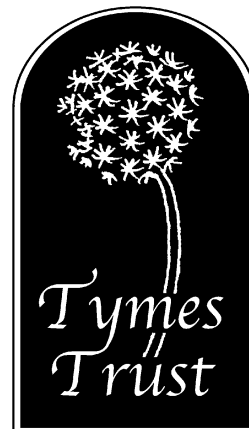


The GPs Good Practice Guide to Education for Children with ME



*Advancing the
care of people
with ME*

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Abstract

This Guide has been produced to assist GPs to manage educational demands on children with ME to preserve health and help them achieve. It incorporates some of the best ideas and practice to come out of years of work in this field.

***The Department of Health now refers to this condition as
CFS/ME***

Many doctors use the term CFS (Chronic Fatigue Syndrome). Others prefer ME (Myalgic Encephalomyelitis) as originated in *The Lancet*.

This guidance concerns the neurological condition defined under the name ME by the World Health Organisation as a disease of the brain and central nervous system.

CONTENTS

PART ONE :

WHY SHOULD GPs INFLUENCE EDUCATION FOR PUPILS WITH ME? 1

How do educational demands affect recovery?	1
What can the GP do?	2
Place of learning – choices and recommendations	2
Curriculum and coursework	3
Examinations	4
Spectrum of severity	4

PART TWO:

QUICK REFERENCE ACTION PLAN 5

A 6-point plan to assist in the management of childhood CFS/ME

PART THREE:

THE TYMES TRUSTCARD 6

For pupils with CFS/ME in school

PART FOUR:

KEY QUOTES FROM THE REPORT OF THE CHIEF MEDICAL OFFICER'S WORKING GROUP ON CFS/ME (DoH 2002) 7

Nature of the illness and symptoms	7
Children and CFS/ME	7
Time-scale for diagnosis in children	7
Spectrum of Severity	7
What clinicians can do	8
Treatment/Management	8
Educational management	8
Child protection	9
Prognosis	9

TYMES TRUST SERVICES AND FURTHER READING 10

APPENDIX: CASE HISTORY 10

Collaborative Care Management

PART ONE : WHY SHOULD GPs INFLUENCE EDUCATION FOR PUPILS WITH ME?

ME is the biggest cause of long term sickness absence from school (Dowsett/Colby JCFS 1997). This is because the typical child with ME is fragile and attendance aggravates the condition. GPs can have a positive influence on the educational demands made on the child so that progress towards recovery is enhanced rather than set back.

Lowered blood flow to certain areas of the brain on effort, coupled with lowered cortisol levels in the brain (both of which are noted in this condition) make it impossible for the child to cope with normal levels of effort and stress without suffering a downturn in their medical condition.

A typical bout of ME lasts around four and a half years. Many last much longer; some are fortunately shorter, but relapse is also a consistent feature in this condition. Because there is no curative therapy, self-management is the most effective way of enabling the body to recover as far as is possible. Both physical and intellectual effort produce a delayed deterioration and patients need to learn to modify their output accordingly.

Since a child has to be educated by law, methods of education used should be commensurate with recovery. Like all medical conditions, each case will need slightly different management based on sound principles.

How do educational demands affect recovery?

Advice Line Records from support organisations and the clinical experience of paediatricians both tell the same story. They indicate that education is a key source of relapse in pupils and students. In many cases it is the main source.

Unsuitable educational demands therefore:

- a) undermine the doctor's medical management and
- b) deprive pupils and students of their legal right to education suitable for their medical and special educational needs.

Attending school is often too demanding physically, even part-time in many cases. It drains what little strength the pupil has and exacerbates central nervous system dysfunction. This produces extreme malaise, and in some cases collapse.

The very purpose of being in school, which is to learn, is undermined because the brain cannot retain information. Attention and cognition are worst affected.

Not only does this result in repeated relapse, but there is also little educational achievement to show for all this effort. Children often come to believe that they are failures. In fact, it is the system of education used that has failed. It has failed them medically as well as educationally.

