

Residential & Workplace Accommodations* and Assistive Technology for **Quadriplegics**

PART-1 ACCOMMODATIONS* (updated to July 2002)

The National Institute for Rehabilitation Engineering (NIRE) is a non-profit organization which operated clinics to design, dispense and fit customized assistive equipment with user training, from 1967 through 1996. Working with disabled people's own doctors and therapists, these NIRE clinics assisted *hundreds* of people having severe and permanent motor impairments. *The N.I.R.E. pioneered the development and use of personalized quadriplegic self-care and mobility aids; appliance controllers; communications aids; adapted computers and office equipment; power wheelchairs (steered and controlled with inertial guidance systems or with breath controls, by people unable to use hand controls); and adapted road vehicles.*

Although the NIRE no longer operates these clinics, it is still active in dispensing "Accommodation" and "Assistive Technology" information, advice and referrals. *PERMISSION is granted for the free copying and distribution of these © papers, provided all copies are complete and unaltered.*

Part-1, this part, discusses "Residential & Workplace Accommodations for Quads"

A separate **Part-2** discusses "Assistive Technology" and "Adapted Vehicles"

QUADRIPLEGICS are individuals unable to move their arms and legs. This often results from neck or spinal injuries which damage or sever the spinal cord. Sometimes, quadriplegia is the result of a neurological disease such as Multiple Sclerosis or Amyotrophic Lateral Sclerosis (ALS or Lou Gehrig's Disease). "Quadriplegia" means to be paralyzed in all four extremities. Some quadriplegics *also* have breathing impairments requiring their use of electrically powered air pumps called "ventilators."

QUADRIPARETICS are similarly disabled except that their four-limb paralyses are less severe. This term signifies partial use of at least one limb and/or a hand or some fingers. Our use of the term "**QUAD**" designates either a full quadriplegic or a quadriparetic. The full term is used when needed. A small percentage of people with Cerebral Palsy are "functional quadriparetics" with stable disabilities that neither worsen nor improve with time. Some Cerebral Palsied also have impaired speech.

THIS PAPER applies to "Quads" who have partial to total paralysis of both arms, both hands, both legs, and both feet. (1) Some Quads can freely move and support their heads; others cannot. (2) Some Quads can position and move their hands but not use the fingers. These people can use a tool attached to one or both hands to typewrite or to press buttons, one at a time. (3) Other Quads cannot use their hands or arms at all. (4) Some Quads have useful finger dexterity in one or both hands.

ACCOMMODATIONS, ACCESS & ASSISTIVE TECHNOLOGY - Both disability types, spinal injury or neurological disease, often become permanent after the first 3 to 6 months of disability, if not arrested, lessened or reversed in that time. The most effective medical care is that given by experienced neurologists within hours after an accident or injury. *This paper offers information and recommendations relating only to "Environmental Accommodations" "Access" and "Assistive Devices" to functionally*

help permanently paralyzed individuals. It does not offer medical advice - except to urge disabled people to be under the care of qualified physicians.

Environmental Access Accommodations may include wheelchair ramps, lifts, elevators, bathroom and kitchen modifications, and special workplace modifications.

Assistive Devices are non-medical tools which relate to and assist with mobility, transportation, communication, activities of daily living, and performance of job related activities. (NOTE: Implanted medical devices, such as pacers or muscle stimulators, are not considered “Assistive Technology.” They usually fit in the realm of “Bio-Medical Engineering.”)

NOTE: This paper is for quads who have adequate to normal speech, hearing and eyesight. Quads who also have impaired speech, hearing or eyesight should contact the N.I.R.E. and request papers dealing with their added disabilities.

For Newly Disabled Individuals, the first major steps take place in the hospital. The patient may have been taken from the accident site to a general hospital for treatment or surgery. If so, the patient’s condition is stabilized and the patient is observed to determine if the paralyses are lessening, worsening or seemingly stable.

