

PHYSICAL THERAPY

The mission of BDSRA is:

To be an international support
and research networking
organization for families
of children and young
adults
with an
inherited
neurological
degenerative
disorder known
as Batten Disease.

“A light in a world of darkness...”

WELCOME

NOTICE TO THE READER

This Batten Disease Handbook is compiled with information from many sources concerning the topics included. Families in the organization have also contributed their specific situations that have been helpful in their own battle with Batten Disease. All material in this book is provided for information purposes only. Although Batten Disease Support and Research Association (BDSRA) has made every reasonable effort to assure the accuracy of the information contained in this book, BDSRA is not engaged in rendering medical or other professional services and advice. BDSRA does not guarantee or warrant that the information in the book is complete, correct, current, or applicable to every situation. BDSRA disclaims all warranties express or implied, concerning this book and the information contained herein. If medical or other expert assistance is required, the services of a competent professional should be attained.

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Batten Disease Support and Research
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PHYSICAL THERAPY MOTOR DEVELOPMENT AND RELATED TOPICS

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PHYSICAL THERAPY

MOTOR DEVELOPMENT AND RELATED TOPICS

I. Physical Therapy

A. What is Physical Therapy?

Physical Therapy is the science of treating people with physical special needs (or those who may develop physical disabilities), to help them minimize and/or maintain basic functional abilities (e.g., sitting, standing, walking) and minimize their condition from progressing as much as possible. This is accomplished through training for daily activities and treatment such as Physical Therapy and Occupational Therapy in using different methods of available treatments.

Physical Therapy (PT), also known as Physiotherapy, was introduced in the United States following WWI (1914) to rehabilitate soldiers following the war. The profession has grown to include many subspecialties such as orthopedics, sports, chronic pain syndrome, industrial rehabilitation for injured workers, as well as, those recovering from injury, surgery, or physical special needs from illness.

Physical Therapy is viewed in other countries and cultures very differently than we do here in the United States. For example, in Holland, Physical Therapy is aggressive in children with progressive neurological degenerative diseases until a diagnosis has been reached. Once Batten Disease has been diagnosed in a child, Physical Therapy stops and activities are individualized for each child as to what they are able to do and what they enjoy doing. They feel that children become very happy and content at being successful in things that they are able to do and enjoy.

Physical Therapy combines passive modalities with therapeutic exercise to strengthen the spine and extremities. A Physical Therapist talks at length with each new child and his/her parents and performs simple tests including checking the strength and range of movement of the trunk, arms and legs. A Physical Therapist, with carefully controlled exercises, can help many children.

Exercises can strengthen muscles and improve a child's range of movement. Exercise also helps some children improve their balance. Your child may perform exercises alone or with a Physical Therapist's help. Active therapy or therapeutic exercise includes stretching and postural modification to strengthen the spine and minimize re-injury. A Physical Therapist may help your child stretch an arm or leg to more functional limits. Passive modalities include heat/cold therapy, ultrasound, electrical stimulation, and joint mobilization. A Physical Therapist has several ways, other than exercise to treat children. The use of warm water whirlpool baths with swirling whirlpool currents often relax stiff and painful joints. Ice packs can reduce swelling and heating pads can ease pain. Massage is another modality that loosens tight muscles. Physical Therapists often help children heal, feel better, gain strength, and regain their use of body parts as much as possible.

So to sum up what Physical Therapy is - it provides treatment that help maximize function, improve mobility, relieve pain, and minimize physical special needs of children suffering from illness or injuries. Physical Therapy is used to: ease the pain of sprains and strains and minimize further injuries, plan treatment programs for children who have neurological, orthopedic, and other disorders, reduce pain and improve motion, test for exercise stress, evaluate low back pain and eliminate functional causes, and rebuild self-confidence and interest in returning to an independent active life as much as possible.

There are Physical Therapy Assistants that perform components of Physical Therapy procedures and related tasks selected by a supervising Physical Therapist.

Also, Occupational Therapists can work with Physical Therapists on a very close level. Occupational Therapists help children improve their ability to perform tasks in their activities of daily living. Occupational Therapists help children succeed in their "occupation" of learning, playing and growing. Occupational Therapy offers creative solutions and resources for carrying out your child's daily activities. Occupational Therapists may help children to increase their functional level, with improving hand function, strengthening hand, shoulder and

torso, and eating skills. In schools, Occupational Therapists evaluate children's abilities, recommend and provide therapy, modify classroom equipment, and in general, help children participate as fully as possible in school programs and activities.

Sometimes Speech-Language Pathologists are needed to assess, diagnose, and treat speech, language, cognitive, communication, voice, swallowing, fluency, and other related disorders. Audiologists identify, assess, and manage auditory, balance, and other neurological systems.

B. What is the purpose of Physical Therapy?

The purpose of Physical Therapy is to help your child return to active life as quickly as possible and to the best your child can accomplish. Physical Therapy strives to reduce pain, increase flexibility, range of motion, and function, build strength, and correct posture. Child/Parent education is an important component in Physical Therapy. Parents/children learn how their spine works, proper body mechanics, common disorders and their causes, benefits of good posture, importance of physical fitness and its relationship to illness and injury, prevention and progress.

C. Who are Physical Therapists?

Physical Therapists are licensed health care professionals in the state or states in which they practice. Prior to practicing, Physical Therapists must obtain either a Bachelor's or Master's Degree in Physical Therapy and pass an examination to be licensed. Physical Therapists must develop an understanding of humanity's spiritual and social needs as well as physical requirements. Physical Therapists must learn to think logically, to analyze, and to interpret. Physical Therapists must be able to establish good interpersonal relationships.

D. What does the Physical Therapist do?

The Physical Therapist talks to the child/parent and evaluates your child's condition by testing joint motion, muscle strength, cardiovascular function, reflexes, and functional skills. If a Physician refers your child, the Physical Therapist will review the Doctor's prescription along with your child's records. After necessary information has been gathered, the Physical Therapist designs a

treatment plan to fit your child's needs and goals. The Physical Therapist will work together as a team toward wellness or to the best possible solution to the therapy.

Physical Therapists help bedridden children and children whose special needs have resulted from sickness and possibly injury to maximize physical, emotional and spiritual health. Specifically, Physical Therapists offer treatment, by checking and evaluating the physical and mental health of an individual child to determine appropriate treatment methods and objectives.

Physical Therapy attempts to help children develop their gross motor abilities, those that involve the large muscles of the body, such as walking, running, crawling, and jumping. By keeping in close contact with parents and teachers, the Physical Therapist can demonstrate and review methods used to encourage development of your child's gross motor skills. Families are expected to continue working with their child on some of the exercises and activities at home as well. This is essential if improvements are to be made. Without carryover of the program to home and school, where children spend most of their time, the effects of weekly or monthly Physical Therapy sessions would be lost quickly. By working with the Physical Therapist, many parents have become excellent co-therapists for their children. The Physical Therapist also can be instrumental in helping parents learn to use assistive technology and devices that have been prescribed for their children.

Exercise Therapy is intended to relieve pain and to improve motor skills for exercising and daily activities, by strengthening your child's muscles, joints, and balance. Exercise Therapists help children with physical special needs or diminished physical strength, maximize and maintain health. Thus, Exercise Therapy means helping children to recover physical abilities to the extent possible through exercise.

Physiotherapy is intended to relieve pain through thermal therapy, water therapy, light therapy, and electric therapy. It also helps to improve circulation.

Training for daily activities is where Physical Therapists train, advise, and instruct children/parents in order to help them act in their daily lives without any or the least amount of difficulty. They also give advice on how to refurbish homes to facilitate training at home.

Physical Therapy provides services to children who have impairments, functional limitations, special needs, or changes in physical function and health status resulting from illness, injury, or other causes. Impairment is defined as loss or abnormality of physiological, psychological, or anatomical structure or function; functional limitation is defined as restriction of the ability to perform - at the level of the whole child - a physical action, activity, or task in an efficient, typically expected, or competent manner; and disability is defined as the inability to engage in age-specific, gender-specific activities in a particular social context and physical environment.

Physical Therapy interacts and practices in collaboration with a variety of professionals, including Physicians, Dentists, Nurses, Educators, Social Workers, Occupational Therapists, Speech-Language Pathologists, and Audiologists. Physical Therapists acknowledge the need to educate and inform other professionals, government agencies, third party payers, and health care consumers about the cost-efficient and clinically effective services that Physical Therapists render. The rapid shift from the Physical Therapist's responsibility for the total care of your child to the current role of administrator and teacher has resulted from the population explosion, the increased public demands for better health care, and expanded Physical Therapy treatments.

Physical Therapists consult, educate, engage in critical inquiry, and administrate. Physical Therapists direct and supervise Physical Therapy services, including support personnel.

Perhaps the most important quality a Physical Therapist must possess is emotional stability. Physical Therapists must be able to think quickly with little or no time for mediation. Tact is an important personality trait for the Physical Therapist to possess, because people are their business. Physical Therapists must be able to inspire

confidence in children and build a solid working framework with children and their families. Moderate mechanical aptitude is helpful too. Knowing how to handle a screwdriver, hammer, and a wrench is useful. Mechanical ingenuity, the ability to conceive and develop new devices, is a great asset because many Physical Therapists are called upon to improve and adapt self-help equipment. Some knowledge of the fundamentals of basic office procedures is also important, particularly of budgeting and accounting. Dealing with people demands a good vocabulary and the ability to speak and write clearly. Physical Therapists direct children, teach families, instruct nursing school students, supervise Physical Therapy students, report on the children's progress to Doctors and demonstrate Physical Therapy procedures at medical staff conferences. Physical Therapists must be able to write effectively because they will be preparing clinical notes on their children, annual reports of the department's activities to the hospital board of trustees, letters of medical necessity to Doctors and insurance companies, and letters to business leaders and prospective employers.

People come in all sizes, shapes, colors, religions, ethnic backgrounds, social levels, and tax brackets. A Physical Therapist must be able to deal with people as they are, with love, understanding and total acceptance, or Physical Therapy may not be the career for them. It is necessary that a Physical Therapist be willing to have close bodily contact with people, no matter how beautiful or ugly, brilliant or stupid, rich or poor they are. Physical Therapists must be able to shift their mental gears very quickly because they must adapt to different personalities in rapid succession. Physical Therapists must be innovative, looking constantly for improved methods of performance. Physical Therapists must be analytical in order to compare the children's performance from one day to the next, to compare children with the same problems, and to determine how new approaches to old problems can be tried.

