

Patients Know Best

Making life better for children and families living with epilepsy

- a pilot project in Luton

Usha Panchal


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Bedfordshire, Luton and Milton Keynes Integrated Care Board (BLMK ICB)




Category: Innovative use of Technology, Social and Digital Media, PENNA Awards 2022

Scope of the project

- 3 year project which commenced in October 2020 and is funded by NHS England.
- Children under 18 years old with complex epilepsy, registered with a GP in Luton and who are seen by consultants at the Luton site of Bedfordshire Hospitals NHS Trusts and Epilepsy nurses at Cambridgeshire Community Services.
- Partner with Patients Know Best to deliver an integrated digitalised patient held record by consolidating information generated by the patient or parent alongside information from primary care and acute care
- It is the UK's most widely used and accessible patient-held record
- Available in over 20 languages and on any internet-enabled device.
- It is also integrated within the NHS App through the NHS login.

Welcome page (PKB)



Settings  Help  Log out 

Home

Welcome Usha Panchal


Welcome to your Patients Know Best online health record for Cambridge Community Services NHS Trust.


Here you will be able to see, share and record your medical information. You will also be able to access care plans and medical correspondence between yourself and clinical teams. As this service develops, your test results, appointment letters, and appointment details will also be available.


To access the record of someone you are caring for, use the [Sharing tab](#) or visit the [library](#) for further information from your team.


Please note: This service is not for emergency use and may not be monitored on a daily basis. For urgent medical care or advice call NHS 111. In case of serious injury or illness call 999 or visit your nearest A & E department.






Information is held about you. We need to have a complete picture of past, current and future health needs and treatment so that we can give you the best care.


Send message 

Invite professional 


Start consultation 

 **Notifications**


 new seizure message received from on 6 Sep 2022 14:54:57	View →
 New seizure message received from on 16 Jun 2022 13:38:34	View →
 New seizure message received from on 16 Jun 2022 13:28:19	View →
 New seizure message received from on 16 Jun 2022 12:30:31	View →
 New seizure message received from on 16 Jun 2022 12:23:15	View →
View all →	




Events & messages →




Health ▼




Treatments ▼




Diary ▼



Files →

































Devices →



Sharing ▼


Care Plans in PKB




Learning Disabilities - Annual Health Checks <i>(In draft)</i> Created by You on Today	General health  Discuss  Delete 
Emergency plan Created by Ms CCSEpilepsy Prof on 13-May-2021 - Edited by you on 01-Jun-2022 - Review date 16-Jun-2022	General health  Discuss 
Seizure Diary Created by Ms CCSEpilepsy Prof on 12-May-2021 - Edited by you on 06-Sep-2022	General health  Discuss 
All About Me Created by You on 17-Nov-2021 - Edited by you on 16-Jun-2022 - Review date 28-Apr-2023	General health  Discuss 
Medical History Created by Ms CCSEpilepsy Prof on 12-May-2021 - Edited by you on 06-Sep-2022 - Review date 06-Sep-2022	General health  Discuss 
Transition <i>(In draft)</i> Created by You on 07-Sep-2022	General health  Discuss  Delete 
Medical History Created by You on 17-Nov-2021 - Edited by you on 01-Aug-2022	General health  Discuss  Delete 
Valproate Guide Created by Ms CCSEpilepsy Prof on 13-Jan-2022 - Edited by you on 01-Jun-2022 - Review date 01-Jun-2022	General health  Discuss 
Health Assessment Created by You on 13-Apr-2022 - Edited by you on 01-Jun-2022	General health  Discuss  Delete 
Care plan for education setting Created by You on 08-Nov-2021 - Edited by you on 01-Jun-2022 - Review date 23-Jun-2022	General health  Discuss  Delete 
Educational Health Care Plan (EHCP) Created by You on 01-Jun-2022 - Edited by you on 01-Jun-2022	General health  Discuss  Delete 
Contacts Created by You on 01-Feb-2021 - Edited by you on 01-Jun-2022 - Review date 06-Jun-2022	General health  Discuss 

Key Components of PKB

- **Two-way communication portal** enables carers and young adults to message and receive information.
- Users can **attach videos and documents for journals and files**
- A **seizure diary maintained by carers** can be accessed live by professionals at any time.
- A **library of medical information about epilepsy**, safety, lifestyle, prognosis, and links to other epilepsy websites which hold authentic information.
- **24-hour secure access to this platform** on any web-based digital equipment such as smart phone, desktop or mobile tablets.
- **Further plan is to integrate PKB with hospital and GP records** for appointments, tests, and discharge letters.

Files holding important documents within PKB
















Settings  Help  Log out 

Home > Files

Files


Upload documents such as letters, reports or photographs. Note, medical documents from your teams will appear in the relevant part of your record e.g. letters in the "Events & messages" section, imaging reports in the "Imaging" section.