What can the GP do?

Teachers may not write prescriptions for medication, yet doctors are permitted – even expected – to write virtual prescriptions for education.

- If a child is thought to need home tuition, distance learning, or needs to be excused from physical education lessons for a considerable period, the school will require medical confirmation of this requirement.
- The GP is the doctor who is most accessible to the family and will often find him or herself in the position of having to make decisions on education.
- The purpose of this Guide is to assist GPs in making those decisions. Whilst each case is unique, certain principles underlie these decisions.
- Energy Efficient Education assists recovery and recommendations can be made that are commensurate with pacing life carefully.

Place of Learning – choices and recommendations

School is typically a place of high energy demand and raised stress levels. Social contact is also exhausting and for many pupils with ME, social contact itself uses the same or more energy as a lesson.

The purpose of school is to educate and to enable the child to achieve qualifications. Every child has a legal right to suitable education for their needs but the law does not state that this must be given in a school. Home educating is growing in popularity.

Social contact, whilst important, should be seen in this context. It can be provided by visits to a sick child's home from teachers and/or the home tutor and by the child's friends with the school's encouragement. Visits to school by the child can also be made for social contact alone, with lessons being delivered at home. This paces energy but also avoids isolation.

Home tuition, tuition in small units, or distance learning can all be provided and may be needed for a considerable time, often for years in cases of ME, to avoid relapse.

The Department for Education and Skills issued statutory guidance for schools in 2002 which makes it clear that all these options, or a flexible mixture of them, must be provided by Local Education Authorities in accordance with need.

The relevant document is: *Access to Education for Children and Young People with Medical Needs*, available from the Department for Education and Skills.

This document states that sick children's needs must come first and that home tuition and other such modifications to venue and style of learning must be available where

required. Even though children usually like learning alongside friends, there are many cases where this is not practicable and ME often falls into this category for long periods.

Access to Education gives LEA policy examples that are *not* part of the guidance but which appear to have been mirrored by other LEAs.

In one example, an LEA is quoted as requiring the child to be provided with a consultant's recommendation before home tuition can be granted.

It is debatable whether this requirement would stand up in law, because *Access to Education* states that children expected to be away from school due to illness for more than 15 days must have educational provision made for them.

Since a consultant's appointment is unlikely to be received within this timescale the GP should ensure that his or her guidance is followed. Schools have a 'duty of care' and if the school or LEA should go against medical advice it could be liable in law.

Curriculum and Coursework

Every child is entitled to a broad, balanced curriculum, but unfortunately, with the effects of this condition on the brain and the thinking processes, this 'entitlement' is in many cases prejudicial to achievement. Unfortunately, it often has the added effect of militating against physical recovery.

- The child may need, in effect, the equivalent of the adult's 'sick note' explaining an absence from work. However, in this case the note will also need to explain the need to reduce the number of subjects over a spectrum from nil (where education may need to be stopped entirely for a while due to the severity of the condition) to a full curriculum later, if the child is robust.
- It is often productive for schools to 'disapply' a child from the National Curriculum and doctors can recommend how many subjects the child should attempt until it is clear that sufficient strength has been recovered to attempt more without adverse effects. Monitoring the child's health becomes important in order to assess this.
- A medical recommendation is usually crucial to the acceptance by the school of the need for a modified curriculum.
- Coursework can also be minimised. Most pupils are asked for more coursework than is eventually submitted to the Examinations Board, and a child with ME may be permitted to submit only the minimum to the school. The GP can recommend this also.
- Distance learning can provide tutored distance learning via computer. Tymes Trust works with a public/private LEA-run partnership. We can give details of suitable modifications for curriculum and coursework to boost achievement and protect health. It also involves live teacher contact. The Satellite School also provides a private service. Contact Tymes Trust for further details.

