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MSIF要感谢Biogen Idec的慷慨捐助，
他们的帮助对本文的发表必不可少。

提升MS患者生活质量的原则

multiple sclerosis
international federation

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

ISBN 0-9550139-0-9

作者：
Michael Trisolini，哲学博士，工商管理硕士
Joshua Wiener，哲学博士
RTI International
Waltham, Massachusetts & Washington, D.C., U.S.A.
Deborah Miller，哲学博士，
克里夫兰临床基金会（Cleveland Clinic Foundation，Cleveland, Ohio, U.S.A）

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摘自Amelia Davis的新著《我的故事：一个多发性硬化症患者的生活摄影随笔》（My Story: A Photographic Essay on Life with Multiple Sclerosis，Amelia Davis © 2002版权所有）的封面照片（www.ameliadavisphotography.com或demosmedpub.com提供该书的在线订购）

鸣谢

特别鸣谢：

受访人

Michael Barnes：英国纽卡斯尔（泰恩河畔）大学（University of Newcastle upon Tyne）神经康复教授

Kathryn Brennan：美国全国计划咨询委员会和美国全国多发性硬化症协会（National MS Society, USA）会员

Sandy Burnfield：英国多发性硬化症信托（UK MS Trust）委员会会员

Sanjay Chadha：英国多发性硬化症信托（UK MS Trust）委员会会员

Peggy Crawford：美国多发性硬化症梅隆诊疗中心（Mellen Center for Multiple Sclerosis, USA）临床心理医生

Jeremy Hobart：英国神经病学研究所（Institute of Neurology）神经病学检查部（Neurological Outcome Measures Unit）

Vanessa Hodges：美国全国计划咨询委员会（National Programmes Advisory Council）和美国全国多发性硬化症协会（National MS Society, USA）会员

Ludwig Kappos：巴塞尔大学附属医院（University Hospital, Basel）和瑞士多发性硬化症协会（Swiss MS Society）医务主任

Peter Kaskel：德国乌尔姆大学（University of Ulm）

Susan Kushner：美国斯利珀里罗克大学（Slippery Rock University）物理治疗系副教授

Dawn Langdon：英国伦敦大学（University of London）临床神经心理医生和高级讲师

Ian McDonald：	西尔维亚•劳里多发性硬化症研究中心（Sylvia Lawry Centre for MS Research），多发性硬化症国际联合会（Multiple Sclerosis International Federation）名誉董事会会员，英国神经病学研究所（Institute of Neurology）临床神经病学名誉教授
Nancy C. Smith：	美国梅隆多发性硬化症治疗和研究中心（Mellen Centre for Multiple Sclerosis Treatment and Research）高级执业护士
Lael Stone：	美国梅隆多发性硬化症治疗和研究中心（Mellen Centre for Multiple Sclerosis Treatment and Research）医疗主任
Alan Thompson：	英国神经病学研究所（Institute of Neurology）神经康复部医务主任、临床主任兼研发主管
Athanasios Vidalis：	希腊Hippocratio 医院精神科
Nikki Ward：	英国英格兰中部大学（University of Central England）健康和社区护理系多发性硬化症执业讲师

监督组

Mike O'Donovan（监督组主席）:	英国多发性硬化症协会（UK MS Society）总裁
Eva Havrdová：	捷克多发性硬化症协会医疗咨询委员会（Czech MS Society Medical Advisory Board）主席
Hans-Peter Hartung：	德国海因里希-海涅大学（Heinrich-Heine-University）神经学系

Tom Houle：美国全国多发性硬化症协会全国咨询委员会委员（National Advisory Board of Persons with MS. National MS Society, USA）

Nicholas G. LaRocca：美国全国多发性硬化症协会（National MS Society, USA）健康护理服务和政策研究主管

Nancy Law：美国全国多发性硬化症协会（National MS Society, USA）客户计划部副主任

Elizabeth McDonald：澳大利亚多发性硬化症协会（MS Society of Australia）医务主任

Xavier Montalbán：西班牙Universitari Vall d'Hebron医院临床神经免疫科主任

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

Mateja de Reya：斯洛文尼亚多发性硬化症协会（Slovenian MS Society）总裁

Peter Rieckmann：德国维尔茨堡大学（University of Würzburg）多发性硬化症和神经免疫系临床研究主任

Paul Rompani：多发性硬化症国际联合会（Multiple Sclerosis International Federation）副总裁

Alan Thompson：英国神经病学研究所（Institute of Neurology）神经康复部医务主任，临床主任兼研发主管

Susan Tilley：多发性硬化症国际联合会（Multiple Sclerosis International Federation）多发性硬化症国际委员会主席

工作组

Mike Dugan：	美国全国多发性硬化症协会（National MS Society, USA）总裁
Nicholas G. LaRocca：	美国全国多发性硬化症协会（National MS Society, USA）健康护理服务和政策研究主管
Nancy Law：	美国全国多发性硬化症协会（National MS Society, USA）客户计划部副主任
Christine Purdy：	多发性硬化症国际联合会（Multiple Sclerosis International Federation）总裁
Paul Rompani：	多发性硬化症国际联合会（Multiple Sclerosis International Federation）副总裁
Susan Tilley：	多发性硬化症国际联合会（Multiple Sclerosis International Federation）多发性硬化症国际委员会主席

