

descriptions

alec finlay

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the poems were composed from responses to a questionnaire devised by alec finlay with guidance from Action for ME. Three hundred people participated. The complete text has been preserved as an anonymous online archive by Action for ME. We wish to express our immense gratitude to the participants.

descriptions, an audiobook, read by Mark Bonnar, is available: descriptions.bandcamp.com

The complete text will be preserved as an anonymous online archive by Action for ME available at actionforme.org.uk/descriptions. We wish to express our immense gratitude to the participants.

guidance for readers

this book – and the audiobook that accompanies it – are distressing and liable to be upsetting. Support is available from Action for ME for anyone affected by ME, including friends, families and carers. We chose to include the words of people with ME in their original form, without editing. We recognize that people's experiences vary greatly; this text can only begin to represent the difficulties that individuals endure. We especially advise discretion in terms of sharing the book with younger readers.

actionforme.org.uk
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descriptions

a patient-led description of ME
composed from the words of people with ME

alec finlay

Action for ME
morning star
2022

I'm not really sure when it started
I can't remember a time
I wasn't tired, even as a child

I've been sick half my life
for about 50 years
over 30 years now
25 years, roughly
24 years now
a couple of decades
17 years and 3 months and counting
almost 14 years
13 years
10 years and 10 months
on and off for 7 years this December
coming up to 6 years
almost 5 years (probably longer)
20 months
a year and a half that I know about for sure
one year
9 months
I stopped counting

my life stopped at 58
when I was in my prime

if 15-year old me
knew I'd still be ill at 50
she wouldn't go through it again

diagnosed when I was 46
was it weeks or years falling
down tired for as long
as I can remember?

I was 27 and one day
just collapsed in the doorway
of Debenhams

I was invincible, 26, young, active, able,
I was on a run and suddenly just couldn't run
literally just stopped

I was 22, just graduated and started
my dream job, I'd just got married
and was perhaps the happiest
I'd ever been

I was 21, at the start of adult life
a life that never progressed
how I thought it would

it crept up on me slowly
a week before my 17th birthday
6 weeks before my GCSEs

by the age of 10 my little sister
turned into my carer

I was 9 years old

I remember the date
very clearly and every
4th June is very upsetting

I'm young, I don't want
to give up living

I didn't realize
I was going to be ill
for the rest of my life

I could never have imagined
I'd be this sick FOREVER

the day before I was bed-ridden
I'd laughed and joked with my mates
I wasn't going to let my body stop me
kept thinking I should be recovering
believed you could overcome ME
with willpower and determination
I'd get better if I kept exercising
but the more I tried to reclaim fitness
pushing myself to work and crashing
my health became permanently worse
then my nightmare came true
and I was bedbound, some days
I couldn't move at all, I felt useless,
broken, a grey shadow, EVERYTHING,
every part of my being, impacted,
I dozed in and out of consciousness,
sleeping in secret, couldn't sit
at the table long enough to eat,
screaming with pain through the night,
couldn't comprehend basic sentences,
put my kettle in the fridge, was
so out of it I tried to open my
front door with a coin

I feel strange sensations all over my body,
tingling hands, creepy crawling feelings, woolly legs, sore feet,
knees gone, bone weariness, limbs empty,
shards of glass in my ears, hyperacusis, never-ending tinnitus,
noise HURTS, ANY noise causes my body to go into spasms,
earplugs all day long, hearing the electricity hum in the plug,
pressure in my eyes, flashing lights, afterimages,
wearing sunglasses inside, going blind in one eye
kidneys wrong, liver hurts,
swollen lymph glands, burning sore throat, mouth ulcers,
shivering, dizzy, wobbly, nauseous all the time, gut ache,
stomach pains, vomiting, IBS attacks, severe diarrhoea,
allergies or intolerances: food upsets you, chemicals make
you sick,
extreme night sweats, temperature raging, vivid fever dreams,
fidgety sleep, internal tremors,
blinding migraines, like my head is being crushed,
slurring words, clumsiness, crying, fainting, wired but tired,
constant buzzing brain fog, head spinning, full of fluff,
staring at the kettle trying to remember what it's called
my mind races, I give speeches in the dark,
sleepy, sluggish, tired, ALWAYS tired, like a drowsy dormouse,
tired, tired, tired, endless crashes, crippling exhaustion in
my blood and bones, exhausted to my core, an ocean wave
of fatigue that swallows me, limbs limp and lifeless, like a
marionette, so weak I couldn't lift a coffee mug,
constant muscular and neurological pain, shuddery, sore, aching
all the time, every movement hurts, the pain, oh god, the pain!
pain here, now there, now here, like acid eating through the
skin, burning, blotchy, on fire, stung by nettles,
pale, drained of life, cold to the touch, pain like an enemy