At some point, the patient is transferred to a rehabilitation hospital or facility where he or she can be given intensive daily physical therapy. Additionally, occupational therapists will teach the patient to perform “activities of daily living” or ADL, using special methods, procedures and tools as needed.

The object of the therapy is to help the patient become as strong, functional, and self-sufficient as possible so as to be able to resume as normal a life as possible. Further prognoses should be obtained as to the likelihood of future lessening or worsening of the functional disabilities. This is important to know when planning costly residential modifications.

Typically, people with spinal cord injuries stabilize so as to experience little change over time. It is the same for the Cerebral Palsied. However, persons with neurological diseases, such as Multiple Sclerosis, may slowly worsen or may go through cycles of worsening and remission, followed by worsening again.

Caregiver’s Age and Health are very important, especially when the disabled person is adult size and heavy to lift and transfer. A handicapped adult who is unmarried and is to live with his elderly mother, would probably need daily assistance from a hired aide because of the mother’s physical limitations. In contrast, a young quadriplegic might well be cared for by a young and healthy spouse without the need for daily help from a paid aide.

Patient’s Age is very significant when planning or implementing rehabilitation of quads or other severely disabled individuals. Fewer structural renovations are needed in a

residence for a disabled child than for a full grown adult. Also, rehabilitation goals and methods may differ for disabled people in various age categories:

1. Children require decisions whether to be schooled at home, in a public school, or in a private school for the disabled. Typically, they need special tools and special training in school - as well as adapted equipment at home for their homework. With effective guidance counseling, the permanently handicapped child can choose a profession or occupation that is appropriate and attainable.
2. Young Adults may need to change their occupational goals and to undertake special education or training for occupations other than originally planned. A mason, for example, may not be able to perform construction work as a quad. He might choose to become a construction office worker – a salesperson or a buyer – in the same field which he knows so well. Or, he might take training for an entirely new occupation – such as computer programmer – in either case depending on special tools and assistive devices.
3. Mature Working Adults with established careers often desire to continue their professional lives and their home lives much as before, with environmental accommodations and using special adaptive equipment, methods and tools. People in this situation often can do what they desire but with many more adaptations and accommodations. *EXAMPLE: The world-famous scientist, Stephen Hawking, has been able to continue his full-time career for over twenty years after becoming a total quadriplegic, and totally non-vocal. He still works full time.*
4. Retired or Retiring Adults sometimes choose to continue in their previous life styles as best they can, remaining in the old residence and trying to work part-time at the old profession. This may require live-in aides or visiting nurses and therapists, which are costly and time consuming. Other quads use their retirement to advantage by moving into a suitable “Assisted Living” center, alone or with their companions, where aides and therapists are always on the premises and available when needed. These quads can live comfortably and socialize with little burden to themselves or to their companions as to cooking, cleaning, shopping, etc. Often, they write, consult, or otherwise occupy themselves part-time.
5. Elderly People in Poor Health may still need to be in assisted living or in a nursing home, whether or not they are quads. Also, quads with severe mental impairments are often better off in facilities staffed for working with quads - as opposed to those facilities with few quads, or none, as residents. They need daily physical therapy, occupational therapy and recreational services so that facility selection is of the utmost importance for these ill or mentally impaired quads.

STEPS TO FUNCTIONAL REHABILITATION

with Environmental Accommodations and Assistive Technology

ACCEPTANCE of the Disability Prognoses and Its Reality ... by the patient and his family are very important to facilitate discharge planning and post-discharge rehabilitation services. If the patient or members of his family refuse to accept a prognosis of permanent quadriplegia - if they persist in thinking the paralyses will abate – then they may not work diligently enough to undergo successful functional rehabilitation. The patient and his family must understand and accept the details of every way in which the patient will be functionally handicapped and need help. Knowing the details allows planning to compensate or work around every functional need. Obscuring the details, to spare the patient’s feelings, will invariably obstruct, delay or block many of the necessary accommodations. This is true for patients in all age groups.

