

KNOWLEDGE IN THE HOPE OF PROTECTING M.E. SUFFERERS FROM UNNECESSARY
SECTIONING

Written January 2019

Although some of the reference links are taken from mental health websites, the Grace Charity for M.E. is NOT insinuating that an M.E. sufferer has a mental illness. We believe passionately that M.E. is a neurological, biomedical illness. The websites, though, might be able to help you in getting released from the terrible act of sectioning sound minded M.E. patients who are neither a threat to themselves nor to others.

1) *Is there anything I can do as an M.E. sufferer to prevent me from being sectioned?*

As a GP is usually involved, it is best to have good relations with your GP if this is possible. Do they have a copy of the International Consensus Criteria?

<http://www.investinme.org/Documents/Guidelines/Myalgic%20Encephalomyelitis%20International%20Consensus%20Primer%20-2012-11-26.pdf>

(ISBN: 978-0-9739335-3-6)

Is your GP aware that the PACE trial, responsible for promoting Graded Exercise Therapy (GET) and Cognitive Behavioural Therapy (CBT) for M.E. sufferers, has been largely discredited¹ by academics and doctors world-wide? Despite this, it is still recommended by NHS England even though the US CDC (United States Centers for Disease Control) in 2017 removed CBT and GET from their website as recommended treatments for ME/CFS.²

The process of detention usually starts because the patient's GP, a family member, a police officer or psychiatrist is worried about their mental health. If you don't feel that you have a mental illness then do whatever you can to convince this list of people that your illness is biomedical. Make sure that they know your views, how you manage your situation and your support network of friends, relatives etc.

Also, have in mind a good solicitor in advance who has an interest in this unjust and terrible act of sectioning those who aren't in need of it.

¹ <http://www.virology.ws/2018/08/13/trial-by-error-open-letter-to-the-lancet-version-3-0/> A letter (13.8.2018) signed by over a hundred academics, patient groups, lawyers, and politicians, was sent to Dr. Richard Horton, editor of the Lancet, calling for the removal of the PACE trial and its recommendations of GET (Graded Exercise Therapy) and CBT (Cognitive Behavioural Therapy) for M.E. sufferers.

² *The Quarterly* published by the 25% ME Group Summer 2017 page 23 www.25megroup.org

You may need legal representation at a Tribunal if you are sectioned to get you released (a list of lawyers who have won cases fighting for M.E. as a biomedical illness is at the end of this paper, as are contacts for legal aid and free solicitors).

It also may be a good idea to get details ready of your MP (Member of Parliament) should you need to contact them. You might want to tell them that you feel you are at risk of being unnecessarily sectioned and could they please be an advocate for you as one of their constituents.

Make sure you are happy with who your 'nearest relative' is – see Point 9 for further information.

Tragically, if you are sectioned, take a mobile phone with you and have it charged ahead of time. Also, take the charger with you. Make sure that trusted people have your mobile number ahead of time.

2) *Why is a person sectioned in the first place?*

This happens if you have a mental illness which needs 'appropriate' assessment and/or 'appropriate' treatment in hospital and you are unwilling to comply with this. Sectioning can only be carried out for *'your health or safety or for the protection of other people.'*³

Obviously this can be very subjective.

The word 'sectioning' is derived from the Mental Health Act 1983.

3) *Who can authorise a sectioning?*

The decision to section someone is usually made by two doctors and an Approved Mental Health Professional (AMHP), who is usually a social worker, or mental health nurse, or psychologist or occupational therapist. One of the two doctors must be a specialist in mental illness. The other doctor is usually the patient's GP although doesn't have to be. One of the two doctors is often known to the patient.

It is also possible for a relative to recommend to medical authorities that someone should be sectioned.

³ <https://www.rcpsych.ac.uk/healthadvice/problemsanddisorders/beingsectionedengland.aspx>

4) *If it's for mental illness, why are M.E. sufferers at risk?*

Tragically and wrongly, some doctors see M.E. as a mental health illness, thus defying the obligatory World Health Organisation's classification which says it is a neurological and not a mental disease (ICD 10 G93:3).

