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提升**MS**患者生活质量的原则



multiple sclerosis  
international federation

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多发性硬化症国际联合会（Multiple Sclerosis International Federation）

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# 前言

照片：理查德·杨(Richard Young)



我母亲35岁那年被确诊患有多发性硬化症，刚开始的生活和平时没什么两样。她承认患有多发性硬化症，这很符合她的性格。她阅读关于多发性硬化症的一切资料，但没有一本小册子或书本能够告诉她为什么会患病、或者这种疾病将如何危及生命。我估计，我母亲在确诊后的10年里看理疗医生的

次数不会超过10次。她住在乡下，不会开车。曾有一个理疗医生在极短的时间内上门看病，但随后不知何故中断了，再也没来过。有一次在妈妈放弃工作后，她衰弱到只能爬着上楼梯，而不是走上去。我派了一个家务佣人到家里，结果也一样。似乎从来就没有足够的资金为多发性硬化症患者提供服务，唯一的选择是送医院。

影响我母亲及其家人的不只是病情的迅速恶化，还有她的生活质量、自尊和独立性的急剧下降或恶化。

生活质量是各国人民都必须为之奋斗的东西，要奋斗就需要有适合在前方的战斗中使用的工具，这就是本文阐述的提升多发性硬化症患者生活质量的原则如此重要的原因。这些原

则为所有多发性硬化症患者提供目标。对于帮助团体和个人专注于对所在社区最为有利的领域，这些原则的战略应用是必备要件之一。

**“生活质量是各国人民都必须为之奋斗的东西，要奋斗就需要有适合在前方的战斗中使用的工具”**

此外，研讨会和在线交流将帮助全世界的人民共享经验和确立最佳实践。本文只是个开始。当您决定将这些原则应用于所在的社区和国家时，它们的影响将源源不断地涌现。

祝您在提升全球多发性硬化症患者生活质量的战斗中圆满成功。

A handwritten signature in black ink, appearing to read 'JKR' followed by a stylized flourish.

**J. K. 罗琳 (J. K. Rowling)**

# 绪言



早在1947年，世界卫生组织（WHO）就将健康描述为一种完整的身心和社会福祉状态，不只是没有疾病或病症。但在过去，大多数健康护理服务侧重于对疾病及其病症的处理，而不是对个人的关注。幸运的是，如今的健康护理已从面向疾病的护理转向以病人的体验和需求为中心的护理，转向诸如享受健康护理服务、独立性和赋权、就业、教育、以

及在评估个人福祉中占据相同权重的其他众多元素。

在全球15家协作中心的帮助下，WHO开发了一个名为WHOQOL-100的生活质量框架。在该框架中，WHO将生活质量定义为个人对所处的文化和价值观体系下的生活定位、以及与其目标、期望、标准和关注的关系的看法。这是一个广义定义，受个人的生理健康、心理状态、独立程度、社会关系、以及所处环境的显著特点影响。

WHO QOL-100框架旨在用作医疗实践、研究、审计和政策制定等一般性场合的工具。因此，我们特别高兴地看到多发性硬化症国际联合会（MSIF）将WHO QOL域矩阵纳入其旨在影响政策制定、提升MS患者生活质量的指导原则。

MSIF是与世界卫生组织建立官方联系的非政府组织之一，我完全支持MSIF推动WHO工作的方式。这些原则为各国

“这些原则为各国MS协会在制定和实施相应的计划、提升终身饱受疾病折磨的患者生活质量时，提供了一个全面而看得见的侧重点。”

MS协会在制定和实施相应的计划、提升终身饱受疾病折磨的患者生活质量时，提供了一个全面而看得见的侧重点。



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精神和药物滥用部  
(Department of Mental  
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Abuse)主管  
世界卫生组织(World Health  
Organization)





# MSIF

## 多发性硬化症国际联合会 (Multiple Sclerosis International Federation)

多发性硬化症国际联合会成立于1967年，成为一个联系各国多发性硬化症协会的国际性组织。

我们有一个共同的愿景：在全球范围内消灭多发性硬化症（MS）。这也是我们与国际性科学团体合作促进国际协作研究的原因所在。与此同时，MSIF继续以各种方式帮助MS患者。

我们以各种语言，就MS的各个方面交流最佳实践、知识、经验和信息。这有助于MS患者做出自己的选择和决定。

我们也致力于提升在全球范围内提供的服务。因此，我们积极鼓励和支持在MS高发地发展有力、高效的MS协会。我们的另一项全球性计划是支持

旨在影响公共政策、使其有利于MS患者的宣传活动。

良好的管制和领导力、透明的财务和管理架构、以及出色的融资能力支撑了我们的各种活动。

作为一名MS患者，我对这种疾病对生活质量的影响——不只是患者本人，还有他/她的家人和朋友——有切身的体会。MSIF提出提升MS患者生活质量的原则，从而引领全球的MS运动，我以身为其中的一分子为荣。



萨拉·菲利普（Sarah Phillips）  
主席兼总裁  
多发性硬化症国际联合会



# 简介

多发性硬化症（MS）是一种慢性致残性疾病，全球约有250万名患者。MS的影响因疾病的类型、患者和病程而异。MS的常见症状包括疲劳、膀胱和肠道疾病、视力问题、震颤、痉挛、说话异常、吞咽障碍、性功能障碍、难以完成日常基本活动（例如，吃饭、淋浴、穿衣和做家务活）、认知功能障碍、行动不便、疼痛和抑郁。体现为这些症状的MS可以显著降低患者的生活质量（QOL）。此外，许多MS患者失去了工作机会，必须依靠亲人或政府的资助计划和其他支持生活。

本报告阐述一些旨在提升MS患者生活质量（QOL）的“原则”。虽然这些原则涵盖健康护理，但它远远超越医疗护理，还包括其他众多领域。此外，这些原则并不侧重于对QOL的评估或衡量，而是侧重于对政府、营利和非营利性健康和社会服务供应商、雇主、以及其他组织向MS患者提供的服务和计划的制定和评估指导。



这些原则的潜在实践者还包括国际组织、各国MS协会、MS患者及其家人、政府、健康和持续护理供应商、研究人员、企业和其他人士，供他们评估现有或拟议中的服务和计划，供他们倡导提升患者的生活质量。

就本身而言，这些基于问题的原则侧重于影响MS患者生活质量的常见问题。例如，由MS的多种症状引发的忧伤和残障、有些情形下不能住在家里、失业、行动不便、以及医疗和社会护理之间缺乏协调等。因此，这些原则与MS的特定类型或阶段并无关联。

要始终记住一点：我们的最终目标是治愈MS。但在找到治疗方法且可以大规模实施之前，还是应该运用多种方法（例如，这些原则阐述的方法）来维持和提升MS患者的生活质量，这点很重要。

这些原则是根据一系列访谈、文献分析、临床实践、计划、作者的研究经验、以及MSIF组织的工作组和技术监督组的复审制定的。

受访对象包括多位国际性MS和QOL专家、MS临床服务供应商和患者（详见鸣谢名单）。监督组和工作组包括来自多个MSIF成员国的MS专家和患者，监督组和工作组成员详见鸣谢名单。

文献分析包括对相关期刊文章、MS临床教科书、各国MS协会的出版物、以及相关网上出版物的分析（详见“参考文献”一节）。“参考文献”一节还包括分配给每个出版物的证据等级。

上述文献分析采用下列证据等级定义：

- 1a 随机对照试验的元分析
- 1b 随机对照试验
- 2a 对照研究（非随机）
- 2b 准实验研究
- 3 非实验、描述性研究（例如，比较研究、相关性研究和案例研究）
- 4 专家委员会的报告、意见和/或权威经验

我们以反映现实状态的方式阐述上述原则。这种积极的态度旨在赋予MS患者相应的权力，让他们远离针对MS患者的被动表述。这些原则描述了极为有效、且满足MS患者需求（而不是告诫患者“应该”做什么）的计划和政策。

这些原则分为下列10个主题部分：

- 独立性和赋权
- 医疗护理
- 持续护理（长期护理或社会护理）
- 促进健康、预防疾病
- 向患者家人提供支持
- 交通
- 就业和自愿活动
- 残疾津贴和现金补助
- 教育
- 住房和社区无障碍建筑

这些原则的制定有一部分是在WHO QOL框架所述五大领域的指导下进行的，包括生理健康、心理健康、独立程度、社

会关系和环境。制定这些原则时参考了上述领域，以确保这些原则涵盖与MS患者有关的QOL所有方面。每个原则指导下的WHO QOL域矩阵如附录1表格所示。

每个章节开头都是说明其主题的一般性陈述和关键问题的引导性讨论，并在后续带编号的段落中阐述这些原则。每个原则末尾的引证说明该原则的支持性文献证明，附录2所列为根据证据等级排列的每个原则的支持性引证编号。





# 原则

## 1.0 独立性和赋权

**MS患者有权充分参与社区事务，有权充分参与对疾病的管理和治疗的决策过程。**

MS是一种严重影响患者生活质量（QOL）的并发症。相关的计划、政策和服务应该帮助MS患者尽可能独立并掌控自己的生活，这点很重要。许多MS患者每天都遇到的不确定性往往导致生活质量的严重下降。

