

# Healthcare Needs Guidance for Merthyr Tydfil Borough Council

Date of issue: June 20<sup>th</sup> 2017                      Review date: June 2020  
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## 1. Introduction

### Overview

Local authorities, education settings and governing bodies in Wales are responsible for the health and safety of children and young people in their care.

Merthyr Tydfil County Council is committed to the provision of high quality care that meets the individual needs of all children and young people in Merthyr Tydfil.

In Merthyr Tydfil, settings are successful at including children and young people with needs of increasing complexity so each setting will inevitably at some time, have a child or young person on roll with a significant healthcare need. There is an expectation that these children and young people are able to, and can safely attend their local mainstream setting.

A child or young person with medical conditions may be considered as disabled under the definition set out in the Equality Act and/or have a statement of special educational needs (SEN). For children and young people with SEN, this guidance should be read in conjunction with the **Special Educational Needs Code of Practice (Wales), 2002**.

### Key Policy Statements

Settings must have a knowledge and understanding of how to routinely manage any child or young person with a chronic condition, and also of any relevant emergency management procedures required. There will be occasions where setting staff may be asked to facilitate a child or young person's attendance or administer medication regularly, or in an emergency situation.

Staff members must receive sufficient and suitable training and achieve the necessary level of competence before they take on the required responsibility. No staff member can be required to administer or supervise medication unless it forms part of their contract, terms and conditions or a mutually agreed job plan.

**Where a medical healthcare plan, individual healthcare plan (IHP) and/or medication for a pupil is not readily available on a given day and places a pupil at risk, the headteacher will assess the risk and has the right to refuse to admit the child into the school until said healthcare plan or medication is provided in accordance with this school policy.\***

**\*However, this should not affect the pupils' attendance. The School, Local Authority and Health Board must liaise with each other as soon as possible.**

A child or young person with a long-term, complex medical condition may require on-going support, medicines or care with interventions. It is also the case that a child or young person's healthcare needs may change over time, in ways that cannot always be predicted, sometimes resulting in extended absences. It is therefore important that parents feel confident that settings will provide effective support for their child or young person's medical condition and that they feel safe and happy.

Settings should:

- **Establish relationships** with relevant local health service. It is crucial that settings receive and fully consider advice from healthcare professionals and listen to and value the views of parents and the child or young person.
- **Consider social and emotional implications** associated with medical conditions. Children and young people may be, or become, self-conscious about their condition

and some may experience bullying or develop emotional disorders such as anxiety or depression around their medical condition.

- **Consider the impact of short term and frequent absences**, including those appointments connected with a child's medical condition; they need to be effectively managed and appropriate support put in place to limit the impact on the child's educational attainment and emotional and general well-being.
- **Consider the impact of long-term absences** due to health problems a child or young person's educational attainment may be affected, impacting on their ability to integrate with their peers and affect their general wellbeing and emotional health. Reintegration back into a setting should be properly supported so that the child or young person with a medical condition can fully engage with learning and do not fall behind when they are unable to attend.

## 2. Legislation and guidance

### LA's Legal requirements

This guidance has been written to provide educational settings with practical help in supporting learners' health care needs while at their setting. The purpose of the guidance is to ensure that all children with healthcare needs are successfully supported in settings across Merthyr Tydfil so that they are afforded their right to play a full and active role in setting life, to remain healthy and achieve their academic potential.

The legislation that this guidance has been issued under is documented in Supporting Learners with Healthcare Needs Guidance Welsh Government 215/2017

(<http://learning.gov.wales/resources/browse-all/supporting-learners-with-healthcare-needs/?lang=en>); pages 3, 4, 5, 27, 28, 29, 30 and 31; which must be followed.

Section 175 of the Education Act 2002 places a duty on local authorities and governing bodies to make arrangements to ensure their functions are exercised with a view to safeguarding and promoting the welfare of children in school or another place of learning. This includes supporting children with healthcare needs.

In meeting the duties under section 175 of the Education Act 2002, local authorities and governing bodies **must** have regard to guidance issued by the Welsh Ministers under this section.

Section 21(5) of the Education Act 2002 places a duty on governing bodies to promote the well-being of learners at the school so far as related to the matters mentioned in section 25(2) of the Children Act 2004, which includes physical and mental health and emotional well-being, education, training and recreation, and social well-being.

All learners with healthcare needs are entitled to a full education. In addition to the duties set out above (Education Act 2002), consideration must also be given to whether the learner is defined as disabled under the Equality Act 2010. Governing bodies must comply with the duties of this Act, including those within an education context. For example, reasonable adjustments for disabled learners must be made and disabled learners must not be discriminated against when making admission arrangements.

In addition the following guidance and policies have been referred to in the writing of this guidance:

- Guidance on the use of emergency salbutamol inhalers in schools in Wales. Guidance. Welsh Government circular no: 015/2014

(<http://learning.gov.wales/resources/browse-all/use-of-emergency-salbutamol-inhalers-in-schools-in-wales/?skip=1&lang=en>)

- Model School Safeguarding Policy 2017/18 for use with schools in Cwm Taf.
- The Social Services and Wellbeing (Wales) Act, 2014, highlights the duty on local authorities, health boards and Welsh ministers to promote the wellbeing of those who need care and support, or carers who need support.
- The Well-being of Future Generations (Wales) Act 2015 which highlights the need to improve the social, economic, environmental and cultural wellbeing of Wales
- Equality Act 2010
- United Nations Convention on the Rights of the Child, 1992
- Focus On the Future MTCBC- Wellbeing in our community 2017-2022

The non-statutory advice contained within this document is issued in exercise of the Welsh Ministers' duty to promote the education of the people of Wales and their power in relation to the promotion or improvement of the economic, social and environmental well-being of Wales.

### **3. Roles and responsibilities**

#### Local authorities

Local authorities including key education staff should ensure education provision is available to learners, and:

- must make reasonable adjustments to ensure disabled children and young people are not at a substantial disadvantage compared with their peers. This duty is anticipatory. For example, learners should not be disadvantaged when leaving primary school and beginning secondary school. In practical terms this means adjustments must be planned and implemented in advance to prevent any disadvantage. Discussions around the responsibility for provision should not impact on the delivery of service, as delays could be detrimental to the education and wellbeing of the learner.
- must make arrangements to promote cooperation between various bodies or persons, with a view to improving, among other things, the well-being of children in relation to their physical and mental health, their education, training and recreation. When making these arrangements, local authorities should ensure appropriate agreements are in place for data sharing. This is through the Wales Accord on Sharing Personal Information (WASPI) Information Sharing Protocols or Data Disclosure Agreements. The Local authority has a WASPI coordinator who can support service providers to develop appropriate agreements.
- must make reasonable provision of counselling services for young people aged 11–18 and learners in Year 6 of primary school. Within schools, this provision should complement the different approaches already in place to support the health, emotional and social needs of learners.
- should work with education settings to ensure learners with healthcare needs receive a suitable education. Where a learner of compulsory school age would not receive a suitable education for any period because of their health, the local authority has a duty to make arrangements to provide suitable education<sup>10</sup>. If a learner is over that compulsory school age but under 18, the local authority may make such arrangements.
- should provide support, advice and guidance, including how to meet the training needs of education setting staff, so that governing bodies can ensure the support

specified within the individual healthcare plan(IHP) can be delivered effectively. (see the section on Individual healthcare plans (IHPs) on page 7 of this guidance)

#### Governor Support Officers-

Government Support Officers need to ensure that Governing bodies oversee the development and implementation of arrangements, which should include:

- complying with applicable statutory duties, including those under the Equality Act 2010 (e.g. the duty to make reasonable adjustments in respect of learners with healthcare needs if they are disabled, as outlined above).
- having a statutory duty to promote the well-being of learners. Schools should give consideration to how they can meet these needs, including providing learners access to information and material aimed at promoting spiritual and moral well-being and physical and mental health (Article 17 of the UNCRC).
- considering how they can support learners to develop the skills, knowledge and emotional resilience required to uphold their rights, and the rights of others.
- ensuring the roles and responsibilities of all those involved in the arrangements to support the healthcare needs of learners are clear and understood by all those involved, including any appropriate delegation of responsibilities or tasks to a headteacher, member of staff or professional as appropriate.
- working collaboratively with parents and other professionals to develop healthcare arrangements to meet the best interests of the learner.
- developing and implementing effective arrangements to support learners with healthcare needs. This should include a policy on healthcare needs and where appropriate, IHPs for particular learners.
- ensuring arrangements are in place for the development, monitoring and review of the healthcare needs arrangements.
- ensuring the arrangements are in line with other relevant policies and procedures, such as health and safety, first aid, risk assessments, the Data Protection Act 1998, safeguarding measures and emergency procedures.

#### Headteachers, teachers-in-charge (PRUs), teachers and other staff members.

The headteacher should ensure arrangements to meet the healthcare needs of their learners are sufficiently developed and effectively implemented. This can include:

- working with the governing body to ensure compliance with applicable statutory duties when supporting learners with healthcare needs, including duties under the Equality Act 2010.
- ensuring the arrangements in place to meet a learner's healthcare needs are fully understood by all parties involved and acted upon, and such actions maintained. In larger education settings it may be more practical to delegate the day-to-day management of a learner's healthcare needs to another member of staff. The headteacher should directly supervise this arrangement as part of the regular reporting and supervision arrangements.
- ensuring the support put in place focuses on and meets the individual learner's needs, also known as person-centred planning.
- extending awareness of healthcare needs across the education setting in line with the learner's right to privacy. This may include support, catering and supply staff, governors, parents and other learners.
- appointing a named member of staff who is responsible for learners with healthcare needs, liaising with parents, learners, the home tuition service, the local authority, the key worker and others involved in the learner's care.

- ensuring a sufficient number of trained staff are available to implement the arrangements set out in all IHPs, including contingency plans for emergency situations and staff absence.
- having the overall responsibility for the development of IHPs.
- ensuring that learners have an appropriate and dignified environment to carry out their healthcare needs, e.g. private toilet areas for catheterisation.
- checking with the local authority whether particular activities for supporting learners with healthcare needs are appropriately covered by insurance and making staff aware of any limits to the activities that are covered.
- ensuring all learners with healthcare needs are appropriately linked with the education setting's health advice service.
- ensuring when a learner participates in a work experience placement or similar, that appropriate healthcare support has been agreed and put in place.
- providing annual reports to the governing body on the effectiveness of the arrangements in place to meet the health care needs of learners. ensuring all learners with healthcare needs are not excluded from activities they would normally be entitled to take part in without a clear evidence-based reason.
- notifying the local authority when a learner is likely to be away from the education setting for a significant period, e.g. three weeks (whether in one go or over the course of the academic year) due to their healthcare needs. Ultimately, what qualifies a period of absence as 'significant' in this context depends upon the circumstances and whether the setting can provide suitable education for the learner. Shorter periods of absence may be significant depending upon the circumstances.
- being mindful of the Social Services and Well-being (Wales) Act 2014. Education settings should be fully aware of this approach and ensure assistance to learners is provided using a holistic approach.

**Any staff member within the education setting may be asked to provide support to learners with healthcare needs, including assisting or supervising the administration of medicines. This role is entirely voluntary. Staff members must receive sufficient and suitable training and achieve the necessary level of competence before they take on the responsibility. No staff member can be required to administer or supervise medication unless it forms part of their contract, terms and conditions or a mutually agreed job plan.**

In addition to the training provided to staff that have volunteered or are contracted to support learners with healthcare needs, the education setting should ensure that staff:

- fully understand the education setting's healthcare needs policies and arrangements.
- are aware of which learners have more serious or chronic healthcare needs, and, where appropriate, are familiar with these learners' IHPs. This includes knowing how to communicate with parents and what the triggers for contacting them are, such as when the learner is unwell, refuses to take medication or refuses certain activities because of their healthcare needs.
- are aware of the signs, symptoms and triggers of common life-threatening medical conditions and know what to do in an emergency. This includes knowing who the first aiders are and seeking their assistance if a medical emergency takes place.
- fully understand the education setting's emergency procedures and be prepared to act in an emergency.
- ask and listen to the views of learners and their parents, which should be taken into consideration when putting support in place.
- ensure learners (or their friends) know who to tell if they feel ill, need support or changes to support.

- listen to concerns of learners if they feel ill at any point and consider the need for medical assistance (especially in the case of reported breathing difficulties).
- make sure learners with healthcare needs are not excluded from activities they wish to take part in without a clear evidence-based reason, including any external trips/visits. This includes ensuring learners have access to their medication and that an appropriately trained member of staff is present to assist where required.
- are aware of bullying issues and emotional well-being regarding learners with healthcare needs, and are prepared to intervene in line with the education setting's policy.
- are aware that healthcare needs can impact on a learner's ability to learn and provide extra help when needed.
- support learners who have been absent and assist them with catching up on missed work – this may involve working with parents and specialist services.
- keep parents informed of how the healthcare need is affecting the learner in the education setting. This may include reporting any deterioration, concerns or changes to learner or staff routines.

In accordance with the Welsh Government statutory guidance the local authority has considered the following points in developing this guidance and its procedures:

- Staff should understand and work within the principles of inclusivity.
- Lessons and activities should be designed in a way which allows those with healthcare needs to participate fully.
- Staff should understand their role in supporting pupils with healthcare needs and appropriate training should be provided.
- Staff should feel confident they know what to do in a healthcare emergency.
- Staff should be aware of the needs of their pupils through the appropriate and lawful sharing of the individual pupil's healthcare needs.
- Whenever appropriate, pupils should be encouraged and supported to take responsibility for the management of their own healthcare needs.

The above section on roles and responsibilities refers to the minimum standards of *expected practice* for the following. These must be followed in accordance with the Welsh Government statutory guidance.

- Local authorities;
- Governing bodies;
- Headteachers;
- Teachers and support staff;
- Pupils and parents/carers;
- NHS Wales school health nursing services, third sector organisations and other specialist services.