within stabbing me repeatedly, every muscle severely bruised,
every cell in my body being ripped apart,
my immune system in overdrive, like the dial has been twisted
fast, my body constantly fighting with itself, everything feels
metered, thinned,
glimpses of how it could've been, laughter, fun, eke it out, eke
it out, though you know you will pay for it,
my body shuts down, energy drains from my body as if
through a syringe, and a canyon comes,
begging for help and answers, stuck in a body that won't do as
it's told, scared, lonely, helpless, emotional meltdowns,
massive fear of abandonment, washed with grief which never
ends, and a soul-crushing all pervasive fatigue, horrible!

"you don't look ill"

"there is nothing physically wrong with people with ME"

"get on your bike and go for a ride, that will fix all your problems"

"if you really wanted to get well, you would"

"must be nice to get to lie down so often"

"you're just tired because you sleep all the time"

"I wonder if your symptoms have become self-reinforcing?"

"your thoughts are wrong, that's why you're ill"

"your brain is just imagining you are in pain"

("joke" message written on the black-board by my teacher and class)

"you are not ill, you are skiving"

"that's the lazy illness isn't it?"

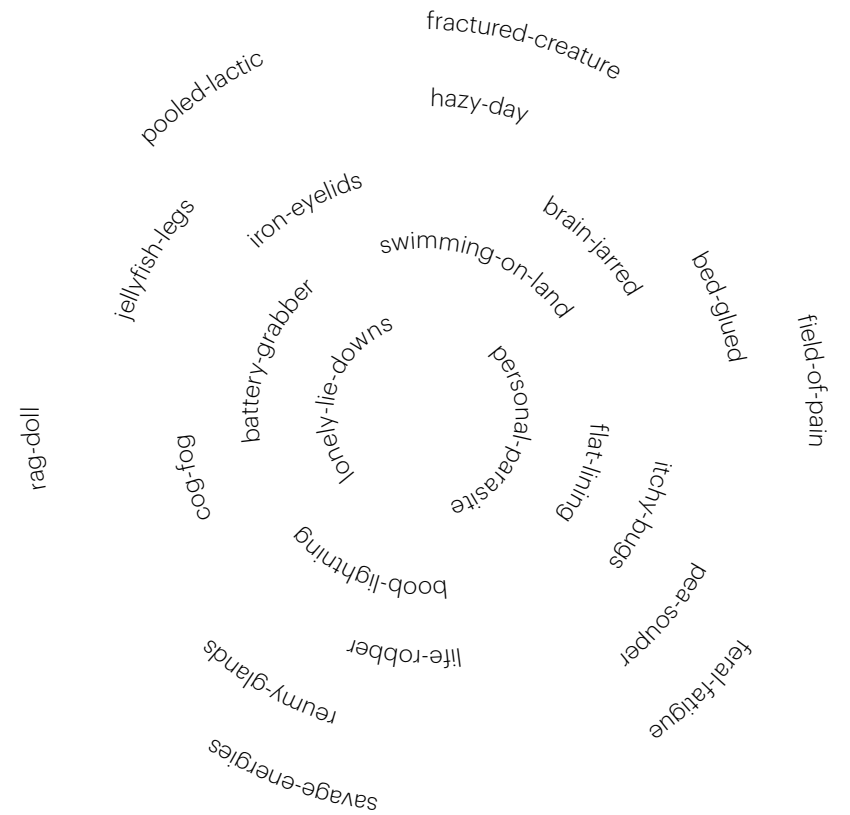
"you're just scared of getting a job"

"does having ME actually affect your life?"