要保持相应的独立性和赋权，MS患者必须有能力充分参与社区活动和对MS的管理和决策，且不会因为经济负担而受到治疗限制。政府应该制定保障患者权利的法律。

**1.1. MS患者必须有能够实现其全部潜能，有机会走到外面，有工作机会，接受教育，做健康人做的其他事情，必须有尽可能多的机会参与社区生活。**<sup>1-31</sup>

**1.2. MS患者及其家人必须参与就MS患者的治疗所作的决策，必须参与影响患者及其家人生活的其他决策。即使MS患者有认知障碍，患者及其家人也必须尽可能深入地参与原则的决策过程。他们必须密切**

配合医生和其他健康护理服务  
供应商。 1,3,4,6,7,17,23,30,32-42

**1.3.** MS患者及其家人可以选择  
相应的治疗和其他服务。因为  
患者各不相同，必须针对患者  
的需求和选择提供相应的服  
务。还应该提供多种服务。

1,3,4,34,43-45

**1.4.** 即使囊中羞涩，MS患者也  
应该享有相应的治疗、计划和  
服务。 1,3,4,27,46-48

**1.5.** MS患者有权掌控影响其生  
活的决策，有权尽可能自己管  
理疾病。为鼓励患者尽可能自  
己管理疾病，MS患者应该能  
够获得多种信息、建议、针对  
MS性质的教育、疾病的治疗  
以及提升生活质量的方法。应  
通过多种渠道提供此类信息，  
包括书本、小册子、网站以及  
健康和社会服务人士。还应该  
向MS患者提供共同或相互支  
持的机会。 1,3-5,7,12,13,17,19,22,23,

25-27,30,32-35,37-40,42,45-47,49-65



**1.6. 必须通过法律，保护MS患者和其他患者的权利，使他们在社会和社区生活的各个方面免受歧视。此类法律的实施必须是一贯的、有效的。此外，此类法律要求政府、雇主、物业业主、运输企业和其他个人或实体做出合理的调整，便于残障人士享受相应的服务。此类法律旨在确保MS患者享有各种类型的金融工具，包括活期账户和储蓄账户、信用卡、保险、贷款以及各类经济援助。** 1,4,9,12,13,17,20,

26-28,35,42,46,47,66,67



## 2.0. 医疗护理

MS患者应该享有适合其需求的医疗护理、治疗和疗法。

MS是一种严重的疾病，享有相应的医疗护理对保证患者的生活质量因而显得极端重要。MS的多种症状和功能性障碍决定了患者需要一系列的服务。此外，疾病的长期性和主要几个护理服务供应商可能无法为众多患者提供服务这两个因素决定了对专业护理服务——MS专业治疗知识——的持续需求。初步诊断时机极为重要，因而必须引起健康护理和其他服务供应商的特别注意。此外，鉴于专业医疗护理对MS患者的重要性，患者必须享有必要的健康护理服务，

包括一流的诊断服务、专业知识和实战经验俱佳的医疗服务供应商、最新的药物和医疗器械、以及满足其症状需求的服务。

### 2.1. 享有医疗护理服务

**2.1.1. 每个MS患者都必须享有证据为证的优质医疗护理。** 1,3,4,24,35,47,68

**2.1.2. 针对MS患者的医疗护理**包括有效的医学治疗，包括症状和病情缓解药物、康复服务、针对MS患者的需求定制



的合适而廉价的实现技术、以及持续的护理服务。MS患者享有适合其需求的医疗护理、治疗和疗法。 2-4,6,7,11,16,17,19,24,32,35,37,42,44,45,47,53,56,57,59,61,69,71-128

2.2. 初步诊断

2.2.1. 医生应该审慎地告诉MS患者MS的主要心理、社会、经济、职业和医疗影响。病人应该有足够的时间向医生提问。应该将新的MS确诊病例报告给各国MS协会、专业MS护士、或具备MS治疗和咨询经验的其他专业人士。

1,12,30,32,33,35,36,40,42,47,56,103,117,129-134

2.2.2. 在初步诊断中，MS患者必须拥有针对新确诊病例的MS信息，拥有当地和全国性医疗、支持、康复和人生规划信息。 1,30,35,36,42,54,56,63,103,106,114,133

2.3 医生、护士、医院和其他医疗服务供应商

2.3.1. 包括神经科医生在内具备MS专业知识的临床医生提供医疗护理服务。为确保针对MS患者可能遇到的多种症状和残障提供及时、专业的治疗，必须由多学科的专业MS医疗队伍提供护理和病例管理服务 1,3,4,6,16,17,27,35,42,61,65,68,103,115,119,122,124,125,128

**2.3.2.** 在适当的情形下，除了医生和护士提供的服务外，还必须向MS患者提供一系列服务，包括生理、职业和语言疗法、咨询和其他服务。将向MS患者明确解释此类服务的宗旨和潜在好处。 1-,6,11,16,17,24,

35-37,42,44,45,47,53,56,59,61,65,68,71-74,

76-78,81,86,90,94-104,106,109,111-119,

121-128,135-138

**2.3.3.** 诸如医院之类的医疗设施必须考虑实体设施和设备，并做出合理的调整，以治疗MS患者的生理残障，包括行走或淋浴困难、难以爬上爬下检查台。 3,35,135

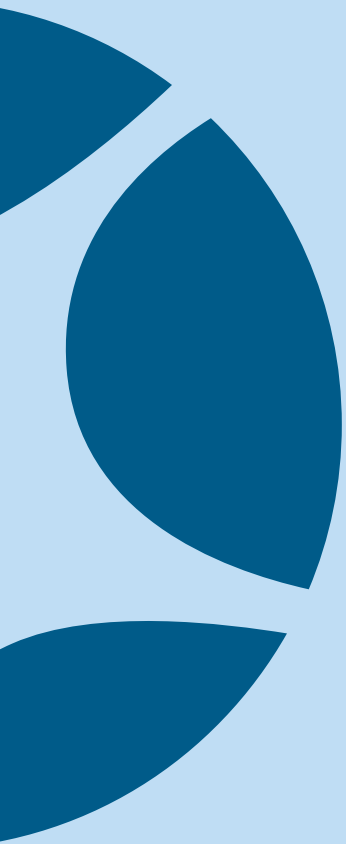
**2.3.4.** MS的治疗必须与其他急性或慢性疾病的治疗相配合，

并持续提供护理服务。不同的服务供应商和医疗护理组织之间的转诊和转移责任规则必须经所有相关各方同意。病人是感觉不到其中的服务中断的。 3,27,30,35,42,124,125,128

**2.3.5.** 临床服务供应商必须在一段较长的时间内，向MS患者持续提供护理服务。持续服务应该侧重于让供应商有足够的时间和动力了解每个病人的MS体验，倾听病人的问题和关注，检查所有症状。此类供应商可以是专业MS护士、专业MS医生、或其他专业MS护理人员。 1,3,4,7,12,30,33,35,54,57,65,

103,137





**2.3.6. 为MS患者提供治疗的所有神经科医生、初级保健医生、护士和其他专业保健人士都必须以促进病人的生活质量为目标，而不是单纯的临床疾病管理。** 1,3,4,6,12,18,19,27,30,40,45,48,49,56,65,70-72,74, 76,94-97,99-102,138,139

## **2.4. 症状处理**

**2.4.1. 必须向MS患者提供既有医疗效果、从文化角度来看也是合适的治疗方案，以消除MS症状。此类症状包括但不限于疲劳、抑郁、认知障碍、性功能障碍、疼痛、膀胱和肠道功能障碍、行走不便、视力问题、以及其他症状。专业保健人士必须系统性考虑MS患者是否出现可能影响生活质量的其他症状或问题（此类症状或问题有时是“隐藏的”）。**

2-4,6,7,11,16,17,19,20,35-37,40,42,44,45,47,48,53,56,57,59,61,65,68-70,72,76-78,82,90,95-99,101-103,105,106,109,110,112,113,115-119,121,122,124-128,135-137,140-152



## 3.0 持续护理（长期护理或社会护理）

MS患者享有一系列与其年龄相符、且有助于其尽可能独立生活的护理服务。

持续护理指居家护理、短期暂替护理、家庭卫生保健、个人护理、成人日间护理、以及旨在消除功能性障碍的其他服务（例如，无法独立吃饭、淋浴或穿衣）。持续护理服务让身患残障的MS患者能更加独立地生活。如果我们实践居家和社区护理或家庭护理原则，并向护理人士提供充分的经济补偿，就可以大幅提高MS患者的生活质量。

**3.1.** MS患者必须享有一系列居家和社区护理或短期暂替护理服务，让他们在家里想住多久

就住多久。 4,8,10,20,35,42,47,81,86,103,115,153,154

**3.2.** 只有在不再适合提供居家或社区护理服务时，才可以提供机构或家庭保健服务（例如，护理院护理）。此类机构提供的服务必须以顾及MS患者——往往比其他人年轻——的利益和需求为目标。

35,42,47,103,155-157

**3.3.** 受薪专业持续护理员必须接受充分的MS具体特征培训，领取足够的报酬和额外福利，并接受充分的监督。



## 4.0. 促进健康、预防疾病

应该向MS患者提供维持积极的健康实践和健康的生活方式所需的信息和服务。

在通常情况下，向MS患者提供的医疗服务主要为医疗护理。但还有其他很多活动和服务可以促进患者的生理健康并预防其他疾病。此类活动包括放松技巧、消除紧张、能量保存技巧、冷却疗法、增氧健身、行走和平衡运动、以及其他健身锻炼。

疾病预防包括免疫（例如，流行性感冒）和其他常规医疗服务（例如，帕氏子宫抹片检查）。实践中发现：受制于各类生理和其他形式的障碍，残疾人士没有享受到充分的预防性护理服务。