A Physical Therapist will need to be courageous. Sometimes it takes courage to convince a Doctor that a different approach to treatment is worth trying. It will take even more courage to fight a legislative assembly in the state capital, or in Washington, for the rights a

Physical Therapist believes will benefit the children they treat. As clinicians involved in examination and in the evaluation, diagnosis, prognosis, intervention, and prevention of musculoskeletal and neuromuscular disorders, Physical Therapists are well positioned to provide those services as members of primary care teams. On a daily basis, Physical Therapists practicing with acute, chronic, Intervention or preventive stages of care, assist children in the following: restoring health; alleviating pain; and reducing the onset of impairments, functional limitations, other special needs, or changes in physical function and health status resulting from illness, injury, and/or other causes. Prevention and wellness activities, including health promotion, are a vital part of Physical Therapy. For acute musculoskeletal and neuromuscular conditions, triage and initial examination are appropriate Physical Therapists responsibilities.

The primary care team may function more efficiently when it includes Physical Therapists, who can recognize musculoskeletal and neuromuscular disorders. Physical Therapy Intervention may result not only in more efficient and effective child care, but also in more appropriate utilization of other members of the primary care team. For certain chronic conditions, Physical Therapists should be recognized as the principal providers of care with in the collaborative primary care team. Physical Therapists are well prepared to coordinate care related to loss of physical function as a result of musculoskeletal, neuromuscular, cardiopulmonary, or integumentary (skin) disorders. Through community based agencies, Physical Therapists coordinate and integrate provision of services to children with chronic neuromuscular and musculoskeletal disorders.

Physical Therapists are involved in wellness initiatives, including health promotion and education that stimulate the public to engage in healthy behaviors. Physical Therapists provide preventive care that forestalls or minimizes functional decline and the need for more intense care. Through timely and appropriate screening, examination, evaluation, and Intervention, Physical Therapists frequently reduce or eliminate the need for costlier forms of care, such as surgery, and also may shorten or even eliminate hospital stays. Physical Therapists are involved in prevention and wellness activities,

screening, and the promotion of positive health behavior. These initiatives decrease costs by helping children:

- Achieve and restore optimal functional capacity
- Minimize impairments, functional limitations, and special needs related to congenital and acquired conditions
- Maintain health (thereby minimizing further deterioration or future illness)
- Create appropriate environmental adaptations to enhance independent function

Before a Physical Therapist begins any test or treatment, your child's confidence must be won. In handling children, it is often necessary to spend as much time in the emotional preparation for treatment as in the actual treatment.

Physical Therapists are committed to providing necessary, appropriate, and high-quality health care services to both children and their parents. Children are individuals who are the recipients of Physical Therapy care and direct Intervention. Children are individuals who are not necessarily sick or injured but who can benefit from a Physical Therapist's consultation, professional advice, or prevention services.

Physical Therapy, which is the care and services provided by and under the direction and supervision of a Physical Therapist includes:

1. Examination

- A. Examination of your child - for the Physical Therapist to gain maximum information regarding your child, he/she should be present at the initial neurological examination and communicate with the Doctor in charge. In this way he/she will gain information regarding:
 1. Your child's illness or injury
 2. General condition
 3. The site and condition of the fracture, if any
 4. The presence of associated fractures or injuries, including any skin lesions
 5. Condition of the chest including the vital capacity
 6. Motor function

7. Sensory function
8. Presence or absence of reflexes
9. Schooling
10. Family history

B. Examination, evaluation, and establishment of a diagnosis and a prognosis are all part of the process that guides the Physical Therapist in determining the most appropriate Intervention. The five elements of child management are as follows:

1. Examination
 - a. History
 - b. Systems review
 - c. Tests and measures
2. Evaluation
3. Diagnosis
4. Prognosis
5. Intervention
 - a. Coordination, communication, and documentation
 - b. Child related instruction
 - c. Direct Interventions
 - d. Outcomes
 - e. Discharge Planning
 - f. Other professional roles
 1. Examining school environments and recommending changes to improve accessibility for students with special needs
 2. Participating at the local, state, and federal levels in policymaking for Physical Therapy services
 3. Performing environmental assessments to minimize the risk of falls
 4. Providing peer review and utilization review services
 5. Responding to a request for a second opinion
 6. Serving as an expert witness in legal proceedings
 - g. Education
 - h. Critical inquiry
 - i. Administration

- C. Examining (history, systems review, and tests and measures) children with impairment, functional limitation, and other health related conditions and special needs in order to determine a diagnosis, prognosis, and Intervention; tests and measures may include the following:
 - 1. Aerobic capacity and endurance
 - 2. Measuring functional capacities
 - 3. Arousal, mental, and cognition
 - 4. Assistive and adaptive devices
 - 5. Community and work (school/play) integration or reintegration
 - 6. Cranial nerve integrity
 - 7. Environmental, home, and work (school/play) barriers
 - 8. Ergonomics and body mechanics
 - 9. Gait locomotion, and balance
 - 10. Skin integrity
 - 11. Joint integrity and mobility
 - 12. Motor strength
 - 13. Muscle performance
 - 14. Neuromotor development and sensory integration
 - 15. Orthotic, protective, and supportive devices
 - 16. Pain
 - 17. Posture
 - 18. Range of motion
 - 19. Reflex integrity
 - 20. Self-care and home management
 - 21. Sensory integrity
 - 22. Ventilation, respiration, and circulation

- 2. **Alleviating impairment and functional limitation** by designing, implementing, and modifying therapeutic Interventions that may include, but not limited to:
 - A. Coordination, communication, and documentation
 - B. Child/parent related instruction
 - C. Therapeutic exercise (including aerobic conditioning)
 - D. Functional training in self-care and home management (including activities or reintegration activities, instrumental activities of daily living, work hardening, and work conditioning)

- E. Manual therapy techniques (including mobilization and manipulation)
- F. Prescription application, and as appropriate for assistive, adaptive, orthotic, protective and supportive equipment
- G. Airway clearance techniques
- H. Wound management
- I. Electrotherapeutic modalities
- J. Physical agents and mechanical modalities

3. Minimizing injury, impairment, functional limitation, and/or any other special needs, including the promotion and maintenance of fitness, health, and quality of life in all age populations.

4. Steps of Treatment

- A. Child evaluation - an assessment of your child's abilities and limitations. 4 types of diagnostic tests may be used:
 - 1. Electrical muscle testing - to determine whether the damage is in the brain, the spinal cord, the nerves carrying the impulse from the spinal cord to the muscle, or in the muscle itself
 - 2. Test of voluntary muscle power - CAT scans help to diagnose and treat children with pain and/or degenerative diseases that affect the joints
 - 3. Joint measurement - with use of a goniometry to measure how many degrees a joint moves
 - 4. Functional activity tests - by assessing your child's activities of daily living (ADL's)
 - a. Exercise programs - how to proceed with exercises, by passive motion, passive assistive motion, active assistive motion or your child moves without any assistance or moves against resistance
 - b. Other treatments, which may include:
 - 1. Hydrotherapy - water treatments
 - 2. Paraffin baths - mixed with mineral oil can help relieve pain
 - 3. Hot packs - to relieve pain
 - 4. Radiant heat - beneficial in promoting the healing of pressure sores

5. Diathermy - a form of heat produced by the resistance of the tissues to the short waves of an electrical current
6. Ultrasound - effective in reducing pain
7. Electrical current - used in testing muscles and nerves
8. The TENS unit (transcutaneous electrical nerve stimulator) to help relieve pain
9. Ice - to reduce pain and spasticity
10. Traction - by stretching the muscles and increasing circulation to aid in the correction of joint dysfunction
11. Vaso-pneumatic pumping - which forces the fluid from the extremities by pressure within a sleeve or stocking
12. Massage - by relieving pain, inducing relaxation, and increasing circulation
13. Acupuncture therapy - to relieve pain

5. Engaging in consultation, education, and research

Direct Interventions, which begin with "therapeutic exercise", are listed in order of preferred usage. This category of tests and measures is referred to as "arousal, attention, and cognition".

The Physical Therapist will subsequently wish to make his/her own examination, adding to the above information by assessment of:

- Respiratory function
- The range of motion of all joints involved and the presence of contractures
- The strength of innervated muscles with particular regard to: completely paralyzed muscles, unopposed innervated muscle groups, and imbalance of muscle groups
- The degree of spasticity, if present
- The presence of edema

When the Doctor and Physical Therapist discuss the treatment required, such factors as the following will be given special attention:

- Chest therapy, especially in relation to the treatment of children on ventilators
- The danger of muscle shortening due to unopposed muscle action and the required positioning of the joints involved
- Severe spasticity and the positioning required to gain relaxation
- The necessity for splinting

After his/her own initial assessment, the Physical Therapist will need to discuss the case with the Occupational Therapist and the Medical Social Worker. Detailed records are kept of the initial assessment treatment and progress of each child. Everyday incidents are also noted, such as the occurrence of bladder infections, slight injury or pressure marks, the first outing, weekends home, and so on.

E. Where do Physical Therapists Work?

Physical Therapists are found in almost every type of medical institution (general hospital, university hospital, specialized intervention hospital, and visiting nurse's station). Physical Therapists will be playing a greater role in the future. Physical Therapists are found in medical or welfare facilities for physically disabled children and clinics or schools for medically and physically disabled children. Physical Therapists are also found in health care facilities, daycare centers, and special nursing homes.

Physical Therapists practice in a broad range of inpatient, outpatient, and community-based settings, including the following in order of most common setting:

1. Hospitals (critical care, intensive care, acute care, and sub acute care settings). Hospital Physical Therapy departments are usually large enough to handle the following equipment:
 - a. Electrotherapy area, which includes: diathermy, ultrasound, infrared, ultraviolet, hot packs, ice, electrical stimulation, paraffin, traction, massage and some of the exercise programs
 - b. Hydrotherapy area includes: a pool or Hubbard tank for underwater treatments, smaller whirlpools

- c. Gym or exercise room, which has: parallel bars, walkers, crutches, canes, and practice staircases for walker training, stall bars, shoulder wheels, pulleys, wrist rolls, finger ladders, wands, weights, bicycles, and floor mats to name a few
2. Outpatient clinics or offices
3. Rehabilitation facilities
4. Skilled nursing, extended care or sub acute facilities
5. Homes
6. Education or research centers
7. Schools and playgrounds (preschools, primary and secondary)
8. Hospices
9. Corporate or industrial health centers
10. Industrial workplace or other occupational environment
11. Athletic facilities (collegiate, amateur, and professional)
12. Fitness centers and sports training facilities.

