



The Brief

I just heard from the mother of the first child with ME whom I ever encountered, when I was Headteacher of a primary school. He was six, poor little lad.

She sent news of her son: 'he is married and has a daughter, 13 months old and a double of himself!' He had a hard time during childhood, but came through ME and eventually did very well.

Back then, he was not given Cognitive Behaviour Therapy (CBT), Graded Exercise Therapy (GET), or any other therapy. He struggled at first with how to pace himself, like any young lad who wants to be up and doing, but with guidance, love and support, he learned how to manage his life and got to a place where his body healed him. Importantly, he *had* a life. He was never encouraged to regard himself as a 'permanent patient'. That, it seems to me, was a positive thing.

Many parents of children on a long term regime to monitor activity programmes seem to spend the time between appointments worrying. Will their child meet the next goal? Can they keep up the goals they have already achieved without backsliding? Will they be able to sleep at the prescribed times? Control of their lives is handed to a therapist or other professional, whom they feel must surely know best.

They may get sound advice. Often, I'm sorry to say, they don't, and yet feel unable to decline it - their own judgements and choices are undermined. Weekly increases in activity are expected - but life is not a race! The body will take as long as it takes to heal. Anxiety about this isn't helpful.

One of the better things to come out of the 2007 NICE Guidance was a reminder that patients *are entitled* to decline treatment without detriment to the 'therapeutic

relationship'. A children's hospital recently told a girl that, as her illness was not responding to their regime (she was travelling long distances for appointments, which in itself set her back) she would be referred to another hospital for a programme to build her up. Knowing that physical over-demand can cause serious relapse in ME patients, and knowing her own daughter's capabilities from her caring role, this mother judged how detrimental such treatment would be. But others may not.

Let's be straight about this; trying to do more isn't a bad thing - it can be positively life-enhancing. Risk is a normal part of existence. But 'boom and bust' - a financial phrase applied to living with ME by our Chair of Trustees years ago and now widely used - is not fun. Don't go there. You can use your own judgement; just try and avoid overdoing things for your stage of recovery, as I almost did, with all my experience, trying to dance at a wake! If you get away with your efforts (wait a week or so to assess this) you may have a new benchmark to work from. There's no magic about this. It's just life.

Tribute : Frances BN Ommanney

I want to say a few words here about Frances, dear friend and member of the Trust's Advice Line Team. Having suffered with ME for years, she eventually succumbed to breast cancer late last year. A former BBC TV producer, the answerphone messages she left me always opened with that effusive 'Darling!' so beloved of thespians. She herself was beloved by all those whom she helped and supported. A good person, if ever there was one.

Facts At Your Fingertips

School Attendance Letters - New System

A computerised system is being implemented nationally which will automatically send out reminder letters about school attendance. ME is the biggest cause of long term sickness absence from school (Dowsett and Colby, *Journal of Chronic Fatigue Syndrome* 1997); it is possible that children with ME and other life limiting conditions will receive these letters.

One of the Trust's members was recently fined for not sending her child to school and with the

government drive to minimise truancy, there is scope for misunderstandings and distress.

The Association for Children's Palliative Care is asking parents who inappropriately receive one of these letters to let them know. Contact Lizzie Chambers, so that they can assess how many families this is affecting. You can email Lizzie on lizzie@act.org.uk with details of your experiences. Website: www.act.org.uk.

Activity Programmes - Red Yellow and Green

A family reports having had a programme given to them involving 'red, yellow and green' levels of activity.

Mother and son report being stressed out and upset by this system, with disagreements over the programme when they normally have a very good relationship.

The report of the Chief Medical Officer's Working Group, published by the Department of Health

in 2002, states: 'No management approach to CFS/ME has been found universally beneficial, and none can be considered a "cure"'. This is still the case.

If a management programme is not helping, you have the right to decline it and to organise your life as best suits you.

To get more quotes from the DoH Report, go to www.tymestrust.org/pdfs/keypoints.pdf

Dutch Study Finds Cognitive Behaviour Therapy Overrated

Drs Koolhaas and Boorder, with Professor Elke van Hoof, former editor of the *Journal of Chronic Fatigue Syndrome*, have produced a paper on CBT: *Cognitieve gedragstherapie bij het chronische vermoeidheidssyndroom (ME/CVS) vanuit het perspectief van de patient* (Cognitive behaviour therapy for chronic fatigue syndrome from the patient's perspective).

In translation, they state:

The most intensively studied psychological therapeutic intervention for ME/CFS is cognitive behaviour therapy (CBT). In recent years several publications on this subject [...] report that this intervention can lead to significant improvements in 30% to 70% of patients, though rarely include details of adverse effects.

The Dutch paper contradicts these findings:

Overall, CBT for ME/CFS does not improve

patients' well-being: more patients report deterioration of their condition rather than improvement.

Only 2% of patients reported themselves cured, 38% reported an adverse effect, and 30% reported no change. There was little impact on the hours people could maintain social contacts or do household tasks; a striking finding was that the number of respondents in paid employment or studying while doing CBT went down as a result.

The authors state:

Our conclusion is that the claims in scientific publications about the effectiveness of this therapy based on trials in strictly controlled settings within universities, have been overstated and are therefore misleading.

Dutch version: ISBN: 978-90-812658-1-2

Diet in ME - is it such a big deal?

