Congenital Hyperinsulinism
Information for Schools

Courage  Hope  Inspiration

May 2019

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Courage

Hope

Inspiration
Welcome to the Children’s Hyperinsulinism Charity’s information booklet designed specifically for educational settings.

One of the many topics of conversation which crops up in our parent support group is managing Congenital Hyperinsulinism (CHI) whilst their child is at school. It is one of our parents’ biggest fears, from not only starting a new school, but changing classes and heading to university too, as well as getting to know new staff and their child’s relationship with their peers.

Having a new pupil start in your class or school brings its own emotions for teachers. Having a new pupil starting with additional medical needs on top, will naturally cause you some concerns and anxiety yourself.

DO NOT PANIC!!

We aim to help you understand more about Congenital Hyperinsulinism itself, and to arm you with some knowledge and tips that will help ensure you put the correct procedures in place to assist your pupil whilst they are in your care. We hope that by reading this information and getting to know your new pupil, that it will help to ensure there is a smooth transition for all.

There is also a whole host of information online to assist you and the links to websites can be found on the appendix page. You will never be alone whilst learning about your new pupil.

The child's parents/carers, medical professionals and our Charity are always here to help and listen. Best of luck on this wonderful new adventure!!

The CHC Trustees

Please note:

The information in this booklet is designed to be a general guide on Hyperinsulinism and the effect on a CHI child. It is not intended to represent the individual child or their particular needs. Parental and Medical Professionals advice on the individual child and their specific care needs/plans should always be sought and documented/adhered to.
What is Hyperinsulinism?

Hyperinsulinism is the inappropriate and unregulated insulin secretion in relation to the blood glucose concentration. It is the main cause of recurrent and persistent hypoglycaemia in infancy and childhood and is a major cause of hypoglycaemic brain injury.

Normally, blood glucose levels are regulated by insulin secretion, however, in Hyperinsulinism, the beta-cells of the pancreas release insulin inappropriately all the time causing low blood glucose levels (hypoglycaemia). The high levels of insulin prevent ketones being made and so the brain is not only starved of its vital fuel glucose, but also prevents ketone bodies being used as alternative fuels.

Hyperinsulinism affects approximately 1:35000 births in the UK alone (1:10 - 15000 worldwide).

It typically presents in the neonatal period, infancy and childhood.

It can be transient, persistent, mild or severe.

So far, up to 12 genetic mutations have been identified along with links to other syndromes such as Beckwith Wiedemann, Turner and Kabuki syndrome.

Other causes of hypoglycaemia can include fasting, postprandial (after meals including dumping syndrome and being protein sensitive), as well as being exercise induced.

Many children with Hyperinsulinism can suffer other issues in relation to the management of the condition such as fluid overload, cardiac/respiratory issues, infections, feeding issues (loss of orality), gastro-oesophageal reflux and feed associated problems such as intolerances and allergies.

Early recognition and prompt treatment are vital in preventing hypoglycaemic brain injury.
Some children with CHI are prone to repeated episodes of hypoglycaemia.

A low blood glucose reading in children with CHI is usually accepted to be less than 3.5mmol per litre.

The first signs and symptoms of hypoglycaemia can be very subtle, when the blood glucose is only slightly low. These include:

- Dizziness
- Tiredness
- Hunger
- Irritability
- Anxiety
- Behaviour change such as stubbornness or crying for no reason
- Sweating
- Blurred vision
- Headache

These subtle signs and symptoms can be very difficult to distinguish from the child’s usual behaviour or condition, or symptoms triggered by other causes such as just being hungry like any other child.

These symptoms and signs of hypoglycaemia listed above, can be difficult to identify in children with some degree of learning disability and hyperactivity, as several children with CHI have.

It is important for the child’s teacher to become familiar with the child and discuss with the parents what their child’s normal behaviour pattern is when the child has normal blood glucose levels, and the visible clues when the child has low blood glucose.