"ME, that stands for Medical Excuse"

"I can't see what else we can do, short of committing you"

"do cardio workouts three times a week, come back to me if you are really ill"



relapses are terrifying,
like a dark wave sweeping over you, a tidal wave, sucked under
by an endless undertow,
like I'm on a tiny boat in a deep, dark, vast ocean, buffeted
by storms which send me off course, no sail, no oars, waves
crashing over me, a tide I cannot swim against or resist
like the clouds are darkening and the world's fading away
like climate change, the result of a system under stress
like a snowy day, the world covered by a blizzard, hidden under
snow, like it didn't exist,
like a butterfly with a heavy stone attached,
like wearing a rucksack which is getting heavier and heavier
and is impossible to put down,
like tumbling down the mountain, slipping down a deep hole
into roiling blankness, with steep sides and no ladder to
climb out, a dark place you'll be stuck forever,
like my entire body is full of poison,
like some sort of blue parasite chewing up bits of my brain,
like a foggy creature that devours time, pouring me over the
branches of my life like a Dali clock, stretched, weak, and thin,
like a Dementor the colour of shadows and sadness, trying
to keep me alive by making me live half alive, that attacks
again, and again!
like a rock in your shoe that never leaves, some days hardly
noticeable, some days pointy and stabbing,
like walking on a tightrope, one false move and you fall,
like being hit with a massive, soft hammer,
like a faulty alarm system that's constantly telling you there's
an intruder you must fight off,

like one off those very old mobile phones only a grandma has,
low on battery, that will never fully recharge,
like a battery in a flashlight when it begins to flicker and fade,
like each millimetre of sunlight is a laser beam,
like there's an iron band around your head, getting tighter
with every movement,
like a suffocating blanket,
like a rubber band wrapped around you and, if you push too
hard, it bounces back and catches you,
like I'm in a suit of armour,
like Snakes and Ladders, but all the squares are snakes,
like two cars, both the same model: one gets refueled, the other
is left empty, and they have to make the same journey,
like moving backwards and forwards between worlds,
like a shadow woven into all aspects of my life,
like I'm looking through dirty glasses,
like stupid, stupid, stupid, I've failed myself,
like stupid, stupid, stupid, I've let myself down,
like a familiar friend,
like it's never going to end,
like a curse,
like my dreams are being ripped away,
like dying a slow death, or being on the edge of death
and wanting to die,
like I'd give anything to not feel like this ever again

it was like I was floating, it's hard to describe,
the words are just out of reach

it's a bit of a blur

it was like walking through deep water
wearing a space suit and I'm Major Tom

I'd no idea what was wrong

it was like nothing else I'd experienced,
like falling into a dark cupboard

*my limbs were weighed down with lead,
things were bright and loud, I was pale and shaky*

it was like slipping down a loose gravel path
not being able to find a firm footing

*I had a shower (I remember that shower!)
and went to bed thinking I would be getting better*

it was like a stealthy thief robbed from me slowly,
my known safe world began to fade away
(I still underestimate its sneakiness)

but surely it would go away soon, right?

it was like when a new baby enters a family
all my energy taken up with survival,
nothing spare to turn into a memory

*I was angry, confused, but hoped that tomorrow
I'd wake up and the symptoms would be gone*

it was like suddenly being unplugged
I ached and sweated, my brain was so foggy
(and fecked), thinking through soup,
I couldn't use my hands properly, couldn't lift the kettle,
the air felt heavy and I was only able to crawl
around the house, climbing the stairs felt
like dragging sandbags behind me,
I couldn't even bathe myself, barely felt
I'd the energy to keep my heart beating

and then I just didn't get better

it was like having an almighty joint that never wore off,
I was in a whirlwind of pain and exhaustion
unaware of the world around me

*I couldn't understand what was happening,
it felt like an out of body experience,
the body on the outside looking down
wondering what was going on*

it was like a heavy stone had moved into my head,
I came to a full stop

I didn't realize I'd never dance, act, or hike again

it was like a lead cloak draped over my body and mind

*now my world's very small
and seen mainly from the horizontal*

it was like my body was shutting down,
bang – I fainted at work, fainted again, and again,
every system in my body started to go wrong,
I got slower and slower until my body stopped functioning

