

ME/CFS Society of NSW Inc.

Youth Pack

Resource for young people with
ME/CFS/FMS

*You do not need to deal with your challenges alone.
We want you to know there is help and hope out there.*

Contacting us:

The ME/CFS Society of NSW Inc can be found at

- Suite 903, 10 Help Street, Chatswood NSW 2067
- Telephone 02 9904 8433
- Why not try our website at www.me-cfs.org.au

If you live outside NSW there are other Societies across Australia, so check out our useful contacts information at the end of this pack.

A special note on terminology:

Throughout this booklet the abbreviated form of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome is used (ME/CFS). CFS is the term developed for adults by the 1994 International Case Definition Standards, however, recently published paediatric-specific case definition uses the label paediatric ME/CFS for adolescents (The CFIDS Chronicles, USA, 2007).

FMS stands for Fibromyalgia Syndrome. There is an overlap of symptoms between FMS and ME/CFS. FMS involves widespread pain of the muscles, ligaments, and tendons. It is a soft-tissue pain syndrome that is classified as non-articular rheumatism in the World Health Organization's International Classification of Diseases. As in other medical conditions, the severity of FMS varies from mild to severe and it can be debilitating.

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CONTENTS

1. ME/Chronic Fatigue Syndrome and YOUTH

- 1.1 Journey to another place
- 1.2 What is ME/CFS?
- 1.3 What are the Symptoms of ME/CFS?
- 1.4 How long will it last? Is there a cure?
- 1.5 Personal experiences

2. Education

- 2.1 Keeping up appearances
- 2.2 Other options
- 2.3 Applying for university with a UAI
- 2.4 Helping others to understand

3. Entitlements and Community Support

- 3.1 Centrelink
- 3.2 Housing
- 3.3 Local Services

4. Relationships

- 4.1 Friends
- 4.2 Family
- 4.3 Feelings

5. How can I assist my recovery?

- 5.1 Finding a supportive and knowledgeable GP
- 5.2 Making a body budget
- 5.3 An important message on drugs and alcohol
- 5.4 Staying positive

Appendix

Letter to educational staff
Letter to parent/sibling
Helpful telephone numbers
Helpful website addresses

1. ME/CHRONIC FATIGUE SYNDROME AND YOUTH

1.1 Journey to another place:

You're in your teens, or early twenties, maybe you're involved in sport, enjoy music, have study commitments and lots of social commitments too! You are enjoying your life and then, without warning, you become ill. You may have flu-like feelings with "foggy" headaches, maybe stomach aches and pains, muscle pain, rashes, fever and chills. It is all a bit daunting because you feel really tired and your concentration levels are low. You're feeling pretty "flat" and sad and all of these symptoms and feelings don't seem to pass as quickly as you would expect.

To the doctor you go...Getting an early and accurate diagnosis of ME/CFS may be difficult as not all doctors treat the symptoms of ME/CFS the same. Your doctor should arrange for you to have blood tests and take a history of your medical health. This will include any significant life issues that may contribute to your current health and well-being. Your doctor will take a comprehensive approach to making a correct diagnosis of your illness as there is set criteria your symptoms must meet in order to be diagnosed with ME/CFS.

There are important health benefits/connections in obtaining an early and stress-free diagnosis from your doctor. The symptoms and the impact of the illness may be reduced if the illness is managed promptly, with belief and support.



A supportive doctor is one who will work with you, exploring the most suitable therapies and treatments. This approach may assist in putting your mind at ease and in turn reduce feelings of anxiety.

A diagnosis of ME/CFS may make you feel really confused, sad and even worried, but at the same time strangely relieved. This does sound odd, doesn't it, but being told by your doctor that you have ME/CFS allows you to know and understand why your body is feeling the way it is. It also helps you explain to your friends and family exactly what is happening to you and why.

1.2 What are ME/CFS and FMS?

Myalgic Encephalomyelitis (ME) or Chronic Fatigue Syndrome (CFS) and Fibromyalgia Syndrome (FMS) are complex and debilitating illnesses that affect many different systems of the body. They must persist for more than 6 months to meet diagnostic criteria.

