



Courage Hope Inspiration

Shared Care for children with Congenital Hyperinsulinism

A child who has been diagnosed with Congenital Hyperinsulinism (CHI) requires shared care between their specialist team, local hospital, CCGs, and GP as well as the Local Authority.

Children with CHI will vary in their needs as all do not present the same. Some children may require little intervention, and some will need a Multi-Disciplinary Team approach. The needs of the child may vary as they grow and develop but it is crucial that CCG's and Local Authorities are aware of a child with CHI within their community to ensure the child, their family, care providers and educational settings have access to the correct support under Section 10 of the Children Act 2004 and Section 3 of the National Health Service Act 2006.

Daily medications, blood glucose monitoring and a strict feeding regime are essential to ensuring that CHI children remain stable. It is essential to be fully aware of the child's Hypoglycaemia Care Plan which is usually provided by the paediatric consultant or CHI specialist team. This will carefully set out a safe blood glucose range for the individual child and will provide a protocol on what to do if the blood glucose level falls below the safe level for them.

Looking after the health and wellbeing of a child with CHI requires cooperation from many parties (see following pages) and a collaborative approach is required.

Whilst this document outlines legislation for England, we recognise the importance for other nations to be included, and the following documents and legislation should be read in conjunction with the information on these pages.

Scotland:

- National Health Service (Scotland) Act 1978 – Section 39
- National Health Service Reform (Scotland) Act 2004
- Clinical and Care Governance Framework, Public Bodies (Joint Working) (Scotland) Act 2014
- NHS HDL 74 Clinical Governance Arrangements, Scottish Executive, 2001
- NHS MEL 29 Clinical Governance, Scottish Executive, 2000
- NHS MEL 75 Clinical Governance, Scottish Executive, 1998
- Education (Scotland) Act 1980 and 2016
- Education (Additional Support for Learning) (Scotland) Act 2014
- Public Health Nursing Services – Future Focus (CEL13) Scottish Government 2013

- UN Convention on the Rights of the Child
- Supporting children and young people with healthcare needs in schools – Dec 2017

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Wales:

- Supporting learners with healthcare needs – Welsh Government, March 2017
- Education Act 2002 – section 175, section 21(5)
- Children Act 2004 – section 25
- Equality Act 2010
- Education Act 1996 – sections 13, 14, 15A, 15B, 19(1), 19(4)
- Social Services and Well-being (Wales) Act 2014
- United Nations Convention on the Rights of the Child

Northern Ireland:

- Supporting Pupils with Medication Needs – DENI
- Code of Practice for the Identification and Assessment of Special Educational Needs 1998 & the supplement to the Code published in September 2005.
- Education (Northern Ireland) Order 1996
- The Special Educational Needs & Disability Act 2016.

Republic of Ireland:

- Education for Persons with Special Educational Needs Act 2004
- Whilst there is limited legislation available, the following websites can offer advice:
 - www.education.ie
 - www.gov.ie
 - www.ncse.ie

Specialised Hyperinsulinism Services (Great Ormond Street, Alder Hey, Manchester Children's Hospitals)

The Specialist CHI Teams diagnose, treat and support children with CHI. They offer a highly specialised service with a multidisciplinary team to ensure the correct treatment and medical management is given. Children will be discharged into the community when it is safe to do so, and parents are trained appropriately. The CHI Service will write to the child's GP to ensure there is a shared care pathway made available to families once they are back home.

Please note that these letters are only sent to GPs and therefore CCGs may not be aware of a child with CHI in the community. CCGs will need to be aware of CHI children to ensure that they have access to the correct medications and other support services such as Community Nursing Teams for example.

It is also worth noting that some children are diagnosed locally without the need of a transfer to a tertiary centre and the same communication between them and the GP will be executed.

Following diagnosis, hospital teams should offer the following:

- Information on the diagnosis of CHI along with signposting to relevant websites/groups for support for families.
- Individual hypo plans.
- Individual care plan for educational settings.
- Supporting letters/documentation for EHCP applications.
- Additional support to families, educational settings, key workers via telephone/email.
- Provide an MDT approach for cognitive function/feeding and to liaise with local services.

Please note that tertiary centres cover a vast area across the UK and Ireland and training for individual educational settings is not always appropriate. Local services will need to assist to help deliver blood glucose training, injection/medication administration. For the more complex child, liaising between local services, tertiary centres and families will help to formulate the most appropriate plan to train others.

