RCPCH Epilepsy Quality Improvement Programme
November 2019 – July 2020

Individualised emergency seizure plan

York Teaching Hospitals NHS Foundation Trust

RCPCH Epilepsy Quality Improvement Programme project team:

Dr Ianthe Abbey, Consultant paediatrician with an interest in epilepsy
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Dr Lisa Harrison, Chief Neurophysiologist

National audit results included within this case study acts as a guide only to performance standards. The service improvements made during the EQIP cannot be entirely attributed to the reported results in the Epilepsy12.

Individualised emergency seizure plan – York Teaching Hospitals NHS Foundation Trust

Project aim

To develop a digital epilepsy passport to communicate information to children and young children with the aim of improving their care and reducing risk by June 2020.

Background

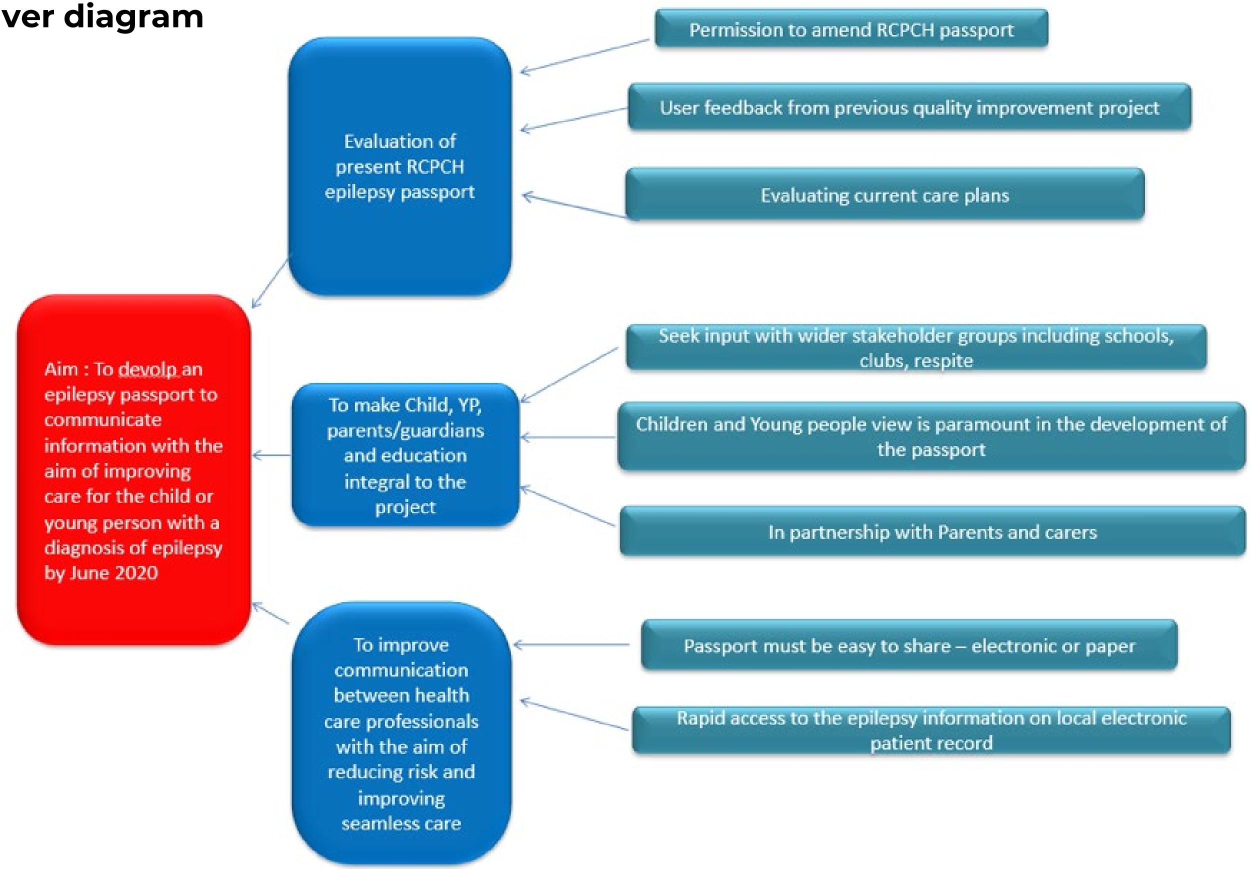
Prior to the EQIP, the York Teaching Hospitals NHS Foundation Trust paediatric epilepsy team experienced the misplacement of paper copy individualised emergency seizure plan for patients with complex epilepsy seen in the Emergency Department (ED). This would result in long delays in clinical treatment or the patient requiring intensive care admission because of the difficulties with locating the digital copy of the plan on the Trust system. Patients' and families' feedback on whether they felt the service held sufficient information on their child's epilepsy were: 70% of families reported the service held sufficient information, 20% felt the current system was helpful to their child, and only 30% felt the schools found the current communication useful. When asked if a passport would be an improvement: 80% of families reported they strongly agreed it would help parents and carers; 90% strongly agreed it would help the child.