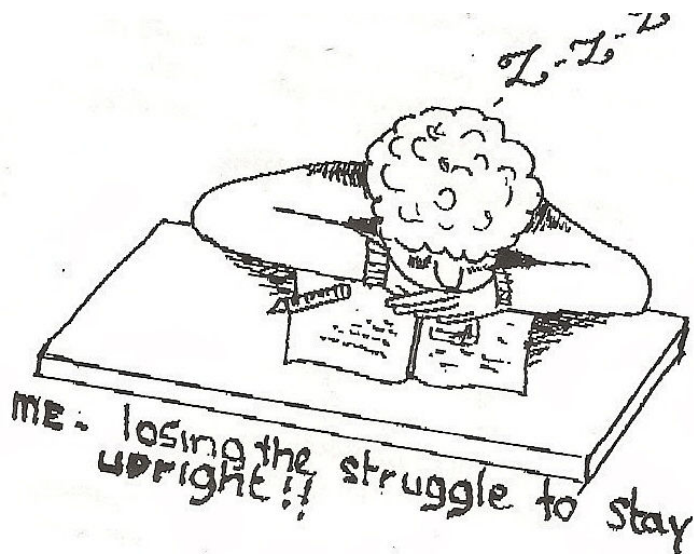
Since 1969, the World Health Organisation's International Classification of Diseases has listed ME/CFS with post-viral fatigue syndrome as a disorder of the neurological system in code G93.3.

The causes are not yet clearly defined or known, however multiple factors may be involved at the same time. The illness most frequently follows an acute infection such as glandular fever or upper respiratory infections and viral 'flus'. Chemical exposure and environmental pollutants can also trigger the illness, as can the experience of a traumatic event, serious accident or undergoing major surgery.

There is currently extensive investigation and research being conducted world-wide looking at the relationship of ME/CFS and the role of persistent infections, challenges to the immune system and environmental toxic exposure. Research is also exploring nuclear imaging of blood flow in the brain, cardiac abnormalities, gut dysfunction, metabolic abnormalities and genetic factors.

1.3 What are the symptoms of ME/CFS?

Usually the most prominent symptom is a debilitating physical and mental fatigue that does not "go away" after you have rested. This fatigue can be made worse if you are under stress or have to use extra physical or mental energy. Everybody is different so some symptoms may vary and may even be inconsistent and 'layered'. Sometimes one particular symptom may become more severe making other symptoms less obvious.



Other symptoms include:

- a feeling of being generally unwell, like you have the 'flu'
- headaches that seem 'different' and 'new'
- Cognitive dysfunction which can be in the form of memory loss in the short term, poor concentration, difficulty processing and computing information or finding the right word, reading, writing, losing track of things, forgetting names, feeling disoriented
- Light-headedness upon standing, balance disturbances and feelings of clumsiness
- Shortness of breath
- Palpitations
- Sensitivities to light, touch and sound
- A feeling of nausea
- Gastrointestinal (stomach) and urinary problems including bloating, flatulence, diarrhoea, constipation and stomach pain
- Recurring sore throat
- Sweating and feverishness
- New sensitivities to certain foods such as yeast, sugar, caffeine, gluten and dairy products, chemicals and medications
- Weight gain or weight loss
- Pain in muscles and joints
- Sleep disturbance with wakefulness, hypersomnia (oversleeping) and insomnia (inability to go to sleep), waking up feeling tired, and an altered "day-night" sleep pattern
- Intolerance to temperature changes, and cold extremities
- A worsening of symptoms with stressors such as new infection, travel, anaesthetic, premenstrual tension

1.4 How long will ME/CFS last?

Accurately predicting the duration and recovery times for any illness is always difficult but even more so with ME/CFS. Some people diagnosed with ME/CFS can remain unwell for some years and yet other people either recover or improve much faster. Younger people are reported to have a higher recovery rate than adults. Usually there is a plateau between six months and six years (National ME/FM Network, 2007).

If you find yourself feeling overwhelmed then try contacting your local ME/CFS Society.

The ME/CFS Society of NSW Inc provide a range of services free of charge. These services include a Social Welfare Worker that is ready to listen to your concerns and may be able to assist you in preparing a personalised strategy. The NSW office can also approach service providers, schools / universities, or your place of employment, if appropriate, to provide information and advocate on your behalf.

1.5 Personal experiences:

My Miracle

Hi, my name is Tamlyn and I am 17 years old. At just 12 years old, I fell sick with a very seriously debilitating illness called Myalgic Encephalomyelitis /Chronic Fatigue Syndrome. I was diagnosed with the illness after having glandular fever.

