



Signposting information for schools seeking support for complex childhood medical conditions



This document provides information for schools and other educational establishments on the following

1. General information about supporting a child with a significant medical condition, including the role of and differences between medical care plans and more holistic health care plans
2. Points of contact for support and information where a school has a child with a medical condition.
3. A list including complex medical conditions experienced by children and young people in Somerset alongside common alternative phrases, abbreviations and equipment carers may use. This list will indicate who might be the most appropriate source of support. This list also specifies whether or Not a medical care plan is likely to be in place. It should be Noted that this list is Not exhaustive.

General information about supporting a child with a medical condition, including the role of and differences between a medical care plan and a more holistic health care plan

- Medical Care Plans: These plans are produced by clinical health professionals treating a child or young person. These plans detail medical procedures which may be required in school.
The Somerset Physical Impairment and Medical Support (PIMS) Advisory Team are often involved with children who have medical care plans and are able to offer support. (See points of contact below)
- Health Care Plans: These plans are more holistic and are the responsibility of the SENCO. Guidance on the schools responsibilities and role in developing and maintaining the health care plan , in conjunction with parents, young people and health care professionals can be found in the document: '[Guidance Document: Supporting Pupils With Medical Needs](#)'. PIMS advisory teachers and School Nurses are also able to support schools with this. (See points of contact below)
- Education Healthcare Plans : Under the Children's and Families Act (2014) these are required for children who meet set criteria outlined in this act. This is a replacement for statements of special educational needs and will include a medical component. Its purpose is to highlight the needs and aspirations of the child or young adult in regard to education, health and social care. They are Not however a detailed plan of the hands on medical care required.

Points of contact for support and information where a school has a child with a complex medical condition

The following contacts relate to medical care only and do Not include other services which may be involved such as voluntary services, respite services, social services etc. This list acts as a guideline only, is Not exhaustive, and may Not be accurate in individual cases. It is always preferable to ascertain from the parent/carer who their principle healthcare workers are.

Job Title	Description	Contact details.
<i>Hospital switchboards</i>	<i>Main switchboards for significant hospitals in the South West.</i>	<i>Taunton (01823) 333444 Yeovil (01935) 475122 Bath (01225) 428331 Bristol 0117 9230000</i>
ADHD Nurses	For Taunton side of Somerset Specialist nurses trained in this condition.	01823 344693
Asthma Nurse	These are found in GP practices however Not all places have one.	Ring GP practice.
Autism Outreach Service	Support for children on the autistic spectrum up to the age of 13.	01458 241460 or via Somerset Direct.
Autism, communication and language team	Support for children on the autistic spectrum	01823 334475
Cardiac liaison nurses (Bristol & Southampton)	A team of specialist nurses who will provide mostly telephone only support for children with complex heart conditions and children with pace makers.	0117 342 8286 (Bristol) 02380 796470 (Southampton)
Children's community Nurses	Services based out of the acute hospital trusts that provide support for children with complex medical needs and those children with life limiting conditions. Check with parents whether their nurse is from	Taunton 01823 344693 Yeovil 01935 384558

	Yeovil or Taunton.	
COMPASS nursing service	A specialist service focusing on children with complex medical needs who are most likely to die before the age of 19. This service is based out of Taunton and Yeovil Hospitals trusts. Also included is psychological support.	01823 344693 + 01935 384558
Constipation Advice	Support for this issue can come from a wide range of services. Check with your school nurse before escalating to more specialist services. Also consider PIMS input. ERIC is a useful source of support. http://www.eric.org.uk/	Yeovil 01935 984771 Taunton 01823 342692
Continence nurse advisor	Support for this issue can come from a wide range of services. Check with your school nurse before escalating to more specialist services. Also consider PIMS input. ERIC is a useful source of support. http://www.eric.org.uk/	Via local school nurse in first instance. Taunton 01823 342692 Yeovil 01935 848254 Bristol 0117 342 8504
Continuing health care team	A specialist service focusing on children who either require technological assistance to breathe or have very fragile conditions needing close nursing input outside of hospital.	01823 344693
Cystic fibrosis nurse	Specialist nurses trained in this condition. Based at local hospitals as well as Bristol and Southampton.	Check with parents who their local team are. 01935 384558 (Yeovil) 01823 344693(Taunton)
Diabetes Nurse specialists	Specialist nurses trained in this condition. Based at local hospitals.	Check with parents who

		<p>their local team are.</p> <p>01935 384694 (Yeovil.)</p> <p>01823 343666 (Taunton)</p>
District Nurses	District nurses only deal with patients over 18 except in extreme cases.	Via local district nurse 'hubs.'
Epilepsy Nurse specialist	Specialist nurses trained in this condition. Based at local hospitals as well as Bristol. For children over 14 they may be linked with an adult epilepsy nurse specialist.	Check with parents who their local team are.
Integrated Therapies Service (ITS)	A service providing physiotherapists/occupational therapists (OT)/Speech & language therapists (SALT)	Advice line 0303 033 3002
Lifetime	A community nursing and psychology service which covers the North part of Somerset as far south as Wells.	01225 731624
Oncology Outreach Nurses (also known as CLIC-Sargent Nurses)	Specialist nurses trained in this condition. Based at local hospitals as well as Bristol.	<p>Check with parents who their local team are.</p> <p>Taunton 01823 344693</p> <p>Yeovil 01935 384558</p>
Practice Nurse	These work in each GP practice. They will do wound dressing, stitches removal, injections and other common tasks. They can be a very good source of information or for directing parents to.	Ring GP practice.

Public Health Nursing (School Nurses)	Support and advice for schools developing healthcare plans. Liaison with consultant paediatricians where appropriate. This may include sign posting for children with complex health needs or a learning and/or physical disability, promotion of self-care, advising parents and carers, referral to other specialists and co-ordination of a range of services.	Taunton and West Somerset 01823 346182 Sedgemoor 01278 410044 Mendip 01749836545 / 85 South Somerset 01935 848220
Renal nurses (Bristol)	A team of specialist nurses based at Bristol's children's hospital who will provide mostly telephone only support for children with kidney conditions.	0117 3428548
Somerset Direct for children	Access point for social services, including short breaks, occupational therapist and other support services.	0845 345 9122
Stoma nurses	Specialist nurses who provide support and training for children with colostomies, ileostomies etc.	Taunton - 01823 333444 Yeovil – 01935 384352
Tertiary specialists.	This refers to doctors based in major specialist units. These can be located anywhere in the UK as different hospitals specialise in different conditions. Most commonly people from the southwest will link to Bristol Children's Hospital or Southampton.	
VNS Nurse (clinical nurse specialist)	Specialist Nurses trained in the care of vagal nerve stimulator (VNS) devices for epileptic patients.	0117 970 1212

Information about complex medical conditions, common phrases, abbreviations and equipment

Please note this list is neither comprehensive nor a detailed medical description of the nature of the disease/condition. This list also includes names of medical equipment and alternative terminology, abbreviations and descriptions of conditions parents might use.