Some years ago I produced a leaflet on diet in ME. I wrote it because unnecessary mystique had built up around the subject. I used personal experience coupled with information and advice from the late Dr Alan Franklin, Consultant Paediatrician, ME and allergy specialist, and Dr Elizabeth Dowsett, then Honorary Consultant Microbiologist for South Essex Health Trust, the UK's foremost expert on the virology of ME.

What emerged was a commonsense leaflet which punctured numerous food myths. It is packed full of simple information you're not usually told.

Dr Elizabeth Dowsett's especial concern is that malnutrition can occur in people with ME who restrict their diet too much. She advises against sugar-free diets for this reason.

Two key recommendations are:

Don't restrict what you eat more than you really need to because you will end up malnourished and this is bad for your healing processes.

Do use your common sense about what agrees with your own body, rather than following some standard recommended diet.

More detailed information includes:

*Minimising bloating and wind pain
Fibre and its problems
The most digestible vegetables
Constipation
Special treats*

And, of course, there are general principles - the 'dos and don'ts'. It's written in accessible everyday language suitable for youngsters; for example:

Do carry a snack with you when you go out. If you start to feel panicky, weepy or just 'weird', eat something. It often works like magic.

Dr Dowsett is a great advocate for ice-cream because it's nice, it's full of nourishment and easy on a sensitive tum. Custard's good too. My own favourite for a painful tum with trapped wind is a tin or carton of creamed rice heated up. YUM.

For dairy problems there are other suggestions.

www.tymestrust.org/pdfs/dowsettcoby.pdf

Quick Tour of ME Symptoms, Management, and Trust Services

In the Spotlight : The Tymes Trust View

Self-Help

ME ~ and My Friends (*a leaflet for your friends*)

The Tymes Trustcard (*a pass card for school*)

School Examinations and ME - Special Assessment Arrangements

The Essex ME Companion

Diet in ME

Reports

Long Term Sickness Absence due to ME/CFS in UK Schools

ME Diagnosis : Delay Harms Health †

Children and Young People : The Key Points

The Forgotten Children : A Dossier of Shame †

Succeeding with ME (*the Virtual Classroom*) †

Our Needs Our Lives (*on CFS/ME clinics*) †

† presentation copies available

Experiences

Mummies Aren't Supposed To Cry

Whispered Words (*the severely affected*)

For Professionals

The Nightingale Definition of Myalgic Encephalomyelitis (ME)

Professionals Referral Service

Teacher Information on CFS/ME

Back to School?

Pushing the Boundaries in ME/CFS

Ten Points on the Education of Children with ME

The SENCO's Key Role in Supporting Pupils with CFS/ME

The Doctor's Guide to ME in Children and Young People

GPs Good Practice Guide to Education for Children with ME

Physios Urged to Go Cautiously

Implications for Schools of the Chief Medical Officer's Working Group Report on CFS/ME

ME/CFS Guidelines for Educational Psychologists

Care of CFS/ME in Children

The Lightning Process - Miracle Cure?

I have often seen the Lightning Process (LP) mis-spelt as the Lightening Process - as in 'enlightenment', perhaps. A form of neuro-linguistic programming (NLP), it's a talking/doing therapy.

Clients are expected to leave support groups, so feedback is sparse, but, like Cognitive Behaviour Therapy (CBT) it uses *conscious thought processes and actions* to try and change people's *mindset*, which may be holding them back.

Three families have told me their children improved. Logic suggests that if this process made them 'better', they may either not have had the classic ME pathology (in which effort makes the patient worse - that's a key diagnostic feature) or they were substantially physically recovered without realising. Either is possible. 'Chronic Fatigue Syndrome' is a wider diagnosis than classic ME, encompassing a spectrum of conditions.

If LP isn't working, therapists seem to think it's the patient's fault, so their clients try hard. They may make unsustainable efforts; the late paediatrician Dr Alan Franklin observed that children with ME can be persuaded to make too much effort for quite a long time, but can then 'crash' badly.

Here's one account:

I did the Lightning Process last September, and made some reasonable progress (not recovery), but found it hard to sustain, and have over the last 2 months relapsed very badly, and am now more unwell than I have ever been.

I feel that the technique does not recognise the differences in types of ME and uses the same approach to fit all. I found that the 'can do' approach encouraged me to push through instead of pace (I

was told I would no longer need to pace myself) and eventually led to a severe crash. I wanted to warn others to be very careful if they are thinking of using this approach.

'Wonder' cures need approaching with caution. One person was put off by the attitude to finance and a disregard of her wish to be careful. Hundreds of pounds were payable upfront, non-returnable, with the first session lasting five hours.

How to decide?

The questions in the Preliminary Questionnaire probably tend to select out people with serious physical limits. Conversely, they may select in those who may be ready to increase their level of functioning but have felt hesitant about trying.

The large financial investment, coupled with the statements they've signed up to, will produce a need to succeed; as with peer group pressure, one wouldn't wish to be seen as a failure.

So by self-selection, the LP client list could be skewed in favour of those who (a) don't have classic ME or (b) are stronger now, but haven't moved on yet. Those who really aren't well enough may end up pulling out, having been told it's their own fault that they aren't getting better. I find that cruel but sadly I do know of such cases.

I once talked with a doctor who said his personal success rates with children with ME were high. In practice, he screened out from his patients any child who he thought had a poor chance of improving. There may be an element of this here.

For a further personal account, see *Vision 2008-1* page 5.

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