, particularly neglected.

GP targets in the new GP contract only relate to the over 16s.

There is a serious problem of lack of resources dedicated to children’s’ services. There are a significant number of general paediatricians who are interested in epilepsy, but there is a real problem in the lack of support for these professionals in particular the lack of dedicated time to work on development of existing services.

There is an even more acute shortage of trained clinicians. This is set out in detail in the Appendix to this report as part of a document produced by the RCPCH/BPNA (See appendix D and E).
Existing National Initiatives

The way forward needs to be considered in the light of two major national developments:

- The National Institute for Clinical Excellence (NICE) is developing evidence based clinical guidelines for the diagnosis, management and treatment of epilepsy by June 2004. This will provide evidence based best practice for epilepsy services.

- The GP Contract introduces an epilepsy register and the requirement to record seizure frequency and review medication for any practice wishing to secure the 16 points under the contract. This gives an opportunity for primary care to develop simple epilepsy management measures, but practices will only act if they are sufficiently motivated and supported.

The Audit showed that existing guidelines were not being implemented in practice. National measures e.g. NICE guidelines will not be effective in improving epilepsy care unless plans are in place to ensure implementation and monitoring. There needs to be national investment to ensure that managers and clinicians are motivated and supported to put these measures into effect.

The Role of the National Assembly for Wales

Stakeholders are looking to the National Assembly for Wales to:

- Give leadership by evidencing commitment to taking forward the recommendations from the Workshop
- Provide national resources to pump-prime key initiatives identified for the short-term and medium term.
- Provide resources to map existing service provision and identify workforce and other resources required to meet objectives
- Address health inequalities by improving the funding of services for people with epilepsy. Health inequalities between the North and South of Wales need to be urgently addressed. The funding for epilepsy services should be equivalent to that of people of diabetes i.e., they need to look at the number of diabetes specialist nurses and diabetes specialists there are in Wales, compare them to the number of specialist nurses and specialists in epilepsy, and act accordingly.
- Formal monitoring of the strategy
- Be involved in the commissioning of services and should define the role of Commissioning Authority.