

Multi-Agency Guidance
for the Management of
Long Term Health Conditions
for Children and Young People

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Foreword

This guidance has been produced following recommendations of a serious case audit in Dorset. It incorporates lessons learnt from that process.

It should be remembered that the majority of children and young people with a long term/chronic health condition manage well with the support of their family and doctor.

The ICD-10 classification of the World Health Organisation **definition of a chronic childhood disease is one lasting 3 or more months or one which occurred 3 or more times in the past year & will probably reoccur; the disease is not yet curable** (or for mental health conditions is highly resistant to treatment); the disease occurs in children 0-18 years of age.

Figures for the number of children experiencing chronic health conditions vary though it has been quoted that 10-30% of children can be affected. The expert patient programme (www.dh.gov.uk) quotes the number of people in Great Britain reporting a long standing illness as 15 million & rising (~1.5 million in the age range 5-15 years - Office National Statistics general household survey).

For the purposes of this document the child with a long term health condition also requires additional support in managing their condition and there is multi-disciplinary involvement.

Such conditions may include, but are not limited to:

- children with asthma under the care of the paediatrician;
- children with diabetes;
- children with epilepsy who have been prescribed emergency treatment;
- children with anaphylaxis who have been prescribed emergency treatment;
- any other complex medical conditions.

The care of their long term condition may be giving rise to concern, e.g., if the child's condition is unstable; the child has a complex medical condition or concordance is poor (and particularly if poor concordance is causing or likely to cause significant harm).

The focus for this document is predominantly on children and young people receiving universal and specialist services. When a child or young person has needs arising from disability, accident or illness that cannot be met by existing universal or specialist services alone, these needs fall under the 'National Framework for Children and Young People's Continuing Care'.

(http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_114784)

This framework sets out an equitable, transparent and timely process for assessing, deciding and agreeing bespoke packages of continuing care for such children and young people under the age of 18.

Universal services are different to continuing care services and these are provided through mainstream generic children's services and fall within the National Framework for Children, Young People and Maternity Services Department of Health 2004 (http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4090552.pdf)

Living with a chronic disease may have a significant impact on a person's quality of life and on their family. Whilst many children and families manage their health well with the support of the health care or multi-disciplinary team, there are some children who will develop complications from their condition. Such complications may further lead to impaired health. In some instances children may die as a natural consequence of their medical condition. Tragically, some children may die as a result of poor management of their health; it is these deaths which are potentially preventable.

Chapter 7 of 'Working Together to Safeguard Children 2010' sets out the procedures to be followed when a child dies. These processes cover expected as well as unexpected deaths. The review of all child deaths in a Local Safeguarding Children Board (LSCB) area became mandatory in April 2008. In Dorset, such child death review processes were initiated in June 2006 (and built on the previous processes in place at Dorset County Hospital). Following on from a recent local child death review meeting, a case audit (similar in process to a serious case review) was undertaken in respect of a child who sadly died as a result of a complication from a long term medical condition. The findings of the case audit identified a number of areas where improvements could be made in the ways agencies work together with families to try to achieve the best outcomes for the child. By these means, it is hoped to reduce the likelihood of a similar event occurring in Dorset in the future.

In order to further disseminate the learning from this case audit and try to achieve best practice, a working subgroup of Dorset Safeguarding Children Board (DSCB) was set up. The remit of this Task and Finish group was to produce pathways such that professionals within agencies (within the limits of their role and responsibilities) may then action specific recommendations from the case audit, namely:

- to improve the response of professionals to failed medical appointments;
- to improve the sharing of medical advice/instructions with parents and child;
- to improve clarity over the responsibility of adults, parents and professional staff around managing medical conditions;
- to improve staff confidence and competence around managing a child with a long term medical condition;
- to improve training content and staff training records relating to managing medical conditions;
- to achieve more clarity of responsibilities when convening a health planning meeting;
- to improve multi agency working – e.g. contribution of the Education Social Work and Attendance Service for children with medical conditions;
- to gain better access to information of those children moving in and out of area;
- to produce guidance for the management of long term medical conditions where poor concordance with recommended therapy (including attendance at appointments) is causing or likely to cause significant harm to the child.

This document has been developed to address these needs. It covers all children and young people with Long Term Health Conditions in the identified settings. The guidance consists of new flowcharts developed by the group, alongside existing documentation in use at Dorset County Hospital Foundation Trust (DCHFT) and within school health locally. The aim is to guide professionals in the management of children with long term/chronic health conditions. Much of what is written will be known to many clinicians/professionals already. The document aims to: (i) reinforce and share good practice, and (ii) have relevant documentation in one place for reference and ease of use.

This document will be shared with neighbouring Health Care Providers.

The document incorporates previous work undertaken by a joint multi-agency working party formerly coordinated by Dorset County Council's (DCC) Children's Services which it now replaces.

Medical needs of children will be considered holistically and a unique decision made as to the nature of training and the amount of support required on an individual basis.

Underpinning Principles

- Right to Entitlement
- Statutory rights to services
- Duty of Local Authority to provide services
- Local Authority Inclusion Vision
- Equality Act 2010

Scope of the advice contained in this guidance

Provision of safe care for children and young people to the age of 18 in the following settings:

- The home setting;
- Health settings;
- Pre schools within the Local Authority (LA);
- Maintained and Independent Schools (including Extended School activities);
- Academies and Colleges;
- Short Break settings;
- Child Care arrangements and enhanced shared care;
- Services designed to enable access to services included in the child's support plan (e.g. transport).

Membership of the Task and Finish group:

Chair:	Dr Julie Doherty	Consultant Paediatrician, Dorset County Hospital NHS Foundation Trust & Designated Doctor for Safeguarding Children, Dorset, Poole & Bournemouth
Deputy Chair:	Angela Baker	Named Nurse for Safeguarding Children, Dorset Community Health Trust
Health reps:	Dr Angela Salter	Named GP for Safeguarding Children, Dorset Primary Care Trust
	Dr Paul Mason	GP, Royal Manor Health Care
	Wendy Milverton	Practice manager, Royal Manor Health Care
	Julia Shutlar	Manager Specialist Community Public Health (Schools) (School Nursing) Dorset Community Health Services
	Katrina Gray	Young People's Health Professional (School Nursing) Dorset Community Health Services
	Lynn Last	Children's Specialist Diabetes Nurse, Dorset County Hospital NHS Foundation Trust
	Dee Watkins	Safeguarding Advisor, Dorset County Hospital NHS Foundation Trust
	Gillian Daubnay-Nunn	Children's Community Nurse, Dorset County Hospital NHS Foundation Trust
Multi-agency reps:	Richard Marchant	Senior Education Officer (SEN), Children's Services, Dorset County Council
	Ginny Daniells	Safeguarding Officer, Children's Services, Dorset County Council

Equality and Diversity

The DSCB expect all staff to be proactive and ensure they respond appropriately with regard to the safeguarding of children and young people. Staff should recognise and support equality and diversity issues and understand the additional vulnerabilities faced by children and young people, including:

- those from Black, Asian and minority ethnic backgrounds;
- children who are disabled;
- refugees or asylum seekers;
- those who are transgender;
- children who have a particular sexual orientation;
- children from all faiths and beliefs;
- those who have diverse communication needs;
- those living in rural settings.

The DSCB does not tolerate any lower standard of care or welfare on the part of any child or young person as a result of them belonging to these groups.

Section 1: General Information

1.1 Recommendations from the Dorset Safeguarding Children Board (DSCB) arising out of Serious Case Audits of Dorset children and young people.

- 1.1.1 The DSCB should establish an interagency project to consider the issues arising from the case audit and draw up necessary procedures and protocols to address the interagency arrangements for the management of long term health conditions of children and young people.
- 1.1.2 Training in relation to safeguarding children and the procedures and protocols that apply should include reference to:
- the legal, policy and human rights imperatives underpinning the practice and procedural framework;
 - and the principles of reaching sound professional judgements.

Roles and Responsibilities (where involved)

- 1.1.3 There should be clarity about the responsibility of parents, adults and professional staff to ensure that proper management is taking place for children and young people with medical conditions. Whilst children and young people will be encouraged to understand and participate in the management of their medical condition, appropriate supervision should continue and monitor the safeguarding measures put in place.
- 1.1.4 Any arrangements made by the DSCB to consider improved processes for the management of medical conditions should include consideration of the contribution that might be made by the Education Social Work and Attendance Service (ESWAS).
- 1.1.5 Consideration should be given to making contact with others with responsibility or interest in their welfare when there are concerns about the ability or willingness of a parent with care of a child to fulfil their responsibilities.
- 1.1.6 Active agencies should record who has parental responsibility in respect of each child / young person, and who exercises caring responsibilities.

Training

- 1.1.7 The procedures addressing the management of medical conditions in children should make clear the personal responsibility of staff to ensure that they have the necessary knowledge & skills to carry out their responsibilities.
- 1.1.8 Staff who have anxiety about their competence/ability to carry out tasks should have a responsibility to draw this to the attention of managers.
- 1.1.9 Arrangements should be put in place to ensure that a record is kept by each agency of all staff who receive training, the date on which this has been received and the content.
- 1.1.10 A record of training, instruction or the provision of essential advice given to staff involved in the management of medical conditions in children should be maintained. These records should detail the training, instruction or advice provided, the extent of the information given, an opinion from the provider on whether or not the recipient has fully understood the issues and any subsequent action required.
- 1.1.11 Managers of staff who have agreed to be involved in the management of children with medical conditions in school settings, should satisfy themselves that the staff have the necessary knowledge and skills to carry out such responsibilities.

Health Care Planning Meeting

- 1.1.12 A Health Care Planning Meeting to consider the management of continuing health needs should clearly identify each of the following:
- the needs of children in school settings;
 - the agency responsible for convening a 'health planning meeting';

- the procedures to be carried out and by whom;
- the role of other agencies;
- what safeguarding controls should take in the event that this responsibility is not appropriately exercised.

Children Moving In And Out of Area

- 1.1.13 The DSCB should consider the adequacy of arrangements for ensuring that records relating to children who require regular medical supervision or attention and move areas are available to staff dealing with the child in the new area.

Record Keeping

- 1.1.14 Partner agencies should make clear to their staff and supervisors that failure to comply with the required standard of record keeping will be likely to lead to formal performance management arrangements.
- 1.1.15 Agencies should carry out random audits of records to review record keeping practice and ensure that supervisors act on these findings.

Safeguarding Children/Child protection

- 1.1.16 The opening of a formal child protection record within an agency should be communicated to all other agencies known to be involved with the family.
- 1.1.17 The procedures (relating to the opening of a child protection record) should provide for consideration of whether members of the family should be informed, a requirement for the recording of reasons why they have not been informed if this is the case and in either event a requirement that other agencies should be informed of the decision and the basis for it.

