

Foreword

17 million people worldwide suffer from a severe, complex, neurological disease that affects every system in the body. It affects people of all ages, genders, ethnicities and income groups. It is more debilitating than most other diseases; when severe it is equal to undergoing chemotherapy, or having multiple sclerosis or late stage AIDS. The most severely affected are confined to bed in a darkened room and have to be tube-fed.

It is called Myalgic Encephalomyelitis, or ME. Some however call it Chronic Fatigue Syndrome. The cause is unknown and there is currently no cure, despite many claims to the contrary.

During the last 14 years I have written many poems, articles, etc on the subject of my M.E. and have now decided to put them all together into this book. I started writing poetry many years ago and, although I first became ill in 1985, the first piece I wrote about my illness was in 2001. After that they just kept coming, partly as a way to express my frustrations.

The articles are more recent and first appeared in a blog: Moons and Junes and Ferris Wheels.

The cover art is from a video I made called Behind the Lies which can be seen on Youtube.

All the work contained in this book is my own original work. However some of the poetry may have been posted online at times, perhaps under a pen name. Poems are arranged in chronological order.

Please excuse any errors in editing. My mind doesn't always function as well as I'd like.

I dedicate this book to all the many thousands of people living with little or no hope of recovery, especially those completely bed-bound. Bless you all.

Everything in this book is the original work of Christine Stromberg
even if it has previously appeared under a pseudonym.

The image on the cover is from my Youtube video: Behind The Lies.

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What Is It Like To Have ME?

What is it like having M.E. they ask. I used to say, it's like a car without fuel. It won't go. But that's a bad analogy. It's more like a car with a faulty alternator. Not everyone will understand what that means, so let me spell it out.

Cars today are run by electrical circuits, as well as fuel. There is a thing called an alternator which charges up the battery as the car is running, otherwise the battery would be constantly drained. When the battery is flat the car won't run. Not only that, the electrically driven windows don't work, the sun roof likewise, the heater or air conditioning, and just about everything else, stops dead. So if the alternator is faulty, the car is in constant danger of being nothing more than an expensive ornament. Filling the car with fuel simply won't help.

Animals are much more complicated than cars, of course. We have cells called mitochondria which make energy, needed to run every system in the body, from the muscles to the brain. This energy is stored in the fat cells, our batteries. Without energy the brain doesn't function, the muscles don't function, the stomach can't digest, etc etc. There is a back up system consisting of adrenalin. You may have heard this referred to as the "fight or flight" hormone. It is produced by the adrenal glands and can be called up in emergencies to give an energy boost. Unfortunately, once used up it takes a long time to replace, so is only for emergencies.

Marathons runner tend to run on adrenalin, and afterwards need some time to recover. The subsequent "crash" is sometimes called payback. For people with M.E. that crash can follow a very small expenditure of energy: talking, thinking, going to the bathroom, eating a meal. Try to imagine how it affects your life, when everything you do leaves you exhausted for days.

If the mitochondria are faulty, we too, just like that car, become pretty useless. Unfortunately being fat doesn't help either because in M.E. the body can't call upon the energy stored in the fat. It doesn't matter how much fuel in the form of food is ingested, it isn't being utilised properly.

Not only that, if the brain isn't working correctly, every system in the body is affected, as the brain controls everything else. The kind of symptoms this leads to are many and varied, some less serious, some very serious indeed. Some people with the illness cope fairly well on a day to day basis, but are seriously short of energy, which is quickly used up and takes a long time to replace. This also leads to fuzzy-headedness as the brain is short of oxygen, often known as brain-fog, which describes it pretty well. An inability to concentrate, to take in information, or remember things. Rather like early Alzheimer's.

At it's most serious, sufferers are completely bed-bound, have to be tube fed, and in constant pain, unable to bear light or sound, as the nervous system is so severely compromised. Roughly 25% of people with the disease are severely enough affected to be

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either bed-bound or at least house-bound. It goes largely unrecognised, because they are rarely seen. Not for nothing is it known as the Cinderella disease, with M.E. acting as the wicked stepmother.

