

# UNDERSTANDING SEVERE ME

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**People with Severe ME currently receive “seriously inadequate healthcare”. A devastating condition that can leave sufferers profoundly disabled for decades, the illness has at long last been awarded priority research status by the Medical Research Council, £8.5 million funding has been allocated for new NHS service provision and NICE have just been asked to prepare guidelines for diagnosis and management.**

**This article is written to raise nurse’s awareness of Severe ME . The seriousness of the condition is emphasised, key symptoms are presented as well as possible service responses in a unique chart and popular treatment options are considered.**

**The author, a Registered Nurse, cares full-time for his wife who has suffered from Severe ME for over ten years now.**

*(approx 2750 words + diagrams and footnotes)*

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## **Understanding Severe ME**

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There are an estimated 62 500 sufferers with severe ME in the UK, receiving 'seriously inadequate' <sup>1</sup> health care. Severe ME is a serious, disabling chronic condition :

Quality of life tests indicate that severe ME sufferers feel every day significantly the same as an AIDS patient feels two months before death. 98% of people with severe ME do not get better. Peterson describes ME as "one of the most disabling diseases that I care for, far exceeding HIV disease except for the terminal stages".<sup>2</sup>

25% of sufferers with severe ME describe themselves as bedridden, and 57% have been either housebound or bedridden for more than six years, illustrating "in numbers rather than words that morbidity

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in CFS/ME can be substantial, despite the opinion of many healthcare professionals to the contrary.”<sup>3</sup>

The World Health Organisation classifies ME as a neurological condition in section G93.3 of their current International Classification of Diseases (ICD 10). The Centres for Disease Control (the US federal agency ) designates it for funding status as "A serious legitimate diagnosis CDC PRIORITY 1 disease of public health importance". The Chief Medical Officer's (CMO) Report (2002) acknowledges that ME is a " genuine condition that imposes a substantial burden on patients,carers and families. "<sup>4</sup>

**Chief Medical Officer's Report (2003) :**

**Severe ME**– “Will be able to carry out minimal daily tasks only, face washing, cleaning teeth,have severe cognitive difficulties and be wheelchair dependent for mobility.These people are often unable to leave the house except on rare occasions with severe prolonged after-effect from effort.”

**Very Severe ME**– “Will be unable to mobilise or carry out any daily tasks for themselves and are in bed for the majority of the time.These people are often unable to tolerate any noise,and are generally extremely sensitive to light.”

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The Medical Research Council have recently announced that research into ME commands priority status. The Department of Health (2003) have at long last released a "cash injection" (£8.5 million) to develop new NHS services for people with ME in England; including the development of centres of excellence and the training of healthcare professionals<sup>5</sup> and the National Institute of Clinical Excellence (NICE) have been asked to prepare

Guidelines for the diagnosis and management of CFS/ME.

Severe ME is described by Cheney (1993) as "a prolonged post-viral syndrome with slow recovery. At worst, it is a nightmare of increasing disability with both physical and neurocognitive components. The worst cases have both an MS-like and an AIDS-like clinical appearance.... The most difficult thing to treat is the severe pain." <sup>6</sup>

Australian researchers found that patients with this disorder had more dysfunction than those with multiple sclerosis, and that in ME / CFS the degree of impairment is more extreme than in end-stage renal disease and heart disease, and that only in terminally ill cancer and stroke patients was the sickness impact profile (SIP) greater than in ME /CFS.<sup>7</sup>

Crowhurst (2003)<sup>8</sup>, a Severe ME sufferer, describes how: "Every day I wake in a state of all-over paralysis unable even to move my fingers or open my eyes. Not only am I unable to move but I am in extreme pain and a state of acute hypersensitivity such that I cannot bear to be touched even lightly and even a whisper seems like a shout."

