

Hemophilia Nursing Manual

Hemophilia Nursing Manual

Hemophilia Nursing Manual

Hemophilia Nursing Manual

# 血友病

护理关怀手册

Hemophilia Nursing Manual

主 编 / 孙 竞

副主编 / 林劲秋 马伯霞 赵 洁



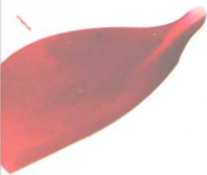
科学普及出版社

He  
Hemophilia  
Hemophili  
Hemophilia N

# Manual

## Manual

ing Manual



ISBN 978-7-110-06977-6



9 787110 069776 >

定价：26.00 元





# 血友病

## 护理关怀手册

Hemophilia Nursing Manual

主 编 / 孙 竞

副主编 / 林劲秋 马伯霞 赵 洁

科学普及出版社

· 北 京 ·



## 图书在版编目(CIP)数据

血友病护理关怀手册/孙竞主编. —北京:科学普及出版社, 2008. 10

ISBN 978-7-110-06977-6

I. 血… II. 孙… III. 血友病-护理-手册 IV. R473.5-62

中国版本图书馆 CIP 数据核字(2008)第 162114 号

自 2006 年 4 月起本社图书封面均贴有防伪标志,未贴防伪标志的为盗版图书。

科学普及出版社出版

北京市海淀区中关村南大街 16 号 邮政编码:100081

电话:010-62103210 传真:010-62183872

<http://www.kjpbooks.com.cn>

科学普及出版社发行部发行

北京长宁印刷有限公司印刷

\*

开本:850 毫米×1168 毫米 1/32 印张:6.375 字数:180 千字

2008 年 10 月第 1 版 2008 年 10 月第 1 次印刷

印数:1—5000 册 定价:26.00 元

ISBN 978-7-110-06977-6/R·726

主 编:孙 竞

副主编:林劲秋 马伯霞 赵 洁

编 委:(按姓氏笔画排序)

马伯霞 中国医学科学院血液病研究所血液病医院

王晓英 中国医学科学院北京协和医院

冯 涛 首都医科大学附属北京儿童医院

孙 竞 南方医科大学附属南方医院

孙 萍 安徽省立医院

朱唯一 上海交通大学医学院附属瑞金医院

祁绍秀 中国医学科学院血液病研究所血液病医院

李魁星 中国医学科学院北京协和医院

林劲秋 南方医科大学护理学院

陈丽霞 中国医学科学院北京协和医院

赵 洁 南方医科大学附属南方医院

鲁先秀 安徽省立医院

滕 彬 山东省血液中心

责任编辑:吕秀齐

封面设计:丁 奎

责任校对:孟华英

责任印制:安利平

## 序 言

随着医学的进步,从技术至上走向人文关怀将成为现代医学模式在实践中转化的必要条件,医学的人文关怀不仅是对人的关怀,也包括对医学技术,对心理健康、生命的终极关怀。

血友病护理关怀概念起源于20世纪40年代末期的英国,首个由综合团队组建的血友病治疗中心(Hemophilia Treatment Centre, HTC)网络于1976年在美国成立。大量实践和研究表明,血友病综合关怀是治疗血友病和其他出血性疾病最理想的模式,这种治疗模式已经逐渐被全球多个国家采用。

专业医护人员对血友病患者及家庭进行全面的治疗、护理及生活指导,其内容不仅包括专业治疗的协调,还包括家庭治疗、患者与家庭的知识教育、心理咨询、社会扶助及长期的追踪管理等。

目前我国还没有形成全国血友病综合关怀网络系统,而且缺少适合中国国情的血友病治疗、护理与康复指南,以及健康教育材料。孙竞教授对本书的编写倾注了大量的心血。本书围绕血友病的发病机制、诊断与治疗、护理常规、综合关怀等方面,以详细生动的语言向读者介绍了血友病护理关怀的知识。适合广大的医护人员、患者及家属阅读,是血友病护理关怀的必备之选。

在此要特别感谢血友病专家 Dr. Koon Hung Luke 的支持,他提供了许多国外先进的血友病护理理念,同时我也要感谢拜耳先灵医药公司拜科奇产品组对本书出版的大力支持。血友病人不仅需要医护人员,还需要更多来自政府和社会各界的关怀。我相信在大家的关心和努力之下,血友病护理关怀事业一定会蒸蒸日上。

A handwritten signature in black ink, appearing to read '陈光' (Chen Guang), written in a cursive style.

