Direct Payments and the administration of emergency epilepsy medication policy

Children and Family Services
Together for Families

May 2020
Personalisation Support Team
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Direct Payments & administration of emergency epilepsy medication policy
May 2020
Introduction

This Policy has been developed following consultation with partners in health, parents and carers, and Epilepsy Action. It has been written to provide clarity for the safe administration of emergency medication for those children and young people who have been diagnosed with epilepsy and whose families have chosen to receive direct payments following an assessment of their need under Section 17 of the Children Act 1989.

Purpose and aim of the Policy

The purpose of this Policy is to set out guidelines for the safe use of emergency rescue medication for children and young people who have been diagnosed with epilepsy. The main aim of the Policy is to safeguard:

- Children and young people, aged between 0 and 18 years of age, who have been diagnosed as having epilepsy and who require the administration of emergency medication.
- Parents and carers as employers of personal assistants through direct payments.
- Personal assistants, as employees, employed by parents or carers of disabled children and young people through direct payments.

Scope

This Policy sets out the local authority expectations in relation to the safe administration of emergency rescue medication for disabled children and young people who have been diagnosed with epilepsy and where direct payments have been assessed as a way of meeting the needs of either young disabled people aged 16 or 17 with capacity, or those of a disabled child. It applies only in relation to the employment of personal assistants.

This Policy does not apply where direct payments are used to purchase care from agencies as these agencies would need to demonstrate that they have their own policies in place and have satisfied the local authority that they are robust enough to safeguard children and young people. This Policy does not apply to schools or settings (for example residential short break settings) where the child or young person attends because these establishments will be covered by their own policies.
The scope of this Policy covers the administration of Rectal Diazepam and Buccal Midazolam for those disabled children and young people who have prolonged seizures to prevent the onset of **status epilepticus**.

**Policy statement**

This Policy has been developed in line with guidance from the National Institute for Health and Care Excellence (NICE) Epilepsies: diagnosis and management clinical guidelines [CG137] published date: 11 January 2012. Last updated on 11 February 2020; and NICE Epilepsy in children and young people Quality standard [QS27] Published date: 28 February 2013.

NICE clinical guidelines are recommendations about the treatment and care of people with specific diseases and conditions in the NHS in England and Wales.

The Royal College of Nursing (RCN) no longer develops clinical guidelines but focuses now on supporting the development of guidelines through agencies such as NICE and supporting implementation through developing online learning and resources. The RCN is involved in the development of all NICE guidelines.

Clinical guideline [CG137] covers diagnosing, treating and managing epilepsy and seizures in children, young people and adults in primary and secondary care. It offers best practice advice on managing epilepsy to improve health outcomes so that people with epilepsy can fully participate in daily life.

It is important to remember that the diagnosis of epilepsy in children should be established by a specialist paediatrician with training and expertise in epilepsy (NICE clinical guidelines), and that each child or young person will have their own individual care plan devised by a medical practitioner.

The Royal College of Nursing Guidelines, 2007, used by the Council for Disabled Children to inform, Dignity and Inclusion: Making it Work for Children with Complex Health Care Needs, guidance sets out an advisory list of those procedures which can be safely taught and delegated to non-health qualified staff and state that the administration of medication or invasive clinical procedures should only be undertaken by staff or carers when prescribed by a qualified nurse or qualified medical practitioner, and that **staff and carers should only agree to undertake these tasks if they feel competent and confident to do so.**

In order to safely and effectively support the care needs of children and young people requiring these procedures, comprehensive training needs to be in place and delivered by appropriately qualified nursing staff.
Non-health qualified staff should be trained to deliver care according to set protocols and guidelines and would not be expected to make independent decisions about a child or young person’s care but refer these to either a parent or health professional.

The permitted tasks for non-health qualified staff and focus of training for these tasks must be on the care as it applies to a named child or young person and not broadly interpreted to include other children in their care.