The term chronic fatigue syndrome (CFS) is the name used by doctors internationally, however this can be an extremely misleading term, for it does not accurately describe the condition. As Shepherd (2004) points out: "Would anyone take Alzheimer's disease seriously if it were renamed chronic forgetfulness syndrome?"<sup>9</sup>

Encephalomyelitis' strictly refers to inflammation within the brain and spinal cord, and because there is growing doubt that this is the actual cause of ME/CFS there is a move to replace encephalomyelitis with encephalopathy (meaning a serious but less specific disorder of brain function).<sup>10</sup>

ME "epidemics", initially considered to be related to poliomyelitis, have been reported from 1934 in the USA, Iceland, Australia, Europe, Alaska and South Africa.<sup>11</sup> Dowsett (2003) estimates that there are epidemics every 10 years.<sup>12</sup> There are acknowledged similarities and overlaps between ME and the post-polio syndrome (PPS).<sup>13</sup>

"The incidence of ME /CFS is known to be rising."<sup>14</sup> Indeed ME is now three times as common as MS in the UK.<sup>15</sup>

Sadly, among many health professionals and in the wider public, there is still a lack of understanding of the condition, alongside a "paucity of good research evidence and very little research investment." Disbelief, especially by GPs and family members makes it very difficult still for sufferers to access services.

#### Aetiology and Pathogenesis

Immune, endocrine, musculoskeletal and neurological abnormalities have been detected in ME sufferers, however the aetiology (cause) and pathogenesis (disease process), are not understood. The disease is heterogeneous - composed of different elements and it is not clear whether ME/CFS refers to one single condition or several distinct diseases bracketed together because of the similarity of their clinical appearance.

As yet there is no satisfactory explanation "as to why people with this illness continue to experience quite severe levels of ill health and disability."<sup>16</sup>

Infection (bacterial and viral) seems to be the most common trigger for ME/CFS with glandular fever, viral meningitis and viral hepatitis precipitating ME/CFS in about 10% of cases. It can also follow infections with herpes virus, enterovirus, hepatitis and other viruses : “ the most implicated viruses being Coxsackie B and Human Herpes Virus 6 (HHV6).”<sup>17</sup>

ME/CFS has been noted to worsen or occur after anaesthetics.<sup>18</sup> Abnormalities involving chemical transmitters in the brain, including serotonin, dopamine and acetylcholine, may explain why many ME/CFS sufferers are so sensitive to the adverse effects of drugs that act on these chemical transmitter systems<sup>19</sup>

Naked eye observation of the brain at post mortem is unlikely to reveal any obvious damage; such as the scar tissue in MS. In ME the changes are much more subtle.<sup>20</sup>

Muscle biopsies and MRI scanning show a variety of muscle abnormalities.<sup>21</sup>

Disturbances in hypothalamic function (hypocortisolaemia) have been registered in a large number of studies , this may explain key symptoms such as sleep difficulties and temperature control problems such as Crowhurst (2003) describes :“I am so tired I cannot wake up properly and I fall back into 2 to 3 further bouts of sleep . Each time the pain, paralysis, numbness, prickling, itching, burning sensations worsen in my whole body. My face, eyes and scalp also burn and itch, my lips are numb, my throat and my tongue are numb, I can barely breathe if it has grasped hold of my chest muscles and diaphragm.”

Brain scans indicate a reduced blood flow (hyperfusion) which has not been demonstrated in any other medical condition<sup>22</sup> Concern has been raised about ME patients who smoke or adopt a low sugar diet thereby : “further diminishing supplies of oxygen and glucose.”<sup>23</sup>

Attempts are being made to classify patient groups “based on a number of factors from immune system abnormalities to severity and onset of illness.”<sup>24</sup> Many doctors “believe it is important to try and identify which subgroups people belong to in order to advise on the most appropriate form of management”<sup>25</sup>

Prognosis is uncertain. Amongst the severely affected however, recovery is extremely rare.

#### Care and Management

A General Practice with a population of 10,000 patients is likely to have 30 – 40 patients with CFS/ME, about half of whom may need input from services.<sup>26</sup> Care and management of ME/CFS though, is an area “beset by confusion and controversy.”<sup>27</sup>

Given that the most severely affected “suffer from additional problems of invisibility, barriers to accessing all forms of care, variable responses to treatments, and under-representation in research”; it is not surprising that “insufficient evidence is available to guide specific management of those people who are severely affected.”<sup>28</sup>

The main principles of management such as they are, rely upon conservation of energy and reduction of stress.