CCGs and Local Authorities

Local Authorities and CCG's have legal responsibilities with regards to children with medical conditions.

Section 10 of the Children Act 2004 requires a local authority to promote cooperation between the authority and 'relevant partners', which includes governing bodies, NHS Clinical Commissioning Groups ('CCGs') and the NHS Commissioning Board.

Local Authorities must make arrangements with a view to improving the wellbeing of children, including their physical and mental health, and education.

If the child or young person has an EHCP, under section 42 of the Children and Families Act 2014, Local Authorities must secure the specified special educational provision as stipulated in the EHCP and the responsible commissioning body must arrange the specified health care provision.

Section 17 of the Children Act 1989 places a general duty on Local Authorities to safeguard and promote the welfare of children in need in their area, a category which includes all disabled children. In some cases, a child's Hyperinsulinism will meet the definition of a 'disability' under Section 6 of the Equality Act 2010:

'A person has a disability if they have a physical or mental impairment which has a substantial and long-term adverse effect on their ability to carry out normal day to day activities'. (Whether a child with Congenital Hyperinsulinism is disabled will depend on the specific details of their case).

Section 3 of the National Health Service Act 2006 also places a duty on CCGs to arrange for the provision of health services to the extent that the CCG considers it necessary to meet the reasonable needs of the persons for whom it is responsible. CCGs are given the power by this section to arrange such services as they consider appropriate in the treatment of illness.

The Royal College of Nursing state:

'Support workers undertaking clinical procedures for children and young people should receive appropriate training from a health care professional or other accredited source in the care they are providing'.

Poor management of a child's Hyperinsulinism at home and in the community, particularly at school, has serious consequences on the child's health and development, and the CCG may be required to take steps to ensure that school staff are provided with suitable training to ensure that a child with Congenital Hyperinsulinism's health needs are met. It is necessary therefore that CCGs and the services they oversee understand the implications that poor management of Congenital Hyperinsulinism can lead to. It is imperative that medical staff (GPs, midwives, health visitors, community nursing teams, diabetes nursing teams etc) have access to training in hypoglycaemia in babies and children and should be encouraged to participate in any training or symposiums made available.

Hypoglycaemia in babies and children can be caused due to a number of reasons, however, Congenital Hyperinsulinism is the most common cause of persistent and severe hypoglycaemia in the first three months of life with 30-50% of these children suffering long-term neurological consequences.

Diabetes Teams, Community Nursing Teams and local hospitals are best placed to help provide blood glucose monitoring training as well as administering medication training, peg/nasogastric feed training etc. for school staff, making this accessible to all who have a pupil with Congenital Hyperinsulinism.

****Please note that every child with Hyperinsulinism should have an individual hypoglycaemia plan/protocol which will clearly set out the safe blood glucose level for that child.****

In the Ofsted document 'Working together to safeguard children', safeguarding and promoting children and young people's welfare is defined as:

- ***Protecting children from maltreatment***
- ***Preventing impairment of children's health and development***
- ***Ensuring that children grow up in circumstances consistent with the provision of safe and effective care***
- ***Taking action to enable all children to have the best outcomes***

With this in mind, and to assist with providing some support for families, it would be worth considering providing childminders, respite providers and extended family members who take an active role in caring for a child with Congenital Hyperinsulinism, with the same training as previously mentioned in the paragraph above.

Schools report they struggle to get the training required due to lack of funds or it being refused by local nursing teams. These teams (Diabetes/community/local hospital nursing teams) report not knowing enough about Congenital Hyperinsulinism, or simply being too overwhelmed as a service and refuse to take on this training.

Training should not be refused, delayed or frustrated by a lack of funding, resources or knowledge of Congenital Hyperinsulinism. Training is vital to ensuring the child is safe and protects the child's health, development, and well-being, therefore it should never be refused.

Schools and Governing Bodies

Section 100 of the Children and Families Act 2014 ('the CFA 2014') requires governing bodies/proprietor of the school or institution must make arrangements for supporting pupils at school with medical conditions.

Schools must have in place policies for supporting children with medical conditions as well as administering medication.

For pupils without an ECHP, pupils must have an IHCP.

In making these arrangements, the governing body is required to have regard to guidance issued by the Secretary of State for Education. The relevant guidance is 'Supporting pupils at school with medical conditions', issued in December 2015. This Guidance is therefore a mandatory relevant consideration for schools.

