

## **Mind the gap: improving the services for children with complex epilepsy**

Children with epilepsy and psychiatric co-morbidities such as learning difficulties and behavioural problems present clinicians with a variety of issues that need an integrated approach involving a multidisciplinary team of health care professionals integrated with social services to provide successful management. However, traditional models of care, the way the health service and social services are structured and even medical training inhibit such co-operation and often leave carers exasperated as they try to find their way through a maze of disjointed care.

The situation prompted Sanofi-Aventis to organise a one-day meeting in London on March 26<sup>th</sup> 2009 to bring together paediatric epilepsy specialists, paediatric psychiatrists, carers of people with epilepsy, nurse specialists and social services professionals to begin the conversation about how things could be made to work better, with the ultimate aim of influencing national guidelines.

In his introduction, chairman Professor Brian Neville, Professor of Childhood Epilepsy at UCL Institute of Child Health and The National Centre for Young People with Epilepsy, said that children with epilepsy may have a whole host of other problems but often the focus for medical management is the seizures while other problems, which may be seen by carers as causing the greatest problems in terms of quality of life, may be pushed into the background. It's almost a case of let's sort out the seizures first and the other problems will largely go away, he commented.

### **Table 1.** Spectrum of problems experienced by children with Worster-Drought syndrome

1. Early difficulties feeding, sleeping, irritability, responsiveness
2. Motor disorder- mild/moderate but context
3. Epilepsy
4. Behaviour/psychiatric problems: ADHD, mood, autistic spectrum
5. Cognitive impairment
6. Speech and language, communication systems
7. Dribbling and glue ears
8. Respiratory infections
9. Feeding problems: dysphagia, gastro-oesophageal reflux, malnutrition
10. Genetic counselling
11. Service implications: medical, family/social, education, involve parent support group

Professor Neville used the example of problems that children with Worster-Drought syndrome (bulbar cerebral palsy) can experience (see Table 1) to underline why a multidisciplinary team approach is crucial to care. Professor Neville felt that some of the issues that need addressing to improve co-operation between the specialties include: paediatricians are variably trained in behavioural disorders; child psychiatrists are largely not trained in paediatrics or neurodisability (including epilepsy); child psychiatry is usually too slow, too selective and separated from the rest of services, and child psychiatry is often perceived by families to be 'intrusive' and not relevant. The intrusive element arises from a "dynamic" or family therapy style of management which may or maynot recognise that children with early onset brain dysfunction may have organic psychiatric disorders which do not arise from their early experiences / management.

Professor Neville suggested that the way forward would be for child psychiatrists to have one year paediatrics training and one year paediatric neurodisability (with epilepsy) training, while paediatricians should have a year of child psychiatric training integrated into training. Clinical services between paediatrics and psychiatry should be integrated.

### **Training issues**

The issue of training was explored in a debate of the motion: 'Does this house agree that current structures and training in child psychiatry and paediatric neurology do not provide an adequate service for children with epilepsy and additional impairments and for their carers?'

Speaking for the motion Professor Christopher Gillberg, Professor of Child and Adolescent Psychiatry, University of Göteborg and Consultant/Visiting/Honorary Professor, NCYPE and UCL -Institute of Child Health in London, contrasted the training in Sweden with what he had been able to find out about training in the UK Clinicians cannot become a child psychiatrist in Sweden unless they have taken at least one year of paediatrics which should preferably include six months child neurology. That is followed by one year adult psychiatry and three years of child and adolescent psychiatry. Child and adolescent psychiatry has been a specialty in its own right for 50 years or more and has its own Royal College so it is not a subspecialty of adult psychiatry. Paediatricians have to have at least half a year of child and adolescent psychiatry which will probably increase to one year. About 30 per cent of child psychiatrists in Sweden are also paediatricians and just under 1 in 100 of the 350 child psychiatrists in Sweden come from adult psychiatry. There are many neuropsychiatric teams across the country that include psychiatrists, paediatricians, neurologists and clinical psychologists. They work in the same building and are run by the same organisation bringing benefits to children with epilepsy, ADHD, autism etc.

Professor Gillberg said his understanding was that all child psychiatrists in the UK come from adult psychiatry and they do not have to have paediatric training. 'I think this is absolutely incredible: how can you deal with children without having training in

children.’

Equally there was no required training for paediatricians in child psychiatry in the UK. However, as Consultant Developmental Paediatrician, and chair of the Royal College of Paediatrics and Child Health Specialist Advisory Committee (Mental Health), Dr Daphne Keen, explained paediatricians are to be offered training for a new subspecialty of paediatric mental health (PMH) which being developed after the 2008 (CAMHS) in full – Child and Adolescent Mental Health Services review recommendation that ‘there is a need for better basic knowledge of child development and MHPW across the children’s workforce. The Government should ensure that all bodies responsible for initial training provide basic training in child development and (MHPW) in full. This should be in place within two years.’