Add file 

	Name	Uploaded by	Date	Notes	
<input type="checkbox"/>	Medication Changes.docx	Miss Usha Panchal	15 Sep 2022	Please find a copy of your child's medication changes	<div>General health </div> <div>Edit </div> <div>View </div>
<input type="checkbox"/>	Health Assessment Care Plan.docx	Miss Usha Panchal	15 Sep 2022	Please find attached the amended Health Assessment Plan for you to check	<div>General health </div> <div>Edit </div> <div>View </div>
<input type="checkbox"/>	Travel Documents.docx	Miss Usha Panchal	15 Sep 2022	Please find attached your travel documents for your holiday to France	<div>General health </div> <div>Edit </div> <div>View </div>
<input type="checkbox"/>	Case Management Plan.png	Miss Usha Panchal	16 Feb 2021	I would like to keep a journal of medications	<div>Sexual health </div> <div>Edit </div> <div>View </div>

0 items selected

Delete Discuss



Integration of GP clinical system with PKB

Authorised	Drug ▾	Last Issued	Review	Issues
28 Apr 2022	Chloral hydrate 500mg/5ml oral solution 100 ml - take 5 mls prn	14 Jul 2022	28 Apr 2023	1 / 6 (12)
28 Apr 2022	Clobazam 5mg/5ml oral solution 300 ml - 1mg (1ml) once a day during the night	15 Aug 2022	28 Apr 2023	3 / 6 (12)
28 Apr 2022	CosmoCol Plain oral powder sachets (Stirling Anglian Pharmaceuticals Ltd) 60 sachet - use as directed	Reauthorised	28 Apr 2023	0 / 6 (0)
28 Apr 2022	FruitiVits oral powder 6g sachets (Vitaflor International Ltd) 30 sachet - use as directed	Reauthorised	28 Apr 2023	0 / 6 (0)
28 Apr 2022	K.Quik liquid (Vitaflor International Ltd) 2250 ml - use as directed	Reauthorised	28 Apr 2023	0 / 6 (0)
28 Apr 2022	KetoCal 4:1 powder vanilla (Nutricia Ltd) 300 gram - use as directed	Reauthorised	28 Apr 2023	0 / 6 (0)
28 Apr 2022	Lactulose 3.1-3.7g/5ml oral solution 500 ml - 10ml once a day	30 Jun 2022	28 Apr 2023	1 / 6 (2)
28 Apr 2022	Levetiracetam 100mg/ml oral solution sugar free 300 ml - give 400mg twice daily	15 Aug 2022	28 Apr 2023	3 / 6 (32)
28 Apr 2022	Liquigen emulsion (Nutricia Ltd) 2000 ml - use as directed	Reauthorised	28 Apr 2023	0 / 6 (0)
28 Apr 2022	Melatonin 2mg capsules 60 capsule - take two capsules daily	14 Jul 2022	28 Apr 2023	1 / 6 (13)
28 Apr 2022	Phenobarbital 50mg/5ml oral solution 400 ml - take 38mg (3.8ml) twice a day	15 Aug 2022	28 Apr 2023	3 / 6 (23)
28 Apr 2022	Sennosides 7.5mg/5ml oral solution sugar free 500 ml - 1x5ml spoon at night	30 Jun 2022	28 Apr 2023	1 (2)

<input type="checkbox"/>	>Chloral hydrate 500mg/5ml oral solution started 28 Apr 2022 take 5 mls prn: Supply Quantity 100 ml: Issued 1: Max Issue 6: Last Issued 14/07/2022	General health
<input type="checkbox"/>	>Clobazam 5mg/5ml oral solution started 28 Apr 2022 1mg (1ml) once a day during the night: Supply Quantity 300 ml: Issued 3: Max Issue 6: Last Issued 15/08/2022	General health
<input type="checkbox"/>	>CosmoCol Plain oral powder sachets (Stirling Anglian Pharmaceuticals Ltd) started 28 Apr 2022 use as directed: Supply Quantity 60 sachet: Issued 0: Max Issue 6	General health
<input type="checkbox"/>	>FruitiVits oral powder 6g sachets (Vitaflor International Ltd) started 28 Apr 2022 use as directed: Supply Quantity 30 sachet: Issued 0: Max Issue 6	General health
<input type="checkbox"/>	>K.Quik liquid (Vitaflor International Ltd) started 28 Apr 2022 use as directed: Supply Quantity 2250 ml: Issued 0: Max Issue 6	General health
<input type="checkbox"/>	>KetoCal 4:1 powder vanilla (Nutricia Ltd) started 28 Apr 2022 use as directed: Supply Quantity 300 gram: Issued 0: Max Issue 6	General health
<input type="checkbox"/>	>Lactulose 3.1-3.7g/5ml oral solution started 28 Apr 2022 10ml once a day: Supply Quantity 500 ml: Issued 1: Max Issue 6: Last Issued 30/06/2022	General health
<input type="checkbox"/>	>Levetiracetam 100mg/ml oral solution sugar free started 28 Apr 2022 give 400mg twice daily: Supply Quantity 300 ml: Issued 3: Max Issue 6: Last Issued 15/08/2022	General health
<input type="checkbox"/>	>Liquigen emulsion (Nutricia Ltd) started 28 Apr 2022 use as directed: Supply Quantity 2000 ml: Issued 0: Max Issue 6	General health
<input type="checkbox"/>	>Melatonin 2mg capsules started 28 Apr 2022 take two capsules daily: Supply Quantity 60 capsule: Issued 1: Max Issue 6: Last Issued 14/07/2022	General health
<input type="checkbox"/>	>Phenobarbital 50mg/5ml oral solution started 28 Apr 2022 take 38mg (3.8ml) twice a day: Supply Quantity 400 ml: Issued 3: Max Issue 6: Last Issued 15/08/2022	General health
<input type="checkbox"/>	>Sennosides 7.5mg/5ml oral solution sugar free started 28 Apr 2022 1x5ml spoon at night: Supply Quantity 500 ml: Issued 1: Max Issue -1: Last Issued 30/06/2022	General health