So you see, there isn't a simple answer. People with M.E. are more or less disabled by it, but all have this one feature...the lack of normal energy which everything needs for a normal life. The reasons are not totally understood yet, due to a lack of research, but it does appear that the brain and spinal cord are affected. In post-mortem examinations this has been shown to be the case. It seems that the mitochondria are not functioning as they should, though could be harder to prove. Dr Sarah Myhill and John Maclaren Howard have an ATP test to measure the mitochondria function, though this may not be something everyone has access to.

However, even that isn't the whole story. Tests on muscle tissue show that sufferers don't have normal muscle response to exercise. Instead of making them stronger, they become weaker. This is the reason why exercise is very bad for people with M.E. - it aggravates the problem.

There is so much more I could say about symptoms but it would take far too long and there are good websites which describe it much better than I can. The Hummingbird site is a good place to find out more.

A recent thought has been that having M.E. is, in part, like living on a planet with much stronger gravity, but less oxygen. The daily struggle is enormous.

Most doctors, under the direction of various governments, choose to regard the whole thing as psychological. Much easier to blame the patient than try to find a cure or pay for disability pensions. Maybe that sounds cynical but the fact remains that time and again nothing is done to help these people. They are largely left to suffer, and what is worse, are castigated and made to feel like criminals, being told to snap out of it, exercise more, think themselves better. If the illness isn't "real" or doesn't have a physical cause, they can draw a line under it and forget it. But the approach used, graded exercise and cognitive behavioural therapy, do not and will not cure the problem of genuine M.E.

It will help people with other forms of chronic fatigue, of which there are many. No argument. But it's easy enough to tell the difference. If graded exercise helps, it isn't M.E. If it makes you worse, it probably is. Lyme disease, which often mimics M.E. having many of the same symptoms, can be treated with antibiotics which often in time effects a cure, though not always. So far nothing appears to help those with actual M.E. and won't, until more research is done to discover the basic problem and the cause of it.

There was a time when M.S. was regarded as psychological. Eventually doctors realised it was real and physical and though it can't be cured, at least sufferers were no longer regarded as malingerers or insane. Hopefully the day will come when M.E. sufferers are treated with the same respect.

Brainfog

Maybe you've heard of brainfog. Perhaps you suffer from brainfog. If not, you may be wondering what brainfog refers to. Well, let me try to explain.

When I developed ME, Myalgic Encephalomyelitis, apart from the devastating and surprising refusal of my body to do the things it could previously do, my sleep suffered dreadfully. I believe this had a lot to do with the brainfog which I then started to suffer. Without proper sleep anyone's brain starts to misfire but added to the neural damage of ME it's a sure-fire way of not being able to function normally.

My sleep at that time was severely affected. Sometimes this meant being awake all night and, obviously, tired all day. Sometimes I did sleep at night, though the sleep was not like real sleep at all. I would become unconscious, switch off you might say, but wake suddenly in the morning without any sense of having slept. No drowsiness, no dreams, and I hadn't moved at all during the night. I don't know what kind of sleep that describes, not being an expert, but it isn't normal and it isn't refreshing or healing.

It would appear that, although I went to sleep, it was only into stage 1 light sleep; I never entered REM sleep in which dreams occur, or reached deep or slow wave/delta wave, sleep. During the deep stages of non REM sleep, the body repairs and regenerates tissues, builds bone and muscle, and appears to strengthen the immune system. So without that it's hardly surprising that ME sufferers are very ill.

I still have disturbed nights and reversed inner time clock issues, though when I do sleep now I do tend to sleep "properly". I have dreams, and often feel that warm drowsiness on waking, though not always.

However, when this lack of proper sleep goes on for months or years, it's no wonder the brain starts to give up. The inability to concentrate is the most obvious symptom. Reading, a favourite pastime, became such hard work. After a very short time my brain would feel "full". And, worse, I would read the same sentence over and over again before it made any sense. Watching tv game shows used to be fun, but now I found that by the time the presenter had got to the end of a question I'd forgotten the start of it. My short term memory was shot.

Losing words, in the way a stroke victim does, is also a problem. Everyone has this problem at times of course, especially as we get older, but with brainfog it's constant. Searching for the word you want is so frustrating, but in time I learned to stop trying and just either find another word that means the same, or just describe the thing I meant. I find now that just changing the subject in my mind, looking away as it were, makes it easier. When I stop trying, the word I wanted will sometimes just pop into my mind.