Many diseases have varying degrees of severity and therefore may not necessarily have all the professionals involved who are listed.

This list does not include basic/common conditions and infectious diseases. Refer to public health guidance or your school nurse in this instance.

If some terminology or a condition is missing contact your school nurse in the first instance.

In the context of this list medical care plans are NOT health care plans. A medical care plan refers to a specific procedure, treatment, medical device or emergency procedure. Medical care plan should have the input of an appropriately trained individual in its construction and training consequences.

The column in relation to whether Somerset County Council Physical Impairment Medical Service (PIMS) should be involved is only advisory. If in doubt PIMS should be contacted for support and guidance. See

- Taunton & West Somerset. (01823) 349317
- South Somerset (01935) 476130
- Sedgemoor (01278) 446445
- Mendip (01749) 678500

Disease, Condition or related medical terminology.	Useful healthcare contacts.	Notes.	NHS or support group Web link	Medical care plan required?	Involve PIMS?
Absences	See 'epilepsy'				Yes
ACE (procedure)	See 'stoma.'				Yes
Achondroplasia	See Dwarfism		http://restrictedgrowth.co.uk/		Dependant of severity of condition.
Acute Lymphoblastic Leukaemia (A.L.L)	See cancer		http://www.nhs.uk/conditions/leukaemia-acute-lymphoblastic/		Yes
Acute Myelocytic Leukaemia (AML)	See cancer				Yes
Addison's disease	Paediatrician Children's Community Nurse	Very rare in children. May require the emergency administration of an intramuscular injection of steroids.	http://www.nhs.uk/conditions/addisons-disease		Yes if injection required.
ADHD (Attention deficit hyperactivity disorder.)	CAMHS, paediatrician, children's community nurse (Taunton and Somerset NHS Foundation		http://www.nhs.uk/conditions/attention-deficit-hyperactivity-disorder/	Dependant on other conditions and severity.	No

Disease, Condition or related medical terminology.	Useful healthcare contacts.	Notes.	NHS or support group Web link	Medical care plan required?	Involve PIMS?
	Trust area only)				
Allergy (No epipen)	School nurse/GP (Dietician may be involved.)		http://www.nhs.uk/conditions/allergies/	Possible, depending on need for oral medication.	No
Allergy with epipen	School Nurse or Children's Community Nurse. (Dietician may be involved.) Paediatrician. Preschool – children's community nurse.	All children with an epipen should have an action plan detailing when to give their epipen device.		Yes (from consultant/ GP)	No
Anapen	See 'allergy with epipen.'	Alternative pen to Epipen used for anaphylaxis.			
Anaphylaxis	See 'allergy' sections.	This condition should be diagnosed by a paediatrician. It is sometimes wrongly used to describe severe allergic reactions.	http://www.nhs.uk/conditions/anaphylaxis/pages/symptoms.aspx		No
Antegrade Colonic Enema	See 'stoma.'				
Aplastic Anaemia	See 'cancer'	This IS NOT a cancer condition but support will come via the oncology		Dependant on severity of	No

Disease, Condition or related medical terminology.	Useful healthcare contacts.	Notes.	NHS or support group Web link	Medical care plan required?	Involve PIMS?
		services.		condition and where about on treatment plan they are.	
Arthritis	See 'Juvenile Chronic Arthritis (JCA)' for main info.	Arthritis can come in many forms. The commonest of which in children is JCA			
ASD or Atrial Septal Defect	See cardiac	Some families will use the initials only whilst others will use the full term. Note ASD also stands for Autistic spectrum disorder as well as Atrial Septal Defect			
Aspergers syndrome	Autism Outreach Team		http://www.nhs.uk/conditions/Autistic-spectrum-disorder/Pages	Dependant on other conditions and severity.	No
Asthma (mild)	GP/ asthma nurse via GP	Defined as those children with blue inhalers only.	http://www.nhs.uk/conditions/Asthma/Pages/Introduction.aspx www.asthma.org.uk	All children with asthma should ideally have some form of plan.	No

Disease, Condition or related medical terminology.	Useful healthcare contacts.	Notes.	NHS or support group Web link	Medical care plan required?	Involve PIMS?
Asthma (moderate)	School nurse/GP/ asthma nurse via GP. These children may have an asthma care plan in place.	Defined as those needing regular steroid inhalers daily.	http://www.nhs.uk/conditions/Asthma/Pages/Introduction.aspx www.asthma.org.uk	All children with asthma should ideally have some form of plan.	No
Asthma (severe/brittle)	School nurse/GP/ asthma nurse via GP/paediatrician . All such children should have an asthma care plan in place written by a consultant paediatrician.	Defined as needing frequent hospitalisation/GP appointments. Significant absence from schools.	http://www.nhs.uk/conditions/Asthma/Pages/Introduction.aspx www.asthma.org.uk	Yes. (strict and prompt adherence is essential as asthma can be life threatening)	Possibly
Ataxia telangiectasia (AT)	COMPASS team Services via ITS paediatrician http://www.atsociety.org.uk/	AT is very rare but presents with a wide range of symptoms which effect multiple parts of the body. AT is life limiting. Check with parents regarding who is involved.		Dependant on severity of condition.	Yes
Atopic	GP/ asthma nurse.	A phrase often used in conjunction with asthma, eczema and allergy.	http://www.nhs.uk/conditions/Eczema-(atopic)/	If a child is described as atopic then some form of health care plan	Possibly.