Other areas that Physical Therapists may become involved in are: industrial clinics, geriatrics, private practice, consultant, home health care, institutions for the mentally ill and mentally retarded, treating the blind (concerned with teaching your child an awareness of body image so that he/she can identify position in space, can maintain good balance and to acquire sufficient coordination to cope with sudden changes in position while moving in a dark world), sports medicine, foreign assignments, teaching, research, and writing.

F. Is Physical Therapy painful?

Sometimes Physical Therapy is uncomfortable or painful. However, the Physical Therapist has treatments available that can help minimize pain. As muscles are stretched and exercised, it is only natural to experience some soreness. As Physical Therapy progresses, range of motion typically increases as does strength and soreness diminishes. In general, children feel better following Physical Therapy and look forward to the next session. If not, reconsider the therapy and replace with enjoyable activities. The topic of pain in regards to children will be discussed later in this book.

G. How long does a Physical Therapy session last?

The amount of time needed depends on the type of Physical Therapy

involved. For example, it may take one child longer to complete their therapeutic exercises than another. Also, as a child makes progress or changes physically, his/her treatment plan is adjusted.

H. Physical Therapy Assistants

The Physical Therapy Assistant is an educated health care professional who assists the Physical Therapist in the provision of Physical Therapy. The Physical Therapy Assistant is a graduate of a Physical Therapy Assistant Associate Degree Program. A Physical Therapy Assistant must graduate from an accredited 2-year program. A Physical Therapy Assistant must pass a written test and then acquire a special license. Most settings require a Physical Therapy Assistant to have certification in cardio-pulmonary resuscitation (CPR). The Physical Therapist of record is the person who is directly responsible for the actions of the Physical Therapist Assistant. The Physical Therapist Assistant may perform Physical Therapy procedures and related tasks that have been selected and delegated by the supervising Physical Therapist. The ability of the Physical Therapist Assistant to perform the selected and delegated tasks should be assessed on an ongoing basis by the supervising Physical Therapist.

Physical Therapists and their assistants have three main goals:

- They try to help children enhance their physical abilities
- They try to minimize permanent disabilities and help children improve or adapt to abilities they have lost
- They work with children to help them feel less pain

I. Occupational Therapists evaluate and treat individuals with illnesses, injuries, cognitive impairments, psychosocial dysfunctions, mental illness, developmental or learning disabilities, physical disabilities, or other special needs or conditions. Evaluation and Intervention focuses on an individual's level of function and involves assessment of performance areas, performance components, and performance contexts. Intervention involves the use of purposeful activity for developing, improving, sustaining or restoring function in performance areas including, but not limited to: daily living skills, work performance, educational performance skills, and leisure skills. The

performance components (sensorimotor, cognitive, psychosocial and psychological) are the elements of performance in which Occupational Therapists intervene for the purpose of attaining an individual's highest level of functional independence. Services of an Occupational Therapist also include: the design, development, adaptation, application or training in the use of assistive technology devices; the design, fabrication or application of orthotic devices; training in the use of orthotic devices; application of physical agent modalities; and the adaptation of environments and processes to enhance functional performance.

Occupational Therapy for young children refers to a form of treatment that will enhance their fine motor skills and control of the smaller muscles of their body. This includes muscles of the arms and hands needed for reaching, grasping, and holding objects. It also involves muscles of the face and mouth that are important for chewing, swallowing, and maintaining lip closure. In addition to improving control of particular muscles, an Occupational Therapist is concerned with improving the way different muscles work together, such as hand-eye coordination. Some types of Occupational Therapy can be useful to children who are overly sensitive to touch or whose touch perceptions appear distorted. These children often experience difficulty interpreting information received through their senses, and benefit from a form of Occupational Therapy called sensory integration. Like the Physical Therapist, the Occupational Therapist will want to work closely with the parents, teaching them how to incorporate exercises into daily routines. The Occupational Therapist also can advise parents on the use of special equipment and the application and use of hand splints and other types of bracing devices. Many Occupational Therapists have been trained to construct hand and arm splints.

1. Questions to ask an Occupational Therapist:

- a. How much direct help does my child really need?
- b. Is there equipment to help my child manage more tasks on his or her own?
- c. Can my home be made safer and more convenient for my child and possibly a caregiver?

- d. How can daily life in my home better meet the needs of *all* family members?
- e. How can the caregiver find assistance for an individual who cannot be left alone in the home?

J. Certified Occupational Therapy Assistants assist with the evaluation and treatment of individuals with illnesses, injuries, cognitive impairments, psychosocial dysfunctions, mental illness, developmental or learning disabilities, physical disabilities, or other special needs or conditions and can perform the tasks of the Occupational Therapist under their supervision.

II. Physical Therapy - Early Intervention

A. Guidelines for Referral

1. A **referral** is defined as - to direct to a source for help or information. A referral to Physical Therapy is indicated whenever there is a known physical impairment, a reason to suspect a delay in gross motor development, or a qualitative impairment in postural or movement skills. A referral to Occupational Therapy is indicated whenever there is a reason to suspect delay or qualitative impairment in the performance of daily tasks and routines, including self-care, play, social interaction, or the performance of school-related tasks. A referral is recommended as soon as a problem is identified to help the family learn about the diagnosis, identify additional supportive services, and master childcare practices that will promote development and minimize further complications.

Depending on local regulations governing the practice of Occupational and Physical Therapists, a referral from a Physician may be required prior to the initiation of Physical or Occupational Therapy. In planning each child's program of therapy, the Physical Therapist reviews your child's medical records, evaluates your child, and identifies your child's problem(s). The Physical Therapist performs tests and evaluations that provide information about joint motion, condition of muscles and reflexes, appearance and stability of walking, need and use of braces, function of the heart and lungs, integrity of sensation and

perception, and performance of activities required in daily living.

2. **The Physical Therapist consults** and works closely with your child's Physician, other health care practitioners and your child in setting treatment objectives that are realistic and consistent with your child's needs. For efficient Intervention in the shortest possible time there are two essential requirements.
 - a. A Physical Therapist must know exactly what to ask your child to do
 - b. The child must do exactly as he/she is asked as much as possible

The 1st depends upon the accurate knowledge and expertise of the Physical Therapist and the 2nd depends primarily upon the confidence of the child/parent in the Physical Therapist. Mutual confidence between the Physical Therapist and the child/parent, therefore plays a large role in the successful Intervention. However, fear also plays a part in their reactions towards each other and this must be overcome.

The child/parent fears:

- That he/she will not be able to do what he/she is asked to do
- That he/she will fall or injure himself/herself
- That he/she is not going to get better or "make the grade"

The Physical Therapist fears:

- That he/she will not know the right thing to say or do
- That he/she will not be able to answer the child/parent's questions
- That your child will not do as asked

Fear of failure is keynote - all parties must accept that they have a common objective and that their united efforts will result in benefits - even though progress may be slow and very variable. Without complete confidence, sympathy, and cooperation between the Physical Therapist and the child/parent, the prospect of benefits may be seriously hampered.

Therapy consists of three specific services:

- Direct service - where the Physical Therapist has frequent contact with your child, either individually or in a group
- Monitoring - involves the development of an Intervention plan that can be effectively carried out by the classroom teacher or other personnel. The plan also will be needed to establish the effectiveness of the Intervention and to update and revise the plan based on the individual student's progress or lack thereof
- Consultation - refers to the sharing of specialized knowledge with other education team members to support the overall goals and objectives of the educational program

3. The Physical Therapist in different service areas

- a. **In Pediatrics** - every child is appealing and lovable, but your child that has special needs, needs more than the expression of love through tender words and cuddling. He or she needs the expression of love through deeds. There is nothing more gratifying to a Physical Therapist than the knowledge that, through his or her efforts, a child with special needs has learned to cope better with life's problems. Perhaps this is the reason why almost every Physical Therapist expresses a desire to work with children for at least a short period.
- b. **In the school setting** - historically, many children with special needs were placed according to their "label". Schools are becoming far more flexible and creative in how they provide services and supports. This change has allowed children with special needs greater participation with typical peers in many different learning environments.

1. **The practice of determining eligibility** for Occupational or Physical Therapy services varies among school systems, as well as, among individual schools within the same system. Furthermore, interpretation of the public laws that determine eligibility may change over time within a local school district. When children are not

eligible for Occupational and/or Physical Therapy services in school, or are eligible for only limited services, families may seek supplemental therapy through hospital-based outpatient centers or private practices if they so desire.

2. Special Education as a Process

When it becomes apparent that your child is in need of special education, a referral must be in writing. Parents are asked for written permission for their child to be evaluated by a team of specialists and are given a copy of their rights, known as the procedural safeguards notice which includes the following:

- A. When notice must be given to parents.
- B. What must be included in the notification?
- C. When prior parental consent must be obtained.
- D. What happens when a parent refuses consent?
- E. Right to an independent evaluation.
- F. Dispute resolution systems, including mediation, prehearing conferences, and impartial due process hearings.
- G. Parental claims for tuition reimbursement.
- H. Rights regarding discipline and suspension.
- I. Surrogate parents.
- J. Rights pertaining to education records.
- K. Complaint procedures.
- L. Applicable laws and regulations.