For the clinicians involved, PKB has meant that:

- partnership working with the parent/carer
- safety of prescriptions has improved
- medication review is much easier
- care plans are easier to maintain
- parents can be directed to the library
- videos are available which involve the parents to explain the different aspects of epilepsy care
- feeding into a National Audit for Epilepsy is much easier
- video secure-upload function means clinicians can give a quick review and opinion on seizures
- parents are able to manage their child's condition
- allows clinicians to prioritise messages
- availability of the seizure diary is helpful

For parents and Children, PKB has meant:

- reduced the burden of care
- all the information can be held digitally in one place
- don't have to worry about misplacing or losing information
- information is easier to retrieve
- **parents not having to keep repeating their stories**
- **patient experience has improved especially during admissions**
- **improved medicines safety**
- **makes appointments with tertiary clinicians more meaningful**
- **communication** with their health and care professionals has improved
- **it has enabled partnership working** for both patients and clinicians
- improved access
- **gives families the confidence to go away on holiday**
- **parents can offload any questions or queries by messaging the clinician's day or night!**

Raising epilepsy awareness in our community

Inspire Radio Station



The Health And Fitness Show

Leaflets explaining PKB in English, Urdu & Bengali



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PKB - A PATIENT HELD RECORD



one central place to store

- Seizure diary and videos
- Epilepsy care plans
- Medical history
- 'All About Me' plan
- Medicines, allergies and diagnoses

Parents, carers and patients can:

- record and share moments when they happen
- message the Epilepsy Team if they need help
- refer to the resource library for help and advice

A PILOT FOR LUTON PAEDIATRIC EPILEPSY
PATIENTS ONLY!

To register call 0333 405 0079

"our first family holiday was saved by PKB when our young child had a seizure that wasn't their usual type. We were able to message our epilepsy nurses Liz and Mary through PKB to ask for advice. Liz and Mary reassured us, meaning we didn't have to take our child to an unfamiliar hospital, or cut our holiday short and come home."



Empowering Epilepsy Care, Saving Time, Improving Lives



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পিকেবি [PKB] - পেশেন্ট হেলথ রেকর্ড



একটি কেন্দ্রীয় স্থান যেখানে সংরক্ষিত থাকে:

- খিঁচুনির [সিজার] ডাইরি ও ভিডিও
- মৃগী রোগীর পরিচর্যার পরিকল্পনা
- চিকিৎসার ইতিহাস
- 'অল অ্যাবাউট মি [আমার সম্পর্কে সব]' পরিকল্পনা
- ওষুধ, অ্যালার্জি এবং রোগ নির্ণয়

মা-বাবা, কেয়ারার এবং রোগীরা:

- খিঁচুনি উঠলে তা রেকর্ড ও শেয়ার করতে পারবেন
- তাঁদের সাহায্যের প্রয়োজন হলে এপিলেপসি টিমকে ম্যাসেজ দিতে পারবেন
- সাহায্য এবং পরামর্শের জন্য রিসোর্স লাইব্রেরিতে রেফার করতে পারবেন

শুধুমাত্র লুটন পেডিয়াট্রিক এপিলেপসি রোগীদের জন্য
একটি পরীক্ষামূলক ব্যবস্থা!

