Paediatric epilepsy and mental health provision
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Patient story

- 16 year old boy
- Mild developmental disorders (dyslexia, dyspraxia, impulsivity, socially naïve)
- Complex family, separated parents, mother temporal lobe epilepsy and anxiety, father family history psychosis and traumatic childhood
- Presented with episodes of “running away” impulsively, investigation by neurology, in process
- Acute episode of severe mania and psychosis with extreme disinhibition and some disorientation
- Neuropsychiatric aetiology proposed (frontal lobe epilepsy) and liaison team managed on paeds ward, needed im medication and restraint and RMNx2
• Psychiatric treatment was necessary to allow neurology investigations to take place so that epilepsy could be diagnosed.

• Manic disorder resolved in a few weeks but ongoing problems with concentration, socialisation, anxiety about diagnosis and treatment, and PTSD from memories of medical and psychiatric admission. Close liaison with neurologists and neuropsychologists was essential and co-location and single records system facilitated this.

• Severity of manic episode was unusual. All the other issues were not.
1. Mental and physical disorders are often colocated in the same patient, these are adult figures.

2. For longterm conditions, the figures are similar in children, see next slide.

3. The circles also represent the separation of medical and mental service organisations, leaving the people with the greatest needs, at risk of neglect by both.

4. Being “sent away” for some components of symptoms makes no sense to patients and is less effective.
LTC and mental health in children

Figure 6.1 Percentage of children with a mental disorder by type of physical complaint

- Epilepsy
- Difficulty with co-ordination
- Soiling pants
- Muscle disease or weakness
- Speech or language problems
- Bed wetting
- Obesity
- Stiffness or deformity of foot
- Kidney/urinary tract problems
- Stomach or digestive problems
- Congenital abnormality
- Migraine/severe headache
- Food allergy
- Hearing problems
- Glue ear/otitis media/grommets
- Eyesight problems
- Asthma
- Diabetes
- Any blood disorder
- Heart problems
- Non-food allergy
- Hay fever
- Eczema

% with a mental disorder
1. Having any physical complaint increases the risk of mental disorder significantly in children – 37% at least in epilepsy.

2. The child-adult continuity is high and adult premature deaths in epilepsy are often caused by suicide or accident not seizures. Treating or preventing childhood morbidity will reduce adult morbidity and mortality.

3. The disorders and difficulties seen in epilepsy are not restricted to “traditional” psychiatric disorder categories.

4. Without co-located and integrated mental health and paediatric care, patients and families are less likely to engage in treatment for both medical and mental health. (NSF 2004 was strong, and correct, on this)
Psychiatric, cognitive or behavioural manifestations of seizures and/or the pathology causing the seizures – behavioural, affective, psychotic symptoms, ADHD-like symptoms - particularly frontal and temporal seizures

Examples are – poor working memory, poor impulse control, manic symptoms, hallucinations, disinhibited behaviour, poor concentration, poor planning, difficulties with social interaction, difficulties with school work, running or jumping caused by seizures……..

Problems related to comorbidities and their treatment can be important – brain tumour, congenital disorder, metabolic disorder, learning disability.
Long-term condition issues are all found in epilepsy:

- treatment adherence
- secondary disorder such as depression or anxiety
- difficulty achieving independence
- anxiety about further seizures or benign symptoms (e.g., eye blinking)
- anxiety about procedures (can be severe)
- school attendance problems and educational issues
- social issues e.g., with peer bullying/friendships
- stigma
- parent or sibling difficulties including psychiatric disorders
- Medically unexplained symptoms including seizure-like symptoms
1. Overall epilepsy is often unpredictable and frightening to child, family or school, causing chronic fear and uncertainty and unhelpful coping strategies and responses to symptoms

2. Any or all of the above problems can co-occur in any child and family in an interactive non-linear way

3. They increase chance of avoidable hospital admission

4. They impair social, educational and personal development of the child and affect adult health and risk also
Longterm prognosis in epilepsy

Premature mortality in epilepsy and the role of psychiatric comorbidity: a total population study, Lancet 16 Nov 2013 Fazel et al

Adult study, compared with controls and with siblings – good methodology

<table>
<thead>
<tr>
<th>Premature mortality</th>
<th>Odds Ratio</th>
</tr>
</thead>
<tbody>
<tr>
<td>All causes</td>
<td>11</td>
</tr>
<tr>
<td>Accident</td>
<td>5.5</td>
</tr>
<tr>
<td>Suicide</td>
<td>3.7</td>
</tr>
<tr>
<td>Suicide with psychiatric comorbidity</td>
<td>23</td>
</tr>
</tbody>
</table>

75.2% who died prematurely had comorbid psychiatric disorder (esp depression and substance misuse) and OR up to 23 for suicide with this combination. These odds ratios are some of the highest in epidemiological research and are similar to those for patients with severe head injury.
Mostly not “traditional” child psychiatry or clinical psychology.