其他

Megan Burgess：	英国希望医院（Hope Hospital）多发性硬化症主任护士
Caron Caldwell：	英国多发性硬化症协会（UK MS Society）多发性硬化症护士基金计划代理经理
Pedro Carrascal：	西班牙多发性硬化症联合会（Spanish MS Federation）总裁
Francisco Delgado：	西班牙多发性硬化症协会（Spanish MS Society）总裁
Peter Flachenecker：	德国Quellenhof神经康复中心主席
Marieluise Gilch：	德国多发性硬化症协会（German MS Society）巴伐利亚分会总裁
Cristina Gómez Ortiz：	西班牙多发性硬化症协会（Spanish MS Society）奥尔蒂斯委员会委员
Maria Jose Flores：	西班牙多发性硬化症协会（Spanish MS Society）

Natasa Koudoun：希腊多发性硬化症协会（Greek MS Society）有氧训练教练

Graham Love：爱尔兰多发性硬化症协会（MS Society of Ireland）总裁

Kostas Michalakis：希腊多发性硬化症协会（Greek MS Society）总裁

Allen O’Connor：爱尔兰多发性硬化症协会（MS Society of Ireland）主席

Izabella Odrobinska：波兰多发性硬化症协会（Polish MS Society）主席

Anastasios Orologas：希腊多发性硬化症协会（Greek MS Society）主席

Mahi Orologas：希腊多发性硬化症协会（Greek MS Society）

Maria Pilar Resta：西班牙多发性硬化症协会（Spanish MS Society）

Dorothea Pitschnau-Michel：德国多发性硬化症协会（German MS Society）总裁

Alun White：英国多发性硬化症协会（UK MS Society）委员会委员

Christiane Zahn：德国多发性硬化症协会（German MS Society）巴伐利亚分会

除了受访人、监督组成员、工作组成员和上述其他人士，MSIF还要感谢下列人士或机构，感谢他们在制定QOL原则的过程中提供的支持：MSIF国际医疗和科学委员会、MS国际委员会委员和成员协会的员工和自愿者、多发性硬化症中心联会（Consortium of MS Centers）、多发性硬化症护士国际组织（International Organization of MS Nurses）、多发性硬化症患者、以及提供宝贵意见和建议的健康业人士。MSIF要特别感谢Biogen Idec，感谢他们为提升多发性硬化症患者或受影响人士的生活质量而与MSIF向着共同的愿景和承诺努力。

内容

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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，这些原则的战略性应用是必备要件之一。

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。

“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。

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。

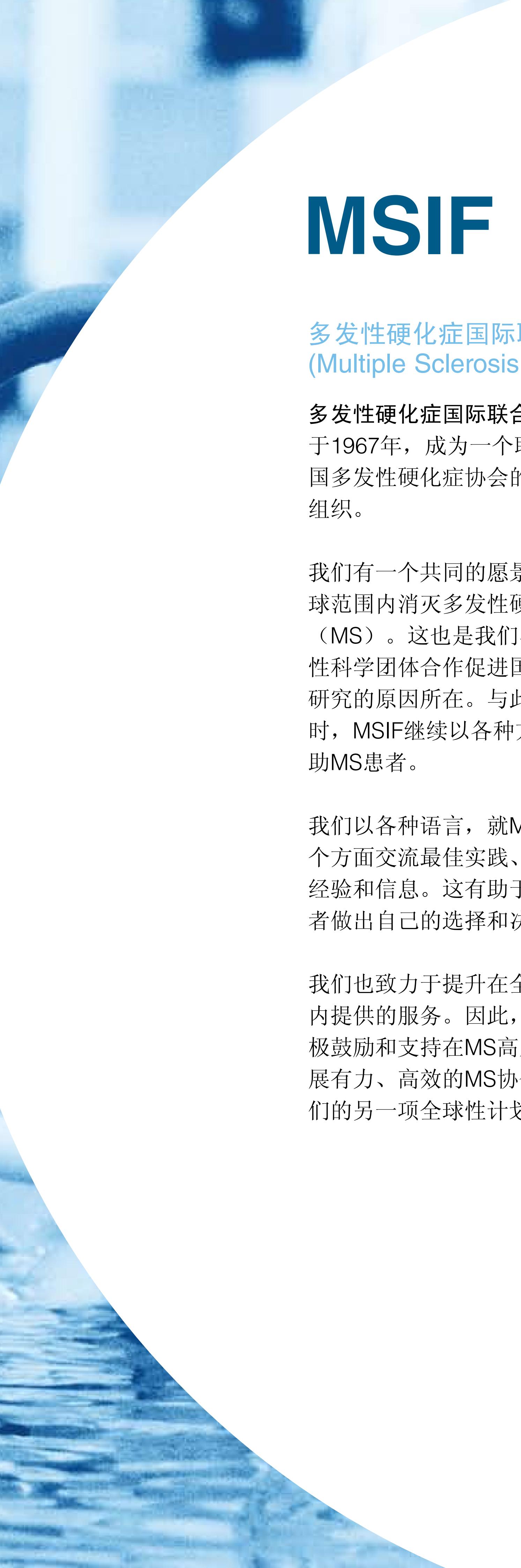
在全球15家协作中心的帮助下，WHO开发了一个名为WHOQOL-100的生活质量框架。在该框架中，WHO将生活质量定义为个人对所处的文化和价值观体系下的生活定位、以及与其目标、期望、标准和关注的关系的看法。这是一个广义定义，受个人的生理健康、心理状态、独立程度、社会关系、以及所处环境的显著特点影响。

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。

> “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。”

贝纳托德·萨拉西诺
(Benedetto Saraceno)，
医学博士
精神健康和药物滥用部
(Department of Mental
Health and Substance
Abuse)主管
世界卫生组织(World Health
Organization)



照片：艾迪•萨法里（Eddie Safarik），MS Australia SWEAT AQUA Program

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。

Sarah Phillips

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患者必须有能力实现其全部潜能，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。[1-31]

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患者都必须享受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护理人士。[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，残障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和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。[15,19]

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

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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

	证据等级					
原则	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。