*I'm a ghost of who I once was,
I live in constant fear of the next flare*

it was like my skin is painted porcelain
with darkness under my eyes

*by the time I'd got dressed for school
I was so exhausted I couldn't stand up*

it was like a gnarly old tree with bent crippled branches
and no leaves, the trunk is the core of my being
the bent and twisted branches my agonised muscles

when I say that it's agony, it really is, and I need help

it was like someone filled my bones with lead,
replaced my muscles with spaghetti, piled bricks on top of me

*I was so far beyond exhausted, I couldn't perceive
the world around me or even my own body*

it was like I felt concreted to my bed, the more
I tried to do the worse it got

*my body didn't belong to me,
I felt like someone from another planet*

it was like trying to move against a strong current,
I tried harder and harder, pushing myself to recover,
and dug deeper and deeper into hell

*I felt I'd let everyone down, because I couldn't
do what everyone else was able to,
felt I'd failed and they won't forgive me*

it was like walking in quicksand, I became more and more tired,
slept and slept and slept, found myself losing time,
just staring at the ceiling, willing myself to move, but I couldn't

*you can see your old life, it calls to you
it doesn't understand, but neither do you*

it was like if I couldn't get to bed and rest my body would break,
I've never felt tiredness like this

I felt like a prisoner trapped in my own body

it was like being in a spinner going around and round,
my vision got foggier and foggier, light was painful,
the noise from the world outside was so loud

I wanted life to be still and for everything to be quiet

it was like crashing a car at 70mph, my body hurt all over

*overdoing things left me with a sense of futility,
I'd do something tiny and pay a hundredfold*

it was like living in a loud dark cloud

*when the fatigue gets so bad
it feels like I could slip into a coma*

it was like I'd been run over and the pain became intolerable,
I felt like a deer caught in headlights and remember
feeling scared I might die

*I believed so much that I was going to die
that I left the front door unlocked
so someone could get in to save my baby*

it was like a long dark tunnel with few pools of light

*it felt like no one believed me,
medical professionals dismissed me,
my family doubted me –
that memory of being doubted
still sits in a deep part of me*

it was like a death, the constant cycle of denial,
determination, and defeat, defeat, defeat

*friends slowly drifted away,
it was several shades of horrible*

it was like a living dream or waking nightmare,
days were taken up with pain and emptiness
yet time slipped by in a second

*it was the darkest time of my life,
I thought I was going mad,
I was in despair*

if I could go back in time then I'd say STOP EVERYTHING,
rest when you need to,
learn your limits, stop trying to keep your old life going,
learn to rest, rest, rest, complete rest,
stop trying to be the 'you' that you once knew yourself to be,
stop, rest, pace,
stop trying to get back to your old life,
rest, give your body a chance to recover,
stop looking for answers,
stop and rest!
stop fooling yourself that you will get better,
rest, do nothing but rest, it's that simple,
stop trying to push through,
don't fight the illness, it's OK to rest, just rest, rest, rest,
do the minimum energy allows,
rest, nothing is more important,
listen to yourself not others,
if you need to rest then rest,
stop saying yes to everything,
rest in a quiet room, give your body what it needs,
stop trying to please other people,
rest more, trust your body,
stop your perfectionist ways,
remember resting is not doing nothing,
stop every single thing you can, stop trying to do anything at all,
take time to rest or you'll make yourself worse,
let it all go and you're more likely to get it all back,
just stop, stop and rest, give in to it, and completely rest,
believe yourself, what you're feeling is real,
you need to rest, rest completely, total rest,

stop running from the pain,
resting now really is your best chance,
be kind to yourself, know that you didn't bring this on yourself,
rest, rest, rest, all I can do is rest,
ride the fear that you've overdone things
and sent yourself back down the snake,
rest!!!! as much as you possibly can,
don't try to push through like the doctors advise,
if you don't rest now it's much less likely you will recover,
you are more ill than you can comprehend,
allow yourself to rest in a dark quiet room
stop seeing the whole staircase, just do one step at a time,
your body told you to rest and it knew best,
go to bed, do nothing but sleep,
rest more than you ever thought possible,
stay there for at least 2 months,
please rest! and don't feel guilty for doing so,
take comfort in doing nothing and stillness,
take two years out and rest,
take time off work, you crazy woman!
be gentle with yourself, rest,
halve everything and then halve it again,
there is no alternative but rest, rest, rest, and more rest!
this is your life now, try and accept it and get support,
rest after everything you do,
slow down, it's OK to be a bear in wintertime,
rest, even when you feel well

