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## Transitional services for adolescents with epilepsy in the UK: A survey

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### ABSTRACT

**Purpose:** To survey the current transitional epilepsy services in tertiary paediatric neurology centres in the UK within the principles of transitional care for young people with epilepsy.

**Methods:** An online web-based questionnaire was sent to the lead epilepsy clinicians in tertiary paediatric neurology centres on behalf of the British Paediatric Epilepsy Group, the specialist epilepsy group of the British Paediatric Neurology Association (BPNA). A transition clinic was defined as a 'clinic or service that provided joint paediatric and adult supervision of care from paediatric to adult services'.

**Results:** Twenty-three centres were approached of which 18 responded and 15 of which provided auditable data. The clinics were held between three and 12 times per year, mostly in the afternoon and sited equally between the paediatric and adult centre. Approximately three to five new, and three to eight follow up patients were seen in each clinic. Most clinics accepted new referrals with a minimum age of 14 and a maximum of 20 years. Most young people were seen only once in a transition clinic before then being promoted into the adult epilepsy service. Very few clinics accepted direct referrals from the GP. Adult, slightly more than the paediatric team provided out-of-hospital advice after the young person was seen in the transition clinic.

**Conclusions:** Young people with epilepsy are a challenging, but interesting group and their care at this time may have a potentially irreversible impact on their life. Their progress from paediatric to adult services should be a dynamic, gradual and smoothly transitioned process to optimise their care. Although recommended by the National Institute for Health and Clinical Excellence (NICE) and the National Services Framework (NSF), the findings of this survey would suggest an un-met need of this population.

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### 1. Introduction

Epilepsy is the most common neurological condition in adolescence<sup>1</sup> and its presence at a critical period in their development<sup>2–4</sup> brings additional and specific needs and concerns which need to be addressed at this critical time of life. The success (or failure) of optimal management of epilepsy in this inherently complex age group may have a potentially irreversible impact on their future life.<sup>5,6</sup>

The transition and transfer of young people from paediatric to adult care is challenging for the young person as well as their families and healthcare professionals.<sup>5–8</sup> The justification for a transition service has in the recent past been partly driven by increased life-expectancy of children with uncommon but serious,

life-shortening disorders, including cystic fibrosis.<sup>9</sup> However, there is also support for the provision of seamless specialist care for young people with epilepsy within a transition format, as endorsed by the National Institute for Health and Clinical Excellence (NICE),<sup>10</sup> Scottish Intercollegiate Guideline Network (SIGN),<sup>11</sup> epilepsy guidelines and the National Service Framework (NSF).<sup>12</sup> In March 2006, an NSF document entitled 'Transition: getting it right for young people'<sup>12</sup> included the following statement: "These young people with neurological disorders and disabilities [defined as difficult or intractable epilepsy syndromes that differ from those seen in adult neurological practice] are the least well served as there is often no service available to take over their care when they leave paediatrics".

Adolescence may be defined qualitatively as a period of life that an individual passes through<sup>13</sup> and quantitatively as an age-range. NICE<sup>14</sup> defines young people as: 'between the ages of 12 and 17 years', and adults as: 'people aged 18 and over'. In practice and pragmatically, 16 or 17 years is generally regarded as the age at which a young person would usually be transferred from paediatric to adult services, or, as a new referral, be seen in an adult rather than paediatric clinic. Children with moderate or

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severe learning difficulties often attend a special school until 19 years of age and this may serve as the trigger to transfer their ongoing care to adult services. Obviously, these tend to be the chronological but not necessarily the emotional or cognitive ages at which they may be regarded as adults.