EARLY - DISCHARGE Planning ... by the staff, the patient and his family are very important. It is tempting, but risky, to plan too far ahead before the hospital discharge. We recommend to NOT plan expensive changes early on. Purchase of a w/c transporter van should be delayed while temporarily using a paid w/c transport service. Complex and expensive home renovations should be delayed, also. Purchase of computer systems, appliance control systems, etc. should be delayed. However, trial fittings, user training and purchase of a power wheelchair should NOT be delayed because independent personal mobility is a necessity at the time of discharge

Permanent Residential Access Accommodations can cost tens of thousands of dollars and can involve structural changes to a residence that cannot later be reversed. Most newly disabled quads cannot afford to pay such costs with their own money. Thus, many months are needed to determine and verify needs and to create written plans that include medical and therapist recommendations, contractor’s proposals, and architectural drawings and approvals. All of these materials must be submitted to governmental agencies such as those for Medicaid, Vocational Rehabilitation, Medicare, applicable insurance companies, if any, etc. in a quest for funding for most or all of the expenses. To gain the required time, it is recommended that the newly disabled quad be discharged to his previous residence with temporary but low-cost accommodations.

Temporary Residential Accommodations should be planned and made with the help of a visit to the patient’s existing residence by the patient’s Occupational Therapist. These are the minimal accommodations which must be met in order for the patient to return home from the hospital. Once at home, the patient and his companion should start making lists of additionally needed and desired accommodations. Such lists will be invaluable for planning more permanent accommodations. The patient and companion should live with the **Minimal Temporary Accommodations** for at least 3 to 6 months before committing to major renovation expenses. It takes at least this long to fully understand the family’s needs and to decide on the best options.

1. Temporary Ramps to facilitate wheelchair entry to and egress from the first floor of the residence.
2. Preparation of a Temporary Bedroom Area on the ground level floor, if a private home. Or, in a suitable area of an apartment, assuming the apartment has an elevator or is w/c accessible.

3. Rental or Purchase of Special Bathroom Equipment – if the patient can access and use the existing bathroom. These appliances might include a bathtub lift or a shower chair, as appropriate; a toilet seat riser and/or special handles - if useful for w/c to toilet transfers; or a Hoyer Lift on wheels - if it will fit and be useful in the existing bathroom.
4. Rental or Purchase of Needed Bedroom Equipment – such as Hoyer Lift for patient transfer; an adjustable bed with mattress and bedsore-prevention pad (as recommended by the hospital therapists); bedside tables – lamps – TV set; a commode chair toilet as recommended by the OTR (if the patient cannot adequately access and use the ground floor bathroom); a space to park and recharge the power w/c when it is not in use. *Note: If the patient cannot bathe in the existing bathroom, then washcloth bathing on the bed may be necessary in the bedroom, for which a baby's bathing stand might be handy for handling the soapy water. (This would be temporary until major bathroom accommodations can be made)* Also, one or more cabinets for easy-access storage of the patient's tools, appliances and medications.
5. Outside Domestic Help Services to avoid overwhelming the patient's companion with the many tasks, chores and services that are needed each day, should be planned and arranged. These might include services, in the home, by any one or more of the following: a home health care aide or practical nurse; a visiting nurse (to give catheter care and/or inject medications); daily to three times per week physical therapy – in the home or at a PT center; visits to the home by an Occupational Therapist to assess and train the patient, the spouse and others in ADL procedures, shortcuts, and use of assistive appliances, etc. (the OTR will also help plan expanded future accommodations whether in the same residence or elsewhere.) Paid house cleaning services may also be helpful.
6. Some Convenience Appliances Can Be Gotten for the patient as soon as it is evident that the patient and spouse are managing and will continue to manage adequately in the temporary accommodations. These appliances might include a work table or desk compatible with the wheelchair; a special telephone that can be used by the patient, unaided; and a personal computer that can be used by the patient, unaided. *Procurement of these devices is discussed in Part-2 of this paper.* Being able to originate and receive telephone calls when alone will greatly help the quad, as will being able to use the internet, to send and receive e-mail, and being able to type, print and (electronically) file letters or papers. Banking can be done through the internet, also, and the financial records can be kept.