Based on these principles, the educational setting should name the person/s with the overall responsibility for managing healthcare needs:

Lead member of staff for managing healthcare needs	Insert name (usually headteacher) or delegated person(s)
Protocol in the absence of this person	Insert details / name



#### 4. Unacceptable practice

MTCBC LA reiterates the advice contained in Welsh Government's 'Supporting Learners with Healthcare Needs' statutory guidance. All staff and governors will need to be aware of the unacceptable practice guidance as outlined in the National Guidance (highlighted in **Appendix 1**), and must avoid these practices.

Please also see the 'Unacceptable Practice' section in the Welsh Government 'Supporting Learners with Healthcare Needs' statutory guidance:

<http://learning.gov.wales/resources/browse-all/supporting-learners-with-healthcare-needs/?lang=en>

#### 5. Individual Healthcare Plans

Governing bodies should ensure their healthcare needs policy includes information on who has overall responsibility for the development of the IHPs. Where healthcare needs are complex, fluctuating, long term or where there is a high risk that an emergency intervention will be needed, an individual healthcare plan will be required (IHP). An IHP may be needed even if a medical condition is normally well controlled.

However, not all pupils with healthcare needs require an IHP. Please see the flowchart below showing the process that should be followed to decide what interventions are most appropriate.

In most cases, especially concerning short-term illnesses such as those requiring a course of antibiotics, a detailed IHP may not be necessary. In such circumstances it may be sufficient to only complete the form in **Appendix 2**.

##### Development of the IHP

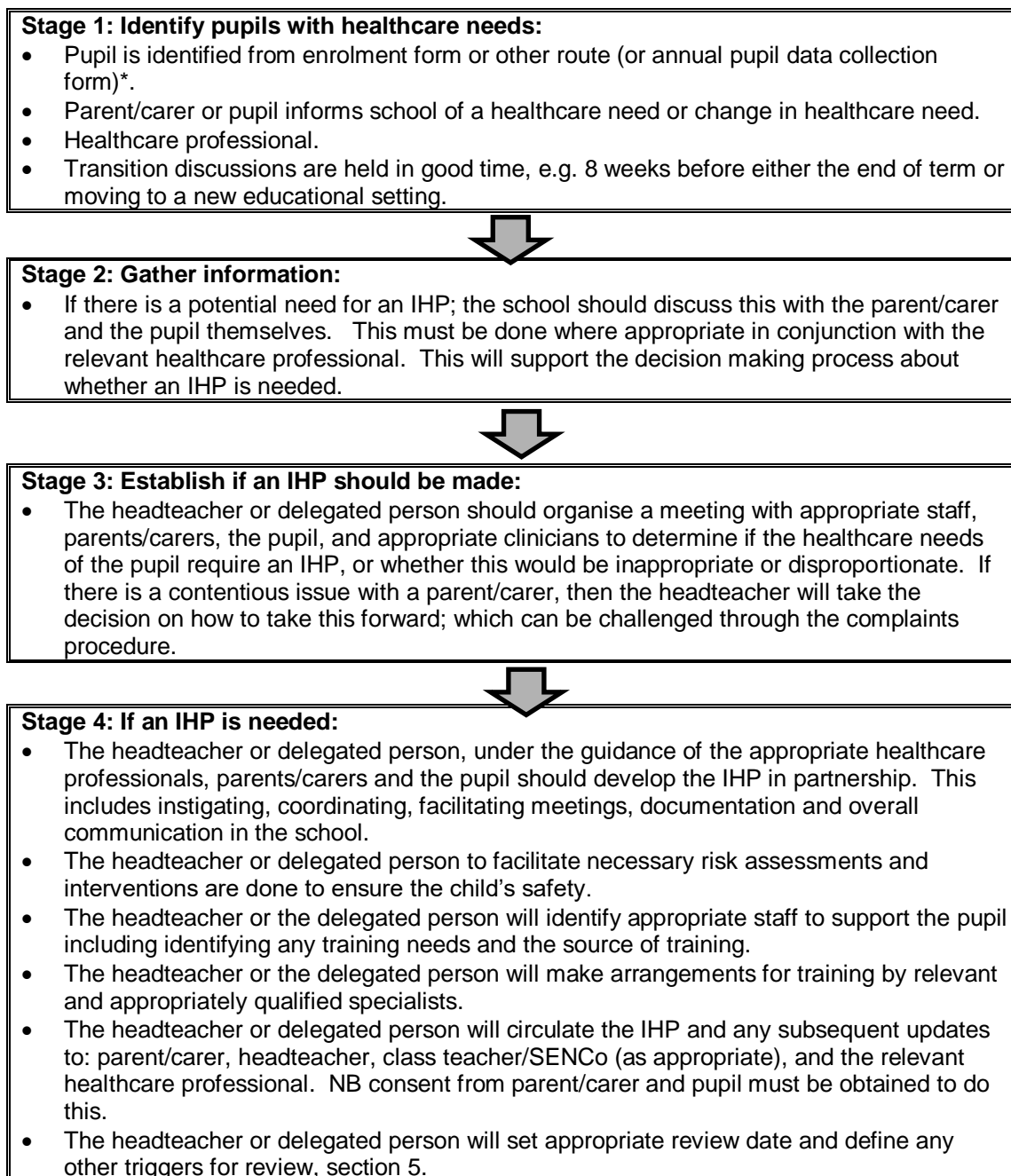
An IHP sets out what support is required by a pupil. It does not need to be long or complicated. When a pupil has continual or episodic healthcare needs, an IHP may be required. If the pupil's healthcare needs are complex and they are changing settings, then the setting will need to start the preparation early to help ensure an IHP is in place at the start of the new term. If any medication is required as part of an IHP, the medication consent form in **Appendix 2** must also be completed.

Stage 1 of the flowchart outlines the process for identifying whether an IHP is needed.

In some cases e.g. short term anti-biotics; at the end of stage 2 'gather information' stage it might be clear that an IHP is not needed. In this case it will not be necessary to progress to stage 3 and 4.

If it is determined that an IHP is required and one has not yet been developed, the IHP in **Appendix 3** will need to be completed with the pupil, parent/carer and relevant health professional. It may not be necessary to complete all sections of this template. Many third sector organisations have produced condition-specific template IHPs that could be used e.g. Asthma UK <https://www.asthma.org.uk/advice/child/manage/action-plan/> or Diabetes UK <https://www.diabetes.org.uk/Guide-to-diabetes/Your-child-and-diabetes/Schools/IHP-a-childs-individual-healthcare-plan/>

**Figure 1 – the process for identifying whether an IHP is needed.**



Adapted from: [Supporting Learners with Healthcare Needs. Guidance. Welsh Government 215/2017](#);

**\*How we collect information about our pupils' healthcare needs\***

6. Our school admission form includes questions about a pupil's health needs and whether any other agencies are involved in their healthcare. **Working with others**

Healthcare and practical support can be found from a number of organisations. In the first instance the LA can offer advice and guidance or signpost to the most appropriate agency. The scope and type of support the service can offer may include:

- offering advice on the development of IHPs.
- assisting in the identification of the training required for the education setting to successfully implement IHPs.
- supporting staff to implement a learner's IHP through advice and liaison with other healthcare, social care and third sector professionals.
- liaising with the Transport Department to ensure the safe transport of pupils with complex health care needs.

Health advice and support can also be provided by specialist health professionals such as GPs, paediatricians, speech and language therapists, occupational therapists, physiotherapists, dieticians and diabetes specialist nurses. In addition, third sector voluntary bodies can provide advice and practical support. Proactively engaging with specialist services can provide practical help when writing and implementing IHPs. They can also provide training and awareness-raising resources, including video links.

## **7. Creating an accessible environment**

The local authority and governing bodies should ensure that their education settings are inclusive and accessible in the fullest sense to learners with healthcare needs. (Please refer to pages 11-13 in the WG statutory guidance). This includes the following.

### Physical access to education setting buildings

The local authority's accessibility strategy outlines its responsibilities to schools under the Equality Act 2010.

*"Improving the accessibility of schools is not just about removing barriers, it is about increasing access in the widest sense, to ensure that teaching and learning is fully accessible to all pupils."*

Similarly, individual schools must carry out accessibility planning and are under a duty to prepare an accessibility plan following the same principles as the strategy prepared by the local authority. The access strategy will assist schools and the authority to fulfil their legal responsibilities under Parts 11 and 111 of the Disability Discrimination Act which have applied to school and LAs in stages since 1996. This Accessibility Strategy assists the local authority and schools to improve access for disabled pupils in a planned and strategic way and in so doing enables disabled pupils to develop their full potential.

### Reasonable adjustments – auxiliary aids or services

The Equality Act 2010 places a duty on learning establishments to make 'reasonable adjustments' for learners who are disabled as defined by the Act. In regard to these learners, auxiliary aids or services (with the appropriate number of trained staff) must be provided. This is the primary responsibility of the governing body and school.

### Day trips and residential visits

Governing bodies should ensure the education setting actively supports all learners with healthcare needs to participate in trips and visits. Governing bodies must be aware of their

legal requirements (see **Appendix 4** Outline of legal framework) to make reasonable adjustments to trips and residential visits ensuring full participation from all learners.

Staff should be aware of how a learner's healthcare needs may impact on participation, and seek to accommodate any reasonable adjustments which would increase the level of participation by the learner. Staff should consider how to accommodate the sharing of personal information with third parties if necessary for off-site activities (in compliance with the Data Protection Act 1998 and in respecting the learner's right to privacy). This may include information about the healthcare needs of learners, what to do in an emergency and any additional support, medication or equipment needed.

#### Social interactions

Governing bodies should ensure the involvement of learners with healthcare needs is adequately considered in structured and unstructured social activities, such as during breaks, breakfast club, productions, after-hours clubs and residential visits.

The education setting should make all staff aware of the social barriers learners with healthcare needs may experience and how this can lead to bullying and social exclusion. A proactive approach is needed to remove any barriers.

#### Exercise and physical activity

The education setting should fully understand the importance of all learners taking part in physical activities and staff should make appropriate adjustments to sports and other activities to make them accessible to all learners, including after-hours clubs and team sports. Staff should be made fully aware of learners' healthcare needs and potential triggers. They should know how to respond appropriately and promptly if made aware that a learner feels unwell. They should always seek guidance when considering how participation in sporting or other activities may affect learners with healthcare needs. Separate 'special provisions' for particular activities should be avoided, with an emphasis instead on activities made accessible for all. Where this might not be possible, advice from healthcare or physical education professionals and the learner should be sought. Staff should also understand that it may be appropriate for some learners with healthcare needs to have medication or food with them during physical activity; such learners should be encouraged to take the medication or food when needed.

#### Food management

Where food is provided by or through the education setting, consideration must be given to dietary needs of learners, e.g. those who have diabetes, coeliac disease, allergies and intolerances.

Where a need occurs, education settings should in advance provide menus to parents and learners, with complete lists of ingredients and nutritional information. Gluten and other intolerances or allergens must be clearly marked. Providing information will help facilitate parent and catering teams' collaborative working. This is especially important when carbohydrate counting is required.

Consideration should be given to availability of snacks. Sugar and gluten-free alternatives should always be made available. As some conditions require high calorific intake, there should always be access to glucose-rich food and drinks.

Food provided for trips must reflect the dietary and treatment needs of the learners taking part. Food provided for snacks in classroom settings should also take the dietary and treatment needs of these learners into account. While healthy school and 'no sweets' policies are recognised as important, learners with healthcare needs may need to be exempted from these policies. Learners needing to eat or drink as part of their condition should not be excluded from the classroom or put in isolation.

### Risk assessments

Staff should be clear when a risk assessment is required and be aware of the risk assessment systems in place. They should start from the premise of inclusion and have built into them a process of seeking adjustments or alternative activities rather than separate provision. In addition, there are duties under the Equality Act 2010 to prepare and implement accessibility strategies and plans. These strategies and plans deal with matters related to increasing participation by disabled learners. They are described in more detail in **Appendix 4: Outline of legal framework**

### Qualifications, examinations and national curriculum assessments (pg 18 WG guidance)

Efficient and effective liaison is imperative when learners with healthcare needs are approaching assessments, including those undertaking examinations in hospital or at home. The coursework element may help learners to keep up with their peers. The home and hospital teachers may be able to arrange for concentration on this element to minimise the loss of learning while they are unable to attend. Liaison between the education setting and the hospital teacher or home teacher is most important, especially where the learner is moving from education setting or home to the hospital on a regular basis.

Awarding bodies may make special arrangements for learners with permanent or long-term disabilities and learning difficulties, or temporary disabilities and illnesses, who are taking public examinations such as GCSEs or A levels. Applications for special arrangements should be submitted by schools to the awarding bodies as early as possible. Full guidance on the range of special arrangements available and the procedures for making applications is given in the Joint Council for Qualifications' circulars *Adjustments for candidates with disabilities and learning difficulties* (2016) [www.jcq.org.uk/exams-office/access-arrangementsand-special-consideration/regulations-andguidance/access-arrangements-and-reasonable-adjustments-2016-2017](http://www.jcq.org.uk/exams-office/access-arrangementsand-special-consideration/regulations-andguidance/access-arrangements-and-reasonable-adjustments-2016-2017) and *A guide to the special consideration process* (2016) [www.jcq.org.uk/exams-office/access-arrangements-and-special-consideration/regulations-andguidance/a-guide-to-the-special-consideration-process-2016-2017](http://www.jcq.org.uk/exams-office/access-arrangements-and-special-consideration/regulations-andguidance/a-guide-to-the-special-consideration-process-2016-2017), which are both accessible from the, Joint Council for Qualifications' website. [www.jcq.org.uk/exams-office/access-arrangements-and-special-consideration](http://www.jcq.org.uk/exams-office/access-arrangements-and-special-consideration)

Adjustments, adaptations or additional time for learners taking the National Reading and Numeracy Tests should be based on normal classroom practice for particular needs. Teachers are expected to use their professional judgement to support learners. Guidance is provided in the current *National Reading and Numeracy Tests – Test administration handbook*. [learning.gov.wales/resources/browse-all/national-reading-and-numeracy-testsadministrationhandbook/?lang=en](http://learning.gov.wales/resources/browse-all/national-reading-and-numeracy-testsadministrationhandbook/?lang=en)

## **8. Education Other Than at School (EOTAS)** **(p19 - 20 WG guidance) –**

Local authorities have a duty (sections 19(1) and 19(4) of the Education Act 1996) to make arrangements for the provision of suitable education for all children and young people of compulsory school age. A learner who is unable to attend their education setting because of their healthcare needs should have their educational needs identified, and receive educational support quickly so they continue to be provided with suitable education. This means education suitable to the age, ability, aptitude of the learner and any special educational needs (SEN) they may have. The nature of the provision should be responsive; reflecting the needs of what may be a changing health status.