Importantly, the Guidance states that the aim of the section 100 duty is:

'to ensure that all children with medical conditions, in terms of both physical and mental health, are properly supported in school so that they can play a full and active role in school life, remain healthy and achieve their academic potential.'

Schools' approaches to the training of staff to meet the needs of children with Congenital Hyperinsulinism should be assessed against how far they support the achievement of this aim.

The Guidance requires the governing body of a school to ensure that the school has a policy in place for supporting children with medical conditions as well as a policy with regards to the administering of medication.

The policy should include provision as to 'who is responsible for ensuring that sufficient staff are suitably trained' (Paragraph 10 in the Guidance, non-statutory section).

As part of this policy, the school must implement a process for drawing up individual healthcare plans (IHCPs) for children with medical conditions if they do not have an Education and Healthcare Plan (EHCP). When determining what information should be included on a child's IHCP, the governing body should consider the level of support needed by the child, who will provide this support, and any training required by that person. School leaders should consult with health and social care professionals, pupils and parents to ensure the needs of children with medical conditions are properly understood and effectively supported.

For some children with Congenital Hyperinsulinism, an EHCP is required, and this will outline any SEND needs a child has and the provision an LA must put in place to help them. Congenital Hyperinsulinism must be listed as a priority under the section, 'Summary of Health Needs which relate to SEN'. Without the correct management of Congenital Hyperinsulinism, the damaging neurological harm that can take effect, will have severe implications on a child's learning and development.

In both the EHCP and IHCP, once medical training requirements have been identified, it is the school governing body that is responsible for the provision of that medical training to staff. The Guidance states in paragraph 16:

Governing bodies must make arrangements to support pupils with medical conditions in school, including making sure that a policy for supporting pupils with medical conditions in school is developed and implemented.

They should ensure that sufficient staff have received suitable training and are competent before they take on responsibility to support children with medical conditions.

When determining what would be 'sufficient staff' the governing body should consider staff illness, courses, annual leave and the need to ensure that the child is supported by properly trained staff on school trips and outings. It is crucial to ensure that if a staff member is absent there remains sufficient trained staff to ensure the child is safe and their education is not disrupted.

The Guidance (paragraph 17) requires the provision of training to staff to follow formal processes which must be set out within a school's policy for supporting children with medical conditions:

Governing bodies should ensure that the school's policy sets out clearly how staff will be supported in carrying out their role to support pupils with medical conditions, and how this will be reviewed.

This should specify how training needs are assessed, and how and by whom training will be commissioned and provided.

Any training provided must be 'suitable' and training must result in a staff member being 'competent' to provide support to a child with the relevant medical condition (both these requirements arising from the Guidance and also as a matter of rational decision making as required by the common law). Training will clearly only be 'suitable' when provided by an individual or organisation with relevant expertise.

Given the specialist knowledge required for blood glucose monitoring and the administration of medications for children with Congenital Hyperinsulinism, schools can only fulfil its duties under section 100 CFA 2014 and demonstrate appropriate regard to the Guidance by engaging healthcare professionals.

Schools (within the content of its policy) should also 'have regard' to the non-statutory sections of the Guidance as a matter of rational decision making. In particular, the Guidance suggests on page 18 that

'the relevant healthcare professional should normally lead on identifying and agreeing with the school the type and level of training required, and how this can be obtained.'

The relevant healthcare professionals in the case of children with Congenital Hyperinsulinism would be their endocrine paediatric consultant (HI specialist or local), school nursing team etc.

Regarding the involvement of a child's family in staff training, it is also made clear on page 18 that:

Governing bodies should NOT require parents, or otherwise make them feel obliged, to attend school to administer medication or provide medical support to their child. Parents should provide specific advice but should not be the sole trainer.

Schools and their governing bodies should consider this guidance before adopting processes and the involvement of the relevant healthcare professional.

****If parents are asked to provide training by themselves, schools and governing bodies would most likely be acting unlawfully.****

Governing bodies of schools also have general obligations under the Education Act 2002, which impact on the training that they are required to provide to staff members in relation to pupils' medical conditions:

The duty on governing bodies of maintained schools to promote the well-being of children under Section 21(5)(a) includes (by reference to section 10(2) of the Children Act 2004) a child's physical and mental health and emotional well-being.

As such, schools must have a policy which promotes the physical and mental health and emotional well-being of children with medical needs, including Congenital Hyperinsulinism.

Section 175 requires a governing body of a maintained school to make arrangements for ensuring that their functions are exercised with a view to safeguarding and promoting the welfare of children receiving education at the school which strongly supports the need to have an effective policy on meeting children's medical needs.

