



MAKING THE INVISIBLE VISIBLE: CHRONIC PAIN MANUAL FOR HEALTH CARE PROVIDERS

Gwenn Herman, LCSW-C, DCSW
Mary French, RN, MSW, LCSW-C



Pain Connection[®] is a registered mark of Pain Connection—Chronic Pain Outreach Center, Inc.

www.painconnection.org

100% of the profits from the sale of this manual are donated to Pain Connection.

Making the Invisible Visible: Chronic Pain Manual for Health Care Professionals

ISBN 978-0-9824359-0-8

Library of Congress Control Number: 2009925660

Printed in the United States of America.

First Printing: April 2009

©2009 Pain Connection—Chronic Pain Outreach Center, Inc.

No part of this book may be used or reproduced in any manner whatsoever without written permission except in the following cases: 1) reprints in the context of reviews; 2) clinicians may copy and use handouts, but copyright statements must be retained. For information, write Pain Connection, 12251 Saint James Road, Potomac, Maryland 20854.

Individual contributors retain all rights to their material.

ALLOW THE INVISIBLE TO BE SEEN!

BY MARTHA LEONARD

Many parts of the body
make up the whole
what treats the physical
may not heal the soul

The exterior appears normal
with only a glance
look deeper, feel stronger
please take the chance

We need community
not more exclusion
the first observation
may be only illusion

The eyes tell a story
many won't want to see
they speak of affliction
the loss of what used to be

It's in taking a moment
offering presence and care
that Life has real value
though burdens we bear

Knowledge brings insight
understanding a key
we mutually grow
into all we can be

Let's offer respect
trusting facts to be true
the silent suffering extends
now far beyond a few

So, please listen and learn
let's work as a team
we bring hope and a purpose—

Allow the invisible to be seen!

*Martha is a Montgomery County
Chronic Pain Support Group member.*



ACKNOWLEDGMENTS

We greatly value and appreciate the contributions provided by all members of Pain Connection, some of whom have shared their stories and writings; these are interspersed throughout the manual. We acknowledge all those who suffer in silence due to chronic pain and hope that the existence of this manual will somehow provide hope and validate their experiences.

We would like to thank those volunteers who gave of their expertise and time by contributing articles and illustrations or by reviewing and editing the content: Dr. Michael April, Kathleen Barron, Lee Ann Blank, Deborah Bowes, Amy Brush, Dennis James Capolongo, Shelly Carlyon, Molly Carr, Robert Cohen, Tracy Councill, Norm Goldstein, Barbara Hammack, Debbie Hammack, Mayan Herman, Colleen Kerich, Sarah Knowlton, Linda Kursek, Dale Lehn, Martha Leonard, Nancy Magnusson, Geoffrey Manifold, Mary Lou Manifold, John Mannes, Kent Mason, Jessie Masterson, Jean McCaw, Jennifer Padden, Katharina Pesquera, Denise Pirnea, Lisa Marie Price, Catherine Rubin, Paula Scheye, Susan Singh, Michael Sitar, Laura Stibel, and Ellen Weiss.

This manual would not have been possible without the Healthcare Initiative Foundation, which funded this project. The Healthcare Initiative Foundation is a nonprofit, grant-making trust governed by an independent, volunteer board of trustees. Their mission is to support organizations that offer solutions for improving the quality and delivery of health care for residents of Montgomery County, Maryland. “We believe that creativity generates solutions. We support both traditional and innovative solutions to health care dilemmas in any form – concepts to test, best practices to implement, efficiencies to execute, equipment to employ and successes to replicate.” We thank Karen Green, Executive Director, for believing in our efforts and letting Pain Connection be known to her board members; Robert H. Myers Jr., Chairman; David Kressler, Vice Chair; Clair A. Parsons, Treasurer; Benjamin Giuliani, Secretary; Stephen C. Eastham, and Kenneth W. Nicholls.

Thank you to Alison Lee for copy editing and Sherry Hutchinson for designing and laying the manual out.



For over six years my son and daughter have told me to write my book, “Making the Invisible Visible,” the story of how the car accident fourteen years ago changed my life and left me with chronic pain. The task of compiling all my work that I developed over these years was too overwhelming for me; I kept putting it off. I daydreamed often of being able to write the book or finding someone who could help me. Having chronic pain, it is a major feat for me to balance my work on Pain Connection and see clients in my small private practice. This took whatever time and energy I had, and many days I could not do anything. The publication of this manual is a true blessing.

On April 12, 1999, I told my pain story to a group of strangers in the Davis Library in Bethesda. I was nervous, unsure of myself, and felt embarrassed that I could be so insecure because of my pain. Pain had taken away my self-confidence. People entered the room like wounded soldiers, silently sitting down and looking at me as if I had all the answers. What I had to share were my experiences, good and bad. I had found ways that helped, and I did not want others to suffer as I had because of the lack of knowledge of health care providers, family, and friends. I wanted to teach people coping skills and hope instead of despair, depression, and loneliness. That day, I regained a part of myself; the group helped me to believe in myself again. I saw that I could still create change, even with the pain, and I regained my sense of self-worth.

I want to thank Cat McClannan who blessed me with her smile and knowledge. I am grateful for meeting Mary French, co-author, and Nancy Magnusson, editor, in making this dream a reality. Each time Mary and I met to work on the manual, the larger it became. Together we dreamed and saw so many possibilities.