**4.1.** 必须就促进健康的一系列实践，向MS患者提供优质的信息和培训，具体取决于病人的喜好、以及此类实践对提升病人生活质量的效果。

1,3,5,7,17,24,25,31,35,36,45,47,51,53,55,56,  
59-61,104,124,126-128,142,148-150,158-165

**4.2.** 临床服务供应商和咨询医生必须鼓励MS患者加强营养和体能锻炼。 1,3,6,16,17,24,35,36,45,47,

51,53,56,59,61,76,104,112,122,124,126-

**4.3.** 医生不得以促进健康和预防疾病为代价，过分强调MS护理的重要性。必须向MS患者提供常规的预防性医疗护理服务。 1,3,6,7,36,42,56,160,168

## 5.0 向患者家人提供支持

向MS患者的家人和护理人员提供相应的信息和支持，以缓解病情。

与MS相关的大多数服务是由患者家人和其他非正式护理人员提供的，他们深受亲戚或朋友罹患MS之苦。旨在帮助患者家人和朋友应对MS带来的压力和其他影响的服务对他们很有好处。

家长患上MS会影响孩子。孩子可能无法彻底理解父母为什么会有这样那样的健康问题，觉得自己不知怎么地让父母染病，或觉得自己被家里人忽视了。在罹患MS症状和残障的情况下，维持为人父母的有效

角色所需的努力是MS患者的主要压力。相反，维持一个有益的父母角色可以提升患者的生活质量。这些原则承认并满足护理人员的特殊需求，帮助他们在家人罹患MS时维持一定的生活质量。

**5.1. 必须向MS患者和受其影响的家人和其他非正式护理员提供相应的服务和培训，还应该告诉他们社区可能提供的支持服务。** 1,3,7,8,10,15,17,20,35,42,47,53,58,64,109, 114, 117,130,169-185

**5.2. 提供持续护理服务的居家护理员或机构必须提供短期暂替护理，减轻MS患者家人和其他非正式护理员的负担。**

1,3,15,35,47,103,126,130,180,183-185

**5.3. 必须定期评估患者家人和其他非正式护理员因护理服务产生的肉体 and 情绪压力和其他个人需求。**

1,3,15,35,42,47,103,117,127,130,136,169-182,184,185

**5.4. 必须向MS患者及其家人提供家庭和社会关系咨询。**

1,3,6,15,17,23,25,35,37,42,47,53,55,57,58,106,109,113,130,152,169-182,184,185

**5.5. 必须向MS患者提供相应的服务，帮助他们承担为人父母的责任。不要让孩子在父母罹患MS时担当护理员的角色。**

1,3,6,25,31,35,37,47,126,130,152,174

**5.6. 必须提供相应的服务，防止患者家人和其他非正式护理员从肉体、经济和心理上虐待患者。**

1,3,117,130,184



## 6.0 交通

向MS患者提供进出所在社区的公共交通服务和私家车辅助驾驶技术。

持续驾驶或提供其他交通工具能够大幅提升MS患者的出行便利。MS患者可能因为自身的功能性残疾、认知障碍、以及助行工具而面临出行困难。而公共交通——往往是他们唯一的出行方式——有时是无法享受或难于享受的。缺乏交通便利可能决定了MS患者只能呆在家里，从而限制了他们参与社区生活的能力。

**6.1. 必须向MS患者提供相应的服务，让他们想开多久的车就开多久。** 3,6,15,17,30,47,124,165

**6.2. 必须向不能驾车或没有驾车的MS患者提供负担得起的交通服务。** 3,6,35,47

## 7.0 就业和自愿活动

必须向MS患者提供相应的支持系统和服务，  
让他们在还能工作时想工作多久就工作多久。

许多MS患者因为MS症状（例如，疲劳、功能性残疾和认知障碍）而失业。失业会严重影响家庭收入和个人的自尊。如果雇主提供帮助并调整他们的工作，有些MS患者就可以继续工作。

可能向MS患者提供一系列调整或适应性服务，包括兼职工作、工作日提供额外的休息、只在上午工作、调低办公室温度、调整工作任务、在家上班、减少出差次数、设置坡道、在办公室附近设置洗手间或提供其他便利。政府和社会服务供应商可以提供职业康复服务和培训计划，为MS患者做出自己的贡献。

对于那些失业的MS患者，替代性活动对维持他们的生活使命感很重要。此类替代性活动包括自愿活动、艺术创作、为其他MS患者提供咨询、协助MS协会或MS中心的管理或宣传活动、投身继续教育等等。


**7.1. 必须向MS患者提供相应的服务，让他们在还能工作时想工作多久就工作多久。** 3,6,9,12,13,15,17,19,20,25-28,30,35,42,46-48,56,59,65-67,124,152,165,186-189

**7.2. 雇主必须调整工作或提供其他适应性或调节性服务，便于MS患者继续工作。应该将MS的性质和症状告诉雇主，让他们知道工作调整如何使MS患者为公司多服务几年。**

3,9,12,13,15,17,19,20,26-28,35,37,38,42,46,47,56,65-67,124,152,165,186-189

**7.3. 雇主应该允许MS患者的家人和其他非正式护理人员请假，以应对患者的突发性需求。应该将患者家人在治疗和应对MS的急性恶化和症状中承担的角色告诉雇主。**

3,13,15,19,28,37,47,189



**7.4. 必须提供相应的职业康复和培训服务，帮助MS患者如愿返回工作岗位或继续工作。**

3,6,12,13,26-28,35,42,46,47,65,67,124,152,  
186,187

**7.5. 必须向从受薪岗位上退下来的MS患者提供辅导，鼓励他们从事其他自愿活动，填补退休产生的空白。应该事先周密规划MS患者从受薪岗位的退休事宜，让他们享受有权享受的所有服务，帮助他们为从事其他职业或活动做好准备，帮助他们克服突发性、计划外退休带来的压力。**

3,8,20,21,25,37,  
42,189

## 8.0 残疾津贴和现金补助

向有需要的残疾人提供相应的津贴和服务，  
提供适当的生活水准，为MS特有的变异性留出余地。

许多失业的MS患者靠残疾津贴、以及接受经济状况调查后才可以领取的现金补助为生。

因此，津贴的领取标准、支付水平和管理直接影响MS患者的生活质量。这些原则承认这类经济援助的重要性，包括申请流程、以及可以在很大程度上影响患者福祉的援助程度和管理灵活性。

**8.1.** 对于公共或私人性质的残疾津贴和接受经济状况调查后才可以领取的现金补助，相应的申领标准和申请程序必须是

公正的，不能过于繁琐，也不能有任何限制。 27,28,46,67

**8.2.** 对于公共或私人性质的残疾津贴和接受经济状况调查后才可以领取的现金补助，相应的现金支付水平应该足以向MS患者提供适当的生活水准。 8,15,28,46,48,67,190

**8.3.** 残疾津贴必须具备一定的灵活性，允许部分残疾的人士享受津贴，便于MS患者在需要时休假或视意愿继续从事兼职工作。 9,28,47,66,67

## 9.0. 教育

MS并不限制MS患者及其家人的教育或职业。

在一个现代化国家里，教育对拥有一份好工作至关重要。此外，为孩子提供教育是家长的主要职责之一。为此，教育机构需要接收MS患者入学，满足他们的特殊需求。例如，教育机构可以让MS患者在不太疲劳的上午上课，可以调低教室温度，允许有认知障碍的学生带人在课堂上录音或做笔记，向患者提供远程学习机会。

**9.1.** 学校、大学和其他教育机构必须在MS患者需要时提供帮助，帮助他们接受与其能力相称的教育。<sup>15,19</sup>

**9.2.** 学校、大学和其他教育机构必须为包括MS患者在内的残障人士提供出入便利。

**9.3.** 学校必须在罹患MS的家长需要时提供帮助，便于他们参加孩子的教学计划、学校的自愿活动和家长老师互动会议。

## 10.0 住房和社区无障碍建筑

无障碍建筑——公共建筑和个人住房和公寓——对MS患者的独立性极为重要。

鉴于许多MS患者罹患的疾病限制其行动，并需要使用辅助设施、滑行车和/或轮椅，社区里的许多房子和建筑不利于他们出入，也不易于使用。

例如，对坐在轮椅里的人而言，需要爬楼梯的建筑和房子往往意味着无法出入其中的大部分房间。MS患者的基本需求之一是拥有一处能够满足他们的特殊需求、提供所需服务和从事喜欢的活动的房子和建筑。