However this could be construed as too simplistic. Crowhurst (2004) for example asks : “ How can you conserve

energy if you don't have it in the first place ? It is much more complex than that. How do you cut down stress when everything is a stress, even moving or staying still ?"<sup>29</sup>

The condition, in its complexity, seems almost beyond one's ability to comprehend . People with ME are "so commonly and unfairly accused of hypochondriasis because they have too many symptoms to permit credibility."<sup>30</sup> Severe ME sufferers often gain the reputation of being "'heart-sink patients" - an appellation referring to the doctor's sinking heart at the sight of a large medical file and the prospect of too frequent clinic attendance's."<sup>31</sup>

Manley (2004) who since 1994 has been collecting and analysing data from over 320 people severely affected by the illness , has found that most severe ME sufferers have had to wait "over four years for diagnosis ."<sup>32</sup> Crucially, diagnosis "is the first step in actively managing the condition."<sup>33</sup> As with other chronic diseases of uncertain aetiology, diagnosis of ME/CFS is dependent upon the "presence of a set of characteristic symptoms together with the exclusion of alternative diagnoses."<sup>34</sup>

**Question :**

**What attitudes have you come across towards severe ME in your practice as a nurse?**

Current criteria suggest that the symptoms should last for 6 months before a diagnosis of CFS/ME can be made, however this threshold is "arbitrary"<sup>35</sup> and the CMO insists that "clinical diagnosis can and should be made well before this time, especially in children and young adults. By 6 months, if symptoms persist, a provisional diagnosis

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usually should be confirmed. But the plan for managing the illness and its consequences should already have been put in place.<sup>36</sup>

As suggested in recent NHS legislation, Nurses should play a key-role, working alongside GP's to assist and support patients through the "uncertain period" of diagnosis,<sup>37</sup> prior to a formal care pathway and the involvement of a skilled multidisciplinary team. The need for a "generic template CFS/ME care pathway"<sup>38</sup> is currently an urgent one. In the development of a care pathway "the emphasis should be on improving the quality of service provision as opposed to managing or reducing costs."<sup>39</sup>

It is crucial to listen to and respect the sufferer's symptoms, even if one does not fully understand them. As Wall (2000) says : "I don 't have much to offer....My injuries are invisible, subtle in neurones, enzymes, cytokines, the intricate inner circuitry of the body that still eludes concise theories, that require scientific minds to make a leap of faith, to become, as it were, believers."<sup>40</sup>

It is vitally important, though almost impossible, to appreciate the sheer scale and impact of symptoms<sup>41</sup> : see Severe ME : Key Symptoms, Impact & Service Response - (attached). Even thinking may be painful. It can be very difficult for someone to communicate their needs, because even the energy required to speak/think can easily precipitate a relapse and/or increase pain or affect one's ability to cope both physically and emotionally.

Hypersensitivity to touch, light, sound often makes it extremely difficult to attend to someone when they cannot bear to be touched , when every sense is heightened and roaring . Gentleness in all procedures is the key , minimising

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stress in the relationship and environment as far as possible. A recent survey (2004) found many severe ME sufferers experienced "poor treatment and inappropriate attitude towards their condition from various healthcare staff. "42

Overarching Principles of Care :

- **Anything you do may lead to an exacerbation of symptoms, which you may not realise.**

**Be ready to stop.**

**Accept the other person's reality and the bizarre and complex reality of the symptoms.**

**External appearance is usually not a marker of symptom severity. Beware of judgements based on anything that you think you know.**

**Unless you have had ME, you cannot imagine how for example a light touch might feel like a sledgehammer or a whisper might literally be a torment.**

**Linda Crowhurst (2004)**

It must be stressed that treatments offered to less severe patients including Cognitive Behavioural Therapy and Pacing (Jackson 2002<sup>43</sup>), are not appropriate in Severe ME/CFS.