中国工程院院士  
江苏省血液研究所所长  
中华医学会血液学分会主任委员



## PREFACE

Hemophilia care has had many recent advances and has grown to be very complex requiring multidisciplinary specialists, costly investigations and treatments supported by comprehensive clinical programs. A successful development has been the expansion of the important Nursing role in comprehensive Hemophilia care. The Hemophilia Nurse is now practicing front line acute care, coordinating complex investigations, and supervise homecare, self infusion, use of blood products and long-term patient management. In this expanded role, the Hemophilia Nurse is a caring teacher and counsellor for patients and families, an active research investigator and strong patient advocate. Today the Hemophilia Nurse is essential in improving the quality of care and quality of life of patients with Hemophilia. The journey in developing Hemophilia Nursing in China is challenging and demonstrates the ongoing hard work, dedication and ingenuity of the Chinese nurses and doctors.

Until 2002, the role of Hemophilia Nursing was very limited in China creating a great impediment in Hemophilia Care development. To spearhead the development, the Hemophilia team at the Nanfang Hospital, Guangzhou with support by the World Federation of Hemophilia (WFH) hosted two national Hemophilia Nursing Conferences held consecutively in 2003 and 2004. These conferences were successful to promote awareness, provide teaching and share experiences among the nur-

ses.

In 2004 when the Hemophilia Treatment Centre Collaborative Network China (HTCCNC) was established Hemophilia Nursing Working Group was formed. This working group recognized the need for a Hemophilia Nursing Practice Manual for China.

In 2005, the nursing team at Nanfang Hospital under Ms. J. Zhao and Dr. J. Sun was awarded a Bayer Program Award Grant and a Canadian Hemophilia Society International Grant to develop this manual appropriate for use in China. Ms. Lin was appointed as the Research Nurse to coordinate research and planning of the project. To ensure the content would be appropriate for practice in China, Hemophilia Nurses from different clinics were invited as contributors. Several of these nurses had WFH training fellowships in Canada, Australia and Singapore. Three regional Hemophilia Nursing conferences were held at Heifei, Beijing and Jinan to share regional practices and experiences many of which have been incorporated into this manual. This manual was completed in 2006 and ratified at the 3rd National Hemophilia Nursing Conference, Guangzhou January 2007. In 2008, Bayer China was very generous to fund the publication.

This is the first Hemophilia Nursing Practice Manual to be published for use in China. With nation-wide distribution, this manual will elevate the awareness and practice of Hemophilia Nursing care across China. The text and the practice guidelines are easy to follow by nurses as they are written by Hemophilia Nurses from different regions of China using their practices and experiences. Many other health care professionals in

Hemophilia Care can also use the manual as a reference text for self-learning and teaching.

I would like to congratulate Dr. Jing Sun, Ms. Zhao, Ms. Ma and Ms. Lin for their leadership and vision in planning and completing this project. We appreciate the enormous contributions of the entire Nursing Team and Hematology Department at Nanfang Hospital, Guangzhou, nurses and patient leaders from different regions across China and the consultants Dr. Koon Hung Luke, Dr. Man-Chiu Poon and the Canadian Hemophilia nurse specialists. We would like to acknowledge the support of the World Federation of Hemophilia, the Canadian Hemophilia Society, Bayer International and Bayer China.

Dr. Koon Hung Luke, FRCPC  
Professor Emeritus and Consultant  
Departments of Pediatrics, Pathology  
and Laboratory Medicine  
Children's Hospital of Eastern Ontario  
University of Ottawa, Ottawa, Canada  
Oct. 2008

## 编者的话

对于血友病,需要一种终生持续诊治的模式。在经济与医疗发达国家,血友病诊治已从单纯模式发展到整体模式,即为多学科医疗专业人员、家庭与社会共同实施的综合关怀模式,其中担当主要角色的护士正是实施这一经济有效模式的关键。血友病护士不仅在血友病多学科医疗中起着主要协助者的作用,更在宣教咨询、家庭治疗、追踪管理等综合关怀方面担当主导作用。因此,普及和提升护士的血友病知识与技能是做好血友病综合关怀的最重要一环,也是编写本手册的初衷。

鉴于国内血友病的诊治与护理尚处于起步发展阶段,许多血液科或儿科一线护士甚至没有血友病的护理经历和学习机会。为此,我们联合国内 6 个血友病治疗中心的护理骨干,结合中国国情编写了第一本深入介绍血友病护理的综合工具书,适于临床一线工作的护士和医师参考使用,亦可为向广大血友病患者及家庭成员进行宣教咨询提供参考。由于我们的经验和知识水平所限,书中不足和疏漏难免,敬请读者不吝赐教。随着我国血友病诊治水平与国际逐渐接轨,我们也希望能够在本书今后再版时加以修正完善。

在本手册的编写过程中,我们一直得到加拿大血友病医学专家 KH Luke 和 MC Poon 的指导帮助;中国医学科学院血液病研究所血液病医院杨仁池教授、中国医

学科学院北京协和医院赵永强教授、安徽省立医院吴竞生主任协助审改书稿;尤其特别感谢一直悉心指导我国血友病工作发展的中华医学会血液学分会主任委员阮长耿院士,他不仅关注本手册的编写,还亲自为其作序。本手册的出版还得到了世界血友病联盟、加拿大血友病协会和拜耳医药公司的大力支持,在此一并致以衷心的感谢。