## 10.1. 住房

**10.1.1.** 必须向MS患者提供基本的家居改善，让他们在社区里想住多久就住多久。

3,8,38,42,47,124,165,191

**10.1.2.** 不得以疾病为由，限制MS患者获得用于家居改善的贷款、补助或其他形式的经济支持。 3,8,38

**10.1.3.** 在所有新落成的住房中，绝大部分房子应该在初始设计和建造过程中提供无障碍设施，且无需改造即可让MS患者入住。 3,8,38,191

## 10.2. 社区无障碍建筑

**10.2.1.** 社区建筑（特别是政府办公楼和教学大楼）应该设置针对MS患者的无障碍设施。

8,47,57

**10.2.2.** 新落成的公共建筑在设计和建造时必须提供针对MS患者和其他残障人士的无障碍设施。 3,8,57



# References

1. Defriez M, Griffiths D, Millett C. The perception of the current provision of care for multiple sclerosis sufferers in the community. *Primary health care res develop* 2003; 4(3):233-43. Level of Evidence: 3
2. Ford HL, Gerry E, Johnson MH, et al. Health status and quality of life of people with multiple sclerosis. *Disabil rehabil* 2001; 23(12):516-21. Level of Evidence: 3
3. Neri M, Kroll T. Understanding the consequences of access barriers to health care: experiences of adults with disabilities. *Disabil rehabil* 2003; 25(2):85-96. Level of Evidence: 3
4. Welburn J. Co-ordinating specialists care packages for people with multiple sclerosis. *Community nurse* 2000; 6(7):11-2. Level of Evidence: 4
5. Barnwell AM, Kavanagh DJ. Prediction of psychological adjustment to multiple sclerosis. *Soc sci med* 1997; 45(3):411-8. Level of Evidence: 3
6. Britell C, Burks J, Schapiro R. Chapter 12: Introduction to symptom and rehabilitative management: disease management model. in: Burks J , Johnson K, eds. *Multiple sclerosis: diagnosis, medical management, and rehabilitation*. New York: Demos Medical Publishing, Inc, 2000. Level of Evidence: 4
7. Burks J. Multiple sclerosis care: an integrated disease-management model. *J Spinal cord med* 1998; 21(2):113-6. Level of Evidence: 4
8. Dyck I. Hidden geographies: the changing lifeworlds of women with multiple sclerosis. *Soc sci med* 1995; 40(3):307-20. Level of Evidence: 3
9. Dyck I, Jongbloed L. Women with multiple sclerosis and employment issues: a focus on social and institutional environments. *Can J Occup ther* 2000; 67(5):337-46. Level of Evidence: 3

10. Finlayson M. Concerns about the future among older adults with multiple sclerosis. *Am J Occup ther* 2004; 58(1):54-63. Level of Evidence: 3
11. Forwell S. Managing the ordinary things of everyday life. *MS in focus* 2003; 1:9-11. Level of Evidence: 4
12. Gordon P, Lewis MD, Wong D. Multiple sclerosis: strategies for rehabilitation counselors. *J Rehabil* 1994; 60(3):34-8. Level of Evidence: 3
13. Gordon PA, Feldman D, Shipley B, et al. Employment issues and knowledge regarding ADA of persons with multiple sclerosis. *J Rehabil* 1997; 63(4):52-8. Level of Evidence: 3
14. Gulick EE. Correlates of quality of life among persons with multiple sclerosis. *Nurs res* 1997; 46(6):305-11. Level of Evidence: 3
15. Hakim E, Bakheit A, Bryant T, et al. The social impact of multiple sclerosis--a study of 305 patients and their relatives. *Disabil rehabil* 2000; 22(6):288-93. Level of Evidence: 3
16. Haselkorn J, Leer S, Hall J, et al. Chapter 17: Mobility. in: Burks J, Johnson K, eds *Multiple sclerosis: diagnosis, medical management, and rehabilitation*. New York: Demos Medical Publishing, Inc., 2000. Level of Evidence: 4
17. Holland N, Murray T, Reingold S. *Multiple sclerosis: a guide for the newly diagnosed*. Second edition. New York: Demos Medical Publishing, Inc., 2002. Level of Evidence: 4
18. Hopman W, Coo H, Brunet D, et al. Longitudinal assessment of health-related quality of life (HRQL) of patients with multiple sclerosis. *Inter J of MS care* 2000; 2(4):3. Level of Evidence: 3
19. Johnson K, Yorkston K, Klasner E, et al. The cost and benefits of employment: a qualitative study of experiences of persons with multiple sclerosis. *Arch phys med rehabil* 2004; 85(2):201-9. Level of Evidence: 3

20. Leino-Kilpi H, Luoto E, Katajisto J. Elements of empowerment and MS patients. *J Neurosci nurs* 1998; 30(2):116-23. Level of Evidence: 3
21. Lundmark P, Branholm IB. Relationship between occupation and life satisfaction in people with multiple sclerosis. *Disabil rehabil* 1996; 18(9):449-53. Level of Evidence: 3
22. McCabe MP, McKern S. Quality of life and multiple sclerosis: comparison between people with multiple sclerosis and people from the general population. *J Clin psychol med settings* 2002; 9(4):287-95. Level of Evidence: 3
23. Mohr DC, Dick LP, Russo D, et al. The psychosocial impact of multiple sclerosis: exploring the patient's perspective. *Health psychol* 1999; 18(4):376-82. Level of Evidence: 3
24. O'Hara L, De Souza L, Ide L. A Delphi study of self-care in a community population of people with multiple sclerosis. *Clin rehabil* 2000; 14(1):62-71. Level of Evidence: 3
25. Reynolds F, Prior S. Sticking jewels in your life: exploring women's strategies for negotiating an acceptable quality of life with multiple sclerosis. *Qualitative health research [Special Issue: Care of Self]* 2003; 13(9):1225-51. Level of Evidence: 3
26. Roessler R, Rumrill P. Strategies for enhancing career maintenance self-efficacy of people with multiple sclerosis. *J Rehabil* 1994; 60(4):54-9. Level of Evidence: 4
27. Rumrill P, Roessler RT, Koch LC. Surveying the employment concerns of people with multiple sclerosis: a participatory action research approach. *J Voc rehabil* 1999; 12(2): 75-82. Level of Evidence: 3
28. Rumrill P, Tabor TL, Hennessey ML, et al. Issues in employment and career development for people with multiple sclerosis: meeting the needs of an emerging vocational rehabilitation clientele. *J Voc rehabil, [Special Issue: Rehabilitation Counseling in the 21st Century]* 2000; 14(2):109-17. Level of Evidence: 4

29. Schwartz CE, Sendor M. Helping others helps oneself: response shift effects in peer support. *Soc sci med* 1999; 48(11):1563-75. Level of Evidence: 3
30. Somerset M, Sharp D, Campbell R. Multiple sclerosis and quality of life: a qualitative investigation. *J Health serv res policy* 2002; 7(3):151-9. Level of Evidence: 3
31. Multiple Sclerosis Society of Australia. MS and parenting. Lidcombe: 1996. Level of Evidence: 4
32. Forbes A, While A, Dyson L, et al. Impact of clinical nurse specialists in multiple sclerosis -- synthesis of the evidence. *J Adv nurs* 2003; 42(5):442-62. Level of Evidence: 4
33. Courts NF, Buchanan EM, Werstlein PO. Focus groups: the lived experience of participants with multiple sclerosis. *J Neurosci nurs* 2004; 36(1):42-7. Level of Evidence: 3
34. Department of Health. The expert patient: a new approach to chronic disease management for the 21st Century. London: 2001. Level of Evidence: 4
35. Freeman J, Ford H, Mattison P, et al. Developing MS healthcare standards: evidence-based recommendations for service providers. London: The Multiple Sclerosis Society of Great Britain and Northern Ireland, 2002. Level of Evidence: 4
36. Giesser B. Talking about the diagnosis of multiple sclerosis. New York: National Multiple Sclerosis Society, 2003. Level of Evidence: 4
37. Halper J, Holland N. Meeting the challenge of multiple sclerosis, Part 2. *Am J Nurs* 1998; 87(11):39-45. Level of Evidence: 4
38. McLaughlin J, Zeeberg I. Self-care and multiple sclerosis: a view from two cultures. *Soc sci med* 1993; 37(3):315-29. Level of Evidence: 3

39. Somerset M, Peters TJ, Sharp DJ, et al. Factors that contribute to quality of life outcomes prioritised by people with multiple sclerosis. *Qual life res* 2003; 12(1):21-9. Level of Evidence: 2b
40. Thorne S, Con A, McGuinness L, et al. Health care communication issues in multiple sclerosis: an interpretive description. *Qual health res* 2004; 14(1):5-22. Level of Evidence: 3
41. Yorkston KM, Johnson K, Klasner ER, et al. Getting the work done: a qualitative study of individuals with multiple sclerosis. *Disabil rehabil* 2003; 25(8):369-79. Level of Evidence: 3
42. National Collaborating Centre for Chronic Conditions. Multiple sclerosis: management of multiple sclerosis in primary and secondary care. Clinical guideline 8. London: National Institute for Clinical Excellence [Web Page]. 2003; Available at [www.nice.org.uk](http://www.nice.org.uk). (Accessed 15 February 2004). Level of Evidence: 4
43. Somerset M, Campbell R, Sharp D, et al. What do people with MS want and expect from health-care services? *Health expect* 2001; 4(1):29-37. Level of Evidence: 3
44. Saunders A, Aisen M. Chapter 26: Sexual dysfunction. in: Burks J, Johnson K, eds. *Multiple sclerosis: diagnosis, medical management, and rehabilitation*. New York: Demos Medical Publishing, Inc, 2000. Level of Evidence: 4
45. Schapiro R. *Managing the symptoms of multiple sclerosis*. Fourth edition. New York: Demos Medical Publishing, 2003. Level of Evidence: 4
46. Roessler RT, Rumrill PD, Hennessey ML, et al. Perceived strengths and weaknesses in employment policies and services among people with multiple sclerosis: results of a national survey. *J Prevent assess rehabil* 2003; 21(1):25-36. Level of Evidence: 3
47. Rumrill P, Hennessey M. *Multiple sclerosis: a guide for rehabilitation and health care professionals*. Springfield: Charles C Thomas Publisher, 2001. Level of Evidence: 3

