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# Chronic Fatigue Syndrome/ Myalgic Encephalopathy (CFS/ME)

*Change for Children - Every Child Matters*

<b>Policy</b>	Estates
HR/Workforce	Performance
Management	IM & T
Planning	Finance
Clinical	Partnership Working

**Document Purpose** Best Practice Guidance

**ROCR ref:** **Gateway ref:** [3779](#)

**Title** [Chronic Fatigue Syndrome/Myalgic Encephalopathy \(CFS/ME\), National Service Framework for Children. Young People and Maternity Services](#)

**Author** DH

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**Target audience** [PCT CEs, NHS Trusts CEs, SHA CEs, PCT PEC Chairs, Special HA CEs, GPs, SHA Children's Leads, NHS Trusts Children's Leads, A&E Departments, Ambulance Trusts, Children's Hospices CEs, Local Authorities, Other Government Departments](#)

**Circulation list**

**Description** [This is the Primary Care Version of the National Service Framework for Children, Young People and Maternity Services.](#)

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## Introduction

The National Service Framework (NSF) for Children and Maternity Services will be published alongside supporting material, which includes a series of exemplar patient journeys. Whilst it is not the role of the NSF or the exemplars to provide detailed clinical discussion on individual childhood conditions or aspects of pregnancy or childbirth, exemplars illustrate some of the key themes in the NSF.

Several factors influenced the selection of exemplar conditions, for example: large numbers of children and families affected, significant cause of illness and distress, wide variability in standards of practice or service provision, and suitability for highlighting the NSF themes. Such themes include the importance of responding to the views of children and their parents, involving them in key decisions, providing early identification, diagnosis and intervention, delivering flexible, child-centred, holistic care, which is integrated between agencies and over time and is sensitive to the individual's changing needs. It is also acknowledged that not every child with the same condition will follow the same journey or have the same type or severity of condition as the one which is illustrated.

The primary audience for the exemplars is professionals from a broad range of backgrounds including education, NHS, social services and the voluntary sector (although they could also be of interest to parents and older children). The exemplars may be useful in a number of ways, for example, to:

- > Highlight further references, which relate to evidence in the NSF and elsewhere, including key clinical guidelines;
- > Stimulate local debate and assist multi-agency partners to re-evaluate the way they collaborate on, commission and deliver children's services, for this and other conditions, to the benefit children and their families;
- > Provide an aid to examining and improving local clinical & non-clinical governance;
- > Provide a multi-disciplinary training tool for staff working with children and young people to raise awareness of specific issues and stimulate discussion;
- > Canvass the views of children and families on specific children's issues (eg via focus groups), provide a non-threatening mechanism to open discussion, such as good and 'not so good' aspects of the current service, and
- > Provide a starting point or template for debate, prior to development of new local strategies for managing complex childhood conditions.

## Megan's Chronic Fatigue Syndrome/Myalgic Encephalopathy (CFS/ME)

	Journey	Children's NSF Theme	Evidence/Links
<b>Identification of Problem</b>	<ul style="list-style-type: none"> <li>&gt; Megan, aged 14 years, has a febrile illness diagnosed by her GP as likely to be a viral infection, followed by generalised fatigue. She had been off school for 2 weeks but tried returning when she felt better. However, she was unable to remain at school for the whole day, due to persisting fatigue.</li> </ul>	Standard 1 – early identification	
<b>Seeking Treatment</b>	<ul style="list-style-type: none"> <li>&gt; Megan then became unwell again with a sore throat, aching limbs, headaches, giddiness and poor sleep.</li> <li>&gt; Megan and her parents decide that it would be best to go and see the GP again. They book an appointment for the next day and her mother accompanies her to the surgery, as father is unable to come on this occasion.</li> </ul>		<i>National Standards, Local Action – Health &amp; Social Care Standards &amp; Planning Framework 2005-2008</i> Access to primary care support within 24 hours
<b>GP Visit 1 2 weeks on</b>	<ul style="list-style-type: none"> <li>&gt; The GP listens to Megan's account of her symptoms and then examines her. Based on the history and observations, the GP answers their questions, discusses possible diagnoses and suggests doing some blood tests and swabs to help reach a diagnosis. Megan and her mother agree to this. The GP also recommends balancing rest with activity to speed recovery and remaining off school for 2 more weeks.</li> <li>&gt; Her GP explains that this is probably post-viral fatigue syndrome and is unlikely to be a serious medical condition. He reassures Megan that he does not think she is malingering and that in the vast majority of cases the condition improves but will take a while.</li> <li>&gt; With Megan and her mother's consent, he writes an explanatory note to Megan's school and suggests a limited amount of school work, sent to her home, could help her to stay in touch. He asks Megan and her mother to come and see him again in 2 weeks, or earlier if required. With their agreement, he also informs the LEA Hospital &amp; Home Teaching Service of Megan's situation to ensure the LEA can make a decision about what is suitable for her at this stage. The DfES "Access" guidance expect that home teaching should be on offer after 15 working days.</li> </ul>	Standard 3 – child centred care, children and young people involved in decisions.  Standard 2 – listening and involving parents in planning care.  Standard 6 – children & young people who are ill – co-ordination of health, social care and education services to meet individual needs.	<i>Access to Education for children and young people with medical needs, DfES 2001 Ch 3; early identification &amp; intervention</i>