The specific efficacy of Graded Exercise and Cognitive Behavioural Therapy is “not supported by survey reports from CFS/ME patients,”<sup>44</sup> indeed 82% of Severe ME/CFS patients stated (2004) that their condition was made worse by Graded Exercise.<sup>45</sup> “Pacing” point out the Myalgic Encephalomyelitis Research Group for Education & Support (MERGE) (2002), “is intuitively sensible but hardly warrants the status of a separate therapy within a healthcare management program.”<sup>46</sup>

In the author’s experience, caring for his wife who has suffered from severe ME for over 10 years, there is very little relief of the symptoms, especially the pain, despite the optimistic tone of some articles. In reality one copes; trying to help and comfort from second to second. There are presently no drugs that treat the underlying disease process.

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Low dose sedating antidepressants such as Amitriptyline or nortriptyline are sometimes prescribed for pain, but always at a much lower dose than that used to treat depression. Severe ME sufferers, as we have seen, are highly sensitive to drugs and dosages must be built up gradually and constantly monitored.

Consideration is also being given to the use of anti epileptic drugs for pain relief. The one most commonly used in ME/CFS is gabapentin (Neurontin), which is also useful in treating the severe nausea that can occur.

Sleep disturbance and a lack of restorative sleep are major problems in severe ME. Hypnotic drugs have a limited role to play, however the use of short-acting drugs such as zolpidem (Stilnoct) can be extremely helpful.<sup>47</sup>

We have pointed out that not enough is known about the underlying disease process so there is no cure available, however Antiviral drugs, Hormonal and various Immunological treatments are used to treat the abnormalities that are known to exist in Severe ME.<sup>48</sup>

Experimental, speculative and generally expensive forms of treatment are also on offer from the private sector, including Ampligen currently undergoing clinical trials in America.

Vitamins, minerals and supplements are popular forms of treatment. The author's wife, for example, finds calcium and magnesium malate helpful for muscle spasm and severe pain. Small clinical trials suggest that carnitine and NADH may be of value.<sup>49</sup>

Very few alternative and complementary therapies have been properly assessed, though acupuncture and homeopathy may be worth trying for some people. There is no evidence to indicate that treatments such as anti-candida programmes - involving dietary restriction, probiotics and anti fungal medication, a road many sufferers travel, " are of any value in ME/CFS."<sup>50</sup>

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Providing any service to people with Severe ME presents unique challenges . Probably the key issue facing nurses will be how to offer an appropriate multidisciplinary service to someone who is unable often or most of the time to cope with human contact .

Question :

How do you help someone with Severe ME when no matter how well intentioned you are, any intervention might be too much for someone so **hypersensitive to sound, light, touch and in chronic pain ?**

Training and education urgently needs to be provided for all staff. In particular Nurses should be encouraged to take up CFS/ME as a specialism within their generic workload.<sup>51</sup> Given the “plethora of epidemiological, neuroanatomical, neuroendocrinological and neuropsychological data”<sup>52</sup> it is simply inexcusable that ME/CFS is still surrounded by so much prejudice and ignorance :

**What clinicians can do:**

Listen to the patient, recognise and believe his or her individual experience.

Acknowledge uncertainty and the impact that this has on the patient, family, and carers.

Provide support and encouragement – e.g. during setbacks.

Provide information on and discuss: the nature of

the condition, approaches to self management, helpful therapies, and how to access other agencies and services.

Agree a name for the condition.

Give advice on symptomatic treatment.

**CMO Report Annex p.12**

"In many respects / ME remains a mystery disease that has defied a plethora of intense medical research investigations."<sup>53</sup> However a titanic battle<sup>54</sup> is raging for legitimisation and acceptance, for as Munson (2000)<sup>55</sup> points out, without acknowledgement : "the ill stay underground, seek medical help irregularly and suffer silently." The current struggle has been likened to the early efforts to gain recognition for AIDS, when : " shame clouded the suffering in mystery."<sup>56</sup>

This article has shown that some progress has been made; the illness can no longer be dismissed or ignored by medical professionals. Yet for patients little has changed,; they continue to live hidden lives of unimaginable suffering . The leap of faith required, to enter into the patient's world without prejudice and with infinite patience will test healthcare professionals to the limit.