In the case of a short absence from school (less than 15 days), schools will need to provide work to be completed at home, if the pupil's condition permits, and will support the pupil to catch up on their return. In the eventuality that a pupil is absent for more than 15 days (consecutive or cumulative) schools should work with the local authority to ensure the needs of the pupil are met. This may require a period of special tuition.

The local authority will take into account any period of education provided in hospital when considering whether it needs to provide EOTAS for a learner and what to provide. If the learner has been in hospital and has received tuition there, their curricular progress and experiences may be different to that of their peers in school. Even so, as much continuity as possible should be ensured. The local authority will provide as many lessons as the learner's condition allows, and as is beneficial, taking into account what is suitable for the learner. It may be necessary to give particular consideration to a learner who is on a course leading to qualifications.

The local authority has a written policy regarding EOTAS for learners with healthcare needs; the Special Tuition Policy. Special tuition is available to provide education for pupils unable to attend schools, including those with medical and psychiatric needs. There is a referral form for this provision and the lead person is David Swallow, who parents, hospital teachers and others should contact. The policy makes links with related services in the local authority such as those for SEN and other local authority support services, educational psychologists, Inclusion, and the Education Welfare Service (EWS).

Where absences are anticipated or known in advance, close liaison between the school and local authority would enable the EOTAS service to be provided appropriately.

Monitoring and evaluation of EOTAS forms a key element in the local authority's strategies. It will seek to ensure that new developments are taken on board, levels of education are of a sufficient standard and that the provision represents good value for money.

Cooperation between education, health and administrative staff in hospital is essential. The aim should be to achieve the greatest possible benefit for the child or young person's education and health, which should include the creation of an atmosphere conducive to effective learning.

Close liaison between home/hospital teachers and mainstream teachers underpins the provision of an effective educational programme for the learners. However, parents can also act as a valuable link.

Learners with complex healthcare needs may be discharged from hospital with a written care plan. Where this happens, the written care plan should be integrated into any IHP.

### Integration

Schools have a key role to play in the successful integration after diagnosis or reintegration of pupils with healthcare needs. They will need to be proactive and work with health professionals and the local authority as appropriate, as well as other pupils, in supporting the transition. This may result in staff requiring suitable and timely training to support the reintegration of a pupil. The support will need to be considered by key parties including the pupil and parent/carer, and should be reflected in the pupil's IHP.

When a pupil is discharged from hospital appropriate information should be provided to parent/carers which should be shared with the school. Schools will need to work with the parent/carer and the hospital to manage the pupil's return, as well as the LA to follow up with the pupil after reintegration.

## **9. School Transport**

All school transport needs relating to pupils with healthcare needs will need to follow that of the local authority.

The authority has a statutory duty to provide pupils with free transport to the nearest available school if they reside beyond 'walking distance' to that school. The law relating to 'walking distance' is defined as two miles for primary age and three miles for secondary age, measured by the nearest available safe walking route. Merthyr Tydfil County Borough Council currently provides transport as follows:-

- for primary age pupils residing over two miles from their nearest or designated catchment area primary school and;
- for secondary age pupils residing over three miles from their nearest or designated catchment area secondary school.

The latest information can be found on the authority's website; or by contacting the School Transport Department (01685) 726256.

The distance criteria apply to all schools including Faith and Welsh-Medium schools. However, where pupils attend, as a result of parental choice, to a schools other than the nearest or designated catchment area school, it must be understood that the parents accept full responsibility for transport costs and arrangements. If a child qualifies for free transport, a place will be provided on a contract vehicle serving the particular area.

Free transport is provided for pupils with additional learning needs who require specialist provision not available in their local schools, irrespective of distance and family circumstances. Specialist provision includes the special school, learning resource bases, including those catering for communication difficulties, hearing impairment, behavioural difficulties and speech and language difficulties. Free transport for pupils with special educational needs is provided on the recommendation of the Principal Educational Child Psychologist and is subject to regular review.

### Special Transport on Medical Grounds

Free special transport to and from school is provided on the recommendation of the Senior Clinical Medical Officer/Principal Educational Child Psychologist and is subject to regular review. Where a pupil has been determined to be entitled to Additional Learning Needs or disability related transport, a needs assessment outlining specific requirements, will be prepared by staff located within the Schools Department, informed in appropriate circumstances by external medical advisors. The needs assessment will form the basis of the precise transport provision

## 10. Sharing information (pages 13-14)

Governing bodies should ensure healthcare needs arrangements, both wider education settings' policies and IHPs, are supported by clear communication with staff, parents and other key stakeholders to ensure full implementation. It is essential that all information is kept up to date.

Both the LA and schools will need to ensure that the managing healthcare needs policy/guidance and the information sharing policy is made available to parents/carers e.g. online and/or hard copy. Because sharing medical information can be a sensitive issue, schools will need to involve the pupil in any decisions as appropriate. To protect pupil confidentiality, schools will need to discuss with the pupil and parent/carer how they can share information about their healthcare needs. Parents/carers will need to be asked to sign a consent form which clearly details the bodies, individuals and methods through which the pupil's medical information will be shared (**Appendix 2 and 3**). This must be done in line with the Data Protection Act 1998 and the WASPI Information Sharing Policy ([www.waspi.org](http://www.waspi.org)).

Furthermore, in the best interest of the pupil schools will need to share information to ensure that teachers, supply teachers, any support staff and temporary staff are aware of the healthcare needs of pupils, including IHPs, particularly if there is a possibility of an emergency situation arising. This will include any changes to healthcare needs, IHPs and medication. The sharing and storing of information must comply with the Data Protection Act 1998 ([www.legislation.gov.uk/ukpga/1998/29/contents](http://www.legislation.gov.uk/ukpga/1998/29/contents)) and not breach the privacy rights of or duty of confidence owed to the individuals. Some examples of how information could be shared are as follows;

- use a noticeboard in the staff room to display information on pupils high-risk health needs, first aiders and certificates, emergency procedures, etc. *Please note that not all staff use the staff room, that the size of your school could make this form of information-sharing impractical, and that at all times the pupils right to privacy must be taken into account.*
- share information with staff about the healthcare needs of pupils on the schools secure intranet or shared drive.
- use staff meetings to help ensure staff are aware of the healthcare needs of pupils they have or may have contact with.

It is important that pupils know who to tell if they feel ill, need support or changes to support them. Following a bout of illness e.g. an asthma attack, schools will need to make sure that this information is shared with staff who will be in contact with the pupil during the rest of the day so that they are aware to look out for any signs of deterioration/further illness. This could include non-teaching staff such as lunchtime staff or reception staff where appropriate. Schools will need to keep a list of what information has been shared with whom and why, for the pupil or parent/carer to view on request. This can be accessed by looking at the pupil's IHP created by the school and/or the medication consent form (**Appendix 2 and 3**).



## **11. Procedures and record keeping for the management of learners' healthcare needs**

### Record Keeping

All administration of medication must be recorded on the appropriate forms. If a learner refuses their medication, staff should record this and follow the defined procedures where parents will be informed of this non-compliance as soon as possible.

The best examples of record keeping include systems where the learner's health care needs records have been computerised to allow quick and easy access by the appropriate staff. Data systems can also allow for easy access to the required information for staff that may be placed into classrooms where they are not familiar with the healthcare needs of the learners.

The operation of such systems must comply with the Data Protection Act 1998.

The education setting should create procedures which state the roles/responsibilities of all parties involved in the identification, management and administration of healthcare needs.

The following documentation should be collected and maintained, where appropriate.

1. Contact details for emergency services (**Appendix 7**)
2. Parental agreement for educational setting to administer medicine(**Appendix 2**)
3. Head of educational setting agreement to administer medicine(**Appendix 2**)
4. Record of medicine stored for and administered to an individual learner(**Appendix 2 & 5**)
5. Record of medicines administered to all learners by date(**Appendix 5**)
6. Request for learner to administer own medicine(**Appendix 2**)
7. Staff training record – administration of medicines(**Appendix 8**)
8. Medication incident report(**Appendix 6**)

New records should be completed when there are changes to medication or dosage. The learning setting should ensure that the old forms are clearly marked as being no longer relevant and stored in line with their information retention policy.

## **12. Storage, access and administration of medication and devices**

(pages 14-17)

Storage, access and administration procedures will always be contextual to the education setting and the requirements of the learner. However, the following general principles should be reflected.

### Supply of medication or devices

Education settings should not store surplus medication. Parents should be asked to provide appropriate supplies of medication. These should be in their original container, labelled with the name of the learner, medicine name, dosage and frequency, and expiry date. Education settings should only accept prescribed medicines and devices that:

- are in date
- have contents correctly and clearly labelled
- are labelled with the learner's name
- are accompanied with written instructions for administration, dosage and storage
- are in their original container/packaging as dispensed by the pharmacist (with the exception of insulin which is generally available via an insulin pen or a pump).

Where non-prescribed medicine is held by the education setting, e.g. liquid paracetamol, it should:

- be in date
- have its contents correctly and clearly labelled
- be labelled with the learner's name
- be accompanied with written instructions for administration, dosage and storage – this can be from the parent
- be in its original container/packaging.

The administration of all medication must be formally recorded using **Appendix 2**. This includes: emergency medication, non-prescribed medication (e.g. paracetamol) and controlled drugs.

#### Accepting/returning medication (including transporting it to school)

It is the parents/carers responsibility to get their child's medication to school. Education settings should discuss with parents/carers how the medication will be transported to school and this will be reflected in the consent form (**Appendix 2**). Medication must only be returned to parent/carer personally.

Secondary schools: Older children may be able to carry/administer their own medication; however parents/carers consent must be obtained first.

#### Storage

The headteacher/delegated person has the ultimate responsibility for ensuring that medicines are stored safely in the school. The headteacher/delegated person will need to ensure that health risks arising from medicines are controlled in line with the Care of Substances Hazardous to Health Regulations 2002 (COSHH). The headteacher/delegated person will ensure secure and appropriate storage of medication.

**Table 1 – exemplar for storage of medication (including controlled drugs)**

*Note: we will never store medication under any circumstances in a first aid box.*

Medication type	Location
Non-emergency medication	<ul style="list-style-type: none"> <li>• All non-emergency medication will be kept in a secure place with appropriate temperature or light controls.</li> <li>• If it is a <b>controlled drug</b>, additional security measures and controls are advisable.</li> </ul> <p><b>Location(s) = will need to be specified by individual settings</b></p>
Refrigerated	<ul style="list-style-type: none"> <li>• Some medicines need to be refrigerated. The refrigerator temperature will need to be regularly monitored to ensure it is in line with storage requirements.</li> <li>• Medicines can be kept in a refrigerator containing food, but should be in an airtight container and clearly labelled.</li> <li>• A lockable medical refrigerator should be considered if there is a need to store large quantities of medicine.</li> </ul> <p><b>Location(s) = will need to be specified by individual settings</b></p>
Emergency medication	<ul style="list-style-type: none"> <li>• Emergency medication must be readily available to pupils who require it at all times during the day or at off-site activities.</li> <li>• All staff will be made aware of the location of emergency medication.</li> <li>• Medicines and devices such as asthma inhalers, blood glucose testing meters and adrenaline auto-injectors (pens) should be readily available to pupils and not locked away. This is particularly important to consider when outside of the education setting's premises, e.g. on trips.</li> <li>• If the emergency medication is a <b>controlled drug</b> it should be kept as</li> </ul>

	<p>securely as possible so as to minimise the risk of unauthorised access while also allowing quick access if this might be necessary in an emergency. For example, keys should not be held personally by a member of staff.</p> <ul style="list-style-type: none"> <li>• <b>A pupil who has been prescribed a controlled drug may legally have it in their possession, if they are competent to do so, and they must not pass it to another pupil or other unauthorised person. Monitoring may be necessary.</b></li> <li>• Where staff administer emergency medication to a pupil, this will be recorded.</li> </ul>
	<b>Location(s) = will need to be specified by individual settings</b>

Asthma inhalers will be stored in a clean dust free container.
--

### Access

It is important for pupils to be told and to know where their medication is stored and how to access it. All school staff will need to be informed where a pupils' medication is stored and how they can access it in accordance with the Data Protection Act 1998 (point 6 and 7).

### Disposal of medicines

When the medication is no longer required, it will need to be returned to the parents/carers to arrange for their safe disposal, e.g. at the end of every term/annually or when the medicines are out of date.

In the event that the parents/carers are unavailable, then school will need to seek advice from the school nurse on the disposal of unused medication left in school. If they are unavailable, the medication will be handed into a local pharmacy. It is important to use sharps boxes for the disposal of needles and other sharps and dispose of appropriately.

### Administration of medicines

- Where the learner is under 16, assistance or administration of prescribed or non-prescribed medicines requires written parental consent, unless Gillick competence is recorded. The administration of all medication should be recorded.
- Where medication is prescribed to be taken in frequencies which allow the daily course of medicine to be administered at home, parents should seek to do so, e.g. before and after school and in the evening. There will be instances where this is not appropriate.
- Learners under 16 should never be given aspirin or its derivatives unless prescribed to them.
- Unless there is an agreed plan for the learner to self-medicate (16 years and above or Gillick competent), all medication should be administered by a member of staff. In other cases, it may need to be supervised in accordance with the IHP.
- Medication should only be administered by suitably trained staff. The movement and location of these trained staff should always be in conjuncture with the learners they support.
- Staff should check the maximum dosage and the amount and time of any prior dosage administered.
- Certain medical procedures may require administration by an adult of the same gender as the learner, and may need to be witnessed by a second adult. The learner's thoughts and feelings regarding the number and gender of those assisting must be considered when providing intimate care. There is no requirement in law for

there to be more than one person assisting<sup>17</sup>. This should be agreed and reflected in the IHP and risk assessment.