Physically, it felt as though my body had just shut down. Little daily activities that most people take for granted became enormous tasks for me. Emotionally, it felt even worse. I had to prove myself to other people about how 'real' my illness was. Some days I felt like telling people that I had cancer; at least then I would get the empathy and understanding that I deserved.

I watched my friends leave me behind whilst I lay there in bed wondering whether or not I had enough strength to stand up in the shower.

The only way that I got through it all was the fact that Mum was right by my side. Every emotion that I went through, Mum went through. We worked so hard together to keep my spirits up and to try and stay positive.

My life is so different now. I live a very active and full lifestyle and emotionally I have never been happier. Please never, ever lose spirit and hope.

Onion Story

Do onions make you cry? Have you ever peeled back the layers one by one? That's what my life with ME/CFS/FM (Myalgic Encephalopathy/Chronic Fatigue Syndrome/Fibromyalgia) has been like over the past 12 years; gradually losing layer by layer of my once active, social, independent life until I hit the centre/rock bottom/got right back to the basic routine of sleeping/eating/bathroom and was like a baby needing 24/7 care because I was too weak to move, talk or do anything other than keep breathing.

After being bed-bound for many years, with most systems of my body affected, I have been gradually adding the layers back onto my life. Now only housebound, every day is still a process of "pacing" and balancing the energy "debit/credit". Do too much and I lose a layer again so it's a slow process but one day I hope to have my "whole onion" back....different to before ME/CFS/FM, but perhaps better because of it, as I now appreciate things that most people take for granted.

Little things to others are a big deal to me and over the years I have had to re-learn a lot of skills, like cleaning my own teeth, being able to hold a pen and write, talking, using the computer, e-mailing friends around the world, sitting up, standing up and walking. I can now get from room to room without help and in the late afternoon/evening when I have my biggest "window" of energy I can help prepare dinner.

It's been a long journey but the love and support given from family and friends have been invaluable sources of strength.

So if your life with ME/CFS/FM feels like the layers of an onion too, keep positive and take heart from the fact that there are many others around the world like you... all at different levels and stages of this illness and all on their own journey... all trying their best.

We all hope for a cure one day – in the meantime we appreciate awareness and understanding from the community.

~ Kerri Stephenson, Living with ME/CFS since age 20.

2. EDUCATION

2.1 Keeping up appearances:

It's difficult to keep up previous performance when all of a sudden things are physically and mentally more difficult. Rather than pretend that nothing has changed, your new needs should be communicated with your school or college. Young people report different experiences with educational establishments. Some schools are more able and willing to be flexible than others. Confide in one or two trusted teachers and use them as your advocates within the school system.

Ask your parents/carers to become involved and let them know you would like some help with talking to your School Principal or Year Co-ordinator in setting up ways to manage your studies. Here are some tips below:

- * Arrange to meet with your School Principal to discuss your illness and make arrangements for how your needs may best be met.
- * It is important your school is aware of your limitations, particularly in relation to sport and exercise, as well as the need for rest.
- * Request that a special box or folder system be set up and kept in a designated safe place, where teachers can leave your school work for you or your parent/carer to collect. A "communication" diary could also be used between you and your teachers so that you are not missing out on important information.
- * Consider setting up a specific email address that both you and your parents/carers can access to enable teachers to email information to you at home.
- * Have in place an agreement/arrangement with the school that simplifies the process of providing sick or late notes when you are unable to attend school.
- * Your need to attend sick bay may be high at times and this should be respected. Ask for the school to accommodate this need freely.
- * Speak to your Year Co-ordinator about having your lessons recorded, particularly when they contain important exam information.
- * Make an application to the Board of Studies for special provisions for rest breaks and separate rooms when undertaking exams.

Having a goal to complete high school or university study is positive however when that goal is unobtainable you may need to adjust your strategy.

Research suggests that ME/CFS is the commonest cause of long term sickness absence from school in previously fit young people (Abbot, 2008).

According to The CFIDS Chronicles (USA, 2007) research has concluded that only 14% of adolescents with paediatric ME/CFS continued to attend school regularly after the onset of the illness, and a third of adolescents with the illness experienced severe activity restrictions and marked drops in school achievement. It is further noted that in some samples, students miss an average of 80 days in a six month period.

Fortunately there are now many ways to study.



2.2 Other options:

- * Attending school on a part-time basis with reduced subject load and hours.