Area of focus

- To create an alert for the individualised emergency seizure plans on the electronic medical records.
- To develop and test a patient held Epilepsy passport, incorporating an individual epilepsy care plan.

Individualised emergency seizure plan – York Teaching Hospitals NHS Foundation Trust

Team driver diagram



Aim : To devolp an epilepsy passport to communicate information with the aim of improving care for the child or young person with a diagnosis of epilepsy by June 2020

Evaluation of present RCPCH epilepsy passport

- Permission to amend RCPCH passport
- User feedback from previous quality improvement project
- Evaluating current care plans

To make Child, YP, parents/guardians and education integral to the project

- Seek input with wider stakeholder groups including schools, clubs, respite
- Children and Young people view is paramount in the development of the passport
- In partnership with Parents and carers

To improve communication between health care professionals with the aim of reducing risk and improving seamless care

- Passport must be easy to share – electronic or paper
- Rapid access to the epilepsy information on local electronic patient record

RCPCH EQIP
Epilepsy quality improvement programme

Individualised emergency seizure plan – York Teaching Hospitals NHS Foundation Trust

Changes

- The team focused on two main changes for their improvement project. The first was to arrange a meeting with their Trust IT development team and the patient safety lead to discuss the effects of when ED staff are unable to find a digital copy of the patient's individual emergency seizure plan, and the length of time it takes in comparison to finding an allergy status for a patient on the hospital system. Emphasising the importance of immediate treatment for patients experiencing seizures when a child arrives in the ED. The meeting resulted in confirming the addition of the alert to the hospital system against all epilepsy emergency seizure plans.
- A review of the RCPCH Epilepsy passport led to the redesign of a Trust version of the passport that went through multiple tests and iterations with NHS colleagues and patients and families. The feedback provided feeds into changes to enable more space for seizure descriptions and emergency rescue plans.

Additional feedback captured from patients and families advised the following:

- Make the passport more user-friendly.
- Incorporate a clear individual care plan.
- Be more specific for the child.
- Aimed at the wrong target audience (e.g., currently focused on doctor-to-doctor communication).

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Results from developing the passport in co-production with patients and families

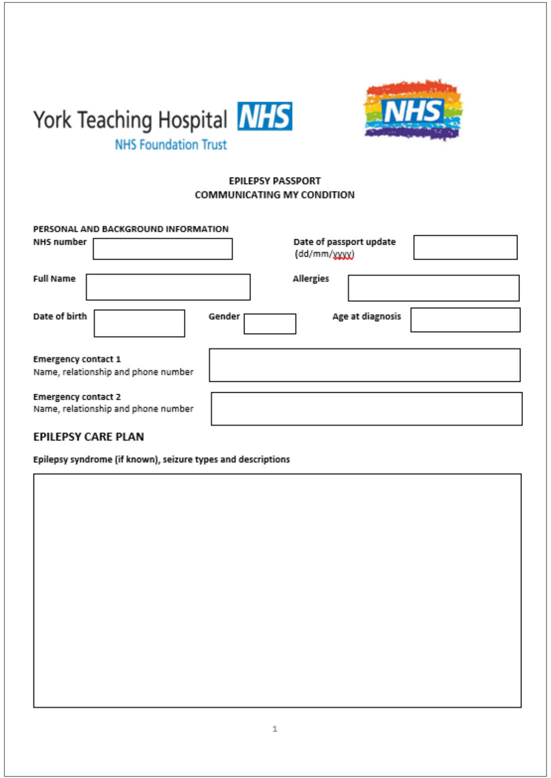
Using PDSA (Plan, Do, Study, Act) QI methodology, the Trust version of the passport went through several tests of change, which highlighted required changes in formatting the document to keep the document concise and created additional use of space for a detailed seizure description for non-medical carers. Identified inconsistencies in the use of medical terminology. The medical language was simplified, and the list of epilepsy syndromes was removed because it was not helpful to parents, carers, or education staff. Changed sections on when to call an ambulance from "If you believe that the child/young person needs urgent medical attention" to "If you remain worried about the child/young person".

Lots of positive feedback had been received, which had been shared widely.

- Reduce the non-drug treatment section to one text box from three text boxes.
- Removed conflicting statements on seizure management; many non-essential parts were removed.
- Electronic links to additional seizure information were added, and the same information was given in paper copy.
- Identified the need to gain permission from BUCCOLAM (the treatment medication for prolonged, acute, convulsive seizures in patients) to include their images for administration guidance.
- Identified the need to approach Epilepsy Action to request the inclusion of their first-aid seizure advice.