Disease, Condition or related medical terminology.	Useful healthcare contacts.	Notes.	NHS or support group Web link	Medical care plan required?	Involve PIMS?
				may be required.	
Autism or Autistic Spectrum Disorder (ASD).	Autism Outreach Team (up to 13) Autism, communication and language team		http://www.nhs.uk/conditions/Autistic-spectrum-disorder/	Dependant on other conditions and severity.	No
Auto Immune Encephalitis	Specialist services in London and Bristol. Paediatrician Children's Community Nurse. Possibly ITS services.	Very rare condition. Vulnerabilities to infection. Risk of seizures. Can have either long or short term impact on learning difficulties, mobility and speech.	http://www.nhs.uk/Conditions/Encephalitis	Dependant on severity of condition and where about on treatment plan they are.	Unlikely
Batten's disease	COMPASS nursing service. Likely input from physiotherapist/OT. Visual impairment services.	This is a degenerative disease with more impact in secondary school.		Dependant on severity of condition	Yes
Beckwith-Weidemann Syndrome	Paediatrician, possibly physiotherapist. Specialist care via Bristol. GP			Unlikely.	possibly
Beta-Thalassaemia	See 'Blood disorders'.		http://www.nhs.uk/conditi		

Disease, Condition or related medical terminology.	Useful healthcare contacts.	Notes.	NHS or support group Web link	Medical care plan required?	Involve PIMS?
			ons/thalassaemia		
BiPAP	See 'ventilator'				
Bladder Augmentation	Paediatrician Urologist GP Possibly children's community nurse.	This is a surgical procedure likely resulting from birth defects. In most cases there are probably other health issues along with this.		No	Yes
Blood disorders such as haemophilia and Evans syndrome.	GP, paediatrician. (in some cases also community children's nurse.) Also clinical nurse specialist at Bristol.			Dependant on severity of condition	possibly
Blood samples (regular) or giving intravenous medicines (portacath, Hickman line, vascath, groshung, PICC, Short long line.)	Children's community nurse. Paediatrician, possibly paediatric oncology nurses, or cystic fibrosis nurses	May have some restrictions on physical activity.		Yes	Possibly
Bone Marrow Transplant	See 'cancer'	Also known as BMT. Not exclusively used in cancer care so check with		Dependant on stage of disease.	Possibly.

Disease, Condition or related medical terminology.	Useful healthcare contacts.	Notes.	NHS or support group Web link	Medical care plan required?	Involve PIMS?
		parents.			
Brain injury	Physiotherapist/OT via ITS. Possibly children's community Nurse Barbara Russell Unit at Bristol Children's Hospital for telephone advice.	Covers a large variety of issues. Seek further clarity from parents in the first instance.		Dependant on severity of condition	Yes
Brain tumour	See 'cancer' Also services via ITS.	Be aware that not all brain tumours are cancerous but the family would still be under the oncology team for long term monitoring. Brain tumours often have resulting disabilities associated with them.	http://www.nhs.uk/conditions/brain-tumours/	Possibly	Yes
broken limb	GP, possibly physiotherapist via Integrated therapy services.			Unlikely.	possibly
Bronchiectasis	Physiotherapists, Children's community nurse Paediatrician. Specialist		http://www.nhs.uk/conditions/bronchiectasis/pages/	Yes	Yes

Disease, Condition or related medical terminology.	Useful healthcare contacts.	Notes.	NHS or support group Web link	Medical care plan required?	Involve PIMS?
	consultant in Bristol.				
Cancer	Oncology outreach nurse specialists Paediatrician. COMPASS			Yes	Yes
Cardiac abnormalities.	If the condition is unresolved then:- cardiac liaison nurse at Bristol or Southampton, children's community nurse. Paediatrician. Specialist consultants. If the condition is resolved then:- school nurse/GP	This condition is very variable in its presentation and issues for schools.		Dependant on severity of condition	possibly
Cardiac child with a pacemaker	Cardiac liaison nurse at Bristol, children's community nurse. Paediatrician. Specialist consultants.			Yes	Yes
Catheter		Very broad term for a number of			

Disease, Condition or related medical terminology.	Useful healthcare contacts.	Notes.	NHS or support group Web link	Medical care plan required?	Involve PIMS?
		devices and needs. Seek further information from parent.			
catheters for urination.	Children's Community Nurse Taunton and Somerset NHS Foundation Trust or Bristol Clinical Nurse specialist for Yeovil. Paediatrician.	Child will most likely be receiving care via tertiary hospitals. Depending on the age and ability of the child or young person a personal care plan may be required and staff may need additional training.		Yes	Yes
Central venous catheter	See 'cancer' or 'cystic fibrosis, or 'blood samples...'	A device implanted into the body which allows easy access for blood sampling and drug giving. Used most often in cancer and cystic fibrosis but occasionally in other diseases such as haemophilia.		Yes	Possibly, dependant on why they have this device.
Cerebral palsy	Mild cases:- services via ITS, GP. Severe cases, children's community nurses, paediatrician and services via ITS	This term covers a huge variety of medical issues. Check with parents/carers in first instance for professionals involved.	http://www.nhs.uk/conditions/cerebral-palsy	Dependant on severity of condition and other medical issues.	Yes

Disease, Condition or related medical terminology.	Useful healthcare contacts.	Notes.	NHS or support group Web link	Medical care plan required?	Involve PIMS?
Chronic fatigue Syndrome	Paediatrician. Possibly CAMHS. Possibly physiotherapist via ITS		http://www.nhs.uk/conditions/chronic-fatigue-syndrome/	Yes	Yes
Coeliac Disease	Dietician	Dietary information essential.	http://www.nhs.uk/conditions/coeliac-disease/	Dependant on medical needs at the time.	possibly
Cold urticaria	School nurse if epipen required.	Rare condition similar to anaphylaxis but caused by rapid change in environmental temperature.	http://www.gpNotebook.co.uk/simplepage.cfm?ID=x20080302215425225450	If epipen required.	No
colostomy	See 'stoma.'				
complex needs		A label medical professions often use and parents may reflect this in conversation. Will need picking apart to see what 'complex' means to the family.			
Congenital Adrenal Hypoplasia	Paediatrician/GP Children's Community nurse in severe cases. www.livingwithcah.com	Manifests in both mild and severe forms. May need emergency intramuscular injection. Early onset puberty is often seen.	http://www.nhs.uk/conditions/disorders-sex-development	Dependant on severity of condition.	possibly

