

# CHRONIC FATIGUE SYNDROME & MYALGIC ENCEPHALOMYELITIS CFS/ME - QUESTIONNAIRE

Dear Madam or Sir

This questionnaire aims to gather information and experiences from people with Chronic Fatigue Syndrome (CFS) or Myalgic Encephalomyelitis (ME) in view of the forthcoming publication of a book dealing with the subject. Given the scarcity of data on CFS/ME, your contribution will be of great value to further the understanding of a condition that is all too often overlooked by the medical community. The objectives of this survey are to raise the public's awareness of CFS/ME but also that of local, national and international institutions, as well as urging the medical community to carry out further research on the matter. A higher visibility is often the first step towards a greater understanding and better treatment. Professor Umberto Tirelli (<http://www.umbertotirelli.it/index-e.php>) is a co-author and supports this initiative, as you can see from his internet site.

I would thus be extremely grateful if you could please fill in this questionnaire, at your own time and pace, and return it to the following address: [herman.salton@exeter.oxon.org](mailto:herman.salton@exeter.oxon.org) There is no need to indicate your full name in your questionnaire—your first name or even, if you prefer, a fictitious name is sufficient. As we believe that CFS/ME requires a global approach in terms of information and research, the questionnaire is also available in French, Spanish and Italian, and will be sent to CFS/ME associations all over the world with the aim of gathering the widest possible sample of experiences from those affected by CFS/ME.

The questionnaire and resulting book focus on the experience of the CFS/ME patient (e.g. communication issues, impact on the patient's life, etc) rather than on the clinical aspects of his or her condition. With the aim of obtaining the widest possible range of experiences, I invite you to forward this questionnaire to other people affected by CFS/ME or their family and/or carers. This questionnaire is available both in a Word and PDF format, the first being suitable for typing, while the second can be printed off, filled in by hand and returned to me by email or post. The questionnaire comprises 22 questions, but any can be omitted, should you wish so or should you be too tired to proceed. However, please bear in mind that the more specific and detailed your answers, the greater will be your contribution to making CFS/ME known and understood.

Thank you very much for your time and effort to fill in this questionnaire. Should you have any question and/or suggestion concerning the questionnaire or book, please do not hesitate to contact me.

With my very best wishes,  
Dr Herman Salton  
LLB/LLM (Italy), MPhil (Oxford), PhD (Auckland)  
14, Walton Street  
Oxford, United Kingdom  
Email: [herman.salton@exeter.oxon.org](mailto:herman.salton@exeter.oxon.org)

---

**1. How old are you, what do you do and for how long have you been suffering from CFS/ME?**

.....  
.....  
.....

**2. Have you ever received a diagnosis of CFS/ME? If so, when and how did the diagnosis come about?**

.....  
.....  
.....  
.....

**3. What kind of symptoms do you suffer from exactly?**

.....

.....

.....

.....

**4. What has changed in your life as a result of suffering from CFS/ME? Did you have to suspend and/or reduce your work/study activities?**

.....

.....

.....

.....

**5. How would you describe the attitude of doctors towards CFS/ME? And of your General Practitioner/Family Doctor?**

.....

.....

.....

.....

**6. Have you experienced any difficulty in explaining the symptoms of CFS/ME to your family, friends and employers? How about your Family Doctor and/or other doctors?**

.....

.....

.....

.....

**7. What kinds of treatment have you tried? Have any of them been effective?**

.....

.....

.....

.....

**8. What do you think are the causes of CFS/ME? Forget for a moment what you have read about it: what does your instinct tell you about the causes?**

.....

.....

.....

.....

**9. Do you agree with the following definition of CFS/ME: “A permanent flu”? Why?**

.....

.....

.....

.....

**10. Do you remember the day when your CFS/ME first began, or was it a more gradual onset?**

.....

.....

.....

.....

**11. Are your symptoms constant or do they fluctuate? In the latter case, have you noticed any kind of regularity in the fluctuations (e.g. a worsening of the symptoms after certain activities)?**

.....

.....

.....

.....

**12. How would you define the seriousness of your CFS/ME: mild, moderate, extreme? Why?**

.....

.....

.....

.....

**13. Have you ever suffered from depression? If so, before or after the onset of CFS/ME?**

.....

.....

.....

.....

**14. Do you experience pain? If so, which kind?**

.....

.....

.....

.....

.....

**15. Do you have memory or concentration difficulties? If so, how do they affect you?**

.....  
.....  
.....  
.....

**16. Have you experienced difficulty with/at work following the onset of CFS/ME? Which ones?**

.....  
.....  
.....

**17. What aspects do you think should be emphasized in a book about CFS/ME (for instance, its impact on professional/social/family life, scepticism of some doctors, etc)?**

.....  
.....  
.....  
.....

**18. What is, in your opinion, the single most problematic aspect of CFS/ME? Are you hoping to heal from it?**

.....  
.....  
.....  
.....

**19. Could you describe the kind of fatigue experienced by you after the onset of CFS/ME? Is it the same fatigue you used to experience prior to the onset, or is it different? In the latter case, how does it differ?**

.....  
.....  
.....

**20. Which first name, real or fictitious, do you wish to be referred with in the book? For privacy reasons, no surnames will be mentioned.**

.....  
.....  
.....

