

## GENERAL PRINCIPLES OF REHABILITATION

**James R. Christensen**

### Rehabilitation and Ataxia Telangiectasia

Rehabilitation has a great deal to offer persons with A-T and their families. However, to utilize these resources wisely and effectively, it is important to understand the goals and basic principles of the rehabilitation process, as well as the limitations of what rehabilitation can and cannot do.

The major goal of rehabilitation is **FUNCTION**: to maximize the function or abilities of an individual, in spite of existing or developing impairments, and to do this in the least intrusive way possible (in a way that is most enjoyable, with least cost, time and effort expended, and least burden to the person and family).

### What constitutes A-T Rehabilitation?

- 1) A **team** of rehabilitation professionals helps to address the challenges facing persons with A-T. While the team in your own geographic area will most likely not include specialists in A-T, they will be specialists in rehabilitation. They will have the evaluation skills and the rehabilitation knowledge that will make their recommendations and treatment appropriate and beneficial. The team may include a rehabilitation physician, psychologist, speech and language pathologist, assistive technology specialist, occupational therapist and physical therapist.
- 2) The prevention of unnecessary **secondary deterioration**. While therapy will NOT eliminate the coordination problems, ataxia and involuntary movements that are part of A-T, it can minimize or prevent secondary problems such as weakness, poor endurance, and progressive orthopedic deformities of the feet.
- 3) The provision and teaching of **compensatory techniques** to minimize the effect of impairments. For example, learning how to best position one's body and arms so that the effect of the tremor or ataxia is minimized when doing a fine motor task; or learning how to repeat only the important word of the sentence when one is tired and consequently having more difficulty being understood.

The major goal of rehabilitation is **FUNCTION**: to maximize the abilities of an individual, in spite of existing or developing impairments and to do this in the least intrusive way possible.

Each person with A-T should have a recreational program, that he/she enjoys doing, and that has been adapted to his/her own individual abilities and desires.

- 4) The provision of appropriate **equipment**, such as braces, a wheelchair, or an adapted computer keyboard with appropriate software. In deciding what type of equipment is appropriate, and when to use it, one needs to remember certain principles. Equipment is useful if it will: a) promote physical and psychological age appropriate independence and function; b) improve safety; c) improve energy efficiency. It is also important to remember that equipment should be used for specific reasons, under certain circumstances. Just because one has a piece of equipment, doesn't mean that one stops an activity that he/she is able to do in an independent, safe and energy efficient manner.
- 5) The provision of appropriate **environmental modifications**, such as grab bars and a tub bench in the bathroom for safety, a ramp to enter the home or learning to access public transportation.

The most important role of the rehabilitation team will be to provide guidance and advice through periodic monitoring (every three to six or 12 months), that will help you meet challenges as abilities evolve and change. In some cases, the team may also provide individual therapy.

Everyone should have a therapeutic activity program, but not everyone needs "therapy" all the time. Each person with A-T should have a recreational program, that he/she enjoys doing, and that has been adapted to his/her own individual abilities and desires. The rehabilitation team can assist with the establishment and ongoing modification of this recreational program, but such a program should be done independently much of the time. The goals of such a program are to maintain optimal fitness, endurance, strength and flexibility. Individual therapy may be required intermittently to make certain that these issues are being addressed appropriately.

Fatigue is frequently a major problem for persons with A-T. It is okay to work or exercise to the point of fatigue, but there is no benefit to working past that point. Remember, when learning anything, try to learn it with the best possible technique. We have a saying in our society that "practice makes perfect." That is not totally correct. It should be "Perfect practice makes perfect." Consequently, **RESPECT YOUR FATIGUE**. When practice begins to cause deterioration in performance, take a break long enough to feel rested, and then start again.

Each person with A-T has individual needs, abilities and disabilities. Consequently, the rehabilitation program must be individualized. However, there are similar issues, which challenge all persons with A-T. Subsequent chapters describe these challenges, the role of therapists in helping address them, and the common recommendations that have been beneficial.