

# ACTIVITIES OF DAILY LIVING AND FINE MOTOR ABILITIES

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## Role of the Occupational Therapist

Occupational therapists are dedicated to assisting with difficulties in the performance of activities of daily living, including self-feeding, dressing, grooming, bathing and toileting, as well as job performance. In general, occupational therapists are interested in arm and hand use, eye-hand coordination, posture as it relates to stability for arm use, and the intellectual understanding necessary to perform motor tasks. Occupational therapists often work closely with physical therapists, who are more concerned with helping to manage problems of mobility and posture, particularly with respect to function of the legs and trunk. The role of occupational therapy in assisting children and young adults with A-T is ongoing, as the passage of time naturally brings new interests and needs to normal developing children. A-T brings new burdens of neurologic impairment. Therapy can take the form of recommending assistive devices, changing the environment or adapting tasks to be more easily accomplished, recommending or assisting with therapeutic exercises, or helping formulate new and more appropriate goals.

## Occupational Therapy Evaluation

The nature of the occupational therapy evaluation changes with growth and development. For a toddler or young child, the day is dedicated to the important tasks of play. Through play, a child explores the outside world and develops the coordination necessary to manipulate it. At school age, the additional responsibilities of attending school, following directions and completing assignments are added to the self-generated interests of play. The occupational therapy evaluation focuses on basic fine and visual motor skills, such as using pencils and scissors, to manage the demands of school successfully. Occupational therapy is also interested in the tasks of self-feeding, food preparation, dressing and grooming for which children naturally assume responsibility. For all adolescents and young adults, the issue of independence takes on great importance. The skills necessary to maximize independence of thought and activity, and for some teens, access to vocational or college programs are an important concern for the occupational therapist.

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whereas physical therapy evaluates gross motor skills (posture, balance, walking). The common area of concern is stability and posture because the trunk, head and feet must be stable for fine-motor control. If an individual is unstable or has uncontrolled movement, the arms will revert to “holding on” in an effort to keep the body steady and prevent a fall. If an individual cannot sit stably and/or hold the head in an upright position, it is difficult to effectively use the arms and eyes effectively. Physical and occupational therapists work together to determine optimal positioning devices and/or techniques that will improve stability and maintain an ideal posture for safety, independence and function in daily activities.

### **General Findings in A-T**

Children with Ataxia-Telangiectasia demonstrate various problem areas that may impact their performance of many activities of daily living.

- **Poor coordination and grading of arm movements.** Many children with A-T have an idea how they want to perform a task, but err in its physical performance. For example, they may extend an arm too far forward or not far enough .
- **Tremors.** As they try to place an object at a specific destination, many patients with A-T are troubled by shaking of their hands. This is as increasingly frequent problem with age. Unfortunately, the harder they try, the greater the shaking.
- **Excessive head and trunk movement.** Extra movement coming from the head and trunk may make it very difficult to complete fine-motor tasks successfully. In order for arms and hands to manipulate objects and work proficiently, movement of the trunk and head must be minimal. Excess movement is not only difficult to control but it is fatiguing, as it wastes a significant amount of energy.
- **Visual Problems.** Difficulty controlling eye movements impacts all visual motor skills (the ability to focus and incorporate precise movement of arm and hand to perform a task).

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### **Occupational Therapy Recommendations**

#### **Improving stability**

Many children with A-T have difficulty controlling arms, trunk and head movements. The increased effort needed to control these movements

interferes with the ability to think about and complete a fine-motor task. Recommendations to increase stability of arms, trunk and head are essential.

Many children with A-T have a strong drive to engage in daily activities. They can be very creative with the use of compensatory patterns to achieve success with preferred tasks. Some of these techniques are very functional, are adapted without thought and are highly recommended. These include keeping arms close to the body, stabilizing elbows on a table and using the trunk to support the arm (for example, sliding an arm up the front of the chest). However, some compensatory patterns which initially are successful in one context may become a hindrance in another. These patterns include bringing the arm away from their body (locking shoulder or elbows may cause increased tremors and decreased control of movement as the shoulder fatigues), or posturing of fingers (locking of finger joints will increase abnormal posturing of the fingers and place the child at risk for skeletal deformities of the hand and wrist). It is important for families and therapists to be aware of the use of abnormal compensatory patterns and try to discourage that use at an early age, while encouraging functional patterns to become habits.

### **Adaptive Seating Systems**

Various adaptive seating components that stabilize the arms, trunk and head will allow the child to control movement better and be more successful with daily tasks. The specific components for the seating system should always be determined by a rehabilitation team that has experience with seating. Some of the possible choices may include a solid seat and back, trunk laterals that fit snugly on either side of the patient's trunk, a vest across the front of the chest, various forms of head rests, and a lap tray to provide a place to stabilize arms.