Use the symptoms and signs listed above as a checklist. Each child with CHI will have a different blood glucose level at which they feel symptoms and show signs.
If the blood glucose goes much lower or drops more quickly, the signs and symptoms become more prominent and obvious. These include:

- Agitation and aggression
- Confusion
- Decreased consciousness and coma
- Seizures

Even when the child’s blood glucose is very low causing changes in behaviour or even seizures it can be difficult to realise at first that there is anything wrong.

**Seizures and epilepsy**

Some seizures are initially subtle and look like a change in behaviour. The most obvious seizures look like vigorous bodily shaking with loss of consciousness, but many seizures do not look like this, particularly at the beginning. Some clues of a seizure include pauses in breathing, eye-rolling, eyes or appearance going vacant, pupils dilating, and lips going blue.

Some children with CHI also have epilepsy. This means the child can have seizures which occur spontaneously, unprovoked and unrelated to low blood glucose at the time of seizure.

Children with epilepsy are usually treated with anticonvulsant medications in addition to any medications they may be treated with for CHI.

Some children may not have been medically diagnosed as having epilepsy, and observations from the child’s teachers may be requested by the child’s doctor to assist with the diagnosis.

**Some children with CHI can have seizures set off by low blood glucose whereas others may have normal blood glucose at the time of seizures, hence it is extremely important to check blood glucose at the time of seizures.**

If the child has been diagnosed with epilepsy by their doctor, then further advice will be available from the doctor and typically an epilepsy nurse specialist regarding the emergency plan should the child have seizures.
Hypoglycaemia can have a damaging effect on brain growth and development, which is why some CHI children will present with learning difficulties and developmental concerns.

A history of severe and/or prolonged hypoglycaemia can cause brain damage visible on a scan.

In some children it is thought to be the underlying genetic cause of CHI that is directly affecting their learning and development.

Children with CHI can sometimes be identified as having physical or intellectual disabilities, at a very early age often before starting at school and may have received the following diagnoses.

- Cerebral Palsy (CP)
- Epilepsy
- Global Development Delay (GDD) and/or learning disability
- Visual impairment

**Cerebral Palsy (CP)**

Cerebral Palsy is an umbrella term to describe abnormal muscle tone, posture and movements in young children with brain injury. Hypoglycaemia is one cause of CP, although most children with CP have other causes.

A child with CP may have physical problems with mobility, using their hands, speech and swallowing. How severely a child is affected by these issues varies enormously and so it is always good advice to look at the individual child and what support they will require to meet their particular needs. In addition, they may receive advice and input from a physiotherapist, occupational therapist and speech and language therapist who can provide more advice for the teacher.

For a more detailed explanation of Cerebral Palsy, please visit the following websites:

https://www.nhs.uk/conditions/cerebral-palsy/

https://www.scope.org.uk/
**Epilepsy**

Epilepsy means the child has a tendency to have unprovoked seizures.

They can present in a variety of ways.

Seizures:

- may be obvious and dramatic such as violent shaking and loss of consciousness.
- can also be very subtle such as vacant stares or pauses in the middle of activities, unusual changes in vision or behaviour.

It is thus easy to mistake other events or behaviours for these types of subtle seizures, such as attention problems which are also common in children with CHI.

Keeping a diary of such events, along with taking a blood glucose level when a child with CHI has a seizure, is a good idea for when you need to seek advice with concerns.

Where a child has been medically diagnosed with epilepsy, they will have individual advice and plans on what to do in the event of a seizure, usually from the child’s paediatrician or epilepsy nurse specialist.

For more advice on epilepsy, please visit:

[https://www.nhs.uk/conditions/Epilepsy/](https://www.nhs.uk/conditions/Epilepsy/)

[https://www.epilepsysociety.org.uk/](https://www.epilepsysociety.org.uk/)

[https://www.epilepsy.org.uk/](https://www.epilepsy.org.uk/)

[https://www.youngepilepsy.org.uk/](https://www.youngepilepsy.org.uk/)
Global Development Delay or Learning Disability

Children with CHI (and CP and epilepsy) often have mild to severe global developmental delay and/or learning disability.