Personally I also lost the ability to type. I had been touch typing for many years but suddenly I found that, although I knew what I wanted to type, my fingers weren't getting the messages from the brain. I would type with the correct fingers but on the wrong hand, or the letters came out in the wrong order, and my thumbs developed a mind of their own

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and stuck spaces in wherever they felt like it. It's like a kind of dyslexia in reverse. There may be a name for it but I don't know that.

This is all very irritating of course. I still tend to spend more time correcting my typos than actually typing, though it's not as bad as it used to be. At my worst I simply couldn't remember the alphabet. And at my age that's not funny. Well, not very funny.

Brainfog, therefore, is a way of describing the brain's inability to think, to concentrate, to work things out. Pretty much as it sounds really. I have to say that I have improved to some extent. I put it down to the handfuls of supplements, recommended by Dr Myhill, an ME specialist; in particular the brain feeding ones, which made a huge difference to my ability to sleep. Fish oils or other foods containing EPA and DHA for instance. The brain is something like 60% fatty tissue, so feeding this is important. However the thing that made the biggest change for me was PhosphatidylSerine, sometimes written as two words, an amino acid vital for neural function. Although normally the body can create it from foods it is being looked at now as a supplement for Alzheimer's patients.

I've seen various articles saying that PS helps, or it doesn't help, or it may help. All I know is that within a few days of taking it I started to sleep normally and over time my brainfog has improved. One quote says:

"Because PS is necessary for effective neurotransmission, PS deficiency is linked to mental impairment, including Alzheimer's and non-Alzheimer's dementia, depression and Parkinson's disease among middle-aged and elderly people."

Natural News.com

So whatever the nay-sayers may claim I know it did wonders for me. I don't have shares in any company whatsoever, so don't imagine I have anything to gain from this statement. I simply want to explain how I have improved my cognitive functions. Mind you, I've had ME for 29 years to date, being mostly housebound for the last few years so it may be possible that this has helped with some degree of recovery. However, the fact that this supplement worked within days, literally, to improve my ability to sleep, dream, and feel more normal, suggests to me that it isn't coincidence. It is, however, purely circumstantial evidence which counts for nothing with most scientists.

To have a brain that is akin to an elderly person with dementia, while you are still young, or fairly young, is very frustrating. We call it brainfog. It occurs in people with Fibromyalgia I understand, and quite possibly in other long term disabilities. My own experience is that it can be improved, if not entirely cured. I hope something I have shared here makes sense to others. I still have some problems myself, after all.

A Short Account of My Experience of ME

At 41 I was as fit as a flea, with three teenage children (and a grandson), three dogs and two cats, as well as a husband. I went running every day and had a daily exercise routine too. Nothing was too much trouble. I also helped out at my church and was about to start an exercise class there.

Then came this illness. Suddenly I could do very little. I tried, time and again, but it was no use. Within a year my already failing marriage ended. I got the chance to move out and did, knowing that as my illness would not be tolerated at home it was all I could do. I took some part time work as part of an income support scheme, and spent every weekend in bed to recover from 21 hours a week of clerical work.

Then I had an emergency hysterectomy, with no counseling whatsoever, which nearly finished me off both physically and emotionally. After a time, to avoid being forced into work I wouldn't be able to do, and having no legitimate excuse for not working, as ME was even less recognised back then than it is now, I went back to school. I did some night school, then college, and won a place at University. It was very hard, even getting there and back was such a struggle. In my first year I dislocated my knee and broke my ankle, which meant more surgery, so took the rest of that year off and started again the following year.

I won't go into all the nightmare events that happened in my life during the next three years, but I was just about coping by doing nothing more than the set work, and finding it more and more exhausting even though I had moved to live very close, about 500m away, to make it easier. I got my degree but lost my then partner. I was then 51.

Since then I have done virtually nothing, or nothing that most people would recognise as living. I did start a post graduate course but was too ill by then to keep it up. I had further surgery three years ago for a low grade malignant Phyllodes Tumour. Now I am 70 and becoming ever more feeble, exhausted, and in pain.

My memory deserts me at times and the coming Christmas celebration is just too much to contemplate. If I don't pick up a bit I will have to cancel it, again.