48. The Canadian Burden of Illness Study Group. Burden of illness of multiple sclerosis: part II: quality of life. *Can J Neurol sci* 1998; 25(1):31-8. Level of Evidence: 3
49. Miller DM, Rudick RA, Baier M, et al. Factors that predict health-related quality of life in patients with relapsing-remitting multiple sclerosis. *Mult scler* 2003; 9(1):1-5. Level of Evidence: 2b
50. Peters T, Somerset M, Campbell R, et al. Variables associated with attendance at, and the perceived helpfulness of, meetings for people with multiple sclerosis. *Health soc care community* 2003; 11(1):19-26. Level of Evidence: 3
51. Stuifbergen AK, Becker H, Blozis S, et al. A randomized clinical trial of a wellness intervention for women with multiple sclerosis. *Arch phys med rehabil* 2003; 84(4):467-76. Level of Evidence: 1b
52. Baker LM. Sense making in multiple sclerosis: the information needs of people during an acute exacerbation. *Qual health res* 1998; 8(1):106-20. Level of Evidence: 3
53. Bashir K, Whitaker J. *Handbook of multiple sclerosis*. New York: Lippincott Williams & Wilkins, 2002. Level of Evidence: 4
54. Box V, Hepworth M, Harrison J. Identifying information needs of people with multiple sclerosis. *Nurs times* 2003; 99(49):32-6. Level of Evidence: 3
55. Crigger NJ. Testing an uncertainty model for women with multiple sclerosis. *Adv Nurs sci* 1996; 18(3):37-47. Level of Evidence: 3
56. Joy J, R Johnston, eds. *Multiple sclerosis: current status and strategies for the future*. Washington, DC: National Academy Press, 2001. Level of Evidence: 4
57. Koch T, Kelly S. Understanding what is important for women who live with multiple sclerosis. *Aust J Holist nurs* 1999; 6(1):14-24. Level of Evidence: 3

58. Miller CM. The lived experience of relapsing multiple sclerosis: a phenomenological study. *J Neurosci nurs* 1997; 29(5):294-304. Level of Evidence: 3
59. Nortvedt MW, Riise T. The use of quality of life measures in multiple sclerosis research. *Mult scler* 2003; 9(1):63-72. Level of Evidence: 4
60. O'Hara L, Cadbury H, De Souza L, et al. Evaluation of the effectiveness of professionally guided self-care for people with multiple sclerosis living in the community: a randomized controlled trial. *Clin rehabil* 2002; 16(2):119-28. Level of Evidence: 1b
61. Polman C, Thompson A, Murray T, McDonald W. Multiple sclerosis: the guide to treatment and management. Fifth edition. New York: Demos Medical Publishing, 2001. Level of Evidence: 4
62. Schwartz CE. Teaching coping skills enhances quality of life more than peer support: results of a randomized trial with multiple sclerosis patients. *Health psychol* 1999; 18(3):211-20. Level of Evidence: 1b
63. Slade A, Tennant A, Ford H. Meeting the information needs of people with multiple sclerosis. *Int J Therapy rehab* 2003; 10(5):211-7. Level of Evidence: 3
64. Vaughan R, Morrison L, Miller E. The illness representations of multiple sclerosis and their relations to outcome. *Br J Health psychol* 2003; 8 (Pt 3):287-301. Level of Evidence: 3
65. Multiple Sclerosis Society of Great Britain and Northern Ireland. Basics of best practice in the management of multiple sclerosis. London: 1999. Level of Evidence: 4
66. O'Day B. Barriers for people with multiple sclerosis who want to work: a qualitative study. *J Neurol rehabil* 1998; 12(3):139-46. Level of Evidence: 3

67. Multiple Sclerosis Society of Canada. Assets and abilities: your guide to work, income security, and multiple sclerosis. Toronto: 2001. Level of Evidence: 4
68. De Broe S, Christopher F, Waugh N. The role of specialist nurses in multiple sclerosis: a rapid and systematic review. Health technol assess 2001; 5(17):1-37. Level of Evidence: 3
69. Thompson AJ. Progress in neurorehabilitation in multiple sclerosis. Curr opin neurol 2002; 15(3):267-70. Level of Evidence: 4
70. McReynolds CJ, Koch LC, Rumrill JrP. Psychosocial adjustment to multiple sclerosis: Implications for rehabilitation professionals. J Voc rehabil 1999; 12(2):83-91. Level of Evidence: 4
71. Ko Ko C. Effectiveness of rehabilitation for multiple sclerosis. Clin rehabil 1999; 13 Suppl 1:33-41. Level of Evidence: 4
72. Jonsson A, Dock J, Ravnborg MH. Quality of life as a measure of rehabilitation outcome in patients with multiple sclerosis. Acta neurol scand 1996; 93(4):229-35. Level of Evidence: 3
73. Freeman JA, Langdon DW, Hobart JC, et al. Inpatient rehabilitation in multiple sclerosis: do the benefits carry over into the community? Neurology 1999; 52(1):50-6. Level of Evidence: 3
74. Thompson AJ. The effectiveness of neurological rehabilitation in multiple sclerosis. J Rehabil res dev 2000; 37(4):455-61. Level of Evidence: 4
75. Arnoldus JH, Killestein J, Pfenning LE, et al. Quality of life during the first 6 months of interferon-beta treatment in patients with MS . Mult scler 2000; 6(5):338-42. Level of Evidence: 2b



76. Bethoux F. Chapter 43: Rehabilitation in multiple sclerosis. in: Cohen J, Rudick R, eds. Multiple sclerosis therapeutics. Second edition. London: Martin Dunitz Ltd, 2003. Level of Evidence: 4
77. Bethoux F, Miller DM, Kinkel RP. Recovery following acute exacerbations of multiple sclerosis: from impairment to quality of life. *Mult scler* 2001; 7(2):137-42. Level of Evidence: 2b
78. Schwid SR, Petrie MD, Murray R, et al. A randomized controlled study of the acute and chronic effects of cooling therapy for MS. *Neurology* 2003; 60(12):1955-60. Level of Evidence: 1b
79. Cohen JA, Cutter GR, Fischer JS et al. Benefit of interferon beta-1a on MSFC progression in secondary progressive MS. *Neurology* 2002; 59(5):679-87. Level of Evidence: 1b
80. Freeman JA, Thompson AJ, Fitzpatrick R, et al. Interferon-beta1b in the treatment of secondary progressive MS: impact on quality of life. *Neurology* 2001; 57(10):1870-5. Level of Evidence: 1b
81. Freeman JA, Thompson AJ. Community services in multiple sclerosis: still a matter of chance. *J Neurol neurosurg psychiatry* 2000; 69(6):728-32. Level of Evidence: 3
82. Gianino JM, York MM, Paice JA, et al. Quality of life: effect of reduced spasticity from intrathecal baclofen. *J Neurosci nurs* 1998; 30(1):47-54. Level of Evidence: 3
83. Granger CV, Wende K, Brownschidle CM. Use of the FIM instrument in a trial of intramuscular interferon beta-1a for disease progression in relapsing-remitting multiple sclerosis. *Am J Phys med rehabil* 2003; 82(6):427-36. Level of Evidence: 1b
84. Kobelt G, Jönsson L, Fredrikson S. Cost-utility of interferon beta-1b in the treatment of patients with active relapsing-remitting or secondary progressive multiple sclerosis. *Eur J Health econom* 2003; 4:50-9. Level of Evidence: 2b

85. Multiple Sclerosis Council for Clinical Practice Guidelines. Disease modifying therapies in multiple sclerosis: evidence-based management strategies for disease modifying therapies in multiple sclerosis. Paralyzed Veterans of America, 2001. Level of Evidence: 4
86. Pozzilli C, Brunetti M, Amicosante AM, et al. Home based management in multiple sclerosis: results of a randomised controlled trial. *J Neurol neurosurg psychiatry* 2002; 73(3):250-5. Level of Evidence: 1b
87. Rice G, Incorvaia B, Munari L et al. Interferon in relapsing-remitting MS. *Cochrane database of systematic reviews*. Issue 4 edition. Chichester, UK: John Wiley & Sons, Ltd., 2001. Level of Evidence: 1a
88. Rice GP, Oger J, Duquette P, et al. Treatment with interferon beta-1b improves quality of life in multiple sclerosis. *Can J Neurol sci* 1999; 26(4):276-82. Level of Evidence: 2b
89. Schwartz CE, Coulthard-Morris L, Cole B, et al. The quality-of-life effects of interferon beta- 1b in multiple sclerosis. An extended Q-TWiST analysis. *Arch Neurol* 1997; 54(12):1475-80. Level of Evidence: 2b
90. Schwid S. Chapter 42: Management of cognitive impairment in multiple sclerosis. in: Cohen J, Rudick R, eds. *Multiple sclerosis therapeutics*. Second edition. London: Martin Dunitz Ltd, 2003. Level of Evidence: 4
91. Shawaryn MA, Schiaffino KM, LaRocca NG, et al. Determinants of health-related quality of life in multiple sclerosis: the role of illness intrusiveness. *Mult scler* 2002; 8(4):310-8. Level of Evidence: 3
92. Vermersch P, de Seze J, Stojkovic T, et al. Interferon beta1a (Avonex) treatment in multiple sclerosis: similarity of effect on progression of disability in patients with mild and moderate disability. *J Neurol* 2002; 249(2):184-7. Level of Evidence: 2b