Virtually none reach referral “threshold” for hard-pressed generic community CAMHS Tier 3 services and are simply not suited to traditional psychiatric illness approach and the skills of core CAMHS tier 3 staff. Most referrals get response of “no psychiatric disorder” or “not for us”

For those that do reach threshold (e.g., psychosis) lack of integration with medical team and lack of specialist expertise in neuropsychiatry and psychology make treatment and engagement very difficult

Specialist knowledge and understanding of the relationships between brain pathology, seizures, treatment side effects and symptoms is essential
Children with epilepsy and their families have complex and high levels of need.

It is established that colocated, integrated services, with staff with appropriate skills (mainly neuropsychology and neuropsychiatry) for children with LTCs, particularly epilepsy, are needed.

This cannot be provided by a separate community CAMHS service in isolation from paediatric service.

Specialist paediatric neuroscience centres are the focus of recent NHSEngland service specification draft (Heyman et al 2015) but it is clear that the needs of the children and families in other services for epilepsy are similar and need to be met in a similar way.

There is a plethora of evidence and guidance already.
Integrated ways of working are a priority for FFV and Future in Mind

Resources and commissioning arrangements already exist for CAMHS, paediatrics and sometimes liaison mental health though with a lot of variation.

There are many potential models, many are staff-cost-neutral and involve improved integration and ways of working.

The way forward?
1. Eg organising onsite integrated clinics/consultation sessions with epilepsy teams with appropriately-skilled members of existing community CAMHS teams
2. Eg existing paediatric liaison provision allocating specific sessions to epilepsy services
3. Eg integrating 3rd sector support organisations into the epilepsy service (counselling, sleep advice, support groups, behavioural support)

* Some other options may require small investment (eg from epilepsy tariff or Future in Mind uplift) to achieve step change in quality.
* Eg adding 0.2 consultant time to existing paediatric psychology provision.

* Some of these models have been implemented successfully in liaison mental health generally.
* The guidance applies equally to the devolved nations and local solutions may vary depending on organisation and commissioning arrangements
Questions, suggestions, plans?

- Contribution of epilepsy and PLN networks?
- ????????????
Networks, collaborations and sources

* The UK Paediatric Liaison Network (chair Anthony Crabb)
* Special thanks to Sebastian Kraemer who collects, collates, digests and presents complex evidence for us all
* NHSE working group on service specification for neuropsychiatry and neuropsychology in paediatric neuroscience
* Richard Brown and other Peterborough paediatricians
* Sally Benson, paediatric psychologist at Addenbrooke’s
• Achieving parity of esteem between mental and physical health
Royal College of Psychiatrists 2012

“Poor mental health is associated with a greater risk of physical health problems, and poor physical health is associated with a greater risk of mental health problems. Significantly, the combined costs of having the individual conditions in isolation are less than the costs of having them co-morbidly – it is the interaction between the mental and physical health problems drives the cost of treatment up.”
Long-term health gains: Investing in emotional and psychological wellbeing for patients with long-term conditions and medically unexplained symptoms.
NHS Confederation 2012

“Living with a severe physical illness impacts on young people themselves, their emotional and social development, and their families. Children living with long-term physical illness are twice as likely to suffer from emotional or conduct disorders.”

The Mental Health Needs of Children and Adolescents: No Health Without Mental Health: the supporting evidence
Academy of Medical Royal Colleges 2009

“Mental health professionals can play a key role in the care of young hospital patients. A lack of compliance to treatment plans, for example in diabetes, may be related to coping, stress, trauma and anxiety – in which case support and psychological intervention may be crucial. Aside from the paediatric wards, where a CAMHS presence is essential, joint working between mental health and acute colleagues has been recommended in joint clinics such as in diabetic, asthma, nephrology as well as oncology and epilepsy/neurology.”
• Improving physical and mental health

RCPsych, RCPCH, RCP, RCPGP 2012 “… children and young people with medical illnesses are at an increased risk for emotional disorders. At times, the emotional and behavioral symptoms can be the early manifestation of the medical illness. … Integrated working between general practitioners, generalist and specialist paediatricians, psychologists, child psychiatrists, specialist nursing staff and other professionals is encouraged while looking after young people with chronic physical, neurodevelopmental or life threatening illnesses. This has been particularly emphasised in the care of young people with diabetes, cancer, respiratory conditions and epilepsy. There is growing evidence base to support this in terms of improving treatment adherence, treating procedural anxieties and improve coping with the illness within the family.”