Examinations

A whole spectrum of modifications can be made to examinations, including sitting the exam at home. However, schools do not always welcome such requests and the GP can provide the support and explanations necessary.

The invigilator at home need not be a teacher but should be an independent adult. The Examination Boards explain that the main purpose of this and other modifications is to enable a child to achieve their best grade within the confines of their illness.

Such Special Arrangements, as they are known, are not intended to give one student an advantage over peers, but to enable a student to show clearly the standard of work of which they are capable. This is the purpose behind all examinations.

Disabling effects on the brain entitle a child to at least 25% extra time for the examination and an adult amanuensis

may do the writing for the child if appropriate.

It means a great deal to sick children to see their efforts rewarded in their final grade. Therefore the GP's support can give a huge confidence boost to the child with ME by anticipating such examination arrangements. Parents are often not aware of them.

Each school has information from the Joint Council of Examination Boards and the school's Examinations Officer will have a copy of the relevant documentation.

SATS – government tests taken at various stages of a child's educational life – do not confer qualifications and in England are used to grade schools in League Tables. The GP may feel that it is counterproductive for a child with ME to spend energy on SATS and may decide in consultation with the family that it would be best to concentrate on exams conferring qualifications.

Spectrum of severity

Cases range from 'mild' to 'very severe' although ME is not in itself a mild condition but a potentially lifelong disability. It can be helpful to think in terms of stages. Milder cases can become severe and chronic unless carefully managed.

Stage One has been called the toxic phase, more obvious in severe cases

Patient feels ill all the time. Any attempt at exercise is *counterproductive*. As in all acute illnesses, a drastic reduction in cognitive activity is usually indicated. However, this need for reduction in physical and intellectual activity will typically persist for far longer than in other illnesses.

Stage Two consists of stabilisation, typically taking several years

Any *excess* activity may cause relapse to Stage One. Extreme caution is needed. Patients may remain in this stage for years and progress may be very slow.

Stage Three has been called recovery but remission may be more accurate

Activities can be gradually increased with confidence.

PART TWO : QUICK REFERENCE ACTION PLAN

A 6-point plan to assist in the management of childhood CFS/ME

1. Diagnose (GP and/or consultant): as promptly as possible

This frees up the family's access to support from various agencies. If a case of ME is suspected, many of the following steps can be taken during the diagnostic process. The illness can become much worse if everyone waits until the diagnosis is confirmed before putting in support for the child.

2. Inform the family of relevant benefits and practical support

This may include wheelchairs and other equipment.

3. Maintain contact with the family to monitor the child's health

Treat symptoms as appropriate. New symptoms may be not be part of ME. Many families feel very alone and frightened at this time.

4. Give details of relevant patient organisations to the family.

5. Monitor the child's level of strength

Does attendance at school exacerbate the illness? What is the child's ability to access any form of education? Consider modifications.

6. Liaise with the school/LEA to set up suitable learning system

The system should help to achieve educational continuity without endangering health. There is no legal requirement to attend school if it is not in the best interests of the child's health.

Also recommend the Tymes Trustcard for pupils in school

**PART THREE : THE TYMES TRUSTCARD
FOR PUPILS WITH CFS/ME IN SCHOOL**

Endorsed by

**Baroness Ashton:
Parliamentary Under-Secretary of State for
Early Years and School Standards
and
The Secondary Heads Association : SHA**

'Activity beyond the level that an individual can usually tolerate will prompt a delayed worsening of symptoms.'

*Report of the Chief Medical Officer's Working Group on CFS/ME
Published by the Dept of Health Jan 2002*

CFS/ME is a chronic, disabling neurological condition. Deterioration after a latent period of 2/3 days may follow even minimal effort.

**Use of the Tymes Trustcard will assist the school to comply with Department for Education and Skills statutory guidance:
*Access to Education for children and young people with medical needs.***

What is the Tymes Trustcard?