- The education setting should have an intimate care policy. It should be followed, unless alternative arrangements have been agreed, and recorded in the learner's IHP.
- If a learner refuses their medication, staff should record this and follow their defined procedures informing parents as soon as possible. If a learner misuses any medication, their parents should be informed as soon as possible. The education setting should ask parents to seek health care advice as appropriate. If parents cannot be contacted immediately, staff need to consider seeking immediate healthcare advice.
- Staff involved in the administration of medication should be familiar with how learners consent to treatment. Further information on this from the Welsh Government can be found in the *Patient Consent to Examination and Treatment – Revised Guidance* (NHS, 2008)<sup>19</sup>.

All staff supporting off-site visits should be made aware of learners who have healthcare needs. They should receive the required information to ensure staff are able to facilitate an equal experience for the learner. This information may include health and safety issues, what to do in an emergency and any other additional necessary support that the learner requires, including medication and equipment.

#### Refrigeration

Some medicines need to be refrigerated. The refrigerator temperature will need to be regularly monitored to ensure it is in line with storage requirements. Medicines can be kept in a refrigerator containing food, but should be in an airtight container and clearly labelled. A lockable medical refrigerator should be considered if there is a need to store large quantities of medicine.

#### Emergency medication

Emergency medication must be readily available to learners who require it at all times during the day or at off-site activities. Medicines and devices such as asthma inhalers, blood glucose testing meters and adrenaline auto-injectors (pens) should be readily available to learners and not locked away. This is particularly important to consider when outside of the education setting's premises, e.g. on trips. If the emergency medication is a controlled drug it should be kept as securely as possible so as to minimise the risk of unauthorised access while also allowing quick access if this might be necessary in an emergency. For example, keys should not be held personally by a member of staff. A learner who has been prescribed a controlled drug may legally have it in their possession, if they are competent to do so, and they must not pass it to another learner or other unauthorised person. Monitoring may be administration procedures will always be contextual to the education setting and the necessary. Where staff administer emergency medication to a learner, this should be recorded.

#### Non-emergency medication

All non-emergency medication should be kept in a secure place with appropriate temperature or light controls. If it is a controlled drug, additional security measures and controls are advisable.

### Change of dose / medication

If instruction is received for a medication dosage change, schools should not change on the pupils/parents/carers instruction alone, but request evidence from the health professional.

If the relevant paperwork is not provided on a given day and places a pupil at risk, the headteacher/delegated person will need to risk assess and has the right to refuse to admit the pupil into the school until the said paperwork is provided in accordance with this policy.

### Adverse effects

If a pupil experiences adverse effects following the administration of medication the setting will need to administer first aid or contact the emergency services as required and will contact the parents/carers immediately. The adverse effect will be recorded on the medication recording sheet in **Appendix 5**.

### Medication errors

If staff in the setting forget to administer medication, administer medication late, provide an incorrect dose of medication, provide an additional dose, administer medication without consent, administer medication by an untrained member of staff or administer medication to the incorrect child, then this will need to be reported to the headteacher/delegated person to seek advice from a healthcare professional or treat the pupil in line with the medical emergency procedures if required. Parents/ carers will need to be contacted immediately and an incident form will need to be completed. **Appendix 7**

## **13. Emergency procedures**

Governing bodies should ensure a policy is in place for handling emergency situations. Staff should know who is responsible for the policy, nominated first aiders and how to deal with common healthcare needs. In situations requiring emergency assistance, 999 should be called immediately. The location of learners' healthcare records and emergency contact details should be known to staff.

Where a learner has an IHP, this should clearly define what constitutes an emergency and explain what to do. Staff should be made aware of emergency symptoms and procedures.

Other learners in the education setting should also know what to do in general terms in an emergency, such as to inform a member of staff immediately. If a learner needs to be taken to hospital, a staff member should stay with the learner until a parent arrives. This includes accompanying them in an ambulance to hospital. The member of staff should have details of any known healthcare needs and medication. **Appendix 6** This also includes information on fire evacuation procedures including that for pupils the middle of being catheterised.

## **14. Training**

The LA will liaise with educational settings to undertake a training needs analysis to ensure that appropriate training is provided, as required. Schools may also request training

through the School Nursing Service for specific healthcare needs such as diabetes, asthma and epipen. Schools should maintain their own staff training records which could be made available to the LA upon request.

Governing bodies must ensure staff who volunteer or who are contracted to support those with healthcare needs are provided with appropriate training. Governing bodies should also ensure their policies clearly set out how a sufficient number of these staff will be identified and supported.

When assisting learners with their healthcare needs, it should be recognised that for many interventions no specialist training is required and the role of staff is to facilitate the learner to meet their own healthcare needs.

IHPs may reflect complex needs requiring staff to have specific information and training. This training may also be in the use of aids such as hearing aids (staff could be shown how to change batteries) and various adaptive technologies. If these have been instigated by health professionals, they can be asked to provide advice suitable for education settings as well as learners and families.

Training provided should be sufficient to ensure staff are competent, have confidence in their ability to support learners and fulfil IHP requirements. Crucially this training should involve input from the learner and parents, who often play a major role in providing information on how needs can be met. However, parents should not be solely relied upon to provide training about the healthcare needs of their child.

If a learner has complex needs, input may be needed from healthcare services and the local authority who will be able to advise and signpost to further training and support.

All staff, irrespective of whether they have volunteered to assist or support learners with healthcare needs, may come into contact with learners who have healthcare needs. It is therefore advisable that all staff have a basic understanding of common conditions to ensure recognition of symptoms and understand where to seek appropriate assistance.

Policies should include a procedure on how to raise awareness of common conditions, a healthcare needs policy and staff roles in carrying out arrangements. New and temporary staff should especially be made aware of what preventative and emergency measures are in place so staff can recognise the need for intervention and react quickly.

If the trained staff who are usually responsible for administering medication are not available, the IHP should set out alternative arrangements. This also needs to be addressed in risk assessment and planning of off-site activities. (**Appendix 8**)

## **15. Reviewing policies, arrangements and procedures**

The LA will seek to ensure that all policies, arrangements and procedures are reviewed regularly and will monitor schools' implementation of this policy.

Governing bodies should ensure that all policies, arrangements and procedures are reviewed regularly in their school. IHPs may require frequent reviews depending on the healthcare need; this should involve all key stakeholders including, where appropriate, the learner, parents, education and health professionals and other relevant bodies.

### Insurance arrangements

The LA follows its legal obligation to provide insurance cover for learners with healthcare needs, which is of an appropriate level for school activities, including off-site activities. This is reviewed annually to take into account any change in needs.

Governing bodies of maintained education settings should ensure an appropriate level of insurance is in place to cover the setting's activities in supporting learners with healthcare needs. The level of insurance should appropriately reflect the level of risk. Additional cover may need to be arranged for some activities, e.g. off-site activities for learners with particular needs.

### **Complaints procedure MTCBC –**

If the learner or parent is not satisfied with the education setting's health care arrangements they are entitled to make a complaint. The governing body must publicise their formal complaints procedure, including how complaints can be escalated from teacher to headteacher, then to the governing body. The school complaints policy states that the governing body decision is final and the only recourse to the local authority is if the complainant asks the LA to review the processes followed but not the decision reached. The schools complaints procedure should also be summarised in the school's policy for supporting learners with healthcare needs.

If the complaint is Equality Act 2010-/disability-related, then consideration of a challenge to the Special Education Needs Tribunal for Wales (SENTW) can be made.

### **Self Esteem**

In addition to the educational implications, there are social and emotional implications associated with medical conditions. Children and young people may be self-conscious about their condition and some may experience bullying, or develop emotional disorders such as anxiety or depression around their medical condition.

In particular, long term absences due to health problems can affect the child or young person's educational attainment, impact on their ability to integrate with their peers and affect their general well-being and emotional health. Reintegration back into setting should be properly supported so that the child or young person with medical conditions fully engages with learning and does not fall behind when they are unable to attend. Short term and frequent absences, including those for appointments connected with a child or young person's medical condition also need to be effectively managed and appropriate support put in place to limit the impact on the child or young person's educational attainment, emotional and general well-being.

### **Self Esteem and Learning:**

- It is important not to make assumptions about strengths and weaknesses based on a child or young person's perceived difficulties
- Allow a degree of risk taking and support failures – we tend to shield children and young people with physical difficulties
- Give lots of varied experiences and opportunities

- Involve the child and young person in target setting and ask what they would like to improve and prioritise
- Don't try for perfection
- Praise carefully – unrealistic praise is demeaning and a child or young person will lose credibility with peers if they are overvalued – children and young people know!

### **Self Esteem and Friendship:**

- Some children and young people may require a teaching assistant (TA) who is assigned for a certain number of hours a day to support physical and learning needs. Staff need to be sensitive to the implications and risks of this and be mindful that the TA does not become the total supporter, carer, advocate and best friend for the child. Children and young people need a variety of people in these roles the same as their peers
- No child or young person should have a TA 'velcroed' to their side during lessons – there should always be daily occasions when the TA physically moves away, allowing peers to interact and support each other.
- Buddy systems, talking partners and small group work can all help to facilitate friendships and increase the confidence of those children who may need encouragement to make friends.

### **Self Esteem and Wellbeing**

- Children and young people with complex medical needs may lack confidence especially if their difficulties require them to be 'singled out' or miss parts of lessons.
- Quite often children and young people's needs are visible to others making other children nervous to approach. It will be especially important in these circumstances for awareness of the child's condition (within reason) to be shared between staff and other children to increase acceptance and inclusion.
- Children and young people who have complex physical/medical needs may find it difficult to join in with games in the playground and staff will need to be aware of these restrictions and provide fun alternatives/adaptations to allow children to feel included and part of the group.
- Increased absences and medical appointments may also mean that the child or young person is feeling anxious due to the other children having more established friendships or that they have missed important work in lessons and feel like they cannot keep up with the rest of the class. It will be important for setting to



## Appendix 1: Unacceptable Practice

[Supporting Learners with Healthcare Needs. Guidance. Welsh Government 215/2017. Page 27](#)

### THIS MUST BE FOLLOWED

#### It is not acceptable practice to:

- prevent learners from attending an education setting due to their healthcare needs, unless their attending the setting would be likely to cause harm to the learner or others
- prevent learners from easily accessing their inhalers or other medication, and prevent them from taking their medication when and where necessary
- assume every learner with the same condition requires the same treatment
- ignore the views of the learner or their parents/carers, or ignore healthcare evidence or opinion (although these views may be queried with additional opinions sought promptly)
- send learners with healthcare needs home frequently or prevent them from staying for normal activities, including lunch, unless this is suitably specified in their IHP
- send a learner who becomes ill or needs assistance to a medical room or main office unaccompanied or with someone unable to properly monitor them
- penalise a learner for their attendance record if the absence is related to their healthcare needs. 'Authorised absences' including healthcare appointments, time to travel to hospital or appointment, and recovery time from treatment or illness should not be used to penalise a learner in any way. This includes, but is not limited to, participation in activities, trips or awards which are incentivised around attendance records
- request adjustments or additional time for a learner at a late stage. They should be applied for in good time. Consideration should also be given to adjustments or additional time needed in mock examinations or other tests
- prevent learners from drinking, eating or taking toilet or other breaks whenever needed in order to manage their healthcare needs effectively
- require parents/carers, or otherwise make them feel obliged, to attend the education setting, trip or other off-site activity to administer medication or provide healthcare support to the learner, including for toileting issues
- expect or cause a parent/carer to give up work or other commitments because the education setting is failing to support a learner's healthcare needs
- ask a learner to leave the classroom or activity if they need to administer non-personal\* medication or consume food\*\* in line with their health needs
- prevent or create unnecessary barriers to a learner's participation in any aspect of their education, including trips, e.g. by requiring a parent/carer to accompany the learner.

*\* For the purpose of clarification, non-personal relates to non-intimate medication.*

## APPENDIX 2

You might want to attach a  
photo of the pupil

### Ysgol XXX

#### PARENT/CARER CONSENT FOR SCHOOL TO ADMINISTER MEDICATION TO A PUPIL

- Our school will not give your child medication unless you complete and sign this form.
- If more than one medication is to be given, a separate form should be completed for each one.
- A new form must be completed when dosage changes are made.
- Where medication is prescribed to be taken in frequencies which allow the daily course of medicine to be administered at home, parents should seek to do so, e.g.

before and after school and in the evening. However we understand there will be instances where this is not appropriate.

- Parents/carers will be informed as stated in the school policy when a child refuses their medication or when emergency medication is administered.
- Parents/carers can request sight of records.
- Without exception pupils must not share their medication for any reason with another pupil.