- * Distance Education: If you are too unwell to keep up with school travel on a regular basis. Sydney Distance Education School encourages learning via written materials, CD, DVD, telephone, email and on the World Wide Web through online lessons developed using the MOODLE learning management system. Students are also engaged through videoconferencing, student online forums, school visits, study days, excursions, peer support and a Students Representative Council. This option is a great way to complete your studies at home and at your own pace. Contact www.sydneyh-d.schools.nsw.edu.au (02) 9383 0200 for further information.

- * TAFE – your HSC can be completed in a number of ways. TAFE NSW provides a relaxed, adult working environment where the emphasis is on self-discipline and individual responsibility. Programs at TAFE include:

One-year, reduced: This program is designed for people aged 20 or over (on March 1 of the HSC year) who need only one or two subjects for work purposes or who want to apply for mature-age entry to university.

Accumulating program: The HSC can be completed over a 5 year period. This enables students to study part time. This program also allows students to repeat a few subjects from a previous attempt (within the 5 year limit).

Open Training and Education Network and Distance Education (OTEN-DE): This open learning program is ideal for those who, are unable to attend regular classes.

* Seeking **special exam provisions** such as large print papers, use of a writer, use of a reader, extension of test time, rest breaks, use of a personal computer, special exam centres, individual supervision, permission to take medication etc. To access application for these provisions contact must be made through your allocated school co-ordinator.

* **Home schooling:** your parents/carers may take responsibility to teach you at home.

The Board of Studies can offer many special provisions to assist you. It is very important that you find out exactly what is required so that you can take an alternative study path. To contact the **Board of Studies special provisions unit** telephone (02) 9367 8117 or (02) 9367 8325

2.3 Applying for university with a UAI:

Once you have completed the HSC, either through your high school, distance education, or TAFE, you will be given the option of receiving a University Admission Index (UAI) – the rank used by universities in offering places. Students are given the choice not to receive a UAI but it is recommended that you get one, even if you do not plan on attending university, because you never know if your circumstances will change. Applications to most universities in NSW and ACT are handled by the Universities Admission Centre (UAC). You can lodge a single application with up to nine course preferences, although some universities require direct applications for some courses.

When filling out the UAC form, it is vital you indicate your disability status. It will not affect your application in anyway, but you will be sent a questionnaire about your particular situation so that the UAC can notify any university that you accept an offer from.

If your UAI is not high enough for your chosen course, don't worry, there are many options available to continue your education: you can either enter a similar course (with a lower UAI requirement) and transfer after a year; you can enrol at TAFE and re-apply after a year on the strength of your TAFE results (often you will be granted credit for TAFE subjects you have successfully completed); or you can undertake a university

preparation program to gain entry as a mature aged student. Similarly, you can apply to do a Special Tertiary Admission Test (STAT) which will give you an assessed result equivalent to a UAI. It is important to check with your chosen university whether they accept STAT results as part of the entrance criteria.

2.4 Helping others to understand:

It is very important that your school and its teachers understand what it means to have ME/CFS/FMS. The NSW ME/CFS Society promotes and encourages teachers and educational environments to:

- ☺ respect and trust you.
- ☺ listen to you! You are the best judge of how you are feeling.
- ☺ talk to you about what it is like living with ME/CFS/FMS as a young person.
- ☺ understand what it feels like to be missing out on hanging out with your friends and family and not being able to do all the “normal” stuff your peers and friends may be doing at the time.
- ☺ empathise with you and understand your feelings.
- ☺ learn about ME/CFS/FMS and to identify with the symptoms.
- ☺ understand that ME/CFS/FMS can be remitting/relapsing conditions, varying from feeling okay to feeling completely exhausted, and to understand how your symptoms may impact upon your capacity to achieve all that is set before you.
- ☺ encourage and promote your social growth by helping you to find a comfortable and quiet place within the school where you can be with your friends when you are not able to participate in other activities.
- ☺ be aware that other students need to know and understand what it means to have ME/CFS/FMS.
- ☺ set realistic and achievable goals for people with ME/CFS/FMS.

If the ‘brain fog’ you are experiencing makes it harder than usual to get your point across, why not try giving your teacher, year advisor, or lecturer a letter? There is a letter ready for you to pull out and sign on page If you are up to it you could write a personalised letter explaining how you feel and what you need.

Depending on your level of health, study may need to take a back seat for a while. Don’t forget that one is never too old to learn.

