

PREFACE

This guide has been prepared for those who are living in the world of ALS. ALS will affect your life in countless ways. Over the course of your disease you will develop a new vocabulary — words such as motor neurons, glutamate and superoxide dismutase. You will face decisions about home modifications, wheelchairs and other adaptive equipment, and medical issues such as feeding tubes and end-of-life decisions. You will become adept at navigating the mazes of health care insurance, disability insurance and financial planning. While, at times, these tasks may seem overwhelming, be assured that there are many resources available through MDA to assist you in your journey with ALS.

The purpose of this guide is to provide a ready source of practical information to help you manage the physical aspects of ALS on a day-to-day basis, through all stages of the disease. The overarching goal is to allow you to maintain function and independence for as long as possible, and always to maintain the best possible quality of life. A major theme running through this guide is the importance of planning early for the inevitable changes that occur over the course of ALS. Preparing for change allows you to maintain con-

trol over decision-making and to make choices that are best for you. We hope that this guide will be a useful resource for you in that regard.

For 15 years I had the privilege of caring for people with ALS. These individuals and their families provided valuable insights about living well with ALS. They emphasized the need for patience and for maintaining a good sense of humor under adverse conditions. They also stressed the importance of identifying priorities, setting realistic expectations, and letting go of the little things that annoyed them, in order to focus on things that mattered more.

Finally, don't be afraid to ask for help, and don't think that using assistive devices is giving in to ALS. Instead, make the most of every means of help possible and allow yourself to live life to the fullest with ALS.

MDA's ALS Division is here to help you every step of the way.

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