Is CFS/ME an especially mysterious illness about which we know little? This chapter’s premise is that we organise what we know or do not know about CFS/ME in different ways in different contexts. Quantitative clinical research creates ‘scientific not-knowing’ which is some distance from what is meant by ‘CFS/ME’ in the outside world, because the scientific method requires artificial diagnostic criteria. ‘Medical not-knowing’ is created by expectations of what ought to be known about CFS/ME in relation to a standard illness such as multiple sclerosis (MS). What we think we do not know about CFS/ME is then structured by the implications of a diagnosis, as outlined in Chapter 13. A medical framework tends also to foster ‘personal not-knowing’ which treats whatever seems unique or odd about a person as irrelevant to the dominant agenda. A review of current academic literature suggests that ‘social not-knowing’ – which regards relationships as of very little relevance to CFS/ME – is another product of the medical-diagnostic point of view.

These kinds of not-knowing have paradoxical effects. People who favour a medical/biological explanation for CFS/ME are at the same time seeking what those explanations tend to resist, namely to be understood as individuals and to be legitimised in their relationships. I suspect that there may be a degree of ‘half knowing’ about the two sides of these contradictions even among people who have very polarised views about CFS/ME as either a psychological or a biological phenomenon. We might advance further in our understandings of CFS/ME if we had a more sceptical attitude to the idea that the condition is a mystery and more openness to relationships and meanings that matter to individuals.

‘So many things we do not know’. A series of medical articles on CFS/ME in the Journal of the Norwegian Medical Association begins with these words, reminding us that this is a diagnosis with an unusual aura

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of mystery surrounding it. Papers on CFS/ME often begin by defining it in such terms as ‘without an identified cause’,2 ‘a disabling condition of unknown origin’3 ‘a controversial illness of unknown etiology’4 and in the popular press, as I said in Chapter 5, CFS/ME is regarded as a ‘deeply mysterious disease’.5 I now want to look more closely at this familiar narrative. There is no question of reviewing the facts about CFS/ME here, of course. The objective of our book has been to explore ways of thinking about CFS/ME rather than to describe mechanisms, and so we are concerned with ways of knowing6 rather than with what is known. The multiple meanings of CFS/ME depend on our many ways of knowing and not knowing, and I suspect that we know more (and also less) about CFS/ME than our thinking habits will allow us to acknowledge.

14.1 Ways of knowing

Frances in Chapter 7 says of her own illness: ‘I do know that it is real. It’s real to me’. If Frances is to make it real for someone else, she must find a way of knowing that is acceptable to that person. Frances’s husband Steve probably knows something of her suffering without the use of words. Intuitions can also be part of the way doctors and therapists get to ‘know’ the illness of their patients/clients, as two clinicians in this book suggest (Laura Saunders in Chapter 10 and myself in Chapter 11). Important things are realised in therapeutic relationships before any need for a formulation. But a very different way of knowing is needed if Frances’s symptoms are to form a pattern that the wider world recognises. Frances says she knows her illness is real because of ‘these muscle twinges .... when my face and my legs start twitching … you know you’re not imagining it all’. The diagnosis of CFS/ME provides a medical ‘way of knowing’ fatigue, twinges, twitching, and so on, and this particular framework has its own unique ways of not-knowing. If we think of CFS/ME as having an as yet unidentified cause then Frances’s bodily experiences can be recognised and acknowledged as real, but the chain of causes and effects leading to her symptoms seem to be a mystery. Paradoxically, they would have been easier to explain if she had had no diagnosis. Her pain and uncontrollable shaking could have been understood in a different way if they had happened while she was being told that her child had drowned. The question of why she was shaking would not then arise. No-one would say ‘I do not know’ because we have common sense knowledge of the forms that shock and grief can take. But common sense is a moveable feast. Clifford Geertz tells a story