5) *What might happen to me if I am sectioned?*

As an M.E. sufferer you may be 'encouraged' to take part in an exercise programme such as GET (Graded Exercise Therapy); or CBT (Cognitive Behavioural Therapy); or be given anti-depressants; certainly you will be told you don't have a physical illness and perhaps suffer from a mental health problem instead and abnormal illness beliefs. They may suggest that you need a healthier 'environment', which is ridiculous as the mental health unit is about as worst an environment an M.E. sufferer can endure.⁴

6) *If I refuse CBT/GET from my GP does that make me in danger of being sectioned?*

The legal answer is 'no', you shouldn't be in danger of being sectioned if you refuse the psychological treatments of CBT/GET; but the medical profession seems to ignore some aspects of law when it comes to treating M.E. sufferers. So, you might be in danger for refusing CBT/GET from a determined team of prejudiced psychiatric 'professionals'.

The following knowledge can help empower you against such a terrible event happening:

- Since 1st April 1995, the World Health Organisation's listing of M.E. (Myalgic Encephalomyelitis) as a neurological disease (ICD-10 G93.3) **has been mandated for NHS implementation**. The most recent review was on 1st April 2012 by the Information Standards Board (4th edition of ICD 10), where the mandate continued throughout the NHS.

Since March 2014, The Information Standards Board has been replaced by the Standardisation Committee for Care Information, SCCI. They have confirmed that the authorisation of ICD 10 in the NHS still stands.

The PACE trial which recommends CBT/GET for M.E. sufferers has been widely condemned as flawed.⁵

⁴ M.E. sufferer Sophia Mirza was told that she needed to go to a 'different environment' – this proved to be a mental health unit. Sophia had previously been looked after quite safely by her mother at home, who was a former nurse. www.sophiaandme.org.uk

⁵ See Footnote 1

- **The NICE guidelines, which support CBT and Graded Exercise for M.E., are not mandatory.** In practice, GPs and all doctors follow the NICE Guidelines: this is because all NHS organisations have a legal requirement to implement NICE guidance. **However, the treatment aspect is not enforceable.**

*'I can clarify that NHS organisations are indeed expected (and in some cases, such as a type of guidance called Technology Appraisal guidance, legally obliged) to implement NICE's recommendations. **This is not the same as saying that the NHS has the power to force a patient to undergo a treatment which they do not want.**'*⁶

Also:

*'NICE clinical guidelines such as CG53 are **not legally enforceable.**'*⁷

'Healthcare professionals should be aware that – like all people receiving care in the NHS – people with CFS/ME have the right to refuse or withdraw from any component of their care plan without this affecting other aspects of their care, or future choices about care.'⁸

In other words, every patient case is individual and a doctor does have the right to express clinical freedom, along with consulting the patient, as to what is best. This may mean refusing Graded Exercise Therapy and CBT.

There is also the NHS constitution; although the following points aren't always implemented, they still remain your rights:

- 'You have the right to receive care and treatment that is appropriate to you, meets your needs and reflects your preferences... '
- 'You have the right to choose your GP practice and to be accepted by that practice unless there are reasonable grounds to refuse, in which case you will be informed of those reasons... '
- 'You have the right to express a preference for using a particular doctor within your GP practice and for the practice to try and comply.'⁹

⁶ Quote from Kathleen Jackson-Heppell, Communications Co-ordinator (Enquiry Handling and Internal Communications for NICE), in an email to the Grace Charity for M.E. dated 15/02/2011

⁷ Quote from Natalie Whelan, Communications Executive (Enquiry Handling) for NICE, in a letter to the Grace Charity for M.E. dated 23rd September 2009

⁸ NICE guidance document on CFS/ME, Clinical Guideline 53, 22 August 2007, page 8. <http://guidance.nice.org.uk/CG53>

⁹ www.gov.uk/government/publications/the-nhs-constitution-for-england

7) *Can I be sectioned whilst in hospital for something else?*

Yes. If you are already in hospital, certain nurses can stop you leaving until the doctor in charge of your care, or their nominated deputy, can make a decision about whether to detain you there under the Mental Health Act. If detained beyond 72 hours the patient should receive an assessment to decide if further detention is necessary. This doesn't just apply to M.E. but to any patient who has gone into hospital for any reason or condition.

8) *What should I do if staff believe wrongly I'm anorexic because I can't eat properly?*

Having swallowing difficulties is called dysphagia, often found in patients with stroke, Multiple Sclerosis and Parkinson's diseases which are all neurological problems. M.E. is also neurological, categorised as such by the World Health Organisation since 1969.

There are biomedical reasons why an M.E. sufferer may not be able to swallow. Some M.E. specialist researchers believe that the gastric mucosa which is infected with enteroviruses may reach the brain by travelling up the vagus nerve, which controls the swallowing reflex.¹⁰

In addition, sufferers can have sensitivities to food, medication and chemicals making it difficult for them to swallow them, as they can have an adverse reaction.¹¹

This shows that an M.E. sufferer is unable to swallow because of a severe symptom of the illness and not because they choose to refuse food and drink.