		Journey	Children's NSF Theme	Evidence/Links
<b>GP Visit 2</b> <b>4 weeks on</b>	√ √	<p>&gt; Two weeks later, Megan visits her GP again, accompanied by both her parents. She reports that there has been no improvement in her symptoms, with persistent head and limb pain. The test results indicate that Megan's illness is likely to have originated with an infection. Her GP recommends another 2 weeks off school, whilst balancing rest with activity and also prescribes analgesia for her pain. If Megan does not feel any better soon, referral to a paediatrician should be considered. The GP, with the family's permission, discusses Megan with the school nurse and writes to update the school and the LEA Hospital &amp; Home Teaching Service. He explains that Megan is not yet fit to attend school but LEA obligations to provide suitable education may be met by providing Megan with a small amount of teaching at her home, which must be flexible according to Megan's condition.</p>	<p>Primary Care Strategy for implementing Children's NSF</p> <p>Standard 6 – children and young people receive high quality care, appropriate to needs.</p>	<p><i>Access to Education for children and young people with medical needs, DfES 2001 3.8 &amp; 3.9 – long-term problems</i></p>
<b>GP Visit 3</b> <b>6 weeks on</b>	√ √	<p>&gt; Two weeks later, Megan and her mother report no improvement, despite doing everything the GP suggested.</p> <p>&gt; The doctor discusses potential diagnoses and mentions the possibility of CFS/ME. He recommends taking specialist advice and offers a choice of 2 paediatricians in the area. They choose the paediatrician who holds clinics in their local hospital.</p>	<p>Standard 6 – children &amp; young people receive timely, high quality, effective care as close to home as possible.</p>	<p><i>Building on the Best: choice responsiveness and equity in the NHS; Dec 2002</i></p>
<b>Paediatric Clinic Visit 1</b> <b>10 weeks on</b>	√ √	<p>&gt; Four weeks later Megan and her parents attend the paediatric clinic. Meanwhile, the GP has sent the test results and a referral letter, which gives a brief history of Megan's symptoms and his suspected diagnosis of CFS/ME.</p> <p>&gt; As Megan is a new patient, she has an hour's appointment with a paediatrician and nurse. They invite Megan to 'tell the story' of her illness and symptoms, which she relates in detail. The paediatrician also asks about similar illnesses in the family. The information is systematically recorded on a locally developed CFS/ME assessment pro-forma. He says that it is highly likely that she has CFS/ME, as she fulfils the relevant criteria.</p>	<p>Standard 3 – child centred care; the child is listened to and involved in decisions about their care. Co-ordinated care.</p>	<p><i>Evidence based guidance for the management of CFS/ME in children &amp; young people, Royal College of Paediatrics and Child Health, 2004 – family history of similar conditions.</i></p> <p><i>A Report of the CFS/ME Working Group to the Chief Medical Office; Jan 2002 Para 5.2.1</i></p> <ul style="list-style-type: none"> <li>- Exclusion tests for other conditions</li> <li>- Diagnose early to reduce disruption to normal activity &amp; education</li> </ul>