It's a 'pass card' signed by the child's Head Teacher and carrying the child's photograph. It states that the child has permission to use the school's disabled facilities or obtain other assistance. Application forms require confirmation of diagnosis. Please support the use of the Tymes Trustcard by your young patients with CFS/ME.

***For more information and application forms for the Tymes Trustcard
apply to***

***Tymes Trust PO Box 4347 Stock Ingatestone CM4 9TE
Tel: 0845 003 9002***

Website: www.tymestrust.org

PART FOUR : Key Quotes from the Report of the Chief Medical Officer's Working Group on CFS/ME (Department of Health 2002)

All statements are contained in the text of the Report; they are not our interpretation of the Report, but direct quotes from it. Taken together they comprise key information on the illness, on how it affects children, and on how it should be managed, including educational management (endorsed by the Department for Education and Skills).

Nature of the Illness and Symptoms

- Chronic Fatigue Syndrome (CFS/ME) is a genuine illness and imposes a substantial burden on the health of the UK population. CFS/ME affects many people and their families in the UK and elsewhere in the world.
- Many of the symptoms of CFS/ME suggest dysfunction of the central nervous system.
- Characteristic or common symptoms include: persistent/excessive tiredness or fatigue; cognitive impairment; postexertional malaise; pain; sleep disturbance; recurrent sore throat; digestive disturbances; intolerances eg of certain foods, medications and alcohol; other symptoms apparently related to the neurological and/or endocrine systems.
- Activity beyond the level that an individual can usually tolerate will prompt a delayed worsening of symptoms.
- Early recognition with an authoritative, positive diagnosis is key to improving outcomes.

Children and CFS/ME

- Children and young people (defined as being of school age) do get and are profoundly affected by CFS/ME, contrary to some professional and public perceptions.
- In children, the commonest age of onset is 13-15, but cases can occur as young as 5.
- A diagnosis in the young must be especially prompt, accurate and authoritative, and second opinions are needed if doubt exists.

Time-Scale for Diagnosis in Children

- When a child or young person has symptoms affecting school attendance for at least four weeks, active steps should be undertaken to identify the cause from a list that includes CFS/ME.

Spectrum of Severity

- Some children and young people with CFS/ME are so severely affected by the disease that they become bed-bound, with a similar degree of cognitive and physical impairment to that experienced by patients with severe neurological conditions.

What clinicians can do

- Listen to the patient, recognise and believe his or her individual experience.
- Acknowledge uncertainty and the impact that this has on the patient, family and carers.
- Provide information on and discuss: the nature of the condition, approaches to self-management, helpful therapies, and how to access other agencies for support and services.
- Agree a name for the condition. [The Report suggests CFS/ME.]
- Give advice on symptomatic treatment.

Note: The Report recommends that patient organisations be contacted for support.

Treatment/Management

- No management approach to CFS/ME has been found universally beneficial, and none can be considered a “cure”. Patient responses suggest that [...] all can cause harm if applied incorrectly.
- As with many chronic conditions, the emphasis should be on improvement and adjustment rather than “cure”. The goal of rehabilitation or re-enablement will often be adjustment to the illness.
- Experience suggests that provision of a wheelchair or other mobility aid does not stop patients working towards mobility without the equipment in the long term; indeed, such aids probably assist remobilisation, with suitable supervision.
- The notion of “once in a wheelchair, never out” is prejudicial: each case must be assessed according to clinical and functional need.
- Although there is no cure for CFS/ME, the condition has been found to improve in most patients both with and without* treatment; it is good practice to encourage patients to become experts in self-management and to choose between treatment options.[*Patients may therefore decline active treatment.]
- Most children who are missing school can be cared for and managed in their homes, with follow-up in primary care or by a specialist such as a community paediatrician.
- Careful listening and respect for parents/carers’ opinions are important factors.

