Direct Payments and the Administration of Emergency Epilepsy Medication Policy

Children's Early Help, Psychology & Social Care Services

Education, Health & Social Care

May 2015
## Current Document Status

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## Version History

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## Equality Impact Assessment Record

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## Document retention

| Document retention period | 5 years in hard and electronic copies. |
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Introduction

This policy has been developed following consultation with partners in health, parents and carers, Epilepsy Action, and the Department of Health. 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 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.

It 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. It 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 Clinical Excellence, 2004; updated NICE clinical guidelines [CG137] published date: January 2012.

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.

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, issued: January 2012), 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.

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 and modified in January 2015.

This policy follows the updated 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 through direct payments the following must be in place:

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

- The disabled child / 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 / young person, which may be updated annually;

- Epilepsy training must have been undertaken by the personal assistant, covering both epilepsy awareness and the administration of rescue medication, before the personal assistant starts working with the child / 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 both the family and the social care worker;

- Adult & Paediatric Basic Life Support Training (resuscitation) must also have been undertaken, by the personal assistant, prior to care of the disabled child / young person who may require emergency rescue
medication. Training must 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 for the receipt of their DBS. However, the personal assistant must not work with the child / young person before their DBS Disclosure is received by the Personalisation Support Team office;

- The cost of attendance at Epilepsy Awareness Training and Adult & Paediatric Basic Life Support Training for personal assistants will be paid by Cornwall Council;

- Parent / carer must ensure that all personal assistants employed by them have received up to date training, overseen by an Epilepsy Nurse Specialist. They must also ensure that the personal assistant attends annual Epilepsy Training, accredited by Epilepsy Nurse Specialists;

- Parent / carer must ensure that all personal assistants employed by them have received up to date Adult & Paediatric Basic Life Support Training; Refresher training must be undertaken on an annual basis by a qualified medical practitioner;

- The core content of the Adult & Paediatric Basic Life Support (resuscitation) training will consist of:
  - Identifying when basic life support is required;
  - To understand the process to follow when performing basic life support;
  - Basic life support including mouth to mouth resuscitation;
  - Techniques to help a victim of choking;
  - Airway management;
  - Resuscitation equipment;
  - 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 must provide evidence of this and will not be required to undertake this training again until such time as the annual Epilepsy Awareness Training and Basic Life Support Training is due. In addition to the basic training, it is expected that the Epilepsy Nurse Specialist will offer individual training as it relates to each child’s unique needs;

- Parent / carer must have full cover Employers Public Liability insurance before any personal assistants are employed and start working with the child / young person. In the first year of receiving a direct payment, the cost of the annual policy will be paid from Cornwall Council directly into the parent / carer’s direct payments bank account. In the second and
future years, this cost should be met from the accrued direct payment funds;

- Parent / carer must ensure that all personal assistants employed by them via direct payments, will have 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 from Cornwall Council directly into the parent / carer’s direct payments bank account. In the second and future years, this cost should be met from the accrued direct payment funds. The personal assistant is responsible for making the insurance application and the parent / carer will re-imburse them the cost from the direct payment funds;

- Parent / carers should be aware and in agreement that the personal assistant 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;

- Parent / carers should be aware that the direct payment funds cannot be used to meet any of the child / young persons’ other medical needs. 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 Children’s Early Help, Psychology & Social Care 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 / carers, or employees.

Any risks identified will be reported through Social Work Team Managers and may be raised at the Children’s Early Help, Psychology & Social Care Senior Management 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 / young person reviews, Direct Payments service user groups, and in consultation with the Epilepsy Nursing Team. The Children’s Early Help, Psychology & Social Care 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 circulated to all practitioners and shared with parents, carers and health colleagues; it will also be available on the 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

The guidance for the management of epilepsy in children and young people is available from the NICE website at www.nice.org.uk

Nice guidelines version CG137 and the quick reference guide are available at: www.nice.org.uk/Guidance/CG137 and can be ordered from the NHS Response Line on 0870 1555 455.

Further information about the National Institute for Clinical Excellence (NICE), the Clinical Guidelines Programme or for versions on the administration of medication for epilepsy guidelines (including the sources of evidence used to inform the recommendations for care), is available at the NICE website at: www.nice.org.uk

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

Evaluation and review

The Policy will be reviewed in June 2016.

Policy Document prepared by: Alison Bancroft, Personalisation Support Team Manager

Policy Document agreed by: Yvette Yates, Senior Manager

Children’s Early Help, Psychology & Social Care Services

Education, Health & Social Care

27 May 2015
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