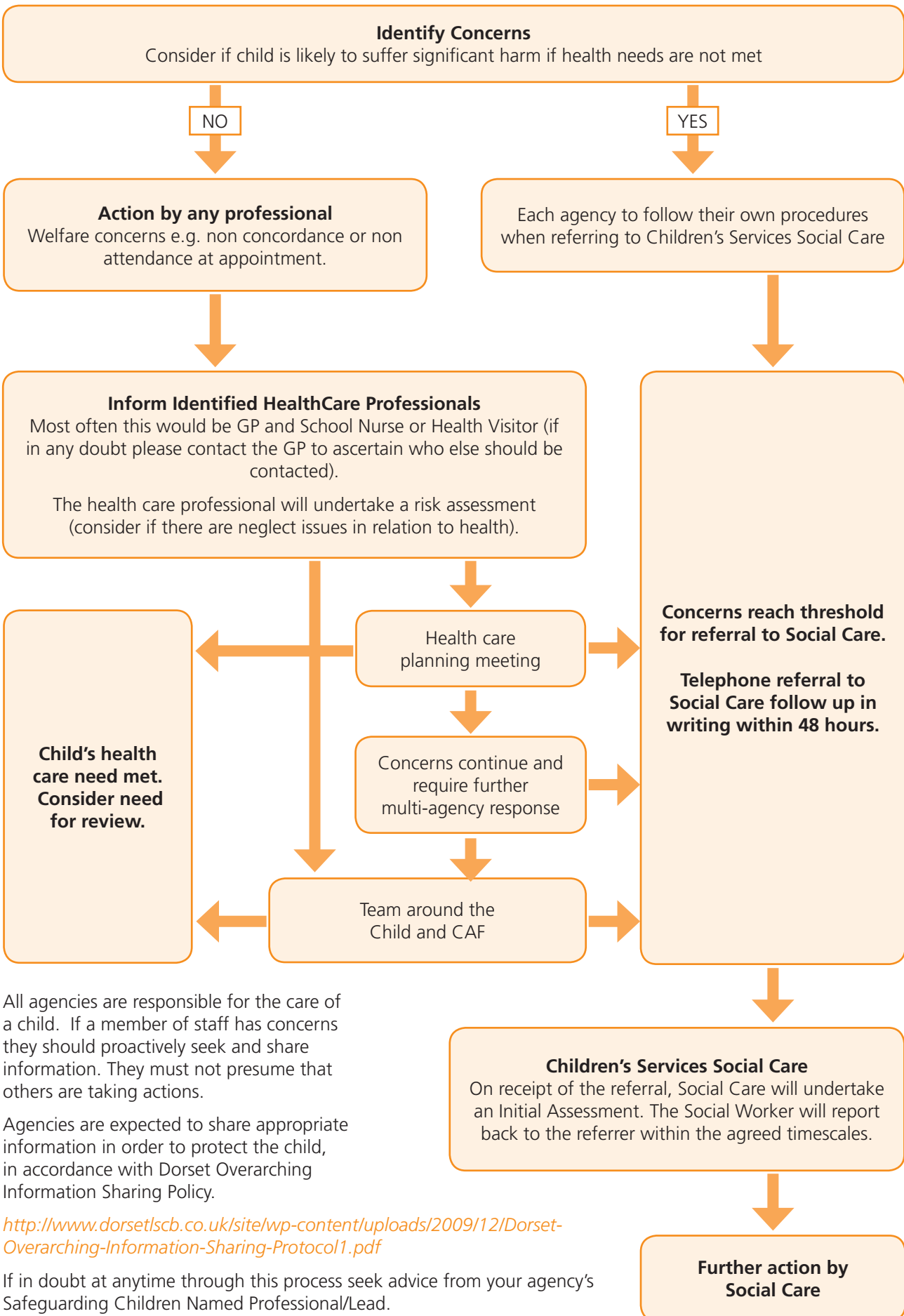
Management of Medical Appointments:

- 1.1.18 Appropriate processes and procedures should be developed to address the approach taken to failed medical appointments and how essential guidance is given to parents and carers.
- 1.1.19 Copies of essential advice or instructions should be given to parents at each visit to a hospital appointment.
- 1.1.20 A record should be kept of when and to whom advice or instructions are given either at a hospital appointment or in response to a failed hospital appointment. An opinion should be recorded as to whether these have been understood.

Guidance for Long Term Health Conditions

Chart A

General Information



All agencies are responsible for the care of a child. If a member of staff has concerns they should proactively seek and share information. They must not presume that others are taking actions.

Agencies are expected to share appropriate information in order to protect the child, in accordance with Dorset Overarching Information Sharing Policy.

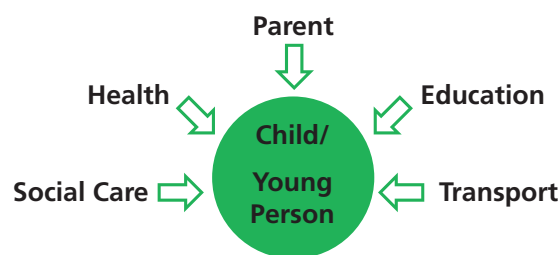
<http://www.dorsetscb.co.uk/site/wp-content/uploads/2009/12/Dorset-Overarching-Information-Sharing-Protocol1.pdf>

If in doubt at anytime through this process seek advice from your agency's Safeguarding Children Named Professional/Lead.

1.2 Roles and Responsibilities

1.2.1 The Role of the Child/Young Person

- Children and young people should be encouraged to participate in the decision making processes and management of their own health needs, as appropriate to their age, understanding and maturity. This may include attending the Health Care Planning Meeting.
- As children and young people mature and become more independent they are able to take on greater responsibility for their own health. A growing independence will enable children and young people to look after and manage their own health better as adults.



Parents

1.2.2 The Role of the Parents

- Parents and carers have prime responsibility for their children's health.
- Whilst children and young people will take on a greater responsibility for their own health as they mature and gain more independence, parents/carers continue to have a responsibility for overseeing their child's health care. Parents/carers should encourage concordance with health care monitoring and treatment to ensure that health care needs are met.
- Parents should inform the school or early years setting about any health needs. (Including me, CDC 2005)
- Good communication is essential to building a partnership. Parents of children with complex health needs will be invited to attend and participate in meetings, reviews, risk assessments and training related to their children.
- Health Care Plans should convey parents' wishes and constitute a binding agreement with the various agencies who have contributed to the Plan. The Health Care Plan should be signed by the parents giving consent for the medical interventions to be carried out by trained non-health professionals.
- Parents should seek agreement with the head of organisations within the Local Authority providing written instructions about the administering of any medication. Except in circumstances, where Fraser competency apply, no child under 16 should be given medicines without their parent's written consent. Parents should expect to be involved and informed at all stages of the risk assessment process. In the case of children with complex medical needs that are identified by Health Services, parents will be asked to sign off risk assessment forms in a meeting with a lead professional, confirming that they understand and agree to the recommendations of the assessment. For most children where medical needs are not complex, parents will be able to agree the Health Care Plan with school or social setting.
- Parents can expect to be made aware of the outcomes of risk assessments and of any reasonable adjustment that is required.

Lead Professional

1.2.3 The Role of the Lead Professional

- The Lead Professional is asked to facilitate a programme of training to be delivered by a relevant and appropriately qualified professional. It should be noted that the identified Lead Professional for a child may not necessarily be a Health professional; it cannot be assumed therefore that reference to the Lead Professional relates to medical personnel. In situations where there is group of professionals supporting a child, the Lead Professional is responsible for drawing together expertise from all agencies in support of that child's needs. There is an expectation that each agency will fulfil its role to ensure the safeguarding and wellbeing of children and to monitor and record their involvement appropriately.

Health

1.2.4 The Role of the Health Care Professional

- The Health Care Professional(s) may be one or more of the following:

- Children's Community Nurse (CCN)
- School Nurse
- Occupational or Physio Therapist
- GP
- Health Visitor
- Paediatrician
- School Doctor.

(Note that the Health Care Professional may not necessarily be the Lead Professional.)

- To convene a Health Care Planning Meeting where appropriate, e.g., support is required in managing the child's Health Care needs in school. Professionals from other agencies may request a Health Care Planning Meeting if they have concerns regarding the Health Care needs of a child/young person.
- To ensure that a Health Care Plan is in place that has been agreed and, where appropriate, signed by parents. (see Health Care Plans)
- To ensure that all agencies are aware of what actions need to be taken in the event of an emergency. (see emergency procedures)
- To undertake a full assessment of the child's health care needs, including a risk assessment of the care required and identification of the level of care required.
- To ensure that a comprehensive Health Care Plan is developed and is updated in accordance with the child's changing needs and in partnership with the parent or carer.
- To co-ordinate required training from Health professionals with appropriate skills.
- To make arrangements for the regular review and monitoring cases.

Trainer

1.2.5 The Role of the Trainer

The training role does not include line management responsibilities for the care workers. The trainer:

- will be accountable for delegated duties in line with The Nursing and Midwifery Code of Conduct (Section 4, par. 4.5, 4.6);
- will be employed by the NHS and will be indemnified by the NHS employing body;
- provides professional advice on the level of care and training required;
- is responsible for the delivery of appropriate advice and training;
- maintaining records of training (which should include an opinion of whether the recipient/trainee has understood the training);
- must ensure that written protocols relating to the care to be given are provided and that all necessary equipment is available;
- is responsible for ensuring that the care worker is informed of any changes to the Health Care Plan;
- should reinforce the need and importance for the trainee to maintain appropriate records of actions and involvement relating to their observations and intervention.

Education

1.2.6 The Role of Schools, School Governing Bodies, Academies and Pre schools

- Individual schools should develop policies to cover their own school needs. The policies should reflect those of their employer. The Governing Body has general responsibility for all of the school's policies even when it is not the employer. Where the Local Authority is the employer, the school's Governing Body should follow the Health and Safety policies and procedures produced by the Local Authority.
- Schools should determine that an employee requested to undergo training in specific medical procedures to support a child agrees to do so. The employee should receive ongoing support and training to enable them to feel both confident and competent to continue their work.
- Safeguarding of children is paramount; schools are responsible for adhering to Health Care Plans, keeping, maintaining and monitoring clear records, and demonstrating that children are provided with appropriate medical support for which training has been given by qualified professionals. It should be noted that failure to adhere to Health Care Plans could render additional insurance cover

otiose and lead to formal performance management arrangements for those who have neglected their responsibility to maintain clear records.