Symptom	Experience	Outcome	Service Response
Sleep Paralysis	Completely unable to move. Difficulties with breathing Difficulties with speech Difficulties with swallowing	Cannot sit up/move/get-out of bed/feed yourself/get a drink/get dressed/talk/go to toilet/wash yourself/answer the door/get the post	Provide physical assistance : Lifting/Supporting ( assisted walking)/Mobility/Dressing/Personal Care/Shopping/ Cooking/Feeding  Knowledge of what

			the person needs in advance.  Sensitivity & Awareness.
<b>Light sensitivity</b>	Cannot bear bright light, maybe any light at all, even with eyes closed.	Need to wear dark glasses, have curtains shut, no lights on or low lights only	Acceptance Be prepared Work in low light situations and/or protect client from light if need light on
<b>Noise sensitivity</b>	Cannot bear loud noise, unexpected noises, banging and thudding in the room or in the environment	May not cope with electrical/mechanical machines i.e. Hoover Listening to speech may be a problem Loud voices/certain tones of voice may cause distress Doors being shut / loud footsteps/ rustling paper/opening drawers/cupboards etc can cause torment	Develop appropriate communication system ie written instructions, low voice, possible sign language, be very gentle and quiet in all movements/actions. Be aware that your noise may cause distress even if not noisy to you. Respond appropriately if you cause noise

Symptom	Experience	Outcome	Service Response
Headaches	They are not normal, they maybe constant or last for days, can be predominantly left-sided, may not respond to drugs.  Also may be the	Scalp sore to touch. Eyes throbbing/burning. Face can hurt as well. May be accompanied by numbness, paralysis, swollen eyeballs,	Be sensitive to noise and light issues.  Awareness of the potential emotional distress of being in constant pain and the potential for the

	experience of head-pain, as opposed to headache.	nausea. May be sharp, throbbing, may be dull but no less severe.	person to be irritable.  Medication
Muscle Weakness/ Variability	May be able to use your muscles one moment and not the next.	Danger of falling/stumbling.  Affects the person's independence : may be not able to use hands/fingers/perform fine movements.  May be able to walk one moment and not the next, or at all.  May not be able to write/type/turn things on and off/cook/clean/attend to personal care/eat.	Mobility issues, may require a wheel chair.  May be bed bound and/or housebound.  May require help with cooking, cleaning, shopping, personal care, with eating, writing, communicating, social interaction, sexual relationships.  May not be able to use stairs or unreliable use of stairs.  Adaptations/aids/equipment

Symptom	Experience	Outcome	Service Response
Sleep Disorder	Real problems going off to sleep.and/or problems in waking-up.  Normal sleep pattern grossly disrupted (little or no restorative sleep).	May be awake at night, distressed, severe fatigue, but still unable to sleep.  Body functions may be altered eg. need to urinate more alongside a severe thirst and need to	Advice on enhancing sleep possible relaxation / breathing techniques.  Reduction of over stimulation.  Warm bath to relax muscles.



	<p>Night insomnia and sleep all day. May sleep more than normal.</p> <p>Body-clock out of sync with normal rhythms.</p>	<p>drink.</p> <p>Low blood sugar because of increased time in bed during the day.</p> <p>Increased irritability.</p>	<p>Drugs to aid sleep</p> <p>Assistance day and night to enable basic needs to be met : toilet, food, drinks etc.</p>
Pain	<p>Whole body may be too painful to touch.</p> <p>Skin itching / burning/ hypersensitive.</p> <p>Muscles throbbing/burning/screaming</p>	<p>May be continuous, may vary in degree.</p> <p>Poor response to drug treatment.</p> <p>Cannot bear to be touched.</p> <p>Difficulty in getting comfortable : seating and bed and wheelchair .</p>	<p>Pain awareness and extreme sensitivity.</p> <p>Knowing how to touch and lift carefully.</p> <p>Patience and time is required to 'flow' with the person.</p> <p>Advice on what is available to alleviate pain :aids and equipment and drugs.</p>

1. A Report of the CFS/ME Working Group : Report to the Chief Medical Officer of an Independent Working Group Jan 2002 p. 44
2. MarshallE.P., Williams M, Hooper A What is ME ? Information for Clinicians and Lawyers 25% Group
3. ME Research Group for Education and Support Unhelpful Counsel ? MERGE's Response to the Chief Medical Officer's Report on CFS/ME April 2002 p.4

