Durable Medical Equipment for Children With Spinal Cord Dysfunction: Implications of Age and Level of Injury

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Abstract

Background: Children with spinal cord dysfunction interact with their environment in different ways than their able-bodied peers. To enable them to participate in typical, age-appropriate activities, they must be provided with various types of equipment. Choosing from available options involves a team approach.

Summary: This article discusses general types of durable medical equipment for mobility (wheelchairs, strollers, standers), communication (including augmentative communication devices and computers), self-care, and recreation. Provision of this equipment for these children enhances their ability to learn and to take part in everyday activities and improves their quality of life.

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INTRODUCTION

Children with spinal cord dysfunction are affected in many ways—medical care, development, mobility, self-care, play, school, and, finally, employment. Various kinds of equipment can lessen the impact of their disabilities and enable them to participate in age-appropriate activities. Infants and young children develop by exploring with their bodies and hands. While their ability to utilize adaptive equipment is limited, they can be assisted with independent mobility in simple ways, such as making adaptations to riding toys. They can learn to use switches and joysticks that later will enable them to access the environment for communication and mobility. Those with tetraplegia can be introduced to head- or mouth-control switches and mouthsticks at an early age. Children with paraplegia or incomplete tetraplegia can begin using standers by 1 year of age and orthotics for walking soon after that. This article presents types of durable medical equipment that can be used at each age and level of injury. Areas to be discussed will include equipment for mobility, communication (including augmentative communication devices and computers), self-care, and recreation.

EQUIPMENT TEAM

As with all other services to children with spinal cord dysfunction, a team approach works best in assessing and prescribing various types of equipment. This team should include the child, family members, relevant therapists, a physician, and an assistive technology specialist. Each team member brings his or her unique knowledge of needs and equipment to the evaluation and prescription that enables the best possible fit between child and equipment.

MOBILITY EQUIPMENT

Types of mobility equipment for children with spinal cord dysfunction (resulting from both injuries and myelodysplasia) vary depending on the child's age and level of function. For the purposes of this discussion, level of function will only be divided into tetraplegia and paraplegia, even though there is great variability in function within these two divisions. Many children with myelodysplasia also have visual-perceptual problems and some have cognitive impairment, which also impacts their ability to utilize mobility equipment. However, even children with moderate cognitive impairment can often learn to successfully drive manual or power wheelchairs.

Infants and Toddlers (Birth to 2–3 Years Old)

Infants and toddlers can be mobilized in ways similar to those used for nondisabled children the same ages, with simple adaptations made in the seating system as needed to support head and trunk. For those who are full-time

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ventilator users, a twin stroller or adapted stroller may be needed to transport all necessary medical equipment. As children outgrow strollers, the decision will need to be made whether the child needs a larger type of stroller, a mobility device he or she can learn to propel independently, or both.

In addition to devices for the parent or caregiver to mobilize the child, all young children learn by independently moving in their environment. If they have no ability to do this because of the level of spinal cord dysfunction, another method will need to be devised. This may include power wheelchairs or powered toys, which can often be easily modified to provide trunk support and hand control instead of foot control for driving. Research has supported the ability of children as young as 18 months to be able to drive power wheelchairs (1).

Preschool Children (3–5 Years Old)

Children from approximately 2 to 3 years of age can learn to self-propel either manual or power wheelchairs, depending on the strength of their arms and the existence of other medical problems (such as respiratory or cardiac disease) that may lessen their endurance and ability to use their arms for wheelchair propulsion. Those with myelodysplasia and perceptual problems may need extended training to learn to safely propel their wheelchairs. Just as normal preschool children should not be unsupervised out of their homes, so, too, must preschool wheelchair users be closely supervised as they move about the community. The best way to know that a toddler or child is able to drive a power wheelchair is to have him practice driving it. Prior to that time, the necessary knowledge can be assessed during informal play sessions or during formal evaluations. Prerequisite knowledge is the understanding of cause-and-effect (ie, knowing that an action causes something to happen) and directionality (knowing that if the joystick is pushed this way, it makes the toy turn this way), and the ability to follow single-step commands (eg, stop). Many toys teach these concepts, and children as young as 18 months can learn them. However, if the child has cognitive or perceptual motor problems, as do many children with myelodysplasia, he or she may need extended teaching and practice on these concepts. Toddlers and young children who are being assessed for their ability to drive a power wheelchair should be tried in the most compact wheelchair, with the drive mechanism underneath their body (such as midwheel-drive wheelchairs). Because the concept of a trailing wheelchair is difficult to understand before a young child has had driving experience, driving a chair with a large part behind the child may result in accidents that may injure caregivers or environmental objects.