Similar provisions apply to proprietors of academies; see the schedule to the Education (Independent School Standards) Regulations 2014, paragraphs 7 and 34.

These sections further oblige governing bodies to ensure that staff members are in receipt of training which is of a sufficient quality to genuinely enable them to support a child with medical conditions.

This will often mean that the training should be provided by a relevant healthcare professional.

Families

Families have a wealth of knowledge about their child and how CHI affects them, from medications, blood glucose patterns, feeding regimes, hypoglycaemic symptoms, or if their child is asymptomatic and therefore requires careful monitoring. Families provide valuable support and advice to schools and good communication between the family and school/care provider should be encouraged.

It is the responsibility of families to provide schools and other community care settings with sufficient and up to date information regarding their child's health and medical needs which may be required.

See page 13 of Supporting Pupils at School with Medical Conditions guidance and page 10 of the RCN Meeting Health Needs in Educational and other Community Settings.

Where a CHI child is due to move school, it would be advisable to provide information to the new setting as early as possible to allow the Governing Staff time to develop an individual healthcare plan (IHCP) for the student and to make arrangements to provide any required training to staff before the child begins.

Families should take an active role in the development of their child's Individual Health Care Plan.

'Parents are key partners and should be involved in the development and review of their child's individual health care plan and may be involved in its drafting'.

Supporting Pupils at school with Medical Conditions Guidance page 13 (non-statutory section).

The family of a child with Congenital Hyperinsulinism should never be expected to take on the role or responsibility of being the 'sole trainer' in a setting.

This is made clear on page 18 of the Guidance 'Supporting Pupils at School with Medical Conditions' which advises 'they should provide specific advice but should NOT be the sole trainer'.

Parents or families should not be expected or required to step in to provide their child's medical needs at school in circumstances when a school has failed to provide the medical training to staff.

Page 23 of Supporting Pupils at school with Medical Conditions Guidance states:

'It is generally not acceptable practice to require parents, or otherwise make them feel obliged, to attend school to administer medication or provide medical support to their child, including with toileting issues. No parent should have to give up working because the school is failing to support their child's medical needs. It is also generally not acceptable to prevent children from participating, or create unnecessary barriers to children participating in any aspect of school life, including school trips, e.g. by requiring parents to accompany the child'.

Every endeavour should be made to ensure that training specific to the child is carried out by the appropriate healthcare professional with the family supporting as appropriate.

It is wise to be mindful that for many families, the circumstances that led to their child's diagnosis may have been traumatising and the impact the diagnosis/way of life/impact on family/siblings and finances for example, will have on daily life for them as a family unit. It

has been noted that some parents suffer with PTSD as a result and may need further support themselves. Families should be helped to access counselling/psychology input if required.

The Children's Hyperinsulinism Charity

The Children's Hyperinsulinism Charity are a small, parent run charity, who specialise in supporting families of children with the rare condition Congenital Hyperinsulinism.

Through their database and online support group, The Children's Hyperinsulinism Charity are in a good position to learn about the issues that are important to families and learn how best they can support them or to look at ways improvements can be made on a national level and within the community.

One of the many struggles for families is having their CHI child adequately supported in school. All too often CHI families report that they themselves are having to give medical training and stay in school to support staff.

Schools report that they struggle to get the training required due to lack of funds, and diabetes/community/local hospital nursing teams report not knowing enough about Congenital Hyperinsulinism, or simply being too overwhelmed as a service and refuse to take on this training. This in turn can delay a child starting school, not being able to attend school or even being able to participate in school activities/outings alongside their peers.

****Children with Hyperinsulinism must not be discriminated against and should not have their education hindered or disrupted due to a lack of training or awareness. Families should never be expected to carry out training or to take time out of work because a school is failing to meet a child's medical needs. ****

The Children's Hyperinsulinism Charity supports educational, day care settings and respite providers by delivering training sessions in partnership with CHI Specialists.

Please note this does not cover practical training for blood glucose monitoring and the administering of medications as the charity's volunteers are not medically trained professionals, and children with Congenital Hyperinsulinism vary in their needs.

The Children's Hyperinsulinism Charity have developed an Information for Schools brochure as well as a Pocket Guide to Hyperinsulinism to assist anyone caring for a child with Congenital Hyperinsulinism which are available by emailing enquiries@hyperinsulinism.co.uk.