3. In evaluating whether programs can best meet your child's needs, you can look for some of these practices:

- A. Collaboration and teamwork among staff who work with your child - the greatest learning occurs when everyone is working toward the same goals
- B. Integrated instruction - many children with special needs require the support of many therapies to achieve their goals. Yet, pulling students out of the classroom to address skills in isolation does not keep your child in the functional environment where he or

she needs to practice the skills. Watch carefully for your child's acceptance of therapies to choose between pull-out programs and inclusive programs

- C. Positive reinforcement practices
- D. Multiple methods of presenting materials
- E. Coordination of strategies throughout your child's day - being consistent
- F. Opportunities for practice in functional environments - including instruction in daily living skills and self care skills
- G. A focus on transition to adult life - by achieving the maximum possible level of independence and by adapting for the future
- H. Environments that incorporate fun into the learning
- I. Ongoing, open communication between the school and a child's family

4. **All schools are required by federal law** to provide special equipment so that qualified students can be successfully mainstreamed into regular education classrooms to the extent appropriate. The primary purpose for your child with special needs is education, with an added treatment program. Motivation is basic to all treatment and the treatment must be planned to develop your child's will to participate. The Physical Therapist must perform testing procedures to evaluate muscle strength and range of motion (ROM); develop an exercise program to develop strength, coordination, balance and activities of daily living (ADL's) skills; and fitting and maintaining any special equipment. Since the effectiveness of the program depends on parental cooperation, a great deal of this work involves parent instruction, demonstration, and conferences to interpret your child's changing needs and the therapies used to meet them. The Physical Therapist needs a great love for children, enthusiasm and patience.

- 5. Roles of the Physical and Occupational Therapists in school settings:**
 - A. Promoting safe and efficient mobility
 - B. Recommending classroom positioning to promote optimal postural control and function
 - C. Modifying classroom materials and routines to improve attention and organization
 - D. Treating specific perceptual and motor difficulties that interfere with school-related achievement
 - E. Providing assistance with self-care as related to such tasks as toileting or assessing the cafeteria
 - F. Contributing to prevocational training

B. Educational Issues

- 1. Areas of child care taught by Physical Therapists:**
 - a. Rationale for treatment
 - b. Home programs
 - c. Strengthening
 - d. Range of motion, stretching
 - e. Postural awareness
 - f. Basic safety precautions
 - g. Prevention, risk factors
 - h. Body mechanics
 - i. Functional mobility
 - j. Signs and symptoms of complications
 - k. Positioning
 - l. Pain management
 - m. Anatomy and biomechanics of complications
 - n. Stimulating home and occupational situations
 - o. Equipment needs and maintenance
 - p. Education of family and caregivers
 - q. Medical terminology
 - r. Psychological adjustments to medical condition
 - s. Surgical procedures
 - t. Skin care, wounds
 - u. Breathing techniques

2. **Methods or tools of child education** used in clinical practice:
 - a. Verbal discussion
 - b. Demonstration
 - c. Care-specific instruction sheets with sketches
 - d. Children working with only one Therapist as much as possible
 - e. Moving the body passively through the desired activity
 - f. Assuming different roles toward your child (teacher, supporter, parent)
 - g. Quiet atmosphere
 - h. Other professional support staff
 - i. Charts of skeleton, muscles, nerves, etc.
 - j. Educating family or caregivers to educate your child
 - k. Three-dimensional models of joints, skeleton, etc.
 - l. Creating situations in which children/parents actively solve problems
 - m. Republished booklets and pamphlets
 - n. Remade checklists of care objectives
 - o. Group classes for children/parents with similar special needs and their parents
 - p. Textbooks (anatomy)
 - q. Videotapes or slides
 - r. Using other children to provide child education
 - s. Using biofeedback equipment
 - t. Demonstrations with dolls

3. **Importance of Physical Therapist's behaviors** related to child/parent teaching
 - a. Developing a trusting relationship with the child/parent
 - b. Developing concrete goals that correlate with the child/parent perceptions and desires
 - c. Developing active listening skills
 - d. Keeping directions simple and in layperson's terms
 - e. Continually assessing one's own effectiveness as a teacher through child/parent response
 - f. Being sensitive to the amount of information the child/parent is capable of receiving
 - g. Demonstrating flexibility by approaching each child differently
 - h. Maintaining communication with other professionals

- i. Understanding that nonverbal communication influences the child/parent response
- j. Not assuming that other professionals educate the child/parent
- k. Determining the learning style of the child/parent
- l. Using input from family

4. Techniques used to assess effectiveness in teaching skills:

- a. Having the child/parent demonstrate what has been taught
- b. Developing objective standards for assessing child performance
- c. Assessing results of function in a task-oriented manner (reaching for a cup)
- d. Having the child/parent explain what has been taught (to the instructor or to others)
- e. Asking other professionals working with your child about how your child performs tasks
- f. Using a checklist to ensure that the objectives have been met
- g. Analyzing performance via videotapes

5. Barriers to delivering education

- a. Child/parent attitudes and acceptance of illness/special needs
- b. Child/parent's passive role and attitude toward Therapy
- c. Child/parent's attitudes or expectations regarding Physical Therapy outcomes
- d. Child/parent's cognitive status
- e. Child/parent's emotional status
- f. Shortage of staff
- g. Lack of trust in Therapist
- h. Lack of time allotted for treatment session
- i. Lack of participation by family and caregivers in educational efforts
- j. Child's physical status
- k. Distractions in treatment areas
 - l. Architectural layout for practicing functional activities
- m. Ineffective participation by family and caregivers in educational efforts (overprotection)
- n. Limited resources (money, equipment)
- o. English is not the child/parent's first language

- p. Sensory deficits
- q. Child/parent's level of education
- r. Inconsistency in teaching among professionals and support staff
- s. Length of inpatient stay
- t. Philosophy of department or institution toward child/parent education
- u. Therapist has a "bad day"

6. Interactional behaviors that facilitate or impede the Therapist's ability to connect with child/parents

a. Verbal

1. Greeting the child/parent in a friendly manner/possible handshake
2. Making positive comments
3. Inquiring about your child
4. Reflecting on your child's feelings
5. Clarifying your child's needs
6. Cutting off child/parent's story
7. Responding only to disease information
8. Failing to give feedback
9. Showing little empathy
10. Not asking about the child/parent concerns
11. Using medical jargon

b. Non-verbal

1. Facing the child/parent
2. Making eye contact
3. Leaning toward child
4. Displaying an open posture
5. Using nonverbal cues to acknowledge active listening
6. Cleanliness and neatness of the Physical Therapist
7. Acting busy
8. Reading notes
9. Doing tasks

7. Preparation for effective teaching and learning

- a. Family system and response to illness

- b. Coping strategies
- c. Cultural influences on child/family education
- d. Child and family needs
- e. Observation of your child and family members
- f. Child-family interview

8. Teaching the child and the family

- a. Physical Therapist's and Physical Therapist Assistant's Role
- b. Motivation for learning
- c. Domains of learning
- d. Planning
- e. Preparation of teaching materials

C. Interventions

Intervention is the science and art of enabling persons with physical, mental or sensory impairments to attain the highest degree of self-sufficiency and equality leading toward usefulness, satisfaction and full participation in community life as is possible.

1. Assessment and Planning for Intervention

Initial assessment typically includes:

- An interview with the parent or other care giver to determine any needs and concerns
- Observation of your child at play or performing functional tasks

Physical Therapists clinically assess your child for muscle tone and strength, joint range of motion, sensory responses and perception, neurological maturation and organization, social and behavior responses, and standardized tests of motor and adaptive development. The treatment plan will take into account results of these assessments, as well as recommendations from all other people involved in the care of your child. The plan should address the model of Intervention that will be used (individual, group, consultative), the optimal frequency of Intervention, recommendations for special equipment or environmental adaptations, and the plan for parent or caregiver instruction. Goals should be developed for a specific time period with objective and measurable outcomes stated. Periodically, the plan

should be evaluated and revised as necessary.

Pediatric Physical Therapy focuses on evaluating and treating sensorimotor development, musculoskeletal alignment, cardiopulmonary status, and neurobehavioral organization in children with physical special needs or developmental delays that place them at risk for decreased functional mobility or for qualitative problems with mobility or postural control. Pediatric Occupational Therapy also addresses sensorimotor and neurobehavioral organization, as well as functional mobility, perceptual maturation, and psychosocial adjustment of children who are at risk for special needs. Occupational Therapists particularly focus on those special needs that limit your child's ability to develop the necessary skills and attitudes for independence in self-care, play, and school performance (the primary "occupations" of childhood). Although play is the therapy medium of choice for most young children, both Occupational and Physical Therapy incorporate a wide variety of other modalities, including exercise, sensory stimulation, splinting or casting, use of assistive and adaptive aids and equipment, and behavior training.

2. Differences between Physical and Occupational Therapy approaches

<u>Intervention objective</u>	<u>Typical OT emphasis</u>	<u>Typical PT emphasis</u>
A. Maintain or increase range of motion, muscle strength	Focus on upper body primarily using purposeful activities that are selected according to their physical demands	Focus on lower body primarily using active or passive exercise
B. Recommend need for assistive technology	Adapted toys, school materials, computers, self-care aids	Wheelchairs, ambulation aids, transfer equipment
C. Splinting and casting to maintain or increase range of motion	Upper extremity	Lower extremity

or to promote functional movement

D. Train in functional skills needed for daily living	Dressing, eating, toileting personal hygiene	Ambulation, managing transfers and other mobility demands
E. Promote developmental progression of skills	Fine motor, adaptive, personal-social domains	Gross motor domain
F. Promote environmental accessibility	Adaptations to home and school environments including: organizing work/play areas for efficiency and creating a sensory milieu that promotes attention and information processing	Reducing architectural barriers that limit full access and mobility including: ramps/lifts and car seats or other transportation devices

Physical Therapy - a child's strength and mobility are the main concerns of Physical Therapists - they will focus in areas such as:

1. Exercising specific muscles and muscle groups
2. Strengthening and range of motion exercises
3. Developing balance
4. Transfer training
5. Bed mobility
6. Aquatics
7. Standing programs
8. Gait training

Occupational Therapy - primarily concerned with the practical activities of your life. The Occupational Therapist will condition and train your child to optimize self-care and ability to work and perform typical daily tasks such as:

1. Grooming
2. Bathing
3. Dressing

4. Feeding
5. Housekeeping
6. Use of automated environmental controls

3. How does Batten Disease affect our children?

Effects on the body, mind, and feelings:

- a. Weakness
- b. Problems with balance or coordination - which can make it hard for your child to sit, stand, or walk even if the muscles are strong enough
- c. Problems with language - may have trouble understanding speech or writing; may understand, but not be able to think of the words to speak or write; or maybe knows the right words, but has trouble saying them clearly
- d. Pain, numbness, or odd sensations - these can make it hard for your child to relax and feel comfortable
- e. Problems with memory, thinking, attention, or learning (cognitive problems)
- f. Poor judgment by doing things that are unsafe
- g. Trouble swallowing - this can make it hard for your child to get enough calories in a 24 hour period or the possibility of aspiration
- h. Problems with bladder and/or bowel control/constipation
- i. Getting tired very quickly, which may limit the participation in an Intervention program
- j. Sudden bursts of emotion, such as laughing, crying, or anger - which may be a signal that your child needs help, understanding, and support in adjusting to special needs
- k. Depression - feeling sad, blue or down in the dumps; loss of interest in things that your child used to enjoy; feelings slowed down or restless and unable to sit still; feeling worthless or guilty; increase or decrease in appetite or weight; problems concentrating, thinking, remembering, or making decisions; trouble sleeping or sleeping too much; loss of energy or feeling tired all of the time; headaches; other aches and pains; digestive problems; feeling hopeless; being anxious or worried
- l. Difficulty with activities of daily living
- m. Weight gain due to medications and immobility

n. Possibility of Osteoporosis

4. As Batten Disease progresses you will see the following types of problems:

- a. Confusion
- b. Communication difficulties
- c. Sensory disturbances
- d. Memory problems
- e. Psychiatric disorders
- f. Denial of symptoms
- g. Personality changes
- h. Behavior disorder
 - i. Planning and self-control difficulties
- j. Eating difficulties
- k. Constipation
 - l. Bladder and bowel control
- m. Mobility issues
- n. Self-care problems
- o. Intervention programs
- p. Financial issues

5. Tips for reducing stress for your child with Batten Disease and for you

- a. Take intervention and care giving one day at a time and be hopeful
- b. Remember that adjusting to the effects of a terminal illness and special needs takes time
- c. Care giving is learned. Expect that knowledge and skills will grow with experience
- d. Experiment until you find what works for you and your child, try new ways of doing activities of daily living, communicating with each other, scheduling the day, and organizing your social life
- e. Plan for "breaks" so that you are not together all the time. This is a good way for family and friends to help on occasion. You can also plan activities that get both of you out of the house
- f. Ask family members and friends to help in specific ways and

commit to certain times to help. This gives others a chance to help in useful ways

- g. Be active in a support group. You can work on problems together and develop new friendships
- h. Be kind to each other. If you sometimes feel irritated, this is natural and you do not need to blame yourself. But do not take it out on the other person. It often helps to talk about these feelings with a friend, professional, or support group
- i. Plan and enjoy new experiences and do not look back. Avoid comparing life as it is now with how it was before the illness

A model has been adapted that list two major approaches to Intervention of Physical Therapy:

- Intervention referring to programs that are designed to restore functions lost through illness or injury, or to help your child and family cope with the loss of function.
- Habilitation referring to strategies and Interventions that help your child acquire new skills consistent with his or her potential and are particularly important for children with congenital delays or special needs.

Both approaches are necessary for children whose special needs occur during their formative years and may limit their ability to reach their full potential.

The most important thing for children with Batten Disease is that they enjoy the activities that are planned for them. Therapy should never be allowed to cause stress. If it does, choose different activities/Intervention.

6. Early Intervention Programs

The role of Occupational and Physical Therapists in Early Intervention programs covers a range of services including: screening for motor dysfunction; monitoring the development of children over time; suggesting specific neurodevelopmental management strategies to families; consulting with other members of the interdisciplinary team; and providing direct therapy. Specific goals may include teaching care givers the appropriate

techniques for handling and positioning. This permits your child to experience more flexibility in patterns of posture and movement and takes advantage of other developmental strengths. Generally, Early Intervention programs focus more on helping families adjust to their child's developmental delay or special needs than on correcting the problems. Attention may be given to encouraging the development of a satisfying and nurturing relationship with your child, as well as, to learning practical methods of supporting your child's development (habilitation) in the natural environments of the home and community. Through the process of developing an individualized family service plan, therapy goals are organized around the family's needs and priorities, taking into account your child's unique abilities.

The key to success in any therapy is the consistency of its delivery and the Early Intervention of parents, so that they can learn to manage their child at home. Legislation governing public education for children with special needs has provided guidelines and financial incentives for the development of statewide Early Interventions systems. Parents are encouraged to participate actively in planning and implementing services in developing competence in advocacy for their child. Programs are individualized according to the specific needs of the family and may include a combination of consultative, home-based, or center-based Intervention.

- a. Elements of effective Early Intervention programs will include the following:**
1. The right timing - Interventions that begin earlier in development benefit children the most
 2. Sufficient intensity - parents and children who participate the most consistently and support activities learned in Intervention generally demonstrate the greatest benefit. When Intervention includes daily activities and stimulation, the benefits appear to be greater. Many children receive only minimal Early Intervention support that may not be sufficient to produce measurable benefits. Thus, parents may need to

advocate a sufficient amount of services and supports for their children

3. Direct engagement of your child - children who participate in Early Intervention Programs that provide direct educational experiences show greater and more enduring benefits than do children in programs that only provide parent information and educational supports. Although home visiting and parent education are very important, often additional direct services matched to your child's individual needs are necessary to promote benefits
4. Multiple types of supports and services - Interventions that provide more comprehensive services to young children, including social, health, and educational services, have worked the best. Programs that focus on just one or two aspects of your child's development usually have not been as successful. Your child's needs, along with his or her strengths, should be considered when developing an individualized family service plan (IFSP)
5. Careful monitoring and responsiveness to individual needs - some children will make more (or less) progress from participation in Early Intervention programs than will other children. The reasons for these individual differences are far from clear, although undoubtedly, both biomedical and behavioral factors are involved. Thus, careful monitoring of your child's progress in Early Intervention programs is essential, and vigorous efforts should be made to modify the supports provided to your child if results are not promising, or if you see negative effects on your child or family
6. Follow-through to maintain early benefits - over time, the initial positive effects of Early Intervention may seem to diminish. This occurs mostly when equally vigorous and high-quality supports are not continued. Parents also know that infants and young children show extremely rapid development, which may level off over time. Early Intervention cannot be viewed as a certainty that will ensure your child's continued success no matter what.

Rather, positive learning experiences and needed supports must be sustained in later years. Parents must facilitate the learned activities in their child's other environments (such as with grandparents, at the zoo, or in the grocery store), or their child will learn to perform skills only in the context of environments in which the skills were taught

7. Cultural appropriateness - Interventions for children and families need to recognize and build on their family's cultural beliefs, traditions, and practices. When Interventions do not respect cultural values and strengths, families are less likely to participate fully, and Interventions are less likely to be effective. Please let professionals you are working with know about beliefs and values that are important to your family

7. How Can Parents/Families Help?

- a. Support your child's efforts to participate in Intervention decisions
- b. Set aside time to talk with your child. You can relax together while playing cards, watching television, listening to the radio, or playing a board game
- c. If your child has trouble communicating, ask the Speech-Language Pathologist how you can help
- d. Participate in the education offered. Learn as much as you can and how you can help
- e. Ask to attend the Physical Therapy sessions. This is a good way to learn how Intervention works and how to help
- f. Encourage and help your child to practice skills learned in Physical Therapy
- g. Make sure that the program staff suggests activities that fit your child's needs and interests
- h. Find out what your child can do alone, what he/she can do to help and what he/she can not do, then avoid doing things for your child that he/she is able to do by himself/herself. Each time he/she does them, his/her ability and confidence will grow
- i. Take care of yourself as the parent/family by eating well, getting enough rest, and taking time to do things that you

enjoy

8. The Role of Family in Physical Therapy, Occupational Therapy and Speech

This role in traditional child care is changing, partly because of economics. Family care is much less expensive than long-term hospital care/Intervention program, and family reinforcement is essential to maintain Physical Therapy gains after your child is discharged from a Hospital or Intervention program. It is also possible for a counselor to provide services to family members as part of your child's therapy. The Rehabilitation Act of 1973 authorizes provision of services to members of your child with special needs family, when such services are necessary to the adjustment or Intervention of your child with a special needs condition. Thus, the counselor can provide services as group counseling to help the family adjust to the special need(s) and aid in Intervention of the family member. If the family is to play a role in the Intervention of your child, then the family must be prepared for that role.

- a. **Selecting the best options for your child** - the following five very good sources of information can help you make choices about Early Intervention
 1. University affiliated programs specializing in developmental disabilities
 2. Each state has an Interagency Coordinating Council (ICC), an advisory group consisting of parents, professionals, policy makers, and representatives of agencies that provide or administer Early Intervention - they can help you with your options and legal rights
 3. Other parents - particularly those who are active leaders in local parent organizations. They see the big picture and can provide very useful tips about how to proceed and where the best supports are in your community
 4. Recent books and journal articles concerning Early Intervention
 5. Professionals who are on the front line are good sources of information by working directly with families and

children in Early Intervention programs. They are aware of innovative methods, attend professional meetings, receive continuing education, and have a reservoir of information from their own first hand experiences

9. Things to Consider When Choosing An Intervention Program

- a. Does the program provide the services your child needs?
- b. Does it match your child's abilities or is it too demanding or not demanding enough?
- c. What kind of standing does it have in the community for the quality of the program?
- d. Is it certified and does its staff have good credentials?
- e. Is it located where family members can easily travel to?
- f. Does it actively involve your child and family members in Intervention decisions?
- g. Does it encourage family members to participate in some Intervention sessions and practice with your child?
- h. How well are its costs covered by insurance or Medicaid and what are your financial liabilities?
- i. If it is an outpatient or home program, is there someone living at home who can provide care?
- j. If it is an outpatient program, is transportation available?

