

Children with medical needs: What schools and settings need to know

A guide for all leadership, all staff,
governors, link person for medical
needs, clinicians, and other agencies



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Children with medical needs: What schools and settings need to know

Legislation and advances in medical science have meant that many more children with potentially complex medical needs are now attending mainstream and special settings.

This guide gives:

- Practical advice to staff in settings who are working with pupils with medical conditions **including mental ill health**, to support an inclusive approach
- Information on statutory guidelines and leadership and Local Authority responsibilities for including pupils with medical needs
- Help and guidance for professionals supporting families, children and young people
- Advice on capturing and acting on the voice of families, children and young people

“What works is strong communication links between the school and hospital and a person responsible to make this happen. A buddy group at school who ‘A’ could keep in touch with.

A parent

Based on the following key principles:

- Positive communication: information gathering by sharing, listening and talking
- Positive relationships: trust between all involved
- Encouragement of pupil independence
- Positive outcomes for all children and young people

Government legislation and statutory guidance

Local Authorities (LAs) have a statutory duty under section 19 of the Education Act 1996 to provide education for pupils who are excluded, unwell or otherwise. This means that where a child cannot attend school because of health problems, and would not otherwise receive a suitable full-time education, the LA is responsible for arranging provision. This may be through a hospital school, a pupil referral unit or a home tuition service. Your LA will be able to tell you what provision is available in your area and should also have a named officer for pupils with medical needs. Further information can be found on page 6 of the statutory guidance 'Ensuring a good education for children who cannot attend school because of health needs' (January 2013): <http://bit.ly/1EJqKcW>

Example of LA guidance from Gloucester – www.gloucestershire.gov.uk/media/17403/la-guidance-for-schools-supporting-pupils-with-medical-needs-amended-5917.pdf

Section 100 of the Children and Families Act 2014, places a statutory requirement upon schools to “make arrangements for supporting pupils at the school with medical conditions”.

“ The Individual Healthcare Plans are useful, but my school were not keen on doing it (I know it was extra paperwork for them). Having it in place made me feel safer at school. Please do these plans for all pupils.

A pupil



Alternative Provision and 'continuity of education'

Children and young people educated in alternative provision are among the most vulnerable. They include pupils who cannot attend mainstream or special school for medical reasons including those who have short or long-term illness.

They may attend one of the following:

Don't forget that mental ill health is a medical condition

Hospital School

A hospital school is a special school within a hospital setting where education is provided to give continuity whilst the child or young person is receiving treatment.

Gloucestershire Hospital Education Service

Year 11 Pupil with Cystic Fibrosis (CF), who was admitted approximately every 3 months for 2 weeks of IV antibiotics. Emotionally immature and with a limited vocabulary (i.e. not age appropriate), E was shy and lacked independence in his learning. Attendance was generally quite good both in his mainstream school and in the Hospital School Room. Medical interventions during hospital admissions were the main reason for E not accessing 100% of the education on offer.

E began to talk about apprenticeship options available at the NHS during his last admission. NHS Career apprenticeship opportunities were shared by the NHS Careers Adviser during a morning session on careers and post-16 planning.

E visited the Hospital kitchen and was given a tour by the Chief Chef who explained the many opportunities available through apprenticeships. E was also able to chat to various people already working in Gloucester Royal Hospital on apprenticeships, porters, catering staff, etc. E found the people easy to talk to and the conversations were useful in helping him begin, for the first time, to look ahead beyond school.

Gloucester Hospital Education Service was represented at Education Health Care Plan reviews and liaised fully with School / Respiratory Team on the concerns and anxieties that were raised by tutors, pupil or parent. Parents were always made welcome in the School Room and GHES staff aided parents in completion of forms e.g. admission to secondary school, etc. Full daily feedback was given to enhance E's learning and behaviour.

A link person in school made the transitions much smoother. The pupil and his parents continued to feel included and part of the school community, and he was keen to be back in school as much as his health allowed.

Home Tuition

Many LAs have Home Tuition Services that can act as a conduit between the school and the pupil on those occasions when the pupil is too ill to attend school and is receiving specialist medical treatment.