Disease, Condition or related medical terminology.	Useful healthcare contacts.	Notes.	NHS or support group Web link	Medical care plan required?	Involve PIMS?
Constipation and faecal soiling	School Nurse, Community continence Nurse, Specialist continence Nurse, GP (possibly CAMHS) PIMS if a medical condition has been diagnosed.	Many children will be simply managed via GP services. Complex cases may involve hospital services. Needs. consult with PIMS for advice staff training and support and support.	http://www.eric.org.uk/	Dependant on under-lying severity and cause. A personal Care Plan should be in place for children with conditions requiring regular /long time adult support and interventions. Consult with PIMS	Yes
Cough Assist machine.	Physiotherapist. Likely COMPASS team or children's community nurses. Specialist services in Bristol.	Unlikely to impact on schooling as these devices are used at home but is indicative of other serious medical conditions.		Dependant on underlying condition.	Yes

Disease, Condition or related medical terminology.	Useful healthcare contacts.	Notes.	NHS or support group Web link	Medical care plan required?	Involve PIMS?
CP (Not child protection.)	See 'cerebral palsy.'	Children with cerebral palsy are often described as having CP.			
CPAP	See 'ventilator'				
Crohn's disease	School Nurse. (Possibly children's community nurse) Local paediatrician and specialist doctor in Bristol.	An inflammatory bowel disease. Symptoms can be varying with flare ups possibly. Surgery and a stoma may be required. Pain, diarrhoea and fatigue may be an issue. Give consideration to toileting needs. Some children with this condition will have a stoma. Other's will received specialised injections.	http://www.nhs.uk/conditions/crohns-disease/	Dependant on severity of condition	Yes
Cystic Fibrosis	Cystic Fibrosis nurse specialist, Physiotherapist via ITS. (Dietician may be involved.)		http://www.nhs.uk/conditions/cystic-fibrosis/	Yes	Yes
Daytime wetting	School Nurse, GP, continence advisor.	May be associated with other continence issues.		Dependant on medical needs at the time.	Yes

Disease, Condition or related medical terminology.	Useful healthcare contacts.	Notes.	NHS or support group Web link	Medical care plan required?	Involve PIMS?
Dekaban - Arima Syndrome	Visual support, paediatrician, tertiary doctors. Renal team at Bristol.	Usually impacts vision and kidneys.		Most likely.	Yes
Diabetes Insipidus	Children's community Nurse and paediatrician.	Such children will usually have other medical conditions. Note that diabetes insipidus is very different from diabetes mellitus	http://www.nhs.uk/conditions/diabetes-insipidus/	Yes	Yes
Diabetes Mellitus	Diabetic nurse specialist. Paediatrician.	Can be life threatening if not quickly acted upon. Good planning preschool entry is required. Some children are now using 'insulin pumps.'	http://www.nhs.uk/conditions/diabetes-type1/	Yes.	Yes
Diamond Blackfan Syndrome (Anaemia)	See Blood disorders Paediatrician, haematologist, possibly children's community nurse.	Severe blood disorder involving the bone marrow.		Dependant on severity of condition.	Dependant on severity of condition

Disease, Condition or related medical terminology.	Useful healthcare contacts.	Notes.	NHS or support group Web link	Medical care plan required?	Involve PIMS?
Di-George syndrome	GP, paediatrician. (Sometimes physiotherapist and OT via ITS, children's community nurse, dietician.)	Child may have learning/behavioural and feeding difficulties. May also have cardiac issues.		Dependant on severity of condition	Yes
Down's syndrome	GP, paediatrician. (On rare occasions may have children's community nurse, physiotherapist, OT etc.) Ups and Down – local charity and a useful resource. http://upsanddowns.net/	May also have cardiac issues.	http://www.nhs.uk/conditions/downs-syndrome/pages/	Dependant on severity of condition but unlikely.	Yes
Drop attacks	See epilepsy				Yes
Duchenne Muscular Dystrophy.	COMPASS nursing service. (Lifetime services in BANES part of Somerset.) Paediatrician. Physiotherapist (ITS)	This is a degenerative condition.	http://www.nhs.uk/conditions/muscular-dystrophy/	Dependant on severity of condition and other medical issues.	Yes
Duodenal	See 'gastrostomy'	A form of enteral feeding involving a			

Disease, Condition or related medical terminology.	Useful healthcare contacts.	Notes.	NHS or support group Web link	Medical care plan required?	Involve PIMS?
		tube.			
Dwarfism	GP, possibly ITS depending on additional mobility problems, possibly paediatrician or specialist doctor.	Possibility of wider health issues depending on cause of condition. Consider access issues.	http://restrictedgrowth.co.uk/	Dependant on other medical issues.	Possibly.
dystrophy	In first instance refer to parents for professionals involved. Likely to have COMPASS input. (Lifetime services in BANES part of Somerset.) Physio/OT via ITS	This is a term covering a large number of rare genetic conditions and refers to a degeneration of tissues. In many cases this is life limiting and impacts on mobility.		Dependant on medical needs at the time.	Yes
Eating disorders	GP, CAMHS, paediatrician, Dietician.		http://www.nhs.uk/conditions/eating-disorders/	Possibly	Yes
EB	See 'Epidermolysis bullosa'				
Eczema	School nurse or GP. Occasionally Community Children's Nurse if wet wrapping is required. (Not	The child may require application of creams during the school day.	http://www.nhs.uk/conditions/eczema-(contact-dermatitis)/	Dependant on severity of condition	No

Disease, Condition or related medical terminology.	Useful healthcare contacts.	Notes.	NHS or support group Web link	Medical care plan required?	Involve PIMS?
	Yeovil)				
EDS	See Ehlers-Danlos syndrome				
Edward's syndrome	COMPASS nursing service. (Lifetime services in BANES part of Somerset.) Paediatrician.		http://www.nhs.uk/conditions/edwards-syndrome/	Dependant on severity of condition	Dependant on severity of condition
Ehlers-Danlos syndrome	Paediatrician, GP, services from ITS	Describes a range of conditions in relation to connective tissues. Hypermobility is a frequent issue. In some cases can spontaneously bruise and be confused for child protection issues.	http://www.nhs.uk/Conditions/ehlers-danlos-syndrome/Pages/Introduction.aspx	Dependant on severity	Dependant on severity
endocrine	Paediatrician, possibly specialist endocrine doctor in tertiary centre.	Endocrine is a wide term synonymous with hormones. You will require further information as the impact can vary depending on the hormones involved.		Dependant on severity of condition	Dependant on severity of condition
Endocrine diseases and conditions	Most likely paediatrician and/or specialist doctor's in tertiary centres.	A very wide term for a multitude of differing conditions. Try to find out which precise condition child has.		Dependant on condition.	possibly