Individualised emergency seizure plan – York Teaching Hospitals NHS Foundation Trust

Results from developing the passport in co-production with patients and families



York Teaching Hospital NHS
NHS Foundation Trust

EPILEPSY PASSPORT
COMMUNICATING MY CONDITION

PERSONAL AND BACKGROUND INFORMATION

NHS number

Date of passport update (dd/mm/yyyy)

Full Name

Allergies

Date of birth

Gender

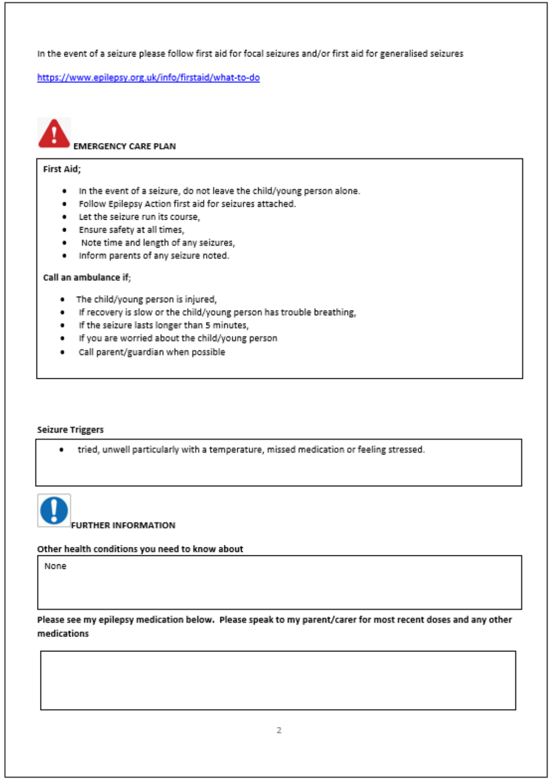
Age at diagnosis

Emergency contact 1
Name, relationship and phone number

Emergency contact 2
Name, relationship and phone number

EPILEPSY CARE PLAN

Epilepsy syndrome (if known), seizure types and descriptions



In the event of a seizure please follow first aid for focal seizures and/or first aid for generalised seizures

https://www.epilepsy.org.uk/info/firstaid/what-to-do

EMERGENCY CARE PLAN

First Aid;

- In the event of a seizure, do not leave the child/young person alone.
- Follow Epilepsy Action first aid for seizures attached.
- Let the seizure run its course,
- Ensure safety at all times,
- Note time and length of any seizures,
- Inform parents of any seizure noted.

Call an ambulance if;

- The child/young person is injured,
- If recovery is slow or the child/young person has trouble breathing,
- If the seizure lasts longer than 5 minutes,
- If you are worried about the child/young person
- Call parent/guardian when possible

Seizure Triggers

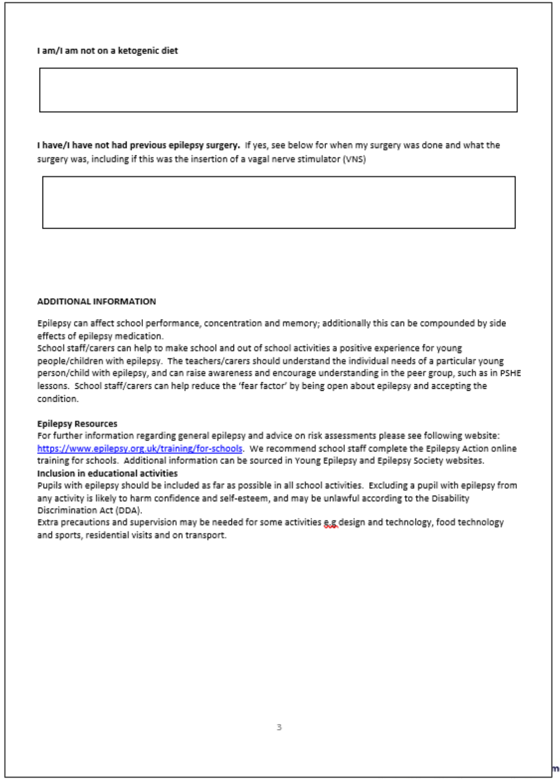
- tried, unwell particularly with a temperature, missed medication or feeling stressed.

FURTHER INFORMATION

Other health conditions you need to know about

None

Please see my epilepsy medication below. Please speak to my parent/carer for most recent doses and any other medications



I am/I am not on a ketogenic diet

I have/I have not had previous epilepsy surgery. If yes, see below for when my surgery was done and what the surgery was, including if this was the insertion of a vagal nerve stimulator (VNS)

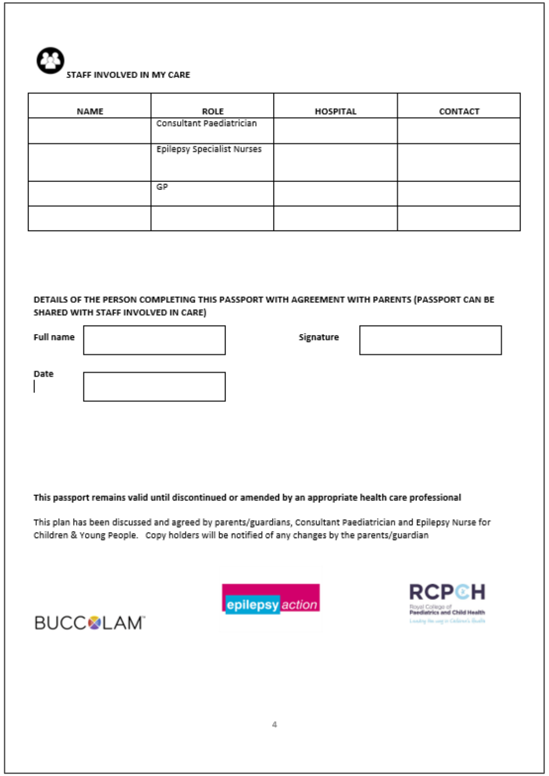
ADDITIONAL INFORMATION

Epilepsy can affect school performance, concentration and memory; additionally this can be compounded by side effects of epilepsy medication.
School staff/carers can help to make school and out of school activities a positive experience for young people/children with epilepsy. The teachers/carers should understand the individual needs of a particular young person/child with epilepsy, and can raise awareness and encourage understanding in the peer group, such as in PSHE lessons. School staff/carers can help reduce the 'fear factor' by being open about epilepsy and accepting the condition.