নিবন্ধন করার জন্য 0333 405 0079 নম্বরে ফোন করুন

"পিকেবি আমাদের প্রথম পারিবারিক ছুটিটি নষ্ট হওয়ার হাত থেকে বাঁচিয়েছিল যখন আমাদের ছোটো বাচ্চার একটি অস্বাভাবিক ধরনের খিঁচুনি উঠেছিল। তখন পরামর্শ চেয়ে আমরা পিকেবি'র মাধ্যমে আমাদের এপিলেপসি নার্স লিজ ও মেরিকে ম্যাসেজ দিতে সক্ষম হই। লিজ ও মেরি আমাদের আশ্বস্ত করেন, যার ফলে আমাদের সন্তানকে একটি অপরিচিত হাসপাতালে নিয়ে যেতে হয়নি, বা আমাদের ছুটির মেয়াদ কমিয়ে বাসায় ফিরে আসতে হয় নি।"



এপিলেপসি পরিচর্যার ক্ষমতায়ন, সময় বাঁচানো, জীবন উন্নত করা



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PKB - ایک مریض کا ریکارڈ



ذخیرہ کرنے کے لیے ایک مرکزی جگہ

- بیماری کی ڈائری اور ویڈیوز
- مرگی کی دیکھ بھال کے منصوبے
- طبی تاریخ
- 'میرے بارے میں سب' منصوبہ
- ادویات، الرجی اور تشخیص

والدین، دیکھ بھال کرنے والے اور مریض یہ کر سکتے ہیں:

- لمحات کو ریکارڈ کریں اور شیئر کریں جب وہ واقع ہوں
- اگر انہیں مدد کی ضرورت ہو تو مرگی ٹیم کو پیغام دیں
- مدد اور مشورے کے لیے ریسورس لائبریری سے رجوع کریں

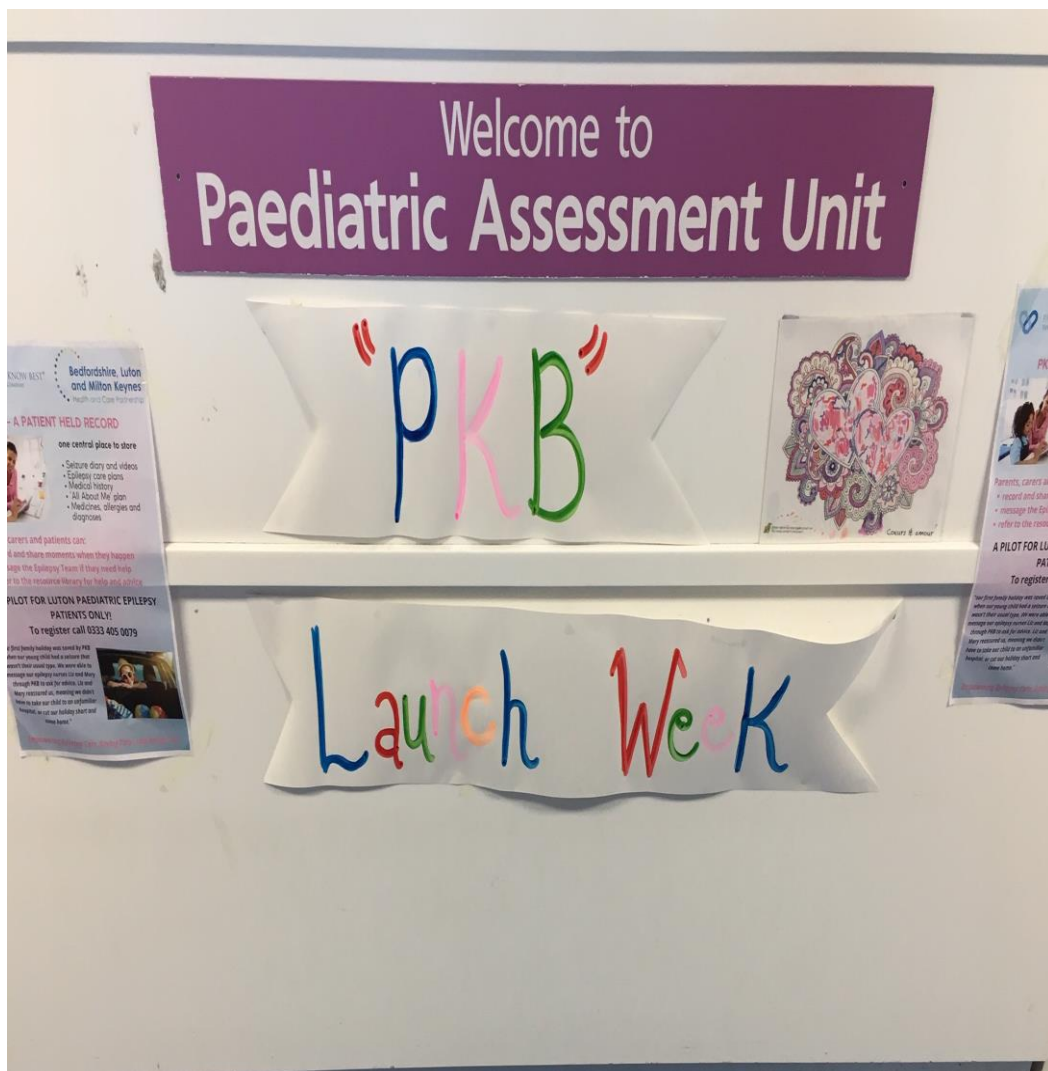
صرف لوٹن پیڈیاٹرک مرگی کے مریضوں کے لیے ایک راہنما!
رجسٹر کرنے کے لیے 0333 405 0079 پر کال کریں