Disease, Condition or related medical terminology.	Useful healthcare contacts.	Notes.	NHS or support group Web link	Medical care plan required?	Involve PIMS?
	Children's Community nurses will sign post for you if necessary.				
Enteral (feeding)	Dietician, Community Nurse, specialist nurse from feeding company (currently Nutricia 2014)	Enteral in this case usually describes a feeding process other than orally. Some parents may use this phrase rather than say they have a gastrostomy (Enteral can have other meanings.) Usually associated with other medical issues.		Yes	Yes
Epidermolysis bullosa	Specialist nurse (Great Ormond Street.) Children's community Nurse. GP, paediatrician.	This condition is very variable in its presentation and issues for schools.	http://www.nhs.uk/conditions/epidermolysis-bullosa/	For severe cases - Yes.	possibly
Epidermolysis bullosa	Specialist service in Great Ormond Street Hospital for Sick Children. Paediatrician, possibly children's community	Very rare skin condition where the skin is damaged or shed easily. May need dressings in school or use of needles to piece blisters. Varying degrees of severity Noted.		Yes (via specialist nurse from great Ormond street.)	Dependant of severity of condition.

Disease, Condition or related medical terminology.	Useful healthcare contacts.	Notes.	NHS or support group Web link	Medical care plan required?	Involve PIMS?
	nurse.				
Epilepsy	<p>Epilepsy nurse specialist for Taunton and Somerset NHS Foundation Trust patients, children's community nurses or school nurse for basic training.</p> <p>Specialist services also based in Bristol.</p>	Some children with epilepsy will be very stable on medication. Others will require rescue medication	http://www.nhs.uk/conditions/epilepsy/	Yes (may also need specialist plans for rescue medication.)	Yes
Epilepsy with VNS device	<p>Epilepsy nurse specialist for Taunton and Somerset NHS Foundation Trust patients, children's community nurses.</p> <p>Clinical Nurse specialist based at Bristol has overview of all such patients.</p>			Yes	Yes

Disease, Condition or related medical terminology.	Useful healthcare contacts.	Notes.	NHS or support group Web link	Medical care plan required?	Involve PIMS?
Epipen	See 'allergy with epipen.'				
Evans syndrome	See blood disorders.				
Ewing's sarcoma	See cancer		http://www.nhs.uk/conditions/ewings-sarcoma/		
External fixator.	Physiotherapist, occupational therapy.	Used either following significant fracture of the limb or due to underlying skeletal issues such as 'short stature' This device is usually seen on legs and occasionally arms. Be aware of body image issues. Surgery usually done in Bristol.		Yes	Yes
Failure to thrive or faltering growth.	Dietician, Paediatrician Children's community nurse if requires enteral feeding.	A term used to describe poor growth. Usually associated with poor food intake or a malabsorption issue		Dependant on severity of condition.	Possibly
Febrile convulsions	See epilepsy (though this does Not mean the child is epileptic)	Unusual in school aged children.	http://www.nhs.uk/conditions/febrile-convulsions/		Possibly
FTT	See 'Failure to thrive'				

Disease, Condition or related medical terminology.	Useful healthcare contacts.	Notes.	NHS or support group Web link	Medical care plan required?	Involve PIMS?
Gastroschisis	GP	This condition should have resolved by the time the child is at school and have No significant medical issues.		No	Unlikely
gastrostomy	Children's Community Nurse and Enteral feeding company Nurse (currently Nutricia 2014). Dietician. (Most initial training will come via the Nutricia Nurse.)	Child may have considerable amount of equipment and feeds may need storing in a fridge. Good advanced planning is very helpful for this.		Yes	Yes
Glycogen storage disease	Dietician, paediatrician.	Emergency care plan required.		Yes	Yes
Grey matter Heterotopia	GP, if epilepsy involved then Epilepsy Nurse specialist.	This condition is very variable in its presentation and issues for schools.		Dependant on severity of condition	possibly
Growth Hormone Deficiency	Paediatrician, GP, Children's Community Nurses.	No medical impact on school though consider body image issues.	http://www.nhs.uk/conditions/restricted-growth/	No	No
Haematological conditions	See blood disorders	A very wide term for a multitude of differing conditions. Try to find out		Dependant on severity of	possibly

Disease, Condition or related medical terminology.	Useful healthcare contacts.	Notes.	NHS or support group Web link	Medical care plan required?	Involve PIMS?
		which precise condition child has.		condition	
Haemophilia	See blood disorders		http://www.nhs.uk/conditions/haemophilia/	possibly	possibly
Heart disease/condition	See cardiac			Dependant on severity of condition	possibly
Heart transplant	See 'cardiac'	Post transplant, careful consideration and support will be required for reintegration into school.		Possibly.	possibly
Hemiplegia	See 'cerebral palsy.'	Term used to describe extent of damage in cases of cerebral palsy.			
Hemolytic-uremic syndrome	See renal	Usually presents in the under 5s but can have long term impact.		Unlikely	No
Henoch-Schonlein Purpura (HSP)	GP, paediatrician. Possibly physiotherapist if joints involved.	HSP occurs most often in the spring season and frequently follows an infection of the throat or breathing passages.		Only if joints are involved.	No
Hickman line	See 'blood samples...'			Yes	Yes

