WORKING WITH CHRONIC ILLNESS

BASIC TEXTS IN COUNSELLING AND PSYCHOTHERAPY

Series Editor: Stephen Frosh

This series introduces readers to the theory and practice of counselling and psychotherapy across a wide range of topic areas. The books will appeal to anyone wishing to use counselling and psychotherapeutic skills and will be particularly relevant to workers in health, education, social work and related settings.

The books in this series are unusual in being rooted in psychodynamic and systemic ideas, yet being written at an accessible, readable and introductory level. Each text offers theoretical background and guidance for practice, with creative use of clinical examples.

Published

Jenny Altschuler

WORKING WITH CHRONIC ILLNESS

Paul Terry

COUNSELLING THE ELDERLY AND THEIR CARERS

Forthcoming

Sheila Ernst, Bill Barnes and Keith Hyde

AN INTRODUCTION TO GROUPWORK

Gill Gorell Barnes

COUNSELLING FAMILIES

Jan Wiener and Mannie Sher

COUNSELLING AND PSYCHOTHERAPY IN PRIMARY HEALTH CARE

Series Standing Order

If you would like to receive future titles in this series as they are published, you can make use of our standing order facility. To place a standing order please contact your bookseller or, in case of difficulty, write to us at the address below with your name and address and the name of the series. Please state with which title you wish to begin your standing order. (If you live outside the UK we may not have the rights for your area, in which case we will forward your order to the publisher concerned.)

Standing Order Service, Macmillan Distribution Ltd,
Houndmills, Basingstoke, Hampshire, RG21 6XS, England

WORKING WITH CHRONIC ILLNESS

A Family Approach

JENNY ALTSCHULER

With contributions by
Barbara Dale and John Byng-Hall

© Jenny Altschuler 1997
Chapter 6 © Barbara Dale 1997
Chapter 9 © John Byng-Hall 1997

All rights reserved. No reproduction, copy or transmission of this publication may be made without written permission.

No paragraph of this publication may be reproduced, copied or transmitted save with written permission or in accordance with the provisions of the Copyright, Designs and Patents Act 1988, or under the terms of any licence permitting limited copying issued by the Copyright Licensing Agency, 90 Tottenham Court Road, London W1P 9HE.

Any person who does any unauthorised act in relation to this publication may be liable to criminal prosecution and civil claims for damages.

The authors have asserted their rights to be identified as the authors of this work in accordance with the Copyright, Designs and Patents Act 1988.

First published 1997 by
MACMILLAN PRESS LTD
Houndmills, Basingstoke, Hampshire RG21 6XS
and London
Companies and representatives
throughout the world

ISBN 978-0-333-62490-6 ISBN 978-1-349-13589-9 (eBook)
DOI 10.1007/978-1-349-13589-9

A catalogue record for this book is available
from the British Library.

This book is printed on paper suitable for recycling and
made from fully managed and sustained forest sources.

10	9	8	7	6	5	4	3	2	1
06	05	04	03	02	01	00	99	98	97

To Sarah and Jack

CONTENTS

<i>Acknowledgements</i>	xi
1 Introduction: The Challenge of Physical Illness	1
Defining what illness means	1
Health and illness: a narrow divide?	3
Illness in a world defined by health	4
Linking mind and body	6
The power of metaphors and images	6
Causal explanations: personal control, responsibility and blame	9
Psychological resilience and facing uncertainty	11
Psychosocial models of illness	13
Conclusions	18
Summary	19
2 Understanding the Impact of Illness on Health-Care Systems	20
Systems theory in the context of health care	21
How does a system work?	21
How do systems deal with entries and exits?	23
What does membership of a system mean?	24
What is the position of an individual in a system?	24
Interface between systems in health care	25
Relationships between professionals and families	31
Relating to other systems	32
Respecting our position in health-care systems: practice guidelines	34
Conclusions	36
Summary	37
3 The Impact of Illness on the Family	38
What is a family?	39
How are challenges specific to each illness?	41

How does treatment organise family life?	42
How do these demands vary over time?	43
How are uncertainty and predictability balanced in family life?	45
What happens to the family's sense of identity?	46
How does care-giving impact on family organisation?	47
How does illness influence family boundaries?	50
How does illness affect family communication?	51
Recognizing what may be gained and lost: balancing hope with acceptance	54
Conclusions	55
Summary	56
4 Using Family Therapy Techniques in your Work	58
Establishing the context	59
Your role as a therapist	61
The process of therapy	67
Conclusions	80
Summary	80
5 What Illness Means to Children	82
Retaining a developmental perspective	83
Communicating and sharing information	84
Play and non-verbal communication	88
Working with childhood illness	90
Working with children who have an ill sibling	95
Working with children who have an ill parent	98
Where an extended family member is ill	102
The particular needs of adolescents	103
Schools: an underutilised resource	105
Questioning our own understanding	107
Conclusions	108
Summary	109
6 Parenting and Chronic Illness by Barbara Dale	110
Normal and chronic illness	110
Social isolation	110
Illness culture: its advantages and risks	111
Understanding the impact of family values on parenting	111
Stress in families with a chronically ill child	113
Changing roles as mothers and fathers	114