93. Zivadinov R, Zorzon M, Tommasi M, et al. A longitudinal study of quality of life and side effects in patients with multiple sclerosis treated with interferon beta-1a. *J Neurol sci* 2003; 216(1):113-8. Level of Evidence: 3
94. Solari A, Filippini G, Gasco P, et al. Physical rehabilitation has a positive effect on disability in multiple sclerosis patients. *Neurology* 1999; 52(1):57-62. Level of Evidence: 1b
95. Sitzia J, Haddrell V, Rice-Oxley M. Evaluation of a nurse-led multidisciplinary neurological rehabilitation programme using the Nottingham Health Profile. *Clin rehabil* 1998; 12(5):389-94. Level of Evidence: 2b
96. Patti F, Ciancio MR, Cacopardo M, et al. Effects of a short outpatient rehabilitation treatment on disability of multiple sclerosis patients--a randomised controlled trial. *J Neurol* 2003; 250(7):861-6. Level of Evidence: 1b
97. Kidd D, Howard RS, Losseff NA, et al. The benefit of inpatient neurorhabilitation in multiple sclerosis. *Clin rehabil* 1995; 9(3):198-203. Level of Evidence: 2b
98. Freeman JA, Langdon DW, Hobart JC, et al. The impact of inpatient rehabilitation on progressive multiple sclerosis. *Ann neurol* 1997; 42(2):236-44. Level of Evidence: 1b
99. Di Fabio RP, Choi T, Soderberg J, et al. Health-related quality of life for patients with progressive multiple sclerosis: influence of rehabilitation. *Phys ther* 1997; 77(12):1704-16. Level of Evidence: 2a
100. Di Fabio R, Soderberg J, Choi T, et al. Extended outpatient rehabilitation: its influence on symptom frequency, fatigue, and functional status for persons with progressive multiple sclerosis. *Arch phys med rehabil* 1998; 79(2):141-6. Level of Evidence: 2a

101. Craig J, Young CA, Ennis M, et al. A randomised controlled trial comparing rehabilitation against standard therapy in multiple sclerosis patients receiving intravenous steroid treatment. *J Neurol neurosurg psychiatry* 2003; 74(9):1225-30. Level of Evidence: 1b
102. Aisen ML, Sevilla D, Fox N. Inpatient rehabilitation for multiple sclerosis. *J Neurol rehabil* 1996; 10(1):43-6. Level of Evidence: 2b
103. Barnes MP, Gilhus NE, Wender M. Task force on minimum standards for health care of people with multiple sclerosis: June 1999. *Eur J Neurol* 2001; 8(3):215-20. Level of Evidence: 4
104. Benito-Leon J, Morales JM, Rivera-Navarro J, et al. A review about the impact of multiple sclerosis on health-related quality of life. *Disabil rehabil* 2003; 25(23):1291-303. Level of Evidence: 4
105. Dierich M. Chapter 24: Bladder dysfunction. in: Burks J , Johnson K, eds. *Multiple sclerosis: diagnosis, medical management, and rehabilitation*. New York: Demos Medical Publishing, Inc, 2000. Level of Evidence: 4
106. Foley F. Talking about sexual dysfunction. New York: National Multiple Sclerosis Society, 2003. Level of Evidence: 4
107. Goodin DS, Frohman EM, Garmany GP Jr, et al. Disease modifying therapies in multiple sclerosis: report of the Therapeutics and Technology Assessment Subcommittee of the American Academy of Neurology and the MS Council for Clinical Practice Guidelines. *Neurology* 2002; 58(2):169-78. Level of Evidence: 4
108. Henriksson F, Fredrikson S, Masterman T, et al. Costs, quality of life and disease severity in multiple sclerosis: a cross-sectional study in Sweden. *Eur J Neurol* 2001; 8(1):27-35. Level of Evidence: 3

109. Holland N. Talking about elimination problems. New York: National Multiple Sclerosis Society, 2003. Level of Evidence: 4
110. Janardhan V. , Bakshi R. Quality of life in patients with multiple sclerosis: the impact of fatigue and depression. J Neurol sci 2002; 205(1):51-8. Level of Evidence: 3
111. Jeffery D. Chapter 23: Pain and dysethesia. in: Burks J , Johnson K, eds. Multiple sclerosis: diagnosis, medical management, and rehabilitation. New York: Demos Medical Publishing, Inc, 2000. Level of Evidence: 4
112. Krupp L, Elkins L. Chapter 14: Fatigue. in: Burks J, Johnson K, eds. Multiple sclerosis: diagnosis, medical management, and rehabilitation. New York: Demos Medical Publishing, Inc., 2000. Level of Evidence: 4
113. LaRocca N. Chapter 22: Cognitive and emotional disorders. in: Burks J, Johnson K, eds. Multiple sclerosis: diagnosis, medical management, and rehabilitation. New York: Demos Medical Publishing, Inc., 2000. Level of Evidence: 4
114. LaRocca N. Talking about cognitive dysfunction. New York: National Multiple Sclerosis Society, 2003. Level of Evidence: 4
115. Litta R. Changing relationships and roles within the family. MS in Focus 2004; 3:9-11. Level of Evidence: 4
116. Logemann J. Chapter 28: Dysphagia. in: Burks J, Johnson K, eds. Multiple sclerosis: diagnosis, medical management, and rehabilitation. New York: Demos Medical Publishing Inc. , 2000. Level of Evidence: 4
117. Minden S. Talking about depression and other emotional changes. New York: National Multiple Sclerosis Society, 2003. Level of Evidence: 4

118. Minden S, Frumin M, Erb J. Chapter 39: Treatment of disorders of mood and affect in multiple sclerosis. in: Cohen J, Rudick R, eds. Multiple sclerosis therapeutics. Second edition. London: Martin Dunitz Ltd, 2003. Level of Evidence: 4
119. Motta R. How to find strategies to manage the unpredictable. MS in focus 2003; 2:10-4. Level of Evidence: 4
120. Murphy N, Confavreux C, Haas J, et al. Quality of life in multiple sclerosis in France, Germany, and the United Kingdom. Cost of Multiple Sclerosis Study Group. J Neurol Neurosurg Psychiatry 1998; 65(4):460-6. Level of Evidence: 3
121. Patti F, Ciancio MR, Reggio E, et al. The impact of outpatient rehabilitation on quality of life in multiple sclerosis. J Neurol 2002; 249(8):1027-33. Level of Evidence: 1b
122. Rizzo M. Chapter 40: Treatment of pain, paresthesias, and paroxysmal disorders in multiple sclerosis. in: Cohen J, Rudick R, eds. Multiple sclerosis therapeutics. Second edition. London: Martin Dunitz Ltd, 2003. Level of Evidence: 4
123. Samkoff L, Goodman A. Chapter 34: Disease modifying drug therapy for multiple sclerosis in clinical practice. in: Cohen J, Rudick R, eds. Multiple sclerosis therapeutics. Second edition. London: Martin Dunitz Ltd, 2003. Level of Evidence: 4
124. Multiple Sclerosis Council for Clinical Practice Guidelines. Fatigue and multiple sclerosis: evidence-based management strategies for fatigue in multiple sclerosis. Paralyzed Veterans of America, 1998. Level of Evidence: 4
125. Multiple Sclerosis Council for Clinical Practice Guidelines. Urinary dysfunction and multiple sclerosis: evidence-based management strategies for urinary dysfunction in multiple sclerosis. Paralyzed Veterans of America, 2001. Level of Evidence: 4
126. Multiple Sclerosis Society of Ireland. Diagnosed with MS? Dublin: 2003. Level of Evidence: 4

127. Multiple Sclerosis Society of Ireland. Taking control of your emotions. Dublin: 2003. Level of Evidence: 4
128. National Multiple Sclerosis Society. Management of MS-related fatigue. expert opinion paper. New York: National Multiple Sclerosis Society [Web Page]. 2002; Available at [www.nationalmssociety.org](http://www.nationalmssociety.org). (Accessed 17 April 2003). Level of Evidence: 4
129. Brechin M, Burgess M. Designing an education tool for MS patients. Prof nurse 2001; 16(11):1471-4. Level of Evidence: 4
130. Janssens A, van Doorn P, de Boer J, et al. Impact of recently diagnosed multiple sclerosis on quality of life, anxiety, depression and distress of patients and partners. Acta neurol Scand 2003; 108( 6):389-95. Level of Evidence: 2b
131. Johnson J. On receiving the diagnosis of multiple sclerosis: managing the transition. Mult scler 2003; 9(1):82-8. Level of Evidence: 2b
132. Parkin D, Jacoby A, McNamee P, et al. Treatment of multiple sclerosis with interferon beta: an appraisal of cost-effectiveness and quality of life. J Neurol neurosurg psychiatry 2000; 68(2):144-9. Level of Evidence: 2b
133. Porter B, Keenan E. Nursing at a specialist diagnostic clinic for multiple sclerosis. Br J Nurs 2003; 12(11):650-6. Level of Evidence: 4
134. Vermersch P, de Seze J, Delisse B, et al. Quality of life in multiple sclerosis: influence of interferon-beta1 a (Avonex) treatment. Mult scler 2002; 8(5):377-81. Level of Evidence: 2b
135. Vanage SM, Gilbertson KK, Mathiowetz V. Effects of an energy conservation course on fatigue impact for persons with progressive multiple sclerosis. Am J Occup ther 2003; 57(3):315-23. Level of Evidence: 2b