sleep eluded me for so long,
I couldn't fall asleep,
I couldn't sleep because of the pain,
I wasn't able to sleep for years,
I need so much sleep,
I could sleep forever,
sleep, sleep, and more sleep,
the more I do the less I sleep,
when I'm asleep I'm not properly asleep,
when I'm awake I'm not properly awake,
I sleep when I can,
I sleep whenever, wherever,
I can sleep all night and still feel like I've not slept,
I'm sleeping my life away and it's still never enough,
there's never a time I couldn't lie down and sleep,
I've slept EVERYWHERE,
my car, a friend's car, on a bus,
train, aeroplane, on a roll of carpet,
in a car park, in the medical room,
in a lay-by, on a park bench
with my shoes as a pillow

you are not mad
you are not alone
you are not lazy
you are not the only one
you are not a failure
you don't have to prove anything
you are not pathetic
you are still you
you're not just a lazy cow
you know your own body
you are invisible
you are still enough
you don't look sick
you are braver than you know
you are sick
you shouldn't have to face this
and I'm so sorry that you are
you are strong!
you can't be there for friends
you will have the odd good days
and often you can't cope with friends
you will eventually get through it
being there for you
you will live again!

LDN has really been helping,
rest is the only thing that helps, rest, and silence is my friend,
massage, cranial osteopathy, a TENS machine for muscle pain,
rest stops the crashes getting worse,
warmth, pacing, opioids, CBD,
lying down, resting,
cuddles feel good, laughter and love,
rest feels good, resting body and mind,
wild swimming, hydration supplements,
rest, rest, and more rest,
restorative yoga, mindfulness, a white noise generator for tinnitus,
rest without feeling guilty,
Gabapentin, Citalopram, Naproxen, Targin, Advil, Zapain,
Co-codamol, used sparingly for pain,
just rest and more rest, napping during the day,
Amitriptyline, Sertraline, Pregabalin for fibromyalgia and anxiety,
strict rest, aggressive rest,
Allegra, Montelukast, Xolair, Cromolyn, Quercetin, Theanine,
rest, ice, water,
Rizatriptan, Metaclopramide,
rest, rest, rest,
Magnesium, B12 injections, Vitamin B1, B-complex,
constantly resting,
Vit D helps with joint pains, multi-vitamins, extra Selenium,
I just rest, forcing myself to lay down,
melatonin helped with my sleep,
rest helps a bit, I curl up in a ball, rest, and say no,
Saccrafloor bouillardii, black liquorice and marshmallow root,
probiotics, turmeric, peppermint oil, ginger oil,
resting, pacing, staying calm,

L-Carnitine, Acetylcholine, cod liver oil, Ribose,
Ubiquinol, Folic Acid, Potassium, for tremors and tiredness,
rest, rest, rest, at the right time,
Osteopathy helped alleviate joint problems,
rest as part of my everyday,
Acupuncture, biofeedback, therapy, chiropractic, vertigo therapy,
really all to no avail,
the only real cure is rest, cuddles, loving kindness, and more rest
Homeopathy helps my digestive system, emotions, energy levels
and muscle ache,
having plenty of rest,
medication and meditation, crystal healing, reflexology, and reiki
give me the most relief,
rest and rest oh and rest, total bed rest,
some whisky in the evenings (which I probably shouldn't say),
rest of course, rest, rest, rest, as if I can do anything else ...
people making an effort to understand my life, crying,
regular rests are the only thing that helps,
hot water bottles, deep heat, warm water, and physical touch,
rest and giving in to it,
Nature,
purely rest,
learning Cornish (on very good days),
pacing, rest, quiet,
rest! and rest!