Indeed many M.E. sufferers are tube fed with various types of feeding tubes. In the tragic case of 21 year old Merryn Crofts, who died from M.E. in May 2017, her need for tube feeding and eventual weight loss at 5 and a 1/2 stone was NOT put down at the inquest to mental health issues such as eating disorders, depression or anxiety. Rather the coroner reported that it was the much misunderstood illness that was likely to have led to the gastrointestinal failure and other complications that caused her to starve to death.¹²

¹⁰ Drs. Byron Hyde and John Chia Questions & Answers section page 10 *The Quarterly Newsletter Summer 2018* www.25megroup.org

¹¹ M.E./CFS A Clinical Case Definition and Guidelines for Medical Practitioners Immune Manifestations page 7, Bruce Carruthers and Marjorie van de Sande 2005 ISBN 097393350X

¹² See article 'ME sufferer who was dismissed as hysterical vindicated in death' *The Times* 29 May 2018 by Lucy Bannerman; also *The Quarterly* published by the 25% ME Group Summer 2018 pages 22-23 www.25megroup.org

9) *If I am sectioned, how can I get out and come home?*

YOU HAVE A RIGHT TO APPEAL THE SECTIONING, WHICH WILL NEED AN APPLICATION – AN APPEAL ISN'T AUTOMATIC. The sooner you or someone else starts appealing the sectioning, the better. A form needs to be filled in. To get the ball rolling with getting out from the hospital and coming home, the person appointed as your 'nearest relative'

can apply for your discharge from detention. Or you can apply yourself. If detained in hospital, a patient is entitled to an advocate straight away, usually an Independent Mental Health Advocate (a free service). Their role is to provide information to the patient concerning their rights.

The appeal will usually involve a hearing at a mental health tribunal, independent from the hospital. The appeal panel will require written reports from your 'responsible clinician' the person who is in charge of your treatment programme for your sectioning. You must also receive any copies written about you. You are entitled to have a solicitor representing you at no cost to you.¹³

The appeal panel usually consists of a judge, a doctor and a lay person¹⁴ (some sources report more specifically that the panel is a judge, psychiatrist and a person with a social care background)¹⁵. Your 'nearest relative' may also attend the tribunal and make a contribution. Your solicitor and the doctor from the panel will work with you before the tribunal.

In England, Wales and Northern Ireland the nearest relative is determined through a strict order of priority, unlike Scotland where someone may choose who their nearest relative is although this must be in writing with signed consent.¹⁶ In England, Wales and Northern Ireland the nearest relative is in the following ranking order: the sectioned person's spouse or civil partner/ cohabitee; next in line is son or daughter (eldest first); next is father or mother; next is brother or sister (eldest first); next is grandparent; next is grandchild; next is uncle or aunt; next is nephew or niece. There are exceptions to this ranking order: for example, if you have a carer who is not related yet has lived with you for more than 5 years the carer could supersede your parents and siblings as the nearest relative. The nearest relative also has to be at least 18 years old unless they are your mother, father, husband, wife or civil partner. If you don't want the chosen person appointed to be your 'nearest relative' you may have to apply to a court to have them

¹³ Royal College of Psychiatrists on Being Sectioned (in England and Wales)

<https://www.rcpsych.ac.uk/healthadvice/problemsdisorders/beingsectionedengland.aspx>

¹⁴ Taken from 'The right to appeal' Camden and Islington NHS Foundation Trust

<https://www.candi.nhs.uk/service-users-and-carers/mental-health-act/being-sectioned/right-appeal>

¹⁵ *Assessment of people with M.E. under the Mental Health Act* October 2015 by Action for M.E. PDF available written by Cathy Stillman-Lowe, Joan Crawford and Dr. Hiroko Akagi

¹⁶ <https://www.mwscot.org.uk/get-help/help-for-carers/being-a-named-person/> Link for more information about being a named person/nearest relative in Scotland.

changed. If you have no-one on the list who can act for you, then you can apply to court to have a friend or an appointed person to be your nearest relative. For further information on your nearest relative/named person the following link can be helpful:

<https://www.mind.org.uk/information-support/legal-rights/nearest-relative/about-the-nearest-relative/#.XCocB7i9GIA>

The following link explains what you might expect from a tribunal:

<https://www.rcpsych.ac.uk/healthadvice/problemsanddisorders/guidementalhealthtribunals.aspx>¹⁷

10) *How long do I need to wait to come home after being sectioned?*

It depends on what Act you've been sectioned under and if you are successful in your tribunal.

