Introduction (1)

"a purposeful, planned process that addresses the medical, psycho-social and educational/vocational needs of adolescents and young adults with chronic physical and medical conditions as they move from child-centred to adult-oriented health-care systems"

Society for Adolescent Medicine, USA

Workshop Outline

1. Why do we need a transition service?
2. Service models
3. Experience of services, good and bad
4. What young people with epilepsy want and get from a transition service
5. What the paediatric neurologist learns from the adult neurologist
6. What the adult neurologist learns from the paediatric neurologist

Case 1
- 17 years-old ‘boy’
- Epilepsy characterised by epileptic spasms
- Severe haemophilia A unmasked by IM ACTH given for infantile spasms
- Recrudescence at 12 years, asymmetric spasms evolving to bilateral convulsive
- Failed CBZ, LVT, PGB, VGB revisited, ZNS
- Bright, cognitively able, musically talented, stammer
- Left-handed, no focal neurology
- No lesion on MRI

Introduction

'I would there were no age between ten and three and twenty, or that youth would sleep out the rest; for there is nothing in the between but getting wenches with child, wronging the ancientry, stealing, fighting...'

William Shakespeare
The Winters Tale, act III, scene iii
Why does C need a transition pathway?

Goals of Adolescence
• to consolidate an individual identity
• to achieve independence from parents
• to establish relationships outside of the family group
• to find a vocation

Why we need transition services
• Young people moving toward (greater) independence
• Increased number of young people
• Increased burden of disease
• Poorly planned transition
  – risk of non-adherence to treatment
  – lack of follow up
  – adverse effects on morbidity and mortality as well as social and educational outcomes
• ‘Collusion of anonymity’

2. Service models

Case 2
• John, 16 years
• Encephalitis at 8 years
• Epilepsy characterised by multi-focal seizures
• VNS device in situ; cosmetically unacceptable
• Body building as a hobby
• Doesn’t want to travel all the way in to central London
Service models

What are the options?

• Disease-focused
• Generic adolescent-focused
• Dedicated adolescent clinics
• Handover clinics
• Primary-care models
• Joint-working
• Liaison
• Specialised workers astride-service

3. Experience of services, good and bad

Case 2

• D, 16 years
• Ring chromosome 20
• Drug-resistant
• Going to Kenya for two months over Summer
• Wants to try the ketogenic diet
• Getting angry with his mother

GOSH/NHNN experience

• Established over 20 years
• Disease–focussed model
• Between 16 and 18-years of age
• (Transition begins before this)
• Adult neurologist and paediatric neurologist
• Hand-over clinic; new and follow-ups until ‘fly-solo’
• Detailed referral information, reports, scans, data
• Clinical notes

What is good

• Specific groups
  – Pre-surgical evaluation
  – Vagus Nerve Stimulation Therapy
What is bad

- Currently no clinical nurse specialist involved
- Setting – adult out-patients
- Ketogenic diet services lacking
- (Matthew’s Friends adolescent service at YE)

4. What young people with epilepsy want and get from a transition service

Case 3

- L; 16 year-old girl
- Epilepsy characterised by seizures with occipital lobe semiology
- Drug-resistant; VNS therapy partial response
- MRI – left occipital lobe mature injury
- Focal abnormality on MRI but epileptogenic zone much wider on EEG and PET

PET

- Left posterior parietal / occipital hypometabolism
- Left mid frontal / anterior temporal hypometabolism

Case 3

- Able, resilient young person
- Skis, sings in choir
- Normal cognition (FSIQ 99) but some specific difficulties with fluctuating verbal weaknesses, affecting language and verbal memory
- Doing GCSEs

Ictal - video
What does L want/need?

- Ongoing PSE with MEG and EEG-fMRI
- Options for new drugs
- Establishing independence
- Psychological support

What young people say that they want

- Active management of transition
- Take into account how attitudes, thinking and behaviour
- Individualised honest approach
- Accessible information about services
- Trusted adult to support, act as advocate and help them to develop self-advocacy skills
- Address loss of continuity of care at transition; ensure new relationships are established
- Share information between services

Viner Arch Dis Child 2008

Young people and epilepsy – adolescent issues interact with epilepsy

Life-style
- Sex, drugs & rock-n-roll
  - Alcohol
  - Recreational drugs
  - Late nights, sleep deprivation, missed AED doses
- Contraception
- Pregnancy
  - Risk of seizures
  - Teratogenicity
- Folate

Quality of life
- Driving
- Career guidance
- Gap year plans
- Mental health
- Associated disabilities
- Genetic counselling
- SUDEP

Compliance

Empowerment
- Ensure appropriate level of understanding
- Seizure diary
- Self-administration of medication
  - Apps
  - Alarms on phone
- Feeling of being ‘in control’
- Parental detachment

Mental Health

How can mental health services and epilepsy services work together

- Self-esteem
- Perceived and real disability
- Higher rates of psychopathology
  - Mood disorder
  - Psychosis
  - Anxiety

Associated Disabilities

Beckung & Uvebrant 1987
Specific issues for the adolescent with disabilities

- Low parental, young person and professional expectations.
- Lack of self-advocacy skills and lack of opportunity to develop and practise these skills.
- Differing views of independence and success.
- Lack of knowledge of existing career and vocational education services.

5. What the paediatric neurologist learns from the adult neurologist

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Case 4: Revisiting investigations

- B: 18 years
- Frontal lobe seizures onset age 14 years
- EEG bilateral
- MRI lesion negative

Case 4: Revisiting investigations

- Bobby: 18 years
- Frontal lobe seizures onset age 14 years
- EEG bilateral
- MRI lesion negative
- By 18 years repeat MRI suggesting left frontal FCD

5. What the paediatric neurologist learns from the adult neurologist

- AEDs
  - Different side-effects
    - LVT and low mood
    - LMT and disturbed sleep
  - Different choices and doses
    - Clobazam perimenstrually
- A time for revisiting investigations
- Different questions
- (Vitamin D)
- How to talk to a young person
Case 5

- F, 17 years
- Severe learning difficulties
- Complex neurodisability
- Parents question – ‘why’

4. What the adult neurologist learns from the paediatric neurologist

- Genetic causes of epilepsy
  - Dravet syndrome SCN1A
  - Early infantile epileptic encephalopathies
  - PCDH19
- AEDS
  - Revisiting vigabatrin
  - Rufinamide, stiripentol
- How to examine a young person with learning difficulties

Key elements for successful transition

- Prepare early
- Appropriate timing
- Co-ordinated transfer process
- An interested and capable adult service
- Administrative support
- Primary care involvement
- Family support

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Conclusion

- The need to provide better services for adolescents is now widely acknowledged
- Transition is one particular and important aspect
- Regardless of the model, there are certain key elements for ensuring transition is “planned, smooth, efficient and expected”:
  - Prepare well in advance; family support; young person’s skills
  - Prepare and nurture adult services to receive them
  - Listen to young people’s views.

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RCPCH

Sophia Varadkar MRCPI, PhD
Consultant Paediatric Neurologist
Epilepsy Unit and Children’s Epilepsy Surgery Service
Great Ormond Street Hospital NHS Foundation Trust