10. Services that may be included in Early Intervention programs

but not limited to, are listed as follows:

- a. Assistive technology devices and services
- b. Audiology
- c. Family training, counseling, and home visits
- d. Health services
- e. Medical services for diagnosis and evaluation
- f. Nursing services
- g. Nutrition services
- h. Occupational Therapy
- i. Physical Therapy
- j. Psychological Therapy
- k. Service coordination services
- l. Special instruction
- m. Speech-Language Pathology

- n. Transportation and related costs
- o. Vision services

11. Types of Intervention Programs

- a. Hospital programs
- b. Nursing facility programs - nursing homes
- c. Outpatient programs including day cares
- d. Home based programs

12. Four types of Intervention strategies that can be used with children demonstrating deficits in home management or care giving are:

- a. Remediating performance areas and performance component deficits - this phase focuses to improve or restore performance to pretreatment levels. Certain parameters need to be considered when measuring the effectiveness in this phase: physical assistance, supervision, task demands, amount of task, type of task, and the environment
- b. Teaching new methods of task performance to compensate for performance area or performance component deficits - this phase focuses on using remaining abilities to achieve the highest level of functioning possible in the areas of home and family management. If your child cannot perform these tasks in the usual manner, then adapted techniques or equipment are used to maximize your child's abilities. This strategy can be used when your child's condition is temporary (bronchitis, or a fractured limb), when precautions need to be taken, when the condition is not amendable to this phase, or when the task speed and proficiency are greatly improved by the use of adaptive equipment or techniques (which allow your child more flexibility). These techniques would require that the Physical Therapist and the child/parent address the following points:
 - 1. Determine what tasks need to be improved (what tasks take too long, cause fatigue, or take too much energy)

2. List all of the steps of the task - including setup, performance, and cleanup
3. Analyze the task - why is it necessary, what is its' purpose, when and where should it be done, and what is the best way for your child to accomplish the task?
4. Develop a new method for performing the task - consider eliminating the unnecessary steps, combining motions and activities, rearranging the sequence of the steps, and simplifying the details of the task by taking the following steps:
 - A. Use correct work height to reduce fatigue and promote good posture. Correct work height in standing should be 2 inches below the bent elbow. In sitting, your child should avoid positions that require lifting the shoulders or "winging out" the elbows
 - B. Prepare supplies and equipment in work areas. Clear area of unnecessary items
 - C. Organize the work center. Having necessary supplies and equipment increases productivity with less effort
 - D. Use labor saving devices - includes wheels for transport and electrical devices
 - E. Fatigue can result in poor body mechanics and reduced safety awareness. Regular rest breaks should be incorporated into the schedule. Alternate light and heavy tasks throughout the day and week
 - F. Use proper body mechanics using a wide base of support, using both sides of the body and keeping objects close to the body, facing objects when reaching or lifting to avoid twisting, pushing rather than pulling objects, and alternating positions and motions to avoid fatigue
- c. Suggesting environmental modifications to make task performance easier - a means of indirectly maximizing your child's function
- d. Educating your child and family to support the above approaches or as a means of minimizing future problems -

these are important because they involve learning new strategies. More importantly, incorporate these strategies in your child's and family's habits and lifestyle. Keep in mind the following:

1. Have a clear plan about the purpose of the teaching session
2. The presentation of information needs to be appropriate to your child's/family's educational and emotional levels
3. Instructions must be clear
4. Ask open-minded questions to ensure everyone's understanding
5. Use your child's/family's responses to determine the amount of information presented during a session
6. Promote the highest level of learning possible, preferably the problem-solving level
7. Illustrate or demonstrate the points being taught

13. Intervention Specialists

- a. Physicians
- b. Intervention Nurse
- c. Physical Therapist
- d. Occupational Therapist
- e. Speech-Language Pathologist
- f. Social Worker
- g. Psychologist
- h. Therapeutic Recreation Specialist
- i. Other Professionals - Orthotist, Dietician, Urologist

14. Getting the most out of Intervention

- a. What can child/parents do?
 1. Make sure others understand that you want to help make decisions about your child's care
 2. Bring your questions and concerns to the program staff
 3. State your wishes and opinions on matters that affect your child or yourselves as parents
 4. Speak up if you feel that anyone is "talking down" to you, or if people start talking about you as if you were not there

III. Families and Behavior

A. Encouraging appropriate child behavior - effective parenting is based on an understanding of your child and his or her current developmental level and needs. You will need to assist your child to develop new skills while providing love and other supports. To enhance, as well as, understand your child's development, you can learn key ways to encourage your child's appropriate behavior. Each of us has our own views about what amounts to a behavior problem. Some of us are upset by a child's slightest whimper, while others can tune out a tag team match. A behavior is considered to be a problem when it occurs too often or too seldom or is inappropriate to your child's developmental level or for the situation at hand.

1. Some problematic behaviors and challenging skill deficits that are common among children with Batten Disease include:

- a. Aggression
- b. Attention problems
- c. Disruptive behaviors
- d. Feeding problems
- e. Impulsivity
- f. Dressing difficulties
- g. Toileting difficulties
- h. Noncompliance with parental requests and teacher recommendations
- i. Self-injurious behavior
- j. Self-stimulatory behavior (such as hand flapping or body rocking)
- k. Social skills deficits
- l. Tantrums

2. When behavior puts your child or others in danger of injury, it is definitely time to get help. When faced with a less severe behavior problem, you may wait, hoping it will get better. In many instances, difficult behaviors only worsen. When in doubt, it is wise to ask for assistance before your child's behavior becomes unmanageable. Friends and relatives are often quick to offer advice about your child's behavior problems, and at times, it may seem to you that everyone is an authority when it comes

to managing *your* child's problem behavior. If common-sense approaches have not worked and you feel concerned, you may wish to seek the help of an expert. Be sure that the professional you choose has experience dealing with children with special needs and their behaviors, and relies on well-documented, scientifically sound procedures. A competent specialist will be able to offer you practical advice on what to do and what not to do. You should first ask your Pediatrician or family Doctor for his advice on a behavior specialist. If there is a child development center near you that serves children with special needs, they may have a qualified person, or you may check the hospital. You may have to go outside your community to find a qualified person.

3. Several things to keep in mind:

- a. Provide positive reinforcement - emphasizing what your child enjoys and does well
- b. Planned ignoring - when it's better to look the other way
- c. Differential reinforcement - being mindful of what you reinforce
- d. Shaping - helping your child learn new skills
- e. Instruction and imitation - modeling for your child what to do

Do not:

- a. Give negative reinforcement
- b. Punishment

If under the guidance of a Therapist, you decide to use a punishment procedure, use the following guidelines:

- Be sure that you can deliver the indicated brief, mild punishment to your child safely and consistently. The punishment is not likely to be effective if your child can ignore verbal reprimands, play with a favorite toy during time-out, or get out of losing a privilege
- Apply the punishment confidently and not in graded steps. A firm but matter of fact "no" is better than an apologetic request to stop, followed by loud reprimands

when your child does not obey. Avoid lectures, nagging, scolding, threatening or sarcastic remarks, extended time-outs, or any physical aggression that may frighten or hurt your child

- In the beginning, apply punishment immediately each time the targeted inappropriate behavior occurs. As the child's behavior improves, there will be less and less of a need to use punishment
- Eliminate any positive or negative reinforcement that is responsible for the problem behavior. When your child misbehaves during a work activity, ensure that the task is completed. Then, simply state the cause or reason for the punishment, describe the consequence and enforce it. If your child has to be removed before the task is complete, return to the task following the punishment
- Be careful that the delivery of punishment is not associated with the later delivery of reinforcement. Expressing your love in the context of apologizing for having disciplined your child may send a confusing message
- Avoid prolonged or extensive use of punishment. It often loses its effect if it is used too long or too frequently. Review the plan and make adjustments if the punishment does not reduce or stop the problem behavior

B. Parent Reactions and Adaptations to Having A Child With A Terminal Illness

Every parent of a child with an illness may ask at one time or another, "Why my child?" For some parents, an answer will help them understand the disorder, choose Physical Therapy, find a support group, or make decisions about having future children. But for many parents, there will be no answers or incomplete ones. In such instances, parents may expend much emotional and physical energy and money searching for a diagnosis. Sometimes the search for a cause can take precious time from the development of a treatment plan.

The most common initial response of parents who have been told that their child has a severe illness is some combination of shock, disbelief, guilt, and an overwhelming sense of loss. In addition, many parents initially deny their child's diagnosis and visit various professionals looking for a more optimistic diagnosis or prognosis. After the initial period of shock and denial, some family members experience depression. This can result from emotional stress combined with the physical strain of following through on the many appointments, procedures, recommendations, and care required by your child. Other factors contributing to depression may be spousal disagreement over acceptance of the diagnosis, assignment of blame, choice of treatment options, and/or responsibility in caring for your child. Symptoms of depression include extreme fatigue, restlessness or irritability, insomnia, eating disorder, or loss of sex drive. In this state, the parent(s) may not be able to ask for help, know what they need, or stay connected to significant support systems.

You may have had concerns about your child's development over a period of months or years. By the time your child's illness was formally diagnosed, you may not have been greatly surprised. Even under these circumstances, however, it may be difficult to hear words spoken aloud that confirm your fears.

You may go through a period of denial, either before or after receiving the diagnosis. Denial is a healthy and, in some ways, necessary stage of the grieving process. On a superficial level, the reaction "It can't be" is perfectly understandable, because we naturally wish bad news to be untrue. On a deeper level, denial over a short-term functions as a protective mechanism that we use to conserve our emotional energy for the critical tasks that we must accomplish, such as child rearing. This phase is normal. Problems arise, however, when denial is prolonged and you are not able to move forward on tasks necessary for your child and family's welfare.

When receiving bad news, people either internalize or externalize their reactions. Internalization is the process of assuming blame

for misfortune. The two most common emotions experienced by people who internalize are guilt and shame. Externalization refers to the process of placing responsibility for events on others. The most common feelings experienced by people who externalize are blame and anger. These two response patterns stem from the unspoken belief that when something bad happens, "It's got to be somebody's fault".

Eventually, when we feel emotionally safe, we let our feelings show. This is usually a time of overwhelming grief. As with shock and denial, grief is a healthy emotion. Parents who are consumed by guilt, shame, blame or anger may not be able to grieve properly. This can create significant problems in the long run. Once parents pass through the stage of acute grief, however, they come to accept the facts about their child's illness/special needs. This transition is marked by the return of some degree of optimism or at least a determination to do the best that one can. Even so, it is normal from time to time to ask yourself "What if?" and wonder how things might have been. It is also normal to re-experience grief at certain life cycle events, such as birthdays, school entry, and other occasions that remind you of what has been achieved and what has not.

