SEXUAL DIFFICULTIES AFTER TRAUMATIC BRAIN INJURY AND WAYS TO DEAL WITH IT

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By

RONIT ALONI, PH.D.

Private Practice Sex Therapist and Rehabilitation Tel-Aviv, Israel

and

SHLOMO KATZ, Ph.D.

Professor of Rehabilitation Department of Psychology Bar-Ilan University Ramat-Gan, Israel Rehabilitation Center for Veterans with Brain Injury Tel-Aviv, Israel



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Dedicated with love to Rotem, Gilad, Yiftach, Shira, Miki, Nava Hadas, and Merav

CONTRIBUTOR

MARIO COHEN, MD, MHA

Head of Rehabilitation Department Director of TBI, Multidisciplinary Outpatient Clinic Alyn Rehabilitation Hospital Kiriyat Yovel, Jerusalem, Israel

PREFACE

This book is the culmination of a number of personal and professional experiences of the two authors.

Dr Ronit Aloni the first, whose interest in sexuality and disability was the result of her studies in Human Sexuality at New York University (NYU). At the beginning of one of the courses entitled, "Sexuality and Disability," the lecturer made the statement that "we are all temporarily able-bodied." These words had a profound impact on Dr. Aloni's professional plans and goals, and took her back on a long journey that started with growing up with a grandfather who had a hand amputation, a father who incurred traumatic brain injury (TBI), and a sister with cystic fibrosis.

After completing her graduate studies at NYU with a focus on the sexuality of persons with disabilities, Dr. Aloni returned to Israel and developed a sexual rehabilitation program at Loewenstein Rehabilitation Hospital, geared for persons after CVA and TBI. The purpose of this project was to develop a previously unavailable, early intervention program in the field of sexuality, to be implemented soon after occurence of the injury. At the same time, Dr. Aloni initiated and set up, in conjunction with the rehabilitation center of the kibbutz movement in Israel, a sexual treatment program with the use of surrogates for persons with disabilities. The need for more knowledge and expertise in the field prompted Dr. Aloni to initiate applied research in the field, which culminated in a doctoral dissertation entitled Designing an early sexual intervention program for the first stage of the rehabilitation of persons with TBI. This book is based on the dissertation, in addition to Dr. Aloni's professional experience as a sex therapist for persons with disabilities. The information and the suggested methods in the book are the result of the experience gained from working with

survivors, their families, and staff in different rehabilitation facilities in Israel.

The second author, Professor Shlomo Katz, is a Professor of Rehabilitation Psychology in the Department of Psychology at Bar-Ilan University in Israel. The program trains rehabilitation psychologists at the master's and doctoral level. As part of his professional and research interests, Professor Katz has been the project director of a rehabilitation center for veterans after TBI in Israel. This center is a cooperative venture of the Department of Rehabilitation of the Ministry of Defense and the Rehabilitation Psychology Program in the Department of Psychology at Bar-Ilan University. The purpose of the rehabilitation center is to improve the quality of life of these veterans and their families. As part of this goal, the sexuality of these survivors, who in many cases were injured during the prime sexual period, became an important issue that needed to be addressed. This led to Professor Katz's interest in the area and the professional relationship with Dr. Aloni, first as one of the supervisors of Dr. Aloni's doctoral dissertation, and second in the writing of this book. Professor Katz recognized the importance and the potential for an intervention program in sexuality as part of the rehabilitation process for these persons.

The book is geared for professionals in the field of rehabilitation and provides a suggested framework for dealing with the sexuality of persons after TBI. The book should provide professionals with an understanding of the issue of sexuality after TBI, and how to plan an intervention program at various stages of the rehabilitation process. Although the book is geared mainly for working with survivors after TBI, there are elements in the program that can also be applied to other disability groups, such as persons with mental retardation and persons with a psychiatric disability.

We would like to thank Dr. Grosswasser, the head of the TBI Rehabilitation Unit, Dr. Cohen, and other members of the staff at the Loewenstein Hospital for their support and help in initiating the sexual intervention program. Dr. Mario Cohen also kindly consented to write the chapter on the physical and medical aspects of sexuality after TBI and we give special thanks to him. Special thanks also to Rhoda Linton, PhD, and Eva Einat, PhD, for their input during the writing of the dissertation.

In addition, we would like to thank the staff of the National Institute for the Rehabilitation of the Brain Injured in Tel-Aviv and Haifa, the

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staff of the rehabilitation center for veterans with TBI, and the Unit for Neuropsychological Treatment and Rehabilitation for sharing their professional experience with us.

Finally, we would like to express our thanks to the survivors and their families for sharing their personal experiences with us. This book is dedicated to all these persons in the hope that the professionals making use of the information will be able to contribute to the quality of life of survivors of TBI and their families.

> S.K. R.A.

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SEXUAL DIFFICULTIES AFTER TRAUMATIC BRAIN INJURY AND WAYS TO DEAL WITH IT

Section I

IDENTIFICATION AND DISCUSSION OF PROBLEMS RELATING TO SEXUALITY AFTER TBI

Chapter 1

TRAUMATIC BRAIN INJURY, DISABILITY, AND SEXUALITY

INTRODUCTION

Noping with the impact of traumatic brain injury (TBI) is described \checkmark in the medical and rehabilitation literature as one of the most difficult tasks that can confront survivors, their families, and professionals (Brooks, 1984; Connell & Connell, 1995; Lezak, 1978; Perlesz, Kinsella, & Crowe, 1999). The National Head Injury Foundation (NHIF) in the U.S. defines Traumatic Brain Injury as "an insult to the brain caused by an external force that may produce diminished or altered states of consciousness which results in impaired cognitive abilities or physical functioning" (NHIF, 1989). Between 55 to 60 % of persons who sustain TBI are estimated as having varying degrees of ongoing physical, cognitive, and behavioral deficits and, therefore, require long-term rehabilitation (Jacobs, 1988; Kalsbeek, McLaurin, Harris, & Miller, 1980). Physical disabilities associated with TBI can include impairments in vision, hearing, speech, and language, fine and gross motor skills, and balance (Boak & High, 1996). Difficulty in concentrating, different degrees of short-term memory loss, poor retrieval of existing information, problems in processing abstract information, and the impaired planning and carrying out of everyday activities are among the cognitive disabilities produced by TBI (Ponsford, Sloan, & Snow, 1995; Rachmani, 1988; Varney & Menefee, 1993). The emotional and behavioral problems and difficulties in coping that persons with TBI and their families experience are not surprising (Armstrong, 1991; Kaplan, 1993; Vogenthaler, 1987), given the extensive impairment and disability that are often a consequence of TBI (Abrahamson & Abrahamson, 1997; Antonak, Livneh, & Antonak, 1993).