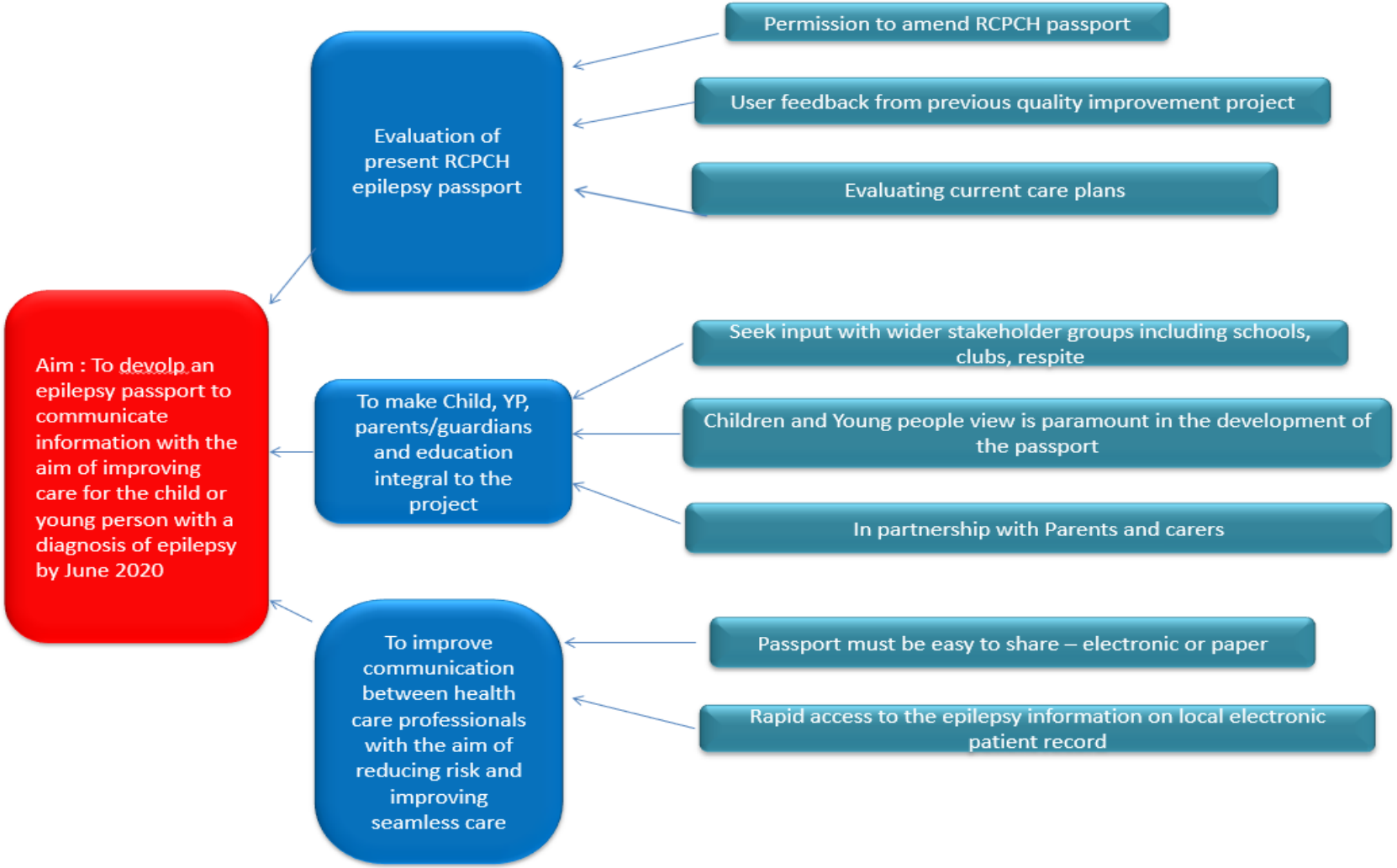
RCPCH EQIP

Epilepsy quality improvement programme

NHS

York Teaching Hospital NHS

NHS Foundation Trust


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

Parents currently find the information to be useful to them.

Four out of five of respondents reported that the Epilepsy Passport had no impact on their life.

Parents think the new passport/IHCP will be useful to them.

Parents think the new passport /IHCP will be useful to their child.

Parents think the new passport /IHCP will be useful for schools and teachers.

Parents thought the York NHS Trust Epilepsy Passport /IHCP is an improvement on current information.

- Strongly Agree
- Agree
- Neither Agree or Disagree
- Disagree
- Strongly Disagree

Review an already developed passport; the RCPCH passport

- Text boxes were too small
- Insufficient space for seizure description
- Midazolam Oromucosal Solution instruction area too limited for those with more than one seizure
- To keep it as a concise document enabling more space for seizure descriptions and expanding of the more valuable parts such as emergency rescue plans

Covid Restrictions!!

Refocus, Rethink, Redesign

- Medical language simplified
- Added space for a detailed seizure description as this is necessary for non-medical carers and describes the child/young person's individual experience of their epilepsy.
- Many non-essential parts removed e.g. removed doses of medication and side effects
- Not child or young person friendly – make it a predominantly electronic document.
- Amalgamation of several different documents – invaluable contribution and support from RCPCH, Epilepsy Action and Buccolam

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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.

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

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

- 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:

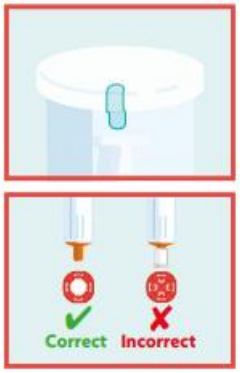
- Ensure the patient is not in any physical danger, remove glasses and loosen tight clothing.
- Support the patient's head with something soft, such as a cushion or your lap.
- Follow the advice of your healthcare professional or follow the Patient Care Plan.

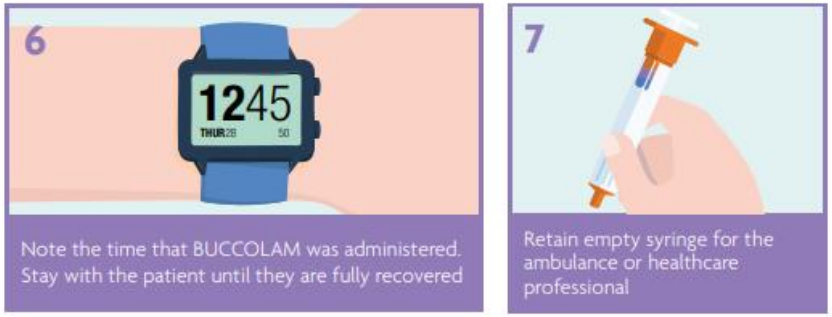
To administer BUCCOLAM correctly:

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.





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

Takeda
Shire, now part of Takeda

Kaizen https://www.universalclass.com/articles/business/adopting-pdca-cycle-in-kaizen.htm

Next Steps

- Ensure all individualized acute emergency seizure plans are accessible on hospital alert system
- Complete formatting and clear with clinical governance
- To roll out the epilepsy passport to all children/young people – make it more child/young person friendly – altering and improving it forever!
- The medical information removed from the original passport needs to be incorporated in an electronic care record.
- With the support of IT, update the child health epilepsy Trust website