When parents first learn that their child has an illness, their lives change immediately, and they must cope with many stresses. They must readjust their expectations for their child, they have to deal with financial issues and a host of healthcare professionals and systems, and they may face social isolation from family and friends. To cope effectively, there may need to be significant changes in family roles, relationships, and organization. Individuals and families differ widely in their response to having a child with an illness, depending on past life experiences, religious and cultural backgrounds, and age of the child at diagnosis. Other factors that may influence familial reactions include attitudes about individuals with illnesses, knowledge about health care practitioners, and receptiveness to accepting help from professionals, friends, and other family members. For example, some individuals with a strong religious faith may believe that God has chosen them to care for a

special child with an illness, while others may think it a curse for past life events. If the diagnosis has been delayed, parents may be relieved to finally receive answers and help for their child. They may also be angry with health care professionals, friends, or family members who previously reassured them that their child would "grow out of it". It is difficult to predict how a particular family member will react to the news that his or her child has an illness. Every family member responds to illness, whether minor or major, differently and at different levels and time, and different methods of adjusting.

At a time when the parent(s) is most in need of support, family and friends may be unable to provide it. Grandparents may not accept the diagnosis or may assign blame to one of the parents, most commonly to the one unrelated to them. Friends may feel uncomfortable in the presence of your child with a severe illness or not know what to say in consolation, and as a result, they often stay away. In addition, parents may be embarrassed by their child's illness or behavior and rarely venture from the house. All of these factors can lead to social isolation. Even if parents want to maintain their social contacts, their child's physical and medical needs may be so complex that simply going shopping becomes a major production and finding a skilled babysitter impossible.

Professionals can be very helpful in helping parents deal with isolation, depression, and discord, especially if these feelings are interfering with the parents' ability to care for their child. They can help examine feelings and develop solutions. Supportive therapy allows parents to ventilate concerns and adapt to their new life circumstances. For most families, the depression lessens as members develop a routine of care, gain access to Early Intervention and respite care services, and begin seeing positive changes in their child's development. Support from friends, extended family, and other parents of children with illnesses can be (re)established over time.

Parenting networks, in which parents educate and support one another, are often very powerful and may be even more effective

than professional information and support. As your child grows older, parental depression may reemerge if the family faces increasing behavior problems, new health care and physical needs, mounting financial concerns, or feelings of inadequacy in meeting the needs of other family members. It is perfectly normal for a parent to feel sorrow from time to time. Only when feelings of sadness and grief become chronic and interfere with the parent's ability to function is psychological Intervention indicated.

The problems associated with your child with a terminal illness may include physical and time demands for in-home care that interferes with parents' jobs, requirements for medical, educational and therapy appointments, financial burdens, added stress level, and specialized needs for recreational programs, legal services, and transportation. Parents or partners often react differently to these problems, perhaps as a result of their separate roles within the family unit or gender-specific issues. In most families, women continue to carry the brunt of the child care responsibilities, although men often are participating more than in the past. This responsibility carries both potential risks and benefits. A mother caring for her child who will remain dependent in daily living skills throughout life is at high risk for stress, depression and burnout over time. If she can efficiently and effectively master her child's care, however, she may feel a sense of accomplishment and competency that is positively reinforcing. In today's society, many Mom's also work, so they not only have to be dedicated to their job, but then come home to care for their children. That is where Dad's can be very helpful.

Meanwhile, the traditional father who focuses on financial issues and long term planning rather than taking part in his child's daily living activities may be avoiding having to deal with the reality of his child or the illness. In contrast, he may find that by participating actively in his child's care, he not only provides relief for the mother, but also experiences pleasure from the enhanced role in daily family life. Gender-specific differences also are found in communication styles. Although men tend to talk in order to impart information, women talk to communicate feelings. This can

lead to miscommunication. The husband may think his wife is complaining when she is sharing her feelings and experiences of the day. The wife may think her husband is insensitive when he imparts information without emotional content. This difference in communication styles is not unique to families of children with terminal illnesses, but it is often accentuated in an environment of increased stress and inadequate financial and emotional resources.

Given these stresses, it has been found that strong marital relationships, good parenting and problem-solving skills, financial stability, and supportive social networks are advantageous for parents who have a child with special needs. For families who lack these supports, professionals need to be available to provide advice and support to ensure your child's optimal growth, development, and safety. Although some marriages are strengthened by this challenge, others deteriorate, especially if the relationship was not previously strong. Strong religious and community affiliation and effective behavioral Interventions in the home are also associated with an increased likelihood of effective family functioning.

Different family members and caregivers may have different reactions to news of your child's illness. The caregiver may suspect something is different about your child first and may not be surprised of the diagnosis of an illness, for the parents, if one is ready to hear the diagnosis and the other one is still at an earlier stage in the reaction process, such as denial, they may have trouble with acceptance. Being at different stages in the grieving process is also typical because people grieve in individual ways. Although it is no longer true as it once was that men are still expected to be "strong" and to not show their grief, they may have more difficulty talking about their feelings. This can create a barrier for fathers in terms of working through their own grief. Problems also arise when each partner grieves privately and is unavailable to provide emotional support to the other. Mothers may be somewhat more prone to blame themselves for their child's illness, particularly if they have some questions about the pregnancy, labor, or delivery.

C. What do we tell our parents (child's Grandparents)?

If relationships with parents have been supportive and based upon mutual respect, then it is relatively easy to go to one's parents for comfort and support in times of distress. If the relationship with one's parents has been difficult, superficial or distant, then sharing the news will be much harder. Sometimes, the grandparents are actually the first to notice a problem in the child, but they may hold their tongues until their own children are able to see and respond to the situation. Sometimes, grandparents experience denial themselves. They may urge you not to "worry" about your child, or they may challenge the validity of your perceptions or the competency of the Doctors and other professionals who have diagnosed your child's illness. Supportive grandparents should be welcomed as allies. If they are unable to fulfill this role, then they should be kept informed, but prevented from intruding on your role as primary caregivers.

Grandparents are also affected by the presence of your child with an illness in the family. Typically, grandchildren are a source of joy, comfort and satisfaction. When a grandchild is born with an illness, however, grandparents grieve for their own loss as well as for their child's loss. They may experience denial more strongly than do the parents of the child with the illness. This can interfere with the family's adaptation to the illness. Yet, grandparents can be extremely helpful to the family as a strong source of emotional support. They may also provide respite care and financial assistance that may be crucial for maintaining your child with a severe illness at home. Counseling, support groups for grandparents, and/or information given via the parents can help them deal with the reality of your child's illness and lead them to become more involved in supporting the family.

D. Effects on Siblings

The siblings of a child with a severe illness have special needs and concerns that vary with gender, age, birth order, and temperament. Often, older male children seem to have an increased appreciation for children with an illness, while older female siblings show increased behavior problems (perhaps because

of being overburdened with child care responsibilities). Near age siblings may have less contact with peers, and younger siblings may show increased anxiety.

Sibling concerns also appear to reflect such situational variables as whether their own needs are being met, how the parents are handling the diagnosis emotionally, what the children are being told, and how much they understand. In addition to recognizing age and gender differences, it is important to acknowledge that children, in general, have mixed feelings about their siblings with an illness. They may be glad that they are able bodied, yet also feel guilty that they do not have an illness. They may worry that they will "catch" the illness or fantasize that they actually caused it by having bad thoughts about their sibling.

Adolescents may question whether they will pass a similar illness on to their future children. Furthermore, because of the extra care and time required by your child with the illness, the unaffected children may think that their parents love their brother or sister more than them. As a consequence, they may act out in order to get attention. On the other hand, they may withdraw, not wanting to ask for attention from their overly burdened parents. To avoid these problems, care must be taken to balance the parenting efforts so that the unaffected siblings are not too often forced into second place.

Despite these concerns, having a child with an illness in a family does not necessarily adversely affect the development of the unaffected siblings. In fact, there is some evidence that these children demonstrate increased maturity, a sense of responsibility, a tolerance for "being different", a feeling of closeness to the family, and enhanced self-confidence and independence.

Siblings fare best psychologically when their parents' marriage is stable and supportive, when feelings are discussed openly, when the illness is explained completely, and when they are not overburdened with child care responsibilities. Parents must remember that children follow their lead. If the parents are upset, so too

will be the children, even if they do not understand why. In contrast, parents who acknowledge their pain while being proud of the accomplishments of all their children, show their ability to adapt to the increased emotional and physical demands of having a child with special needs. This sets the tone for the entire family.

Parents should also avoid burdening siblings with care giving responsibilities. It has been shown that mothers of children with an illness are more likely to put child care demands on the siblings and reprimand them more. Parents must also recognize that their other children often feel torn between protecting and caring for their brother or sister with an illness and being accepted by children outside the family who may tease them and their sibling. Siblings should be informed at an early age about their brother's or sister's illness, so their knowledge is based on fact, not misconception. This must be done in an age-appropriate fashion with the sibling feeling free to ask questions. These sessions will need to be repeated as the children grow older and can handle more information. By the time siblings have reached adolescence, the parents may be ready to share with them information about genetics, estate planning, guardianship arrangements, and wills.

Many siblings possess greater tolerance and compassion toward persons with a severe illness than their peers. They also are more accepting of individual differences. Many feel good about their role in the progress made by a brother or sister with special needs. Experience with a special needs brother or sister has led many to a career in the field of human services, including social work, education, medicine, and psychology. Children, sometimes even more than adults, tend to blame themselves when they sense that an event has upset the family. Children view themselves as the center of the universe. Therefore, they magically think that they must be responsible for anything that happens in their universe. This is especially true of preschool children. The first thing parents need to do is to reassure the other children that this did not happen because of anything that they thought or did. (This advice may sound strange, until you stop to ask yourself (as a parent) the following question: "How many times have I tried to

blame myself for my child's illness, even though the Doctors keep telling me it was not my fault?") It is also important to tell the other children that the illness is not something they will "catch".

Parents need to share their own feelings with their other children in a way that will be understandable to them. "Mommy and Daddy feel very sad because your brother has a problem that we can't fix," might be the explanation for a preschooler. If the other children are older or when your preschooler is older, simple explanations for the cause of the illness, if known, may be appropriate.