School-Age Children (Approximately 5–12 Years Old)

School-age children need increased freedom in their environment and need to explore in larger areas. A child

who can independently propel a manual wheelchair in the one room of a preschool may not be able to propel throughout the larger elementary school and playground. Thus, power mobility may become necessary to promote independence in this larger setting. With the beginning of elementary school, many children are transported by a school bus. All wheelchairs that will be transported in any kind of vehicle should be transit-ready and meet WC19 standards (2).

Adolescents (13 Years and Older)

Adolescents need more independence than younger children and thus must be provided with mobility that allows them the maximum freedom in their environments. Their schools are typically larger, and they will probably want to explore their communities. Even when adolescents with spinal cord dysfunction have the ability to walk short distances or propel a manual wheelchair on level surfaces or for shorter distances, they may not be able to keep up with nondisabled peers. To give them the ability to keep up, they may need both a manual wheelchair for indoors and exercise and a power wheelchair for longer distances and outdoors. Another consideration about whether to use manual or power mobility is the preservation of shoulder function. Many studies have addressed the issue of shoulder problems in persons who are long-term wheelchair users (3–5). Whether the wheelchair prescription will take future shoulder overuse into account will depend on the judgment of the physician. Most pediatric specialists do not consider this in their prescriptions and leave shoulder problems to be dealt with by their colleagues who work with adults with disabilities.

As adolescents reach the age of driving, they will need to have a wheelchair and vehicle that they can manage independently, if at all possible. For the adolescent with limited arm function or who is a power wheelchair user, this vehicle will most likely be a van with a lift and wheelchair securement system. Such a system may be very different from one used when the adolescent is transported by an able-bodied adult who can manage a mechanical ramp and 4-point tie-down restraints. To allow true independence by the wheelchair user, the lift must be powered and the tie-down system must be a docking system that allows the wheelchair to be automatically tied down when it is driven into place. The biggest limiting factor in gaining true independence in this area is the high cost of vehicles with necessary adaptations. Table 1 shows various options for mobility at different levels and ages.

General Principles of Seating and Mobility

While mobility equipment enables the child or adolescent to move about his environment, the seating system enables him to sit safely and comfortably in the mobility device. Goals to be achieved in prescribing mobility devices and seating systems for children of all ages with

Table 1. Equipment Options for Mobility at Different Levels and Ages

Age, y	Level	Manual	Power	Control	Special Features
0–3	Paraplegia	Stroller or twin stroller	Riding toy	Hand	
	Tetraplegia	Stroller or twin stroller	Riding toy or power w/c*	Hand	
3–10	Paraplegia	Manual w/c or adapted stroller	None except in special circumstances		
	Tetraplegia	Manual w/c or adapted stroller	Power w/c	Hand, chin, TTK [†]	Tilt, recline, vent tray, standing
>10	Paraplegia	Manual w/c	None except in special circumstances		
	Tetraplegia	Manual w/c	Power w/c	Hand, chin, TTK	Tilt, recline, vent tray, standing

*TTK = tongue-touch keypad, w/c = wheelchair.

spinal cord dysfunction include: (a) improve the quality of life, (b) maximize function, (c) normalize tone, (d) increase comfort, (e) distribute pressure, (f) provide support, and (g) provide transportation. The order of importance of these goals depends on the age of the child, the specific level of spinal cord dysfunction, and the child and family members' preferences.

Evaluation for seating systems should begin with a complete neuromusculoskeletal examination, which includes tone, reflexes, range of motion, strength, sensation, balance, perceptual motor skills, functional level, independence in transfers, and cognition. Width and height measurements should be taken as part of this examination to determine the size of wheelchair and components. Discussion should then be held with the child (if old enough) and caregivers to determine the conditions in which the wheelchair will be used (eg, only indoors, outdoors on pavement, or outdoors on rough terrain). How will the wheelchair be transported: by automobile, by van with or without lift, or only on the school bus? Based on this, it should be determined whether a power, power-assist, or manual wheelchair is the best for the situation. If a manual or power-assist wheelchair is decided upon, the type of frame needs to be determined: adapted stroller, folding, rigid, reclining, or tilt-in-space. Most adapted strollers do not allow the child to self-propel, but these may be suitable for the child who usually walks or the child who is unable to propel any type of wheelchair. Deciding between a folding or rigid-frame wheelchair is usually a personal choice of the user and his caregivers. Rigid-frame wheelchairs are usually lighter-weight and more durable, but they are larger to store in a car trunk or closet. Reclining or tilt-in-space wheelchairs are helpful for children who need changes in position in the wheelchair and are unable to do it themselves. Table 2 summarizes characteristics of available types of wheelchairs.

The differences between power-assist and power wheelchairs should be presented to the child and family.