编 者

2008年10月20日

# 目 录

## 第一篇 血友病概述

### Introduction to Hemophilia

一、患病率 Prevalence .....	1
二、遗传规律 Inheritance .....	1
三、临床表现 Clinical Manifestations .....	2
四、诊断 Diagnosis .....	4
五、治疗 Treatments .....	4
(一)替代治疗 Replacement Therapy .....	4
(二)辅助止血 Assistance Hemostasia .....	5
(三)物理治疗 Physiotherapy .....	5
(四)外科治疗 Surgical Therapy .....	6
(五)综合关怀 Comprehensive Care .....	6
(六)基因治疗 Gene Therapy .....	7

## 第二篇 血友病护理常规

### Nursing Routine of Hemophilia

第一章 症状护理 Symptom Nursing .....	8
第一节 关节出血 Joint Bleeding .....	8
一、基础知识 Basic Knowledge .....	8
(一)病理 Pathology .....	8
(二)临床表现 Clinical Manifestations .....	8
(三)常规处置 Routine Management .....	9

二、护理 Nursing .....	9
(一) 护理观察与评估 Survey and Assesment .....	9
(二) 护理措施 Nusing Intervention .....	11
(三) 健康教育 Health Education .....	12
第二节 肌肉及软组织出血 Muscle/Soft Tissue Hemorrhage .....	16
一、基础知识 Basic Knowledge .....	16
(一) 病理 Pathology .....	16
(二) 临床表现 Clinical Manifestations .....	17
(三) 常规处置 Routine Management .....	17
二、护理 Nursing .....	17
(一) 护理观察与评估 Survey and Assesment .....	17
(二) 护理措施 Nusing Intervention .....	18
(三) 健康教育 Health Education .....	19
第三节 口腔出血 Mouth Bleeding .....	22
一、基础知识 Basic Knowledge .....	22
(一) 原因及临床表现 Cause and Clinical Manifestations .....	22
(二) 常规处置 Routine Management .....	23
二、护理 Nursing .....	24
(一) 护理观察与评估 Survey and Assesment .....	24
(二) 护理措施与健康教育 Nusing Intervention and Health Education .....	25
第四节 鼻衄 Epistaxis .....	27
一、基础知识 Basic Knowledge .....	27

(一)原因及临床表现 Cause and Clinical Manifestations .....	27
(二)常规处置 Routine Management .....	27
二、护理 Nursing .....	29
(一)护理观察与评估 Survey and Assesment .....	29
(二)护理措施 Nursing Intervention .....	29
(三)健康教育 Health Education .....	29
第五节 血尿 Hematuria .....	31
一、基础知识 Basic Knowledge .....	31
(一)病因 Pathogenesis .....	31
(二)临床表现 Clinical Manifestations .....	31
(三)常规处置 Routine Management .....	32
二、护理 Nursing .....	32
(一)护理观察与评估 Survey and Assesment .....	32
(二)护理措施 Nursing Intervention .....	33
(三)健康教育 Health Education .....	34
第六节 消化道出血 Gastrointestinal Bleeds .....	36
一、基础知识 Basic Knowledge .....	36
(一)病因 Pathogenesis .....	36
(二)临床表现 Clinical Manifestations .....	36
(三)常规处置 Routine Management .....	37
二、护理 Nursing .....	38
(一)护理观察与评估 Survey and Assesment .....	38
(二)护理措施 Nursing Intervention .....	38
(三)健康教育 Health Education .....	40
第七节 擦割伤 Cuts or Scrapes .....	42



一、护理观察与评估 Nursing Survey and	
Assesment .....	42
二、护理措施 Nursing Intervention .....	42
三、健康教育 Health Education .....	42
第八节 血友病急症 Life-threatening Emergency	
Bleeding .....	43
中枢神经系统出血 Central Nervous System Bleeds .....	43
一、基础知识 Basic Knowledge .....	43
(一)临床表现 Clinical Manifestations .....	43
(二)常规处置 Routine Management .....	44
二、护理 Nursing .....	44
(一)护理观察与评估 Survey and	
Assesment .....	44
(二)护理措施 Nursing Intervention .....	45
(三)健康教育 Health Education .....	46
咽部/颈部出血 Pharyngeal Bleeds .....	46
一、基础知识 Basic Knowledge .....	47
(一)病因 Pathogenesis .....	47
(二)临床表现 Clinical Manifestations .....	47
(三)常规处置 Routine Management .....	47
二、护理 Nursing .....	48
(一)护理观察与评估 Survey and	
Assesment .....	48
(二)护理措施 Nursing Intervention .....	49
(三)健康教育 Health Education .....	49
眼内出血 Intraocular Bleeding .....	50
一、基础知识 Basic Knowledge .....	50
(一)病因及分类 Pathogenesis and Classification .....	50
(二)临床表现 Clinical Manifestations .....	51