136. Barrett M. Sexuality and multiple sclerosis. Toronto: Multiple Sclerosis Society of Canada, 1999. Level of Evidence: 4
137. Heerings M. The role of the MS nurse. *MS in focus* 2003; 1 :14-6. Level of Evidence: 4
138. Rothwell PM , McDowell Z, Wong CK, et al. Doctors and patients don't agree: cross sectional study of patients' and doctors' perceptions and assessments of disability in multiple sclerosis. *Be med J* 1997; 314(7094):1580-3. Level of Evidence: 3
139. Benito-Leon J, Morales JM, Rivera-Navarro J. Health-related quality of life and its relationship to cognitive and emotional functioning in multiple sclerosis patients. *Eur J Neurol* 2002; 9(5):497-502. Level of Evidence: 3
140. Amato MP, Ponziani G, Rossi F, et al. Quality of life in multiple sclerosis: the impact of depression, fatigue and disability. *Mult scler* 2001; 7(5):340-4. Level of Evidence: 3
141. National Multiple Sclerosis Society. Disease management consensus statement. New York: National Multiple Sclerosis Society [Web Page]. 2002; Available at [www.nationalmssociety.org](http://www.nationalmssociety.org). (Accessed 13 March 2003). Level of Evidence: 4
142. Mathiowetz V, Matuska KM, Murphy ME. Efficacy of an energy conservation course for persons with multiple sclerosis. *Arch phys med rehabil* 2001; 82(4):449-56. Level of Evidence: 1b
143. Flensner G, Lindencrona C. The cooling-suit: case studies of its influence on fatigue among eight individuals with multiple sclerosis. *J Adv nurs* 2002; 37(6):541-50. Level of Evidence: 3
144. Foley FW, LaRocca NG, Sanders AS, et al. Rehabilitation of intimacy and sexual dysfunction in couples with multiple sclerosis. *Mult scler* 2001; 7(6):417-21. Level of Evidence: 2b



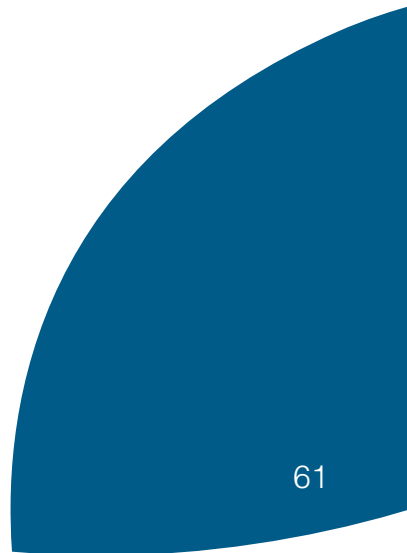
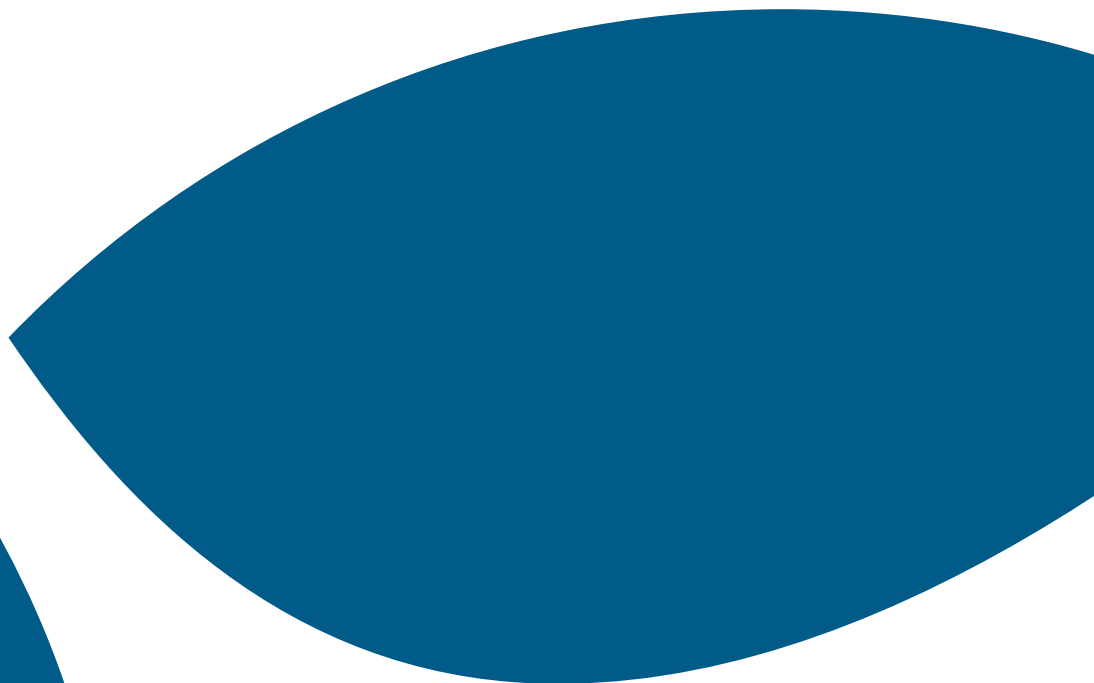
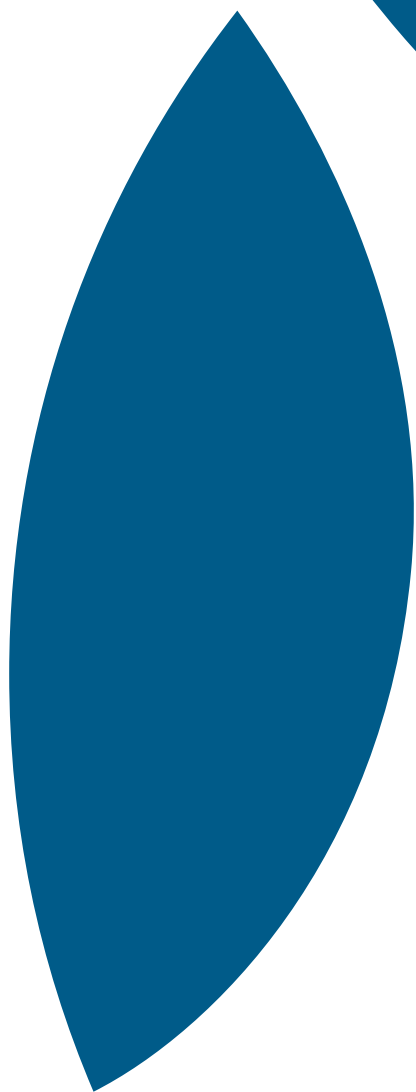
145. Fruehwald S , Loeffler-Stastka H, Eher R, et al. Depression and quality of life in multiple sclerosis. *Acta neurol Scand* 2001; 104(5):257-61. Level of Evidence: 3
146. Metz LM, Patten SB, Archibald CJ, et al. The effect of immunomodulatory treatment on multiple sclerosis fatigue. *J Neurol neurosurg psychiatry* 2004; 75(7):1045-7. Level of Evidence: 3
147. Mohr D, Cox D. Multiple sclerosis: empirical literature for the clinical health psychologist. *J Clin psychol* 2001; 57(4):479-99. Level of Evidence: 4
148. Ward N, Winters S. Results of a fatigue management programme in multiple sclerosis. *Br J Nurs* 2003; 12(18):1075-80. Level of Evidence: 2b
149. Kasser SL, Stuart ME. Psychological well-being and exercise behavior in persons with and without multiple sclerosis. *Clin Kinesiol* 2001; 55(4 ):81-6. Level of Evidence: 3
150. Beatus J, O'Neill JK, Towesend T, et al. The effect of a one-week retreat on self-esteem, quality of life, and functional ability for persons with multiple sclerosis. *Neurol rep* 2002; 26(3):154-9. Level of Evidence: 2b
151. Consortium of Multiple Sclerosis Centers. Multiple sclerosis quality of life inventory: technical supplement. New York: National Multiple Sclerosis Society, 1997. Level of Evidence: 3
152. Multiple Sclerosis International Federation. MS - the disease [Web Page]. Available at [www.msif.org](http://www.msif.org). (Accessed 7 June 2004). Level of Evidence: 4
153. Devitt R, Chau B, Jutai JW. The effects of wheelchair use on the quality of life of persons with multiple sclerosis. *Occup ther health care* 2003; 17(3/4):63-79. Level of Evidence: 3
154. Blake DJ, Bodine C. An overview of assistive technology for persons with multiple sclerosis. *J Rehabil res dev* 2002; 39(2):299-312. Level of Evidence: 4

155. Flynn S. Multiple sclerosis: the treetops model of residential care. *Br J Nurs* 2002; 11(9):635-42. Level of Evidence: 3
156. Buchanan RJ , Wang S, Ju H. Analyses of the minimum data set: comparisons of nursing home residents with multiple sclerosis to other nursing home residents. *Mult scler* 2002; 8(6):512-22. Level of Evidence: 3
157. Buchanan R, Lewis K. Services that nursing facilities should provide to residents with MS: a survey of health professionals. *Rehabil nurs* 1997; 22(2):67-72. Level of Evidence: 4
158. Sutherland G, Andersen MB, Stooze MA. Can aerobic exercise training affect health-related quality of life for people with multiple sclerosis? *J Sport exercise psychol* 2001; 23(2):122-35. Level of Evidence: 1b
159. Stuifbergen AK, Roberts GJ. Health promotion practices of women with multiple sclerosis. *Arch phys med rehabil* 1997; 78(12 Suppl 5):S3-9. Level of Evidence: 2b
160. Stuifbergen AK, Seraphine A, Roberts G. An explanatory model of health promotion and quality of life in chronic disabling conditions. *Nurs res* 2000; 49(3):122-9. Level of Evidence: 3
161. Oken BS, Kishiyama S, Zajdel D, et al. Randomized controlled trial of yoga and exercise in multiple sclerosis. *Neurology* 2004; 62(11):2058-64. Level of Evidence: 1b
162. Mostert S, Kesselring J. Effects of a short-term exercise training programme on aerobic fitness, fatigue, health perception and activity level of subjects with multiple sclerosis. *Mult scler* 2002; 8(2):161-8. Level of Evidence: 1b
163. Husted C, Pham L, Hekking A, et al. Improving quality of life for people with chronic conditions: the example of t'ai chi and multiple sclerosis. *Altern ther health med* 1999; 5(5):70-4. Level of Evidence: 3