Power-assist wheelchairs allow the child to begin the propulsion cycle manually, with the mechanical power source then providing assistance. A power wheelchair requires only minimal movement of a hand, foot, chin, or other part of the body. A power-assist wheelchair provides more exercise for the child than a power wheelchair but cannot be used by a child with high tetraplegia or medical conditions that greatly limit endurance. A decision about what type to prescribe requires consideration of the child's abilities, the need for exercise, the type of vehicle the wheelchair will be transported in, and available financial resources. Algood et al (6) looked at the relative merits of a power-assist wheelchair compared with a manual wheelchair in adults; however, the principles likely apply to children as well. Table 3 summarizes the pros and cons of different types of wheelchairs.

Another issue that needs to be addressed when considering a power or power-assist wheelchair is exercise. For a child who has the ability to propel a manual wheelchair, that is a valuable source of exercise. If it is decided that a power wheelchair provides more independence at school and in the community, then a manual wheelchair should still be used in smaller spaces, at home, and at school whenever possible.

Components that need to be determined include type of wheels and casters, hand rims, drive mechanism (eg, one-arm drive, specialized hand rims), armrests, brakes, and positioning belt. The next step is to determine the type of seating system needed: standard upholstery with or without a pressure-relieving cushion, linear system, standard molded system, or custom-molded system.

If a power wheelchair is chosen, the same positioning principles as above apply. In addition, the drive mechanism must be determined. Options include hand-driven joystick, chin control, head control, tongue-touch keypad, and pneumatic switch. If possible, the child should try the various options and choose which he or

Table 2. Physical and Mechanical Characteristics of Available Types of Wheelchairs

	Rigid Frame	Folding Frame	Tilt-in-Space	Reclining Frame	Tilt-in-Space and Reclining Frame
Weight	Lightest				Heaviest
Durability	Greatest		May be problematic		May be problematic
Use	Pt* can self-propel	Pt can self-propel	Pt dependent	Pt dependent	Pt dependent, need to open hip angle
			Needs change in position	Need to open hip angle	Needs change in position
Use with custom-molded back	Yes, rarely done	Yes	Yes	No	No
Fold	Back folds down	Folds	Not easily	Not easily	No
Size when folded	Box and wheels	Narrower			
Vehicle needed	Car, van	Car, van	Easier in van	Easier in van	Van

*Pt = patient.

she prefers, with guidance from the rehabilitation team for first-time power wheelchair users. Young children and those with cognitive or perceptual impairments may need a long training period to learn to safely use power mobility. This training has been extensively discussed in Kangas (7).

All individuals who use power wheelchairs or who ride in their manual wheelchairs in vehicles should have headrests and their wheelchairs should be WC-19 compliant, meaning that the equipment has passed crash testing. A current list of compliant wheelchairs can be viewed at the following Web site: <http://www.ercwts.pitt.edu/WC19.html> (2).

This site discusses the meaning of WC19, provides safety information for using wheelchairs in vehicles, and provides an updated list of wheelchair models that are WC19 compliant.

Many factors determine what kind or kinds of mobility devices and seating systems are to be used. Making this determination involves a whole team: the child and family members, therapists, a physician, an assistive technology provider, and, perhaps, teachers.

COMMUNICATION EQUIPMENT

Communication equipment or assistive technology includes equipment that enables the child or adolescent

to communicate with caregivers and others in his/her environment. Equipment includes that which provides voice output or communication as well as computers and other devices for written work. Before a child can use any type of equipment, he or she must first develop a reliable method of access. This may include a simple on/off switch, joystick, keyboard, mouse, trackball, tongue-touch keypad, or head array or controller. If the child is capable of using several interface methods, then he or she should choose the method he or she prefers for each type of device to be controlled. Ideally, the child should be given a chance to practice with each type of controller before making this decision.

Infants, Toddlers, and Preschool Children (Birth–5 Years Old)

Infants and very young children can begin learning that an action done by them makes something happen. This learning of cause-and-effect occurs by age 18 to 24 months in typically developing children and is the basis of understanding how to use a switch. There are many toys that promote this learning, and many can be modified for use with a simple switch for those with impaired upper-extremity function. More complex is a joystick that combines cause-and-effect with directionality. Children as young as 2 years of age can learn to activate a joystick

Table 3. Pros and Cons of Different Types of Wheelchairs

	Manual	Power-Assist	Power
Highest ASIA* level	C5	C5	All
Energy expenditure	Highest	Intermediate	Lowest
Shoulder trauma	Highest	Intermediate	Lowest
Ease of transportation in a vehicle	Easy	Intermediate	Difficult

*ASIA = American Spinal Injury Association Impairment Scale.

to move a toy. This activity can be used for practice prior to attaching the joystick to an assistive device.

School-Age Children and Teenagers (6 Years and Older)

When children begin school their worlds expand and expectations for written work increase each year. While a child with weak arms may be able to write a few words or short sentences, he or she may not be able to write a paragraph or several pages. Thus, equipment must be considered that will allow independence in this area of schoolwork. Another option is dictating to an aide who then writes the work, but this is not always acceptable to the child or teacher.