Epilepsy Resources
For further information regarding general epilepsy and advice on risk assessments please see following website: https://www.epilepsy.org.uk/training/for-schools. We recommend school staff complete the Epilepsy Action online training for schools. Additional information can be sourced in Young Epilepsy and Epilepsy Society websites.
Inclusion in educational activities
Pupils with epilepsy should be included as far as possible in all school activities. Excluding a pupil with epilepsy from any activity is likely to harm confidence and self-esteem, and may be unlawful according to the Disability Discrimination Act (DDA).
Extra precautions and supervision may be needed for some activities e.g design and technology, food technology and sports, residential visits and on transport.

Individualised emergency seizure plan – York Teaching Hospitals NHS Foundation Trust

Results from developing the passport in co-production with Epilepsy Action



STAFF INVOLVED IN MY CARE

NAME	ROLE	HOSPITAL	CONTACT
	Consultant Paediatrician		
	Epilepsy Specialist Nurses		
	GP		

DETAILS OF THE PERSON COMPLETING THIS PASSPORT WITH AGREEMENT WITH PARENTS (PASSPORT CAN BE SHARED WITH STAFF INVOLVED IN CARE)

Full name ______ **Signature** ______

Date ______

This passport remains valid until discontinued or amended by an appropriate health care professional

This plan has been discussed and agreed by parents/guardians, Consultant Paediatrician and Epilepsy Nurse for Children & Young People. Copy holders will be notified of any changes by the parents/guardian

BUCCOLAM™ epilepsy action RCPCH Royal College of Paediatrics and Child Health

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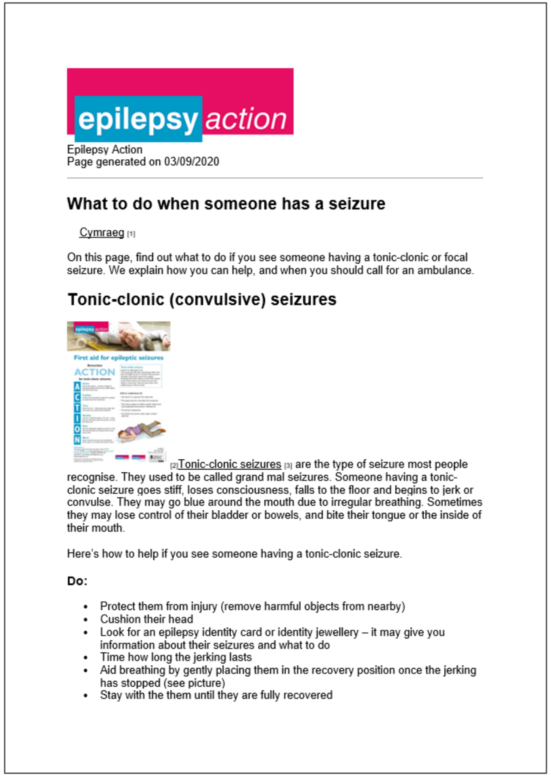


epilepsy action

Epilepsy Action
Page generated on 03/09/2020

What to do when someone has a seizure

Cymraeg [1]

On this page, find out what to do if you see someone having a tonic-clonic or focal seizure. We explain how you can help, and when you should call for an ambulance.

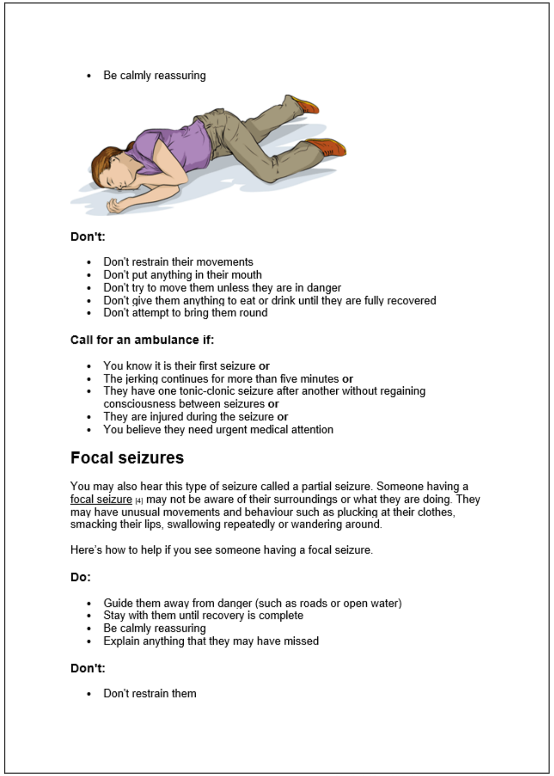
Tonic-clonic (convulsive) seizures

[2]Tonic-clonic seizures [3] are the type of seizure most people recognise. They used to be called grand mal seizures. Someone having a tonic-clonic seizure goes stiff, loses consciousness, falls to the floor and begins to jerk or convulse. They may go blue around the mouth due to irregular breathing. Sometimes they may lose control of their bladder or bowels, and bite their tongue or the inside of their mouth.