3. ENTITLEMENTS AND COMMUNITY SUPPORT

Please note: For most government payments you will need Australian residency status.

3.1 Centrelink:

Disability Support Pension (DSP)

You may get a Disability Support Pension if you have an illness, injury or disability and are over 16 years. This payment is means tested (if you have a partner their income will also be measured). You will need to provide a report from your doctor on your impairment and work capacity.

Since the Welfare to Work initiative (1st July 2006), there have been some changes. You will be required to attend an interview with a Job Capacity Assessor. The Assessor will use 'Impairment Tables' to rate your impairment according to the severity of your medical condition and your ability to work. You need at least 20 points to get the DSP.

It is important that you present all of your health information. Get reports from everyone you have seen in relation to your illness and write a list of things you would like to say at the meeting. Because people with ME/CFS/FMS do not look 'sick' it is sometimes difficult for the Assessors to gain an accurate picture of what life for you is really like. Just attending the interview can be a strain - the Assessor will not get to see you when you are recovering from the interview at home.

If you feel that you have been unfairly assessed you have the right to appeal. There are stages of appeal. You can ask to speak to an Authorised Review Officer within Centrelink (by person, phone or internet). If you are still not satisfied you can take it to the Social Security Appeals Tribunal (SSAT) which is an independent statutory body.

Carer Allowance

If you are over 16, too unwell to look after yourself and need daily care, then your carer may be entitled to Carer Allowance (adult). This is a Centrelink payment that is not means tested. NB You need a health professional's report to establish eligibility.

Rent Assistance

Depending on your income, Centrelink may be able to help with rent assistance. Rent Assistance is paid at a rate of 75 cents for each dollar of rent you pay above the relevant rent threshold, up to a maximum rate. For details of thresholds contact your closest Centrelink office.

3.2 Housing:

If you qualify for a Disability Support Pension (or are on a supported income and feel that your ability to earn future wages is compromised) it is worth considering housing. Will you be able to afford / maintain independent housing some years down the track? You may be fortunate enough to be living with family now but what happens if / when it is no longer possible to reside in the family home?

Even though it is difficult to think about, if you are 18 or over, acting now could save you some stress later. Young people are often not aware that Department of Housing waiting lists can be 15 years + in certain areas. To apply you need to contact the Department of Housing and complete a Public Housing application form. If approved you will get something known as a 'T-number'. Once you have this number you will also be eligible for other 'Community Housing' schemes.

If you are eligible for public housing you will also probably qualify for 'Rent Start'. This is where you are assisted with 75% of a new bond. If you cannot sustain current private rental accommodation due to ill health and are in need of assistance now, go to your nearest Department of Housing office. Although waiting lists are long you may be prioritised depending on your personal situation. There are also some alternative housing schemes especially for younger people in need.

If you recover, then obviously you will not need any housing assistance and your application can be withdrawn.

3.3 Local Services:

The number of local support services available typically varies depending on whether you live in a metro or rural area. Services that may be of assistance to you include mobile libraries, subsidised assisted travel, help with shopping/cleaning, personal care and counselling services. Contact your Council/Neighbourhood office or call your ME/CFS Society for details. If you would like to do a search yourself try the Local Information Network for Community Services (LINCS) website www.datadiction.com.au/lincs/.

4. RELATIONSHIPS

4.1 Friends:

It is really important to tell your friends about ME/CFS/FMS. Give them a copy of this Pack! Tell your friends how you are feeling and how this varies from time to time. Looking "well" doesn't have to mean you are feeling well! It may even be hard for your friends to come to terms with their own separation from you. Allow some time to speak about each others feelings. Reassure your friends that you understand how they may also be feeling about you.



Keep a positive mind about friends and remember the importance of communicating with them. If your friends don't know about your illness, when you are forced to make excuses about why you are not able to go out, they will almost certainly internalise these 'rejections' and assume that you don't like them. If they are aware of your limitations then there might be scope to make alternative plans, e.g., they could come over to visit. More importantly they will ask you next time there is something happening.

Spending an entire day out with friends may leave you feeling exhausted and not well for a number of days after. Instead, arrange to spend the part of the day with your friends when you know you usually feel okay. This way you are still having positive social contact and at the same time, looking after your physical needs by not overdoing things.