	Journey	Children's NSF Theme	Evidence/Links
<p><b>Paediatric Clinic Visit 1</b> <b>10 weeks on (cont.)</b></p> <p style="text-align: right;">v v</p>	<ul style="list-style-type: none"> <li>&gt; However, the paediatrician advises doing further tests to exclude important conditions, which may present with similar symptoms. Megan and her parents agree to the recommended tests, which are done during the same hospital visit, to avoid an extra trip.</li> <li>&gt; The nurse explains the support and package of care provided through the hospital for those with CFS/ME. The team develops a management plan, tailored to individual needs with the family. It is regularly reviewed with the health professionals.</li> <li>&gt; The nurse tells Megan and her parents that if a diagnosis of CFS/ME is indicated (based on exclusion of other conditions) recovery will be slow and steady but staff will provide support for parents in caring for Megan. The management plan will help to speed up her progress. She explains the condition, and provides written information from the Royal College of Paediatrics &amp; Child Health (RCPCH) and contact details of AYME, a specialist charity for young people with CFS/ME.</li> <li>&gt; As part of her agreed management plan, Megan will make notes on her current symptoms, as a baseline record, and then keep a daily diary of how she feels, her sleep pattern, appetite, activities, etc.</li> <li>&gt; The nurse recommends a programme of gentle activity and says these should be paced according to Megan's daily symptoms and that she should continue the analgesia already prescribed by her GP. Megan and her parents agree to this approach.</li> <li>&gt; The family are informed that, if required, the paediatric team may access the regional specialist CFS/ME team for advice. The team is multi-disciplinary and consists of specialist consultant, specialist nurse, physiotherapist, occupational therapist (OT), dietician, psychologist, child psychiatrist, social worker, teacher and links to other services.</li> </ul>	<p>Hospital Standard – reduce repeat visit, where possible.</p> <p>Standard 3 – Holistic care.</p> <p>Standard 6 – children and young people who are ill – services co-ordinated around individual needs.</p> <p>Standard 2 – supporting and empowering parents.</p> <p>Standard 7 – provision of appropriate specialist care, as required.</p>	<p><i>Young Person's Guide to CFS/ME 2004</i> <i>Royal College of Paediatrics &amp; Child Health</i> <a href="http://www.rcpch.ac.uk">www.rcpch.ac.uk</a></p> <p><i>Association of Young People with ME (AYME)</i> PO Box 605 Milton Keynes MK2 2XD Tel: Helpline 08451.232389 Tel: Admin 01908.379737 Email: <a href="mailto:info@ayme.org.uk">info@ayme.org.uk</a></p> <p>A Report of the CFS/ME working group to the CMO, Jan 2002 Para 5.2.2 - Management includes use of diary - Non-coercive approach</p> <p>Evidence based guidance for the management of CFS/ME in children &amp; young people, Royal College of Paediatrics and Child Health, 2004 diary of activity to help determine baseline level of functioning.</p>

		Journey	Children's NSF Theme	Evidence/Links
Paediatric Clinic Visit 1 10 weeks on (cont.)	√	<ul style="list-style-type: none"> <li>&gt; The paediatrician, with the family's permission, writes on behalf of Megan, to the LEA Hospital &amp; Home Teaching Service and the home school and recommends individual education arrangements, as required, until she has fully recovered, which could include home tuition.</li> <li>&gt; It is also agreed that Megan will return to the clinic in 4 weeks for review and to receive the test results.</li> </ul>		<i>Access to Education for children and young people with medical needs, DfES 2001</i>
Paediatric Clinic Visit 2 14 weeks on	√	<ul style="list-style-type: none"> <li>&gt; Four weeks later Megan and her mother return to the clinic. Megan's diary shows that she has been feeling worse, has remained bed-bound for the past week and has become intolerant of noise and light. Her limbs are painful, which has caused difficulty with some normal daily activities. The consultant reports that the blood test results have excluded some, but not all, suspected diagnoses. He discusses with Megan and her mother the test results and the best way forward. Due to Megan's poor condition, she has not been able to establish regular home tuition.</li> </ul>	Standard 3 – <ul style="list-style-type: none"> <li>- involving young people in their care.</li> <li>- information about diagnosis and about services.</li> </ul>	
Hospital Assessment 14 weeks on	√	<ul style="list-style-type: none"> <li>&gt; On the basis of Megan's story and symptom diary, the consultant suggests a brief 48 hour stay in hospital for further tests and assessments, to help provide a firmer diagnosis, by exclusion of other conditions. This would help to avoid repeated hospital day visits. Megan and her mother agree and the doctor organises the relevant tests to be carried out. As a bed is currently available, Megan is transferred straight from the clinic to the ward.</li> <li>&gt; Megan is provided with a side room in the adolescent ward, where it is quieter and curtains reduce the bright light.</li> <li>&gt; Following a physiotherapy assessment, she is introduced to a flexible programme of activity, suited to her current ability. With Megan and her mother's agreement, this includes gentle dry land exercises and the option of sessions in the hydrotherapy pool, whilst visiting hospital.</li> <li>&gt; Megan finds some daily activities difficult and the OT discusses what she would like to achieve and provides guidance on how to adapt self-care, educational and recreational tasks, grading activity levels.</li> </ul>	Standard 7 – hospital standard - young person friendly environment.	<i>Evidence based guidance for the management of CFS/ME in children &amp; young people, Royal College of Paediatrics and Child Health, 2004 – hospital stay for assessment and initial management plan.</i>  The Report of the working group on CFS/ME to the CMO, Jan 2002 <ul style="list-style-type: none"> <li>- Differential diagnosis assessment</li> <li>- Multi-disciplinary teams</li> <li>- Treatment plan</li> </ul>