"بمباری پہلی خاندانی چھٹی PKB نے اس وقت محفوظ کی تھی جب ہمارے چھوٹے بچے کو دورہ پڑا تھا جو ان کی معمول کی قسم کا نہیں تھا۔ ہم اپنی مرگی کی نرسوں لڑ اور مریم کو PKB کے ذریعے مشورہ دینے کے لیے پیغام بھیجنے کے قابل تھے۔ لڑ اور مریم نے ہمیں یقین دلایا، یعنی ہمیں اپنے بچے کو کسی ناواقف ہسپتال میں لے جانے کی ضرورت نہیں تھی یا اپنی چھٹیاں مختصر کر کے گھر آنے کی ضرورت نہیں تھی۔"

مرگی کی دیکھ بھال کو بالاختیار بنانا، وقت کی بچت، زندگیوں کو بہتر بنانا

PAU Launch Week (25th July 2022)



Parents sharing their stories with local executives



A podcast with the executives



Liz Stevens (Childrens Epilepsy Specialist Nurse)

Cambridgeshire Community Services NHS Trust

Questions relevant to young people

Gender: how do you prefer to be known?

Select

Other:

My epilepsy (and how to manage)

Think about describing your seizures to a friend - what would you say?

How would you tell your friend the first aid you would need for one of your seizures?

What did you talk about at your last appt?

How am I doing in this section?



More on mental health

Thinking about my mental health

What do you like about school for you?

e.g. seeing friends, sports, subjects

What do you not like about school?

e.g. friendship problems, learning

Do you worry about having a seizure at school/work/outside etc?

Select

How do you deal with exam stress?

How am I doing in this section?

☐ 😊 ☐ 😐 ☐ 😞

☐ 😊 ☐ 😞

How does epilepsy impact on your life?

Have you ever experienced bullying?

Select

How do you feel about your epilepsy?

☐ 😊 ☐ 😐 ☐ 😞

☐ 😊 ☐ 😞

How do you deal with your emotions?

How happy with daily life are you?

☐ 😊 ☐ 😐 ☐ 😞

☐ 😊 ☐ 😞

Co- production with young people



Development of PKB digital epilepsy transition programme

Partnership with Children's Epilepsy Nurses and Young Epilepsy but with focus on views/opinions of young people

Local but including other areas of UK

Free text and drop down options

My medications

How do you remember the name and dose of your medicine?

How do you remember to take your medicine?

How often do you miss a dose?

- ✓ Select
- Never
- Rarely
- Sometimes
- Often
- Always

How am I doing in this section?



How would you get your repeat medicines?

What young people told us

Enable young people to engage-
good way to start

Helps young people to think about their future which includes epilepsy

Questions all good likes the section on mental health-
made her think of her own needs

Helped me to engage in transition work

We have ownership of the process

Answers will be much richer than the programme used before

Thank you for
making me
part of this

Title pending...



Lily's Story



Medical History and medicines showing on PKB

General health

Medical History

Action plan

In the boxes below please provide us with details of your child's medical history.

Pregnancy — any concerns?

Birth history — Prematurity / Concerns at delivery / Admitted to special care

Immunisation status up to date? ☐ Yes ☐ No

If incomplete, why?

Previous surgeries

PlansMedicinesLibrary

Medicines

Add medication

Current medicines

☒

Resource ThickenUp Clear powder (Nestle Health Science)

started 12 Sep 2022 ending 10 Oct 2022

use as directed: Supply Quantity 127 gram

General health

☐

Source: Apollo on behalf of Dr Aasim Siddique, Barton Hills Medical Group entered on 14 Sep 2022

Dm+d: 35325911000001103 (Medication)

Received via Integration (HL7)

☒

Hyoscine 1mg/72hours transdermal patches

started 06 Sep 2022

ending 30 Sep 2022

apply half patch every 72 hours: Supply Quantity 4 patch

General health

☐

Source: Apollo on behalf of Helen Duffy, Barton Hills Medical Group entered on 14 Sep 2022

Dm+d: 38898011000001108, CTV3: dh87. (Medication)

Received via Integration (HL7)

☒

Chloral hydrate 500mg/5ml oral solution

started 28 Apr 2022

take 5 mls prn: Supply Quantity 100 ml: Issued 1: Max Issue 6: Last Issued 14/07/2022