Blended Learning Team, West Sussex Alternative Provision College

In Year 5 one pupil received home tuition for 1 year, following an operation to remove a brain tumour. During that time the pupil kept in touch with his classmates by sending letters and photographs of what he had been learning. This enabled the pupil to still feel part of the class and encouraged his peers to stay in touch with him. When the pupil was ready to begin transition back to school, professionals met together to discuss his needs and put together a health care plan. As well as for the plan, his views were sought regarding how much he wanted to tell his peers about the treatment; he chose to create a presentation to his class on his first visit. The class also watched a Clic Sargent video, with opportunity given afterwards to ask questions.

The home tutor met with the class teacher to discuss suitable classroom strategies which would enable the pupil to access learning. This was particularly important as the brain tumour had impacted significantly on his ability to learn. These strategies were also outlined in his Pupil Passport that was kept on his desk at all times and shared with support staff. A clear transition plan was put together which included opportunities to attend assemblies and playtimes as well as lessons, increasing the hours gradually over a six week period. The pupil was initially supported in class by his home tutor, giving him the confidence to adjust to the classroom whilst being with a familiar adult who knew his needs well.

Medical Pupil Referral Units (PRUs)

Medical PRUs are local authority establishments that provide education for children unable to attend their registered school due to medical needs, including mental ill health, and can involve a short-term or long-term illness.

Northampton Hospital Education Service

A primary school had a Year 1 pupil with a diagnosis of leukaemia. Rather than commission someone to do home teaching, they worked with their local Medical PRU to develop an Individual Health Care Plan. The school used one of their Higher Level Teaching Assistants to teach the pupil at home in the afternoons when he wasn't well enough to attend. This meant that the pupil continued to keep up with his peers, had a link person in school and the transitions in and out of school were much smoother. The pupil and his parents continued to feel included and part of the school community, and he was keen to be back in school as much as his health allowed.

Terminology

'Acute' and 'Chronic' conditions

Medical practitioners might refer to a child's diagnosed medical condition as being "chronic" or "acute".

Acute

Conditions which are severe and sudden in onset.

Examples:

broken bone

asthma attack

Chronic

Long-developing conditions which are persistent or long-lasting. This term is often applied when the course of the disease lasts for more than three months.

Example:

osteogenesis imperfecta (known as 'brittle bones')



Illness is only one aspect. Please see the things I am good at.

A pupil



Osteogenesis imperfecta, a **chronic** condition, may make a child more prone to a broken bone, an **acute** condition.

Life-limiting/life-shortening

Conditions for which there is no reasonable hope of cure and from which children or young people will die. Some children might live into early adulthood, but their life will be shortened as a result of the diagnosed condition. Some of these conditions cause progressive deterioration increasing a child's reliance on parents and carers.

Life-threatening

Life-threatening conditions are those for which curative treatment may be feasible but can fail, such as cancer.

For more information see 'Together for Short Lives' www.togetherforshortlives.org.uk

For further reading around bereavement and associated support -

Winston's Wish: <https://shop.winstonswish.org.uk/collections/books>

For use with children:

<https://www.booktrust.org.uk/booklists/g/grief-and-loss-5-8-year-olds>

Leadership including link person for medical needs

Are you complying with the law?

- Schools **must** have a named person as the link for medical needs
- Schools and LAs have a duty under the Equalities Act (2010) to **make reasonable adjustments** and **ensure equality of opportunity** for their pupils including:
 - provision of additional adult support if needed
 - adjustments to the environment
 - provision for equipment needed for accessibility and
 - curriculum adjustments
- Governing bodies have a duty to **make arrangements to support pupils at school with medical conditions**
- The registered school is responsible for outcomes of a pupils education and maintaining them on the school roll
- After 15 days consecutive or cumulative absence across a year, the LA is responsible for educational alternative provision
- Schools must have a policy for supporting children with ongoing health needs, including providing a named person who can be contacted by the LA and parents

See www.medicalconditionsatschool.org.uk/documents/Medical-Conditions-Policy.pdf for an example of a school policy.

How ready is your school to meet medical needs?