Many young people with ME/CFS/FMS find it helpful to make new friendships with others who are in a similar situation. Interacting with people who understand your experiences can be a really great way of re-energising your self-belief and spirit. It's easy to go online and join a chatroom with others around the world who are your age and are learning to live with a similar illness. (See the contact list for web addresses.) If you prefer the face to face kind of friendships, contact your Society for details of a ME/CFS/FMS Support Group for younger people. If there are no groups running in your area why not think about starting a group of your own? Meetings can be organised to take place in your own home or somewhere neutral like a library community room, or café. There will be guidance available from your Society to help you get started.

4.2 Family:

Adolescence is typically when you begin to separate from the holds of your parents and follow your own path. Any gains in independence can take a beating when you become ill with ME/CFS/FMS. You are suddenly reliant on your family for care and/or money to subsidise you while you may be out of work and needing to pay medical expenses. If you still live at home you may feel that your parent(s) begin to take over in an attempt to 'fix' you. They may begin to make plans about your medical treatment, try to influence what you eat and generally 'fuss'. While this can be frustrating, be thankful that you have someone supportive in your life that wants to help. Try to communicate your feelings while acknowledging their attempts to be supportive.

Parents typically want the best for their children; it is difficult for them to see you suffering. Some parents may go into denial and find it hard to believe that you are ill. They might tell you to get out of bed and sort yourself out, in an attempt to get things back to 'normal'. If this resonates with your experience try getting a written diagnosis from your doctor or encourage them to call a ME/CFS Society for information. If they have held high hopes for you (in relation to educational achievement, career etc) you may feel that you are letting them down when you cannot live up to their expectations due to your illness. The key is to try and improve communication. If attempts to talk tend to end in arguments try to write a letter (example in Appendix).

4.3 Feelings:

It is normal and real to feel down, lonely, isolated and empty, even guilty, angry, depressed, lonely, and anxious. It is important that you reach out and share those emotions with your family and friends, your doctor, your School Counsellor, or anyone you trust and feel safe and comfortable with.

Remember that help is available, and there are many strategies and ways you can manage these feelings to reduce the negative impact such emotions can have on your health.

Don't forget the ME/CFS Society of NSW also provides a telephone support service for young people with ME/CFS/FMS. We are here to help you and listen to you. Maybe you would like a friend to talk to us so they will understand more about ME/CFS, too.

5. HOW CAN I ASSIST MY RECOVERY?

Although it may feel like you have no control over the illness that has taken over, there are still things that you can do to benefit your mind and body.

5.1 Finding a supportive and knowledgeable GP:

It's important to feel that you have an ally in your GP. If you don't feel adequately listened to and are dissatisfied with your current treatment consider finding an alternative GP. The ME/CFS Society of NSW has a database of medical practitioners who have been recommended by members of the Society. If you want to stick with your current GP but would like him/her to learn more about ME/CFS then there are medical Guidelines available from your Society.

5.2 Making a body budget:

The process of getting better doesn't have to mean you miss out on doing all the things you enjoy but it does mean you have to prioritise the energy and time you have to make room for feeling good. Keeping a diary of what you do and how you feel is a good way of getting an accurate picture and understanding of what activities or triggers result in feeling rotten, or better still, feeling good afterwards!

Learning to make choices about what activities to skip and which ones to participate in, or when to schedule rest before a big event, are very important strategies for young people with ME/CFS/FMS. Lots of little steps at your own pace can ease the big hike in the long run so if you know you have to complete certain tasks within a deadline, try to spread your time out evenly. Break up the hard stuff with lots of regular rest and relaxation time in between. Allow your body to cope with what you demand of it.

Taking charge of your life, your body, your energy is very important in how you see yourself and believe in your own abilities.