	Journey	Children's NSF Theme	Evidence/Links
<p><b>Hospital Assessment 14 weeks on (cont.)</b></p>	<p>v v</p> <ul style="list-style-type: none"> <li>&gt; The consultant assesses Megan's symptoms and amends her prescribed analgesics for headaches and limb pain, which should also help to improve her poor sleep pattern and quality of life.</li> <li>&gt; Megan and her family see the same nurse as before, who has arranged for the specialist nurse to join her. They can raise and discuss family issues relating to Megan's CFS/ME and how it impacts on the parents and siblings. The nurse explains that, for equipment needs at home, assessment and provision would normally be organised by an OT or nurse.</li> <li>&gt; The paediatric team's social worker introduces herself to Megan and her family, offers support for non-clinical issues which may arise and provides her contact details. The social worker explains the range of services available to Megan and her family, e.g. special mattress or bed (if severely affected) and respite care/short breaks.</li> <li>&gt; The health professionals continue to liaise with the education service. The teacher at the hospital school discusses with Megan what she has been doing at school and contacts Megan's home school and the LEA Hospital &amp; Home Teaching Service to keep them in touch with her condition, her progress and needs for educational support.</li> </ul>	<p>Standard 2 – support for the parents and family.</p> <p>Standard 3 – holistic child centred care in the context of the family.</p>	<p><i>Evidence based guidance for the management of CFS/ME in children &amp; young people, Royal College of Paediatrics and Child Health, 2004 – as first line, pain control with simple analgesia</i></p> <p><i>Access to Education for children and young people with medical needs, DfES 2001 Ch 4; continuity of educational provision</i></p> <p><i>Evidence based guidance for the management of CFS/ME in children &amp; young people, Royal College of Paediatrics and Child Health, 2004 – health professionals to liaise with school.</i></p>

	Journey	Children's NSF Theme	Evidence/Links
<p><b>Management Plan (post-hospital assessment)</b> ✓ 14 weeks on</p>	<p>&gt; Megan's tests and assessments are completed and the consultant reports that as the suspected conditions have been excluded, he is reasonably sure that Megan has CFS/ME. Her management plan is reviewed and amended before going home and this includes an agreement about appropriate course of action in case of deterioration. Megan and her mother agree to return to the clinic in 4 weeks. Meanwhile, they agree a plan in which –</p> <p>(1) Megan and her mother will -</p> <ul style="list-style-type: none"> <li>&gt; ensure a balance of rest and activity, according to physiotherapist's advice and her own capability,</li> <li>&gt; continue medication to reduce symptoms,</li> <li>&gt; try to maintain as much independence as possible in self-care and other daily activities, according to OT advice.</li> <li>&gt; reduce light and noise, as required,</li> <li>&gt; continue to keep a daily symptom diary.</li> </ul> <p>(2) The paediatric team will –</p> <ul style="list-style-type: none"> <li>&gt; provide telephone advice,</li> <li>&gt; ensure rapid transfer of information between professionals (electronic where possible) to maintain high standards of co-ordinated care.</li> <li>&gt; ensure copies of all health, social/educational correspondence are sent to the family,</li> </ul> <p>(3) The consultant will -</p> <ul style="list-style-type: none"> <li>&gt; write to Megan's GP practice to ensure that they are fully informed of Megan's condition and management plan. This is important for providing integrated and/or shared care and also to enable primary care to provide proper health support for non-CFS/ME health issues which may arise.</li> <li>&gt; Inform the community therapy and nursing service about Megan, so that the therapists, health visitor and school nurse are aware of her condition and need for support.</li> <li>&gt; Write to the LEA Hospital &amp; Home Teaching Service and to Megan's school to inform them about the nature of Megan's illness and suggest a meeting between health and education partners to discuss setting up a personal education plan. As well as home teaching (which must be subject to review according to Megan's condition), this might include ways to encourage contact from school friends and staff to reduce social isolation.</li> </ul>	<p>Standard 7 – hospital standard Planning care in hospital and on discharge.</p> <p>Standard 2 – supporting and empowering parents</p> <p>Standard 3 – co-ordinated care, information and involvement in decisions</p> <p>Standard 6 &amp; 7 – co-ordination of services between care providers.</p>	<p><i>National Standards, Local Action – Health &amp; Social Care Standards &amp; Planning Framework 2005-2008</i> <i>Priority 2; PSA target -supporting people with long-term conditions</i></p> <p>The Report of the working group on CFS/ME to the CMO, Jan 2002</p> <ul style="list-style-type: none"> <li>- Differential diagnosis assessment</li> <li>- Multi-disciplinary teams</li> <li>- Treatment plan</li> </ul> <p><i>Evidence based guidance for the management of CFS/ME in children &amp; young people</i>, Royal College of Paediatrics and Child Health, 2004 referral to therapy services, experienced in treating CFS/ME for assessment and appropriate treatment</p> <p>The Report of the CFS/ME working group to the CMO, Jan 2002</p> <ul style="list-style-type: none"> <li>- education plans</li> <li>- home tuition</li> </ul> <p>Access to education for children and young people 2001 5.3 personal education plan</p>