Here's how to help if you see someone having a tonic-clonic seizure.

Do:

- Protect them from injury (remove harmful objects from nearby)
- Cushion their head
- Look for an epilepsy identity card or identity jewellery – it may give you information about their seizures and what to do
- Time how long the jerking lasts
- Aid breathing by gently placing them in the recovery position once the jerking has stopped (see picture)
- Stay with the them until they are fully recovered



- Be calmly reassuring

Don't:

- Don't restrain their movements
- Don't put anything in their mouth
- Don't try to move them unless they are in danger
- Don't give them anything to eat or drink until they are fully recovered
- Don't attempt to bring them round

Call for an ambulance if:

- You know it is their first seizure **or**
- The jerking continues for more than five minutes **or**
- They have one tonic-clonic seizure after another without regaining consciousness between seizures **or**
- They are injured during the seizure **or**
- You believe they need urgent medical attention

Focal seizures

You may also hear this type of seizure called a partial seizure. Someone having a focal seizure [4] may not be aware of their surroundings or what they are doing. They may have unusual movements and behaviour such as plucking at their clothes, smacking their lips, swallowing repeatedly or wandering around.

Here's how to help if you see someone having a focal seizure.

Do:

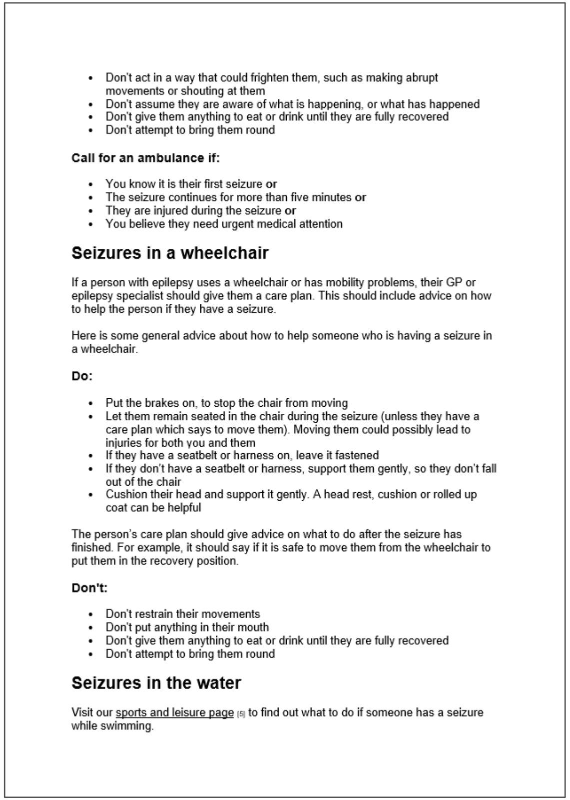
- Guide them away from danger (such as roads or open water)
- Stay with them until recovery is complete
- Be calmly reassuring
- Explain anything that they may have missed

Don't:

- Don't restrain them

Individualised emergency seizure plan – York Teaching Hospitals NHS Foundation Trust

Results from developing the passport in co-production with BUCCOLAM



- Don't act in a way that could frighten them, such as making abrupt movements or shouting at them
- Don't assume they are aware of what is happening, or what has happened
- Don't give them anything to eat or drink until they are fully recovered
- Don't attempt to bring them round

Call for an ambulance if:

- You know it is their first seizure **or**
- The seizure continues for more than five minutes **or**
- They are injured during the seizure **or**
- You believe they need urgent medical attention

Seizures in a wheelchair

If a person with epilepsy uses a wheelchair or has mobility problems, their GP or epilepsy specialist should give them a care plan. This should include advice on how to help the person if they have a seizure.

Here is some general advice about how to help someone who is having a seizure in a wheelchair.