Have you and your staff:

- Informed parents about your LA Local Offer? This will give them access to independent advice and support services for their child/young person eg Local Authority Independent Advice and Support Service (SENDIASS)
- Discussed risk assessment and confidentiality at the initial planning meeting?
- Agreed what information the parents and the young person want shared and with whom?
- Identified any necessary training programme(s) for staff to ensure the inclusion of each pupil and allocated appropriate resources e.g. staff training on individual medical conditions, personal care and emergency care as well as recognition of mental health needs?
- Ensured all staff understand roles and responsibilities to administer medication and set-up training from school nurse or other health professionals e.g. Epipen and Asthma, Epilepsy?
- Fully explored all uses of ICT to keep your pupil fully in contact with school?

'Supporting pupils at school with medical conditions' (DfE, 2015) includes templates and links to other useful resources

(<http://bit.ly/1ISCK5a>):

- writing healthcare plans,
- administration of medicines,
- staff training record,
- emergency contacts and
- model letter to invite parents to a planning meeting.

Checklists & Prompts: transition from hospital to school

Communication with families:	Communication with school staff:	Communication with a young person:
• Address and mobile number? • How and when will there be regular communication with keyworker/teachers? • Can the family help with any training needed for staff or suggest appropriate professionals to deliver training? • Medication and personal care? • Dietary requirements? • Exercise programme? • Future hospital appointments • Home school – address and contact person? • Hospital school - address and contact person? • Professionals involved with pupil/student - list after discussion with family?	• Training required for all staff/ specialist staff? Providing time? • Methods of information sharing with staff? • Accessibility and adaptation of resources required? • Access & understanding of policies in school for children with SEN/medical needs? • What happens when a child is unwell? Appropriate routes of contact for teachers?	• What is the best way the school can help the pupil/ student? • School curriculum – what reasonable adjustments will have to be made to ensure inclusion? • Weekly timetable - daily start and end times when reintegrating into home school? • Homework support? • Support for emotional wellbeing – keyworker, Circle of Friends? • Medication and personal care? • Dietary requirements? • Access and mobility in the whole school environment? • Exercise programme?

Designated Medical Needs Link Person should:

1. Liaise with staff from the hospital school/home tuition/Medical PRU
2. Ensure there is a meeting(s) with parents/carers and relevant professionals from all agencies including advisory teachers, school nurse or nurse specialist, clinicians, social care, therapists (see <http://bit.ly/1ISCK5a> for a handy template)
3. Consider how to raise awareness for staff, peers and other parents (CLIC Sargent provides resources and lesson plans see www.clicsargent.org.uk/news/07-05-2014-clic-sargent-launches and the videos for KS 1,2,3 www.youtube.com/user/clicsargent)
4. Establish any adult support needed for transition
5. Consider a flexible timetable

Working together, a multi-agency approach

A smooth and welcoming transition

Communication with and support for families and the pupil is key for successful transitions and outcomes. It is important that their voices are heard.

‘Thanks for listening’ - A parent talks about the experiences of her son in hospital and his transition from Primary to Secondary school:

<https://vimeo.com/236925320>

Watch the video from Safe in School about how young people have had their medical needs met:

www.medicalconditionsatschool.org.uk

Tower Hamlets Support for Learning Team

J is a nursery age child with a complex medical condition moving into Reception. His transition was helped by the following:

- A focus on ‘parents as the experts’
- Local Authority Specialist Teacher for Medical Needs (STMN) met with parents to support the development of a trusting relationship between school and other professionals
- STMN visited the new school with J’s parents and kept in contact by text and phone calls
- A Care Plan, with a focus on practicalities, was written with contributions from professionals, the school nurse and parents
- STMN with class teacher carried out observations of what J can and cannot do as a result of the conditions and finding unobtrusive adjustments so that he can join in with peers
- An appropriate training programme delivered for all staff who work with J
- Further information provided for school to access from LA e.g. Local offer
- As J moves up the school, medical needs link person to review the Care Plan regularly and disseminate information to all relevant staff

The Children's Hospital School at Great Ormond Street Hospital & University College Hospital

E is a Year 6 pupil with Autism, Dyslexia and Leukaemia. He was out of school for the crucial period of transition from primary to secondary school.

The hospital school gave a strong focus on continuity to support the significant number of transitions i.e. between hospital school, home tuition, primary school, hospital school, home tuition and secondary school.