	Journey	Children's NSF Theme	Evidence/Links
<b>Management Plan</b> √ <b>(post-hospital assessment)</b> <b>14 weeks on (cont.)</b>	<p>(4) The hospital nurse will -</p> <ul style="list-style-type: none"> <li>&gt; Inform the community therapy and nursing services about Megan, so that the therapists and school nurse are aware of her condition and need for support.</li> </ul> <p>(5) The hospital teacher/service will –</p> <ul style="list-style-type: none"> <li>&gt; Follow-up the consultant's letter and liaise with Megan's school, to arrange a meeting of partner agencies to discuss her individual needs.</li> </ul>		
<b>Home Tuition</b> √ <b>17 weeks on</b>	<ul style="list-style-type: none"> <li>&gt; Three weeks later Megan re-starts her home tuition for one hour, 3 mornings a week, as she is currently unable to complete the statutory minimum of 5 hours teaching per week. Her LEA home tutor and class teacher have been in contact, to ensure that Megan is kept in touch with her class work, as much as possible.</li> </ul>		<p>The Report of the CFS/ME working group to the CMO, Jan 2002</p> <ul style="list-style-type: none"> <li>- education plans</li> <li>- home tuition</li> </ul>
<b>Paediatric Clinic Visit 3</b> √ <b>18 weeks on</b>	<ul style="list-style-type: none"> <li>&gt; Megan and her mother are also due to return to the outpatients' clinic. First they see the physiotherapist and occupational therapists for a review of progress. Megan reports to the paediatrician that she still has little stamina but has improved slowly since she was in hospital. A couple of school friends visited her at home for a short time.</li> <li>&gt; However, she feels rather 'down' and misses the company of friends. The paediatrician says that although it is natural to feel depressed when you don't feel well, if Megan would like to chat about this at greater length, he can arrange for her to see the joint assessment paediatrician and the psychologist as part of the CFS/ME team. He advises that an early appointment to resolve her difficulties may help to avert the need for medication. A provisional appointment is booked to coincide with Megan's next clinic visit, which they agree will be in 4 weeks' time.</li> </ul>	<p>Standard 3 &amp; 6 – co-ordination with other agencies.</p> <p>Standard 9 – early intervention for mental health and well-being</p>	<p><i>Evidence based guidance for the management of CFS/ME in children &amp; young people, Royal College of Paediatrics and Child Health, 2004 – the importance of psychological well-being</i></p>

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<p><b>Paediatric Clinic Visit 4</b> 20 weeks on</p>	<p>∨</p> <ul style="list-style-type: none"> <li>&gt; By the next clinic, Megan's condition has stabilised. She is still feeling 'down' and thinks it would help to have more company. The consultant suggests that she may be well enough to go to the LEA's teaching centre for one session a week, whilst continuing home tuition. He explains that the centre provides an alternative or interim stage for children and young people who cannot attend their school and offers education on a temporary and/or part-time basis. She would then have the opportunity to mix with other young people, without the hustle and bustle of mainstream school. Megan is pleased with this idea and the consultant agrees to contact the LEA and home school to advise on Megan's condition and explain what support will be needed at the teaching centre.</li> <li>&gt; Megan takes up her appointments with the joint assessment paediatrician and the psychologist from the CFS/ME team, who are running sessions alongside the paediatric clinic. Megan sees them by herself for the first part of the meeting and her mother joins them half way through. The psychologist assesses Megan's problems and then they discuss and work out some useful strategies together. Megan is clear that, although she is feeling down, she does not want to be referred to a psychiatrist or have any tablets for depression but would like to see a psychologist again. The CFS/ME team psychologist says Megan can be followed up by the local Child &amp; Adolescent Mental Health Services (CAMHS) team psychologist.</li> <li>&gt; A referral letter is sent from the clinic to the CAMHS team psychologist. A letter is also sent to the GP, to update the primary care team on Megan's progress and her need for continued support at home.</li> <li>&gt; One week later, and one month after Megan has started home tuition, the LEA receives the consultant's letter about the teaching centre. The LEA agrees and asks her home tutor to discuss this at the next home visit. Megan confirms that she would like arrangements to be made for her to go to the teaching centre. Staff are advised, through the consultant's letter, of Megan's condition and how it is being managed, which professionals are working with her and how they can be contacted.</li> </ul>	<p>Standard 3 – co-ordinated, child-centred services according to individual needs.</p> <p>Standard 10 – young people to be active partners in decisions about medication.</p> <p>Standard 9 – mental Health and wellbeing of young people - awareness that some physical health problems bring greater risk of having mental health problems.</p>	<p><i>Evidence based guidance for the management of CFS/ME in children &amp; young people, Royal College of Paediatrics and Child Health, 2004 - close liaison with education ensure education is part of management plan.</i></p> <p><i>Health for all children. Fourth edition 2003 Health in schools – liaison between health agencies/professionals and education/ school services</i></p> <p>The Report of the CFS/ME working group to the CMO, Jan 2002 para 5.2.4 - Need to be aware of need for psychological support</p> <p><i>Circular 14/96: Supporting pupils with medical needs in school DfEE</i></p> <p><i>Supporting pupils with medical needs: a good practice guide DfEE/DoH 1996</i> <a href="http://www.teachernet.gov.uk/medical">www.teachernet.gov.uk/medical</a></p>