Permanent Residential Accommodations should be planned during this 3 to 6 month trial period. An unknown variable which differs in every situation is how the quad and his companion adjust to their new situation. If there is one quad and one companion, then one must ask: can the companion stay at home as a fulltime caregiver? Or must the companion work at a full-time job, thus having to pay an aide to be at home each

workday? Is the companion healthy enough and strong enough to perform the necessary tasks of shopping, cooking, and housekeeping for two, PLUS all the tasks of a full-time caregiver? Will the companion continue to enjoy all this work and responsibility? Or, will he or she become overwhelmed by it all? The answers to these questions usually become evident during the initial 3 to 6 months after discharge from the hospital.

Basic choices need to be made about the questions just asked. Also, as to whether the existing residence should be expensively modified – if it is a private home that is owned by the quad and/or the companion. Or, whether they should be in a rented apartment which is approved for adapted, disabled occupancy – or whether they should reside in a “Group Assisted Living Facility” where most or all needed services are provided. Note: some such facilities accept disabled people, only – others can accept and comfortably accommodate both a quadriplegic and the non-disabled spouse, companion or parent.

TYPICAL ENVIRONMENTAL ACCOMMODATIONS for Quadriplegics ... may include these features:

1. **Ceiling Mounted Lifting Machines** with ceiling tracks, for patient transfers. These affect the structural integrity of the building and thus require the services of an architect, in addition to those of the installing contractor. Typically, a track runs between the bedroom and the bathroom. This accommodation is very costly but far better than using a Hoyer Lift on wheels. Some quads can operate the lift alone, unaided. Others require help from aide, spouse, parent or companion.
2. **Permanent Wheelchair Ramps** for front, side or rear door entry and exit are much safer and longer lasting than temporary ramps. They cost much less than elevators and, unlike elevators, the ramps work just as well during power outages.
3. **Wheelchair Elevators** may be needed for a private home, to access the second and higher floors. These are prohibitively expensive and, being inoperative during power failures, can be dangerously confining. We often recommend to not use such elevators to access higher floors in a private residence. Instead, a two or three room addition can sometimes be made to an existing house at ground level, to provide accommodating rooms: bedroom, den and bathroom without need for an elevator and without an elevator’s costs and hazards. If the lot size permits this, then this is the recommended course. It also makes the house easier to sell.
4. **Enlarged Hallways and Rooms** may be necessary in some residences. This is very costly. Adding on one or two rooms and a bath is less costly and more satisfactory in most instances.
5. **Special Bathroom Facilities** might include either a bathtub with a special patient lift - or a stall shower with an appropriate roll-in shower chair. An Occupational Therapist can help determine which is best and how to design and implement the chosen tub or shower arrangement. The doorway needs to be wide and the bathroom needs to be large enough for wheelchair navigation and transfers. The sink needs to be at an appropriate height and have open legroom underneath with

an offset drain trap (with no cabinet). It also needs to have special handles and a special spigot for easy use by the quad in his wheelchair. The toilet needs to be wheelchair accessible and the correct height, and there needs to be an overhead ceiling lift to facilitate transfers back and forth between w/c and toilet. The toilet needs to have a spray cleaning system built-in if the quad cannot handle and use toilet paper. There will need to be appropriately mounted mirrors and storage cabinets in the bathroom. There should also be an alarm and intercom system so that the quad can call for assistance if needed.