Emergency Sectioning lasts up until 72 hours (3 days) during which time an assessment should be made if the patient is sectioned further under Section 2 or Section 3

Section 2 is detention only without imposed treatment. It lasts for 28 days and an assessment may also be going on for further detention under Section 3. If you've been sectioned under Section 2, you have to appeal within 14 days. The tribunal must take place within 7 days of application.

Section 3 This is detention combined with treatment. It lasts up to six months and then possibly renewed for a further six months and then annually. The treatment can only be given to the patient if they are sectioned. So, if the patient can receive the 'recommended treatment' outside of being detained, they could make that point for their release. If you've been sectioned under Section 3, the hearing should take place within 8 weeks of application. You can appeal once in 6 months of being detained. After that you can appeal once in each renewal period.

It is possible to come home and be discharged before a section comes to an end.

For further advice about discharge from detention, the following link may help: <https://www.rethink.org/living-with-mental-illness/mental-health-laws/discharge-from-detention/tribunals>

¹⁷ Information taken from Rethink Mental Illness <https://www.rethink.org>

11) *Can having Power of Attorney (Healthcare) help?*

There are two types of Power of Attorney: one for finance and the other for health. The person appointed as your replacement (attorney) should you be unable to make a decision for yourself in the future, needs to be arranged whilst you still 'have capacity'. The Mental Capacity Act of 2005 has decided that all of us can have decisions made by doctors to treat us if we 'lack capacity'. Lacking capacity is when you are unable to make a decision for yourself. A patient over 16 yrs of age who is judged as lacking mental capacity (even temporarily) can have decisions made for them by medical staff. This is meant to be in the patient's 'best interests' but is not always. You can only appoint a Power of Attorney (Healthcare) or make an Advance Decision if you are 18 or over.

Power of Attorneys can be drawn up by solicitors but they are much cheaper via a gov.uk website. Once drawn up, it needs to be registered with the Office of the Public Guardian.

<https://www.gov.uk/power-of-attorney/make-lasting-power>

Having Power of Attorney could only help if the person sectioned also 'lacked capacity' in the opinion of some doctors.

12) *Has any sectioning of an M.E. sufferer been beneficial to them?*

We have heard that the sectioning of a young man diagnosed with M.E. who also had genuine mental health problems was beneficial to him as he was given regular meals. (This was not a first-hand witness account but from a source.) Of course, you don't need to be sectioned in order to have regular meals. This paper, however, is attempting to make a stand in favour of sufferers **who do not need sectioning**, especially as M.E. is often still seen wrongly as a mental health illness. In fact, there is much detrimental harm done to M.E. sufferers who have been sectioned, as the treatment offered is usually psychological, performed by doctors/nurses who believe wrongly that M.E. is a mental health issue. Sufferers complain of bright lights, noise and being forced to do activity if sectioned. In Denmark, it has been reported that a sufferer had toxic levels of drugs forced upon her (thankfully this sufferer is now released from hospital and has come home).¹⁸

¹⁸ Patient is Ms. Karina Hansen and this reference is from Daily Kos publication October 10th 2018
<https://www.dailykos.com/stories/2018/10/10/1803351/-Karina-Hansen-is-FREE>

13) *What are the documented outcomes for those M.E. sufferers who are sectioned?*

The account of severe M.E. sufferer Sophia Mirza is well documented.

www.sophiaandme.org.uk Sophia was released after 2 weeks of being sectioned; she already had a solicitor involved before the sectioning as she was threatened with this before it took place. Tragically Sophia died in 2005 after the sectioning, from renal failure due to M.E.

A young woman with severe M.E. was sectioned in Germany but came home in 2015. Doctors had even changed her diagnosis of M.E. to 'Pervasive Refusal Syndrome'.¹⁹

There is feedback from the website Phoenix Rising concerning a man who has been sectioned at least twice in the UK, in London and Devon, who has a diagnosis of M.E. The reports are that he has been injected with clozapine (antipsychotic drug). It appears that at the time of writing this (October 2018) that he is still sectioned in Torquay, Devon (please let us know of any updates).

There is a well documented case from Denmark when a young woman was forcibly removed from her home in Denmark in front of her family²⁰ in 2013. She returned home after four and a half years of being institutionalised, helped by a petition of almost 3,000 signatures and a court case.