Do:

- Put the brakes on, to stop the chair from moving
- Let them remain seated in the chair during the seizure (unless they have a care plan which says to move them). Moving them could possibly lead to injuries for both you and them
- If they have a seatbelt or harness on, leave it fastened
- If they don't have a seatbelt or harness, support them gently, so they don't fall out of the chair
- Cushion their head and support it gently. A head rest, cushion or rolled up coat can be helpful

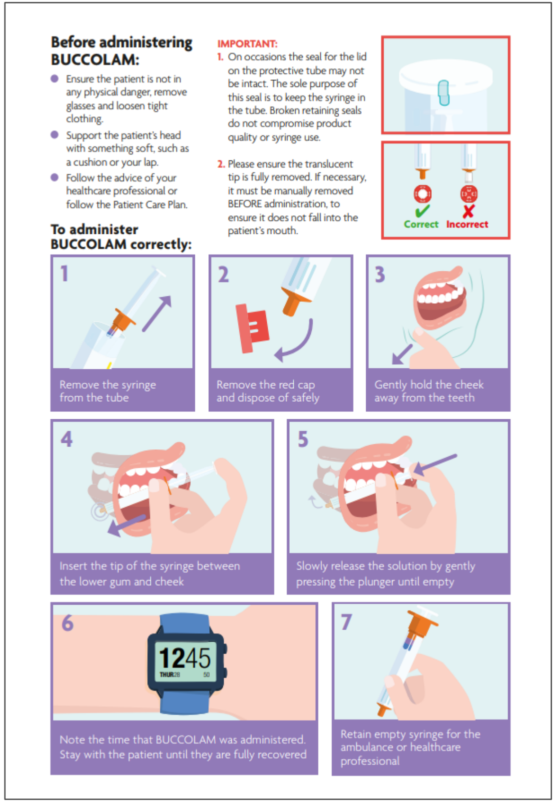
The person's care plan should give advice on what to do after the seizure has finished. For example, it should say if it is safe to move them from the wheelchair to put them in the recovery position.

Don't:

- Don't restrain their movements
- Don't put anything in their mouth
- Don't give them anything to eat or drink until they are fully recovered
- Don't attempt to bring them round

Seizures in the water

Visit our sports and leisure page [5] to find out what to do if someone has a seizure while swimming.



Before administering BUCCOLAM:

- Ensure the patient is not in any physical danger, remove glasses and loosen tight clothing.
- Support the patient's head with something soft, such as a cushion or your lap.
- Follow the advice of your healthcare professional or follow the Patient Care Plan.

IMPORTANT:

1. On occasions the seal for the lid on the protective tube may not be intact. The sole purpose of this seal is to keep the syringe in the tube. Broken retaining seals do not compromise product quality or syringe use.
2. Please ensure the translucent tip is fully removed. If necessary, it must be manually removed BEFORE administration, to ensure it does not fall into the patient's mouth.

To administer BUCCOLAM correctly:

1 Remove the syringe from the tube

2 Remove the red cap and dispose of safely

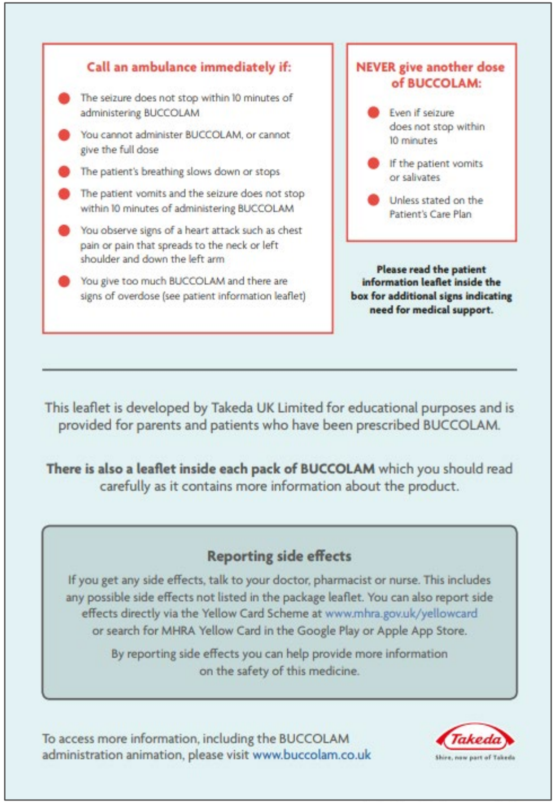
3 Gently hold the cheek away from the teeth

4 Insert the tip of the syringe between the lower gum and cheek

5 Slowly release the solution by gently pressing the plunger until empty

6 Note the time that BUCCOLAM was administered. Stay with the patient until they are fully recovered

7 Retain empty syringe for the ambulance or healthcare professional



Call an ambulance immediately if:

- The seizure does not stop within 10 minutes of administering BUCCOLAM
- You cannot administer BUCCOLAM, or cannot give the full dose
- The patient's breathing slows down or stops
- The patient vomits and the seizure does not stop within 10 minutes of administering BUCCOLAM
- You observe signs of a heart attack such as chest pain or pain that spreads to the neck or left shoulder and down the left arm
- You give too much BUCCOLAM and there are signs of overdose (see patient information leaflet)

NEVER give another dose of BUCCOLAM:

- Even if seizure does not stop within 10 minutes
- If the patient vomits or salivates
- Unless stated on the Patient's Care Plan

Please read the patient information leaflet inside the box for additional signs indicating need for medical support.

This leaflet is developed by Takeda UK Limited for educational purposes and is provided for parents and patients who have been prescribed BUCCOLAM.

There is also a leaflet inside each pack of BUCCOLAM which you should read carefully as it contains more information about the product.