If it is difficult to use a wheelchair within the home, it is highly recommended that the family provide the child with a good support system. Some recommendations would be a Rifton chair. Various adaptive seating components may be used to stabilize the arms and trunk. If this is not possible, it is important to provide a chair that gives good trunk and head support. It is best to have the feet firmly "planted" on the floor or a support. A table or tray placed in front of the child can lend support for the arms. Lateral supports provided by a rolled up blanket or towel can help maintain trunk stability. It is important to remember that these recommendations are intended to improve fine motor control. Consequently, one would use the above adaptations when it was important for function, rather than use them all the time.

### **Activities of Daily Living**

Various pieces of adaptive equipment may be recommended to increase success and independence with activities of daily living. Some specific examples include:

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### **Self-Feeding**

- Built-up handles to improve grasp on an object
- Bent-angled spoons to decrease wrist turning as food nears the mouth
- Dycem, a sticky type place mat, to help stabilize bowls and plates
- Scoop bowl with suction cup bottom to decrease bowl movement
- Encouraging whole-handed grasp of a spoon by the shaft of the handle to increase stability
- Elbows stabilized on the table (proper manners for children with A-T) to steady the hand
- Decreasing the distance of hand to mouth movement by placing a 6- or 12- inch platform under the plate to help decrease spillage
- Choosing finger foods and textures such as mashed potatoes that are easy to self-feed

### **Bathing & Toileting**

- Tub bars and toilet rails to increase safety and independence with performance of bathing and toileting
- Bath and shower chair to decrease fatigue, increase safety and increase the ability to bathe independently
- Bath Mitt with liquid soap or “soap on a rope” to allow for increased participation with bathing and eliminate worry about dropping the washcloth and soap
- Provide a urinal for boys who can use one and have difficulty transferring to a toilet. Pants can be modified so that a Velcro flap replaces a zipper.

### **Grooming**

- Use electric toothbrush, if sufficient arm stability can be achieved, to clean teeth better than is possible with a manual brush.

### **Dressing**

- Modify clothing to simplify dressing, undressing and arranging clothes for toileting. This includes using loose fitting clothing with elastic waist bands, without fasteners, and modified shoe closures (self-holding shoe strings, Velcro closure).

- To help with self-dressing, it may be useful to find ways to improve trunk stability and “free up” the arms to assist with the task. This may involve dressing in a chair or sitting against a wall or the base of a bed.

### **School**

- Built-up handles for pencils to improve grasp and decrease pressure at fingers. The handle should be made of rubber or foam because individuals with A-T usually maintain a “death grip” on the pencil in an effort to control tremor and maintain stable movement.
- Wrap-around desk or desk that supports the forearms to stabilize the upper arm for fine movements of the hand. Support of the elbows and forearms helps to increase stability of the hand and encourage wrist extension.
- Slant board or easel with a clip at the top can be used to hold a paper. Positioning the board at a 45 degree angle often provides the best wrist and forearm stability, thus increasing control of writing and pencil grasp. It can also help some persons with A-T to look at the material more easily.
- Computer access is very helpful for most A-T patients. Although many of them learn to write, the burden of writing legibly often outweighs the benefit to learning. Tremors and ataxia interfere with legibility and speed. While use of a computer is usually slow and somewhat difficult, it allows many A-T patients to have a means of legible written communication, as well as easy access to information and opportunities for socialization via the Internet. Children with A-T often benefit from having an Assistive Technology evaluation to recommend appropriate keyboard and mouse control adaptations. These recommendations and components should increase both ability and success.
- Use of a personal aide may be recommended within the school environment. An aide can help transport the child from class to class and assist with toileting, dressing and eating. The aide may also help as a scribe, assisting with note taking and other written output, as well as other aspects of daily school life.
- Occupational therapy services may not be needed in school on a regular basis. However, regular review of the classroom environment may identify specific areas that interfere with the child’s ability to perform fine-motor tasks and interact with peers.

### **Home Environment**

Adaptations to the current home environment are often needed in order to increase the child’s current level of independence. Listed below are some general recommendations that will increase safety and independence within the home.

### **Bathroom**

- Although the majority of children enjoy a bath, increasing problems with balance can be particularly troublesome in the tub. A shower stall and use of a shower chair will ease the job of the caregiver to assist with transfers while allowing increased safety and independence.
- Use of toilet rails to facilitate safe transfers on and off the toilet
- If possible, modify sinks to allow wheelchair access. If not possible, place a chair at the sink and provide a mirror at eye level to increase ability to participate in grooming tasks.
- Place grooming items close at hand within a plastic container with compartments. Remember to stabilize the box to prevent it from falling.