Educational Management

- Nearly all children who are severely affected and many who are moderately affected will require the provision of home tuition and/or distance learning. Some young people will be too severely affected by their illness to participate in any form of education, even at home.
- An educational plan is not an optional extra but an integral part of therapy.
- A young person who is likely to have special needs, including home tuition, should be identified early in the diagnostic process, preferably by a GP or paediatrician.
- Specifically, a young person with CFS/ME should never be forced to study but instead should be encouraged to set a pace that is likely to be sustainable, then have their progress regularly reviewed.

- Some more severely disabled children may need home tuition and/or distance learning on a longer-term basis. In addition to the time of a tutor or therapist, this may require information and communications technology, which can also help improve social contact.

Child Protection

- In cases of CFS/ME, evidence clearly suggestive of harm should be obtained before convening child protection conferences or initiating care proceedings in a family court.
- Neither the fact of a child or young person having unexplained symptoms nor the exercising of selective choice about treatment or education constitutes evidence of abuse.

Prognosis

- Overall, there is wide variation in the duration of the illness, with some people recovering in less than two years, while others remain ill after several decades.
- A minority of those with CFS/ME remain permanently severely disabled and dependent on others.
- Most people with CFS/ME can expect some degree of improvement with time and treatment, so a positive attitude towards recovery needs always to be encouraged.

TYMES TRUST SERVICES AND FURTHER READING

Tymes Trust is the longest established UK national organisation supporting children and young people with ME. The Trust specialises in a personal approach. Prime Minister Tony Blair has publicly endorsed the Tymes Trust.

The Trust played a major role in the children's section of the Chief Medical Officer's CFS/ME Working Group Report published by the Dept of Health in January 2002.

Tymes Trust Advice Line : 11.00am – 1.00pm Monday-Friday Tel: 0845 003 9002.

The Trust's Professionals Referral Service enables doctors, teachers and other professionals to consult ME experts in their own fields.

Tymes Magazine for families and professionals is free to those under 26 years of age and available on subscription to those over 26.

Children and Young People with ME Consultant paediatrician Dr Alan Franklin's practical booklet of diagnostic and management advice for physicians. Available from Tymes Trust.

Zoe's Win Jane Colby's child-friendly book on coping, for families and professionals. Recommended particularly as 'a starting point for families whose youngster has just been diagnosed [...] easy to read and very accessible throughout.' *Special Children* 'A little gem.' Dr Anne Macintyre. Published by Dome Vision.

APPENDIX : CASE HISTORY COLLABORATIVE CARE MANAGEMENT

The team of professionals involved in the care of young Sarah Gill saw it as their prime duty to provide to their client – the child – full information about her entitlements in order to maximise the chances of a good recovery. This was done by involving the family as a full part of the professional team helping her to recover.

‘All living organisms have a capacity to heal,’ says Consultant Paediatrician Dr Alope Agrawal

When I met my first patient with ME it was she who taught me the most valuable lesson, which has been the guiding principle for me to treat youngsters with ME.

This child said to me: ‘You doctors are very good at fixing things when you know what’s wrong but with me you don’t know what’s wrong do you? So

you can’t fix it – but can I still come and see you? Not too often – I will have to deal with my own disease – but I just want to be reassured that one day things will be better.’

The course of the illness is such that at times children lose courage, at times the parents do, and at times even professionals such as doctors can too.

Health, as we define it, is a state of social, physical and mental wellbeing and with an illness like ME, all three aspects of health suffer. It is very important for carers of youngsters with ME to feel that they can turn to somebody for support. It is in this appropriate setting that the child can then start to recover.

These have been my driving factors, apart from all the other medical evidence that has shaped my clinical practice in looking after these children. I see myself as somebody who can also refer children to other agencies if the need arises, so my role is not only in supporting them but also making sure that they do not develop any other physical illnesses, which they can do, just like anybody else.

I do not want to under-estimate the importance of the education that the children miss out on. The majority of children with ME miss a lot of school, and education can be a source of difficulties. Most importantly, their social life can also become restricted.