Reporting side effects

If you get any side effects, talk to your doctor, pharmacist or nurse. This includes any possible side effects not listed in the package leaflet. You can also report side effects directly via the Yellow Card Scheme at www.mhra.gov.uk/yellowcard or search for MHRA Yellow Card in the Google Play or Apple App Store.

By reporting side effects you can help provide more information on the safety of this medicine.

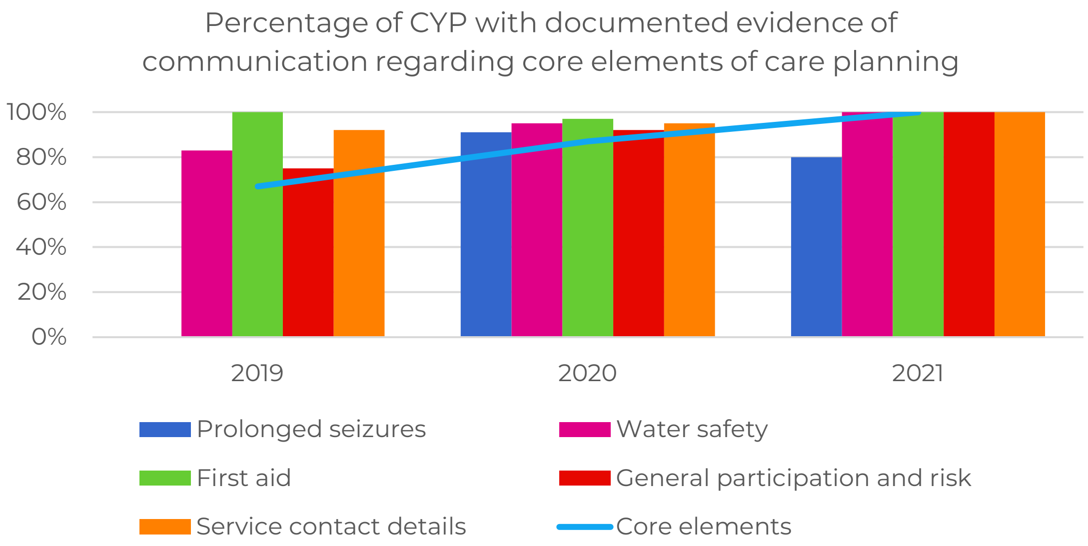
To access more information, including the BUCCOLAM administration animation, please visit www.buccolam.co.uk

Audit results for cohort 3 – Comprehensive care planning content – York Teaching Hospitals NHS Foundation Trust

NICE recommends that children and young people with epilepsy have an agreed and comprehensive care plan (Quality statement 4).

100% of children and young people diagnosed with epilepsy in York Teaching Hospital NHS Foundation Trust had documented evidence of communication regarding relevant core elements of care planning.

The percentage of CYP with evidence of communication regarding each element of care planning has continued to increase in 2021.



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Audit results for cohort 3 – Comprehensive care planning content – York Teaching Hospitals NHS Foundation Trust

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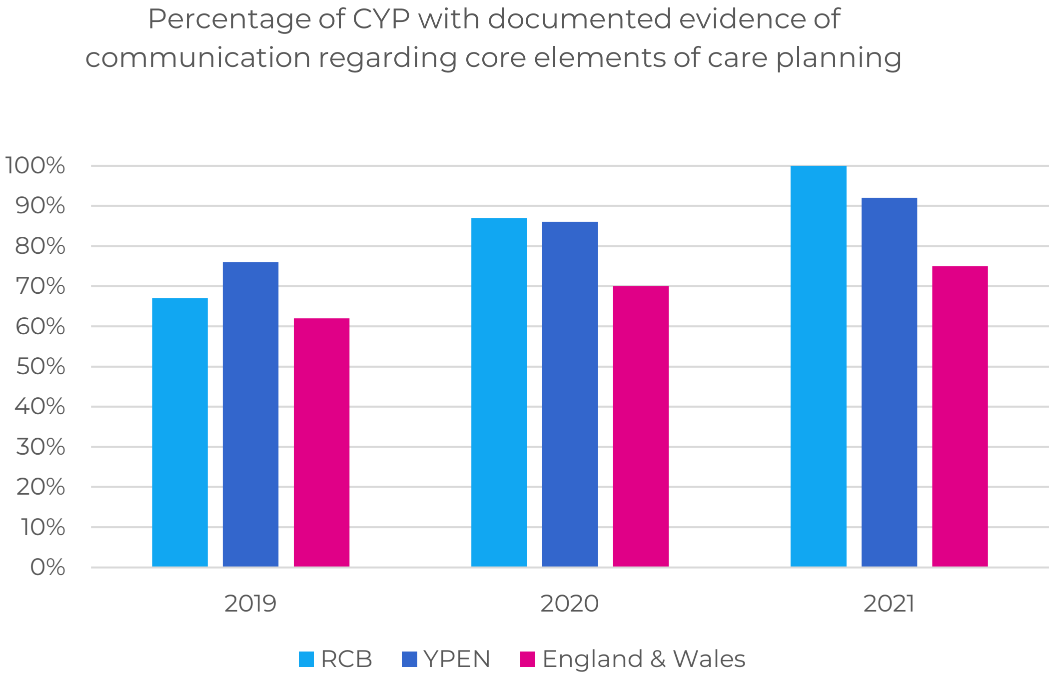
100% of children and young people diagnosed with epilepsy in York Teaching Hospital NHS Foundation Trust had documented evidence of communication regarding relevant core elements of care planning.