Assertiveness in spouse relationships	114
Parents protecting professionals	114
Direct work with families	115
Conclusions	125
Summary	126
7 Working with Adults who are Ill	127
How does the life cycle affect adults' responses?	128
Accommodating to change	129
Making sense of the illness	130
What does an illness mean to an adult's sense of self?	132
What might illness mean for couple relationships?	134
Addressing similarity and difference	137
How are losses balanced against potential gains?	140
How does practical care-giving impact on relationships?	142
How does gender impact on how care is negotiated?	145
Addressing Stigma in illness	151
How can a sense of dignity and quality of life be retained?	152
Conclusions	154
Summary	155
8 Personal and Practical Issues for Professionals	157
What does appropriate distance mean?	159
Facing personal limitations and vulnerabilities	161
How does emotional vulnerability relate to our family of origin?	162
What contributes to stress amongst health professional?	164
How do context and role contribute to stress?	165
How can this be addressed in clinical practice and training?	167
How does this relate to gender?	169
How do technology and policy changes help or hinder health care?	171
Can we avoid de-skilling the families we meet?	171
Personal anxieties about health	173
Mirroring within professional systems	174
How do we manage personal and professional boundaries?	176
Suggested guidelines	177
Conclusions	177
Summary	178

9 Clinical Epilogue: A Family's Experience of Adjusting to the Loss of Health	179
<i>by John Byng-Hall</i>	
Accepting that the illness is chronic	179
Fighting the illness, versus yielding to its implications	180
Mourning the loss of a healthy future	180
Helping families hear bad news	181
How illness scripts evolve across generations	182
Helping to mourn the loss of health	183
Tracing illness scripts down the generations	184
Avoiding ignoring vague symptoms in the presence of stress	186
Exploring what may resonate across generations	187
The dangers of making psychiatric diagnoses on past history of emotional problems	188
When to tell bad news: sooner or later?	189
Giving patients space and listening	190
Encouraging family support during medical consultations	191
Recognising anger and assertiveness are better than self-pity and bitterness	191
The family's advice to professionals	193
Conclusions	194
Summary	194
<i>Additional Information</i>	195
<i>References</i>	201
<i>Index</i>	209

ACKNOWLEDGEMENTS

Over the course of my clinical work, I have been privileged to meet many families facing life-threatening and chronic illness who have had the courage to risk sharing their fears, hopes and practical struggles. It is these families I would first and foremost like to acknowledge. Details of all families discussed here have been significantly altered to ensure anonymity.

I would also like to thank my colleagues, members of the Tavistock Systems Team and Illness Research Project. Whilst writing this book, Barbara Dale and I have been involved in clinically-based research focusing on gendered patterns of caring in adult and parental relationships. Inevitably, much of that thinking is reflected here. Several of the families discussed were seen with Barbara Dale and Charlotte Burck, so that our shared clinical insights have informed the ideas presented in this book.

I would also like to thank Dr Dora Black, Dr Richard Trompeter and colleagues at the Royal Free Hospital for their support in paediatric liaison. Thanks to Dr David Katz and Dr John Launer for consultation on the medical conditions considered here, and to members of the Psychodynamic Approaches to Cancer Reading Group for sharing thoughts on the connections between systemic and psychodynamic work. Thanks to Susan Altschuler, Gill Brace, Harriet Galgut, Helene Joffe, Jill Matus and Susan Lonsdale for their advice and discussion, and to Jackie Lemer for her careful reading of the typescript. Of course, particular thanks go to Stephen Frosh and Frances Arnold for suggesting I write this book, and their support over what has at times felt a long journey.

Finally my thanks go to my own family, for their flexibility and support while I've been writing. Particular thanks to David for his careful critique, proof reading and encouragement, and to our children, Gabriel and Marla, for reading the children's books recommended here, their computer consultation and good humour.

JENNY ALTSCHULER

NOTE

Note: Feminine pronouns have been used throughout the text for the sake of simplicity, rather than using both masculine and feminine, when not referring to a specific person.