Some children only have global developmental delay or learning disability without any physical problems of CP and without epilepsy. In these children, it may not be obvious until after the child has started school.

Sometimes the learning difficulties are in specific areas – such as remembering facts or events – rather than across the board.

A developmental or community paediatrician referral is important to identify the medical cause for these learning difficulties whereby the child may need to undergo further tests and appropriate measures are taken to support children in the community.

Additional advice is also available from the educational psychology service.

https://www.mencap.org.uk/

Visual Impairment

Visual impairment is a specific difficulty seen in children with CHI particularly those with severe new-born hypoglycaemia. This is because hypoglycaemia particularly injures the parts of the brain that are responsible for vision. This is often called “cerebral visual impairment” or “cortical visual impairment” (CVI) because the visual impairment is due to problems in the brain and not the eyes.

CVI can be severe, at the level of blindness, whereas other children have subtle CVI, which may be identified for the first time only at school because they have difficulty with reading, seeing the whiteboard or apparent clumsiness.

It is therefore good advice for the teacher to seek advice if they notice the child having difficulties with vision. Additional advice is also available from the specialist teacher for visual impairment.

For more information on CVI, please visit:

https://cvisociety.org.uk/
The above impairments (CP, epilepsy, learning disability and visual impairment) are the most well-recognised and evident neurological effects of CHI and hypoglycaemia. However, it is clear from long-term studies of children with CHI that there is an increased rate of other difficulties that impact on learning and development and benefit from additional support in the school.

It is therefore wise to be mindful of the following as reasons for a child’s difficulties.

- Dyspraxia or developmental coordination disorder (DCD)
- Specific learning difficulties (dyslexia, dyscalculia)
- Attention difficulties including Attention-Deficit/Hyperactivity Disorder (ADD or ADHD)
- Specific language impairment
- Specific cognitive and sensory problems (e.g. planning, memory)
- Hearing impairment
- Social communication or social skill difficulties

Some of these may not become apparent until a child reaches secondary school age when the cognitive demands of learning increase. It is good advice to seek specialist advice (developmental or community paediatrician) from the relevant medical professionals if there are any concerns.
Dietetics

Feeding difficulties are common in children with Hyperinsulinism. The more severe the CHI, the increase incidence of feeding problems. Excessive insulin contributes to gut dysmotility, thus babies with CHI suffer reflux. They can have poor tolerance to large feed volumes increasing the risk of vomiting and in turn this can cause a child to become hypoglycaemic.

Some medications used to treat CHI can suppress the appetite making babies and children less interested in feeds/eating.

Frequent NG (nasogastric) tube passing infants face causes oral sensitivity and therefore oral feeding could be affected.

**MDT (Multi-Disciplinary Team) Approach**

An MDT Approach should be introduced at an early age with access to a Speech and Language Therapist, helping families with techniques to overcome feeding/food aversions and to establish oral feeding as soon as possible. It is also recommended that the family have access to a Psychologist.

**Feeding options**

Sometimes a CHI child does not eat orally, or has problems eating, and therefore may require additional feeds via NG (Nasogastric) tube or a Gastrostomy. These can be used alongside oral feeds to help achieve stable blood glucose levels and help the child meet their nutritional requirements.

The frequency of feeding depends on the age of the child and where possible the child’s normal feeding/eating pattern should be maintained.

Please ensure that you liaise with the parent/carer to understand the additional feeding requirements of your CHI pupil (if any).
**Psychological Impact**

**Living with illness – Think ‘Bio-Psycho-Social!’**

Children living with medical conditions often have numerous, complex and simultaneous factors which impact on their presentation.