Name of child	
Date of birth	
Class / form	
Healthcare need	
Routine or emergency medication	
<b>Medicine</b>	
<b>Note: medication must be in the original container if dispensed by the pharmacy.</b>	
Name, type and strength of medicine (as described on the container)	
Date dispensed	
Expiry date	
Dose and frequency of medication	
Method of administration	

Timing of medication	
Duration of treatment	
Special precautions	
Special requirements for administering medication e.g. two staff present, same gender as pupil.	
Storage requirements	
Who will deliver the medication to school and how frequently?	
Who will receive the medication?	
Does treatment of the medical condition affect behaviour or concentration?	
Are there any side effects that the school needs to know about?	
Is there any medication that is being administered outside of school day that we need to know about? Are there any side effects that we should be aware of?	
Any other instructions	
Pupil to self-administer medication under supervision from a stored location	Yes / No (please circle) <i>If yes, pupil must also sign declaration*</i>
Pupil to carry and self-administer medication	Yes / No (please circle) <i>If yes, pupil must also sign declaration*</i>
Procedures to take in an emergency	
<b>If the school has an emergency inhaler:</b>  If your child is prescribed an inhaler have you given consent for your child to use a school emergency inhaler on a separate consent form?	Yes / No (please circle)
Agreed review date	<i>To be completed with the school</i>
Name of member of staff responsible for	<i>To be completed with the school</i>

the review		
<b>INDIVIDUAL HEALTHCARE PLANS (IHP)</b>		
Healthcare Plan from health professional attached if appropriate	Yes / No (please circle)	
IHP created by school attached if appropriate (appendix 3)	Yes / No (please circle)	
Guidelines provided by health attached if appropriate e.g. patient information sheet	Yes / No (please circle)	
Review date of the above		
<b>Contact details</b>	<b>Contact 1</b>	<b>Contact 2</b>
Name		
Daytime telephone number		
Relationship to the child		
Address		
Post Code		
In the best interests of the pupil the school might need to share information with school staff and other professionals about your child's healthcare needs e.g. nursing staff.  Do you consent to this information being shared?	Yes / No (please circle)	
<ul style="list-style-type: none"> <li>• I have read and agree to the school giving medication in accordance with the school policy. I understand my parental/carer obligations under the Welsh Government guidelines (<a href="http://learning.gov.wales/resources/browse-all/supporting-learners-with-healthcare-needs/?skip=1&amp;lang=en">http://learning.gov.wales/resources/browse-all/supporting-learners-with-healthcare-needs/?skip=1&amp;lang=en</a>).</li> <li>• The above information is, to the best of my knowledge, accurate at the time of writing and I give consent to school staff to administer the medicine in accordance with the information given above and the school policy.</li> <li>• I will inform school of any new information from health professionals in regard to my child, e.g. if there are any changes in dosage or frequency or if it is stopped. I will ensure that this is in writing from the health professional.</li> <li>• I understand that it is my responsibility to replenish the medication supply in the school and collect expired or unused medication.</li> <li>• Where correct medication is not readily available on a given day and places the child at risk, the headteacher has the right to refuse to admit my child into the school until said medication is provided.</li> </ul>		

- **It is my responsibility to provide in-date medication which is correctly labelled.**
- I consent for the information in the form to be shared with health professionals/emergency care.
- If my child has received any emergency medication prior to school, I will inform the headteacher/delegated member of the school staff before school starts.

Parent/carer signature:

Date:

I would like my child to administer and/or carry their medication

Parent/carer signature:

Date:

\*If yes to these questions: I agree to administer and/or carry my medicine. If I refuse to administer my medication as agreed, then this agreement will be reviewed.

Pupil signature:

Date:

\*\*\*\*\*

## HEADTEACHER/DELEGATED PERSONS AGREEMENT TO ADMINISTER MEDICATION

It is agreed that *(insert child's name)*..... will receive *(insert name and quantity of medication)* .....at *(insert time medicine is to be administered)* .....

(Name of pupil).....will be  
given their medication / supervised while they take their medication by (*insert name of  
member of staff*).....  
.....

This arrangement will continue until (*e.g. either end date if course of medication or until  
instructed by parents/carers*).....

Name (headteacher/delegated person): .....

Signed:.....Date: .....  
.....

- ☐ Individual Healthcare Plan in place; OR
- ☐ Individual Healthcare Plan not required

**Appendix 3**  
**Ysgol XXXX**

You might want to attach a  
photo of the pupil to the IHP

**Model Individual Healthcare Plan (IHP)**

(Adapted from [www.medicalconditionsatschool.org.uk/](http://www.medicalconditionsatschool.org.uk/))

*Links to IHP templates for specific medical conditions:*  
<http://medicalconditionsatschool.org.uk/>

Please note: this is a very comprehensive IHP. Not all sections will be applicable. The school only needs to use the sections that are relevant and helpful to the care of the pupil.

If health professionals have already provided their own health care plan, the school might not need to create an IHP as long as the one from the health professional covers all the information that the school needs.

**Section 4 of the policy will be followed when developing this IHP.**

**1. PUPIL INFORMATION**

**1.1 Pupil details**

Pupil's name:	
Date of birth:	
Year group:	
Nursery/School/College:	
Address:	
Town:	
Postcode:	
Medical condition(s): <i>Give a brief description of the medical condition(s) including description of signs, symptoms, triggers, behaviours.</i>	
Allergies:	
Date:	
Document to be updated/reviewed:	

Review triggers:	
------------------	--

## 1.2 Family contact information

Name:			
Relationship:			
Home phone number:			
Mobile phone number:			
Work phone number:			
Email:			

## 1.3 Essential information concerning this pupils' health needs

	Name	Contact details
Specialist nurse (if applicable):		
Key worker:		
Consultant paediatrician (if applicable):		
GP:		
Headteacher:		
Link person in education:		
Class teacher:		
Health visitor/ school nurse:		
SENCo:		
Other relevant teaching staff:		
Other relevant non-teaching staff:		
Person with overall responsibility for implementing plan:		
Person responsible for administering/supervising medication:		
Arrangements for cover in these two peoples absence:		
Any provider of alternate provision:		

This pupil has the following medical condition(s) requiring the following treatment.	
Medication administration	Please complete parent/carers agreement for school to administer medication form ( <a href="#">Appendix 2</a> ) and



	attach to this IHP.  Form 1 =  Form 2 =
--	---

### 1.4 Sharing information and record keeping

In the best interests of the pupil the school might need to share information with school staff and other professionals about your child's healthcare needs e.g. nursing staff.  Do you consent to this information being shared?	Yes / No (please circle)
What records will be kept about the pupil's healthcare needs, and how it will be communicated with others?	

### 2. ROUTINE MONITORING (IF APPLICABLE)

Some medical conditions will require monitoring to help manage the pupil's condition.

What monitoring is required?	
When does it need to be done?	
Does it need any equipment?	
How is it done?	
Is there a target? If so what is the target?	

### 3. EMERGENCY SITUATIONS

An emergency situation occurs whenever a pupil needs urgent treatment to deal with their condition.

What is considered an emergency situation?	
What are the symptoms?	
What are the triggers?	
What action must be taken?	

Are there any follow up actions (e.g. tests or rest) that are required?	
---	--

#### 4. IMPACT OF MEDICAL CONDITION AND MEDICATION ON PUPIL'S LEARNING

*(Impact statement to be jointly produced by health professional and a teacher)*

How does the pupil's medical condition or treatment affect learning? <i>i.e. memory, processing speed, coordination etc.</i>	
Actions to mitigate these effects	
Does the pupil require any further assessment of their learning?	

#### 5. IMPACT ON PUPIL'S LEARNING and CARE AT MEAL TIMES

	Time	Note
Arrive at school		
Morning break		
Lunch		
Afternoon break		
School finish		
After school club (if applicable)		
Other		

- ☐ Please refer to home-school communication diary
- ☐ Please refer to school planner

#### 6. CARE AT MEAL TIMES

What care is needed?	
When should this care be provided?	
How's it given?	
If it's medication, how much is needed?	
Any other special care required?	

#### 7. PHYSICAL ACTIVITY

Are there any physical restrictions caused by the medical condition(s)?	
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Is any extra care needed for physical activity?	
Actions before exercise	
Actions during exercise	
Actions after exercise	

## 8. TRIPS AND ACTIVITIES AWAY FROM SCHOOL

What care needs to take place?	
When does it need to take place?	
If needed, is there somewhere for care to take place?	
Who will look after medication and equipment?	
Who outside of the school needs to be informed?	
Who will take overall responsibility for the pupil on the trip?	

## 9. SCHOOL ENVIRONMENT

Can the school environment affect the pupil's medical condition?	
How does the school environment affect the pupil's medical condition?	
What changes can the school make to deal with these issues?	
Location of school medical room	

## 10. EDUCATIONAL, SOCIAL & EMOTIONAL NEEDS

Pupils with medical conditions may have to attend clinic appointments to review their condition. These appointments may require a full day's absence and should not count towards a pupil's attendance record.

Is the pupil likely to need time off because of their condition?	
What is the process for catching up on missed work caused by absences?	
Does this pupil require extra time for keeping up with work?	
Does this pupil require any additional support in lessons? If so what?	
Is there a situation where the pupil will need	

to leave the classroom?	
Does this pupil require rest periods?	
Does this pupil require any emotional support?	
Does this pupil have a 'buddy' e.g. help carrying bags to and from lessons?	

### 11. STAFF TRAINING

Governing bodies are responsible for making sure staff have received appropriate training to look after a pupil with regard to healthcare administration, aids and adaptive technologies. School staff should be released to attend any necessary training sessions it is agreed they need.

What training is required?	
Who needs to be trained?	
Has the training been completed?	
Headteacher/delegated person signature	

### 13. TRANSPORT TO SCHOOL

What arrangements have been put in place?	
Who will meet the pupil in school?	

### 14. PERSONAL CARE

For pupils requiring intimate care as part of their IHP, please refer to the schools intimate care policy.

What arrangements have been put in place in relation to any personal care needs across the school day?	
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### 15. PLEASE USE THIS SECTION FOR ANY ADDITIONAL INFORMATION FOR THE PUPIL.

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**We suggest the following are stored together:**

- ☐ IHP from health
- ☐ Medication consent form (if applicable)
- ☐ Statement of SEN / individual education plan / learning and skills plan
- ☐ One page profile
- ☐ Risk assessment
- ☐ Personal evacuation plan

## **16. SIGNATURES**

	<b>Name</b>	<b>Signature</b>	<b>Date</b>
Headteacher/delegated person			
Young person			
Parents/ carer			
Health professional			
School representative			
School nurse			

## **Appendix 4: Outline of legal framework**

Within the educational context, various duties are placed on both schools and local authorities that are relevant to the safeguarding and welfare of learners. The main provisions are outlined in the sections below. This outline is not an exhaustive list of the relevant legislation, and nor is each section an authoritative statement or description of the laws themselves.

### Statutory duties on governing bodies of maintained schools

- In discharging their functions relating to the conduct of the school, governing bodies of maintained schools (including maintained nursery schools) must promote the well-being of learners at the school. (Section 21(5) of the Education Act 2002). This duty relates to all learners, including those with healthcare needs.
- Governing bodies of maintained schools (including maintained nursery schools) must make arrangements for ensuring that their functions relating to the conduct of the school are exercised with a view to safeguarding and promoting the welfare of children (i.e. those under 18) who are learners at the school (see section 175(2) of the Education Act 2002).
- Governing bodies are also subject to duties under the Equality Act 2010 – see below.

### Statutory duties on local authorities

- Local authorities have general functions in relation to providing education for their area (see in particular sections 13 to 14, 15A, 15B of the Education Act 1996).
- A local authority must make arrangements for the provision of suitable education (at school or otherwise) for children of compulsory school age who may not otherwise receive it for any period due to illness, exclusion from school or otherwise (see section 19(1) of the Education Act 1996). For young persons (i.e. those who are over compulsory school age, but under the age of 18), local authorities have a power (rather than a duty) to make such arrangements in those circumstances (see section 19(4) of the Education Act 1996). In determining what arrangements to make under section 19(1) or (4) in the case of any child or young person, the local authority must have regard to any guidance given by the Welsh Ministers.
- A local authority must make arrangements for ensuring that their education functions are exercised with a view to safeguarding and promoting the welfare of children (i.e. those under 18 – see section 175(1) of the Education Act 2002).
- Local authorities in Wales have a duty under section 15 of the Social Services and Well-being (Wales) Act 2014 to provide services in their area with the purpose of preventing or delaying the development of people's needs for care and support and a range of related purposes.
- Local authorities must make arrangements to promote cooperation between various persons and bodies. This includes a health board and NHS trust within the local authority area. The arrangements are to be made with a view to:
  - improving the well-being of children within the area
  - improving the quality of care and support for children provided in the area
  - protecting children who are experiencing or at risk of abuse, neglect and other harm (see section 25 of the Children Act 2004).
- The Education (School Premises) Regulations 1999 S.I. 1999/2 set out requirements (LA responsibility) regarding facilities at maintained schools. These include requirements regarding accommodation for medical examination, treatment of learners and the care of sick or injured learners (regulation 5).

- Local authorities also have duties under the Equality Act 2010 – see below.

## **The Equality Act 2010**

Disability is a protected characteristic under the Equality Act 2010. Some learners with healthcare needs may be disabled for the purposes of that Act; others may not be. There are various duties under the Equality Act 2010 which are relevant in the context of learners with healthcare needs who are also disabled.

The responsible body of a school must not discriminate, harass or victimise disabled learners and in some cases, other particular persons. The responsible body is also subject to a duty to make reasonable adjustments (section 85 of the Equality Act 2010). Local authorities must prepare and implement an accessibility strategy in relation to schools for which they are the responsible body. This is a strategy for (over a particular period):

- increasing the extent to which disabled learners can participate in the schools' curriculums
- improving the physical environment of the schools for the purpose of increasing the extent to which disabled learners are able to take advantage of education and benefits, facilities or services provided or offered by the schools
- improving the delivery to disabled learners of information which is readily accessible to learners who are not disabled.

(See paragraph 1 of Schedule 10 to the Equality Act 2010.)

The responsible body of a school must prepare and implement an accessibility plan.

Such a plan involves the same content as an accessibility strategy, except that it relates to the particular school (paragraph 3 of schedule 10 to the Equality Act 2010). In relation to a maintained school and maintained nursery, the responsible body is the local authority or the governing body. In relation to a PRU, it is the local authority.

Local authorities and the governing body of local authority-maintained educational establishments (e.g. maintained schools) are subject to the public sector equality duty. This requires them, in the exercise of their functions, to have due regard to particular matters related to equality (section 149). They are also under specific duties for the purpose of enabling better performance of the public sector equality duty (see the Equality Act 2010 (Statutory Duties) (Wales) Regulations 2011 S.I.2011/1064).