ME was someone else's worry,
a secret condition talked about in whispers,

an illness of darkness, in bed, in silence,
in a dark room with the curtains closed,

a despotic cruel illness which destroys
people's lives and makes them disappear

I thought ME was a form of burn-out,
I thought ME was about being lazy,
I thought ME was Yuppie Flu,
an illness Del Boy coveted as a badge of honour,
I thought people were faking, putting it on,
(to my shame),
I thought ME was my failure

I've been accused of being a liar, a faker, and malingerer,
been told I'd given in to the illness

I've become known as "the flake", or "the one who is always ill",
become a child again, needing my family's support

it's very lonely,
it stopped me in my tracks,
destroyed my life, broke my spirit

it's made me very strong

when I'm ill, I forget what it's like to feel well,
when I'm well, I never forget I've been ill,
but I can't fully recall how it feels

*ME doesn't mean to be mean, it's the way
he's made, soft and squishy and fluffy
(and blue?!), he just needs a good hug*

pain induces panic, all my energy goes
into trying to keep myself calm

*I know myself better, instead of thinking about my
disease, I started to think
of a new chapter in my life*

I tried to pretend I was OK, but I feel
incredibly ill every minute of every day

*I'm trying to grow with my diagnosis
instead of against it, be kind and patient,
learn to accept this is going to take time,
surrender and explore the possibilities
within my boundaries*

I don't know who I am anymore,
my life hasn't just been ruined,
it has been taken from me entirely

*I've gained pain, fatigue and incredible wisdom,
learnt to dream smaller, find happiness in little things*

I become a geometric point in space,
that feeling is desolate, but inchoate,
and seems to last a very, very long time,
all time is now and always and forever:
I am only I, and barely even that

*then slowly I regain the ability
to wonder if I'm finally dead
and, after another eternity, I realize
that dead people don't wonder
about such things, so I must be alive*

I do a lot of pretending,
the tune I whistle is that of a mockingbird,
as I press my lips to the windows
my voice is too shrill to be heard

*I'm a shell of who I was, but that shell has learned
not to look at the remains with sadness,
enjoy all the little happy things,
the sun shining brightly (on the days it does),
the beauty in a raindrop on a cobweb*

*(on the days it doesn't), despite everything,
life has its beauty, and, with love, it's doable
and workable*

I know the disease better than I know myself,
what it's done to me, what it continues to do,
what it's going to do in the future

it's just an illness, I don't fight it, I give it no power

I've been ill enough that I've not wanted to survive

when I'm asleep and dreaming I can do anything

it felt like I was drowning and yet everyone
was calling me an inspiration

*I've had so many wakeful nights,
but I've seen beautiful winter dawns
that I would otherwise have slept through*

friends gave up waiting for me,
the more ill I got the less
they wanted to know me

*now I live the ME way, we have a saying,
hubby and me, he's doing what he can,
I'm doing what I can't!*

I don't have a life anymore

*everything I've achieved has been
in spite of having ME, I've never truly
let the illness win, and absolutely
will not allow it to steal my positivity!*

my life is over: I'm a musician
who can no longer play any instrument

*it's made me more resilient, more in tune
with myself, with more understanding
of the human condition*

I just don't care what happens to me,
the grief of losing yourself is almost unbearable

*being sick guided me to my true calling:
I can still help others who are ill*

it feels humiliating to have to ask
for so much help, even as I repeat
"this will not last forever"

*your outer world decreases, your inner world expands,
I reinvented myself within my limitations
and, in the long term, I'll get through this*

I miss the life I had,
I found that illness stopped me being the best I could be,
made me a person I don't want to be,
I had to stop driving,
I only run in my dreams,
I parented from the couch,
I was no longer bubbly,
I don't have the energy to be funny, and playful,
and all the things that make me who I am,
I lost my nursing career,
I lost my identity, my plans, and dreams,
I couldn't even hold my baby,
I regressed to an infant state,
I have never been well enough to work,
I am very anxious about when I will next crash,
I had a week recently where I was eating off dirty plates
because I couldn't cook and wash up,
I lost more of myself every day,
I lost my personality,
I lost every friendship I had before my diagnosis,
some drifted, some ended
I lost every part of myself that makes me me,
I am alive but not living,
I will die alone in bed

friends don't understand
and the circle keeps getting smaller,
no-one has stuck with me,
I felt they'd left me
but they probably felt I'd left them

