

55 Reasons why it is difficult to treat a person with Very Severe ME

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Stonebird : the lived experience of Severe ME

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All the time that ME is treated only as a fatigue illness the health needs of the very severely affected, who feel unimaginably ill in every moment, who are not generally part of research and whose experience is poorly if at all understood, are massively at risk, for some of the following reasons; this is not an exhaustive list by any means :

1. It is impossible for the person to travel to a clinic or a hospital.
2. It is extremely difficult to find a knowledgeable GP or consultant .
3. There is little, if any choice of biomedical ME consultants.
4. Knowledge of how to approach or communicate with a person with Very Severe ME is minimal.
5. The system expects people to fit into it and is not very accommodating of those who cannot.
6. Hypersensitivity to touch makes physical contact unbearable, dangerous, impossible without harming the person with Very Severe ME.
7. Hypersensitivity to noise makes it difficult to impossible to bear the sound of the voice of the GP or consultant, let alone all the background noise and any other noise exposure.
8. The impact of noise may cause the person to be damaged and physically harmed for weeks, months, even indefinitely.
9. The impact of chemical sensitivity means the person cannot go into environments where ordinary cleaning agents, perfumes, chemicals are used.
10. The person with multiple chemical sensitivity cannot bear to be in the presence of people wearing perfume on their body or clothing. It will harm them and cause increase

in symptoms. They cannot afford to have anyone visit them and bring their perfume and chemicals into their house, without dire consequences.

11. Light sensitivity may make it impossible for a person to be in a room with ordinary light. Exposure to light can be agonising and harmful.

12. It may be impossible for a consultant to examine a patient or write notes or see instruments in low to dark light, which is the only way a person with Very Severe ME can be seen; even the noise of a pen on paper can be too much to bear.

13. Cognitive issues make it difficult for the person to remember what needs to be said, to access information within their mind. There are blocks on every level of communication in Severe ME. Communication requires inward and outward pathways to function properly; these are not there, reliably or at all, for the person with Very Severe ME.

14. Processing difficulties in the brain make it difficult to impossible to understand questions or information and to answer adequately or comprehend meaning. Any mental demand can lead to massive deterioration: instantly.

15. There is not enough energy for the person to explain their history and symptoms or express their concerns about their health, even if the person can temporarily access it. The effort of speaking, if the person is able to speak, is too much and can lead to a post-exertional crisis. The full reality of a person's disability and illness experience can be missed if the moment they manage to communicate is considered the norm, when it is in reality rare to impossible.

16. Extreme pain and physical discomfort make it difficult to concentrate and deal with complex interactions with other people, especially as the interaction itself will most likely increase the pain even more.

17. Paralysis makes any interaction impossible, you cannot function when you are completely paralysed either mentally or physically; you cannot even speak or open your eyes. Transient awake paralysis can hit any muscles at any moment.

18. Drug sensitivity and allergy make it risky to even attempt to try and take new drugs and nutritional medicine, even if needed.

19. Any drug at normal dose is likely to be too high for the person with Very Severe ME or may not be tolerated at all, even at a lower dose.

20. If regular injections are suggested/required, the treatment may not be accessible because of skin sensitivity, pressure sensitivity, neurological and muscle pain, hyperesthesia, the risk of intolerance of the drug, the inability to cope with another person in the room, the noise and chemical exposure, the energy required to interact, is unlikely to be there. If the person is required to be in a different posture, it is likely to be impossible for them and can endanger their health to try.

21. A blood pressure cuff can be too painful to put on and bear the increased pressure, as it is pumped up. Harm can be done if this is ignored.
22. Taking blood samples, may be difficult to impossible, in any one moment, especially if you have to apply a blood pressure cuff and the person cannot bear it. Increased pain and exacerbation of symptoms as a consequence may be persistent. Veins may be hard to find or persistently collapse, causing additional stress and difficulties gaining enough blood. Pain may be so extreme that the additional pain of a needle puncturing skin may be too much to tolerate. Extra time and flexibility are always required, plus a willingness to adapt to the persons physical reality.
23. The weight and pain of a cannula pressing on hypersensitised painful skin and muscles may be intolerable.
24. Various different postures required may be impossible to achieve for examination.
25. Physical contact itself, required for physical examination, literally causes deterioration of symptoms and increased pain, spasms, paralysis, cognitive dysfunction to worsen. There will always be a post- exertional reaction, which is essential to consider and take into account and can be extreme and lead to massive deterioration and distress.
26. Providing a urine or stool samples is not the simple act that it is for ordinary physically functioning people. How is the person to capture the urine or stool with paralysed or numb hands with poor co - ordination, spasms, muscle dysfunction. How is the person to understand instructions with severe cognitive dysfunction similar to Alzheimer's?
27. Any test or treatment involving equipment is likely to be impossible to manage and potentially harmful from over exertion which leads to cognitive and physical deterioration and risks the persons ability to tolerate or cope with any deterioration especially if the impact lasts months or years. The health of the very severely affected is so frail that inappropriate intervention can even lead to death.
28. Two way communication may be impossible and even if possible will be limited complex and potentially harmful, leading to severe post- exertional impact. It is essential that anyone trying to communicate with a person with very severe ME understands the way the person communicates, what they can tolerate and how little energy they have and not ignore or forget the persons reality.
29. Experimenting with treatment is a very high risk strategy without knowing if the person will be able to tolerate recommendations and without understanding possible reactions. Should never be undertaken without due consideration of risk and possible side affects with careful consideration of possible impact in advance with a strategy in place to support the person should they choose to go ahead. People with very severe ME are desperate for help and so open to mistreatment and defensive blaming by professionals who simply have not understood the frailty or risk. They are at massive

risk of deterioration and harm being inadvertently or carelessly done to them; for this reason a proper Risk Assessment should always be performed.