I sometimes wonder where it will all end. I have a cat, who is a blessing but costs in terms of energy and who is becoming old and sick herself. I also have eleven grandchildren whom I rarely see, and 4 great grandchildren whom I don't imagine I will ever see. My children all live too far away and have lives which prevent them visiting. Sometimes the loneliness is hard emotionally, and certainly getting through the days is, physically.

If I was suddenly healed of this tomorrow, at my age there is no way I will ever again be the person I was at 40. I have lost nearly 30 years of any meaningful life, merely existing as I do, virtually housebound, only going out for vital appointments. I try to stay

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cheerful but it's not always easy. I get depressed at times, and over emotional at others. I'm sure the short days of winter aren't helping and the approach of Christmas is always hard, with its focus on family and jollity, neither of which are part of my life, and haven't been for years.

So this is it. A potted account of my illness. Or at least, the one that has taken away so much. My life now is all online, as are my friends, so it isn't all bad.



It's The Little Things

It's the little things. The big things, well, people understand it more. For instance, I haven't been able to go shopping for years now. It's tough not being able to choose your own groceries or whatever, something most people don't have to think about, but at least there are supermarkets who will do it for you and deliver their choices to your door. This works well enough most of the time until they don't have what you ordered and the person doing the choosing for you has very different ideas from you. It's a bit like Christmas, every week, but not in a good way. You open the bag wondering what surprise you're in for this time. Will it be something you wanted, or not?

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Like most people who get home deliveries I have been presented with substitutions - food I would never buy, don't like, would never eat, or just don't want. I am then in a dilemma. If I don't take it, what do I eat instead? And if I send it back it will just be thrown away, which I find unacceptable. Problem. Stress. Stress I don't need. But on the whole I manage.

Going out when absolutely necessary is simple, I call a cab and struggle the rest of the way.

Housework? It just doesn't get done, mostly. Luckily I was never all that house-proud. My bedroom looks like a jumble sale. The living room is in chaos. I always joke that no one will ever break in because it looks like the place has been turned over already. I move hesitantly, sloth like, around the house, resembling mountaineers at a high altitude, body and brain on go slow. Except when they're at a dead stop. But there's no one here to see it, so I don't care.

No, like I say, it's the little things. Like turning over in bed. You're probably thinking: "What? Turning over in bed? I can do that in my sleep!" Indeed you can, and I'm sure you do. Film of sleeping people shows just how often most people do it, moving around all night long. I used to do it myself once. And on good nights I still do. But on the bad ones...well. The thing is, we have to turn sometimes to keep the circulation going, to avoid pressure sores, going numb, etc.

But if your body is flatly refusing to do it, what then? I have nights where I wake up in exactly the same position I went to sleep in, having not moved at all, the sheets totally undisturbed. I have other nights where I wake up just to turn over, a bit at a time. because it takes quite a lot of effort and concentration.

It's as if my subconscious is behaving like an orchestra without a conductor. No one is telling which bit of me to move next. Even awake it can be just the same. Have you seen those people who scale sheer rock faces with no help? That three points of contact rule. It's a bit like that sometimes. Move this foot, move this hand, now this one, now that one, and so on, until you get where you want to be. It can take quite a time. And a lot of effort, when your limbs feel like lead. Such a little thing, you'd think, but it takes forever.

Making a cup of tea is another. You're sitting in your seat with a dry mouth, trying to decide if you really need that drink or can you do without a bit longer. It does make me sound awfully lazy, I know. But it's not that. It's the effort it takes to haul your body out of the chair, stumble to the kitchen, then realising you didn't bring your cup with you so you have to go back for it. Then you fill the cup with water and tip it into the lightweight camping kettle to boil. You put the teabag into the cup, pour on the water, shuffle over to the fridge for milk, add the milk, go back to the fridge to put the milk away. Then you have to pick up the cup of tea which feels like a lead weight and try to get it back to the living room without spilling it, set it down and collapse into the chair. By which time you're too exhausted to drink it.

Another little adventure, just one of many during the day in the life of someone with ME.

But before you can start your day of course you have to get out of bed. Now many people will lie in bed thinking about whether they want to get up or not. Not many people lie in bed thinking about how they are going to get up. I do. On bad days anyway. On good days, if I've been sleeping well for a while and have some energy to spare I can get out of bed reasonably easily. Even if it means forcing myself to find the energy, which is counter productive as I suffer for it later. On bad days it's a whole other story.