Dr Keen emphasised that a consultant in PMH was envisaged as a paediatrician with mental health training and not a psychiatrist. Dr Keen explained that the role of these consultants was envisaged as:

- Enhancing paediatric management and collaboration with mental health in
- Removing artificial, arbitrary, barriers between paediatrics and CAMHS, as well as duplication of input
- Improving links between services; work across boundaries by delivering training, facilitating referral pathways

In future, Dr Keen speculated, there may be scope for merging the CAMHS and paediatric services in a similar way that orthopaedics and surgery are integrated.

Dr Paramala Santosh, Head of the Centre for Interventional Paediatric Psychopharmacology (CIPP), Great Ormond Street Hospital for Children, London, and Senior Lecturer in Child and Adolescent Psychiatry, Institute of Child Health, London, and Institute of Psychiatry, London, argued that UK training in child psychiatry was good enough to provide adequate care, but service delivery was another matter.

‘I don’t believe you have to have one year’s training in paediatrics to know how to treat children because you could work with children in intensive care and all sorts of settings and still not be able to manage a child who has actually got autism,’ He said. In fact a background in adult psychiatry could be an advantage. A lot of child psychiatry involves working with families so experience with adults is important. Often psychopathology in parents or carers has a huge impact on the way children behave. So, Dr Santosh reasoned, being able to pick up problems in adult carers and deal with those was going to be very important.

In terms of service delivery, Dr Santosh agreed that it could be better. One way to achieve that would be to improve communication between neurologists, paediatricians, psychiatrists and social and educational service professionals. Use of information technology, video conferencing to facilitate virtual meetings and the like might be a way forward, he suggest

## **One family's story**

Whether it's a problem caused by training or lack of communication the disjointed nature of services for children with complex neurological and psychiatric problems is real. The situation was vividly and painfully illustrated by the experience of Ann Maxwell whose son Muir had his first seizure aged four months and was not diagnosed until age seven years with severe myoclonic epilepsy of infancy (SMEI) or Dravet syndrome. But his seizures were not controlled until age 10 years when stiripentol, which has a European Orphan Drug licence for Dravet syndrome, was added to Muir's drug regimen.

The specific features of Dravet Syndrome differ in every child. However, almost all have their first seizure in the first year of life. Usually this is in a febrile illness. Brief febrile seizures are common in childhood, affecting about 4 per cent of children. The first seizures in Dravet Syndrome are often prolonged and characterised by generalised clonic or hemi-clonic seizures. Sometimes an infant's first febrile illness is after their first set of immunisations, and if a seizure occurs at this time families and some physicians may understandably, but mistakenly, blame the immunisation for the epilepsy and subsequent developmental problems.

As a result of their experiences Ann and husband Jonny established and run the Muir Maxwell Trust ([www.muirmaxwelltrust.com](http://www.muirmaxwelltrust.com)) a paediatric epilepsy charity which aims to make a difference by providing children and their carers with practical support and by speeding up what can be a frustratingly slow diagnostic process.

Not wishing to offend those she criticised, Ann gave a graphic account of her family's medical journey to find a diagnosis and treatment for Muir. Her comments summed up the problems the health service and social services have in delivering effective care for children with complex needs. 'In the course of our journey we met many people all specialists in their own field; some were outstanding, true pearls, alongside others who were much less helpful, and some were positively obstructive. The support at times was prolific but never co-ordinated and at times chaotic.'

With so many people involved in Muir's care life became an endless stream of hospital appointments: 'so much duplication and a total lack of sharing of information; for me it was about deleting the useless ones and maximising our exposure to the good ones.'

But it is not just the fault of individuals that care is not delivered optimally. Some pearls are hindered by the system and sometimes resources are denied or just not available and the situation is set to become worse in the recession, Ann said.

Ann Maxwell said better co-ordination might be achieved through a key worker. But it might help to adopt an intervention prevention approach so that problems that are known to be likely to occur, such as speech and language difficulties, can be identified and planned for before they begin to have a significant impact. So an agenda is set at the point of diagnosis that determines care throughout a patient's

treatment. The care could be co-ordinated by a key worker and sometimes that key worker could be the patient's carer.

Dr Brian Jacobs, Consultant Child Psychiatrist at The Maudsley Hospital and Honorary Senior Lecturer at the Institute of Psychiatry, London, describing his work with children with neurological and psychiatric problems, a small number of whom have epilepsy, commented that he was particularly glad to have a social worker as part of his team who does a lot of the liaison work with social services. 'She talks their language and can learn enough of our language to ask the awkward questions of me until I explain in a way that she feels she can discuss with social services.' Dr Jacobs felt that the social worker was much more effective in getting some action out of social services than he would be.