Hence, children with ME lose out on all fronts: physical health – as they

have symptoms which I cannot explain; mental health – since their illness does not lend itself to a strict psycho-analytical approach; and social health – since they are often not well enough to socialise or be sent back to school.

As a paediatrician I see myself fulfilling a very small but important role in providing support to the child and the family, identifying any physical health needs that may arise, and providing the right environment for the child to get better.

All living organisms have a capacity to heal and I think there is no reason why a child with ME, given the right support, will not *self-heal*.

THE EDUCATIONAL DIMENSION

**‘Everything needs to be tailored specifically to the individual young person,’ says
GP Dr Nigel Hunt**

One of the important skills one should learn early on in one’s career as a doctor is to know one’s limitations.

Thus it was that I recognised that to achieve a holistic approach to ME I could extend the team around the child to encompass the educational dimension.

In this way there was the potential to bring about real achievements educationally as well as in terms of medical care. Thus my collaboration

with former head teacher Jane Colby was born.

My patient Sarah Gill, also a patient of Dr Agrawal, has been a member of Tymes Trust for many years. At one time she was severely ill.

Her continuing success story illustrates the importance of an open-minded collaborative approach so that the professions can work together to maximise the potential for young people with ME.

Everything needs to be tailored specifically to the individual young person.

Any plan needs to be flexible and must adapt to the changing and often fluctuating clinical condition whilst at the same time empowering the young person on the road of lifelong learning.

Sarah (at age 20) said:

‘I’m feeling a lot better and stronger now. I still have to be careful – if I do too much I get headache and tired – but at last I’m actually working. I do data input in the offices of a large consultancy company.

‘Initially I taught myself this on the computer at home and I’m learning more as I go along. For the moment, my art has had to go on the back burner but I’m glad to be out and about – and earning!’

Sarah’s Story

The Family's Perspective

Before ME Sarah's life revolved around the arts. She was a talented musician taking grades in flute and keyboard. She could play a large assortment of instruments - penny whistle, pan pipes, recorder The house rang with music. Her quiet times at home were spent with her arts and

crafts. Popular at school, Sarah went to parties and discos, enjoyed ice-skating and cycle rides with friends. Family interests were long country walks, our love of the coast and long holidays away taking in the fresh air. Trips to London were another feature of Sarah's busy, happy life.

Onset of ME During the summer of 1997 Sarah was in poor health, having suffered from four bouts of viral illness. Each bout left her weaker than the last. Headaches became a main symptom but it was her lack of energy which caused most concern. Sarah was pale and exhausted, and lost a great deal of weight. Her GP saw her often. There seemed no end to her illness; her health steadily got worse, her memory was affected making it often impossible to remember her music. Often she even forgot how to play.

In November 1997 her consultant paediatrician confirmed GP Dr Nigel Hunt's diagnosis, initially of Post Viral Fatigue. We had at last a name for this illness. Christmas came and went. Sarah aimed to go to school part-time,

April 1998 A month to remember in our family life. Sarah's health was deteriorating fast and she was now having to spend long periods of time in bed. Although exhausted, she was unable to sleep, was in a lot of pain and unable to walk far. She became unable to stand lights or noise. Weakness became more of a problem as she started to lose the use of her limbs and collapse. Conversation was difficult as she was very affected by poor memory and her speech was slurred. We had been advised that she was doing too much, but our daughter had to learn this for herself and come to terms with it. It was a very painful time for us as parents, helping and supporting her as she went through this learning process.

Dr Hunt became our most frequent visitor. He and her paediatrician continued to support us but Sarah's self-confidence was at an all time low and she was turning to us as parents to

but it became less and less feasible. She became unable to go out, and had to give up her beloved music as her memory problems and the pains in her limbs made it impossible for her to continue. Life at school was very hard as she was no longer able to keep up with her work. If she attended a lesson she was unable to recall the work.