The percentage of CYP with evidence of communication regarding each element of care planning has continued to increase in 2021, with most core elements achieving 100%, above regional and national average results.

Percentage of children with documented evidence of discussion of:	2019	2020	2021	2021 – YPEN	2021 – England & Wales
Core elements of care planning	67%	87%	100%	**92%**	**75%**
Parental prolonged seizures care plan	0%	91%	80%	**97%**	**92%**
Water safety	83%	95%	100%	**94%**	**84%**
First aid	100%	97%	100%	**98%**	**87%**
General participation and risk	75%	92%	100%	**94%**	**85%**
Service contact details	92%	95%	100%	**98%**	**93%**

Audit results for cohort 3 – Comprehensive care planning content – York Teaching Hospitals NHS Foundation Trust

The percentage of CYP with evidence of communication regarding core elements of care planning has continued to increase in 2021 and has risen above national and regional levels.



Audit results for cohort 3 – Individualised emergency seizure plan – York Teaching Hospitals NHS Foundation Trust

NICE recommends that children and young people with a history of prolonged or repeated seizures have an agreed written emergency care plan (Quality statement 6).

80% of children and young people diagnosed with epilepsy in York Teaching Hospital NHS Foundation Trust and on rescue medication had a parental prolonged seizure care plan.

The percentage of CYP with evidence of a documented Individualised emergency seizure plan has remained above national and regional levels in 2021.

Performance indicator 10: Comprehensive Care Planning agreement	2019	2020	2021	2021 – YPEN	2021 – England & Wales
% of children and young people with epilepsy after 12 months where there is evidence of a comprehensive care plan that is agreed between the person, their family and/or carers and primary and secondary care providers, and the care plan has been updated where necessary	67%	90%	88%	**86%**	**70%**
% of children and young people with epilepsy after 12 months that had an individualised epilepsy document with individualised epilepsy document or a copy clinic letter that includes care planning information	75%	100%	96%	**94%**	**91%**
% of children and young people with epilepsy after 12 months where there was evidence of agreement between the person, their family and/or carers, as appropriate	75%	90%	88%	**90%**	**79%**
% of children and young people with epilepsy after 12 months where there is evidence that the care plan has been updated where necessary	67%	92%	92%	**88%**	**75%**

Individualised emergency seizure plan – York Teaching Hospitals NHS Foundation Trust

Challenges

- Schools and many other organisations were closed due to the COVID-19 pandemic, which made it difficult to perform tests of the plan in schools, activity clubs, and short-break facilities.
- Epilepsy nurses during the pandemic were being moved predominantly off-site, which became a barrier for the team to provide fast and effective communication with their patients.
- In May, there was recognised apathy amongst the team about the EQIP project, and due to the effects of the pandemic, the project became a low priority.
- Completing the tests and acting upon the changes became time-consuming due to cross-site working. Some team members were working from home, and annual leave was taken at different stages of the project. IT skills were also a challenge!

Individualised emergency seizure plan – York Teaching Hospitals NHS Foundation Trust

Outcomes – the team achieved the following:

- ✓ Increased engagement with IT led to creating an alert for individualised emergency seizure plans on internal systems that is accessible for ED teams.
- ✓ 100% of the individualised emergency seizure plans were uploaded to the Trust system.
- ✓ Developed the structure and content of a locally tested epilepsy passport in co-production with patients, families, and Epilepsy Action.

National audit results confirmed:

- ✓ 100% of children and young people diagnosed with epilepsy in York Teaching Hospital NHS Foundation Trust had documented evidence of communication regarding relevant core elements of care planning.
- ✓ The percentage of CYP with evidence of communication regarding each element of care planning continued to increase in 2021.
- ✓ Most core elements achieved 100%, above regional and national average results.
- ✓ The percentage of CYP with evidence of communication regarding core elements of care planning continued to increase in 2021 and has risen above national and regional levels.
- ✓ 80% of children and young people diagnosed with epilepsy in York Teaching Hospital NHS Foundation Trust and on rescue medication had a parental prolonged seizure care plan.

Individualised emergency seizure plan – York Teaching Hospitals NHS Foundation Trust

Lessons learnt

- We worked collaboratively as a team over the course of the programme and were able to develop better working relationships, despite the difficulties experienced with the pandemic.
- The team plans to distribute the developed passport electronically to families with embedded links that signpost them to extra information, whereas previously this would have been in paper format.
- Stay positive as much as possible!
- In many ways, virtual and remote working have benefited both staff members and families. Although there was no replacement for face-to-face contact, the team plans to continue to review the service changes made.
- Families were generally very understanding of service constraints.
- Many families preferred virtual contact during the pandemic, which could be integrated into future processes.

Visual presentation of team project intervention

- **Video presentation**
- **Poster**

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https://eqip.rcpch.ac.uk

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@RCPCHEQIP

EPILEPSY12

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