Types of Communication Equipment

Types of communication equipment for speech vary from that which is simple and readily available in any environment to that which is high tech. Examples of the former include pictures, head nods or eye blinks, or eye-pointing to pictures or letters. If a child has a tracheostomy, communication can be facilitated by the use of an uncuffed tracheostomy tube or a one-way speaking valve. A one-way speaking valve should never be prescribed until an assessment has been done to insure that there is adequate space between the tracheostomy tube and the trachea for air to flow up toward the mouth. Speech language pathologists are usually the professionals who do this assessment. The speaking valve should only be used when the child is awake and in the presence of an adult who can quickly remove it if there are airway problems. Communication in a child with a tracheostomy and ventilator can be facilitated by using either an uncuffed tracheostomy tube or by deflating the cuff of the tube to facilitate voicing. Ventilator parameters can be modified as tolerated. Larger breath volume and longer inspiratory time facilitate oral speech volume and length of phrases. An inline one-way speaking valve may be used if the child has an uncuffed tracheostomy tube and evaluation of airway space has been done as noted above.

Written-communication devices may include splints that hold a pencil or pen for those who have some arm function or mouthsticks for those who have no arm function. Computer access may be via keyboard or modified keyboard (eg, larger size), mouthstick, pneumatic switch, head mouse, or switch. Speed can be increased with the use of word-prediction software. Voice-activated word-processing software may be recommended, but it is difficult to use in a noisy area or for children who have dysarthria or weak voices. Many children who have some arm function prefer to use their hands in place of voice-activated software, because of their familiarity with using their hands.

Use of both low-tech methods and high-tech assistive technology should be begun as soon as the child is able, because even children as young as 2 or 3 years old can

learn to use mouthsticks and switches. The sophistication of the device can be increased as the child becomes older and has more capabilities.

EQUIPMENT FOR ACTIVITIES OF DAILY LIVING

In deciding which equipment to recommend for activities of daily living (ADLs), the child must be evaluated and his/her abilities compared to age norms. Toddlers and preschoolers may do little more than feed themselves, so in them this may be the only focus of ADL training and equipment. Since feeding is one-way the child can control his environment; gaining independence in this may help the child to be more cooperative in other areas. Feeding devices are usually splints with adapted utensils and plates. A simple feeding device for a child with arm function but no grasp (eg, a child with a C5 or C6 injury) is a palmar band that holds a spoon or fork.

Equipment for dressing is often rejected as being too cumbersome and slow. Such equipment includes reachers, stocking aids, Velcro instead of other fasteners, loops on clothing to enable it to be gripped more easily, and other clothing modifications (eg, elastic waistbands, shoes with no ties) to make dressing easier. Bathing and grooming equipment includes long-handled sponges and combs, special bath benches or chairs, and catheter clips to assist in holding bladder catheters. For adolescent girls with tetraplegia who desire independence in intermittent catheterization, a Mitrofanoff urinary diversion procedure may be recommended. This procedure places the urinary stoma at the umbilicus, which is more accessible than the perineum.

The most important aspect of determining ADL equipment is to analyze what needs to be done, then to determine what is available to assist the child in doing the task independently or with minimal assistance. There is no substitute for ADL instruction by an experienced occupational therapist.

Although many kinds of ADL equipment are available, much of this equipment is rejected by children, teenagers (and even adults), and their parents as being too cumbersome and too slow. Time constraints and lack of patience often force children and adolescents to let somebody perform most ADLs for them.

RECREATION EQUIPMENT

A wide range of recreation equipment is available to accommodate children of all ages. Recreation is often the most neglected area during acute rehabilitation following spinal cord injuries. Children and adolescents should be introduced to adapted sports and recreation prior to initial discharge, and this area should be further discussed at rehabilitation clinic visits. Recreational activities often can be used to achieve new rehabilitation goals, such as strengthening or increasing endurance. Some insurance companies will reimburse for the purchase of recreational equipment in lieu of sessions of physical or occupational therapy. For example, the

purchase and use of an adapted bicycle may be substituted for several sessions of physical therapy at a lower cost when the cost-differential is noted. Children and families should be provided with information about local and national resources for various types of recreation. The local Center for Independent Living (8) may be a good starting place in learning about what is available. Rehabilitation professionals should also act as advocates in establishing adapted recreation programs and adapting regular programs to meet the needs of children with spinal cord dysfunction.

CONCLUSIONS

In conclusion, rehabilitation equipment in all areas enables children and adolescents with spinal cord dysfunction to participate in “typical” activities of children their ages. The range of equipment available is huge, and its use is only limited by its cost and the child’s desire to use it. Children’s ability to participate with their peers in a wide range of activities and their quality of life is improved by the use of these types of equipment.

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