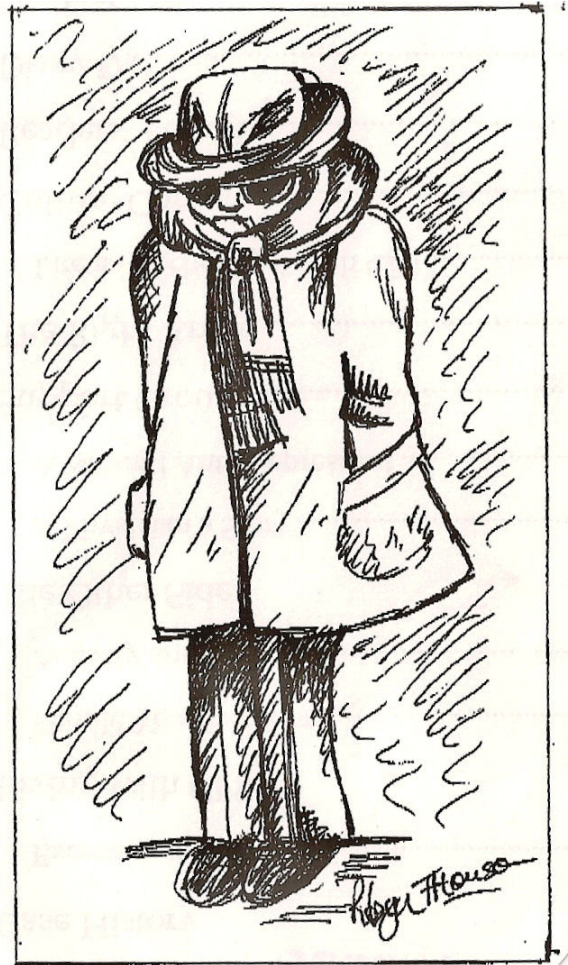
5.3 An important message on drugs and alcohol:

Drugs and alcohol affect people in many different ways. It is very important to remember that whilst recreational drug use is always a risky behaviour, and never safe, it becomes increasingly risky when used in conjunction with other medication that you may be taking to treat symptoms of ME/CFS/FMS. Depending on your health and the effects ME/CFS/FMS has on your body, your ability to metabolise drugs and alcohol may be significantly impaired. If you are taking non-prescription drugs regularly you might be considering reducing or stopping your use. There is help out there; your first step is to want to make a change.

For information about drugs and their effects contact the National Drug and Alcohol line on (02) 9361 8000. Your Doctor, School Counsellor, and local Community Centre can assist you as well with information.

5.4 Staying positive:

Total health and wellbeing are not just dependant upon feeling or not feeling sick. The feeling of being 'ill' or being 'well' are only one part of the many dimensions to positive wellbeing. The environment in which we live, the thoughts and feelings we hold, the perceived and real stressors and pressures we experience, the emotions we feel and express, the way we frame a challenge, even the expressions we hold on our face are just a few of the things that can affect our wellbeing. When you are feeling stressed your body prepares itself to take on the stressor. This involves very intricate processes occurring within the autonomic nervous system, which in turn involves the endocrine and immune systems. The message here is to look outside the dimensions of how we normally view health. In order to work with your body, boost and bolster it up as much as you can with happy thoughts and positive plans. Believe in yourself, listen to your body and see the dimensions in your life moving towards better days.



**And skulking out of the shadows
He came.....
The vitamin Pill Dealer.**

APPENDIX

Letter to educational staff:

Date

Dear

As you may know by now, I am sick with Myalgic Encephalomyelitis / CFS /Fibromyalgia. The illness is poorly understood in the general community so I accept that you may be wondering why I have not been able to make it regularly to class and why I am not my 'usual self'.

My symptoms include headaches, an inability to think clearly ('brain-fog'), dizziness, body aches, sensitivity to chemicals (e.g. personal perfumes/deodorants/cleaning products/Science Lab) and overwhelming tiredness. All these make it incredibly difficult to get to lessons. When I do manage to make it into the classroom it is often difficult to stay focused, take notes and even sit up for any length of time.

I am still here trying to learn because I want to achieve my educational goals. Some days are better than others. When I can't make it in I still want to learn and achieve my goals however my body has prevented me from doing so. Please don't be disappointed in me; although you might not see it, I am still doing my best.

I need to be especially cautious when doing Exercise (e.g. sitting up, walking, climbing stairs) and Sport.

There are many things you and the school could do to help, these are:

- Please be understanding and flexible if possible.
- Let me take work home. (This will save me the energy it takes to physically make it into the classroom. It will also enable me to work at the time when I am feeling my best in the day and at my own pace.)
- Allow me to ask questions. (Perhaps you could link me up with a peer or allow me to email a staff member.)
- Prioritise essential learning tasks.
- Arrange for missed work, notes, school newsletters and so on to be made available for easy collection (e.g. a folder in the front office).
- Tape important lessons.
- Make educational videos or audiotapes available.
- Ensure that other staff are aware of my limitations .
- Minimise administrative requirements (e.g. presenting notes for being late).