Imagine waking up and you can't move. Your whole body feels like lead, lifeless, heavy, immovable, like gravity has increased somehow in the night. After a time you can maybe open your eyes, perhaps wiggle toes or a little finger. Good! You wait. After a time you can turn your head. Great! Wait some more and the arms feel like they're less heavy, so you try moving them. Yes! Success!

The body is still lying there like a beached whale, but things are improving. In time you can wriggle a bit but the legs are still lying there, two great lumps of meat. Oh you can feel it if you touch them. They aren't numb. Just going nowhere. Eventually, after what feels like an eternity, you can move them a bit, slide them around on the bed. The beached whale has gone, to be replaced by an elephant seal. Things are looking up!

That's when I wait until I start to feel my bladder. When I feel that it needs emptying I know my body has finally woken up and I can make it off the bed to stagger with still wobbly legs to the bathroom. Rather like a mermaid newly transformed who isn't used to having legs yet.

This whole procedure can take up to an hour. For me it's never a case of do I want to get up. I have never enjoyed just lying in bed doing nothing. But now I spend most of my time reclining or lying, occasionally sitting, and rarely walking. Boring? Yes, it can be, though I have my computer and books and so on to stop me from going stir crazy. And I write.

Every little thing has to be thought about, things others take for granted, things I once took for granted. And this with a brain that is itself compromised. Short term memory is crap. Sometimes I feel like I'm developing dementia but I know it isn't that. It's just ME. Just, she says. Right.

Yes, I know there those much worse off than me, some who can never leave their beds at all, who can't stand any noise or light, have to be tube fed, or are stuck in hospitals being treated like criminals. I am extremely thankful that my level of disability allows me some modicum of independence. I would go crazy otherwise, not being good around people. I am thankful that I have a home, a pension which allows me to eat and buy the essentials, a daughter who cares even if she can't visit often. Maybe it's being thankful for those things that keeps me going. The big things. But the little things? Those are a nightmare.

Another Merry Christmas

A blast from the past... written 12/24/2002, before I became housebound.

Christmas Eve. Late afternoon. Sheffield.

Today I decided to go and do some shopping. It was either that or go without Christmas Dinner altogether. I did have a cold sausage left over, but, well, you know. It's bad enough being alone at Christmas without sitting down to a left over sausage decorated with a sprig of holly.

If I had any holly of course.

Fortunately the shops are open Christmas eve, so no problem there. Unfortunately my legs were on a go slow while debating the advisability of going on an all out strike.

Fortunately I have a wheeled shopping trolley so I walked (walked? Make that staggered) it round to where I garage my car. Unfortunately, the car had decided that this was a good day to die. So it did.

Fortunately, the shop I wanted is a downhill walk, though of some distance. Unfortunately this means that it's an uphill walk back with a full shopping trolley.

Fortunately it was a nice dry day for a walk, and I managed to get everything I'd written on my list. Unfortunately I'd forgotten to write "Stuffing" on my list.

Fortunately the fish and chip shop was on the way home, and open, so I treated myself to battered cod and chips to eat out of the wrappings on the way home. Not easy while using both hands to push a loaded trolley uphill, but worth it I thought.

Unfortunately it started to rain at that point, so I stuffed the yummy hot food into the trolley to eat it later. With luck it would still be warm by the time I got it home.

Fortunately it wasn't too cold, and I enjoyed it. Unfortunately so did my cat.

Fortunately I had some time to spare so I thought it would be nice then to go online and see what delights Christmas would bring to a lonely old woman. Unfortunately what I received was a rude email from someone I'd thought was a friend. Huh.

Things were getting better by the minute. I poured myself a small drink to calm down or cheer up, or something like that. Fortunately I had bought some in advance of Christmas. Good job too.

Unfortunately alcohol makes me ill, so I just know that I'm going to pay for this.

What more can happen? No, don't tell me. I really don't want to know.

Merry Christmas everybody.

How Quickly

How quickly now my brain-fogged mind
reaches saturation point
decides it's had enough
and goes on strike.

Too soon, too soon it closes down,
too soon the eyes begin to ache
struggle briefly,
then give up the fight.