'Transfer' and 'transition' are not synonymous, although they are often regarded as such. Transition is a more dynamic process and implies a planned and structured move from paediatric to adult care, which in practice should include appropriate preparation and discussion with the young person, prior to transfer to a different clinic or service for continuing care. In contrast, transfer is usually interpreted as representing a single event of passing a person's medical care either back to their GP or to an adult or specific adolescent service. Transition can be defined as: *'the process of changing from one state or condition to another'*.<sup>15</sup> Sir Ian Kennedy in his report 'Getting it right for children and young people: overcoming cultural barriers in the NHS so as to meet their needs' highlighted the changes in the policy, training and resources needed to put the young person at the centre of care and stressed the need for professionals to be trained in the management of both children and young people.<sup>16</sup>

The first reported transitional service for young people with epilepsy in the UK was in Liverpool in 1991.<sup>17</sup> It seemed appropriate to review the national provision of such a service, twenty years later, and on the background of the NICE, SIGN and NSF publications.

## 2. Methods

Between September and December 2011, a survey was undertaken of all paediatric tertiary epilepsy centres in the UK to identify transition epilepsy services. Twenty-three centres were identified. This was undertaken on behalf of the British Paediatric Epilepsy Group (BPEG) using 'SurveyMonkey', a web-based questionnaire. The survey was registered with the Clinical Audit Department of Alder Hey Children's NHS Foundation Trust. In September 2011 an explanatory letter was sent to tertiary paediatric neurology centres in the UK inviting them to participate and with a link to the survey. A reminder was sent out two months later to non-responders. A transition epilepsy clinic was defined as a *'clinic or service that provided joint paediatric and adult supervision of care from paediatric to adult services'*. The questionnaire is enclosed as Appendix 1.

## 3. Results

Twenty-three centres were approached of whom 18 responded. One centre submitted duplicate and another centre submitted triplicate responses. Clarification of the responses was subsequently obtained from these two centres. Fifteen of the 18 centres stated that there was a specific transition epilepsy clinic as defined above. Eleven (73%) centres had a named paediatric neurologist who was the lead in the transition epilepsy service. Detailed information was provided by the 15 centres, the results of which are summarised below.

## 4. Frequency, timing and venue of the clinics

The transition clinics were held between three and 12 times per year (median four); in five centres they were held monthly and every three to four months in most centres.

Seven of the 15 centres (47%) held clinics in the afternoon. Of the remaining eight centres, five were in the morning, one in the evening, one both in the afternoon and evening and one both in the morning and afternoon.

Seven of the 15 clinics (47%) were based in an adult neurology/epilepsy unit; seven in a paediatric neurology/epilepsy unit (47%) and one centre alternated the transitional clinics between the two sites.

## 5. Staffing the clinic (Figs. 1 and 2)

Fourteen of the 15 clinics (93%) were supervised jointly by an adult and paediatric neurologist, both with specific interest and expertise in epilepsy. In two centres, three different paediatric neurologists shared the clinic service with a single adult neurologist who had a specific interest in epilepsy. One transition clinic was supervised by the paediatric and adult epilepsy nurse specialists without any medical input; this is a model used in at least one other country.<sup>18</sup>

Five of the 15 clinics (33%) were supported by both paediatric and adult epilepsy nurse specialists. Four (27%) were supported by an adult epilepsy nurse specialist and the remaining six clinics (40%) had no epilepsy nurse specialist support.

## 6. Clinic list and waiting times

Most clinics assessed both new and follow-up patients. Seven clinics (47%) assessed only new patients only once after which they were followed up in an adult epilepsy clinic.

Between three and five new patients and between three and eight follow up patients were assessed in each clinic. The largest clinic assessed five new and eight follow-up patients in its monthly clinic.

The waiting time for new patients was between one and 12 months (mean three, median five months). In some centres, clinics were only booked on *ad-hoc* basis depending on the number of young people awaiting transition.

Thirteen of the 15 clinics (86%) assessed young people who only had epilepsy and those who had epilepsy 'plus' (specifically those with significant learning difficulties [and who attended a special school] or autistic spectrum disorder, or both). Only one centre operated a separate transition clinic for each group and staffed by the same professionals.