		Journey	Children's NSF Theme	Evidence/Links
Teaching Centre 22 weeks on	√	<ul style="list-style-type: none"> <li>&gt; Megan starts to attend the teaching centre for 2 hours, one morning a week, in addition to her home tuition. She finds this beneficial and enjoys the company. She also receives regular news from the class teacher at her home school, so that she can stay in touch with her school work.</li> </ul>	Standard 3 – holistic/integrated care.	<p><i>Access to Education for children and young people with medical needs, DfES 2001</i></p> <p>PSA target – maximise school attendance</p>
Paediatric Clinic Visit 5 24 weeks on	√	<ul style="list-style-type: none"> <li>&gt; At the next visit to the clinic, Megan has a review with the physiotherapist and OT, which includes analysis of coping strategies and activities. These aim to provide creative achievement or social contact within agreed tolerance levels. She also sees the CAMHS psychologist, to review her progress. The paediatrician checks on any changes in her symptoms and discusses whether Megan needs any alteration to her analgesia. Megan would still prefer not to have medication for depression and by staying within her structured programme, she has learned that she can also reduce her need for analgesia.</li> <li>&gt; They also agree that there is no need for another clinic appointment for 3 months, on the proviso that Megan or her parents can have access, by phone, to the paediatric team for advice before that date, if required. During this time, Megan's fatigue persists but the limb pain reduces with the use of prescribed analgesia. School friends visit from time to time but this has recently been less frequent.</li> </ul>	<p>Standard 10 – young people involved in decisions about their medication.</p> <p>Standard 9 – mental health needs of children with concurrent health problems.</p> <p>Standard 1,3,8 – timely access to healthcare advice.</p>	NHS Improvement Plan 2004 empowering patients to book appointments to suit their needs
Paediatric Clinic Visit 6 37 weeks on	√	<ul style="list-style-type: none"> <li>&gt; Three months later, at the next paediatric clinic, Megan sees the OT and physiotherapist, who discuss her progress and suggest an incremental increase in her activities. The paediatrician suggests increasing her hours at the teaching centre and she reports that she is feeling less isolated and depressed since starting to go there.</li> <li>&gt; Megan has been invited to an afternoon play followed by a party put on by her class at school. She asks the paediatrician whether it is advisable to attend. He advises her to go but to ensure transport is available at an agreed time to take her home.</li> </ul>	Standard 9 – psychological needs of young people.	<p>Evidence based guidance for the management of CFS/ME in children &amp; young people, <i>Royal College of Paediatrics and Child Health, 2004</i> – graded activity programmes to be considered.</p> <p>Disability Discrimination Act 1995 – promote inclusion of disabled people and those with long-term conditions</p>