The school situation was not proving to be supportive of her needs and both Dr Hunt and the paediatrician corresponded with the school. In January 1998 it became obvious that the work situation for us as parents had to change in order to be there for Sarah, who was increasingly ill. I changed my employment and took part-time work locally, enabling me to get home at lunch-times.

find answers and help. We felt so inadequate at dealing with this little heard-of illness. The more Sarah tried to get back to normal the worse she got. I had read a library full of books on ME but it was not like having human contact with someone who knew the effects this illness has on both the patient and their family. We needed someone to talk to. We had got tired of people saying: 'Is that what they call school phobia?' when there was our daughter, so ill and putting up such a fight to get into school.

One of our biggest problems was trying to guide Sarah on her education. We had found it difficult to discover what to do about her exams. On one of Dr Hunt's visits I shared my serious concerns for Sarah, who was by now beginning to despair. He mentioned Jane Colby. About nine o'clock the same evening Dr Hunt knocked on our door with a fax from her advising him: 'There's so much that can be done.'

Suddenly we had facts and all the information we had so longed for. We had turned the corner - we had knowledge. Sarah's aim at that time was to become an Interior Designer. At Jane's suggestion we investigated

June 1998 *The wheelchair which Dr Hunt had ordered for Sarah arrived. Sarah had fallen so many times and had hardly been able to walk, often being unable even to get to the toilet. We realised that she needed someone present all the time for her own safety so I left my part-time job. This resulted in a better quality of life for Sarah, as her small store of energy was no longer totally expended on mundane tasks. Sarah had told Dr Hunt that she would not use a wheelchair, but she used it from the first day of its arrival - I was there to push it for her - and although she said 'Legs is best' it enabled us to go out again together. She applied successfully for an orange badge and home tuition kicked into gear in September 1998.*

However, Sarah's memory was very poor still, and by now she was suffering a form of dyslexia. School proved too much and one of her subjects involved too much. Life was just school, home tutor, illness and sleep. Our team set about arrangements again and with their support Sarah studied Art for one hour a week through home tuition. Her tutor helped her, her confidence grew, and she achieved excellent work, which restored her pride in herself. Sarah says: 'My tutor was excellent and understood the needs of a pupil who is suffering with ME. Without his help

Sarah obtained further qualifications but her strength was not always up to the increased demands this entailed. Undeterred, she is now working, doing data input in the offices of a large consultancy company. Having learned through experience what could be done at home, she has taught herself the skills that she needed.

disabled access to Further Education College. This gave Sarah so much hope for the future as she now knew she only needed two GCSEs to access the course.

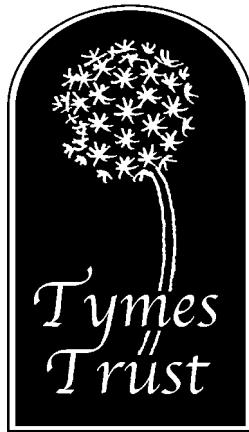
and guidance I would not have had the confidence to take my Art GCSE. I would like to say thank you.'

Through the help of the Home Tuition Service Sarah was able to take her Art exam at home with her tutor as invigilator. Sarah was so pleased that the Tuition Service allowed this. She explains: 'It was such a relief to me to have my tutor, as I feel so comfortable with him, and he understood my need for breaks.' Sarah achieved a Grade B and everyone was over the moon.

We as a family cannot praise enough the care that we had. It started with our GP, Dr Hunt, who was always there for us. It was he who brought in an educational expert who opened the education doors for us. Our consultant paediatrician, Dr Agrawal, was always there to support us and invited Jane Colby to meet with fellow consultants.

There has been a great deal achieved in helping Sarah. Sarah came to terms with her illness very well; even when she was still very ill she managed to feel what it is like to achieve.

The family has a different outlook on life now; we are positive in that we know we can cope with whatever happens in the future.



We, as a family, cannot praise enough the care that we had.
It started with our GP, who was always there for us.
It was he who opened the education doors for us.

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