I had to learn the hard lesson
most people don't care if you're suffering,
everyone is going to abandon you
but you will find a way to be OK

grieve as you go, be kind to yourself,
friends see me doing normal stuff,
talking and laughing,
but they don't see the days spent
sobbing with pain when I can't even
look after myself

I've fewer friends
but a deeper friendship
with those close to me,
my few new friends
have been more valuable
because they accept me with ME

I've made stronger connections
with those least likely
and lost a few I thought
would stick by me

those who leave are not true friends,
the diamonds will remain
my friends who are still with me
are utterly wonderful people
and I feel I may have lost my mind
if I hadn't had them to talk to

I've survived thanks to the charity
of friends, saw the good in a wider
range of people, and now
I have friends with similar limitations,
I find friendship in letters
from people I will probably
never meet, who share
the thing that dominates
our lives so totally

family are the only people
who see my full reality,
it breaks their hearts,
we laugh and have such
special moments together,
but also some terrible ones,
we're tighter than ever
but the strain is huge,
they feel guilty I can't join in
and I feel guilty they can't just
enjoy themselves for worrying

by 13 I was removed from school
3 friends saw me weekly

something they decided to do themselves
they re-introduced me to a boy

I knew from primary
I fell in love with that boy

and have been with him ever since
I don't think they know

how they got me through
such a lonely, housebound childhood

nor how important those
weekly visits were to me

my world is the size of my bed
going downstairs is a journey

being out in the world is a rare treat
travel is a chore to be prepared for

everything seems so far away!
other people walk for me

I plan my travels around car parks and benches
seeing less one sees more deeply

I journey in my imagination
through space and time

all those things that matter so much to you, they don't
really matter at all, not compared to health,
I gave up one thing after another,
going on holiday, laughing, being spontaneous, the joy
of carefree decisions,
driving my car, singing along country roads, time on the canals,
playing hockey and running,
to just be able to run free, just run like a child!
I would love to swim again, even once,
exercise classes and walks in the countryside,
sailing, walking and cycling,
cycling gave me so much freedom,
walking, just walking, it's such a basic thing,
a big stompy walk with my dog in all weathers,
listening to the birds, the dappled sunlight,
I miss walking and dancing! hiking, jogging,
(10ks regularly), and dirt bike riding,
I miss a really hard climb and sitting at the top,
looking down on the world with tea and cake,
rock climbing, ski, ice skate, aerobics, dancing,
the sensation of being at one with my body,
playing tennis, I was a rising star at my club,
singing and acting, I want to be a famous actress,
I played the big drum and miss the power of the beat
pervading my whole body,
I miss the ability to do what I want when I want to do it,
playing my accordion, going to music festivals,
jumping around in the mosh pit,
Taekwon-Do, my ju-jitsu, karate, working towards my black belt,

my horsey life, grooming my lovely horses after a ride,
gardening, going to the beach, seeing friends, now I watch
from my window,
going to school, because I love to learn,
teaching was my life calling,
reading a book,
keeping on top of the housework,
standing up in the shower,
I'm so tired at the end of the day, I struggle to cook for myself
and can't eat many of the things I love,
I used to love baking, it was how I coped with any big emotion,
throwing my little boy around and laughing with him,
caring for my mum,
when someone touches me, my skin feels numb but,
at the same time, so sensitive,
working full-time, socialising, and a loving relationship,
I miss making love to my still beautiful wife

then came the day I couldn't say
my own name, the day I stood
before my class and wasn't able
to bring up the lesson in my mind,
the day I told my principal I was done

dealing with doctors, and getting a doctor
to believe me, have been the hardest things

my doctor told me I wasn't ill,
my doctor, who was a friend, told me there's no such thing
as ME,
my doctors continued to tell me that there was nothing
wrong with me,
my doctor made me feel as if I was making a mountain
out of a molehill,
my doctor wouldn't see me,
my doctor puts the phone down when I mention ME,
my doctor told me to go away and not book any more
appointments unless I got worse,
my doctor said he didn't believe in ME and anyone thinking
they had it could "piss off",
my doctor said it was anxiety,
my doctor said it was depression and lack of motivation,
my doctors said there was nothing wrong, all in my head,
my doctors said see a psychiatrist, a psychologist, take
anti-depressants, get a life!
my doctor said "you either have ME or hypochondria", so I asked,
"do you think I have ME?", and he replied "I don't believe in ME",
my doctors were awful, blaming me and my 'neurotic' mum for
my illness – seeing her in tears coming out of the appointment
that I'd been banished from was awful,
my doctor blamed me for not getting better,
my doctor said I was lazy,
my doctor said I was work-shy,