## 7. Criteria for referral into the clinic

The minimum age for a new patient to be accepted was older than 15 years in nine centres (60%), between 14 and 15 years in three (20%) and less than 14 years of age in three (20%). The maximum age for a new patient to be accepted was 18 years in five centres (33%) and between 19 and 20 years in the remaining 10 centres (67%).

In seven clinics (47%) a young person was transferred on to the adult epilepsy service after the first new patient assessment. In most other centres, there was no fixed number prior to transfer to

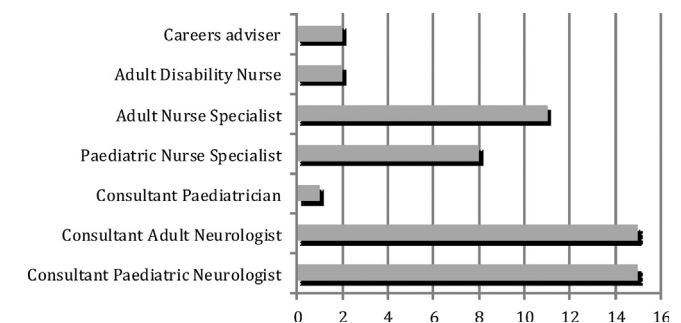


Fig. 1. Number of different professionals that staffing the transition epilepsy clinic.

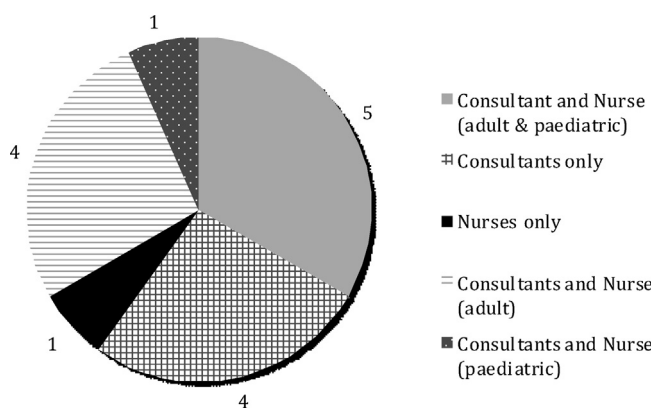


Fig. 2. Combination of different professionals who attend the transition epilepsy clinic.

the adult service. Some centres used fixed 'entry' and 'exit' from the transition clinic at 13 and 18 years of age respectively. Most centres' approach was to promote the young person to an adult service at the discretion of the clinic staff and in agreement with the young person, their family, or both.

Three of the 15 clinics (20%) accepted new-patient referrals from general practitioners (GP). All referrals were between 16 and 20 years of age and for young people in whom epilepsy had relapsed, having previously been under the care of paediatric services and discharged, or who presented for the first time with *de novo* epilepsy.

## 8. Support for families

Five of the 15 clinics (33%) provided young people and their families with written information about the transition clinic, which was usually provided before the young person was seen in the transition clinic.

Following the first new patient clinic attendance in the transition clinic, subsequent out-of-clinic advice was provided by the adult team in eight centres (53%). In four centres (27%), advice could be sought from both the paediatric and adult services and in the remaining three centres (20%), advice was provided by the paediatric team.

## 9. Additional information

Respondents were asked to provide additional, free-text comments. Many emphasised that a transition service was not valued and was at a risk of being withdrawn from their institution. A number commented on the discrepancy of paediatric epilepsy services being largely regional in contrast to adult epilepsy services being predominantly district-based. One centre indicated that paediatric and adult epilepsy nurse specialists supervise transition with the medical staff providing a detailed written summary. Two centres stated that adolescents were 'prepared' prior to attending the transition clinic, and then promoted immediately to the adult clinic. Finally, three centres interpreted their service as essentially a 'handover', rather than a transition service.