## **Social Services and Well-being (Wales) Act 2014**

- The Social Services and Well-being (Wales) Act 2014 ('the 2014 Act') is a single act that brings together local authorities' duties and functions in relation to improving the well-being of people who need care and support, and carers who need support. The Act provides the statutory framework to deliver the Welsh Government's commitment to integrated social services departments with a strong family orientation. From a Welsh policy and delivery perspective, the 2014 Act seeks to ensure that care and support provided to young people is delivered in accordance with the principles outlined in the UNCRC.
- Local authorities in Wales have a duty under section 15 of the 2014 Act to provide preventative services in their area. The purpose of these services would be to prevent or delay people developing a need for care and support.
- The 2014 Act was developed using the 'people model' which focuses on providing sustainable social services to people (being children, adults and carers) in line with their unique needs. This means that children are not treated in isolation but instead as part of families and communities. This has allowed the 2014 Act to provide a cohesive and more integrated care system.
- Well-being and the outcomes people wish to achieve are at the centre of the legislation; the definition of well-being in the Act, and the well-being

statement, both recognise that securing rights and entitlements is key to ensuring that children can speak for themselves or have someone who can do it for them so that they are involved in the decisions that affect their life.

### **Common law**

As part of the common law, those responsible for the care and supervision of children, including teachers and other school staff in charge of children, owe a duty of care to act as any reasonably prudent parent would when taking care of their own children. A person who is responsible for the care and supervision of children should do what is reasonable for the purpose of safeguarding or promoting the child's welfare. However, this is subject, for example, to a court order prohibiting certain steps being taken in relation to that child without the court's consent (section 3(5) of the Children Act 1989).

### **United Nations Convention on the Rights of the Child (UNCRC)**

The Welsh Government is committed to the UNCRC as the underpinning basis for its policies concerning children and young people. The approach outlined in this document is based upon and consistent with UNCRC provisions, which include that:

- children have a right to an education (Article 28)
- adults should think about the best interests of children and young people when making choices that affect them (Article 3)
- children who have any kind of disability should have the care and support required so that they can lead full and decent lives (Article 23)
- every child has the right to say what they think in all matters affecting them, and to have their views taken seriously (Article 12).

### **Other relevant provisions**

The Data Protection Act 1998 regulates the processing of personal data, which includes the holding and disclosure of it.

The Learner Travel (Wales) Measure 2008 places duties on local authorities and governing bodies in relation to home-school transport.

The Misuse of Drugs Act 1971 and regulations deals with restrictions (e.g. concerning supply and possession) on drugs which are controlled. Learners may be prescribed controlled drugs.



Good practice suggests that this form should be contained in a bound and numbered book to avoid a threat of tampering.

## APPENDIX 5 - Ysgol XXX- RECORD OF MEDICATION ADMINISTERED TO A PUPIL

Good practice suggests that only one form is used per child in case a parent/carer wishes to see it.

Name: \_\_\_\_\_ Class: \_\_\_\_\_

Amount of controlled drugs received: \_\_\_\_\_ Signature: \_\_\_\_\_ Date: \_\_\_\_\_

Amount of controlled drugs handed back to parent/carer: \_\_\_\_\_ Signature: \_\_\_\_\_ Date: \_\_\_\_\_

CHECKS: a) Check consent form first; b) Medication must be in its original container with the label attached; c) If prescribed, it must have been dispensed by a pharmacist; d) Must have the expiry date and be in date; e) Must have the name of the child; f) Must have the name of the drug; g) Must have the dosage size and frequency; h) The medication has been stored according to the storage instructions; i) How much medication is left; j) Check the maximum dosage;

k) Check the amount and time of any prior dosage administered. If there is a problem, contact headteacher/delegated person and then parent/carer.

Date	Time	Name of medication	All checks above undertaken	Dose Given	Controlled drugs only: amount remaining	Any reactions	Medication refused/not administered	Reason	Parent/carer informed & how	Staff 1 signature	Staff 2 signature

ATTACH IHP / CONSENT FORM TO THIS FOR

**Medication/healthcare incident report**

Pupil's name:			
Home address:			
Telephone number:			
Date of incident:		Time of incident	

**Correct medication and dosage:****Medication normally administered by:**

	Pupil
	Pupil with staff supervision
	Nurse / school staff member

**Type of error:**

	Dose administered later than scheduled time
	Omission
	Wrong dose
	Additional dose
	Wrong pupil
	Dose given without permission on file
	Dietary
	Dose administered by unauthorised person
	Other

**Description of incident:**

--

**Action taken:**

	Parent /carer notified: date and time -	
	School nurse notified: date and time -	
	Physician notified: date and time -	
	Poison control notified: date and time -	
	Pupil taken home	
	Pupil taken to hospital	
	Other: details:	

<b>Notes/further comments:</b>
--------------------------------

Name:		Role:	
Signature:		Date:	

## **Appendix 7**

### **Contacting emergency services**

#### **Request for an Ambulance**

Dial **999**, ask for an ambulance, and be ready with the following information where possible.

1. State your telephone number (insert phone number)
  2. Give your location as follows [insert your address].
  3. State that the postcode is [insert your address].
  4. Give the exact location in the education setting [insert a brief description].
  5. Give your name.
  6. Give the name of the learner and a brief description of symptoms.
  7. Inform Ambulance Control of the best entrance and state that the crew will be met and taken to [name location].
  8. Don't hang up until the information has been repeated back.
- Speak clearly and slowly and be ready to repeat information if asked to.

**It is recommended that a complete copy of this form be by all telephones in education settings.**

#### **Fire evacuation drill - generic**

In the event of a fire during toileting time {pupil name}'s LSA {LSA's name} will ensure {pupil name} is placed back into chair and a blanket is over {pupil name} and will exit at nearest fire exit.

(clean blanket to be kept in the accessible toilet/physio room)

Evacuate the child from the building via the nearest exit (child to be kept in a place of safety until ALL other pupils have evacuated the building).

#### **Fire evacuation drill for catheterised pupils:**

If the pupil is in the middle of being catheterised and the fire alarm sounds, the following action should be taken:

- Remove the catheter
- Wrap the child in a blanket (clean blanket to be kept in the disabled toilet/physio room)
- Return the child to their chair
- Pick up the emergency catheter kit \*
- Evacuate the child from the building via the nearest exit (child to be kept in place of safety until ALL other pupils have vacated the corridor)
- Telephone the child's parent and explain that the catheter has had to be removed
- IF THE PARENT CANNOT BE CONTACTED or cannot reach the school within an hour, find a safe, private place in which to reinsert the catheter

\*For this purpose, schools should set aside a spare catheterisation set and keep readily available in a clean bag/box

## **Fire evacuation drill – schools with lifts**

### **Lifts must not be used in the event of a fire.**

Lifts will be used on a daily basis to access all areas of the school.

In the event of a fire, evac chairs must be used to assist wheelchair users with leaving the building.

{pupil name}'s 1:1 {LSA's name} has been identified as the designated leader in the event of an emergency. The evac chair timetable identifies 2 assistant leaders who will support {LSA's name} in evacuating {pupil name} from the building, in the evac chair, if this is deemed appropriate.

## Appendix 8: Staff training record – administration of medicines

Please ensure that the Education Workforce Council registration is updated accordingly.

Name of setting

Name

Type of training received

Date of training completed

Training provided by

Profession and title

I confirm that [name of member of staff] ..... has received the training detailed above and is competent to carry out any necessary treatment.

I recommend that the training is updated [please state how often] .....

Trainer's signature .....Date

I confirm that I have received the training detailed above.

Staff signature ..... Date

Suggested review date

## **Appendix 9- Quick Reference Guide to Common Conditions**

The knowledge and understanding of a condition is essential when planning to meet the needs of a child or young person with a medical condition.

There are a wide variety of conditions that settings may encounter, and medicine is advancing so quickly that new conditions and syndromes are being diagnosed on almost a daily basis. The medical conditions which are the most common cause for concern in settings are asthma, diabetes, epilepsy and severe allergic reaction (anaphylaxis).

This section provides some basic information about these conditions and others but it is beyond the scope of this document to provide more detailed medical advice. It is important that the needs of a child or young person are assessed on an individual basis, as the severity and possible implications of a particular condition can vary greatly between individuals.

### **QUICK REFERENCE GUIDE to Anaphylaxis**

Anaphylaxis is an acute, severe allergic reaction requiring immediate medical attention. It usually occurs within seconds or minutes of exposure to a particular food or substance, but on rare occasions may happen a few hours after exposure.

Common triggers include peanuts, tree nuts, sesame, eggs, cow's milk, fish, certain fruits, and also penicillin, latex and the venom of stinging insects (such as bees, wasps or hornets).

The most severe form of allergic reaction is anaphylactic shock, when the blood pressure falls dramatically and the patient loses consciousness. This is rare among children below teenage years. Children and young people with this form will need to have access to their emergency medication (epi pen).

Less severe symptoms may include tingling or itching in the mouth, hives anywhere on the body, generalised flushing of the skin or abdominal cramps, nausea and vomiting.

#### **Essential for settings:**

- Epi pen training
- A Health Care Plan

#### **Points to consider:**

- Potential triggers
- Food and classroom activity/management (precautionary measures)
- Cross contamination of food/resources (playdoh)
- Location of emergency medication
- Liaison with the Education Catering Department

In December 2014 the **Food Information for Consumers (Regulation (EU) 1169/2011)** came into force obliging food manufacturers and caterers to make information on 14 allergens readily available to consumers. The Education Catering department manages compliance with the legislation on behalf of the settings it operates within by producing an allergen matrix for each of its primary and secondary settings. These matrices list all the

food items produced and served onsite and highlight the 14 main allergens that may be present. See Appendix 3 for further details of legislation.

**Further information can be found from:**

The Anaphylaxis Campaign

[www.anaphylaxis.org.uk](http://www.anaphylaxis.org.uk)

Allergy UK

[www.allergyuk.org](http://www.allergyuk.org)

Food Standards Agency

[www.food.gov.uk](http://www.food.gov.uk)

**QUICK REFERENCE GUIDE to Asthma**

One in ten children or young people in the UK have Asthma. The most common symptoms of asthma are coughing, wheezing, and a whistling noise in the chest, a tight feeling in the chest or getting short of breath. Younger children may verbalise this by saying that their tummy hurts or that it feels like someone is sitting on their chest, and some children or young people may only get symptoms from time to time.

There are two main types of medicines used to treat asthma, relievers and preventers. Usually a child will only need a reliever during the setting day. Relievers (Blue inhalers) are medicines taken immediately to relieve asthma symptoms and are taken during an asthma attack. They are sometimes taken before exercise.

Preventers (Brown, Red, Orange inhalers, sometimes tablets) are usually used outside of setting hours.

**Children and young people with asthma need to have immediate access to their reliever inhalers when they need them.** Inhaler devices usually deliver asthma medicines. A spacer device may be used with the inhaler, particularly for a young child, and the child may need some help to use this. It is good practice to support them to take charge of and use their inhaler from an early age, and many do.

Children and young people who are able to use their inhalers themselves should be allowed to carry them with them. If the child is too young or too immature to take personal responsibility for their inhaler, staff should make sure that it is stored in a safe place but readily accessible, and clearly marked with the child's name. For a child with severe asthma, the health care plan professional may prescribe a spare inhaler to be kept at setting.

**Essential for settings:**

- A Health Care Plan
- Training for staff in the use of inhalers/spacer devices
- An awareness of triggers and signs and symptoms of an asthma attack.
- All staff to be aware of the location of Emergency Medications

**Points to consider:**

- An 'Asthma Friendly' Environment in order to remove as many potential triggers as possible



- Children and young people with asthma should participate in all aspects of the setting day including physical activities. Inhalers should always be available during physical education, sports activities and educational visits.
- Physical activity benefits children and young people with asthma in the same way as other children and young people. Some activities are more likely to bring on asthma symptoms. Some children and young people may need to take their reliever medications before any physical exertion.
- Warm up activities are essential before any sudden activities especially in cold weather. Particular care may be necessary in cold or wet weather.
- A Risk Assessment should be considered

**Further Information can be found from:**

Asthma UK Cymru

[www.asthma.org.uk](http://www.asthma.org.uk)

**QUICK REFERENCE GUIDE to Brittle Bone Disease**

It is difficult to estimate the amount of people in the UK with this condition as it cannot be identified by a single test. The best estimate would suggest that approximately 1 in every 15,000 people will have the condition.

It is known as Osteogenesis Imperfecta (OI) and is a disorder of the collagen which provides the framework for bone structure. This weakens the joints and makes them liable to fracture even without trauma. As the composition of the bone is not correct this puts further stress on the joints and muscle groups causing hypermobility and muscle fatigue. This can result in aches and pains and can compromise the quality of life for the child/young person. The severity of the condition can vary greatly.

**Essential for settings:**

- A Health Care Plan/ Fracture Management Plan
- A Risk Assessment

**Points to consider:**

- Gaps and loss of learning due to frequent absences. Children may need time off due to frequent fractures or health appointments/hospital stays and this will need to be planned ahead of time if possible with a plan in place for any missed work. Children should be encouraged to return to setting as soon as possible. Home schooling may be an option in extreme circumstances
- The possibility of hearing loss- this is a medical complication of OI which can occur at any time.
- The need for additional training /advice regarding manual handling at certain periods when children may be in plaster or recovering from a fracture
- The flow of people through high traffic areas during the setting day, children/young people may need to leave earlier or later to move around the setting safely
- The effect on drawing/writing skills. Children and young people tend to have lax joints which make it very difficult to sustain this activity to an acceptable standard.

Alternative assisted technology may need to be considered as the child or young person progresses through the key stages

- Additional support during playtimes and unstructured hours due to the increased risk of fractures occurring
- The management of the condition during setting trips and physical activity

**Further Information can be found from:**

**Brittle Bones Society**

[www.brittlebone.org.uk](http://www.brittlebone.org.uk)

This website has various downloadable factsheets giving information and advice for primary and secondary settings and ideas for including children in PE successfully.

## **QUICK REFERENCE GUIDE to Cerebral Palsy**

Cerebral Palsy is damage to the brain either before, or during birth, or as a result of injury or infection during the early years. It is a non-progressive condition but functional ability may deteriorate over time. It leads to variable impairment of the co-ordination of muscle action, with a resulting inability to maintain 'normal' movements.