To help identify and address these, it is helpful to look at the Biological, Social and Psychological factors which may be contributing to a child’s experiences. Some examples are below:

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<th><strong>BIOLOGICAL:</strong></th>
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<td>Possible cognitive impairment</td>
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<td>Current health</td>
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<td>Age and developmental stage</td>
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<th><strong>SOCIAL:</strong></th>
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<td>Culture</td>
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<td>Family Finances</td>
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<td>School</td>
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<tr>
<th><strong>PSYCHOLOGICAL:</strong></th>
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<tr>
<td>Beliefs about illness</td>
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<td>Illness journey so far</td>
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<td>Understanding medical needs</td>
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<td>Coping with treatments – day to day and acute</td>
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<td>Mood</td>
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<td>Anxiety (including procedural anxiety)</td>
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<td>Body image</td>
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<td>Self esteem</td>
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<td>Identity in context of illness</td>
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<tr>
<td>Managing uncertainty</td>
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<tr>
<td>Making decisions about treatment</td>
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A cycle

One way of understanding a child’s experiences of living with medical needs is in a cycle. Their physical health, thoughts, feelings and behaviour are all linked, as in the two examples below.

These two different cycles highlight how a child may present differently at different times.
School Transitions

There will be different psychological challenges and support needs occurring at each stage of a child’s school career.

Starting School:
- Parent handover of trust & responsibility for child’s health
- Anxiety for parent and child about new environment and routines
- Child has ideas about ‘fairness’ e.g. “It’s not fair I have to get medicines when others go out to play”
- Child is managing a ‘non-visible’ difference that other children may not know about

Progressing through school:
- Child experiences increased curiosity about medical needs
- Child may require increasing amounts of age appropriate information to support understanding of their medical needs
- Establishing identity in context of living with medical needs – including increased comparison with friends

Secondary School:
- Making decisions about letting new friends know of medical needs
- Increasing independence around own care
- Managing challenges of adolescence in addition to medical needs

Transition to Adult Medical Services:
- Coincide with leaving school
- Increased thoughts of the future including relationships, family, employment and how medical needs might influence this

Changes in one part of life can affect how we cope in other parts of life. It is therefore important to think about how any school transitions may affect other parts of the ‘bio-psycho-social’ model.
Children with CHI often have cognitive difficulties and may experience difficulties with memory and attention.

It is always advisable to liaise with the child's medical team and local educational psychology services if you have concerns about a child's learning.

General strategies for supporting children with memory and attention:

<table>
<thead>
<tr>
<th>Attention</th>
<th>Memory</th>
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<tbody>
<tr>
<td>Multi modal presentation – verbal instructions with visual cues or demonstration</td>
<td>Information broken down into small chunks</td>
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<td>Specific praise – naming the task and achievement</td>
<td>Maps of the lesson shared and given to keep</td>
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<tr>
<td>Manageable and graded increase in duration of concentration</td>
<td>Visual timetables</td>
</tr>
<tr>
<td>Rewards for effort – ticks and stickers</td>
<td>Post-it Notes, lists</td>
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<tr>
<td>Short and direct instructions</td>
<td>Step by Step instructions</td>
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<tr>
<td>Advanced warnings</td>
<td>Working within templates to reduce memory load</td>
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<tr>
<td>Minimise distractions in the immediate environment</td>
<td>Problem solving support</td>
</tr>
<tr>
<td>Support with planning</td>
<td>Support with frequent revision of learned information</td>
</tr>
<tr>
<td>Consistent routines</td>
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**Talking about feelings**

Children may require different support at different ages to talk about their feelings, such as:

- **Emotions** - words that they can choose from to name their feelings.
- **Prompts** such as pictures of facial expressions showing different emotions.
- **Creative and non-verbal ways** to share their feelings such as play and drawing.
- **Use of metaphors**, for example:
  - Rucksacks (having lots of feelings can be like having a big heavy back pack full of books that you have to carry round all day. Giving out some of the books (i.e. talking about feelings) lightens the load and makes it easier to get on with things you enjoy)
  - Noticing ‘meta’ feelings for teenagers e.g. are they feeling annoyed that they feel worried? Or cross that they feel sad?