6. **Special Kitchen Accommodations** may also be desired, especially if the quad wants to be able to prepare and serve food and cleanup afterwards. It is relatively inexpensive to provide, in the kitchen area, a dining room table that is wheelchair compatible. However, to equip a kitchen for quadriplegic access to cabinets, refrigerator, stove, oven, microwave oven, and countertops - requires major work and is very expensive. An occupational therapist can be very helpful in planning and designing this type of kitchen, especially when working in cooperation with an architect and contractors. *If a house has only the one kitchen, these modifications are so extensive and "different" looking as to greatly reduce the salability of a house after the work has been completed.* However, if the main kitchen is left alone and a small "quad accessible" kitchenette is included in the add-on room discussed above, then the house's value is not lowered nearly so much. (The same can be said of the bathroom alterations.)

7. **Funding All These Residential Accommodations** is a major challenge for the quad and his companion, spouse or parent. **MEDICARE:** Enrollees (65 or older) may have lifts, wheelchairs, respirators and power wheelchairs paid for on presentation of proof or "Medical Necessity." There is no income test for these benefits. The equipment vendors should know how to apply. **OTHER FUNDING:** Typically, for **low-income people**, state **Medicaid** will meet many of the costs if – and only if – the costs for facilitating outside, independent living are to be less than the costs for housing the quad in an assisted living facility or nursing home. If the person has a long life expectancy (and is relatively young) then the one time accommodation costs, high as they are, will cost the state far less than the recurring costs of nursing home care. For **middle-income** people, it is often necessary to take a second mortgage to self-finance the required modifications. This is complicated by the need to make monthly payments to repay the new loan, and by the fact that the resale value of the home may be significantly lower, after the modifications, than before. For **wealthy or high-income people**, these expenses can often be met out of pocket. If the quad has no spouse, companion or parent to live with, it is far easier to get into, and live in an appropriate assisted living facility or nursing home. In some areas there may be the option to live in an apartment shared with other quads, who share the costs (using public funds or their own funds) of one or two paid aides who assist all three or four quads. The most difficult arrangements are when a quad and his spouse, companion or parent desire to live in a private home that has been renovated to be fully accessible and quad-compatible.

8. **Assistive Technology Devices, Appliances, and Tools** will be needed in the newly made “accessible and accommodating” residence. See Part-2 of this paper for information about these devices and appliances and tools.
9. **Workplace Accommodations** for the employed or self-employed quadriplegic are often financed by the state’s federally funded “Vocational Rehabilitation “ program. Either the disabled employee or the employer should contact the state agency for an on-site workplace assessment, recommendations and funding. The state agency should be contacted as early as possible, even while the newly disabled quad is still in the hospital. *Assistive Technology Devices will be needed by quads in the accommodating workplace and are usually paid for by the state agency. See Part-2 of this paper for information about these devices.*
10. **Transportation Accommodations** are also important and may involve public or private transportation. In many urban and suburban areas, free or low-cost “Dial A Ride” **door-to-door bus or van service** is provided. Generally, this is more reliable and more comfortable than using public buses or trains. While **subway trains** are often not wheelchair accessible, **surface trains** more often are accessible. Some **public buses** can load, transport and unload people in wheelchairs. Information about this should be available by telephone from your city or county administrators. **AMTRAK trains** often are wheelchair accessible but **commuter trains** may or not be accessible. As for air travel, most **airlines** will load, transport and unload wheelchair users while storing and transporting the wheelchair. There are certain safety requirements and restrictions relating to transporting power chair and their batteries. Air travelers must discuss this with the airline they plan to fly with, to avoid last minute boarding problems. Some airlines allow disabled passengers to have a companion along on a free or discounted fare. **Private wheelchair transport vans** are a great convenience for many quads. These vans are costly to own, maintain and operate. Some people pay **van taxi services** to transport them. Others buy their own vans which are driven by the quad, by a family member or by a paid driver. Part-2 of this paper deals with this subject in greater technical detail. ***ALL WHEELCHAIRS, AND w/c OCCUPANTS, MUST BE SECURED IN PLACE, in vans, TO PREVENT INJURIES OR DEATH IN CASE OF SUDDEN STOPS OR ACCIDENTS!***

For additional information or free technical support, please email: nire@warwick.net or contact us by regular mail or telephone.

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