Some children or young people with cerebral palsy may be of average or above average cognitive ability, but this may be masked by a physical impairment affecting mobility and co-ordination, speech, swallowing and sensory impairments such as vision and hearing difficulties. These can often be accompanied by epilepsy. The term 'cerebral palsy' covers a wide range of ability and need.

**Spastic Cerebral Palsy** – the muscles are stiff and difficult to control and there is a decreased range of movements in the joints. Within the definition there are 3 types of cerebral palsy:

- Hemiplegia – either the right or the left side of the body affected
- Diplegia – legs are affected, there may be some or no effect to the arms
- Quadriplegia – all four limbs affected

Frequent associated difficulties may include:

- Visual perceptual difficulties
- Spatial awareness/motor planning issues
- Epilepsy

**Athetoid cerebral palsy** – the muscles rapidly change from floppy to tense in an involuntary way. A child or young person finds movements hard to control, and it may take a great deal of effort to achieve any activity. Speech may be hard to understand due to difficulty controlling the tongue, vocal chords and breathing. There are also likely to be difficulties with eating and drinking.

**Ataxic cerebral palsy** – the child or young person may have unsteadiness of movement and poor balance, walking may be jerky, hands shaky and speech may be slow, spatial awareness maybe impaired.

**Essential for setting:**

- A Risk Assessment

**Points to consider:**

- More time between activities and lessons, and at meal times
- Alternative means of recording information (assistive technology)
- Ensure appropriate equipment are in place and are fully accessible to the child or young person
- Flexibility in uniform requirements to promote independence
- Visual perception for a child or young person in a wheelchair (at a lower level)
- Manual Handling Training is essential if the child or young person requires handling

**Further information can be found from:**

Bobath

[www.bobathwales.org](http://www.bobathwales.org)

## **QUICK REFERENCE GUIDE to Cystic Fibrosis**

Cystic Fibrosis is a life-limiting inherited condition caused by a faulty gene that controls the movement of salt and water between cells. This causes mucus to gather in the lungs and digestive system. There is currently no cure for cystic fibrosis but the condition can be managed by physiotherapy and exercise, medication and nutrition. The severity of the condition varies greatly between children. People who have cystic fibrosis should not meet face to face as although bacteria is not harmful to people without the condition people may have bacteria which is harmful to each other

### **Lungs**

People who have cystic fibrosis are susceptible to a range of infections and reduced lung function. Infections need to be treated with antibiotics and may mean that the child or young person may miss periods of education. In some cases a lung transplant is the only way to effectively manage the condition and will mean a long period of recovery away from setting and continued medications.

### **Digestive System**

Mucus produced by the condition can block the ducts in the pancreas halting the flow of digestive enzymes. This can cause malnutrition, poor growth, physical weakness and delayed puberty. Children and young people may need to take enzyme supplements at mealtimes to help digestion and may require a high fat, high calorie diet.

**Essential for settings**

- A Health Care Plan

- A Risk Assessment
- Awareness training for staff
- Close liaison with medical professionals

### **Points to consider**

- The child or young person may require a small amount of physiotherapy exercises to be carried out in setting
- The child or young person may require additional supervision at lunchtimes to ensure that supplements are taken and to try to encourage eating well
- Treatments for the condition need to be prioritised which may mean that children and young people have less time available to complete homework or coursework
- Children and young people should be encouraged to participate fully in PE lessons but must be mindful at times where the child is unwell or feeling unusually tired
- As adolescence approaches young people may struggle emotionally and may benefit from setting counselling

### **Further information can be found from:**

NHS Direct

[www.nhs.uk](http://www.nhs.uk)

The Cystic Fibrosis Trust

[www.cysticfibrosis.org.uk](http://www.cysticfibrosis.org.uk)

### **QUICK REFERENCE GUIDE to Diabetes**

Diabetes is a condition where the level of glucose in the blood rises. This is either due to the lack of insulin (Type 1 Diabetes) or because there is insufficient insulin for the child's needs or the insulin is not working properly (Type 2 diabetes).

There are currently around 1,300 children with diabetes in Wales. Around 97% of these have Type 1 diabetes, meaning that they are entirely dependent on injected insulin to live. There are also a small number of children with Type 2 diabetes and with other rarer forms of the condition, and the incidences of both Type 1 and Type 2 diabetes in children have been rising for a number of years.

Each child or young person may experience different symptoms and this should be discussed when drawing up the health care plan. The majority of children and young people with this condition will require injections of insulin each day. Children or young people with diabetes need to ensure that their blood glucose levels remain stable. They may check their levels by taking a small sample of blood and using a monitor at regular intervals.

Staff should be aware that the following symptoms, either individually or combined may be indicative of low blood sugar- a hypoglycaemic reaction in a child with diabetes:

- Hunger
- Sweating
- Drowsiness
- Pallor
- Glazed eyes

- Shaking or trembling
- Lack of concentration
- Irritability
- Headache
- Mood changes, especially angry or aggressive behaviour

Settings will need to have a plan in place to respond and all staff will need to be aware of how to manage this.

**Essential for setting:**

- A Health Care Plan
- Staff training when Insulin Injections are needed

**Points to consider:**

- Regularly breaks to monitor blood glucose, or to eat/drink
- Food and classroom activity/ management (precautionary measures)
- Location of emergency medication/ alternative foods
- A Risk Assessment should be considered

**Further information can be found from:**

Diabetes UK

[www.diabetes.org.uk](http://www.diabetes.org.uk)

JDRF

[www.jdrf.org.uk/setting-resources](http://www.jdrf.org.uk/setting-resources)

**QUICK REFERENCE GUIDE to Restricted Growth (dwarfism)**

Restricted growth, sometimes known as dwarfism, is a condition characterised by short stature, resulting from a medical condition causing slow growth. It can be caused by more than 300 distinct medical conditions such that the symptoms and characteristics of individuals with dwarfism vary greatly.

There are two types:

**Disproportionate** dwarfism is characterised by one or more body parts being relatively large or small in comparison to those of an average sized individual, with growth variations in specific areas being apparent. The trunk is usually of average size with limbs being proportionately shorter, the head usually larger and a prominent forehead. Orthopaedic problems can result in multiple conditions.

**Proportionate** dwarfism, the body appears normally proportioned, but is usually small. Height is significantly below average and there may be long periods without significant growth. Sexual development is often delayed or impaired into adulthood. In some cases intellectual disability may be part of proportionate dwarfism unlike disproportionate dwarfism.

Physical difficulties vary according to the specific underlying syndrome. Many involve joint pain caused by abnormal bone alignment or nerve compression that can cause pain and disability. Reduced thoracic size can restrict lung growth and reduce pulmonary function and some forms of dwarfism are associated with disordered function of other organs.

Mental effects also vary depending on specific underlying syndromes. In most cases such as achondroplasia mental function is not impaired. The social and emotional implications may be more disabling than the physical symptoms.

**Essential for setting:**

- A Risk Assessment

**Points to consider:**

- More time to move around setting between lessons /activities
- More time to complete tests/exams if manual dexterity is an issue
- A step (portable or permanent) in the bathrooms and at water fountains
- Modifications to the environment eg: lowered mirrors/ hand dryers
- Modified requirements for PE
- Emotional wellbeing, there may be an increased risk of bullying or children may be lacking in confidence to participate in setting life.

**Further information can be found from:**

Restricted Growth Association

[www.restrictedgrowth.co.uk](http://www.restrictedgrowth.co.uk)

**QUICK REFERENCE GUIDE to Epilepsy**

Children and young people with epilepsy have repeated seizures that start in the brain. An epileptic seizure, sometimes called a fit, turn or blackout can happen to anyone at any time. Seizures can happen for many reasons. At least one in 200 children has epilepsy and around 80 per cent of such children attend mainstream setting. Most children and young people with diagnosed epilepsy never have a seizure during the setting day. Epilepsy is a very individual condition.

Seizures can take many different forms and a wide range of terms may be used to describe the particular seizure pattern that individual children and young people experience. Children with epilepsy may also experience behavioural changes. Parents and health care professional should provide information to settings, to be incorporated into the individual health care plan, setting out the particular pattern of an individual child's epilepsy. If a child does experience a seizure in setting/setting, details should be recorded and communicated to parents including any factors which might possibly have acted as a trigger to the seizure.

During a seizure it is important to make sure the child is in a safe position, not to restrict a child's movements and to allow the seizure to take its course. In a convulsive seizure putting something soft under a child's head will help to protect it. Nothing should be placed in their

mouth. After the convulsive seizure has stopped the child should be placed in the recovery position and stayed with until they are fully recovered.

An ambulance should be called during a convulsive seizure if:

- It is the child's first seizure
- The child has injured themselves so badly they have problems breathing after a seizure
- The seizure lasts longer than is set out in the child's health care plan.
- A seizure lasts for 5 minutes
- If you do not know how long a seizure usually lasts for the child
- There are repeated seizures, unless this is usual for the child as set out in the child's health care plan.

**Essential for setting:**

- A Health Care Plan to include the location of emergency medication
- A Risk Assessment
- Training for Staff

**Points to consider:**

- Medication can affect alertness, attention and memory (tiredness)
- Information missed due to absences
- Individual triggers for seizures
- Identification of a quiet, safe, calm zone for recovery
- How to manage the other children in the classroom

**Further Information can be obtained from**

Epilepsy Wales

[www.epilepsy-wales.org.uk](http://www.epilepsy-wales.org.uk)

## **QUICK REFERENCE GUIDE to Haemophilia**

Haemophilia is a genetic condition passed down through families. It affects the clotting factors in the blood and the body's ability to manage bleeding. A child or young person with haemophilia may bleed for longer than a person without the condition when injured. Children or young people with severe haemophilia may also experience bleeding in the joints of the body and excessive bruising when injured. Most people who have haemophilia are boys due to the way that the condition is inherited.

The two most common types are Haemophilia A and Haemophilia B. Both have the same symptoms but are caused by different factors in the blood and have slightly different treatments. Haemophilia is a treatable condition and children born with the condition are likely to have a normal life expectancy and an excellent quality of life.

Treatments are usually in the form of preventative medications given by regular injections. Sometimes to minimise the need for continuous injections children/young people are given an implantable port which is placed surgically into a blood vessel and allows easy access for treatments. If this is the case there will be a specialist nurse involved who can provide staff with any information needed. Injections can usually be given outside of setting hours.

In mild and moderate cases treatment may only be needed on an on-demand basis in periods of injury/bleeding. Each child's case will be individual and advice can be sought from the child's doctors.

Minor cuts and scrapes/nose bleeds should be managed with normal first aid procedures and only are a cause for concern if bleeding continues for longer than is normal for that child. If staff are concerned then medical advice should be sought immediately.

Any physical trauma should be checked by a doctor.

### **Essential for settings:**

- A Health Care Plan
- A Risk Assessment

### **Points to consider:**

- Supervision and safety during high risk activities, contact sports in particular should be avoided
- Mobility issues due to pain or bleeding in joint
- The amount of staff who are First Aid trained, there may need to be more staff readily available to respond to emergencies particularly in a busy secondary setting.

### **Further information can be found from:**

The Haemophilia Society [www.haemophiliawales.org](http://www.haemophiliawales.org)

The Haemophilia Society [www.haemophilia.org.uk](http://www.haemophilia.org.uk)

NHS Choices [www.nhs.uk](http://www.nhs.uk)



## **QUICK REFERENCE GUIDE to Head injuries: Brain Injury, Meningitis, Brain tumour, Stroke**

An Acquired Brain Injury (ABI) is an injury caused to the brain since birth. Injuries resulting from trauma are known as Traumatic Brain Injuries but an Acquired Brain Injury also covers situations such as tumours, strokes and encephalitis among others.

Children and young people who have a Traumatic Brain Injury may initially experience a period of unconsciousness and post traumatic amnesia. If unconsciousness lasts for 6 hours or more with post traumatic amnesia lasting for 24 hours or more, the injury is classed as severe and children /young people with these injuries may have long term physical needs and emotional and behavioural effects. These may include balance problems, headaches, dizziness, memory problems and difficulty controlling their emotions.

A stroke happens when the supply of blood to an area of brain tissue is interrupted either by a blood clot or a bleed in the brain. Children/young people who experience a stroke will experience different effects and severity according to which areas of the brain were starved of oxygen. Children will need a period of rehabilitation and recovery will be varied.

Brain Tumours are rare in children and the cause usually remains unknown. Children/young people will experience different treatments, the side effects of which can be very tiring, may cause the child to feel sick, may cause hair loss and throughout treatment the child will be at a greater risk of catching an infection. Children will not usually attend setting during treatments but the side effects can continue for some time afterwards and need to be planned for when children return to setting.

Meningitis is an infection of the protective membranes which surround the brain and spinal column. It can be life threatening if not treated quickly and can result in permanent damage to the brain or nerves. Symptoms can include: high temperature, vomiting, headache, blotchy rash that doesn't fade when a glass is rolled over it, dislike of bright lights, drowsiness and fits. Medical attention should be sought immediately.

### **Points to consider:**

- Carefully planned re-integration to setting
- After effects of the conditions i.e. epilepsy, reduced stamina, short and long term memory problems, emotional and behavioural problems, physical difficulties
- Absences due to therapies or follow up appointments
- Training for staff if handling is required or if health care needs are present.
- A Risk Assessment and Health Care Plan will be necessary
- Robust liaison with the relevant health professionals and family will be of utmost importance

### **Further information can be obtained from:**

Headway [www.headway.org.uk](http://www.headway.org.uk)

SCOPE [www.scope.org.uk](http://www.scope.org.uk)

NHS choices [www.nhs.uk](http://www.nhs.uk)

## **QUICK REFERENCE GUIDE to HIV positive**

Human Immunodeficiency Virus damages or destroys cells in the immune system leaving them unable to fight infections and certain cancers. The most common route for infection is from mother to child during pregnancy, labour and delivery or breastfeeding and is spread through infected blood or body fluids. Other causes of infection may be through blood transfusions although due to extensive testing in western countries this has become more and more infrequent. More infrequently the virus can be spread through sexual abuse or sexual relationships and drug use using infected needles.