- Managing Medicines in Schools and Early Years Settings (DfES/Department of Health, 2005) provides advice for schools and their employers to help in the development of such policies. It explains the roles and responsibilities of employers, parents and carers, Governing Bodies, head teachers, teachers and other staff and of local health services. It considers staffing-issues including employment of staff, insurance and training. Other issues covered include schools proactively following the agreed Health Care Plan provided by Health, confidentiality, record keeping (with suggested pro forma), the storage, access and disposal of medicines, home to school transport, and on-site and off-site activities.
- Policies need to refer to specific arrangements made for children on Educational Visits for whom medical interventions are necessary.
- Policies and Care Plans should include details of relevant Health and Safety issues, such as infection control and storage of medication.
- The school must ensure that the parents/carers of every prospective pupil completes the health questionnaire (see Appendix 1) before a child is admitted to the school or shortly thereafter. If the school becomes aware that the child has developed a long term health condition then parents/carers should be asked to complete a further health care questionnaire.
- Health Care Plans should include information about the emergency arrangements made for children requiring agreed medical intervention. Local policies should also make reference to how and when risk assessments and emergency arrangements are reviewed.
- Headteacher or the designated member of staff should ensure that back up cover is arranged in the event of staff absence/non-availability. Cover staff must have appropriate training and skill to be able to carry out the agreed intervention/responsibilities and to maintain records accurately.

Local Authority

1.2.7 The Role of the Local Authority

- Children's Services provide a general policy framework to guide schools in developing their own policies on supporting children with medical needs.

Education Social Work & Attendance Service

1.2.8 The Role of Education Social Work & Attendance Service (ESWAS)

- Education Social Workers link with key staff in school and use attendance information to identify pupils whose attendance is of concern. They work directly with pupils and their parents and carers who have below 80% attendance with a significant amount of unauthorised attendance.
- To support involvement with the ESWAS service it is essential that schools have robust systems in place to identify patterns of absence and unauthorised absence.
- Where there are concerns that health needs are impacting on attendance for children with long term health needs, the school staff would need to obtain information through liaison with parents, GP, School Nurse and the appropriate practitioners involved. Schools could refer cases to ESWAS if they believe that health problems are given for absence but that this is not corroborated through medical information.
- The Education Social Worker should be invited to the Health Care Planning Meeting or the Team Around the Child Meeting to see if there is a future role for the service where there are attendance issues.

Social Care / Early Years

1.2.9 The Role of the Employer of the Designated Care Worker or Manager of the Fostering Team

- Criteria under the national standards for under 8 year olds Day Care make it clear that Day Care providers should have a clearly understood policy on the administration of medicines. In the case of a child with complex medical needs, if the administration of prescription medicines requires technical or medical knowledge then individual training may be provided to staff from a qualified health professional. Training is specific to the individual child concerned.

The Employer or Manager will:

- be responsible for ensuring that the employee who is the designated carer has a good understanding

- of the care and procedures to be undertaken, and has been fully trained and, where applicable, that competencies have been met;
- be responsible for identifying who will undertake the role of care worker;
- be responsible for ensuring that training is kept up to date;
- ensure that consent for care has been given by the parent;
- ensure that only the designated carer(s) undertake the care for which training has been received;
- ensure clear, written records are maintained. (It should be noted that failure to adhere to Health Care Plans could render additional insurance cover otiose and lead to formal performance management arrangements for those who have neglected their responsibility to maintain clear records);
- ensure that monitoring of the designated care worker takes place at agreed and regular intervals;
- ensure that a risk assessment has been undertaken in accordance with Health and Safety Regulations and that appropriate insurance cover is in place.

Designated Care Worker

1.2.10 The Role of the Designated Care Worker

- Responsible for confirming that he/she fully understands the care to be given, including any clinical procedures;
- has a responsibility to undertake training and, where applicable, undergo assessment of competency; not to undertake any procedures without proper training and assessment. The onus is upon the Designated Care Worker to identify and attend such courses;
- should inform the trainer if he/she does not feel competent or confident to carry out a procedure either ahead of training or at any point thereafter;
- should inform the child's named Community Childrens Nurse, or school nurse, and the parent of any changes in the child's care needs;
- must ensure that contemporaneous records are maintained.

Transport

1.2.11 The Role of Transport Providers

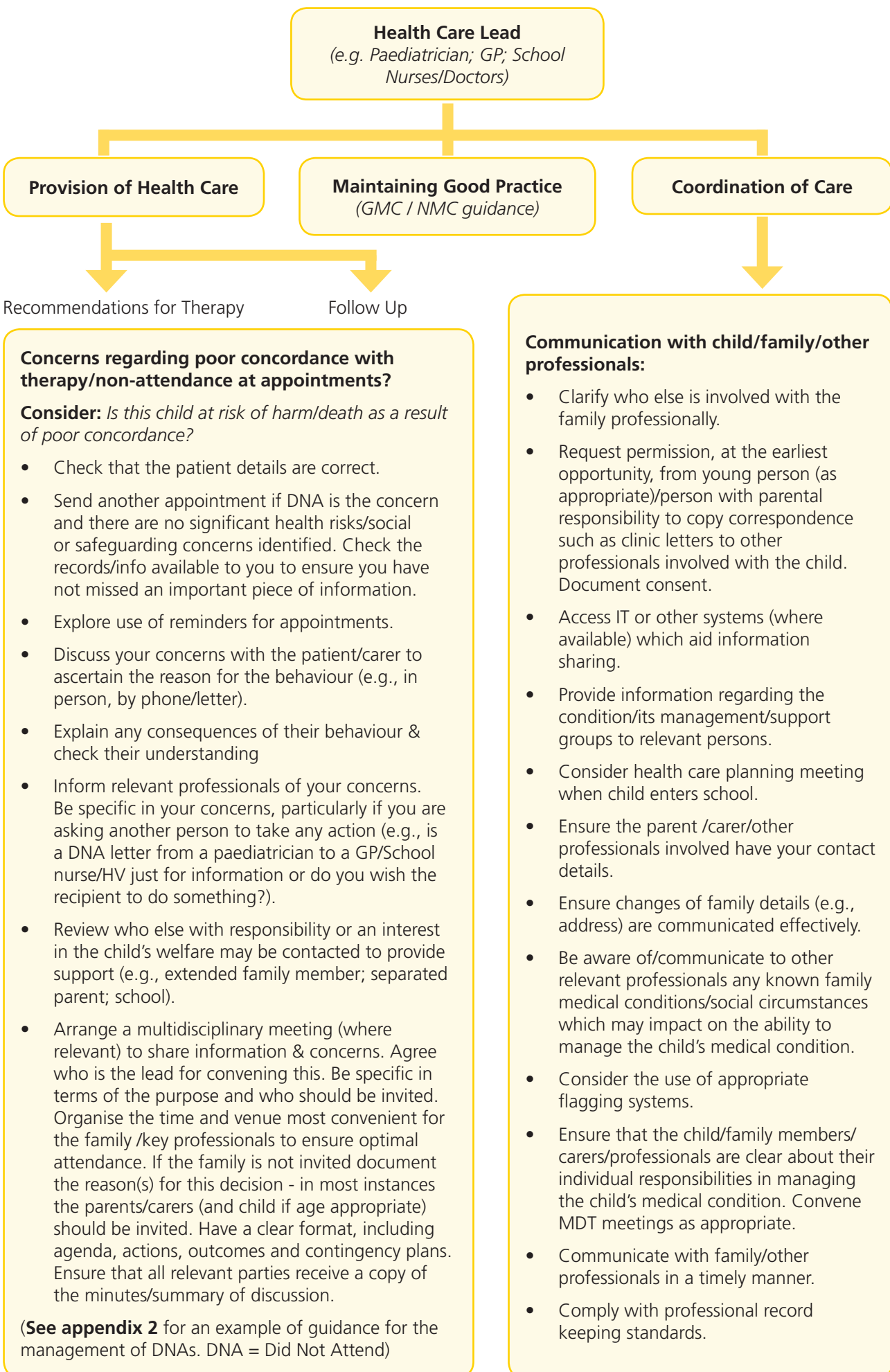
- Some children with complex health needs will require the local authority to provide transport to and from school, home and other care settings. All drivers and Passenger Assistants (PA) must have first aid training which is currently provided by the Local Authority. Additional training should be provided by Health professionals and given to PAs who are required to support children with complex health needs.
- Drivers and Passenger Assistants (PA) have set procedures that are used in the case of an emergency. These are set out in the transport providers' handbook.
- Drivers and Passenger Assistants can be expected to undertake Level One and Level Two tasks as described by paragraphs 3.2.2 and 3.2.3 in this document. In order to accomplish these tasks, training is provided by qualified, Dorset County Council staff on a regular basis.
- For children requiring specific Level Three tasks intervention whilst using transport, the Local Authority Transport officers should carry out an appropriate Risk Assessment. These children should carry Health Care Plans with them on each journey which clearly state emergency contact details. Appropriate training may be required for Passenger Assistants (PA), e.g., use of Oxygen and suction.
- Where administration of medication or other procedures are required the PA should have received specific training. Staff transporting children who are at risk of anaphylactic shock should be trained in the use of an EpiPen for emergencies.
- An ambulance should be called in emergency situations that cannot be covered by basic First Aid training. Drivers are aware of the area that do not have mobile phone network coverage and have contingency plans to overcome this difficulty.

2. Health

Guidance for the Management of Long Term Health Conditions

When managing long term health conditions healthcare professionals need consider each of the 4 areas below:

CHILD	FAMILY	ENVIRONMENT	PROFESSIONAL
<p>Give information about the condition appropriate to the child's age & understanding.</p> <p>Be clear about who has responsibility for managing each aspect of the condition.</p> <p>Check that the child is registered with a GP practice and ideally one who can deliver care locally.</p> <p>Consider arrangements for transitional care at an appropriate stage.</p> <p>(An example of a transitional care pathway is provided as Appendix 3)</p> <p>Consider issues which may contribute to poor concordance with therapy/attendance at follow up appointments.</p> <p>Consider any safeguarding issues and instigate child in need / child protection procedures where appropriate.</p> <p>Consider use of CAF</p> <p>Proactively seek information from other professionals/agencies involved with the child/family.</p> <p>Communicate child protection matters as relevant to colleagues in other agencies who are known to be involved with the child/family.</p> <p>Flag health records appropriately.</p>	<p>Provide information (verbal, written, website/ support group details) about the condition appropriate to parental understanding. Consider patient held records.</p> <p>Copies of essential advice/ instructions should be given to parents/carers at each visit.</p> <p>Be clear about who has responsibility for managing each aspect of the condition.</p> <p>Arrange any training family members/carers may require in order for them to manage the child's medical condition.</p> <p>Consider arrangements for transitional care at an appropriate stage.</p> <p>If there are concerns regarding the ability or willingness of a parent/carer to fulfil their responsibilities, consider who else with responsibility or an interest in the child's welfare may be contacted to provide support.</p> <p>www.dcsf.gov.uk/everychildmatters/strategy/parents/ID91askclient/thinkfamily/tf/</p> <p>Manage failed medical appointments</p>	<p>Consider whether any additional support/ equipment is needed to enable the family manage the child's medical condition within the home, e.g., critical care package.</p> <p>Consider what support/ training education/other staff may need in helping manage the child within school/child care settings.</p> <p>Consider the need for a Health Planning Meeting within school. If required, be clear who is responsible for convening, chairing and providing a summary of the meeting. This is usually the school nurse or paediatrician.</p> <p>Determine whether there is/need be involvement of the Education Social Work and Attendance Service (ESWAS).</p> <p>Provide information to carers re management of the child's medical condition on holiday, where appropriate.</p>	<p>Have an appropriate job description which clarifies their role and responsibilities.</p> <p>Have the necessary knowledge, skills & attitudes to perform their duties. Should staff have any anxiety with regard their competence they should draw this to the attention of their line manager +/- supervisor.</p> <p>Records of training should be kept & be readily available, including that given to carers/other staff (e.g., in schools). Detail the extent of info provided. It is helpful to issue a feedback form or short assessment to determine & evidence the 'trainees' understanding.</p> <p>Comply with the required standard of record keeping. Keep records of when and to whom advice/instructions are given, including an opinion as to whether these have been understood.</p> <p>Request and check receipt of previous healthcare records if the child has moved into the area.</p> <p>Communicate and include other professionals, e.g., GP, school in a timely manner – particularly if requesting action(s) of that colleague. Consider use of telephone or email rather than letter by post.</p>



2 Health - Management of Chronic Illness

Chart B

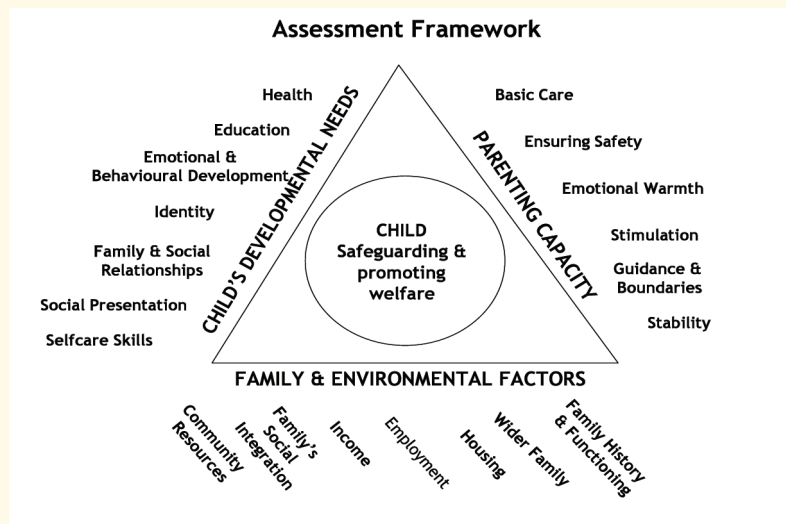
Child or Young Person Presents with Chronic illness as defined in this policy.

The nature of the chronic illness requires: regular assessment and monitoring within Primary Care Services and/or by a Paediatrician

Parents/Carers are responsible for the monitoring and health of their child/children; however professionals also have a safeguarding responsibility to the child/children

Failures to attend for appointments, with Primary Care Staff or with a Secondary Care Provider should be notified to the General Practitioner for the child. The GP, with the lead clinician, is jointly responsible for monitoring the child's health care and attendance.

The General Practitioner and/or lead clinician is in the best position to consider any potential risk factors that may impact on the child's health care and well-being by using the assessment framework. Particular consideration to be given to information on domestic abuse, substance misuse and emotional well being of parents/carers as these potentially impact on their care of the child/children.



If parental behaviours impact or potentially impact on the health of a child the GP can discuss their concerns with the Health Visitor or School Nurse (depending on age of the child) and may also share relevant information with the school on a need to know basis. Consider use of the Common Assessment Framework (CAF)

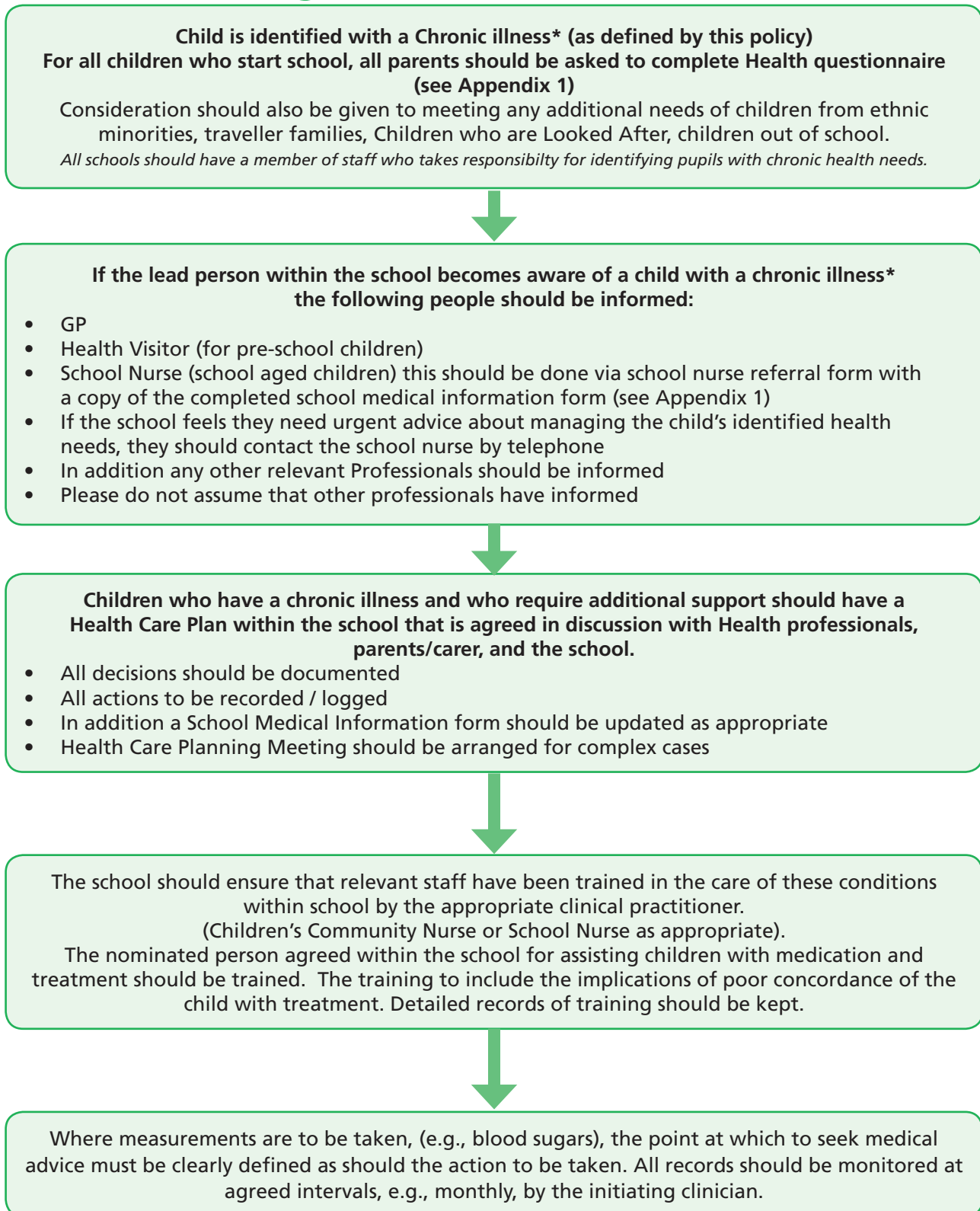
Discuss with paediatrician if they are involved in the child's care.

Consider discussion with your Trust's Safeguarding Children Lead.

Refer to Local Authority Childrens Social Care if there are significant child care concerns.

Section 3: Education, Care and Training

Chart C



*A chronic illness is one lasting 3 or more months or one which occurred 3 or more times in the past year & will probably reoccur and is not yet curable. (ICD-10; WHO definition)

For the purposes of this guidance the child/ young person requires additional support in managing their long term health condition and there is multidisciplinary team involvement. The care of their long term condition may be giving rise to concern.

3.1 Health Care Plans

3.1.1 Reference should be made to Chapter 4 of 'Managing Medicines in Schools and Early Years Settings' (DFES 2005).

The main purpose of an individual health care plan for a child with medical needs is to identify the level of support that is needed. Not all children who have medical needs will require an individual plan. A short written agreement with parents may be all that is necessary (see Appendix 4).

3.1.2 Health Care Planning Meeting

When is it appropriate to hold a meeting?

- In order to review a Health Care Plan (minimum annually).
- As a new entrant is enrolled at a school or early years setting (see Appendix 1).
- Following a significant incident that establishes a need for a Health Care Plan.
- Following and change of medical condition or circumstance.
- Following new medical advice.
- At Transition times – preschool to school, school to school, to another Local Authority.
- Where concerns arise with regard the health care of a child/young person.

3.1.3 Purpose of meeting:

1. To gather the key personnel associated with the medical needs of a child/young person:
 - Headteacher or Head of Setting
 - the parent or carer
 - the child / young person (if appropriate)
 - Early Years practitioner/class teacher / tutor / Head of Year
 - Care Assistant
 - Staff who are trained to administer medicines
 - Staff who are trained in emergency procedures
 - School Nurse / Doctor / Health Visitor
 - Children's community Nurse
 - Children's Therapist
 - Paediatrician
 - GP
 - ESWAS (if there are attendance issues)
2. To establish the medical and nursing needs of a child / young person;
3. To view risk assessments associated with the care and needs to a child / young person and to agree on appropriate actions and support required, including training needs;
4. To identify and name the individuals who have responsibility for supporting the child / young person in identified settings;
5. To specify the roles of parents, school staff, healthcare professionals;
6. To structure a plan showing all above information;
7. To discuss contingency measures if parents/carers/child do not cooperate with the plan.

The Health Care Plan most generally used in Dorset will have a top sheet that is split into four quadrants and have a common appearance. Further detail may be added to the Health Care Plan, e.g., examples, *Moving and Handling advice, illustrations of equipment, etc.*

3.1.4 Who is responsible for convening the meeting?

The responsibility for convening a Health Care Planning Meeting lies with Health. In practice it will usually be the School Nurse or Paediatrician who has responsibility for convening, chairing and providing a summary of the meeting. This role may be delegated following clear agreement between the Health professional and the relevant professional from another agency. The meeting should be minuted in such a way that includes reference to the agreed contingency measures.