4. Annexes to the Report of the Working Group on CFS/ME (Jan 2002) p.7
5. Clark C (2003) GOV'T ANNOUNCES £8.5 M FOR ME SERVICES InterAction 45 August 2003 p 2
6. In Marshall et al op cit
7. ibid
8. Crowhurst L (2003) LIST OF SYMPTOMS unpublished paper.
9. Shepherd C (2004) ME/CFS A GUIDE TO RESEARCH, DIAGNOSIS AND MANAGEMENT Sussex & Kent ME/CFS Society p.3
10. ibid
11. Goldenberg D.L. (1988) Fibromyalgia and othe Chronic Fatigue Syndromes : is there evidence for Chronic Viral Disease ? Seminars in Arthritis and Rheumatism 18 : 2: pp 111-120
12. Betty meets Shropshire Enablement Team The Quarterly Issue 16 Winter 2003 p. 5
13. Marshall et al (2001 op cit
14. ibid
15. Betty meets Shropshire Enablement Team op cit
16. Shepherd (2004) op cit p.6
17. Marshall et al (2001) op cit
18. ibid
19. Shepherd (2004) p.6
20. Horsfall L (2004) in conversation with the author
21. Dowsett E.G. (undated) Brain Problems in ME is there a simple explanation ? BRAME
22. Shepherd (2004) op cit p 6

23. *ibid*
24. Dowsett E.G. (Undated) BRAIN PROBLEMS IN ME - IS THERE A SIMPLE EXPLANATION ? *op cit*
25. Vanness JM et al (2003) "Subclassifying Chronic Fatigue Syndrome through Exercise Testing" *Med Sci Sports Exerc.* 35(6) 908-13
26. Shepherd (2004) *op cit* p.7
27. Who Cares ? A submission by MERGE to the Scottish Executive's Short Life Action Group on CFS/ME July 2002 p.8
28. CMO Report p.44
29. *ibid*
30. Dowsett E.G. (undated) Brain Problems in ME is there a simple explanation ? *op cit.*
31. *ibid*
32. Manley K (2004) MONITORING PATIENTS WITH SEVERE ME Interaction Issue 47 February 2004 p. 10
33. CMO Report Annexes *op cit* p. 4
34. *ibid*
35. *ibid*
36. *ibid*
37. MERGE Who Cares *op cit* p. 3
38. *ibid* p.4
39. *ibid*
40. Wall D.(2000) ENCOUNTERS WITH THE INVISIBLE in Munson P (ed) STRICKEN VOICES FROM THE HIDDEN EPIDEMIC OF CHRONIC FATIGUE SYNDROME Haworth Press New York p. 23
41. 25% M.E. Group INFORMATION LEAFLET FOR HEALTH CARE/SOCIAL SERVICES FOR SEVERE M.E. PATIENTS : A PATIENTS PERSPECTIVE 25% M.E. Group, 4 Douglas Court, Beach Rd, Barassie, Troon, Ayrshire KA 10 66Q

42. SEVERELY AFFECTED ME (MYALGIC ENCEPHALOMYELITIS) REPORT ON QUESTIONNAIRE ISSUED JANUARY 2004 Report Prepared by  
25% ME group report Date : 28th February 2004
43. Jackson E 2002 AN OVERVIEW OF CHRONIC FATIGUE SYNDROME Nursing Standard Dec 11 Vol 1/no13 p48
44. MERGE UNHELPFUL COUNSEL ? MERGE's response to the Chief Medical Officer's Working Group report on CFS/ME April 2002
45. Severely Affected ME Report (2004)
46. ibid
47. Shepherd (2004) op cit p.11
48. ibid
49. ibid
50. ibid
51. Who Cares ? op cit
52. Dowsett E.G (undated) Does "Chronic Fatigue" Adequately Describe Myalgic Encephalomyelitis ? BRAME
53. Millen N (2001) A Sociological Study of Chronic Fatigue Syndrome and the Micro Politics of Change in Illness Construction. Health Sociology  
Section. Sydney University
54. ibid
55. Munson P (2000) INTRODUCTION Stricken op cit. p.8
56. Patricia P (1994) A SMALL GATHERING OF BONES, Heinemann, Oxford p.81 in Munson P op cit p. 10