- Allow me access to a rest area (preferably not sick bay as I am susceptible to infections).
- Provide two sets of text books, one for home and one for school, to avoid the need for heavy bags.
- Minimise environmental and chemical sensitivities which can exacerbate symptoms: poor air quality e.g. gas heating, inadequately ventilated rooms, chemistry laboratory fumes, art mediums, glues, perfumes etc.
- Reduce my subject load if I am not coping.
- As a last resort grant time off. I am still young and may need to return to study when my health has improved.

Thank you for listening. Your support is valued.

Kind regards

Letter to parent/sibling:

Dear

Please respect that I am doing the best I can while I feel this way. It's not that I'm lazy or trying to get out of things. I want my life back on track and for things to go back to 'normal' just as much as you.

I'm sorry if I take my anger and frustration out on you when there is no one else around.

I realise that my illness has brought changes into your life too. It has changed the way that our family 'operates'. I can't ask you not to worry as I know you will anyway.

I appreciate the things you are doing for me while I am weak, in pain and tired. I can however, still do some things for myself – and I need to do them so that I feel I still have some control over my life.

Some things you can do to help me are:

- Give me space.
- Help me when I ask for assistance.
- Make it easier for me, if possible, to get to appointments.
- Speak slowly and wait for a response.
- Avoid using deodorant sprays, hair spray, perfume, aftershave, cleaning products etc anywhere near me.
- Respect my choices around medical treatment.

Thanks for trying to understand,

I love you,

Helpful telephone numbers:

AHMF (Alison Hunter Memorial Foundation)	(02) 9958 6285
Alcohol & Drug Information Service	(02) 9361 8000
Arthritis NSW (for information on FMS)	(02) 9683 1633
Carers NSW	1800 242 636
Centrelink	13 1021
Centrelink Career Information Centre	(02) 9209 1661
Centrelink Newstart Allowance	13 2850
Centrelink Disability Services	13 2717
Centrelink Youth and Student Services	13 2490
Centrelink Abstudy	13 2317
Commonwealth Carelink Centre	1800 052 222
Crisis Accommodation Line	1800 234 566 or (02) 9265 9081
Department of Housing	1800 629 212
Domestic Violence Counselling and Advice	1800 656 463
Ethnic People with Disabilities Info Line	(02) 9569 1288
Family Drug Support	1300 368 186
Grief Support	(02) 9489 6644
Home Schooling Info Line	(02) 9367 8395
Isolated Patients' Travel and Accommodation Assistance Scheme	(02) 9424 5764
Lifeline (24hr line)	13 1114
ME/CFS Society of ACT	(02) 6290 1984
ME/CFS Society of NSW	(02) 9904 8433
ME/CFS Society of QLD	(07) 4632 8173
ME/CFS Society of SA	(08) 8410 8929
ME/CFS Society of VIC (inc. TAS and NT)	(03) 9888 8798
ME/CFS Society of WA	(08) 9346 7477

Mobility Parking Scheme	13 2213
NICAN Sport and Recreation Line for People with a Disability	1800 806 769 or (02) 6241 1220
Open Learning University Entrance Program Information	1300 363 652
Parent Line (9.00am- 4.30pm Mon-Sat)	13 2055
Primary Distance Education Info	(02) 9568 9888
Salvo Youth Line	(02) 9360 3000
Sydney Distance Education High School	(02) 9383 0200
TAFE - Open Training Scheme	1300 362 346 or (02) 9715 8333
Translating and Interpreting Services	13 1450
Unifam - family support	(02) 9633 4555
Wesley Counselling Services	(02) 9951 5566
Welfare Rights Centre Free Legal Information Service	(02) 9211 5300

Helpful website addresses:

www.groups.yahoo.com/group/sleepyteenzzz

Australian website designed by adolescents living with ME/CFS

www.me-cfs.org.au

The ME/CFS Society of NSW Inc. official website

www.pediatricnetwork.org

Website designed for adolescents with ME/CFS/FM

www.tymestrust.org

UK website for Youth with ME/CFS

www.immunesupport.com

Website containing general dietary information for ME/CFS/FM

www.ahmf.org

The Alison Hunter Memorial Foundation – adolescent perspectives on ME/CFS

www.users.bigpond.com/mefmtba/youth

Website for young people with ME/CFS/FM

www.lawstuff.org.au or www.ncylc.org.au

National Children's and Youth Law Centre

www.datadiction.com.au/lincs/

Community services directory