Professionals from other agencies may request a Health Care Planning Meeting if they have concerns regarding the health care needs of a child/young person.

3.1.5 **What to do if there are child protection concerns.**

See Chart A and the pan-Dorset Inter Agency Safeguarding Children Procedures.

www.dorsetscb.co.uk/site/advice-for-people-working-with-children/local-inter-agency-procedures/

3.1.6 **When School should open a Child Protection File.**

- The designated senior person (DSP) for child protection in the school has responsibility for opening a separate child protection file for a child when the school have discussed the child with social care.
- In practice this means that if Social Care attend the Health Care Planning Meeting or there is a Team Around the Child Meeting, that Social Care attend, or the school, or Social Care initiate a discussion about the child then a Child Protection File should be opened (see Appendix 3 of the Schools Child Protection Procedures).
- The DSP and who ever in the school has the lead for Health Care Planning for individual pupils will need to ensure that there is regular liaison about the child. The DSP must be informed where there are issues of poor concordance.
- The opening of a formal child protection record within school (and the basis for it) should be communicated to the school nurse (if they have involvement with the child or the child has a HCP) and any other agencies known to be involved with the family. The School Nurse should then be responsible for notifying the GP and paediatrician (if paediatric involvement).
- If the child does not have a HCP / School Nurse involvement, consideration should be given by the school to notifying the child's GP.
- Appropriate members of the family should be informed about the opening of a Child Protection Record. Where parents/ carers are not informed, the reasons for this should be clearly recorded.

Chart D

Anaphylaxis Care Plan

Photo:	Name:
	Date of Birth:
	Contact Nos:
	Parents/carer:
	Home:
	Work:
Allergic to:	Mobile:
	GP:
	Consultant:

WHAT TO LOOK OUT FOR:	ACTION TO TAKE:
<p>Airway:</p> <ul style="list-style-type: none"> • Rapid onset of wheezing/difficulty in breathing • Difficulty in swallowing • Swelling of face, lips, tongue • Itching sensation of throat or tongue • Feeling of tightness, a lump in the throat or of a fat tongue <p>Breathing:</p> <ul style="list-style-type: none"> • Breathlessness • Noisy breathing (wheezing/rattle/croup) • Unable to talk in sentences • Distress, panic • Blue around the lips and tongue <p>Circulation:</p> <ul style="list-style-type: none"> • Pale clammy skin • Redness/hives/itching • Drowsiness • Stomach ache/Vomiting • Losing consciousness. 	<p style="text-align: right;">will need his/her</p> <p>EMERGENCY TREATMENT IMMEDIATELY</p> <ul style="list-style-type: none"> • Divide the thigh into quarters. Give the Epipen into the upper, outer quarter. • Hold for the count of ten and then massage the area • At the same time instruct another to Dial 999 for ambulance • Stay with the child and encourage him/her to lie down. If breathless let child find a comfortable upright position. Observe closely • Ensure the airway is clear • If child is unconscious place him/her in recovery position • Give second Epipen after 5 minutes if there is no improvement or the child's condition worsens • Commence resuscitation if necessary • Contact the parent/carer

Health Care Plan developed by:	(PRINT and SIGN)
Agreed by parent/carer:	(PRINT and SIGN)
Agreed by school:	(PRINT and SIGN)
Date:	
Review date:	

Education, Care & Training

3.2 Education Care and Training – Levels of Care and Targeted Training

- 3.2.1 The care that a child requires can be categorised into the levels of training the nature of which will be determined by a Health professional considering individual cases and considering environmental and personnel factors. This guidance is specific to level three tasks. Further clarification of levels of care and requisite training should be discussed and agreed with the child's Children's Community Nurse (CCN) or School Nurse.

Basic guidance on the following lists may change and Health professionals will identify when further training is required. This will be considered when each case is due for regular review.

3.2.2 Level One Tasks

For these tasks, the care worker will receive a general basic training from their employer and/or Health Care professional. Tasks at this level should be included in a general induction. These skills are transferable and include:

- Disposal of clinical waste;
- Infection control;
- Intimate Care;
- Personal Care;
- Assisting a child with eating and drinking (where a child has a defined eating difficulty);
- Communicating with a child with complex needs;
- Promoting continence.

3.2.3 Level Two Tasks (revised August 2008)

These tasks are required to meet a health need. The care worker will receive either individual or group training from an appropriate trainer for specified child/children. Tasks included are:

- Moving and handling;
- Emergency treatments covered in basic first aid training including airway management;
- Care of a child who has epilepsy;
- Care of a child who has a chronic/long term/life limiting condition.

The emergency services must be called in situations that arise which are unforeseen, e.g., when:

- a child is not responding to or is not improving following intervention;
- an unexpected reaction occurs that is not identified in a Health Care Plan;
- displaying signs of cardiac or respiratory difficulties.

In these cases it would be helpful if a person trained in First Aid was present if available, whilst awaiting attendance of the emergency services.

3.2.4 Level Three Tasks

These tasks require training before intervention can take place. Training programmes should be assessed by using the charts overleaf.

ASSESSMENT TOOL FOR TRAINING – 3 stages

STAGE 1 – THE INDIVIDUAL CHILD – assess the individual child and decide which category they meet (if more than one the chart escalates towards red).

CHILD	COLOUR	MORE INFORMATION
Child with highly complex needs – e.g., ventilation, tracheostomy.	R	This training will usually be led by a Community Children’s Nurse (CCN) or a specialist nurse. It is essential that advice is sought from the lead health professional.
Child with severe spectrum of their chronic illness – e.g. epilepsy, asthma.	R	
Child with poor control or management of their disorder – e.g. poor control of diabetes.	R	
Child with multiple health issues.	R	
*Child who is highly vulnerable – subject to a protection plan, poor compliance / engagement from child +/-families.	R	
Child with nursing needs – e.g., gastrostomy, oxygen dependent.	A	This training will be provided by a CCN, school nurse, other specialist practitioner or a specific resource – training tool, reps / charity leads. This child may have a community nurse but maybe managed by the community team – GP / School nurse e.g. anaphylaxis / allergies. This child will have a specific care plan.
Child with a chronic condition requiring regular review / intervention – e.g., diabetes, epilepsy (with prescribed emergency medication), cystic fibrosis.	A	
Child requiring life saving intervention rarely – e.g., anaphylaxis.	A	
Child with significant additional needs – e.g., communication, eating/ drinking etc.	A	
Child with an illness managed by parents / GP – e.g., controlled asthma, allergy, infection, epilepsy with <u>no</u> prescribed emergency medication.	G	
Child who requires assistance – e.g., personal care, lifting handling.	G	This child will usually be managed in primary care. The school will be responsible for most systems relating to this type of issue e.g. first aid training / management of lifting and handling. Risk Assessment to be undertaken by the school.
*Expert patient – independent child (usually teenager) who undertakes own care needs with minimal assistant.	G	
		*Advice should be sought to agree competency for this group of ‘expert’ children.

Proceed to Stage 2 

STAGE 2 – INTERVENTION – colour code the skill required.

CHILD	COLOUR	MORE INFORMATION
Specialist skills – ventilation, tracheostomy, mitroffanoff.	R	Module based training led by specialist or CCN. Individual competency / confidence checking – can take months to complete.
Nursing Intervention – medication via naso-gastric tube, gastrostomy care, suction, injections, catheterisation, oxygen, blood sugars.	R	Training programme with individual competency / confidence checking – can take from one day – weeks. Variety of training methods relevant for each skill / situation.
Emergency care – rectal medication, Anaphylaxis, Buccal Midazolam, Nebulisers.	A	Group based sessions usually led by school nurse. In most cases not appropriate to competency assess.
Regular use, low intervention or over the counter medication – inhalers, paracetamol, antibiotics.	G	One to one or group base can be led by school or advice sought from school nurse.
Basic care needs – personal care, first aid, lifting and handling.	G	Led by school, safer working policies should be in place.
Specialist skills / chronic illness but individual does not require competency but an awareness of how best to support designated carers -cystic fibrosis, diabetes, asthma.	G	Could be led by a number of professionals and will range from information sheets to direct training depends on individual case and advice should be sought from lead health professional – school nurse or CCN.

STAGE 3 – Use the chart below to find an overall colour guide from stage 1 and 2

		INTERVENTION		
		RED	AMBER	GREEN
CHILD	RED	R	R	A
	AMBER	R	A	G
	GREEN	A	A	G

COLOUR	ADVICE – remember cases are individual if in doubt ask a health professional
R	<p>Speak to the child's health lead as an individualised training package needs to be set up. There should be</p> <ul style="list-style-type: none"> Consent form with parental agreement to share relevant information across health and education. Individual Care Plan
A	<p>Seek advice from the school nurse to advise on the type of training required.</p> <ul style="list-style-type: none"> Consent form appropriate if accessing care from the hospital (Consultant or CCN) Individual Care Plan
G	Most cases managed in school with advice from school nurse as necessary.

3.3 Training, skills and competency

- 3.3.1 It should be noted that a trainer who has not witnessed a trainee fulfilling a task cannot sign them as competent unless they are actually performing the procedure in real time. In some cases it may be sufficient to acknowledge that training has been provided for a Designated Care Worker that would enable them to carry out a procedure; this can only be agreed by a Health professional or nominated professional for specific tasks. Competencies, in general, are specific and agreed for a named child only and should not be commuted to another child without Health Professional approval.
- 3.3.2 Specific training is given in respect of a named child and is not transferable. General training can be applied where appropriate and stated in a Health Care Plan.
- 3.3.3 A copy of the completed training record which has been signed off by a the Health Professional should be held by:
- the care worker;
 - the employing agency;
 - the trainer;
 - and within the child's Health Care Plan.
- 3.3.4 The Designated Care Worker has a duty to complete and maintain appropriate records in the interests of safeguarding a child for whom they are attached and responsible. Employers have a responsibility to ensure that these duties are carried out and that employees are appropriately trained and remain competent and confident to continue working with a named child.

3.4 Record of Training

- 3.4.1 Records should be kept by each agency of all staff who received training, the date on which this has been received and the content.
- 3.4.2 A record of training, instruction or the provision of essential advice given to staff involved in the management of medical conditions in children should be maintained. These records should detail the training instruction or advice provided, the extent of the information given, an opinion from the provider on whether or not the recipient has fully understood the issues and any subsequent action required.
- 3.4.3 The model form below identifies specific content as recommended by the DCSB. This is more comprehensive than the suggestion in the document, 'Managing Medicines in Schools and Early Years Settings', and covers safeguarding procedures learned from serious case audits in Dorset. It must be remembered to include the additional information on any document to address this purpose.

3.4 Record of Training Form

Chart E

Staff training record to support the medical needs of a child or young person.

Name of School/Setting:

Name:

Details of training provided:

Date of training completed: --

Training provided by:.....