my doctor laughed when I told him it took all my energy to
brush my teeth,
my doctor persisted in putting 'Tiredness' on my sick-line –
Every. Single. Fecking. Time.
my doctor diagnosed me and said, "you don't need
to come back",
my doctor said, "I have a patient with MS, she has a job and that
is a real illness",
my doctor saw me as "just a lazy teenager, come back in a few
weeks if you're still not right, there's nothing wrong with you,
try harder, stop coming back,"
my doctor said, "I think you have post-viral fatigue syndrome,
there is nothing we can do for you and you may never recover",
my doctors are well meaning but appallingly ill informed,
my doctor told me to go for a walk, which made me more ill,
my doctor told me to keep relapsing even if it's painful!!!
my doctor said "even if you are too tired to do something, just
do it anyway",
my doctors have been kind enough but absolutely clueless,
my doctor was very helpful and supportive,
my doctor thought GET might be helpful, quite the opposite

GET made me worse,
GET resulted in relapse every time,
GET caused me to become bed-ridden for a while,
GET left me bedbound for months,
GET put me in a wheelchair when I was 15
and took away the last shred of wellness
I was clinging onto

you need to push don't
overdo it try to do
more you are doing
too much you need to
overdo it you do too
little don't push to do
less you need to try
to push too much

even when I was a nurse,
even though I've always
been very empathetic,
I had no understanding
of the challenges
of living with ME

speaking as a medical professional
the system is very poor
with regards to diagnosis,
treatment, and support

the only thing that's tougher
to cope with than ME
is the doubt and lack of seriousness
of the medical profession,
that is soul destroying

it took Long Covid for many
to believe our illness is real,
there are so many medical
professionals with Long Covid who say
*"we didn't know it was like this,
we're sorry to those
we've mistreated in the past"*

a doctor will say ME is *"a lesson
in acceptance"*, and you will think
he's a knob, but it turns out
to be one of the most sensible things
a doctor says

it's mitochondria, not hypochondria,
if I could have hibernated
until Science caught up with us
then I would

though there's very little I can do
I have a little dance in the kitchen
(which makes me ache, sometimes for days and days)
I get the feck out the flat
(it takes me a week to recover)
I garden, which is my happy place
(the next day I can't feel sore all over)
I go for little outings in nature, the air in the woods soothes me
(I turn around long before I want to)
sometimes the choice is between pacing and feeling alive
*(there are times when I think, feck it! absolutely feck this!
and I crack on)*
I try to sing
(despite the numbing weariness)
I collect Teddy Bears and they give me joy
I rest and then bake brownies on the floor
I potter, chat, reach out to people like me in letters
(I know I'm going too far, it's worth it though!)
I brush my teeth, come downstairs
(payback is a bitch, and yes I will pay)
a bit of quilting
(causes intense pain)
I go to work, smile at people, and remember better times
I LOVE when we're all together, laughing and happy
(but it's exhausting and I have to withdraw after a short time)
I play with slime and listen to Billie Eilish
I will never not respond to my daughter if she needs me
(no matter how much pain I'm in)

through a gap in the curtains
I can see blue sky

*“when I read what I’ve written it sounds made up,
I hate that, because it’s not what I feel or know
to be true, so I think it’ll be fascinating
to see how your descriptions idea unravels.”*

Ingrid A	Coral Bohne	Abbey Ellis
Jean Aberdein-Smith	Donna Booth	Emily
Tammy Ackley	Lauren Bourne	Emma
Adele	Gaynor Boxall	Erin
Elisa Ahmer	David Bradshaw	Bridget Evans
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Marion Michell	Tamara Stein	
Margaret Moore	Stevie	

*“your question asks for descriptive language and imagery,
but how can I answer when my brain has left the room,
leaving a shell behind?”*

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how could a disease
be so mysterious
and treated so poorly?

Action for ME

