



# A Leader's Manual

For Dementia Care-Partner  
Support Groups

For use with *The Dementia Care-Partner's Workbook*

Edward G. Shaw M.D., M.A.

Alan D. Wolfelt Ph.D., C.T.



# Contents

<b>INTRODUCTION</b> .....	8
Welcome, support-group leaders! .....	8
A word about <i>The Dementia Care-Partner's Workbook</i> .....	9
Why dementia care-partner support groups are important .....	10
The eight central needs of dementia care partners .....	11
<b>BEFORE YOU BEGIN A SUPPORT GROUP</b> .....	12
Deciding on a support-group leader .....	12
Needs assessment .....	13
Group format .....	14
Choosing a place and time of day to meet .....	15
Setting the number of members .....	16
Deciding on the number of lessons and frequency and length of meetings .....	16
Recruiting and screening group members .....	17
Strategies to publicize the group .....	17
Establishing ground rules .....	19
Baseline and end-of-group assessments .....	20
<b>BASIC SKILLS OF THE SUPPORT-GROUP LEADER</b> .....	21
Responsibilities of the support-group leader .....	21
Qualities of the support-group leader .....	22
Empathy .....	22
Respectfulness .....	23
Warmth and caring .....	23
Genuineness .....	24
Trustworthiness .....	24
Defining leadership style .....	25
Basic counseling skills of the support-group leader .....	26
Active listening .....	27
Restating .....	27
Clarifying .....	27
Summarizing and paraphrasing .....	28
Questioning .....	28
Interpreting .....	28
Confronting and reality testing .....	28
Reflecting feelings .....	28
Supporting .....	28

Empathizing .....	29
Facilitating, linking, and initiating.....	29
Goal-setting.....	29
Evaluating and giving feedback .....	29
Suggesting.....	29
Protecting and blocking.....	30
Self-disclosure.....	30
Modeling.....	30
Silence .....	30
Terminating.....	31
The nature and art of companionship .....	31
<b>SUPPORT GROUP BASICS .....</b>	<b>32</b>
Basic needs of support group members .....	32
The five developmental phases of a support group.....	32
Phase One (forming): Warm-up and establishing group purpose and limits .....	33
Phase Two (storming): Tentative self-disclosure and exploring group boundaries.....	34
Phase Three (norming): In-depth self-exploration and confronting the realities of caregiving .....	35
Phase Four (working): Commitment to healing and growth .....	36
Phase Five (closing): Preparation for and leaving the group .....	38
Challenges in the group.....	39
Lack of leader preparation and/or training .....	39
Discrepancies between group members’ expectations and leader’s expectations .....	39
Challenging members .....	40
Amy the Absent.....	40
Ann the Advice-Giver .....	41
Albert the Academic.....	41
Bob the Blamer.....	42
Charlene the Challenging.....	42
Fred the Forced.....	43
Holly the Holy Roller .....	43
Ivan the Interrupter.....	43

Paul the Preacher/Teacher .....	44
Ralph the Rambler .....	44
Sarah the Socializer .....	45
Wally the We-Sayer .....	45
Determining when a group member needs individual counseling and asking a group member to leave the group .....	46
When the group just doesn't seem to be going well and you're not sure why .....	47
The leaders aren't doing their job well or don't work well together.....	47
The members don't mix well together.....	47
When a group member or their loved one with dementia dies.....	48
<b>MEETING PLANS FOR LESSONS ONE THROUGH TEN OF THE DEMENTIA CARE-PARTNER'S WORKBOOK .....</b>	<b>49</b>
A few introductory words for leaders before jumping into meeting plans .....	49
A few words about members doing homework .....	49
Anatomy of a meeting plan.....	50
If you plan to do baseline and end-of-group assessments.....	50
Before the group begins.....	50
Before group ("warmup") .....	51
Opening the group.....	51
Mindfulness Moment.....	51
Check-in.....	52
Education .....	52
Discussion .....	53
Preview of next meeting and homework.....	53
Mindfulness Moment.....	54
Closing .....	54
After group ("afterburn") .....	54
Leader and co-leader decompression time.....	54
<b>MEETING ONE: Telling Your Story from the Beginning.....</b>	<b>56</b>
Meeting overview and key topics.....	56
Opening.....	56
Mindfulness Moment.....	57
Check-in.....	58
Education and discussion.....	58
Preview and closing.....	58

