

Transition a guide from
Children's Epilepsy services to
Adult Epilepsy services

For people with additional needs



Hello,

We are the adult epilepsy nurses, our names are Pru and Shelly.

We thought rather than just a leaflet by its self we would do a pack of information to be given to you and your family at an early stage. We know that moving from adults to children's services can be a worrying time, as there is new people and the services can run slightly differently.



Hello

We are hoping that by you having this pack it will give you some understanding of what to expect and how to expect it. Also to give you an over sight of our adult service and how this is run. Through this we are hoping that by the time you or your child comes through to our service most of the questions will be answered and this will be smoother for you.

We don't expect you to read and take this all in at one time, it is for you to read and go through at your own time. If there are any questions, please don't hesitate to ask your children's epilepsy nurse or ourselves.

Best wishes,

Pru and Shelly

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When does transition start?

Transition is the process of moving from children to adult services. In different services this can start from the age of 16 through to the age of 18.

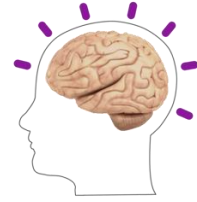
Within the epilepsy services the official transition will start when the young person is 17 and a half. But do not worry, prior to this there will often be informal discussions between the services in relation to young people coming through.

At 17 and a half a referral will be sent in to the adult's services, we will then contact you to say we have the referral. At this point we can't start working with your child directly, however we can start to attend relevant meetings and getting to know you and your child. Once the referral has been received in we can look at your child's GP records so we can gain a background of information prior to meeting yourselves.

Adult Epilepsy Nursing Service

Who do we see?

We will accept anyone who has a Bedfordshire CCG GP, with a confirmed diagnosis of epilepsy, 18 years old and not under another epilepsy specialist nurse (this does not include children's nurses during transition).



When your child is being referred for transition if they are currently under Bedford hospital, with the above criteria they will come through to our service.

If your child is being referred for transition but they are currently under a specialist hospital they maybe under the specialist nurse within the hospital. Please do not worry there will be ongoing discussions in relation to this to ensure that this is identified as soon as possible.

Unfortunately, within Bedfordshire adult services we cannot support someone with epilepsy who is under another epilepsy specialist nurse.

How do we work?

As an adult service we try to promote that the young person/carers/family have the knowledge of their epilepsy, as you will know your child the best. As a service we focus upon the epilepsy alone, if due to the epilepsy there are additional needs we can signpost to the relevant support networks. For example if your child is having oxygen whereas the children's team would have supported this, as an adult this will now be supported through the district nursing team.

How is our service run?

We are community based, so we aren't in the hospital. We have developed the service as a predominately virtual service, therefore appointments will be on video calling and letters will be through emails. We will ask your consent in relation to this when we have received the email. We have focused upon this as we know the impact of many medical appointments can be on young people and their carers. Also it allows us to meet your child and yourselves in a relaxed environment. If it is not appropriate for your child to attend the initial assessment, please don't worry this will be discussed prior to the assessment.



We also appreciate that there are some families who technology does not work for and prefer a face to face service, we do still offer these services. This would be at our site at Bedford North Wing hospital, we will provide details of any services.

For all new patients we will need to complete an initial assessment, this is a detailed assessment and can take up to 1 hour.

We do also offer telephone appointments, if there is anything you wish to discuss between appointments you can call up and be put on to our telephone clinics. We are also aware that many families are often managing quite a few different items, therefore we can also communicate through email, if this is of support.

What services and support do we provide?

As mentioned above with adult services we are focusing upon the epilepsy and the impact that this may have on your child. We also promote independence.

We offer care planning advice and support, support in relation to your child's epilepsy, signposting to appropriate services and referrals.



Mental Capacity Assessments and Best Interest Assessments

We just wanted to make you aware of this terminology. Whilst in children's services as the parents you often make the decisions for your child. As your child turns 16 there will be a change in how this is approached, as the Mental Capacity Assessments and Best Interest Assessments will start to be used. A mental capacity assessment is a 'tool' used to assess someone's capacity (understanding), this has to be used at each time a decision/change is being made. Under the law it is required, no one can presume that someone does not have capacity, therefore this has to be completed.



This does not mean that you are not involved, as always parents or carers are fully involved.

There may be occasions where we have to refer your child to different services, therefore we just wanted to make you aware of this terminology.

If you would like further information you can either contact your social worker, ask the transition worker in your child school.

Useful websites

There are some helpful websites that you may find useful:



Epilepsy action: www.epilepsy.org.uk

Epilepsy action has a range of resources, information and guidance in relation to epilepsy. This can be for anyone who is supporting someone with epilepsy. They also have a supportive telephone helpline.

SUDEP action – www.sudep.org

SUDEP action raises the awareness of SUDEP (Sudden Unexpected Death in Epilepsy). There is useful information and awareness in relation to this. Additionally, there is a link to a mobile app called EpsMon that they have developed that can help monitor and track seizures.

Epilepsy Society – www.epilepsysociety.org.uk

Epilepsy action has a range of resources, information and guidance in relation to epilepsy. This can be for anyone who is supporting someone with epilepsy.

Young Epilepsy - www.youngepilepsy.org.uk

Epilepsy action has a range of resources, information and guidance in relation to epilepsy. This can be for anyone who is supporting someone with epilepsy.

Local services

Hospital LD Liaison Nurses:



There are learning disability nurses based at both the Luton and Dunstable hospital and at Bedford hospital. They can offer support in relation to making sure hospital appointments are accessible for the patient and any reasonable adjustments that could be made. Please do contact them if there is any hospital appointments or hospital visits. If you are able to contact before they will be able to support with developing a hospital passport to support during any admissions.

Bedford Hospital: 0776813244 or 07833294335

Luton and Dunstable Hospital: 01582 718271

Easy read information:

Epilepsy action has a range of information that is in easy read format to make this accessible to all. As a service we are developing these to be relatable to Bedfordshire. Please go to view at:

<https://elft.nhs.uk/service/464/Bedfordshire-Community-Epilepsy-Specialist-Nurse-Service>

If there is not one available and you feel it is required please do let us know by emailing on : elft.epilepsyservice@nhs.net

Transition Questions

We have left this page blank for you to note any questions you may have in relation to transition.