

Children and Young People Epilepsy Services: New Video System

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Introduction

The purpose of this patient information booklet is to tell you about vCreate, our new online video system, which will help us continue to support you and your child or young person on their epilepsy journey.

This information is a guide only and the clinical team will help you understand how to get the best from this new service and to answer any questions you may have about it.

If you have any more general questions about epilepsy in children and young people you may find it helpful to have a look at further information on our website:

<https://www.ulh.nhs.uk/patients/patient-information-library/epilepsy-and-seizure-management-in-paediatrics/> or please do ask a member of our team.

What is vCreate?

vCreate is a secure online service which allows patients, carers and family members to upload videos of epilepsy episodes/seizures in real time so they can be viewed by their healthcare team to help them better understand the patient's condition.

Some of our patients' carers and families have already been sending photos and videos to their clinical team via WhatsApp on their mobile phone or tablet, but vCreate is a much more secure and safe way of sharing these images. It also opens this opportunity to those who may not have access to or be comfortable using social media.

vCreate is widely used by many other Trusts across the NHS nationally. It has proved to be especially helpful for clinical teams supporting patients with long term conditions like epilepsy, for whom 'seeing' an episode or any change when the person is not in hospital or a clinic situation, helps them to build the best possible 'picture' of that patient.

How will vCreate help your healthcare team better understand your child or young person's condition?

The videos you take with your smartphone or tablet and share with your clinical team will help them:

- Assess the patient's symptoms more accurately
- Capture episodes and see symptoms as they occur in real time as these can often provide information that is difficult to capture during an appointment
- Support their diagnosis and treatment plans for the patient
- Help them know which questions they need to ask you about the episode to ensure they capture as much information as possible
- Monitor changes in the patient's condition
- Help inform what advice, guidance and reassurance they may best give to you whilst the patient is at home to reduce unnecessary visits to hospital or clinic

Do I have to use this service?

No. It is entirely voluntary and a matter of choice, but consent is needed either from the child or young person themselves or for the carer or parent who can act legally on their behalf.

If your child is under 12 or older but unable to make a decision independently the clinical team will email the consent form to you as the parent or carer requesting it be completed and returned to them. This form will be stored as part of the patient record for the child or the young person.

For children 12 years and above, they will receive the form directly by email from the clinical team seeking their consent to use the service.

How will it work for me and my child or young person?

If your healthcare team believe that using videos may help them better understand the patient's condition you will be invited to use the vCreate system and one of the team will discuss it with you.

Will it be difficult to use?

No, providing you have a smartphone, tablet or laptop on which you can receive emails and take videos as vCreate is a digital online system.

What will I have to do?

Once you have consented to use vCreate, you will receive an email from your clinical team containing a personal registration link.

When you click on the link, you will be asked to:

- Confirm your consent
- Create a password
- Activate your account

During registration, you may also be offered the opportunity to give consent for videos to be used for:

- Research
- Education
- Training

How do I use the system?

When an epileptic episode or symptom occurs, try and record as much of that as you can on your phone or tablet in the usual way.

As you may not know when such an episode will happen or you may not have your phone or tablet immediately to hand when it does, we do not expect you to always be able to capture everything so just do what you can. Any and all information will be helpful to the clinical team.

Please remember the welfare of the patient and keeping them safe is the priority at all times, so do not worry if you are on your own and need to focus upon supporting the patient rather than taking the video.

Even if you are unable to capture the episode on your device, after it has happened and the patient is safe again, please try and note down the time it took place, where the patient was at the time, what the patient was doing and how long it lasted so you can share this information later with the clinical team.

How do I upload the video?

Log in to your vCreate account and:

- Select the video you want to send from your device
- Answer a few short questions which will appear on your screen
- Upload the video securely when you are prompted to do so

Typically, depending upon the length of the video, uploading usually takes only a few minutes.

The original video remains on your device as your personal record.

What do I do if I am having problems using the system or loading the video?

The vCreate platform contains a number of helpful tips to help you use the system. If the problem persists and you need technical help you can contact vCreate via email; theteam@vcreate.tv and they will respond as soon as they can.

Do not worry if you cannot send the video straight away as you will have it on your own tablet or phone so you can try again later.

If the problem continues you can let your clinical team know and they will look into it for you.

What happens after the video has been uploaded?

The vCreate system will automatically alert your clinical team that you have sent a new video.

The healthcare team will review the video as soon as they can and they may wish to ask you some questions about it and discuss it with you. They may contact you via:

- Phone
- Email
- Letter
- Secure vCreate messages

Who else will have access to a video?

Our epilepsy team are all clinical experts in their own right but there may be occasions when they feel a second opinion from a specialist child and young person neurologist would be helpful. The team will arrange this from one of what are known as tertiary centres, which for us are Queen's Medical Centre in Nottingham and Sheffield Children's Hospital.

If they feel a second opinion is needed, the video you have taken will be shared via vCreate with one of those specialists in Nottingham or Sheffield.

That specialist will view the video and provide their clinical opinion to your clinical team who will consider it as part of their overall assessment of the episode they have seen.

Any clinical diagnoses and/or decisions made by the team will be recorded in the patient's healthcare records.

How secure are the videos and any supporting information?

The vCreate digital tool has been approved for use within NHS services and uses secure cloud storage hosted by Microsoft Azure.

Each video:

- Is protected by secure login systems
- Is stored securely on the 'cloud'
- May only be viewed by the authorised healthcare professionals and system administrator involved in the care of the patient who is the subject of that video
- If and when the patient care ends, their account is closed
- If and when a member of our clinical team leaves the Trust, their account is closed and they will no longer be able to access any of the videos

The videos are part of the clinical records for the patient so, in addition to the secure 'cloud' storage, they are also covered by our digital safety and information governance processes and protocols, which are strictly monitored at all times. You can, therefore, be confident the protection of patient confidentiality and integrity is afforded the highest priority.

How do we let you know what we think about vCreate?

Feedback from our patients and/or their carers and families is really important to us and helps us continue to improve the service both for now and into the future.

Once you have used vCreate you may receive a survey from us asking for your views about it, but you can also discuss it with your clinical team or ask them if you have any other questions about the service.

IMPORTANT – vCreate is NOT an emergency service

Do not use vCreate for urgent medical concerns

If you need immediate advice or urgent medical assistance:

- Contact your clinical team directly
- Call NHS 111
- Call 999 in an emergency
- Attend your nearest Emergency Department if required

Epilepsy charities:

- www.epilepsy.org.uk
- www.epilepsysociety.org.uk
- www.youngpilepsy.org.uk

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Lincolnshire Community and Hospitals NHS Group has worked with AccessAble to create detailed Access Guides to facilities, wards and departments at our sites.

www.accessable.co.uk/united-lincolnshire-hospitals-nhs-trust

<https://www.accessable.co.uk/lincolnshire-community-health-services-nhs-trust>

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If you require this information in another language or alternative format, please email the Patient Information team at ulth.patient.information@nhs.net