If you have significant concerns about a child’s emotional wellbeing, consider making a referral to local CAMHS.

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**‘Living well’ with medical needs**

It is possible to ‘live well’ when it comes to psychological wellbeing for children who have a medical condition.

School teachers can help the child to recognise and notice their strengths, skills, coping strategies, characteristics and achievements. This can help the child to understand that CHI is ‘One part of you, but it’s not all of who you are!’
Your pupil, after discharge from hospital, will require their blood glucose to be monitored throughout the day to ensure the child is not going hypoglycaemic. The child will have a specific care plan in place from their specialist team and it is vital that this is adhered to. Should there need to be flexibility on timings of monitoring/feeds, you MUST check with the parent/carer BEFORE any changes as this could have a profound effect on the child.

Blood glucose monitoring helps to detect patterns too such as illness, stress, poor feeding, hormonal changes etc. all which can influence blood glucose readings and it’s important to be aware of this.

A common method is by using a blood glucose monitor and lancing device. This gives a snapshot of what the blood glucose level is at that moment in time. Many children with CHI become used to this method as it becomes a part of their daily routine although for some it can be stressful.

Another method of testing blood glucose is with a CGM (Continuous Glucose Monitor). This is a small device that is worn just below the skin and measures blood glucose continually throughout the day and night and alerts you to hypoglycaemic episodes. There is a slight time delay with this method and so a finger-prick test with a lancing device may also be required.

Speak with the parent/carer about the child, which method is used, what works and doesn’t work should they become distressed at all and work together to help form solutions.

For children with CHI the blood glucose range should be between 3.5 and 10.0 mmol/L. The parent/carer will inform you of what range their child sits comfortably at, for example, 4.5–6.0 mmol/L. Dependent on the child, this can differ, particularly if their blood glucose is not stable or if there are other underlying medical issues, such as the child being protein sensitive or they have a condition called dumping syndrome.

Learning about your pupil with CHI does not happen overnight and may take weeks or months to start building a picture. Do not rush this process as you want to ensure you are providing the right care. Always communicate with the parent/carer about this and if you have any worries.
Instructions specific to the needs of the CHI child should always be kept with their blood glucose testing kit.

It is also essential to have supported input from the school nurse/community nurse.

There are a number of ways in which blood glucose is tested and monitored and the parent/carer will let you know which method and which equipment their child is currently using.

**Example: Blood glucose testing**

- Wash hands thoroughly or wear protective gloves.
- Open test strip tub and remove a strip ensuring no contact is made on either end.
- Immediately close test strip tub to ensure no moisture gets in and to prevent contamination.
- Put test strip into monitor. Monitor will automatically switch on.
- Choose area to be tested (side of fingertip, big toe or heel – NOT thumb and forefinger).
- Clean area to be checked with moist/alcohol free wipe and dry with swab/clean towel.
- Prick the chosen area with the lancing device (follow the manufacturers guide regarding how to use individual lancing devices).
- Gently massage chosen area.
- Wipe 1st spot of blood away with clean swab/towel.
- Gently massage chosen area to obtain a teardrop size blood sample.
- Collect blood sample on test strip.
- Wipe blood away with swab/clean towel.
- Await reading.

**Please Note:** This is an example only and you should ALWAYS refer to the parent/carer and appropriate nursing teams for further guidance.
Upon discharge from hospital, your pupil will have had a care plan to adhere to. Whilst these are essential to the everyday monitoring and treatment of a child with Hyperinsulinism, throughout their life, it is adapted as and when required. This could be due to further complications of the management of hypoglycaemic episodes, for example.

Our parents are filled with anxiety and strive to keep their children safe at all times. It is essential that you work together with parents/carers to ensure that the routine at home is incorporated into the school day with minimum impact to the child’s structure and routine.