Disease, Condition or related medical terminology.	Useful healthcare contacts.	Notes.	NHS or support group Web link	Medical care plan required?	Involve PIMS?
Hirschsprung's Disease	Dietician. GP, paediatrician.	May have soiling issues.		No	possibly
HSP	See Henoch-Schonlein Purpura				
Hunter's Disease	Paediatrician, GP	May be associated with other medical conditions.		Dependant on severity of condition	possibly
Hydrocephalus (shunt in place)	Children's community Nurse	Likely part of a wider condition.	http://www.nhs.uk/conditions/hydrocephalus/	Yes	possibly
Hypermobility	Most likely services from ITS such a physiotherapist and occupational therapist. Paediatrician, GP	Describes a wide range of issues and may be linked to an underlying condition such as Ehlers-Danlos syndrome. Discuss with parents further for more information.	http://www.nhs.uk/Conditions/Joint-hypermobility/Pages/Introduction.aspx	Dependant on severity	Dependant on severity
hypochondroplasia	See 'dwarfism'	Condition which affects bone growth. May also have mild learning difficulties. Condition can be of varying degree. Consider body image issues.	http://restrictedgrowth.co.uk/Hypochondroplasia		

Disease, Condition or related medical terminology.	Useful healthcare contacts.	Notes.	NHS or support group Web link	Medical care plan required?	Involve PIMS?
Hypopituitarism	See 'endocrine'	May need emergency injection of hydrocortisone. Usually part of a wider health deficit		Yes if injection required.	Dependant on other conditions.
Hypopituitarism or any condition needing emergency hydrocortisone injections.	Children's community nurse. Paediatrician. Endocrinologist (Bristol.)			Yes	Yes
ICS (Intermittent Self catheterisation)	See 'catheters for urination.'	Process where the patient passes a tube up their urethra to aid passing urine. Will need intimate care as sometimes the child cannot perform this procedure themselves.		Yes	Yes
Idiopathic Thrombocytopenia	Haematologist. Paediatrician, GP	Autoimmune disease resulting in low platelet count and therefore at risk of increased bruising and protracted bleeding.	http://www.itpsupport.org.uk/ http://www.patient.co.uk/health/Idiopathic-Thrombocytopenic-Purpura-(ITP).htm	Yes	Unlikely.

Disease, Condition or related medical terminology.	Useful healthcare contacts.	Notes.	NHS or support group Web link	Medical care plan required?	Involve PIMS?
Ileostomy	See 'stoma.'		http://www.nhs.uk/conditions/ileostomy/	Yes	Yes
Intermittent self catheterisation	See 'catheters for urination.'			Yes	Yes
ITP	See Idiopathic Thrombocytopenia				
Jejunal	See 'gastrostomy'	A form of enteral feeding involving a tube.		Yes	Yes
Jext	See 'allergy with epipen.'	Alternative pen to Epipen used for anaphylaxis.	http://www.jext.co.uk/	Yes	No
Jouberts syndrome	Paediatrician. Depending on severity other professionals including physiotherapy, occupational speech therapy and visual support. community children's nurses and specialist support from tertiary	Wide range of symptoms from those being only slightly impacted to those with complex special needs. Assess on individual basis.	http://www.gosh.nhs.uk/medical-information/search-for-medical-conditions/jouberts-syndrome/jouberts-syndrome-information/ http://www.jsuk.org/	Dependant on severity of condition	Yes

Disease, Condition or related medical terminology.	Useful healthcare contacts.	Notes.	NHS or support group Web link	Medical care plan required?	Involve PIMS?
	doctors.				
Juvenile Chronic Arthritis (JCA)	Physiotherapist (via ITS) Specialist nurse and Bristol Children's Hospital	This is a very variable condition both in severity and variability day to day.	http://www.nhs.uk/Conditions/Arthritis/	Yes	Yes
Juvenile idiopathic arthritis (JIA)	Physiotherapist (via ITS) Specialist nurse and Bristol Children's Hospital	This is a very variable condition both in severity and variability day to day.		Yes	Yes
Kidney disease/failure	See 'renal.'				
Kidney Transplant	See 'renal.'	Post transplant, careful consideration and support will be required for reintegration into school.		Possibly.	possibly
Lennox Gastout Syndrome	See 'epilepsy'			Yes	Yes
Leukaemia	See 'cancer'		http://www.nhs.uk/conditions/leukaemia-acute/	Yes	Yes
Liver transplant	Specialist services (usually from Birmingham) Paediatrician.	Post transplant, careful consideration and support will be required for reintegration into		Possibly.	possibly

Disease, Condition or related medical terminology.	Useful healthcare contacts.	Notes.	NHS or support group Web link	Medical care plan required?	Involve PIMS?
		school.			
Lyme disease	GP, school nurse for sign posting	Refer to your public health guidelines.	http://www.nhs.uk/conditions/lyme-disease/	Unlikely but dependant on severity of after effects of infection.	No
Lymphoedema	Paediatrician,GP, Lymphoedema nurse.		http://www.nhs.uk/conditions/lymphoedema/	Dependant on severity of impact of disease.	possibly
Meningitis	School Nurse for sign posting, GP	There may be complications post meningitis which will need support. This may be around limb loss and/or hearing issues.	http://www.nhs.uk/conditions/meningitis/	Dependant on severity of impact of disease.	possibly
Metabolic diseases and syndromes	Most likely paediatrician and/or specialist doctor's in tertiary centres. Dietician Children's Community nurses will sign post for you if necessary.	A general phrase referring to any genetic condition related to absorption of food and the chemical processes this involves. Most of these conditions will have their own name and associated issues. Try to find out which precise	http://www.nhs.uk/conditions/metabolic-syndrome/	Dependant on severity of condition.	possibly

Disease, Condition or related medical terminology.	Useful healthcare contacts.	Notes.	NHS or support group Web link	Medical care plan required?	Involve PIMS?
		condition child has.			
Microcephaly	Paediatrician/GP Children's community nurse	Usually associated with other medical conditions. Learning difficulties possible but Not always so.		Most likely due to other medical issues.	possibly
Mitrofanoff	See 'stoma.'			Yes	Yes
Moebius Syndrome	GP, Paediatrician, various members of ITS service. Hearing support, dietician. http://www.moebiusyndrome.com/index.cfm	Extremely rare genetic condition. Strong link with autism in 30% of cases. Can have multiple problems.		Most likely.	Yes
Mucopolysaccharoid disease	Paediatrician, GP	May be associated with other medical and learning issues.		No	Yes
Nasogastric tube	See 'gastrostomy' for main information	Sometimes called NG tubes. These tubes are usually for short term use.		Yes	possibly
naso-gastric tube (NG tubes)	Children's Community Nurse and Nutricia Nurse. Dietician. (Most initial training will	Child may have considerable amount of equipment and feeds may need storing in a fridge. Good advanced planning is very		Yes	Yes