30. There are no NHS medical consultants, that we are aware of, to turn to, who have the necessary medical knowledge and experience, or who are willing to travel to the home, in the UK currently – there is little hope of finding one . So many symptoms of the most severely ill are either ignored or dismissed and overlooked and not properly understood.

31. The knowledge base required to safely and adequately suggest and provide tests, treatments, ongoing support, for Very Severe ME with complex neurological dysfunction is apparently not available within the NHS currently or if it is, it is inaccessible to the most profoundly disabled and severely ill patients, with an ME label. It is not adequate to state ME is a fatigue condition and ignore swathes of symptoms that are profoundly disturbing, distressing and due to real physical dysfunction, which would be taken gravely seriously in other illnesses, such as stroke, heart failure, diabetes, cancer and other more rare genetic and other diseases. There is an associated confusion with what is co-morbid and what is ME – there does not seem to be a universal holistic, medical approach to the complex interaction of symptoms.

32. There is a need for partnership, in working out how to offer medical support and assistance safely. There is a need for humility and an ability to admit ignorance, lack of knowledge and to take responsibility for actions and reactions and wrong treatments and methods, especially a need to comprehend the very real risks and dangers of deterioration and opposite reaction to that hoped for or desired, that again we have rarely found.

33. A person with Very Severe ME is unlikely to tolerate or cope well with the physical demands of invasive treatment, even if required.

34. A person with Very Severe ME is likely to be extremely drug sensitive ; they require an awareness of anaesthetic sensitivity that is generally not provided by professionals. The person and/or their carer is more often put in the situation of having to guess what is safe, as professionals are themselves seem unaware. How can they be given safe advice when their symptoms are not adequately investigated or properly medically explained, in the first place ?

35. People with Very Severe ME just cannot access everything required to negotiate with doctors surgery and hospital settings, treatments, follow up appointments, Physiotherapy, OT, medical assessments, operations etc. They are at grave risk of harm because of the dearth of aware medical consultants to back them up and make safe recommendations.

36. People who live away from direct contact with public places and people due to profound hypersensitivity and fragility are extremely vulnerable to exposure to infections and less able to fight them off, risking increased deterioration of health if they catch anything.

37. Because of the confusion and collusion with the psychiatric lobby and the wrongful focus purely on fatigue, it is extremely difficult to know who it is safe to trust and who will not harm you. Harm can be done through lack of understanding or misdirected interpretation of illness and lack of understanding of how to help the most severely affected, whose physical experience is so much more extreme and complex than those mildly affected, whom professionals are more likely to have encountered if at all.

38. Extremely physically ill hypersensitive people with severe multi- system dysfunction who have little tolerance for face to face interactions are easy to misinterpret.

39. Extremely physically ill hypersensitive people with severe multi- system dysfunction who have little tolerance for face to face interactions are easy to misrepresent in a health service determined to focus on a psychosocial interpretation. The current NHS pathway is woefully inaccurate and inadequate.

40. Extremely physically ill hypersensitive people with severe multi- system dysfunction who have little tolerance for face to face interactions are easy to misunderstand.

41. Extremely physically ill hypersensitive people with severe multi- system dysfunction who have little tolerance for face to face interactions are easy to mistreat.

42. Extremely physically ill hypersensitive people with severe multi- system dysfunction who have little tolerance for face to face interactions, are easy to have wrong and inaccurate reports written about them, expressing opinions as fact; wrong opinion based on lack of knowledge – this can do much harm.

43. There is not enough accurate, adequate explanation or study of individuals symptoms to help identify them accurately, or protect people with Very Severe ME and provide informed documents to help inform others.

44. Private tests and treatments are often too expensive to conduct.

45. Private consultants are often too expensive to pay for home visits, even if willing.

46. The person with Very Severe ME is physically profoundly ill and often cannot undertake the risk of trying to get help, from an unknown consultant or doctor, when any interaction and effort leads to profound consequences of health deterioration, temporary or permanent or very long term.

47. Hospitals, outpatient departments and doctors surgeries are not generally geared up to accommodate multiple chemical sensitivities, noise sensitivity, light sensitivity, need for bed rest etc. Being exposed to the major physical trauma of travel and then being exposed to so many people, interactions and so many sources of noise and chemicals and infections will be too much for the person with Very Severe ME.

48. Sitting and standing or tilting will be extremely difficult to impossible for the person with very Severe ME and could endanger their health or be intolerable and harmful to attempt.