Dr Santosh, gave a clinician's perspective on managing children with complex co-morbid neurological and psychiatric problems based on his experience at the Centre for Interventional Paediatric Psychopharmacology (CIPP) which manages children in four main clinics:

- Complex Developmental Neuropsychiatry Clinic: Children or adolescents with complex neuropsychiatric disorders, especially those with combined developmental disorders
- Childhood dementias clinic: Children and adolescents with childhood dementias in the context of genetic or medical disorders (eg metabolic disorders such as Hurler's syndrome, Hunter's syndrome, Sanfilipo, Gaucher's disease, etc)
- Childhood traumatic brain injury psychopharmacology clinic: Children and adolescents with acquired brain injury who have behavioural problems are assessed and treated.
- Complex paediatric psychopharmacology clinic: Children and adolescents who have developed unusual or serious side-effects.

The prevalence of ADHD in epilepsy is three to five times greater than normal. Co-morbidity in ADHD with epilepsy is similar to that in ADHD without epilepsy reported in the literature.

Dr Santosh commented that managing children with co-morbid epilepsy and ADHD presented a number of problems and required a lot of work to persuade families that behavioural approaches to tackle the symptoms of ADHD were as important as treating the epilepsy. Equally giving medication for ADHD and expecting that to solve learning problems was not going to work because of the impact of seizures on cognitive abilities.

In children with ADHD and epilepsy or possible epilepsy neurologists and paediatricians seem happy to prescribe medication for behavioural symptoms but reluctant to prescribe antiepileptics if they are not absolutely sure that there is epilepsy. Dr Santosh said the situation had become worse in recent years which he found hard to understand, because in his experience at least 50 per cent of children

who have behavioural symptoms in the context of epilepsy or suspected epilepsy show significant behavioural improvement when prescribed an anti-epileptic. (Not my experience but Santosh said it!)

### **Good practice**

Despite the problems of achieving the right care for those with complex epilepsy there are examples of good practice where teams have achieved co-ordinated care. The National Centre for Young People with Epilepsy (NCYPE; [www.ncype.org.uk](http://www.ncype.org.uk)) a national charity providing specialist services and support for children and young people aged 5 to 25 years with epilepsy and other neurological conditions, including Asperger syndrome, autism and a range of learning difficulties. The centre takes a multidisciplinary approach to assessment and care and involves the family as well as the patient in putting an individualised package of care together. Residential, school and home visits are done as part of the assessment process.

Conducting assessments over a number of days means that co-morbid problems such as ADHD, autism spectrum disorder (ASD), etc, and the impact they are having on patients and their carers can be identified and appropriate care, such as referral to a child and adolescent mental health service team, can be arranged.

So, for example, for many children with learning difficulties and epilepsy who come for assessment because of difficulties managing behaviours the focus has been on the epilepsy when in fact the family is more concerned about the behavioural issues related to other disorders which really impact on quality of life. In these cases NCYPE is able to recommend referral to CAMHS for ongoing management and support.

### **Predictable problems**

Professor Mike Kerr from Cardiff University underlined that many problems that people experience in adulthood can be predicted from aetiology and epilepsy syndrome as well as problem that arise in childhood such as feeding problems that are likely to continue into adulthood rather than go away as a patient progresses from paediatric and children's to adult services care.

Physical care is particularly important because nothing is there for people. About 80 per cent of children with neurodisability will have epilepsy into adulthood. So needs are predictable and should be planned for, Professor Kerr said. For example, a study by Ogawa found that 39 per cent of children with Lennox Gastaut syndrome had early appearance of swallowing difficulty. And 29 per cent had progression of mental deterioration. Despite that many needs children have will not be catered for when they reach adulthood. A good example is dysphagia. For example, children who have needed PEG feeding and can be predicted to continue needing it in adulthood will often find that services are not available when they become adults.

Professor Kerr said we should be ensuring transition if nothing else because of the National Sentinel report which found:

- 50 of the 180 deaths were people with learning disability
- Had seen a consultant less often in last three visits
- Only 2 saw a learning disability specialist
- Three were lost in transition

There are real barriers to transition: paediatric team not letting go feeling adult services inferior; patient finds it hard to come to terms with adult doctors; the family – concerns over adult environment and loss of control; the adult team – less used to paediatric conditions and MDT work.

Professor Kerr concluded that transition was a key moment in the health pathway. It was not simply about transfer of care. The adult needs of children with learning difficulties and epilepsy can to some degree be predicted.

### **The meaning of quality of life**

Dr Rod Scott, Reader in Paediatric Neurosciences and Honorary Consultant Child Neurologist at UCL Institute for Child Health in London, underlined the importance of aiming to improve quality of life which for people with severe epilepsy refractory to drug treatment may not be all about achieving seizure freedom as that may not be a realistic aim in itself. Indeed the evidence suggests that for those who have not responded to a first or second line antiepileptic the chance of achieving seizure freedom is small.

For children with severe epilepsy learning disability and behavioural disorders have a disproportionate impact on quality of life compared with seizures. ‘These aspects therefore deserve management in their own right, and we need to be careful we don’t make things worse by giving too much drug therapy,’ Dr Scott said. So the aim of treatment should be to balance quality of life, impact of disability, impact of seizure frequency and antiepileptic load, he concluded.