164. Becker H, Stuifbergen A. What makes it so hard? Barriers to health promotion experienced by people with multiple sclerosis and polio. *Fam community health* 2004; 27(1):75-85. Level of Evidence: 3
165. Rogers S. Things I wish someone had told me: practical thoughts for people newly diagnosed with multiple sclerosis. Lidcombe: MS Society of Australia. Level of Evidence: 4
166. Stuifbergen AK. Physical activity and perceived health status in persons with multiple sclerosis. *J Neurosci nurs* 1997; 29(4):238-43. Level of Evidence: 3
167. Petajan JH, Gappmaier E, White AT, Spencer MK, Mino L, Hicks RW. Impact of aerobic training on fitness and quality of life in multiple sclerosis. *Ann neurol* 1996; 39(4):432-41. Level of Evidence: 1b
168. Cheng E, Myers L, Wolf S, et al. Mobility impairments and use of preventive services in women with multiple sclerosis: observational study. *BMJ* 2001; 323(7319):968-9. Level of Evidence: 3
169. Schwartz L, Kraft GH. The role of spouse responses to disability and family environment in multiple sclerosis. *Am J Phys med rehabil* 1999; 78(6):525-32. Level of Evidence: 3
170. Rivera-Navarro J, Morales-Gonzalez JM, Benito-Leon J. Informal caregiving in multiple sclerosis patients: data from the Madrid Demyelinating Disease Group study. *Disabil rehabil* 2003; 25(18):1057-64. Level of Evidence: 3
171. Sato A, Ricks K, Watkins S. Needs of caregivers of clients with multiple sclerosis. *J Community health nurs* 1996; 13(1):31-42. Level of Evidence: 3
172. McKeown LP, Porter-Armstrong AP, Baxter GD. Caregivers of people with multiple sclerosis: experiences of support. *Mult scler* 2004; 10(2):219-30. Level of Evidence: 3

173. McKeown LP, Porter-Armstrong AP, Baxter GD. The needs and experiences of caregivers of individuals with multiple sclerosis: a systematic review. *Clin rehabil* 2003; 17(3):234-48. Level of Evidence: 4
174. Harrison T, Stuifbergen A. Disability, social support, and concern for children: depression in mothers with multiple sclerosis. *J Obstet gynecol neonatal nurs* 2002; 31(4):444-53. Level of Evidence: 3
175. Hainsworth MA. Helping spouses with chronic sorrow related to multiple sclerosis. *J Psychosoc nurs ment health serv* 1996; 34(6):36-40. Level of Evidence: 3
176. Gregory RJ, Disler P, Firth S. Caregivers of people with multiple sclerosis: a survey in New Zealand. *Rehabil nurs* 1996; 21(1):31-7. Level of Evidence: 3
177. Dewis ME, Niskala H. Nurturing a valuable resource: family caregivers in multiple sclerosis. *Axone* 1992; 13(3):87-94. Level of Evidence: 3
178. Chipchase SY, Lincoln NB. Factors associated with carer strain in carers of people with multiple sclerosis. *Disabil rehabil* 2001; 23(17):768-76. Level of Evidence: 3
179. Cheung J, Hocking P. The experience of spousal carers of people with multiple sclerosis. *Qual health res* 2004; 14(2):153-66. Level of Evidence: 3
180. Boeije H, Duijnste M, Grypdonck M. Continuation of caregiving among partners who give total care to spouses with multiple sclerosis. *Health soc care community* 2003; 11(3):242-52. Level of Evidence: 3
181. Aronson KJ. Quality of life among persons with multiple sclerosis and their caregivers. *Neurology* 1997; 48(1):74-80. Level of Evidence: 3
182. Aronson KJ, Cleghorn G, Goldenberg E. Assistance arrangements and use of services among persons with multiple sclerosis and their caregivers. *Disabil rehabil* 1996; 18(7):354-61. Level of Evidence: 3

183. Cockerill R , Warren S. Care for caregivers: the needs of family members of MS patients. *J Rehabil* 1990; 56(1):41-4. Level of Evidence: 3
184. Miller D. Caring for the carers. *MS in Focus* 2004; 3:12-6. Level of Evidence: 4
185. Carton H, Loos R, Pacolet J, et al. A quantitative study of unpaid caregiving in multiple sclerosis. *Mult scler* 2000; 6(4):274-9. Level of Evidence: 3
186. Beatty WW, Blanco CR, Wilbanks SL, et al. Demographic, clinical, and cognitive characteristics of multiple sclerosis patients who continue to work. *J Neurol rehabil* 1995; 9(3):167-73. Level of Evidence: 3
187. Busche KD, Fisk JD, Murray TJ, et al. Short term predictors of unemployment in multiple sclerosis patients. *Can J Neurol sci* 2003; 30(2):137-42. Level of Evidence: 3
188. Fraser RT, Johnson EK, Clemmons DC, et al. Vocational rehabilitation in multiple sclerosis (MS): a profile of clients seeking services. *Work* 2003; 21(1):69-76. Level of Evidence: 3
189. Jongbloed L . Factors influencing employment status of women with multiple sclerosis. *Can J Rehabil* 1996; 9(4):213-22. Level of Evidence: 3
190. McCabe MP, De Judicibus M. Multiple sclerosis and economic well-being: role of health, age, and duration of illness. *J Clin psychol med settings* 2003; 10(3):139-47. Level of Evidence: 3
191. Thapar N., Bhardwaj S.M. Overcoming the tyranny of space: experiences of multiple sclerosis patients. *Social work abstracts* 2000; 36(2):822. Level of Evidence: 3



## 附录1：WHO QOL域矩阵

	生理健康	心理健康	独立程度	社会关系	环境
1.1			✓	✓	✓
1.2			✓		✓
1.3			✓		✓
1.4			✓		✓
1.5	✓	✓	✓	✓	✓
1.6					✓
2.1.1	✓	✓			✓
2.1.2	✓	✓			✓
2.2.1		✓			✓
2.2.2	✓	✓	✓		✓
2.3.1	✓	✓			✓
2.3.2	✓	✓			✓
2.3.3			✓		✓
2.3.4	✓	✓			✓
2.3.5	✓	✓			✓
2.3.6	✓	✓	✓	✓	
2.4.1	✓	✓			✓
3.1			✓		✓
3.2			✓		✓
3.3					✓
4.1	✓	✓			✓
4.2	✓	✓			
4.3	✓	✓			✓
5.1		✓			✓
5.2		✓			✓
5.3	✓	✓			✓
5.4		✓			✓
5.5		✓			✓
5.6	✓	✓			✓
6.1			✓		✓
6.2			✓		✓
7.1			✓	✓	✓
7.2			✓	✓	✓
7.3			✓		✓
7.4			✓	✓	✓
7.5			✓	✓	✓
8.1			✓		✓
8.2			✓		✓
8.3			✓		✓
9.1			✓		✓
9.2			✓		✓
9.3			✓		✓
10.1.1			✓		✓
10.1.2			✓		✓
10.1.3			✓		✓
10.2.1			✓		✓
10.2.2			✓		✓

## 附录2：按证据等级分类的支持文献编号

原则	证据等级					
	1a	1b	2a	2b	3	4
1.1					22	9
1.2				1	8	10
1.3					3	4
1.4					6	1
1.5		3		2	24	15
1.6					9	7
2.1.1					5	2
2.1.2	1	9	2	9	17	43
2.2.1				4	6	9
2.2.2					4	8
2.3.1					4	15
2.3.2		7	2	5	11	41
2.3.3				1	1	1
2.3.4					3	5
2.3.5					7	6
2.3.6		3	2	4	11	10
2.4.1		6	1	8	18	43
3.1		1			6	6
3.2					3	4
3.3						
4.1		6		3	11	16
4.2		5		1	8	21
4.3					4	5
5.1				1	24	10
5.2				1	7	4
5.3				1	18	8
5.4				1	23	12
5.5				1	5	6
5.6				1	2	2
6.1					4	4
6.2					2	2
7.1					17	14
7.2					16	12
7.3					6	2
7.4					9	9
7.5					6	2
8.1					2	2
8.2					5	2
8.3					3	2
9.1					2	
9.2						
9.3						
10.1.1					5	3
10.1.2					3	
10.1.3					4	
10.2.1					3	
10.2.2					3	

### 证据等级

1a 随机对照试验的元分析

1b 随机对照试验

2a 对照研究（非随机）

2b 准实验研究

3 非实验、描述性研究（例如，比较研究、相关性研究和案例研究）

4 专家委员会的报告、意见和/或权威经验

\* 证据等级：基于鸣谢名单所列的受访者和监督组成员提供的专家意见。