A typical care plan will incorporate how to treat hypoglycaemic episodes, a feeding plan, medications and advice if the child is needing to be admitted to hospital.

We advise that you follow the Specialist Hospitals Care Plan, familiarise yourselves with the child’s routine and ask questions – lots of them!

**Care Plans are subject to review and are tailored to the individual child. Should you require further guidance or advice, please contact the parent/carer in the first instance or the child’s Specialist Hyperinsulinism Paediatric Team.**
The roles of the Community and School Nurses is to provide a child-centred service to meet the health needs of children and young people, whether they be in mainstream or Special Education, to enable them to achieve their full potential.

The aims of these services, is to:

- Promote equality and inclusion for children and young people with health needs.
- Make the service fair and just and to reduce inequality.
- Focus their aims as a service to meet the needs of the school population as it is now and to prepare for the future.
- Ensure they have a flexible approach to meet the needs of children and young people.
- Reach out to Children and Young People who have special educational needs and may have health needs and are home schooled.

These teams work in partnership with education, health and social care and other agencies to reduce inequality and help to improve outcomes for children and young people.

There are numerous ways in which they offer support, such as:

- Perform Health assessments including hearing and vision screening.
- Deliver immunisation programs.
- Health Promotion.
- Participate with Safeguarding Children in collaboration with Education and Social Care.
- Offer Continence assessments. This may not happen in all counties, i.e. they may have a continence team who complete this.
- Participate in Health Reviews with Community Consultant Paediatricians.
- Attend transition reviews and annual reviews where a health need has been identified and participate in the transition.
- Train and support identified education staff to enable them to deliver safe competency based, individualised care to children and young people.

As well as the above, these teams provide drop in and telephone support for parents and carers.
There is no doubt that understanding and receiving an EHCP for your child/pupil is a minefield. Many parents are unaware that they can independently seek a Statutory Assessment and the whole process of collating evidence can be stressful for them.

Work with parents/carers to address any concerns you or they may have and ensure that communication remains paramount in helping the child gain the correct support they need to achieve their full potential. Keep copious records and get as many views as you can over time.

It is essential to note that whilst some children with CHI may not appear to require an EHCP, there is a mountain of evidence to support the neurological and psychological harm should their medical condition not be managed appropriately. The long-lasting effects of poor management can lead to brain damage and thus cause long term effects on their education and learning and the detrimental effects last a lifetime.

Special Needs Jungle have produced flow charts which help parents/carers and schools with the EHCP process as well as Annual Reviews.

Some top tips from Special Needs Jungle:

1) Communicate to parents/carers how their child is doing, whether they require support and at what level, or if they are already receiving SEND Support and how long they have been on the SEND register. Make sure they know who the school SENDCo is.

2) Provide parents/carers with a record of educational and/or behavioural interventions used and comments about how they have worked or not, and include who delivered the intervention, when, over what period, how it has been monitored and whether the pupil achieved their target.

3) Assessments to consider for the child would be Educational Psychologist, Speech and Language and Occupational Therapy.

4) Should you feel that the child may have other needs such as ASD, ADHD, Dyslexia etc, liaise with and support the parents/carers in your findings and use signposting and possible referrals if necessary, to their GP, Paediatrician or CAMHS for example.
**Prior to starting school**

For parents it’s advisable to visit a range of schools at differing times to get a true picture. If possible, visit with someone who offers you support such as Portage so that you can really listen. Speak with other parents that attend the setting or the Health Visiting Team for school recommendations.

Does your child/pupil need an EHC Plan? If so, contact your local SEND advisory team or Portage for support. They will help you through the process of applying for an EHCP.

Always ask to speak to the school SENDCo.