		Journey	Children's NSF Theme	Evidence/Links
<b>Set-back</b>	∨ ∨	<ul style="list-style-type: none"> <li>&gt; Megan attends her school play and party and agrees with her mother the time by which she will be home. However, she comes home much later, extremely fatigued.</li> <li>&gt; Over the next few days, Megan's symptoms become much worse again, she ceases to attend the teaching centre and for 2 weeks she remains confined to bed. Megan's mother phones the paediatrician who suggests that Megan, by extending her visit to the school play and party, she may have pushed herself too hard. He advises balancing rest with activity in the first instance, with gradual re-introduction of increased activity as Megan improves.</li> <li>&gt; However, Megan remains unwell with the return of her previous symptoms. She suffers another prolonged sore throat with fever and becomes increasingly reluctant to eat and drink. Her parents are finding it difficult to ensure she receives adequate nutrition.</li> <li>&gt; Over the course of a month, she starts to lose weight. After discussion by telephone with the paediatrician, he suggests taking further advice from the CFS/ME team, to which the family agree. A home visit to Megan is arranged between the CFS/ME team consultant and the local paediatrician who has been caring for Megan.</li> </ul>	<p>Standard 8 – promote social inclusion of children and young people with long-term conditions.</p> <p>Standard 1 – timely access to appropriate advices.</p> <p>Standard 3 – holistic care adapted around individual needs.</p>	<p><i>Evidence based guidance for the management of CFS/ME in children &amp; young people, Royal College of Paediatrics and Child Health, 2004 – graded activity programmes</i></p>
<b>Tube Feeding</b>	∨ ∨	<ul style="list-style-type: none"> <li>&gt; As a result of Megan's assessment at home, the consultants recommend a period of tube feeding to build Megan's strength and improve her resistance to infection. The doctors also recommend that Megan should be admitted briefly to hospital, with her mother as the main carer, to learn tube feeding technique. Megan and her family agree and the admission is arranged immediately for Megan and her mother.</li> <li>&gt; After her mother's training and guidance from medical, nursing and dietetics staff, and once she and the staff feel confident about her tube feeding skills, they are discharged and continue care at home. The GP is updated on Megan's condition. Support is available, if required, from trained ward staff via telephone, 24 hours, or from a community matron/nurse who pay regular home visits.</li> </ul>		<p><i>Evidence based guidance for the management of CFS/ME in children &amp; young people, Royal College of Paediatrics and Child Health, 2004 – paediatrician to pay home visit home and manage care in patient's home if CFS/ME prevents travel to outpatients' clinic</i></p> <p><i>National Standards, Local Action – Health &amp; Social Care Standards &amp; Planning Framework 2005-2008</i> Priority 2; PSA target -supporting people with long-term conditions</p>

		<b>Journey</b>	<b>Children's NSF Theme</b>	<b>Evidence/Links</b>
<b>Tube Feeding (cont.)</b>	∨	<ul style="list-style-type: none"> <li>&gt; Megan's visits to the teaching centre cease temporarily. She is visited by her home tutor for short periods to keep in touch and provide education, as appropriate.</li> <li>&gt; Over a period of 3 months, the community matron/nurse visits Megan and her family at home on a regular basis to provide support and advice and to monitor change. After 3 months, Megan's appetite improves and the tube feeding is no longer required. As Megan improves, her mother arranges for her to attend the paediatric clinic the following week.</li> </ul>	Standard 3 – holistic care adapted around individual needs.	<p>NHS Implementation Plan 2004 – people with long-term conditions supported to receive more care at home</p> <p><i>Supporting People with Long-term Conditions 2004, Ch2 – Case management for patients with complex long-term conditions and high intensity</i></p>
<b>Paediatric Clinic Visit 7 56 weeks on</b>	∨	<ul style="list-style-type: none"> <li>&gt; At the next paediatric clinic, Megan sees the various health professionals in the team, including a review by the paediatrician and nutritional advice from the dietician. The physiotherapist advises on activity and exercise to re-mobilise Megan and suggests, as a short-term measure, the use of a wheelchair to facilitate an earlier return to the teaching centre. Megan agrees and the physiotherapist organises the loan of a wheelchair. The hospital teacher contacts Megan's teaching centre and the paediatrician writes to Megan's GP practice, to update them on progress and to explain her current needs. It is agreed that if Megan maintains an improvement, her next clinic visit can be in 2 months.</li> </ul>	Standard 3 & 8 – child-centred, integrated service, which is tailored to young person's needs.	<p>Disability Discrimination Act 1995 – promote inclusion</p> <p>Special Educational Needs Disability Act (SENDA) 2002 – flexible educational provision to facilitate access</p>
<b>Growing Up</b>	∨	<ul style="list-style-type: none"> <li>&gt; Megan, now 15 years, continues to remain in contact with paediatric team and attends the clinic every 3-6 months, depending on variation in her condition. Megan is able to receive support and advice from different health professionals, according to her needs. She increasingly takes the lead in discussion with the professionals, as she matures, although her parents still attend clinic to provide support.</li> <li>&gt; The paediatrician discusses self-management strategies and ways to offer support. He introduces the possibility of taking part in the Expert Patient/Parent Programme (EPP) to empower the family in managing Megan's CFS/ME. The doctor also informs them of other sources of support, such as AYME's workshops for young people with CFS/ME.</li> </ul>	<p>Standard 4 – respecting and involving young people in their care.</p> <p>Standard 2 – empowering parents.</p>	<p>NHS Implementation Plan 2004 – Expert Patient Programme (EPP)</p> <p><i>AYME – Positive Living Project for Young People with ME 2002 – 2005</i></p>