Profession and title of trainer:.....

I confirm that.....[name of member of staff]:

has received training detailed above and has the skill set to carry out any necessary medical intervention

has received a group session covering the training as detailed above

I recommend that the training is updated (please state how often)

Trainer's signature:

Date: --

I confirm that I have received and understand the training detailed above.

Staff signature:

Date: --

Suggested Review Date: --

Copies of this record go to:.....

.....

Education, Care & Training

Glossary

CAMHS	Child and Adolescent Mental Health Services
Care Pathway	<p>Clinical / Care pathways are used to systematically plan and follow up a patient focused care program.</p> <p>They may include an explicit statement of the goals and key elements of care based on evidence, best practice, and patient expectations. They are used to facilitate communication, the coordination of roles, and the sequencing of the activities of the multidisciplinary care team, patients and their relatives.</p>
Child	Refers to a child or young person up to the age of 18 years of age or young person for whom Children's Services and/or Health Services are provided; those with Statements of Special Educational Needs will be supported to the age of 19 years old. Young people in transition may require support of Adult Nursing Teams.
Children in Care	Children looked after by the Local Authority, usually in a foster placement or residential home, by voluntary agreement with parents or by virtue of a Court order, where the Local Authority shares parental responsibility with the parents and has day to day responsibility for the child's welfare and safety.
CCN	Children's Community Nurse
Children's Nurse	Refers to Registered Sick Children's Nurse or Registered Nurse (child branch), Registered General Nurse.
Concordance	An agreement reached after discussion between the patient and others that takes into account the patient's beliefs and wishes in determining whether, when and how treatment is to be taken. Patients become participants in, rather than just recipients of, their Health Care.
Continuing care needs	When a child or young person has needs arising from disability, accident or illness that cannot be met by existing universal or specialist services alone.
DCC	Dorset County Council
DCHFT	Dorset County Hospital Foundation Trust
DNA (or WNB)	Abbreviation for 'Did Not Attend' and is associated with Out patient appointments. This term may migrate to 'Was Not Brought' (WDB) over time. Both abbreviations may be used.
DSCB	Dorset Safeguarding Children Board
Employing Agency	Refers to the body that hold responsibility for the care worker delivering the care.
Employee working in the role of a care worker	A non-health professional who has been trained to undertake tasks or procedures for a child with continuing care needs. They may be employed by any of the statutory agencies.
ESWAS	Education Social Work and Attendance Service

Young people under 16 have a right to confidential medical advice and treatment if the provider assesses that the young person:

- understands the advice and has the maturity to understand what is involved this includes;
- what the treatment will involve ;
- what the implications of not having the treatment are ;
- what alternatives may be available ;
- what the practical effects on their lives of having, or not having, the treatment will be;
- their physical/mental health will suffer if they do not have treatment;
- It is in their best interest to give such advice and treatment without parental consent;
- will continue to put themselves at risk of harm if they do not have advice and treatment;
- cannot be persuaded by the doctor or health professional to inform parental responsibility holders, nor allow the doctor to inform them (they understand the consequence in terms of emotional support of not informing parents/ carers).

Fraser Guidelines

These guidelines are assessing the young person's capacity to consent. To have capacity to consent they must be able to comprehend and retain information material to the decision, especially as to the consequences of having or not having the intervention in question, and must be able to use and weigh this information in the decision making process.

GP	General Practitioner or Family Doctor
GPwSI	General Practitioner with Special Interest
Health Care Professional	Refers to a Health Care worker who is registered with a statutory body and has professional accountability – e.g. Nurse, Speech Therapist, OT, Physiotherapist
Health Care Plan	A plan which sets out the child's health needs and the care required to meet those needs. The plan will be part of the child's overall support plan.
HV	Health Visitor
Intervention (defined)	A prescribed procedure delivered as part of a Health Care Plan which is within the skill and scope of a designated carer.
Lead Professional	A named professional who coordinates the Health Care Plan and the child and Family Support Plan. The Lead professional is not necessarily a Health Service professional.
OPA	Out Patient Appointment
OT	Occupational Therapist (Health)
Parent/Carer	Refers to the child's main carer. This may be a parent, guardian, grand parent or foster carer. Parents, as defined in section 576 of the Education Act 1996 include any person who is not a parent of a child but has parental responsibility for or care of a child. In this context, the phrase 'care of the child' includes any person who is involved in the full-time care of a child on a settled basis, such as a foster parent, but excludes baby sitter, child minders, nannies and school staff.

Permitted Tasks	The Royal College of Nursing (RCN) advice identifies tasks which it recommends should not be carried out by non health professionals.
Qualified trainer	A professional with a skill set to undertake training. This person will usually be a Children's Community Nurse, Specialist Nurse or School Nurse and may also be designated as the Child's named nurse, or other identified professional.
School Nurse	Registered nurse either employed as a Young Peoples Health Professional or as a Public Health Practitioner
TCI	Abbreviation indicating 'To Come In'
Transport	<p>Drivers and when appropriate Passenger Assistants (PA) convey children to and from a designated place of learning. Medical intervention where required will be supported with a Risk Assessment Plan and Health Care Plan which will be carried on journeys with a child in identified as have a significant life threatening condition.</p> <p>All Dorset Passenger Transport (DPT) driver are trained in First Aid (one day course)</p>
Transition	<p>The planned move of adolescents with long term conditions from child-centred to adult orientated health care.</p> <p>This includes, but is not limited to transfer which is the successful handover of care to adult services.</p>

Further Reading and Useful Documents

Managing medicines in schools and early years settings

Department for Education and Skills / Department of Health (March 2005)

www.teachernet.gov.uk/publications

Search using ref: 1448-2005DCL-EN

Includes: Useful templates
 Legal framework

The NHS Confidentiality Code of Practice

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4069253

NHS Records Management Code of Practice

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_41317487

National Framework for Children and Young People's Continuing Care

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_1147844

(This document provides useful reference for when a child or young person has needs arising from disability, accident or illness that cannot be met by existing universal or specialist services alone.)

Care Pathway exemplars

National Service Framework for Children, Young People and Maternity Service- Type I diabetes in childhood and adolescence (July 2010) www.diabetes.nhs.uk/news.php?o=245

National Service Framework for Children, Young People and Maternity Service – Continence issues for a child with learning difficulties (Sept 2010) www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_119304

Working together to Safeguard Children

<http://www.education.gov.uk/publications/standard/publicationdetail/page1/DCSF-00305-2010>

Appendix 1

Health Questionnaire for all new children starting at this school or where there is a change in medical circumstance

Health Questionnaire for all new children starting at this school or where there is a change in medical circumstance.

Child's Surname:
 Date of Birth:
 Lives with (name):
 Address:
 Address (if different to above):

In an emergency please contact:

1st Contact Name:
 Relationship to child:

2nd Contact Name:
 Relationship to child:

GP Name:

First Name:
 Relationship to child:
 Tel (home):
 Tel (mobile):
 Tel (work):
 email:
 Parent / Guardian name(s):
 Tel (home):
 Tel (mobile):
 Tel (work):
 email:
 Tel (home):
 Tel (mobile):
 Tel (work):
 email:
 GP Address:

Professionals that may be known to your child:

	Name	Contact Details
Health Visitor		
School Nurse		
Hospital Consultants		
Psychologist		
Social Worker		
Community Nurse		
Physiotherapist		
Speech therapist		
Occupational therapist		
Portage worker		
Other (please specify)		

Click to access these documents

Please could you answer all of the questions below, if you answer yes to any of them please give details in the space underneath:

1. Have you ever been told that your child has an illness, any allergies or any medical condition that we should be aware of?
 Details: Yes/No

2. Does your child take any medicines or tablets regularly?
 Details: Yes/No

3. Does your child require a special diet?
 Details: Yes/No

4. Does your child need any help with personal care i.e. feeding, dressing, toileting?
 Details: Yes/No

5. Does your child use any special equipment in their day, e.g. wheelchair, splints, hand rails, walking frames, protective helmet, etc.
 Details: Yes/No

Form completed by (print name) Date:

Signature:

Please photocopy and provide to School Nurse.

Appendix 2

Specimen Letter to Parent/Guardian – Sharing Information

To Parents /Guardians,

To help us to provide the best care for your child it may be necessary for us to visit them in settings away from home i.e. nursery or school, and to share and discuss their information with other people. These may be staff looking after them in playgroup and/or nursery and will include the Health Visitor. With older children this might include teachers, assistants, first aiders, lunchtime supervisors and will also include the school nurse.

Where necessary we will provide training to these members of staff so that they can care for your child, recognising and managing any health related problems should they occur.

We would always endeavour to inform parents/guardians of any training sessions/visits to school and you can, if you wish, have the names of those people that have been given training.

If you are happy for us to share your child's details in this way, please sign below:

Signature:
 Print Name:
 Relationship to child:

If you have any concerns, or do not wish your child's information to be shared please discuss with your Specialist Nurse/CCN.

Click to access these documents

Appendix 2 Example 1

Guidance for the Management of Paediatric Patients Referred as Emergencies to the Children's Ward but who Do Not Attend (DNA)

Initial referral (e.g., via General practitioner, GP)

Record details of:

- The caller i.e. name, designation & contact telephone number
- The child i.e. name; age or date of birth (DOB); address or contact tel no
- The reason for referral & the child's clinical condition

These details will inform the risk assessment and help you in the future management should the child not attend as expected.

If the referral comes via bed bureau they should have recorded details of the referrer and demographic details for the child.

Patient does not attend



The length of time you wait before progressing to the next stage will depend upon the level of concern and the original reason for referral.

Is there a CPO flag?

Ward clerk or senior nurse checks PAS to determine whether the child has a CPO flag

(which indicates that the child protection office i.e. CPO holds additional information regarding the child/ siblings. It does not necessarily mean that the child is the subject of a child protection plan).

Ward clerk/nurse informs the specialist registrar (SpR)/consultant of the outcome of this check.

Nurse/Doctor contact CPO (ext 4748) to ascertain further details to inform the risk assessment.

(This may not be possible out of hours, though if there are immediate significant concerns some records may be accessed by requesting access to the children's centre via the porters)



Contact the family

Dr / senior nurse agree who will contact the family to ascertain the reason for non attendance.

If concerns remain that the child needs to be seen:

- Arrange for the child to attend either Kingfisher; the nearest Minor Injuries Unit (MIU) or the out of hours GP service.
- Contact MIU/GP to inform them of the plan and ask that they inform you of the outcome (i.e. the child's attendance/further non attendance)
- Record your actions/telephone discussions

Patient still does not attend or family cannot be contacted



Consider

- Contacting the GP/Health Visitor (HV) to arrange a home visit (at the most suitable / appropriate time)
- Contacting Children's Social Care to discuss concerns & formulate a further plan of action
- Contacting the Police to check upon the safety of the child

Your decision will be informed by your previous risk assessment/level of concern regarding the child's safety.