## 10. Discussion

This survey has identified all or certainly the vast majority of transition clinics for young people with epilepsy within tertiary paediatric epilepsy services. However, there are some transition clinics in England that operate within secondary care and are sited in a District General Hospital (DGH) (RA, personal communication). A general paediatrician with specific training and expertise in

epilepsy provides the paediatric input to these clinics, sometimes with nurse support, and an adult neurologist. It would be interesting to know how many of these clinics exist because the prevalence of epilepsy would dictate that the currently available tertiary transition clinics would not enable all young people with epilepsy in the UK to benefit from such a service. There is no reason why a secondary care, DGH-based, transition service would, and could not provide an effective transition for most young people with epilepsy.

Perhaps predictably, no two centres operated the same transitional structure and practice. The reasons for this are likely to be multi-factorial and a full discussion is outside the scope of this paper.

Although the issue of transition from paediatric to adult services is not new and is largely accepted, some remain unconvinced about its importance and particularly its cost-effectiveness. It would seem reasonable to briefly outline the options for the on-going management of young people aged 16–19 years.

The first would be to remain in paediatric care. The only benefit of this option would be to provide the young person with continuity of care. This may be relevant for the child with significant physical or learning difficulties, or both, who is likely to remain in special secondary school education until 19 years of age but inappropriate for the majority for the following reasons: first, it is unlikely that the paediatrician will have the knowledge and experience (and therefore confidence) of dealing with what, traditionally, have been adult issues (sex, contraception, pregnancy, driving and employment regulations, *etc.*) and because their communication skills are more likely attuned to either young children or their parents. Second, because it would be wholly inappropriate for a 19, 20 or 21 year old to continue to be seen in a paediatric clinic, even if the clinic time was more tailored to the convenience of the young person, such as in evening. Third, because it might be inherently difficult for the paediatrician, who has known the child for many years and in effect has 'grown up with the child', to 'let go' and allow the young person to become independent; this approach is often shared by the 'child's' parents. There is a danger that both the paediatrician and the parents may subconsciously collude to keep the child a child.

The second is to be discharged back to their GP. This is potentially unsatisfactory as the young person is denied continuity of specialist epilepsy care and advice at a critical time of their life. Although there is a quality and outcomes framework (QOF) for patients with epilepsy aged 18 years and above in the General Medical Services (GMS) or General Practitioner contract, in reality this might simply relate to an annual review of their antiepileptic medication and 'tick-box' exercise. Consequently, these young people may remain on anti-epileptic medication unnecessarily (as the epilepsy may have entered a spontaneous remission) and they may not receive appropriate or indeed any career and pre-conception advice and counselling.

The third is to be referred to an adult physician or neurologist, neither of whom may have an interest or knowledge (or both) in epilepsy. The principle of adult practice is for appointments to be infrequent and only to see patients if they have 'problems'. This is likely to be optimistic, as well as being too late as and when any problem is disclosed. In addition the often very different approach taken by and amount of contact with, adult services may be too much of a change from that provided by paediatric services. Consequently, the young person (and their family) may be reluctant to attend adult clinics with implications for their long-term management.

The fourth and final option is to be transferred to a transition service, whereby the young person's care may be supervised in a specific clinic that operates separately from a paediatric or adult

clinic and is able to provide continuity of specialist epilepsy care that is not only adolescent-specific, but is able to address specific adult issues. Up until the recent publication of the RCPCH e-health programme on Adolescence Health,<sup>7</sup> there had been no precise definition of, or established criteria for a transition service. One model of this service has been described previously.<sup>3</sup>

It is not possible within this paper to discuss the practical aspects of where a transition clinic should be sited, the time of day and frequency of the clinics and which professionals should staff them. These issues are likely to be determined by many, including local factors. However, it would seem reasonable to comment on two issues. First, justification for the transition clinic to be based in an adult hospital could be on the premise that the young person would be able to establish links and develop confidence with the adult personnel and environment during the transition period. Second, transition should be a dynamic process and a single, 'one-off' assessment in a 'transition' clinic is arguably too brief to allow time for the young adult to acclimatise to their new clinic personnel and environment whilst they separate from the paediatric team. Some teenagers with long-standing epilepsy who have been managed for a long time in paediatric care may benefit from one or more follow-up appointments in the transition clinic to enable them to develop confidence and trust in the adult environment. This process might also help the adult team to better understand the nature and complexity of the many childhood epilepsy syndromes as well as the young person themselves. A similar approach with more strict criteria, maintenance of patient registry and the preservation of the detailed paediatric medical records has been described about the grown-up congenital heart (GUCH) disease population with development of guidelines by the European Cardiac Society.<sup>19,20</sup>