Disease, Condition or related medical terminology.	Useful healthcare contacts.	Notes.	NHS or support group Web link	Medical care plan required?	Involve PIMS?
	come via the Nutricia Nurse.)	helpful for this.			
Nephrotic Syndrome	See renal		http://www.nhs.uk/conditions/nephrotic-syndrome/	unlikely	possibly
Neuroblastoma	See cancer		http://www.nhs.uk/conditions/neuroblastoma/	Yes	Yes
Neurofibromatosis	GP, Paediatrician. Possibly other professionals dependant on severity of symptoms	Very wide range on presentation. Maybe some body image issues if child has classic café-au-lait spots.	http://www.nhs.uk/conditions/neurofibromatosis/	Unlikely but dependant on severity of condition	Unlikely
Neurological disease or condition.	Most likely paediatrician and/or specialist doctor's in tertiary centres. Children's Community nurses will sign post for you if necessary.	A very wide term for a multitude of differing conditions. Try to find out which precise condition child has.			
Neuropathic Bladder	Urologist, paediatrician. Community nurse possibly.	May have significant incontinence issues. Involve PIMS at early stage.		Dependant on severity of condition	Yes
NG	See 'gastrostomy' for main	Short for nasogastric tube. These		Yes	Possibly

Disease, Condition or related medical terminology.	Useful healthcare contacts.	Notes.	NHS or support group Web link	Medical care plan required?	Involve PIMS?
	<p>information</p> <p>Children's Community Nurse and Nutricia Nurse. Dietician.</p> <p>(Most initial training will come via the Nutricia Nurse.)</p>	tubes are usually for short term use.			
Niemann-pick's disease	<p>Paediatrician. COMPASS team or community nurses. Neurologists. Likely other ITS professionals.</p> <p>http://www.niemannpick.org.uk/</p>	Three types of this condition.		Dependant on severity of condition	Yes
Ommaya Reservoir	See 'Hydrocephalus (shunt in place)'			Yes	Yes
Oncology	See 'cancer'				
Oxygen therapy.	Children's community Nurse, paediatrician, Air	Be aware of storage issues as well as informing fire brigade and local		Yes	Yes

Disease, Condition or related medical terminology.	Useful healthcare contacts.	Notes.	NHS or support group Web link	Medical care plan required?	Involve PIMS?
	Liquide.	insurance issues. Why is the child having oxygen?			
Pacemaker	See 'Cardiac child with a pacemaker.'			Yes	Yes
Peritoneal dialysis	See 'renal'			Yes	Yes
PICC line	See 'blood samples...'			possibly	unlikely
Pierre-Robin Syndrome	Children's community nurse, GP, SALT, hearing support.	This condition should have resolved by the time the child is at school and have No significant medical issues. May have long term problems with speech / hearing		Unlikely though there may be body image issues.	Yes
Portacath	See 'blood samples...'			Yes	unlikely
Prada-Willi Syndrome	GP, paediatrician. Possibly dietician	May have issues around food.	http://www.nhs.uk/conditions/prader-willi-syndrome/	Unlikely but will need a wider health care plan.	Yes
primary pulmonary hypertension	Cardiac specialist, cardiac nurses, community nurses,	Usually treated before school but may have long term impacts.		Dependant on severity of	Yes

Disease, Condition or related medical terminology.	Useful healthcare contacts.	Notes.	NHS or support group Web link	Medical care plan required?	Involve PIMS?
	possibly COMPASS team.			condition.	
Propionic acidaemia	Metabolic Specialist at tertiary centre. Paediatrician. Dietician.	Very rare condition affecting 1 in 100 000 children. Main feature is a strict, low protein diet.	http://nutrition.nutricia.com/conditions/propionic-and-methylmalonic-acidaemia	Yes, via dietician.	Unlikely
Pulmonary hypoplasia	Paediatrician, community nurse or COMPASS team depending on severity. Physiotherapist possibly.	Severe cases usually do Not survive to childhood though medical advances may change this.		Yes	Yes
Pulmonary lymphangiectazia	Paediatrician. COMPASS team.	Usually does Not survive to childhood though medical advances may change this.		Yes	Yes
Quadriplegia	See cerebral palsy			Yes	Yes
Raised intracranial Pressure.	Paediatrician. Possibly children's community nurse.	May have a shunt inserted if Not resolving. (See Hydrocephalus (shunt in place))		Dependant on severity of condition.	possibly
Renal issues (complex)	Paediatrician or renal consultant in Bristol. There are renal specialist nurses	Some of these children may be on home or hospital dialysis. They may have tubes permanently inserted in		Dependant on severity of condition	possibly

Disease, Condition or related medical terminology.	Useful healthcare contacts.	Notes.	NHS or support group Web link	Medical care plan required?	Involve PIMS?
	in Bristol as well who would provide telephone support.	them or stomas.			
Retinoblastoma	See cancer. Visual services also likely involved.	Child will possibly have a false eye following treatment.	http://www.nhs.uk/conditions/retiNoblastoma/	Yes	Yes
Retts Syndrome	COMPASS team	It is highly unlikely this will be seen in mainstream schools.	http://www.nhs.uk/conditions/Rett-syndrome/	Yes	Yes
Rubinstein-Taybi syndrome	GP. May have other professionals dependant on severity of condition including cardiac services, dieticians, ITS etc.	This condition can be quite variable in presentation. Usually this is accompanied by special educational needs.		Dependant on medical needs at the time.	Yes
Russel Silver Syndrome	Paediatrician, GP	May be associated with other medical conditions.		Possibly	Possibly
Sanfilippo syndrome (mucopolysaccharidosis III)	Paediatrician, COMPASS service) , physiotherapist.	Children with this condition often have a high threshold of pain. A degenerative condition. Symptoms		Yes	Yes