General health

☐

Source: Apollo on behalf of Dr Maria Stratford, Barton Hills Medical Group entered on 14 Sep 2022

Dm+d: 8357711000001101 (Medication)

Received via Integration (HL7)

☒

Clobazam 5mg/5ml oral solution

started 28 Apr 2022

1mg (1ml) once a day during the night: Supply Quantity 300 ml: Issued 3: Max Issue 6: Last Issued 15/08/2022

General health

☐

Source: Apollo on behalf of Dr Maria Stratford, Barton Hills Medical Group entered on 14 Sep 2022

Dm+d: 8368611000001103, CTV3: d266. (Medication)

Received via Integration (HL7)

☒

CosmoCol Plain oral powder sachets (Stirling Anglian Pharmaceuticals Ltd)

started 28 Apr 2022

use as directed: Supply Quantity 60 sachet: Issued 0: Max Issue 6

General health

☐

Source: Apollo on behalf of Dr Maria Stratford, Barton Hills Medical Group entered on 14 Sep 2022

Dm+d: 28751911000001106, CTV3: ae4n. (Medication)

Received via Integration (HL7)

Journal Entry (PKB)

Appointments

Journal

Journal

Add entry



2/9/22-11/9/22

12 Sep 2022 12:22

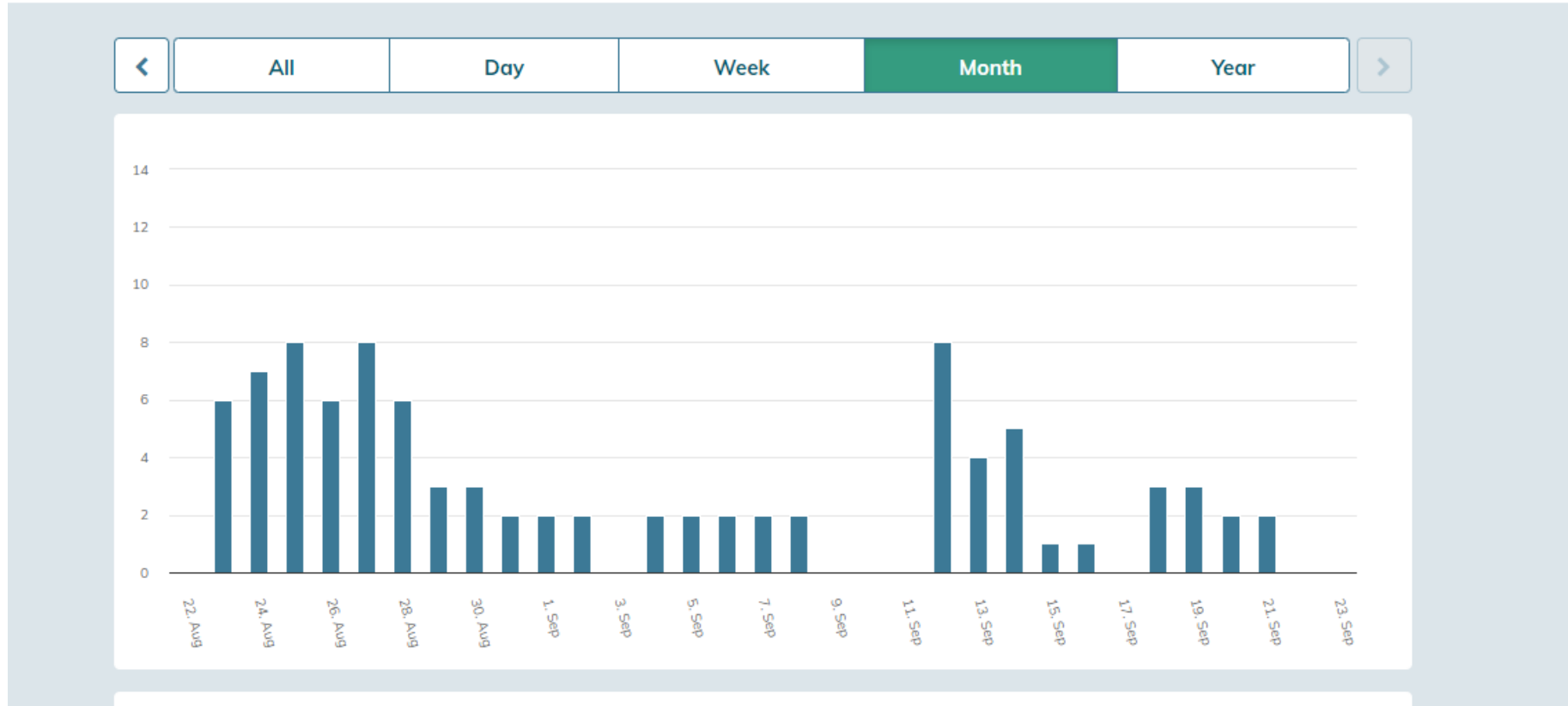
Lily has had a great first week back to school. She has settled into tulip class so well.