### **Other rooms within the home**

- Wider door frames for easy wheelchair access throughout the home, along with tiled floors for easier wheelchair movement.
- Modify kitchen table and/or computer table to allow the wheelchair to be used. This will provide much needed support for sitting and allow optimal control of arms and hands.

Though these suggestions may be ideal, in many circumstances restrictions of home layout, finances or features of the disease may make them less practical. In almost all cases, however, creative thinking by families and therapists can be useful to maintain independence and safety with daily activities.

Many times, families do have the resources to adapt their home but have questions about where to locate information on making their homes more accessible. Although there many local companies that may be able to assist, listed below are a few national resources that may be able to help with specific questions in regard to handicap-accessible home adaptations and/or equipment.

- The NAHB (National Association of Home Builders) Research Center—400 Prince George’s Blvd., Upper Marlboro, MD 20772-8731, Phone (301) 249-4000, Fax (301) 249-0305. They have numerous books and pamphlets (for a fee) that provide specific information on handicap-accessible building products and guidelines for widths, sizes, etc.
- Crane Plumbing--1235 Hartrey Ave., Evanston, IL 60202, Phone (708) 864-9777, This is a plumbing company that has a specific line of bathroom fixtures designed for handicap accessibility
- See physical therapy chapter for additional information and web sites.

## **Recommendations for higher-level activities of daily living**

Many adolescents and adults with A-T want to live fully or partially independent. Their goal may be to live in their own apartment or in a college dorm. The degree of independence that is possible and the recommendations to facilitate this goal need to be addressed on an individual basis. It is highly recommended that the family and the patient with A-T work closely with an occupational therapist within their community. By making a home visit, a therapist can evaluate the needs to realize these goals, or help to develop intermediate goals as necessary. There are many resources that may help with independent living. For example, a personal care assistant may help with activities such as tub transfers and shopping for groceries.

### **Power Mobility**

Power mobility also may be suggested, not in an effort to decrease walking, but to increase a child's independence within his community and to conserve energy for other activities. Power mobility may be considered if a child fatigues quickly or falls too much. Also, as a child begins to want to be with his or her friends and increase his or her independence, power mobility may be an option, allowing the child to go when and where he or she wants, rather than depending on someone to push the wheelchair. Before ordering any type of power mobility, a child should be assessed by therapists who have experience with this type of equipment.

### **Encouraging Independence**

Motor performance in children with A-T is variable from day to day, and this will result in variable ability to perform tasks. To encourage success, let patients be responsible for as much of a task as possible. Provide some assistance but don't be too quick to complete the activity. Practically speaking, this advice doesn't work all of the time, such as on school mornings when everyone is in a rush and time is limited. When time is an issue, be practical. Choose the skill you want to work on—dressing for example—and plan to do this on a weekend, when everyone has the luxury of more time. This will turn the whole experience into a much more successful and positive one. Choose your goals and battles—you can't fight them all at once. In addition to personal activities, responsibility for some household chores should also be given, bearing in mind the patient's physical abilities. Think of this as training for independent living. When time permits, they should be encouraged to feed themselves all or part of a meal, using appropriate foods such as sandwiches, pizza and French fries.

### **Other Recommendations**

It is critical to remember that children with A-T need to be allowed to be children. Provide them with opportunities to play and be successful in order to develop self-esteem. Crafts and games can be fun and therapeutic and, at the same time, address fine-motor skills that increase strength, range of

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motion and dexterity. Older children may enjoy exercise programs that are tailored to their level of ability. Children with A-T are usually fairly “easy going” and persistent with tasks that would often frustrate others. They may enjoy various activities that seem somewhat difficult, such as stringing beads, coloring and playing video games. As long as they are enjoying the activity and feel good about the results, they should be encouraged to continue. However, the family may need to monitor for frustration and fatigue, and help the child as needed for continued success in preferred tasks. In all cases, the A-T patient, his or her parents and teachers must learn to respect fatigue. If an individual becomes tired, he or she will not gain strength or refine skills. It is better to rest for a little while before proceeding.

Individuals with A-T are just people who want to do the same things the rest of us do. They just have more “hills” to climb in order to be successful. We can learn a great deal from this population, mainly that patience, motivation and a good sense of humor, are helpful to tackle life’s everyday challenges. We must always try to remember that they have their own drives and goals for life and that the most important thing we can do is try to encourage them to be the best that they can be.