Record all decisions

Appendix 2 Example 2

Guidance for the Management of Paediatric Patients who Do Not Attend (DNA) for their Outpatient Appointment

This applies to both new and follow up appointments.

1. If the patient DNAs their outpatient appointment the usual administrative checks of demographic details will be undertaken.
2. When confident that demographic details are correct, the hospital will contact the patient / carer advising them that they have missed an appointment. A copy of this letter will be sent to the GP.
3. Clinicians will be made aware of any patient who DNAs and will make a clinical judgement about whether to:
 - a) rebook the patient/send for again (PSFA);
 - b) issue the standard Trust DNA letter (and discharge unless patient/carer rings);
 - c) dictate an individual letter to GP/HV/Carer (to highlight concerns and send for again). This letter may include a request for further information e.g. exploration of the family circumstances to determine why the child is not being brought to clinic;
 - d) dictate an individual letter to GP/HV/Carer (to offer management advice and discharge);
 - e) convene a multidisciplinary planning meeting to share appropriate information and consider how best to meet the child's Health Care needs.

The clinician should record (where appropriate) their rationale for their decision by completing both sides of the paediatric outpatient data form and signing the form.

4. This form is then filed within the patient's hospital notes for reference.
5. All Paediatric DNAs must be discussed with the consultant.

PATIENT/CARER CANCELLATIONS

1. Patients/carers who ring in to change the date or time of their first appointment will be offered a new appointment.
2. The Trust will notify the named consultant and GP of patients/carers who ring in to cancel & not rebook their appointment.
3. The clinician and GP should be notified of any patient/carer who cancels and re-books their / their child's outpatient appointment more than twice consecutively.
4. In the event of points 2 or 3 above the clinician should review the child's hospital notes and consider whether to:
 - a) accept the cancellation / rebooking made by the patient / carer;
 - b) dictate an individual letter to GP/ HV / Carer (to highlight concerns + send for again) ;
 - c) dictate an individual letter to GP / HV /Carer (to offer management advice + discharge);
 - d) convene a multidisciplinary planning meeting to share appropriate information and consider how best to meet the child's health care needs.
5. The clinician should record their rationale for their decision.

Appendix 2 Example 3

Outpatient Data Form: Paediatric

Dorset County Hospital **NHS**
NHS Foundation Trust

(NB. Print double-sided)

Clinic - location/date/time:	PAS PATIENT LABEL
Time seen:	

Circle one code only	TREATMENT PLAN DECIDED (Patient's 18 week 'Referral to Treatment' clock has stopped).
02	First definitive treatment started today
03	Start of watchful wait period where treatment is not clinically appropriate at this stage and no treatment has been given
04	This appointment is part of planned programme of treatment/intervention/surveillance (i.e. patients undergoing procedures at pre-defined intervals).
05	Patient discharged completely
06	Patient DNA d/Cancelled
07	NEW DECISION TO TREAT/TREATMENT NOT YET GIVEN / TREATMENT PLAN NOT YET DECIDED (Patient's 18 week 'Referral to Treatment' clock continues) No treatment plan yet agreed.
08	Tests, assessments, results or further discussion with other clinicians, or the patient, before treatment can start.
09	Referred on to another health professional for the same condition, inter departmental, or a tertiary referral. This could either be within the same department, inter departmental, or via Booked Admissions. (Not for patients who are undergoing procedures at pre-defined intervals (see 04))
009	Added to a waiting list for a definitive procedure, which will be performed within a treatment clinic / OPD

DNA Instructions:

Please send for again (PSFA)	
Issue standard DNA letter (discharge unless patient/carer rings)	
Individual letter to GP/HV/Carer (to highlight concerns and send for again)	
Individual letter to GP/HV/Carer (to offer management advice and discharge)	
REASONS: (optional)	

PLEASE COMPLETE THE FORM OVERLEAF AND FILE IN THE PATIENT'S NOTES

Click to access these documents

OPA Instructions:		DISCHARGED	
In: weeks/months	Location:	Additional Information:	No OPA required
Patient Seen By:			
Consultant		Senior House officer	
Associate Specialist/Staff grade		GP Trainee	
Clinical Assistant/GPwSI		Allied Health Professional	
Specialist Registrar		Nurse practitioner/Specialist	

DNA Paediatric Appointment

View reason for referral / follow up:

	Yes	No
Is there a problem which needs Paediatric assessment and management?		
Do you need to give carer/GP/HV/school nurse/other professional any advice?		
Are there any social issues of relevance?		
Are there any chronic health problems?		
Are there any safeguarding issues?		
Do you have any more information before I can discharge this child/young person?		
Would a multi-agency strategy discussion/meeting be helpful?		

Answered yes to any of the above questions, discharge with the standard DNA letter appropriate. The rationale for your action should be clear from the documentation in the patient's notes.

If answered no, the issue should be discussed with the consultant.

A Strategy Discussion/Meeting should be convened for children with long term health conditions/safeguarding issues, who repeatedly DNA appointments, as other professionals also have concerns of which you are unaware. Repeated non-attendance at health appointments may be a sign of neglect or an indication of need for family support.

Printed by: Date:

PLEASE ENSURE THAT THIS FORM IS FILED IN THE CORRESPONDENCE SECTION OF THE PATIENT'S NOTES

Appendix 3

Transition for young people with Long Term Health Conditions.

Definition:

Transition is the planned move of adolescents with long term conditions from child-centred to adult orientated health care. This includes, but is not limited to, transfer which is the successful handover of care to adult services.

Key Principles:

1. Young people with long term health conditions have a right to a managed transition process when moving from paediatric to adult care.
2. Transition is a process, not an event.
3. Transition should address the medical, psychosocial and educational/vocational needs of the young person.
4. Transition should not compromise the young person's current care or treatment options.
5. Transition begins in paediatric services, but adult services are responsible for its successful completion. Paediatric services should retain primary responsibility for treatment until a clearly defined moment of transfer to adult services takes place.
6. Transition works best when coordinated and overseen by a named key worker, usually the paediatric consultant or specialist nurse.
7. Transition should be provided by multidisciplinary teams of paediatric and adult health professionals working together.
8. The young person (and their parent(s)/carer(s) should the young person wish) should be involved or represented in planning their transition. Each young person should have an individual transition plan that is reviewed on an annual basis.
9. Hospitals should have a transition policy covering all conditions.
10. The hospital should aim continually to review and improve its transition service for the benefit of young people, their families and the hospital staff.

Timing:

Factors to be taken into consideration when determining the onset of transitional care and subsequent transfer to adult services:

- Child and Adult services currently available;
- disease treatment and compliance with therapy;
- stability of the condition and current complications – where possible transfer should occur during remission or comparative stability of symptoms;
- duration of condition;
- sources and quality of the young person's support – from family, professionals and their peers;
- the young person's physical, cognitive and psychological maturity;
- the young person's emotional, relationship and communication skills.

Process at DCHFT:

1. The key worker for young people with a long term health condition will, in most cases, be the Consultant Paediatrician with a special interest in that area. In some cases it may be deemed more appropriate for the key worker to be the specialist nurse in the long term condition. The key worker will be agreed and named on the young person's individual transition Care Plan.

- Transition will incorporate the following stages: (The age ranges given below are a guide only and will vary according to the developmental stage of the young person.)

Early stage (12 – 14 yrs) - usually initiated by the paediatric team. Aims:

- Introduce the concept of transition to the young person and family;
- Discuss the need for the young person to develop their autonomy at the same time as being supported by their family;
- Discuss the young person's awareness of their health care needs;
- Assess the young person's level of understanding;
- Provide information and education about services available;
- Gradually introduce the concept of seeing the health professional on their own;
- Consider introductions to the specialist nurse in adult services (where available).

Middle stage (14-15yrs) Aims:

- Help the young person and their family to further understand the transition process and the services provided by the adult team;
- Support the young person in practising the skills required for transfer;
- Young person to begin to set goals for participating in their own care;
- Young person demonstrates increasing degree of autonomy;
- Introduce to specialist nurse for adult services (if not already done so).

Late stage (15-17yrs) Aims:

- The young person and their family feel confident about leaving the paediatric system;
- Young person has a considerable degree of autonomy over their own care;
- Young person to attend a joint adult and paediatric clinic for 1-2 appointments prior to formal transfer of care to the adult team.

- Key worker to commence the Transition Care Plan & Checklist and update this at each stage of the transition process.
- Transfer of care to the adult team will usually be between the ages of 16 – 18 depending upon the needs of the young person.

Quality Assurance:

The transition process, along with the specialist service in general, will be monitored and evaluated by means of:

- audit (National and local)
- patient/carer satisfaction surveys
- feedback from the paediatric and adult teams.

Useful resources for young people:

www.ibdtransition.org.uk

What to expect from your doctor/hospital during transition

www.teenagehealthfreak.org

Health information for teenagers

www.cicra.org

Crohn's in Childhood Research Association

www.nacc.org.uk

National Association for Colitis and Crohn's Disease

References:

www.ibdtransition.org.uk Transition guidelines from CICRA and NACC, endorsed by BSPGHAN with separate leaflets for health professionals, patients and parents.

www.rcn.org.uk/_data/assets/pdf_file/0011/78617/002313.pdf Adolescent transition care. Guidance for nursing staff. Royal College of Nursing.

Appendix 4

Model Forms for the Management of Medicines in Schools and Early Years Settings

Target group: ALL children and young people in maintained schools, independent schools, Pre-school and Early Years settings, Academies and Colleges.

This appendix contains examples of FORMS as recommended in the document 'Managing medicines in schools and year years setting' that should be used to record, monitor and log the activities in supporting a child's medical needs.

Form 1	Emergency planning - request for an ambulance
Form 2	Healthcare Plan
Form 3A	Parental agreement for school/setting to administer medicines
Form 3B	Parental agreement for school/setting to administer medicines
Form 4	Head teacher/Head of setting agreement to administer medication
Form 5	Record of medicine administered to an individual
Form 6	Record of medicines administered to all children
Form 7	Request for child to carry his/her own medicine
Form 8	Example of Health Care Plan (See Chart D, page 18)
Form 9	Authorisation for administration of rectal diazepam



All forms set out below are examples that schools and settings may wish to use or adapt according to their particular policies on administering medicines.

Versions of these forms are available from <http://www.teachernet.gov.uk/m>

Appendix 5

Example of a Care pathway for a young person with a long term health condition and poor concordance

Please note that all characters appearing in this example are entirely fictitious. Any resemblance to real persons is unintentional and coincidental.