She had put on weight, she now weighs 20.2 kg which is a massive improvement.

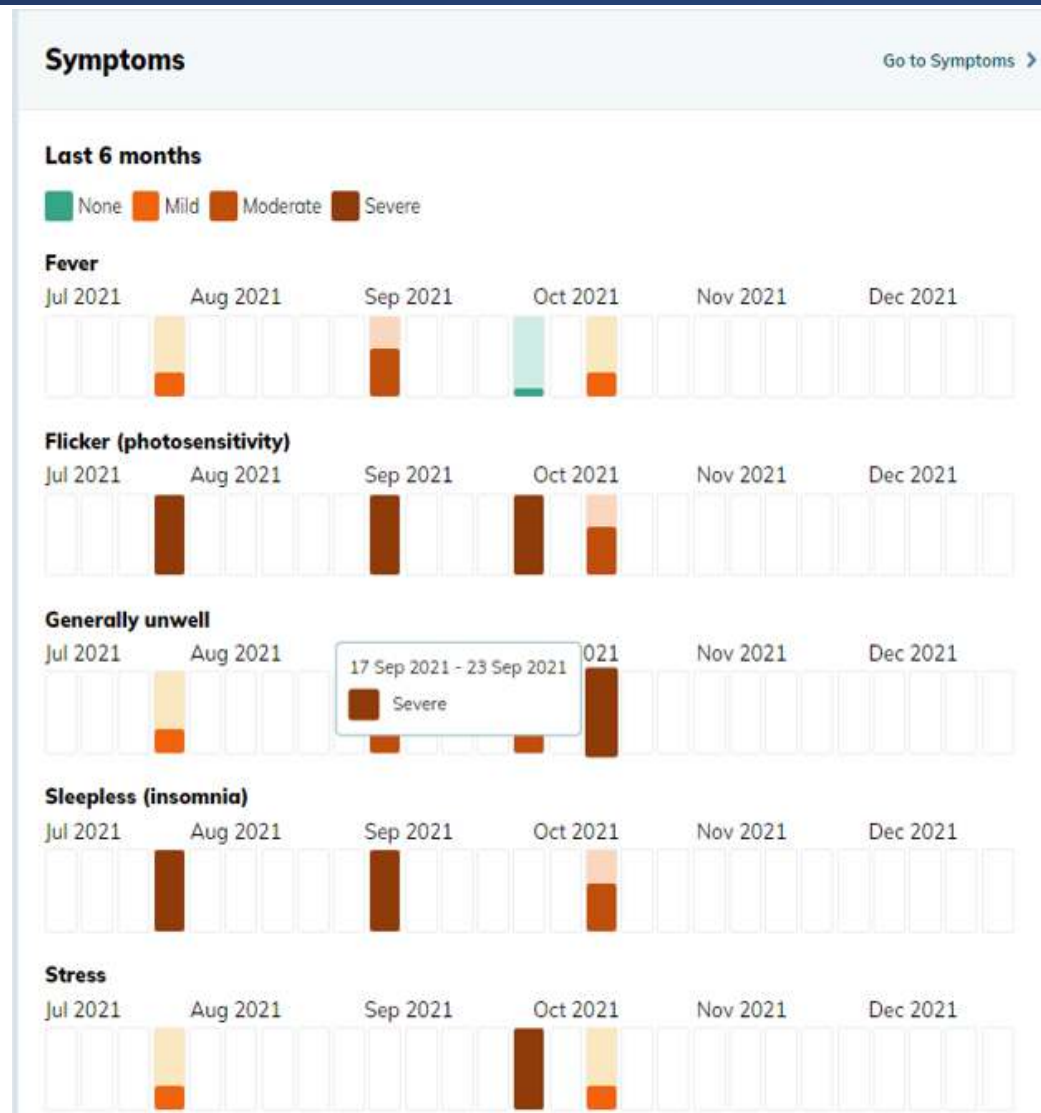
She has only had one seizure at school this week. 🥳🥳🥳🥳🥳🥳

📍 General health

Seizure diary Aug - Sept 2021



Seizure Triggers (PKB)



Seizure Diary

Monitoring

Update date

23/09/2021

13:21

Symptoms

[Go to Symptoms >](#)

Fever

None

Mild

Moderate

Severe

Flicker (photosensitivity)

None

Mild

Moderate

Severe

Generally unwell

None

Mild

Moderate

Severe

Sleepless (insomnia)

None

Mild

Moderate

Severe

Stress

None

Mild

Moderate

Severe

Tired (fatigue)

None

Mild

Moderate

Severe

Measurements

[Go to Measurements >](#)

Lennox-Gastaut syndrome

- This epilepsy syndrome is uncommon and occurs in between 1 and 5 in every 100 children with epilepsy.
- However, it is the most common type of intractable (difficult to treat) childhood epilepsy. It is also known as an 'epileptic and developmental encephalopathy' because the epileptic seizures and the abnormal EEG are thought to be important in these childrens' developmental delay and learning difficulties.
- The most common time for Lennox- Gastaut syndrome to start is between 3 and 5 years of age although it can start as early as 18 months or as late as 7 years of age.