For parents, go with a list of questions:
- What will the school do to support your child?
- How will they do this?
- Are they flexible in their practices?
- Look at their policies around SEND and inclusion, Health and Safety, Care and toileting and lunchtimes.
- If it’s a mainstream setting, do they have other children with a medical/SEND need?
- How do they integrate SEND children with their peers?
- Speak with staff members if possible and most importantly speak with other parents whose children attend that setting.

Seeing the class and the potential class teacher and the staff member allocated to your child if they are to receive 1-1 support will help parents to understand the environment their child will be in, and for staff, what potential risks there are and what possible adaptations need to be made.

For schools, ask questions:
- How is your pupil managed at home?
- Is there an MDT in place?
- What additional support may the child require in and around school?
- Think about the integration of the pupil within the classroom environment, around school and with their peers.
- Ask what training is available and whether they can signpost you to relevant websites or professionals.
It’s important to ensure that there is a vigorous culture of continuous professional development in school that allows for provision in relation to specific conditions and presentations.

Always take away as much information as you can about CHI and how it affects your pupil.

Re visit and double check on what you need more clarification on.

Some parents may have, or it is advised for parents to have, a Communication Passport. These are booklets designed to be carried about with the child and are particularly useful for hospital admissions, playgroups and starting school. They can be put together by the parents themselves or with the help of perhaps a Speech and Language therapist to incorporate a lot of information to know about the child such as how they communicate, their likes and dislikes, family members, their care plan, hypo treatments, emergency contacts etc. It is a foundation model that schools will find particularly useful in the beginning when getting to know the child and is also helpful when applying for an EHC Plan.
It is also good to have a designated medical/hypo treatment box that the child will attend school with. Both schools and parents can use this checklist to ensure they have the correct items:

- Hypo plan
- blood glucose testing monitor
- additional testing strips and lancets
- cleaning wipes
- booklet for recording of blood glucose readings
- medications
- hypo treatments such as glucogel, SOS powders, glucotabs, glucojuice
- snacks and juice

**Once you know where your child/pupil will be going**

Request a home visit; this will give you time to talk through everything around the needs of the child.

Allow as much time as reasonably possible as CHI children are often complex, and it is advisable to ensure you take away as much information as you can.

If your child/pupil is at another setting, then suggest school staff go and visit to see how the child's needs are managed within an educational and care context.

Ask to speak to the Head Teacher and SENDCo again to check that you are all clear around expectations and roles. Check that there are systems in place for emergencies.

Ensure that you have an up to date care plan in place for your child/pupil.
Liaise with professionals

It is vital that school staff receive training around CHI prior to the start of school.

This ideally should happen in June/July if your child is starting in September to allow the staff to have a full understanding of the requirements and to have time to practice and put systems in place.

Make sure that the staff have a list of contact numbers/emails of professionals that they can go to for advice.

Ensure that staff know they can ask you any further questions – an open policy around ‘no question is a daft question’ is always the best!

For additional guidance on supporting pupils with medical conditions at school, please visit:


Things to consider

- Make sure that there is a pre-arranged system for the recording of information around blood glucose levels etc.
- Make sure that you have agreed what will happen to the equipment daily; where will medication be stored?
- Have you thought about food/snacks etc. and who will purchase these?
- Have you considered activities or clubs such as PE or swimming? How might this impact on your child/pupil?
- What will happen if your child/pupil has a 1-1 and they are absent? What systems are in place? Is there a team of people trained?
- How will you ensure training remains current? Can you signpost the school to further reading/training/support groups/other schools?
- Make sure that you have a communication system either in the form of email or a communication booklet to ensure that all information is always passed on.
- Have you considered scheduled appointments? If you know when these are, think ahead and ensure that school work is prepared for these times.
Every child with CHI is different.

Every day is different for the same child.

The same tasks for a child with CHI can have a different outcome i.e. sometimes hypoglycaemic, sometimes not.

Know your pupil’s signs and symptoms but remember not all CHI children are symptomatic. Discuss with parents/carers about how your pupil presents.