Effective transition strategies included:

- Sharing of the E's personal passport and social stories to support his time in hospital
- Visits by the hospital teacher to both primary and secondary schools, including an Annual Review, at the secondary school
- Video chat with peers in his home school
- Meeting home tuition teacher at E's home to share specific programmes and strategies
- Sharing detailed reports and his school work

What went wrong?

Prior to discharge from hospital things were going well for E. However, this changed during the preparation for transition to secondary school which led the pupil to say that he felt "the secondary school did not really care about me".

- The secondary school made minimal contact except sending texts and emails asking where he was
- The school sent a 15-page blank school report for the year he did not attend

Over the whole period of hospitalisation until returning to school, E lost most of his friends and felt isolated.

Considerations for the future

His mother wanted all those involved in education to understand and think about the following:

- The strain on the family - Mum suddenly becomes "everything: teacher, nurse and caregiver"
- The importance of a 'named person' at school with whom to make links
- Provision for mental health and well being
- The importance of extracurricular opportunities

Pupils with medical needs: 1

- If the child or young person has been off school for a significant period of time it is likely they will need a gradual transition. Consider starting with short periods of time in school and increasing hours over a few weeks or months. Try to include social aspects of the day into the transition, like assemblies or break-times, as these will be just as important in helping the child feel part of the school community again
- Children who have spent long periods of time in hospital, sometimes in isolation, may find the noise and business of the classroom overwhelming; they may need a quiet, safe place to go to
- What behaviours are you seeing? Are these a manifestation of their anxieties, their medical condition or their inability to tell you how they are feeling?
- Consider where in the classroom the pupil should sit in order to access their learning. Has their medical condition impacted on their hearing, sight or movement? If so, adjustments will need to be made within the classroom



The card my tutor group sent me for my birthday was a surprise and meant a lot. You think you are forgotten when you are not in school. A little thing means a lot.

A pupil



Can a school place a pupil on a part-time timetable?

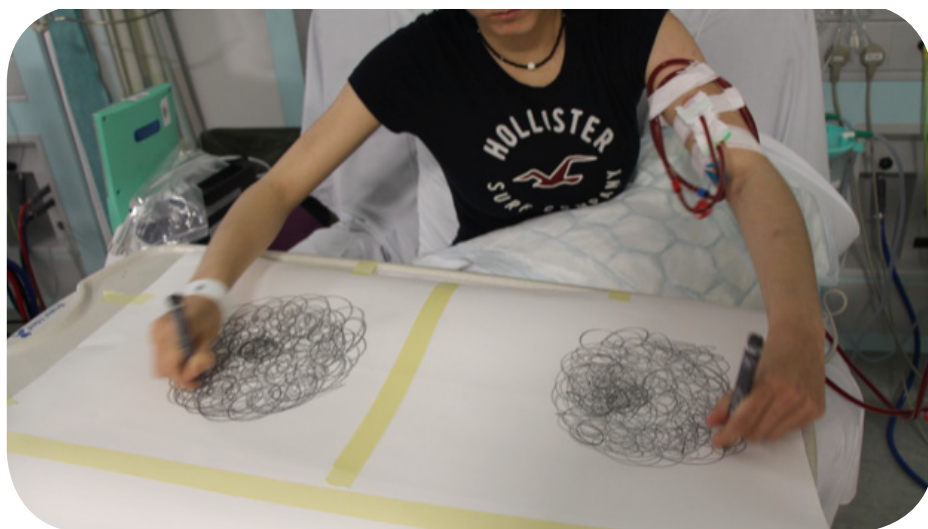
As a rule, no. All pupils of compulsory school age are entitled to a full-time education. In very exceptional circumstances there may be a need for a temporary part-time timetable to meet a pupil's individual needs. For example where a medical condition prevents a pupil from attending full-time education and a part-time timetable is considered as part of a re-integration package. A part-time timetable must not be treated as a long-term solution. Any pastoral support programme or other agreement must have a time limit by which point the pupil is expected to attend full-time or be provided with alternative provision.