Video uploaded onto the PKB Platform

Journal

Record your own observations about your health here.

Add entry



Miss Usha Panchal ⓘ

New seizure


16 Jun 2022 13:37

Seizure triggers:

Description of the seizure:

What happened after the seizure:

 Buzz Lightyear - Seizure (DOG).MOV

 General health




Miss Usha Panchal ⓘ

Messaging within PKB

Back to my patients Summary Events & messages Health Treatments Diary Files Devices Sharing

Events & messages

Send message 

As discussed on the phone. I am confirming that I have discussed the latest change in seizures with Dr Tekki Rao. He recommended that if she had another prolonged seizure of a head drop followed by recurrent episodes of head and eyes turning to right with apparent loss of awareness and dribbling, to call 999 after 30 minutes and give midazolam on their arrival if the cluster continues and there are no concerns about breathing.

Hopefully she will settle down and have a good holiday

Kind regards
Liz

Send a message

Do not use this for urgent problems as your message may not be read immediately.

To: **Patient**

☒ Miss Usha Panchal

If the person you want to message is not listed you can invite them if you know their email address.

Subject

Message

Dear Dr Allen,

Just to let you know Usha had a seizure today in the morning.
More info in the seizure diary. Video of the seizure is in the journal.

Thank you
Mum

Attachment

+ Add file

Up to 10 GB



Seizure diary translated into French

Mesures

[Allez dans Mesures >](#)

Doses de médicaments de sauvetage données dans une journée (compte)

0

Nombre de médicaments manqués aujourd'hui

0

Type de convulsion n°1 (comptage quotidien)

1

Type de convulsion n°2 (comptage quotidien)

2

Type de convulsion n°3 (comptage quotidien)

0

Type de convulsion n°4 (comptage quotidien)

0

Seizure Diary

Surveillance

Actualiser la date

14/09/2022



14:11

Symptômes

[Allez dans Symptômes >](#)

Fièvre

Aucun

Légère

Modéré

Sévère

Scintillement (photosensibilité)

Aucun

Légère

Modéré

Sévère

Généralement malade

Aucun

Légère

Modéré

Sévère

Insomnie

Aucun

Légère

Modéré

Sévère

Stress

Aucun

Légère

Modéré

Sévère

Fatigué (fatigue)

Aucun

Légère

Modéré

Sévère

Emergency Care Plan (PKB)

Action plan

Attached is the PDF of your child's emergency care plan. Please note — A member of the Epilepsy team will inform you if you need this treatment.

This care plan has been individualised to meet the needs of your child and should be followed in the case of an emergency, when rescue medication is required.

Please note — only trained family members and professionals are advised to administer rescue medication.

Please see videos below of how to give Buccolam & Epistatus for emergency treatment. Please check your brand of medication to ensure you watch the correct video.

Buccolam

Click [here](#) for more information about Buccolam.



Emergency care plan Buccolam 2 doses.doc (1).pdf ^

1 of 2



Luton and Dunstable Hospital
NHS Foundation Trust

Date:

Review date:

EMERGENCY PLAN OF CARE FOR SEIZURES

Name:	Danny Duck-TestPatient	DOB:	01 Jan 2001
NHS:		Hospital No:	
Mother:		Contact No:	
Father:		Contact No:	

Current Medication

(Epilepsy medication only - If there is a list of other medications, supply separate appendix of medication from main care plan if attending hospital)

Description of Seizures:

(Include any details on duration, frequency and recovery of seizures requiring rescue medication)

Name of Rescue Medication	Buccolam pre filled syringes mg/mL
Route of Rescue Medication	Buccal
First Dose:	mg pre-filled syringe
Second Dose:	mg pre-filled syringe

Do not repeat treatment within 24 hours or give more than twice in week / month
If Midazolam brand is changed contact Nurse so the Care Plan can be revised

Directions for use

(Eg for seizures lasting more than 5 minutes. Please specify directions for seizure clusters)

Guidelines for the Community

Identify need for Emergency Medication – if seizure continues for ... minutes

Give buccal Midazolam —mg as Buccolam pre-filled syringe

Seizure stops – stay with Danny until fully recovered

Download file

PKB is first and only PHR integrated
with NHS App and NHS login

NHS Login single sign-on into PKB
NHS App user interface embeds
PKB functionality



Luton Epilepsy Clinicians and project team





Lily's Family

THANK YOU