	Journey	Children's NSF Theme	Evidence/Links
Growing Up (cont.) √	<ul style="list-style-type: none"> <li>&gt; In conjunction with school staff, the OT helps Megan to further develop her own coping strategies, to enable her to manage her condition and achieve the tasks which are most important to her.</li> </ul>		
Regular Reviews √	<ul style="list-style-type: none"> <li>&gt; Megan, her family, the paediatric/specialist team, LEA and school continue to liaise in relation to Megan's health and education needs, with a formal educational review on an annual basis and interim reviews, as required. From year 6, educational reviews also include a Connexions advisor, who is able to provide support for social service and work issues, such as, access to suitable work placements.</li> <li>&gt; As Megan improves, she is able to return to mainstream school part-time for a few subjects only, whilst maintaining some attendance at the teaching centre for additional support. The OT visits Megan at school and they discuss with her teachers how she can access various subjects and what adaptations and special equipment may be required. In this way, Megan has an adaptable education programme, which is flexible in the short-term and maximises her school attendance in the longer term.</li> <li>&gt; In due course, Megan ceases to attend the teaching centre and takes up suitable extra curricula activities at school. Megan, her parents, teachers and Connexions advisor discuss whether she should delay taking her GCSEs by one year, to allow more time to catch up lost schooling. Megan is reluctant as she does not wish to be separated from her peer group. Thus, it is agreed that Megan can join GCSE courses in a reduced number of subjects, where she is at an appropriate level. These arrangements will be flexible and open to regular review. The LEA and school use Megan's medical and therapy reports to negotiate with the exam boards to ensure that Megan does not have too many exam sittings on one day and to provide extra time for each exam and, if necessary, a later start. Megan was delighted that the results enabled her to continue with post-16 education. Megan says she would prefer to continue her studies at the local further education (FE) college. The Connexions advisor offers to liaise with the medical and therapy teams, advise on available course options and provide support.</li> </ul>	<p>Standard 3, 8 – integrated multi-agency support</p> <p>Standard 8 – flexible service which adjusts to young person's changing needs.</p> <p>Standard 4 – growing up; flexible services, responsive to changing needs.</p>	<p>PSA target – maximise school attendance</p> <p><i>Removing the Barriers to Achievement, The Government's Strategy for Special Educational Needs (SEN) DfES 2004</i></p> <p><i>Access to Education for children and young people with medical needs, DfES 2001 – adaptable provision to meet young person's needs</i></p>

	Journey	Children's NSF Theme	Evidence/Links
<b>Regular Reviews (cont.)</b> √	<ul style="list-style-type: none"> <li>&gt; Megan's health, in relation to CFS/ME, continues to be monitored and she is reviewed at the paediatric clinic 3-6 monthly, according to her needs.</li> </ul>		
<b>Transition to Adult Services</b> √	<ul style="list-style-type: none"> <li>&gt; Megan, now aged 17 years, continues to have CFS/ME symptoms, although the type and severity of her symptoms vary over time. She learns how to pace her day-to-day activity, in order to minimise the impact of CFS/ME on her life. At FE college, she is able to pursue her chosen courses of study and the Connexions advisor, education, health and social services continue to provide support. Connexions liaises with the OT to help assess how Megan could access various work experience options and first employment opportunities.</li> <li>&gt; Now that Megan is approaching adulthood, she is informed that, in addition to AYME, there is a voluntary organisation which provides support and information for adults with CFS/ME and is given the contact details for 'Action for ME'.</li> <li>&gt; At the paediatric clinic, the paediatrician discusses with Megan her transfer to an adult team led by a physician specialising in the care of adults with CFS/ME. Megan is happy to consider this, but expresses concern that the adult team will be unfamiliar with her care. It is explained to her that transfer is a gradual process, which involves a period where she has access to both teams via joint clinic appointments. Megan is also assured that she will not lose contact with all her familiar health carers, as her GP practice will provide continuity of support throughout the transition and thereafter. Only after she is comfortable with having her care transferred, will it become a formal arrangement. Megan is happy with the plan and agrees to 'give it a go'.</li> </ul>	<p>Standard 2, 4, 8 – ongoing support for patients and family.</p> <p>Standard 4, 7 &amp; 8 – transition to adult services should be planned in consultation with the patients and carers.</p>	<p><i>Association of Young People with ME (AYME)</i> PO Box 605 Milton Keynes MK2 2XD Tel: Helpline 08451.232389 Tel: Admin 01908.379737 Email: info@ayme.org.uk</p> <p><i>Action for ME</i> PO Box 1302 Wells, Somerset BA5 1YE Tel: 01749.670799 Email admin@afme.org.uk www.afme.org.uk</p> <p><i>Evidence based guidance for the management of CFS/ME in children &amp; young people, Royal College of Paediatrics and Child Health, 2004 – ensure appropriate arrangements are in place before transfer to adult services</i></p>

CFS/ME

**Notes**



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