Finally, the survey did not investigate the important issue of long-term, adult follow-up once a young person has been transferred to adult services. In Liverpool, two adult neurologists with a specific interest in epilepsy provide the ongoing, adult care for all the young people with epilepsy who have been seen in the transition clinic.

## 11. Conclusion

It is currently difficult, even impossible in some parts of the UK, to develop a transition service for young people with epilepsy; in part this relates to the increasingly health-economic and cost-effective pressures within the NHS. Predictably, there are many issues that may militate against both the survival of pre-existing and the development of new transition clinics. These include the philosophies and personalities of the medical staff who may wish to establish a transition service; disagreement between Trusts over where a transition clinic should be based; and financial issues relating to consultant and epilepsy nurse sessions, and which Hospital Trust or the newly-established Clinical Commissioning Groups (CCGs) should be responsible for funding such a service. CCG-funding might be facilitated if the transition clinic accepted referrals directly from GPs of young people who present with *de novo* epilepsy. However, most GP-generated referrals are likely to represent only a very small minority of young people who would benefit from a specific transition epilepsy service.

The transition from paediatric to adult services is a major milestone for an adolescent with a chronic illness such as epilepsy. Transitional care for young people with epilepsy is not fully integrated into clinical services across different areas despite a strong professional consensus that this represents best clinical practice. Although challenging, this work can be very rewarding for the young person and their healthcare professionals. It falls on clinicians working along with national groups including BPEG under the auspices of the RCPCH, in collaboration with the

Association of British Neurologists (on behalf of the Royal College of Physicians) to try and improve transitional care service for young people with epilepsy.

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## Appendix A

*BPEG members:* Colin Dunkley, Sherwood Forest Hospitals, Nottingham; Dierdre Peak, Sandya Tirupathi and Don Hanrahan, Royal Belfast Children's Hospital, Belfast; Sunny Philip and Rajat Gupta, Birmingham Children's Hospital, Birmingham; Jayesh Patel, Frenchay Hospital, Bristol; Alasdair Parker, Addenbrooke's Hospital, Cambridge; Frances Gibbon and Johann te Water Naude, University Hospital of Wales, Cardiff; Ailsa McLellan, Royal Hospital for Sick Children, Edinburgh; Mary O'Regan, Sameer Zuberi and Stewart Macleod, Royal Hospital for Sick Children, Glasgow; Colin Ferrie and Neti Gayatri, Leeds General Infirmary, Leeds; Nahin Hussain, Leicester Royal Infirmary, Leicester; R Schwartz, Central Middlesex Hospital, London; Sophia Varadkar, Great Ormond Street Hospital for Children, London; Leena Mewasingh, St Mary's Hospital, London; Tim Martland, Royal Manchester Children's Hospital, Manchester; Anita Devlin, Great North Children's Hospital, Newcastle; William Whitehouse, Queen's Medical Centre, Nottingham; Tony McShane, John Radcliffe Hospital, Oxford; Helen Basu, Royal Preston Hospital, Preston; Chris Rittey, Sheffield Children's Hospital, Sheffield; Andrea Whitney and Fenella Kirkham, University Hospital, Southampton; Geoff Lawson, Sunderland Royal Hospital, Sunderland.

## Appendix B. Supplementary data

Supplementary data associated with this article can be found, in the online version, at <http://dx.doi.org/10.1016/j.seizure.2013.02.014>.

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