Sept 2001

Frustration

I used to have a life.
I never was a sprinter, even as a child, but yet I had a life.
Trained as a dancer, worked to pay my way;
and later on left home and danced upon the stage.

Got married, had children, one, two, three; and,
still only 21, I did the things that mothers do,
cleaned the house, the school run,
helped my husband with his work,
went to church, taught Sunday School, camping with the kids.
Life was very busy.

I took my dogs for long walks up into the hills,
and life was hard but, nonetheless,
I coped as much as anyone and maybe more than some,
and never did I guess, not even for a minute,
that one day soon my life would end,
well, life as I knew it.

Who could have known a bout of flu, or something very like it,
would lay me so low? Would take away my freedom,
and leave me a prisoner of this all too solid flesh?
To be reduced to this! A desiccated vegetable
too weak to hold a cup of tea, too tired to even think.

Doctors looked cynical,
Well, I was a woman. And middle aged at that!
I must be depressed. Or better yet, neurotic.
And ever since I've done the rounds: blood tests,
and "Are you depressed?"

"No", I try to tell them.
Went to University and got a good degree.
Does this sound like depression?
I rather think not. And only exhaustion
made me give up on my longed for PhD.

But still and yet they ask me boringly, repeatedly,
"Are you depressed?"
No, I'm frustrated, I need to get a life!
My body won't allow me to do the things I want to do,

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to walk and dance and sing, oh how I long to sing!
I want to dance the night away just like I used to do,
or even go out walking, or have a holiday.

Instead I watch TV, and chat to people on the net
and, quietly and unobserved, go out of my mind.

© 2001

On living with ME

Why don't I get angry?

Rant and rave?

Why this?

Why me?

And why so long?

Truth is, I can't afford it,
the energy required.

Just getting through each day...

I've none to spare for anger.

An unstrung marionette

lying deserted, abandoned.

But no, not that,

for then I'd never move at all,

and move I must.

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A beanbag, yes, but filled -
not with light and fluffy stuff -
much heavier than that.

Lead shot, that's it.

Or better yet,

lead jello.

Yep, that's me.

Lead jello.

With brainfog.

And tiresome sensitivity

to noise and light

and chemicals

and eyes that ache

and muscles too

and coughing, sneezing,

laughing, wheezing...

Oh yes, I still laugh.

What else is there to do

When life's a joke?

Sentence Without Reprieve

On days like this I wonder why, why I crawled put of the slime,
simply sleeping my life away seems such a waste of time,
such a pointless existence such a futile attempt.

There's no-one here to know or care whether the place is unkempt
whether I bother to dress myself, whether I eat or drink
if I have energy enough to rouse myself to think.

It wasn't always this way; once I had a life
those days were filled with doing, with laughter or with strife.
Now that energy is scarce life often seems too hard,
it's a rare and precious commodity, something I jealously guard
but on days like this when sleep is all, all that I can achieve
I wonder how I'll ever survive this sentence without reprieve.

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Brain Fog.

I forget to pay my bills, I forget to take my pills,
I forget to clean my teeth and brush my hair;
Most mornings I get changed into clothes however strange,
Though some days I'm too tired to even care.

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I forget to clean or dust, though who's to say I must
When there's no-one here to notice anything?
And last month I forgot to arrange my bulbs in pots,
So I won't have any flowers in the spring.

I forget to make a drink, leave my dishes in the sink;
I forget about the toast under the grill;
And although it may seem crazy, my brain is just so hazy
I forget to ring the doctor when I'm ill!

I struggle through the days, my thoughts a misty haze,
Trying to make sense of why I'm here.
My children rarely call, one never does at all,
And yet I feel I ought to persevere.

I rarely leave the house, I'm as quiet as a mouse,
So people rarely notice me at all;
The postman calls of course; the aggravating source
Of piles and piles of junk mail in the hall.

No-one bothers me, so I read or watch TV,
I write to penfriends, paint; and stuff like that;
And sometimes when I'm sad, or the pain is really bad,
I go to bed and snuggle with my cat.

And now it's mid November, and I hope I can remember
To send a birthday card that's almost due.
It's for my grandson, Kain; I can't forget again,
He'll think I just don't care - and that's not true.

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