Watch for behaviours – what you think is normal childhood behaviours and isn’t usual behaviour of that child with CHI, may be a sign of a hypoglycaemic episode – it’s always best to liaise with the parent/carer to understand what is/isn’t normal for their child and they will advise whether to check blood glucose levels.

There are several factors that can contribute to a hypoglycaemic episode, such as:

- **Temperature** – being too hot/cold can influence blood glucose levels as the body is working hard to regulate itself thereby using more energy – some CHI children cannot self-regulate.

- **Illness** – fever, sickness, sore throat, ear ache, generally feeling unwell for example all influence blood glucose levels but all CHI different and you may see levels go higher than usual so be mindful of the child’s normal blood glucose range.

- **Fasting** – if a child is not eating due to feeling unwell or may have a sore throat for example, this can cause blood glucose levels to change.

- **Exercise** – any type of exercise can affect blood glucose levels i.e. PE, swimming, outdoor/indoor play (running, skipping, jumping), longer walks than what they are used to – anything which may use excess energy.

- **Body changes** – from losing/gaining teeth, hormones, developing body.

- **Using the brain** – exams, tests, including spelling tests or any work that requires more concentration than usual.

- **Hospitalisations and appointments** – many CHI children develop anxieties around these which can cause them stress and impact blood sugar levels.

- **Other causes of anxiety** - school plays, show and tell in front of the class or an upcoming school test.
Changes in routine – school holidays, playscheme etc. are particularly more difficult with children who present with Autism/ADHD or Sensory Processing Disorder which can cause stress and anxiety above what is normal for them. Even for CHI children without these added difficulties, the body reacts differently to changes in routine and environments.

Be mindful of children with Autism/ADHD or children who cannot communicate due to being non-verbal or who use communication systems such as PECS. These children may not be able to communicate how they are feeling or that something is wrong, and they do not necessarily understand what is wrong and they may display so many different behaviours such as extreme head banging for example.

It’s also worth mentioning that blood glucose levels can go higher in some circumstances or situations – again every child is different so speak with the parent/carer for a better understanding of what to expect with your CHI pupil.

Examples of higher readings would include: excitement/adrenaline rush, stress/anxiety, illness.

Lastly - always listen to the parents/carers – they are the experts in their child and if you have any questions, they are your first port of call.

Embrace the changes & the challenges but most of all celebrate the child’s uniqueness.
Signs & Symptoms — quick reference

**Poor Feeding**
- Lethargy
- Fast Heart Rate

**Jitteriness**
- Irregular Body Temperature
- Weak / High pitched cry

**Restless/irritable**
- Floppiness/Poor Body Tone
- Pale / Bluish colour to skin tone
- Seizures / Eye rolling
- Apnoea
- Unresponsive Breathing

**Headaches**
- Sweating
- Dizzy
- Confusion

**Hunger**
- Staring
- Can’t Concentrate

**Weakness**
- Irritable

**Blurred Vision**
- Shakiness
- Fast Heartbeat

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www.hyperinsulinism.co.uk
@CHCharityUK

HYPOGLYCAEMIA WITH CLINICAL SIGNS IS A MEDICAL EMERGENCY
Appendix

The Children’s Hyperinsulinism Charity
www.hyperinsulinism.co.uk

GOSH - Great Ormond Street Hospital for Children
www.gosh.nhs.uk/conditions-and-treatments/conditions-we-treat/hyperinsulinism

NORCHI - Royal Manchester Children’s Hospital & Alder Hey Hospital
https://norchi.nhs.uk/

Special Needs Jungle
www.specialneedsjungle.com

I.P.S.E.A
www.ipsea.org.uk

Statutory Guidance for Supporting Pupils with Medical Conditions at School
The Children’s Hyperinsulinism Charity have collaborated with the following contributors to ensure we bring this booklet to you with the most up to date information in the care of a child with Congenital Hyperinsulinism. They have been generous in the sharing of their expertise, knowledge and time and to them we are eternally grateful.

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