The Royal College of Nursing paper dated October 2014, Managing children with health care needs: delegation of clinical procedures, training, accountability and governance issues states: For all unregistered and non-health qualified staff, training for clinical procedures must be child specific and task specific. Each member of staff must be individually assessed and registered nurses who may undertake group training for some aspects have a professional responsibility to ensure each staff member is fully competent.

In this respect the registered nurse is responsible for ensuring staff members are trained for each individual child and that they are individually assessed for each child. It is never acceptable for parents, unregistered health staff, non-health qualified staff or unregistered and non-health qualified company representatives to assess staff as competent.

Rectal diazepam is prescribed for a minority of children and young people who require emergency treatment for seizures to prevent status epilepticus which can result in brain damage or death. Status epilepticus is a condition characterised by a seizure (convulsion or fit) or a series of seizures that last for 30 minutes or more without complete recovery of consciousness. If a seizure continues for more than five minutes, it may not stop unless rapid treatment is given.

Since 1971 rectal diazepam has been commonly used as an emergency treatment for prolonged seizures and for febrile convulsions in young people. Rectal diazepam is prescribed by a medical practitioner and must have clear guidelines for its administration in the form of a care plan.

Recommendations by the Joint Epilepsy Council state that it is the employer’s responsibility to ensure that the named individuals who are willing are adequately trained and up-to-date in the administration of rectal diazepam.

Buccal midazolam is being increasingly used as an emergency treatment for prolonged seizures and for febrile convulsions in young children. This has resulted in its inclusion in the National Institute for Clinical Excellence (NICE) clinical practice guidance on the diagnosis and management of epilepsy in children and adults published in 2004, updated in 2012, 2016 and 2020.
This Policy follows the guidance on Direct Payments, for Community Care, Services for Carers and Children’s Services 2009 issued by the Department of Health. The guidance is available on the Department of Health’s website.

Policy details

For the administration of emergency medication by trained care staff employed by parents or carers through direct payments the following should be in place:

- An enhanced Disclosure & Barring Service (DBS) check for all personal assistants providing care and support to the disabled child or young person;

- The disabled child or young person must have a diagnosis by a paediatrician and prescribed medication by a paediatrician. There should be an up to date individual care plan, for the administration of rescue medication and treatment, for the child or young person, which may be updated annually;

- Epilepsy training should have been undertaken by the personal assistant, covering both epilepsy awareness and the administration of rescue medication, before the personal assistant(s) starts supporting the child or young person. The training programme must be overseen and approved by the Epilepsy Nurse Specialist. Where a personal assistant does not meet the criteria set by the Epilepsy Nurse Specialist to be judged competent to administer the rescue medication, then the Epilepsy Nurse Specialist will inform the child or young person’s parent or carer;

- During the covid-19 pandemic, the following interim measures have been arranged for online epilepsy awareness training to be delivered to personal assistants via Microsoft ‘teams’:
  
  - The Personalisation Support Team will check with the parent or carer of the disabled child or young person to ask if the personal assistant has access to Microsoft ‘teams’. If the personal assistant does have access, the Epilepsy Nurse Specialist will be contacted, and a training date will be arranged. In addition to ‘teams’ training, the personal assistant should also attend classroom epilepsy awareness training as soon as this becomes available.

  - Adult & paediatric basic life support training (resuscitation) should also have been undertaken by the personal assistant, prior to the care of the disabled child or young person who may require emergency rescue medication. Refresher training should be undertaken on an annual basis and delivered by a qualified medical practitioner;
• Epilepsy awareness training, and adult & paediatric basic life support training can be undertaken by the personal assistant before an Enhanced DBS Disclosure is received, in readiness of their DBS notification. However, the personal assistant must not be employed to provide care and support to the child or young person before their DBS Disclosure is issued and before Cornwall Council have been notified (Personalisation Support Team office);

• The cost of attendance for the adult & paediatric basic life support training for personal assistants can be paid from the accrued direct payment funds held in the nominated account. If there are insufficient funds held in the nominated account, parents or carers should make this known to the Personalisation Support Team and an additional one-off payment to cover the course costs for the personal assistants(s) will be paid into the nominated account;

• Parents or carers should ensure that all personal assistants employed by them via direct payments, who are willing and have agreed to undertake these specific tasks, have received up to date training, overseen by an Epilepsy Nurse Specialist, this training should be undertaken on an annual basis. Parents or carers should ensure that personal assistants are made aware of any changes to their child or young person’s daily epilepsy treatments or Epilepsy Emergency Plan.