Disease, Condition or related medical terminology.	Useful healthcare contacts.	Notes.	NHS or support group Web link	Medical care plan required?	Involve PIMS?
		change with age.			
Scoliosis (curvature of spine)	Orthopaedics, physiotherapist	Often associated with other conditions in special needs children. Children may wear a body brace or require surgery.	http://www.nhs.uk/conditions/Scoliosis/	Possible, depending on severity of mobility.	possibly
Sensory processing issues	OT (ITS)	May link with behavioural or continence issues.)		Dependant on medical needs at the time.	Yes
Short long line'	See 'blood samples...'				
Shunt	See hydrocephalus (shunt in place)	'shunts usually refer to the devices implanted in the brain but on rare occasions parents may use this word to describe other surgical shunts in different organs (kidneys and bladder are common)		Yes	Yes
Sickle Cell Anaemia	See 'blood disorders.'	The disorder mainly affects people of African, Caribbean, Middle Eastern, Eastern Mediterranean and Asian origin. Pain can be a significant symptom of	http://www.nhs.uk/conditions/Sickle-cell-anaemia/Pages/Introduction.aspx	Unlikely	Unlikely

Disease, Condition or related medical terminology.	Useful healthcare contacts.	Notes.	NHS or support group Web link	Medical care plan required?	Involve PIMS?
		this condition.			
Sideroblastic Anaemia	See blood disorders.				
Spastic quadriplegia	See 'cerebral palsy.'	Term used to describe extent of damage in cases of cerebral palsy.			
Spastic Quadriplegia or hemiplegia	See cerebral palsy	Yes this is politically correct and will appear on medical letters though some parents may Not be comfortable with its use. Usually relates to the severe end of the cerebral palsy spectrum.		Yes	Yes
Spina bifida	Dependant on severity. children's community Nurse, paediatrician. Physiotherapist, OT via ITS.	Many such children will have bowel/bladder issues. (See section on <i>catheters for urination.</i>)		Dependant on severity of condition	Yes
Spinal arachnoiditis	Dependant on severity of condition. May have paediatrician, physiotherapist.	Pain is a significant component of this condition.		Dependant on impact of condition.	possibly
Spinal Muscular Atrophy (SMA)	COMPASS nursing service. Paediatrician.	This condition varies depending on the type of condition and its		Dependant on severity of condition and	Yes

Disease, Condition or related medical terminology.	Useful healthcare contacts.	Notes.	NHS or support group Web link	Medical care plan required?	Involve PIMS?
	Physiotherapist, OT via ITS.	degenerative condition.		other medical issues.	
Stevens Johnson Syndrome	Paediatrician or specialist doctor. GP	Very rare and dangerous condition. Treated in hospital unless mild and child should be on supportive care once returned to school.		Depends on supportive care. May be on medication or need support for skin damage such as creams.	Unlikely.
stoma	Stoma care nurses via local hospitals. Children's Community Nurses. Also Clinical Nurse specialist at Bristol.	Child will most likely be receiving care via Bristol Children's Hospital. Do Not assume a stoma is always the same as a colostomy. Ask parents for clarification.		Yes	Yes
Stroke	Paediatrician, neurologist. Maybe services via ITS	Children can have strokes.	http://www.nhs.uk/conditions/Stroke/	Dependant on severity of after effects of stroke.	possibly
Talipes (feet turned in)	Physiotherapy, Orthopaedic doctors. PIMS	Most likely this would have been picked up and dealt with before school begins.	http://www.nhs.uk/conditions/Talipes/	May need a plan depending on impact to	Possibly

Disease, Condition or related medical terminology.	Useful healthcare contacts.	Notes.	NHS or support group Web link	Medical care plan required?	Involve PIMS?
				mobility.	
Tetralogy of Fallot	See cardiac	Most likely repaired before school but on going surgery or issues may remain into older age.		Unlikely	Unlikely
Thalassaemia	See 'blood disorders'				
Tonic clonic seizures	See epilepsy				
toxic epidermal necrolysis	See Stevens Johnson Syndrome				
Tracheo-oesophageal fistula	GP/paediatrician if still involved.	This condition should have resolved by the time the child is at school and have no significant medical issues.	http://www.nhs.uk/conditions/oesophageal-atresia/	Unlikely	Unlikely
Tracheostomy	Children's community nurse, paediatrician, Possibly COMPASS and Continuing Health care Team	Most likely this will be part of a wider medical condition. Will need complex planning well in advance of school entry.		Yes	Yes
Transient ischemic attack	Paediatrician, neurologist. Maybe services via ITS	This is a 'mini stroke.' Children can have strokes.	http://www.nhs.uk/conditions/Transient-ischaemic-attack/	Dependant on severity of after effects of stroke.	Possibly

Disease, Condition or related medical terminology.	Useful healthcare contacts.	Notes.	NHS or support group Web link	Medical care plan required?	Involve PIMS?
Transposition of the great arteries	See cardiac	Most likely repaired before school but on going surgery or issues may remain into older age.		Possibly	Possibly
Treacher Collins Syndrome	CCN, paediatrician, possibly hearing support, dietician.	The impact of this medically is seen more in primary school. May have a tracheostomy. Potentially may need early school entry planning.	http://www.cafamily.org.uk/medical-information/conditions/t/treacher-collins-syndrome/	Dependant on medical needs at the time.	Yes
Turner's Syndrome	Paediatrician	Only effects girls. May have Lymphoedema	http://www.nhs.uk/conditions/Turners-syndrome/	Unlikely.	Yes
Varadi Papp Syndrome	See Jouberts syndrome				
Vascath	See 'blood samples...'			Yes	Yes
Vaters' syndrome	Paediatrician, community nurses, specialist services from Bristol, multiple professionals via ITS.	Varter stands for V ertebrae, A nus, T rachea, E sophagus, and R enal (kidneys).		Yes	Yes
ventilator	Continuing health care team (CHCT) (Lifetime services in BANES part of	Will need complex planning well in advance of school entry. Link with		Yes	Yes

Disease, Condition or related medical terminology.	Useful healthcare contacts.	Notes.	NHS or support group Web link	Medical care plan required?	Involve PIMS?
	Somerset.)	PIMS service.			
VNS	See 'Epilepsy with VNS device.'			Yes	Yes
VP shunt or ventricular-peritoneal shunt	See hydrocephalus (shunt in place)			Yes	Yes
VSD (Ventricular septal defect)	See cardiac	Some families will use the initials only whilst others will use the full term.		unlikely	No
Wet wrapping	See eczema	Very unusual in school aged children.		Possibly	Possibly
Young Simpsons syndrome	COMPASS team, paediatrician, multiple professionals via ITS. Dietician. Specialist doctors from Bristol.	Very rare condition with significant complex needs.		Yes	Yes

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