DfE November 2016

: the impact on learning

- Find out what equipment and resources they have been using with their home tutor/hospital school to aid their learning and consider whether these can be made available in the classroom
- Children who have worked 1 to 1 for long periods of time will be used to direct instructions. Consider how they will adapt to being part of a class. Is there an adult or peer who can check they have heard and understood the instructions?
- What can the pupil achieve independently?
- Investigate if the child or young person would like a 'buddy' for moving around school and give some informal support in the early stages e.g. carrying books or bag
- How have you kept in touch and maintained visibility of the pupil in their 'home' school?
- They may struggle with no longer being the centre of attention

“ Just because I look OK please
remember I may not be feeling well.
A pupil ”



Classroom strategies – what has worked

- Allowing the pupil to sit near the door with a 'Time-Out' card that can be used to indicate pupil needs to leave the classroom
- Being aware of tiredness
- Being aware of missed learning
- Preparing the rest of the class about what to expect, how to act etc.
- Asking after the young person (even when they aren't there – See below 'Panda in my Seat')
- Displaying a photo of the pupil in the staff room (especially in secondary) – don't forget to discuss this with parents and the young person first



Panda in my seat

The Children's Hospital School Leicester

This is a very simple idea to help maintain the visibility of a child with their school and peers when they are absent for medical reasons.

The 'Panda' has a backpack which can be used to hold notes from friends, or work from teachers, and it is taken regularly to and from the ill child and the school by the parents. The kits also include a book to help teachers explain to students the situation their classmate is facing and how it affects them, teacher companion guide, along with other items that can be utilized by the child and/or their classmates.

In Leicester we have used this with primary aged children who are inpatients in Hospital or those who are being taught at home. It works best with those who are expected to be away from school for longer periods of time. The 'panda' sits in the child's seat in their classroom to act as a physical reminder to the other children.

There are many positive outcomes to the idea. The child feels part of the class and can keep up to date with the work and any news. The classmates and teacher remain in contact and have a physical reminder of the child. It encourages parents to communicate with both the home school and hospital school.

www.youtube.com/watch?v=zKQVzMZYzBY

Key points for inclusion

- Has the identified link person from the school been in contact with the family?
- Have the office staff been informed?
- Has the school stayed in touch with the pupil and their family? <https://www.youtube.com/watch?v=zKQVzMZYzBY>
- Has the pupil been invited to celebrations and trips?
- Have friends been encouraged to stay in touch?
- Consider your school policy on attendance, and how it is managed and celebrated; what impact will this have on a pupil with a medical condition e.g. if a pupil is attending part-time for the required sessions, can this be celebrated?
- Think pupil first – Don't only focus on the medical condition and forget the child as a person - what are their strengths? Think about the child's wellbeing
- Keep up NOT catch-up
- Consider the impact on learning and wellbeing or behaviour after an absence of months, or even years later
- Positive and regular links with medical alternative provision ensures that information about the curriculum is shared so that the pupil does not miss areas being taught in their registered school
- Anticipate how to include children in their school life, thinking well ahead for trips, hospital appointments and possible absences
- 'Parallel planning' and flexibility is helpful e.g. Plan A - participation if a child is well and at school and Plan B what shall we do if this child does have another debilitating respiratory infection this winter?

Be aware of the impact of chronic illness on other members of the family!

Siblings may feel neglected by parents and carers when their brother or sister has a chronic illness. They may struggle to deal with the stresses of parents managing the condition within the household, and have feelings of guilt, anger, jealousy, anxiety, and even wonder if they caused the illness. In school, siblings may display withdrawn behaviours or angry outbursts.

They may not have all of the equipment they need for school, and may forget letters, homework etc. School staff need to be understanding of their needs at this difficult time.

If you Walked a Day in My Shoes

If you walked a day in my shoes you would know
That it is tiring when your body aches all the time,
That I cried when I missed the school trip,
That I dragged myself in to school to get 90% attendance,
That 90% was 200% for me,
That I paid for it at the weekends,
That I was in bed recovering,
That I missed the parties and the fun,
That I didn't get a certificate for trying,
That only the well children get those.

If you walked a day in my shoes you would know.....
That it is tiring feeling unwell all of the time,
That I cried because I just want to be well,
That I want to be in school like my friends,
That I've missed so much it feels scary,
That I paid for it at the weekends,
That I was doing catch-up because I was behind,
That I missed the parties and fun,
That I didn't get a certificate for trying,
That only the well children get those.