<b>MEETING TWO: Basics of Alzheimer’s Disease and Other Dementias</b> .....	60
Meeting overview and key topics.....	60
Opening.....	60
Mindfulness Moment.....	60
Check-in.....	61
Education .....	61
Discussion .....	62
Preview and closing.....	62
<b>MEETING THREE: Brain Structure and Function, Activities of Daily Living, and Dementia Stages</b> .....	63
Meeting overview and key topics.....	63
Opening and Mindfulness Moment .....	63
Check-in.....	63
Education .....	64
Discussion .....	65
Preview and closing.....	65
<b>MEETING FOUR: Adapting to Changing Relationships</b> .....	66
Meeting overview and key topics.....	66
Opening and Mindfulness Moment .....	66
Check-in.....	66
Education .....	67
Discussion .....	67
Preview and closing.....	68
<b>MEETING FIVE: Coping with Grief and Loss</b> .....	69
Meeting overview and key topics.....	69
Opening and Mindfulness Moment .....	69
Check-in.....	69
Education .....	69
Discussion .....	70
Preview and closing.....	70
<b>MEETING SIX: Stress and Self-Care</b> .....	72
Meeting overview and key topics.....	72
Opening and Mindfulness Moment .....	72
Check-in.....	72
Education .....	72
Discussion .....	73
Preview and closing.....	74

<b>MEETING SEVEN: Getting More Help and Transitioning Care</b> .....	75
Meeting overview and key topics .....	75
Opening and Mindfulness Moment .....	75
Check-in .....	75
Education .....	75
Discussion .....	76
Preview and closing .....	77
<b>MEETING EIGHT: Legal, Financial, and End-of-Life Issues</b> .....	78
Meeting overview and key topics .....	78
Opening and Mindfulness Moment .....	78
Check-in .....	78
Education .....	78
Discussion .....	79
Preview and closing .....	79
<b>MEETING NINE: Existential and Spiritual Questions</b> .....	81
Meeting overview and key topics .....	81
Opening and Mindfulness Moment .....	81
Check-in .....	81
Education .....	81
Discussion .....	82
Preview and closing .....	82
<b>MEETING TEN: Retelling Your Story Starting Today</b> .....	83
Meeting overview and key topics .....	83
Opening and Mindfulness Moment .....	83
Check-in, education, and discussion .....	83
Yarn toss .....	83
Resources .....	84
Closing .....	84
<b>APPENDICES</b> .....	85
Appendix 1: Support Group Ground Rules .....	86
Appendix 2: Zarit Caregiver Burden Scale .....	87
Appendix 3: Geriatric Depression Scale and Geriatric Anxiety Scale .....	89
Appendix 4: Support Group Leader's Overview .....	91
Appendix 5: The Eight Central Needs of Dementia Care Partners .....	96

Appendix 6: Symptoms of the Four Most Common Forms of Dementia .....	98
Appendix 7: Understanding Our Emotions Exercise .....	100
Appendix 8: Activities of Daily Living and the Stages of Dementia .....	101
Appendix 9: Wellness Wheel and Wellness Plan .....	105
Appendix 10: Support-Group Participant Evaluation Form .....	107
Appendix 11: Resource for Support Group Members .....	110
Appendix 12: Certificate of Dementia Care-Partner Support Group Participation .....	111
<b>SELECTED REFERENCES .....</b>	<b>112</b>
<b>PRESENTATIONS, TRAININGS, AND CONSULTING BY DR. SHAW AND DR. WOLFELT .....</b>	<b>112</b>
<b>FEEDBACK .....</b>	<b>112</b>
<b>ABOUT THE AUTHORS .....</b>	<b>113</b>