HIV usually leads onto AIDS (Auto Immune Deficiency Syndrome) but not all people who are HIV+ have AIDS.

HIV is managed by antiviral drug treatments intended to stop the virus becoming resistant to any one drug. Children may be taking a drug regime even if they are showing no symptoms as a preventative measure and to improve general health and long term survival. Symptoms that may be seen are frequent childhood infections, failure to thrive and achieve developmental milestones, brain or nervous system problems characterised by seizures, difficulty walking or poor performance in setting.

### **Essential for setting:**

- A Health Care Plan
- A Risk Assessment
- Clear procedures and policy for managing first aid incidences in particular dealing with any bleeding

### **Points to consider:**

- Staff awareness of the condition
- How to manage any incidences of bleeding
- Self Esteem and confidence may be affected due to any stigmas surrounding the condition or lack of awareness of other children and young people.
- Children and Young people have the right to have their status kept confidential
- Family bereavement may be more common as it is likely that caregivers are infected too.

### **Further information can be found from:**

WebMD [www.webmd.com](http://www.webmd.com)

NHS Choices [www.nhs.org.uk](http://www.nhs.org.uk)

AVERTing HIV and AIDS, Global Information and advice [www.avert.org](http://www.avert.org)

## **QUICK REFERENCE GUIDE to Juvenile Arthritis**

“Arthritis is caused by inflammation of the joints. It causes pain, swelling stiffness and loss of motion. Juvenile arthritis is the term used to describe arthritis in children. The most common type that children get is juvenile idiopathic arthritis (from unknown causes)” ([www.niams.nih.gov](http://www.niams.nih.gov))

Children with this condition may complain of pain in situations where it would not normally be expected such as on waking and this may lessen throughout the day. Joints in the hands, feet, neck or jaw may be painful. Children may also experience stiff joints and may struggle to perform normal movements and activities. They may complain that a joint feels hot, which is a sign of inflammation. Children may also experience fevers that can be at any time and are very transient in nature. Children may also experience weight loss. It can also cause sleep disturbances so at times children and young people may be very tired during the day and struggle to concentrate.

Flare ups in the condition can occur due to infections, in times of stress or due to changes in medication.

Other forms of the condition are Juvenile Lupus, (an auto-immune disease which affects the joints, skin, kidneys, blood and other areas of the body) Juvenile Scleroderma, (a condition which causes the skin to tighten and harden) and Fibromyalgia (causes stiffness and aching, along with fatigue and other disrupted sleep).

### **Essential for settings:**

- A Risk Assessment
- If medication is required for pain relief a Health Care Plan will be needed

### **Points to consider:**

- Fluctuating condition will have good days and bad days where fatigue is overwhelming
- Depleted energy levels resulting in lack of motivation
- Reduced self-care skills, children and young people may need extra time to dress and undress
- Regular breaks and places to rest, children and young people may need extra time to move between lessons
- Alternative means of recording information (assistive technology) or more chunky implements for writing and mark making
- Children may need regular prescribed medication throughout the setting day to manage pain and the condition
- PE lessons may need to be adapted to include more low impact sports and activities

### **Further Information can be found from:**

Arthritis Care	<a href="http://www.arthritiscare.org.uk">www.arthritiscare.org.uk</a>
Children's Chronic Arthritis Association	<a href="http://www.ccaa.org.uk">www.ccaa.org.uk</a>
Kids get arthritis too	<a href="http://www.kidsgetarthritisoo.org">www.kidsgetarthritisoo.org</a>
Arthritis Foundation	<a href="http://www.arthritis.org">www.arthritis.org</a>

## **QUICK REFERENCE GUIDE to ME/CFS (Chronic Fatigue Syndrome)**

Chronic Fatigue Syndrome causes persistent fatigue (exhaustion) that affects everyday life and doesn't go away with sleep or rest. It is also known as ME (myalgic encephalomyelitis).

This usually occurs following a viral infection and is characterised by persistent fatigue and muscle pain. The fatigue is made worse by even minimal physical and mental exertion and there is a prolonged recovery period. There is no specific treatment for the condition but the condition is managed by drug therapy for pain, and a slow programme of graded activities to build up stamina. A hormone imbalance can also cause the condition or problems within the immune system. Stress and emotional trauma is also thought to be a consideration. It is a serious condition that can cause long term illnesses and disability but for most people, in particular children and young people, it will improve over time.

There are varying degrees of severity:

- Mild - People are able to carry out their daily activities but may need to take days off to rest
- Moderate - People may experience reduced mobility, sleep disturbances and may need rest in the afternoons on a daily basis
- Severe - People struggle to carry out simple daily tasks and may have difficulty concentrating. Some people may be unable to leave their house

It usually affects people in their early 20's but can develop in young people as young as 13.

### **Essential for setting:**

- Risk Assessment
- If medication is needed a Health Care Plan will be required
- A plan in place to address any absences and missed work
- Training for staff in Manual Handling if the child/young person is a wheelchair user

### **Points to consider:**

- Regular breaks and places to rest
- Opportunities to revisit and consolidate skills
- Learning may be affected due to poor concentration levels
- Depression due to a restricted social life and isolation
- Flexible timetable
- Consideration of home tutoring when necessary
- Staff awareness of the condition so that symptoms are understood and responded to appropriately
- Physical exercise will cause an increase in the symptoms in the hours that follow

### **Further information is available from:**

NHS Choices

[www.nhs.org.uk](http://www.nhs.org.uk)

ME Association

[www.meassociation.org.uk](http://www.meassociation.org.uk)

Association of Young People with ME  
factsheet-England)

[www.ayme.org.uk](http://www.ayme.org.uk) (Education

## QUICK REFERENCE GUIDE to Muscular Dystrophy

Muscular Dystrophy is a group of progressive neuromuscular disorders. It is caused by a faulty gene so can be inherited although the fault can be spontaneous. There are different types depending on where the fault lies on the gene. The term 'dystrophy' refers to a progressive weakness of the muscles due to the breakdown of the muscle fibre. Some conditions are life limiting and others are milder.

### Main types of Muscular Dystrophy

**Duchenne (this is the most common and severe)** – This condition mainly affects boys and is diagnosed when the child or young person is still young and begins to have difficulty with mobility. Between ages 6 – 11 mobility will start to deteriorate, and in their teens they will experience problems with respiratory muscles affecting breathing. Life expectancy is shortened. Children and young people with this condition may need a wheelchair by the time they are 8-14 years old. Gross motor skills are mainly affected but during the teenage years the heart muscles may become affected and children and young people may need regular medical appointments.

**Becker** – This is very similar to Duchenne's but is a milder form of dystrophy which progresses at a slower rate, also affecting boys. Symptoms usually start in the teenage years.

**Myotonic** – This type mainly affects the smaller muscles first including those in the face, jaw and neck. As well as this, people can experience muscle stiffness, excessive sleepiness, difficulty swallowing and learning and behavioural difficulties in children.

### Essential for setting:

- A Risk Assessment
- Training for staff in Manual Handling
- An awareness of the progression of the condition so changes can be monitored.

### Points to consider:

- Appropriate accessibility arrangements during lessons and outside
- Low stamina and physical fatigue
- Susceptibility to changes in temperature
- Eating and swallowing difficulties
- Alternative arrangements for recording information
- Assistance with toileting and self-care (this may increase as the condition progresses)

### Further information can be found from:

Muscular Dystrophy	<a href="http://www.musculardystrophyuk.org">www.musculardystrophyuk.org</a>
NHS Choices	<a href="http://www.nhs.uk">www.nhs.uk</a>
KidsHealth	<a href="http://www.kidshealth.org">www.kidshealth.org</a>

## **QUICK REFERENCE GUIDE to Neurofibromatosis**

Neurofibromatosis is a group of genetic conditions which affect the nervous system and the skin. Although the condition is genetic, it is not always passed through families, as the genetic mutation can occur spontaneously. It occurs in all races and between males and females.

**NF1** - This is more common and varies widely in its severity. This type causes pale coffee coloured patches on the skin and small, soft, non-cancerous bumps on or under the skin. Children and young people may be easily distracted and be restless and fidgety. They may have a poor short term memory and struggle to recall things that have just been learnt. They may forget homework tasks and need frequent reminders to do things. Their co-ordination may be affected and they may be clumsy and accident prone. They may have difficulty transferring skills and processing tasks. They may misinterpret facial cues and may not understand social rules and may seem immature for their years preferring the company of younger children to their peers.

**NF2** - This type is far less common. Symptoms usually occur in the teenage years and usually begin with gradual hearing loss, tinnitus and unsteadiness, particularly when walking on uneven ground or in the dark. This is due to benign tumours which grow on the hearing nerves. Over time these tumours are likely to cause deafness. The tumours are very slow growing and may not cause issues for many years.

In addition to this tumours may also grow on other parts of the nervous system such as the lining of the brain, the spine and the skin. Although they are not cancerous the position and size of the tumours can be a problem.

**Schwannomatosis** - This is very similar to that of NF2 but with the absence of the vestibular (hearing nerve) tumours. Symptoms only start to appear in adulthood although the mutation in the gene is present from birth.

### **Essential for settings:**

- A risk assessment
- An awareness of the characteristics of the condition so that difficulties are not misinterpreted
- Training for staff if difficulties affect children and young people's mobility

### **Points to consider:**

- Safety and accessibility to equipment and areas of the setting.
- Adjustments to allow for progressive hearing loss, liaison with specialist teams
- Strategies to address the learning difficulties that may be present, these will benefit all children
- Wellbeing and self-esteem if tumours are visible
- Children and young people may require careful monitoring to ensure any changes are noted and passed on to parents and medics

### **Further information can be found from:**

The Childrens' Tumour Foundation

[www.ctf.org.uk](http://www.ctf.org.uk)

The Neuro Foundation

[www.nfauk.org](http://www.nfauk.org)

## **QUICK REFERENCE GUIDE to Sickle Cell Anaemia/disorder**

This disorder affects the red blood cells which contain a special protein called haemoglobin (Hb). The function of haemoglobin is to carry oxygen from the lungs to all parts of the body. It is an inherited condition from both parents. If the gene is inherited from one parent then the Child or young person will be a sickle cell carrier and have enough normal shaped cells to carry out daily living activities. They do however need to be cautious when doing activities where there is less oxygen.

Children and young people with sickle cell disorders have haemoglobin which is a different shape to normal haemoglobin. This occurs when the blood cells gives up it's oxygen to the tissues of the body it sticks together causing the haemoglobin to have a sickle shape.

This means that because of their shape they cannot squeeze through small blood vessels and this stops the oxygen from getting to certain parts of the body. This in turn can lead to severe pain and damage to organs. When this occurs it is called a Crisis and hospital treatment may be required. Sickle cells do not live as well as normal shaped cells and therefore this causes a constant state of anaemia.

Complications can include jaundice, crisis within the chest area which can cause breathing difficulties, stroke, priapism (painful, persistent erection-this needs medical attention if it continues longer than 2 hours) and bedwetting even into teenage years.

It is more common in children of African and Caribbean descent and those from the Eastern Mediterranean, Middle East and Asia. Children are usually diagnosed in pregnancy or through family history.

### **Essential for Settings**

- A Health Care Plan
- Awareness Training for Staff

### **Points to consider**

- Settings need to be aware that the following things can increase the risk of a crisis:
  - Exercise which over exerts the child or is in cold weather
  - Stress
  - Infections
  - Not enough water to drink -children and young people will need to be encouraged to drink sufficient amounts of fluids to keep the cells moving and free access to the toilet.
- Children may need painkillers and regular medications
- Children may be embarrassed if they are having bedwetting episodes or episodes of priapism.
- Children may experience frequent absences from setting due to treatment during crisis and will need a plan in place to keep up with their school work.

### **Further information can be found from:**

The Sickle Cell Society

[www.sicklecellsociety.org.uk](http://www.sicklecellsociety.org.uk)



This website contains information booklets aimed at children aged 5-10 and 11-16 and an information guide for settings.

## QUICK REFERENCE GUIDE to Spina Bifida

This condition is a fault in the spinal column in which the neural tube fails to form correctly around the spine and a section of the vertebrae is also affected. This leaves a gap in which the spinal cord is exposed. There are 3 main types of spina bifida and an associated condition is often hydrocephalus (excess cerebral fluid).

**Spina Bifida Cystica**- This is characterised by a cyst on the back, rather like a large blister covered by a thin layer of skin. Myelomeningocele is the most serious and most common form of this type of spina bifida. The spinal cord is damaged and not properly developed so, as a result, there is always some paralysis and loss of sensation below the damaged region. Bladder and bowel problems occur in most people with this type and they may require interventions to maintain function. Menigocele is less severe and in this type the sac only contains meninges which are the tissues that cover the brain and spinal cord and cerebro-spinal fluid.

**Spina Bifida Occulta** – This is a mild form of spina bifida estimated to occur in 5-10% of the population and is only usually identified when being x-rayed for an unrelated problem.

**Hydrocephalus** - This condition is where there is additional fluid around the brain which can cause pressure on the brain. It is common in children and young people with Spina Bifida due to the imbalance in the nervous system from the lesion in the spine, but can also be present for other reasons and can occur during pregnancy or after birth.

In order to avoid damaging the brain from a build up of fluid, children and young people with hydrocephalus usually have a **Shunt** fitted. This is a tube that is sited in the brain to allow the fluid to drain away. Shunt Alert Cards are available from Shine Charity.

### Essential for setting:

- A Health Care Plan
- A Risk Assessment
- Training for staff in carrying out any medical procedures
- Staff awareness training if the child has a Shunt in situ.

### Points to consider:

- Safety and accessibility to equipment and areas of the setting
- Alternative seating or places to sit during lessons
- Assistance with continence and personal care

### Further information can be found from:

The Shine Charity

[www.shinecharity.org.uk](http://www.shinecharity.org.uk)