If you walked a day in my shoes you would know.....
That I am more than just my illness,
That the paperwork you do for me is worth it,
That I want your help and kindness,
That I have dreams for the future,
That I am trying as hard as I can,
That sometimes just being at school is a miracle,
That I will repay your efforts with being the best I can be,
That I'm not asking for a certificate for trying,
Just see me for who I am.

Pupils at Gloucestershire Hospital Education Service were asked what they would like their school's Head Teachers to understand about having a long-term medical need. This poem was one young person's response.



Further Information

'Supporting Children with Medical Conditions' Routledge ISBN 978-1-138-91491-9:

www.medicalconditionsatschool.org.uk

Directory of medical conditions: <https://www.cafamily.org.uk>

Supporting children with a medical or mental health condition at school - Chelsea Community Hospital School: www.wellatschool.org

DfE:

Supporting pupils at school with medical conditions' (DfE, 2015) includes templates and links to other useful resources: <http://bit.ly/1SCK5a>

Education for children with health needs who cannot attend school : <http://bit.ly/1EJqKcW>

Section 19, Education Act 1996: <http://bit.ly/2o6C93B>

Section 100, Children and Families Act 2014: <http://bit.ly/2F4XWB6>

Clic Sargent:

www.youtube.com/user/clicsargent

<https://publications.clicsargent.org.uk>

www.clicsargent.org.uk/content/teachers

Great Ormond Street Hospital:

www.gosh.nhs.uk/welcome-childrens-hospitalschool

Children's Cancer and Leukaemia Group:

www.cclg.org.uk



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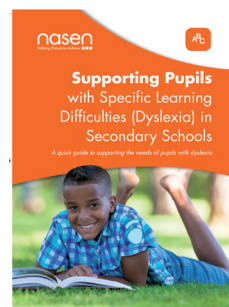
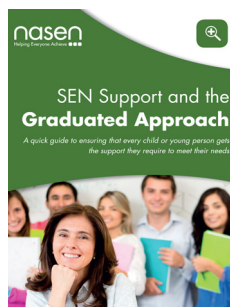
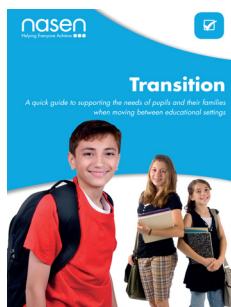
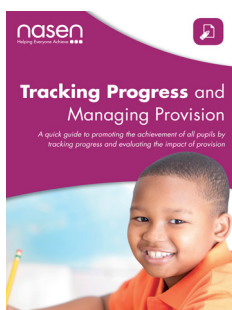
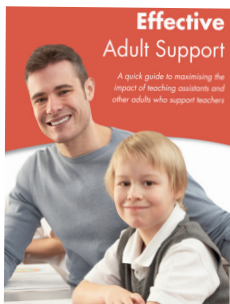
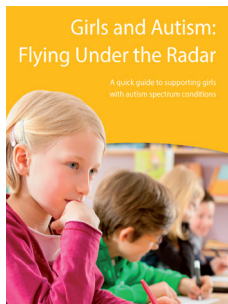
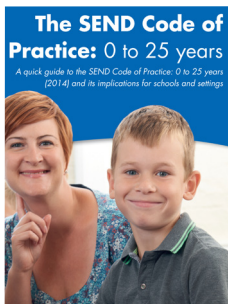
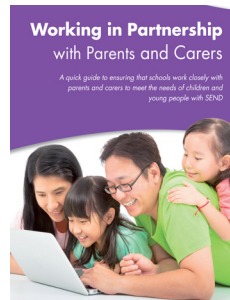
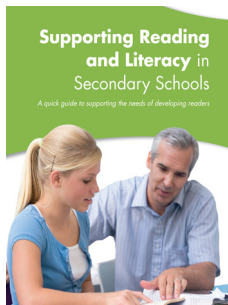
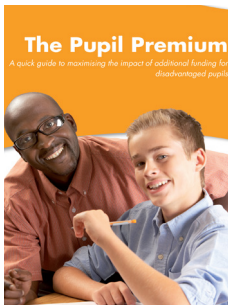
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