• The core content of the adult & paediatric basic life support (resuscitation) training will consist of:
  o Identifying when basic life support is required;
  o To understand the process to follow when performing basic life support;
  o Basic life support including mouth to mouth resuscitation;
  o Techniques to help a victim of choking;
  o Airway management;
  o Resuscitation equipment;
  o Calling the emergency services.

• If a personal assistant, in another worker role, has already undertaken epilepsy awareness training and adult & paediatric basic life support training, within the past twelve months, the personal assistant should provide evidence of this and will not be required to undertake this training again until such time as the annual epilepsy awareness training and refresher basic life support training is due.
• In addition to the basic training, it would be expected that the family discuss with the Epilepsy Nurse Specialist individual training for personal assistants as it relates to each child or young person’s unique needs;

• If a personal assistant has a First Aid Certificate that is valid for three years, parents or carers should ask to see this. The Council strongly recommends that personal assistants undertake annual refresher training, over half a day, during any three-year certification period. Although not mandatory, this will help maintain the personal assistant(s) basic skills and enable them to keep up to date with any changes to first aid procedures;

• Before any personal assistants are employed, parents or carers should make sure that they have either Home Employment Insurance with Healthcare; or they have full cover employment liability insurance and each personal assistant has their own carers insurance in place which covers them for the administration of medication prior to them starting work. In the first year of receiving a direct payment, the cost of the annual policy will be paid by Cornwall Council directly into the parent or carer’s nominated bank account. In the second and future years, this cost should be met from the accrued direct payment funds; If a personal assistant takes out a carers insurance policy, they are responsible for making the insurance application themselves and parents or carers can reimburse them the cost of the policy from the nominated account. **Insurance cover may not be valid if personal assistants have not attended appropriate training or refresher training**;

• Parents or carers should be aware and in agreement that the personal assistant(s) they employ must not undertake any medical interventions with regards to any other medical care needs the child or young person may have. This includes care of tracheostomy, suctioning, gastrostomy care, ventilation, or administration of nebulisers or oxygen;

• If the child or young person has a high level of medical need, the personal assistant employed must not take sole responsibility for the care of the child or young person, and there will need to be another adult who is able to meet their health needs present at all times.
Consultation and engagement

The need for this Policy has been discussed with parents and carers, the staff of the Disabled Children & Therapy Services, the Epilepsy Nursing Team, and colleagues in Health.

Performance and risk management

This Policy will be reviewed on an annual basis, or sooner if practitioners identify any risks to disabled children and young people or parents or carers, or employees. Any risks identified will be reported through Social Work Team Managers and may be raised at the Children and Family Services Senior Leadership Team meetings for discussion and possible inclusion on the directorate risk register via Spa net. Monitoring and evaluation of the effectiveness of the Policy will be through individual child or young person reviews, direct payments service user groups, and in consultation with the Epilepsy Nursing Team. The Children and Family Services action plan includes the monitoring and evaluation of policies and procedures as one of its objectives.

Communicating the Policy

This Policy document will be shared with parents, carers and health colleagues; it will also be available on the Council’s web site.

Breaches and non-compliance

If the Policy and procedures set out in this document are not followed then the Local Authority will not be able to offer direct payments to disabled young people, or the parents and carers of disabled children and will seek alternate provision from an appropriately qualified provider to meet their need.

Information and training


Information on the National Institute for Health and Care Excellence (NICE) website is available at: www.nice.org.uk

Further information on training personal assistants for epilepsy awareness and adult and paediatric basic life support (resuscitation) is available from the Personalisation Support Team, Cornwall Council.
Evaluation and review

The Policy will be reviewed in May 2021.

Document information

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Policy document agreed by:
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Children and Family Services
Together for Families Directorate

Alternative formats

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