



25% M.E. Group
Support for Severe M.E.

<https://25megroup.org/about-us>

An informative new video series, produced in the UK, called **Dialogues for a neglected Illness - or Dialogues for ME/CFS**, produced by **Josh Biggs and Natalie Boulton**, includes two fifteen minute videos about Severe ME: Severe & Very Severe ME/CFS; and Symptoms and Management of Very Severe ME/CFS. These can be viewed and shared for free online.

My words can't do justice to these videos and I highly recommend you view them, however I will give a detailed description of these two videos for those whose symptoms prevent them from watching informative videos.

<https://www.dialogues-mecfs.co.uk/films/severeme/>

I was particularly excited to learn about this new video series about ME which includes videos about Severe ME being made by the producers and directors of the brilliant 2011 documentary **Voices from the Shadows** which looked at five people with Severe ME to illustrate the neglect and disbelief faced by people with Severe ME. I found that film so powerful that, despite having very little money, I bought several DVD copies to give to my new GP, my Social Worker, and to show to my new carer. It had a powerful effect on them. You can find out more about **Voices from the Shadows** here <https://voicesfromtheshadowsfilm.co.uk/>

(Please note that this film is not suitable for children and young people who may find it too disturbing to watch)

These videos are not just useful for those who suffer from Severe and Very Severe ME, but for everyone who has ME, their families, their friends, their health and care professionals. Those with ME know that over-exertion leads to temporary (and sometimes permanent) deterioration. Some people become severely affected by ME very quickly, others (like myself) deteriorate over time. Maybe the people you share these videos with will be more understanding about how vital it is that you don't overdo things, that you need to prevent worsening your symptoms. By watching these videos you can perhaps arm yourself with more knowledge, understanding, and advocate for better treatment for people with Severe ME. With such a wide range of symptoms and experience of people with ME, these short videos can't cover every single issue that people with Severe ME suffer and they don't discuss those, like me, who didn't have sudden onset Severe ME, but I think they've done a really good job of producing videos which give powerful insights into the lives of sufferers and how doctors and carers can help.

You might recognise some of the names of those featured in this video:

** The first video includes contributions from Dr William Weir, Caroline Kingdon, Dr Nigel Speight, Dr Charles Shepherd*

** The second video includes contributions from Dr Nigel Speight, Dr Nina Muirhead, Dr William Weir, Caroline Kingdon - Research Fellow and Nurse, Prof Todd Davenport*

** Tom Kindlon and his mother Vera Kindlon, Rob, Naomi Whittingham, Robert (Bob) Courtney, Anne Oertegren, Sophia Mirza. John Peters, Graham McPhee also discuss the patient's perspective.*

DETAILED DESCRIPTION OF THE VIDEOS – particularly useful for those who find it difficult to watch informative videos.

Severe & Very Severe ME/CFS shows how sudden onset ME devastates lives and how approximately 25% of those affected by ME are housebound and need extensive support - how even minimal exertion such as reading a book can lead to worsening of symptoms. We learn that some of the most severely affected patients can be in total body pain, paralysed or almost paralysed, tube fed, catheterised - how those caring for people severely affected have feared that their loved ones might die from the illness. As many people reading this review may already know, the prognosis for younger patients is better than for adults, some make full recovery. Sadly, the prognosis for adults with Severe ME is not great. At the very severe end of spectrum some have sadly died, and there is an upsetting number of suicides, due in part to lack of medical and care support. Because many who suffer from Severe ME are totally bedbound or housebound, they are excluded from medical care because they can't get to clinics so they need doctors to keep in touch - by phone or video consultations, home visits and doctors need to make sure that patients receive the benefits they need and appropriate nursing care. Sadly, doctors often face difficulties when trying to get help from specialists in local hospitals who are unwilling to help or to make home visits. [My own GP (in the UK we register with a local medical doctor known as a General Practitioner) is supportive of me having phone consultations, email requests and, when needed, home visits.]

I am one of the lucky few regarding phone consultations and home visits by my GP who even made a special home visit to me the day before his practice went into its Covid-19 practice changes. He told me that all patients would initially have phone consultations (they were also investigating the use of video calls) and if the doctors decided they needed to see the patient in person, the doctor would visit the patient at the patient's own home. I wonder if his supportive attitude is because of the powerful influence he felt from viewing the Voices from the Shadows DVD I gave him. Many of us are hoping that the phone, Skype and other initiatives implemented by medical professionals during the Covid-19 pandemic will lead to a more flexible and supportive attitude to our needs in the future.