I could not have done any of this without my husband, Malcolm. Malcolm has always been by my side advocating for me, taking care of me and our children when I was unable, driving me to medical appointments and countless meetings, helping me set up events, editing my work, providing legal expertise to Pain Connection, and, most of all, being my best friend. I leaned on him for strength, my sanity, and stability. Malcolm is a witness to everything that I have experienced. My children, Daniel and Mayan, were only 5½ and 4 years old at the time of my accident. I used to feel horrible that they did not remember me without pain; then I was thankful that they did not remember me during those years when I was lost in pain. Now I am grateful that they see me as I am today. When I was at my lowest, they taught me how to love myself again. I am so proud of who they have become. I am truly blessed to have my family.

The birth of Pain Connection was my link back to life. I want Pain Connection to be a light in leading chronic pain sufferers out of their darkness and give them hope that change is possible.

Gwenn Herman

PREFACE

There are 76 million Americans suffering from pain who are not receiving adequate treatment. There are many barriers to treatment including lack of effective interventions, untrained health care providers, financial limitations, and stigma. People with pain fall between the cracks of our flawed health care system. Even those lucky enough to have insurance find needed services are not covered under private health insurance, workers' compensation, or disability insurance.

The beginning of Pain Connection dates back to April 1999 with the start of a single chronic pain support group. This group, started by Gwenn Herman, continues to meet monthly at the Davis Library in Bethesda, Maryland. Following a motor vehicle accident that resulted in chronic pain, Ms. Herman felt compelled to reach out to others to provide support and treatment that she had found lacking during her own experience.

Since the start of the first support group, and with the help of local media coverage, many more people have become aware of this health care crisis, and the organization has developed groups in many counties in Maryland. Medical professionals have begun to refer clients to Pain Connection support groups, which are focused on healing and positive change. Information on various chronic pain conditions and resources are shared in the groups.

The chronic pain support group provides a forum for those isolated and alienated by chronic pain, struggling with a lack of services to address disruptions to the physical, emotional, and social self. The group provides a safe place to voice concerns, problem-solve, gain support, and learn self-help skills such as meditation and guided imagery, so people in pain can survive another day.

Pain Connection is a nonprofit, community organization whose mission is to help people with chronic pain and their families by providing information and resources, professional training, psychosocial support, a peer support network, a speakers' series, community outreach/education, support groups, therapy groups, a newsletter, and a website. Our work aims to improve the quality of life of those suffering from chronic pain, decrease their sense of isolation and alienation, increase their control of their condition and treatment, and maintain their independence.

Pain Connection plans to establish an outreach center, which will provide individual, couples, and family counseling; weekly support groups; seminars and classes; a 24-hour hotline; case management; training programs; occupational therapy; a library with access to the Internet; and transportation for those in need.

HOW TO USE THIS MANUAL

We recognize that people living with pain may be seen in a variety of health care settings including doctor's offices, emergency rooms, hospices, day treatment programs, addiction clinics, mental health outpatient clinics, and in private practice. It is vital that health care providers understand how to work with people in pain. We hope this manual will help providers reach out to people suffering alone with pain and expand the Pain Connection network to other cities and states in the country.

We have written this manual specifically for health care providers so they may become more familiar with some of the challenges facing this population and be able to educate and assist their clients. We feel it is vitally important to assist clients in accessing their own innate healing ability by becoming focused on internal healing and not just on an external cure.

Our goal is to make this manual practical, helpful, and easy to use. You will notice as you make your way through this manual that it is a dynamic tool containing many handouts, which may be copied and utilized in your work with individual clients as well as with groups. *You may photocopy handouts in this manual to use with your clients; however, copyright is limited to your personal use with your individual clients or groups.* If you would like assistance in forming your own Pain Connection chronic pain support group, please contact Pain Connection. We welcome new members to our Pain Connection family. We are also available for supervision regarding your work with clients.

Chronic pain is a complex issue that requires a large knowledge base in many areas, including neurology, anatomy and physiology, pharmacology, human development, and psychology, to name just a few. Treatment approaches are as varied as the many different kinds of chronic pain conditions that exist, so, of course, this manual is in no way an exhaustive work on the management of chronic pain. This manual contains original work and a compilation of some of the most important areas of knowledge needed to address the multiple complex issues regarding chronic pain. Hopefully, it also gives voice to human suffering, including the words and thoughts from those who live in pain.

After reading this manual, the provider will be able to:

- ◆ Understand chronic pain and the complexity of chronic pain.
- ◆ Provide accurate information to the client and normalize the client's experience.
- ◆ Understand the myths and misconceptions that perpetuate stigmas and interfere with effective treatment.
- ◆ Understand the predictable psychosocial processes people experience.
- ◆ Assist clients in building a multidisciplinary treatment team.
- ◆ Assist clients in taking control of their pain by communicating their needs effectively to others.
- ◆ Identify all components of an effective treatment plan.

- ◆ Understand the role of a Pain Connection support group leader and the support group process.
- ◆ Understand the psychological effects of chronic pain, including grief and depression.
- ◆ Understand the relationship between trauma and chronic pain.
- ◆ Provide coping strategies, cognitive interventions, and self-care skills.
- ◆ Have a basic understanding of many different complementary and alternative treatment approaches available to clients.
- ◆ Understand implications of chronic pain on the family.
- ◆ Provide information and resources.
- ◆ Maintain a healing therapeutic relationship.

Key to symbols



Personal stories are noted in the table of contents in orange italics and appear in the text in orange boxes and this symbol. The stories are either from those who suffer from chronic pain themselves, family member of a person who suffers from chronic pain, or somebody who helps those manage their chronic pain.



Instructions for handouts are noted by this symbol.