Key issues	Journey	Children's NSF theme	Evidence / links
First seizure (fit)	<p>Home: Alice has her first generalised tonic-clonic seizure at the age of 14 years. The seizure lasts 3 minutes. Her mother is very frightened by the event and calls 999.</p> <p>Ambulance service: The ambulance arrives, by which time the seizure has stopped and Alice is sleeping. The ambulance crew take Alice and her mother to the Emergency Department at their local hospital.</p> <p>Emergency Department (ED): Alice is assessed in the ED. A history of the event is taken from mother. Alice was previously well; she lives with her mother Jane and 10 year old brother Ben. Alice's mother and father, Paul, divorced 4 years ago. Alice has contact with her father. There is no family history of epilepsy. Alice is becoming more awake and is able to answer some questions herself but cannot recall anything about the seizure. Alice is examined and no abnormal signs are found. The doctor decides to perform some baseline blood tests after gaining verbal consent from Alice and Jane. The doctor refers Alice to the paediatric team for further assessment and a period of observation as this was Alice's first seizure.</p> <p>Paediatric ward: The paediatrician makes a further assessment and gains additional history. Alice had a normal birth and has no significant past medical history. She is making good progress at school. Jane has a past medical history of depression; she is not currently taking any medication. Alice and Jane are given an explanation regarding the management of children / young people who have had a single seizure. Alice's blood test results are normal, as is an ECG (heart rate & rhythm recording). After a period of observation Alice is declared fit for discharge home. The nurse looking after Alice provides Jane with a leaflet to remind her about what to do should Alice have another seizure. A copy of the discharge summary is given to Jane; further copies are sent to Alice's GP and the school nurse. A copy is also sent to Alice's father, Paul, (in discussion with Jane). An outpatient's appointment is made for Alice to see the consultant paediatrician soon in clinic to ascertain whether Alice has had further seizures and determine the need for further investigation or treatment.</p> <p>School: Jane informs Alice's tutor of Alice's seizure and the advice they have been given from the hospital. The tutor encourages Jane to update the health questionnaire for school. The tutor liaises with the school nurse and the school health records are updated. School carries out a risk assessment in terms of Alice's epilepsy.</p>	NSF core standard 3 Child, Young Person and Family Centred Services	<p>NICE guidance CG20</p> <p>The epilepsies: the diagnosis and management of the epilepsies in adults and children in primary and secondary care. www.nice.org.uk</p> <p>The quick reference guide for epilepsy in children and young people can be found at: http://www.nice.org.uk/lnicemedia/live/10954/29530/29530.pdf</p>

Key issues	Journey	Children's NSF theme	Evidence / links
<p>First outpatient appointment (OPA)</p>	<p>Alice attends the clinic with her mother. Jane reports that Alice has not had any further generalised tonic-clonic seizures but mentions that, a few times in the morning, Alice has experienced sudden jerks of her arms. Jane has looked on the internet and is also concerned regarding possible absence seizures as there are times when Alice appears to be staring or ignoring her. Jane also tells the paediatrician that Alice's tutor had mentioned that Alice has recently been noticed to daydream in class –she wondered whether this was connected with her medical condition. The consultant paediatrician explains that she thinks Alice has a type of epilepsy called Juvenile Myoclonic Epilepsy (JME) and that an EEG (a recording of brainwave patterns) can be helpful in making the diagnosis in some types of epilepsy. Alice & Jane agree to Alice having this test. The paediatrician discusses treatment for JME and after considering this Alice says she would like to wait until the results of the EEG come back, if the EEG is going to be performed soon. The paediatrician reminds Alice & Jane of basic safety precautions they can take whilst waiting for formal diagnosis and treatment. She explains that it would be helpful to seek some further information from Alice's tutor regarding her progress at school and the 'blank spells' that have been noticed there. Consent is gained for this liaison and also for the sharing of copies of the clinic letter with school health. Jane has signed the Hospital Trust's consent form stating that she would like to receive a copy of the clinic letter. The paediatrician asks Alice if she would like her own copy and ascertains that Alice's father, Paul, has also expressed a wish to receive a copy of the clinic letter. Follow up in the paediatric clinic is arranged.</p>	<p>NSF core standard 4 Respecting and Involving Young People in their Care</p>	
<p>Diagnosis of a long term health condition</p>	<p>Paediatrician: The paediatrician receives the results of the EEG which confirms that Alice has JME. She has also received a letter from Alice's tutor outlining concerns that Alice does appear to be having blank spells at school which are starting to impact upon her work. She arranges to bring forward Alice's OPA to discuss the results and start appropriate medication. Alice attends with both her parents. They are pleased that the paediatrician has asked to meet with them as, the previous day, Alice had a generalised tonic-clonic seizure lasting 6 minutes. They called an ambulance but as Alice recovered fairly quickly whilst the paramedic was in attendance and they were due to see the paediatrician they did not come to hospital. As well as being given general information regarding epilepsy, its treatment (including potential side-effects) & lifestyle choices they are informed that most people with JME need to take medication for life as it is common for seizures to return if the medication is withdrawn. The paediatrician commences Alice on regular anticonvulsant medication as well as prescribing buccal midazolam for use should Alice have a seizure lasting more than 5 minutes. Alice is advised that seizures are more likely to happen if a person does not get enough sleep so it is advisable for people with this type of epilepsy to maintain regular sleeping habits.</p>	<p>NSF core standard 2 Supporting parents of teenage children NSF standard 6 Children with Long Term Conditions NSF standard 10 Access to safe and effective medicines that are prescribed on the basis of the best available evidence</p>	<p>BNF for Children, 2011 www.bnfc.org Epilepsy Action www.epilepsy.org.uk Contact a Family www.cafamily.org.uk www.teenagehealthfreak.org</p>

Key issues	Journey	Children's NSF theme	Evidence / links
<p>Diagnosis of a long term health condition</p> <p>Cont.</p>	<p>She is also asked whether she drinks alcohol as seizures may occur if a person with JME drinks too much alcohol. Alice denies drinking alcohol. The small risk of sudden unexpected death in epilepsy (SUDEP) is discussed sensitively as well as ways in which one can reduce further this small risk. The paediatrician also discusses the need to balance safety precautions with maintaining as normal a life as possible for Alice and the family. The family are given information about helpful websites and details of support groups should they wish to make contact. The paediatrician also provides the family with the contact details of the health team should they wish to talk to a health professional between clinic appointments. The paediatrician records the assessment and discussion in Alice's medical records. Copies of the clinic letter are distributed as previously.</p> <p>School Health: The school nurse arranges to see Alice, with consent from Jane, who attends the first appointment with Alice. The school health information form is completed and consent for information sharing (as appropriate) is gained. Alice is stepping up her medication towards the treatment dose as explained to her by the paediatrician. She has not noticed any side effects and feels the jerks and absences have reduced in frequency. Her tutors confirm that Alice's concentration has improved. The school nurse arranges training for staff (as relevant) regarding epilepsy and its management in school. A health care plan is agreed for Alice.</p>		<p>Medical conditions at school: A policy resource pack www.medicalconditionsatschool.org.uk</p>
<p>Follow up in the outpatients department</p>	<p>Alice attends the clinic with her mother. Alice's seizures are reported to be well controlled on her medication. Alice takes responsibility for her own medication, though Jane checks with Alice that she has taken it. During the time that Alice is seen alone, she expresses some concern that her mother does not let her engage in some activities that she previously enjoyed such as cycling and swimming. The paediatrician explores these issues further with Alice & Jane and explains that young people with epilepsy can continue most sports/ leisure activities with sensible precautions in place.</p>		<p>http://www.epilepsy.org.uk/young-people/sport-leisure</p>

Key issues	Journey	Children's NSF theme	Evidence / links
<p>Failure to attend subsequent OPA x2</p>	<p>Paediatrician: Following the first failure to attend the OPA, the paediatrician arranges for a further appointment to be sent to Alice. The Did Not Attend (DNA) record form is completed, as per the hospital DNA policy, and filed in Alice's medical record.</p> <p>Following the second non-attendance the paediatrician:</p> <ul style="list-style-type: none"> · Writes to Alice's parents, her GP and school health to inform of & ascertain any known reason for the failure to attend (including whether there has been any change of address of which the hospital were unaware). She also requests any further information, where known, from colleagues in terms of Alice's health & school progress · Completes the DNA form <p>GP: The GP checks his records for Alice and the family members registered at his practice. He notes that Alice's last repeat prescription has not been collected and informs the paediatrician. The primary care records for Alice are flagged to alert the team regarding collection of prescriptions and to monitor outpatient attendances. The GP liaises with pharmacy to monitor collection of medication.</p> <p>School: Alice's tutor informs the school nurse of concerns that Alice is having more absence seizures, alongside which there has been a deterioration in her concentration and behaviour.</p> <p>School Nurse: Liaises with Alice's tutor and Head of Year. A referral to the educational psychologist is being considered. The school nurse arranges to see Alice in school & updates the paediatrician with the new information ascertained. Alice has admitted to not taking her medication and staying out late with friends; Alice is also worried regarding her mother's health.</p> <p>The school nurse, in discussion with the paediatrician, arranges a Health Care Planning meeting within school. She invites Alice, her parents, the paediatrician, GP and Alice's tutor.</p>		

Key issues	Journey	Children's NSF theme	Evidence / links
<p>Team Around the Child (TAC) meeting</p>	<p>Following the Health Care Planning meeting there is an initial period where clinic appointments are kept, Alice's concordance with taking her medication improve and her education progresses well</p> <p>Multi-Agency: After several months however, Alice fails to attend 2 further consecutive clinic appointments with the paediatrician. In liaison with the school nurse, the paediatrician ascertains that Alice's attendance at school has also been raised as a concern by the Head of Year. The paediatrician has been unable to make telephone contact with Jane- she therefore decides to arrange a Team Around the Child Meeting, having explained in a letter to parents her reasons for doing so and making clear the expected benefits to Alice & the family of such a meeting. She sends a letter of invitation to Alice and her parents, the GP, school nurse, Alice's tutor / Head of Year and to the Assessment Team in Children's Social Care (including an inter-agency referral form with the invitation for Children's Social Care). A lead professional is agreed and a Common Assessment Framework (CAF) is commenced.</p> <p>School: A child protection file is opened within school. Children's Social Care are aware of this as a social worker attended the TAC meeting.</p>	<p>NSF standard 6 Co-ordination of health, social care and education services to meet individual needs</p>	<p>Services that are integrated- Common Assessment Framework (CAF) http://www.dcsf.gov.uk/everychildmatters/strategy/delivering-services/caf/cafframework</p> <p>NICE guidance: CG89 When to suspect child maltreatment: full guideline (p76) http://www.nice.org.uk/nicemedialive/12183/44954/44954.pdf</p> <p>Quick reference guide (p12): http://www.nice.org.uk/nicemedialive/12183/44872/44872.pdf</p>



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