I hope that many people who suffer from Severe ME will be able to show this relatively short video to their health and care professionals and also to their own family and friends to let them see what Severe ME can be like. I, personally, did not become severely affected straight away. I was constantly advised to "push through", to "try harder". That was before we all had internet and smart phones or tablets. Perhaps if we'd had easy access to videos like this back then, people like me could have learned what happens when you push someone who has ME. Perhaps I would never have become Severe. So I think this is a powerful video for everyone with ME. When people trivialise your condition and say you're just a bit tired, you can show them this video and explain that you are staying within your energy capability in order to avoid making yourself more ill, possibly permanently more ill.

Symptoms and Management of Very Severe ME/CFS discusses more about symptoms and possible treatment/management to help easy patient suffering. Symptoms such as total body pain, severe continuous headache, cognition and concentration problems, sensitivity to touch, being turned in bed, toileting, sensitivity to sound are all problems which are discussed. Patients and their family tell in their own words about the symptoms. The benefits of pacing are discussed, as doing too much brings back the symptoms and pain to those who have fortunately improved a little. Anything sensory: light sensitivity, smell sensitivity, touch sensitivity, reading, thinking, can all exacerbate symptoms and pain. Patients exposed to light, smells or touch can take some weeks to recover from the extra pain

caused by these events. Those who enter a patient's bedroom need to be very quiet, maintain a quiet voice level and keep the lighting low. Reading, thinking, breathing and bed mobility can all exacerbate symptoms. A safe, low sensory environment is essential for some of the most severely affected.

Although there may be no curative treatment, doctors can help. Pain is often resistant to conventional painkillers, but Amitriptyline, Carbamazepine, anticonvulsants like Gabapentin and Pregabalin may be useful. Sometimes opiates are the only effective painkillers.

Sleep dysfunction is discussed. Dr Speight advises that patients in general should not try to fight the sleep experience, that sleep hygiene measures can actually be harmful. Those who feel the need to sleep, say 12 hours a day, should be allowed to, and those who can't sleep can sometimes be helped with drugs like Melatonin or anti-histamines.

Abdominal pain, sometimes due to secondary food intolerances and nausea need to be managed. We hear about how one man was badly treated when he sought help - how he was not given the help he desperately needed, but was instead sectioned (being admitted to hospital and being detained, whether or not you agree to it, under the UK Mental Health Act 1983) and told if he lost weight again he would be sectioned again and we learn how he ultimately took his own life.

More recently, doctors and patients are becoming aware of a quite frightening condition - Mast Cell Activation Syndrome - which is a severe intolerance due to histamine release. This condition is not a cardinal part of ME, but it may be an added complication for some people with Severe ME, and it has been linked to recent fatalities. It is useful for those who do suffer from this to know that it is responsive to oral Sodium Cromoglycate, anti-histamines - H1 and H2 blockers (not proton pump inhibitors).

Inability to move due to extreme weakness. Darkened rooms. How some can't move their own head, need to be toileted, can't speak, can't open their eyes. Some lose the power of speech and breathing can be painful. We are told that these severely affected patients, with a more severe phenotype, have a glycolic impairment in addition to the mitochondrial impairment. The effort of eating and drinking and toileting can be too exhausting for some of the most severely affected and Dr Speight advises that gastro nasal tube feeding and a urinary catheter (to avoid using energy to use the commode) at an early stage to reduce the amount of energy expended.

Those who can't move in bed need help from those who care for them by turning them in bed to avoid bedsores.

Doctors sometimes misdiagnose those with severe ME/CFS and wrongly diagnose them as having a psychiatric illness - "Functional Neurological Syndrome" which can lead to inappropriate/harmful treatments such as CBT, GET, reablement.

Myoclonic jerks (shock-like jerks of muscles or groups of muscles) are discussed.

Children with ME are sometimes misdiagnosed with PRS (Pervasive Refusal Syndrome). Dr Speight has been involved in 20 cases over the last 5 years where parents of children with ME have been incorrectly accused of FII (Fabricated or Induced Illness). Such misdiagnoses can lead to harmful treatment regimes.

Regular supportive contact with a doctor or consultant is essential. Sufferers of Severe ME still get other illnesses which need treatment and they need their medical practice and consultants to arrange home

visits. The importance of listening, rather than enforcing the doctor's opinion on how quickly the patient can do things, was advised, to gain patients' and families' trust.

The video ends with three typed lists:

- * symptoms occurring commonly in Very Severe NR/CFS
- * advice on Practical Management which sums up the information provided in the video and also refers to Orthostatic Intolerance
- * Principles of Care

Review by Jan Johnson
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