14) *Can children with M.E. be sectioned?*

Unfortunately, children can also be sectioned. What appears to be more common though for children with M.E. is that the parents may be faced with child protection threats. This may happen through a misdiagnosis of a child's illness: for example, instead of a true diagnosis of M.E. they may be wrongly labelled as having Munchausen's syndrome by proxy (also known now as Fabricated or induced illness or FII) whereby a parent is blamed for the illness of their child. It is a form of child abuse, occurring when a parent or carer, usually the child's biological mother, exaggerates or deliberately causes symptoms of illness in the child.

To presume this is the reason behind a child genuinely suffering from M.E. is completely horrific and unacceptable.

¹⁹ *The Quarterly* Winter 2015 Good News from Germany page 6 published by the 25% ME Group
www.25megroup.org

²⁰ https://me-pedia.org/wiki/Karina_Hansen

For parents to have care proceedings take place against them, Social Services would be involved. Children may be threatened to be removed from their homes and placed in foster care or a hospital practising psychological therapies which may include a secure locked ward. Of course, a true M.E. sufferer is unlikely to improve from these suggestions with a probability of further deterioration, as well as the awful distress involved.²¹

A patient over 16 yrs of age who is judged as lacking mental capacity (even temporarily) can have decisions made for them by medical staff.

In England, Wales and Northern Ireland a person is a child until their 18th birthday when they legally become an adult. In Scotland, child protection orders can only be carried out on a person who is under 16 years old, although parents in Scotland still have parental responsibility for their children up until aged 18.

The same description applies that a child can only be sectioned if they are considered to be a risk to themselves or others.

Tymes Trust is a registered charity which helps children and young people with M.E.
www.tymestrust.org Tymes Trust, PO Box 4347, Stock, Ingatestone, CM4 9TE,
Tel: 0845 003 9002

15) *Will I have to pay for my solicitor?*

The website for the Royal College of psychiatrists states that a person who has been sectioned can have a legal representative at no cost to them. You have to make sure, though, that the lawyer understands M.E. and why being sectioned will only make the symptoms of M.E. worse.

The Law Society <http://solicitors.lawsociety.org.uk/>

Tel: 020 72421222

Legal aid is when the government helps with legal costs for a client.

Further information to see if you qualify for free legal aid from Citizen's Advice Bureau:

<https://www.citizensadvice.org.uk/law-and-courts/legal-system/finding-free-or-affordable-legal-help/>

²¹ See the film *Voices from the Shadows* by Natalie Boulton and John Biggs
www.voicesfromtheshadowsfilm.co.uk 2011

- 2) Josephine Van Lierop
Josephine is an employee of Slater Gordon Lawyers (London and Edinburgh offices)
She has succeeded in a disability discrimination claim for a 'CFS' sufferer, Sept. 2015
Tel: 0131 718 4179
Website: www.slatergordon.co.uk

- 3) Richard Colbey
Richard works for Lamb Chambers. He won a case in 2012 for a 'CFS' sufferer against their insurer, who dismissed M.E. as a functional disorder.
www.lambchambers.co.uk
email: richardcolbey@lambchambers.co.uk
Tel: 020 77978300
020 7797 8302

- 4) Brian Barr solicitors
www.brianbarr.co.uk
Tel: 0161 737 9248
Based in Manchester
Brain Barr solicitors have a special interest in representing clients with fibromyalgia, chronic pain, CRPS (Complex Regional Pain Syndrome) and Chronic Fatigue Syndrome/ME

- 5) Katherine Sheldrick
Hempsons Solicitors
www.hempsons.co.uk
Tel: 0161 228 0011 (general enquiries)
Ms. Sheldrick: 0161 234 2467 Her email: k.sheldrick@hempsons.co.uk
Email: manchester@hempsons.co.uk (general inquiries)

Hempsons have solicitors nation-wide, in London, Harrogate, Newcastle as well as Manchester .

Ms. Sheldrick (Manchester based) helped a doctor who treated M.E. biomedically to win a legal battle in 2017.

If any of these lawyers are used please give us feedback. Also, we'd like feedback generally about this paper. www.thegracecharityforme.org

With thanks to a member of the 25% ME Group for their assistance with this document.

Disclaimer: *Although the Grace Charity for M.E. aims to prevent unnecessary sectioning of M.E. sufferers, we cannot be held responsible if such a terrible incident does occur.*