Even more important as parents is the ability to convey to your other children that their feelings are normal - whether these feelings consist of irrational self-blame or resentment because of the extra attention you may need to give your child with the illness. "It's ok to feel angry. Mommy and Daddy sometimes feel like that ourselves," is often the best response, even as you remind your other children that it is not okay to act out these feelings of resentment in ways that can hurt other people. Saying this may be difficult, but it is preferable to responses such as "How can you say that about your brother? Don't you know he has a problem?" The ability to listen sympathetically to the other children in this fashion is directly linked to how well you, as parents, have been able to deal with such feelings yourself. If parents are still focused on their own coping, they will find it hard to give their children the emotional space they need to ventilate their own feelings.

It is also important to have one-to-one contact with each of the children on a regular basis so that they know how special they are. To achieve this, parents will need to manage their time and work on developing a network of supportive friends, extended family, and professionals to help with their children when they need it. Finally, it is important to reinforce to the children that people in a family should take care of each other. There are many good books on this subject in the children's section of the library or larger bookstores suitable for reading with the other children. There are also sibling

support groups that may be helpful, such as the Sibling group associated with Batten Disease Support and Research Association.

While most of your attention is focused on your child with an illness, it is easy to put aside the other children's needs. Remember, people of all ages can feel stress. Even the youngest child can sense when their parents are sad or something is wrong. Most of us want to know the truth, and children are no exception. Parents need to avoid thinking they must protect their children from emotional pain, and keep in mind that they must remain compassionate.

Children, like adults, need accurate, understanding information to help them comprehend what has happened by discussing the unique needs of your child with a severe illness and how they may affect family life. Parents will help their children adjust. This is particularly important if your child has medical or physical problems requiring much of the parents' time and attention. If no explanation is offered about why so much of parents' time is spent with their child with special needs, the other children may draw their own conclusions - maybe a parent is angry with them, maybe they love the special needs child more than they love the other child, or maybe they will also develop the illness.

E. How will other family members and friends react?

Relatives, upset by the news, may insist the problem will go away or that the Doctors were wrong. Some may argue that "this child" should be institutionalized. Others may say that Einstein did not talk until he was 4 or that "so and so" took forever to walk and now is perfectly "normal". Some may try to blame someone, such as "our side of the family is healthy, so the bad genes must come from your side." Some may fail to understand or are reluctant to talk to you about your feelings. Remember, grandparents, aunts, uncles, brothers, sisters, and friends are making their own adjustment to the situation and at the same time may be trying to spare your feelings. The best solution is to help each other by providing support and assistance when needed. Like it or not, having a child who has special needs is a family affair.

F. Effects on the child with a severe illness

Prior to school age, the child with an illness may not realize he or she is different from other children. By school age, most children with an illness are aware of their abilities and disabilities and may need help in dealing with feelings of being different. If your child is given proper support, he or she can learn to cope with their special needs. First must come acceptance in the home. If your child is seen as being worthwhile by parents and siblings, your child's self-image is usually good. This acceptance includes being part of family activities (religious, recreational, and vacations); participating as much as possible in developmentally appropriate family responsibilities; and being permitted to discuss the illness openly, depending on the age of your child. Discussing and modeling how to handle different situations at home improves your child's ability to cope with social situations in the community as well. This is very important because acceptance outside of the home can be difficult to achieve.

1. **Experiencing An Illness** - feelings we may not think our children with Batten Disease experience:
 - a. Change in identity - you are still yourself
 - b. Emotional responses
 1. Sense of tragedy
 2. Denial
 3. Grief
 4. Anger
 5. Depression
 6. Hope
 7. Acceptance
 8. Humor
 9. Need for emotional support
 10. Need for adaptability
 11. Family
 12. Living as independently as possible
2. **Classmates** may tease your child with an illness and schoolwork may prove difficult to achieve, especially in an

inclusive setting. This is particularly problematic if the teachers and school personnel have not been adequately informed and trained about the specific physical and cognitive needs of your child. Furthermore, if your child's communication or social skills are limited, this may interfere with interpersonal interactions. If your child is not accepted by others, he or she may develop a poor self-image and exhibit depression or behavior problems. The transition to school can be eased by preparing the class for your child's entrance. If possible, the child's parents should be included in this planning. Parents can help explain their child's illness and the necessary adaptations to both teachers and students. They can also share with the school staff their hopes and fears for their child's education and future. Your child with an illness gains self-confidence through participation in activities in which he or she can be successful. These can be either integrated or special activities.

3. **The philosophy of inclusion** (or integration) is that children who are differently challenged are accepted in general activities with appropriate adaptations or assistance. This however, should not preclude either participation in segregated programs, such as Special Olympics or development of friendships with children who have similar illnesses. Some children with an illness will need encouragement and assistance in socializing and developing friendships. Summer camps that welcome children with special needs provide an avenue for children to develop important socialization skills and experience independence from parents. This not only encourages personal growth for the child, but for his or her parents and campmates as well. Children learn to appreciate people with a severe illness. This will prepare them for a future where they live and befriend people with severe illnesses.
4. **Adolescence** is a difficult time for all children, and for children with an illness the problems are often magnified. As

is true of other adolescents, these children may become preoccupied with comparing themselves with their peers, yet the desire for sameness and peer approval in areas of physical and intellectual development may be unattainable because of their illness. This will be less of an issue if the adolescent with the illness has a strong peer group or has already come to terms with being "different". If your adolescent has just acquired the illness or is having emotional or behavioral difficulties, counseling may be helpful in working through his or her concerns.

When parents find out that their child has a severe illness, it may not seem possible to return to the everyday world. Making contact with professionals, support groups, and other parents who share similar experiences will help parents find the strength to develop and foster the health and well-being of their child with an illness. Understanding that parents are not alone and that other families have gone through what they are going through is half the battle. The rest is coming up with solutions. Parents will end up as an expert on their child, and will be capable of helping others. Families can survive and emerge whole.

G. Some additional suggestions parents may find helpful.

1. Celebrate your child's successes - all of them. This recognition is most important to foster your child's social, physical and psychological development. Surround yourself with positive people who will do the same
2. Learn about your child's illness. It is best if both parents go to meetings with the Doctor or other health care specialists, especially when diagnostic information is shared or treatment plans are developed. If you are a single parent, try to bring a family member, friend, or other advocate with you to help support you and your child and to help you remember the information you are given. If you think of questions before the visit, write them down and take them with you to the visit. Consider using a tape recorder during the session, and ask for a copy of the report generated from the visit. Read up on the

- illness, attend lectures, search the web, and ask questions
3. Seek help when needed, even if you never did before, but be specific about what you need. Get involved in parent support and information groups through your child's Early Intervention program, the medical center where your child may have been diagnosed, or through regional or national programs specific to your child's illness
 4. Learn about local and national organizations that can keep you updated regarding diagnostic and therapeutic information specific to your child's problems. Publications such as *Exceptional Parent* (a general magazine for parents of children with special needs) and reputable web sites such as www.bdsra.org, www.familyvillage.wisc.edu or www.pacer.org provide useful information, but be sure to crosscheck information you get from the web, because it is not always accurate
 5. Learn to be an advocate for your child - get active and speak out. Advocacy may include involvement with your local school or medical center. Work with others to benefit not only your child, but all children with special needs. Be kind to yourself when you discover that you are very motivated and active at one time and not at another. These ups and downs are to be expected. Listen to your body and your spirit, so that you do not overwork them
 6. Have realistic expectations for your child - developing a clear understanding of your child's strengths and weaknesses can help prevent unnecessary disappointment and discouragement. Suitable expectations are a protection against the extremes of pessimism or unrealistic optimism. Focusing on what your child can do will further help you recognize what can be accomplished and how you can help your child enjoy the activities. Sometimes this can be difficult to do. It is not always easy to pinpoint a child's capabilities

H. **Providing health care services** to children with special health care needs will continue to be a challenge in the 21st century. Citizens must focus on designing a system of health care that meets the needs of children and families in a coordinated, comprehensive, inclusive, culturally sensitive, and family-oriented manner. Because

this group of children has the potential to use significant health care resources, they are vulnerable to cost-cutting initiatives. Therefore, health care providers and child advocates must cogently express the value of necessary services and supports to the child, family, and community. Managed care offers the potential to efficiently use resources and ultimately shift from costly delivery models to less costly, coordinated prevention focused delivery models. A great deal of attention will need to be given to the potential impact of any proposed system wide change for children with a severe illness to ensure that they are cared for in an appropriate manner.

IV. Body mechanics for parents and care givers

The musculoskeletal system is composed of bone, muscles, and joints, as well as their associated ligaments and tendons, which work together to permit movement. Defects within the system are a major cause of decreased motor ability in childhood.

A. Practicing good body alignment and movement is also a part of providing a safe environment by preventing injury to your child and to yourself. Alignment is defined as the proper relationship of the body segments to one another. When the segments are properly aligned, it is easier to maintain body balance. Balanced posture means a body that is stable, steady, and not likely to tip or fall, including the ligaments and muscles being used effectively. The force of gravity affects balance also. Various terms are used to describe body movements:

- Flexion - bending a joint as in the elbow
- Extension - straightening out a joint like a knee
- Abduction - to move an extremity away from the midline of the body
- Adduction - to bring an extremity back to the midline of the body

Body Mechanics is the use of proper posture and body movements that are necessary in order to limit stress and strain on the musculoskeletal structures. Proper posture and the use of body mechanics are based upon the alignment and functioning with the

following four principles:

- Using the larger and stronger muscles to perform heavy work

Lifting and Carrying "Do's and Don'ts"



DO have a transfer surface that is clear of objects.

DO have a stable transfer surface.



DO NOT have objects on the transfer surface.



DO NOT have an unstable transfer surface.

Lifting and Carrying "Do's and Don'ts" (continued)



DO lock the wheelchair brakes whenever moving the child in or out of the wheelchair.

DO tell the child what you are going to do.

DO wear non-skid, low-heeled footwear (both helper and child).

DO keep feet apart for a wide base of support.

DO remember to unfasten all seat belts and harnesses.



DO bend at the hips and knees.



DO NOT bend forward at the hips while standing with the knees straight.

Lifting and Carrying "Do's and Don'ts" (continued)



DO keep your back straight.



DO NOT relax your back and let it round.



DO lift by holding the child at the waist or by holding the child's crossed arms.



DO NOT lift with the child's arms.

Lifting and Carrying "Do's and Don'ts" (continued)



DO hold the child as close to you as possible.



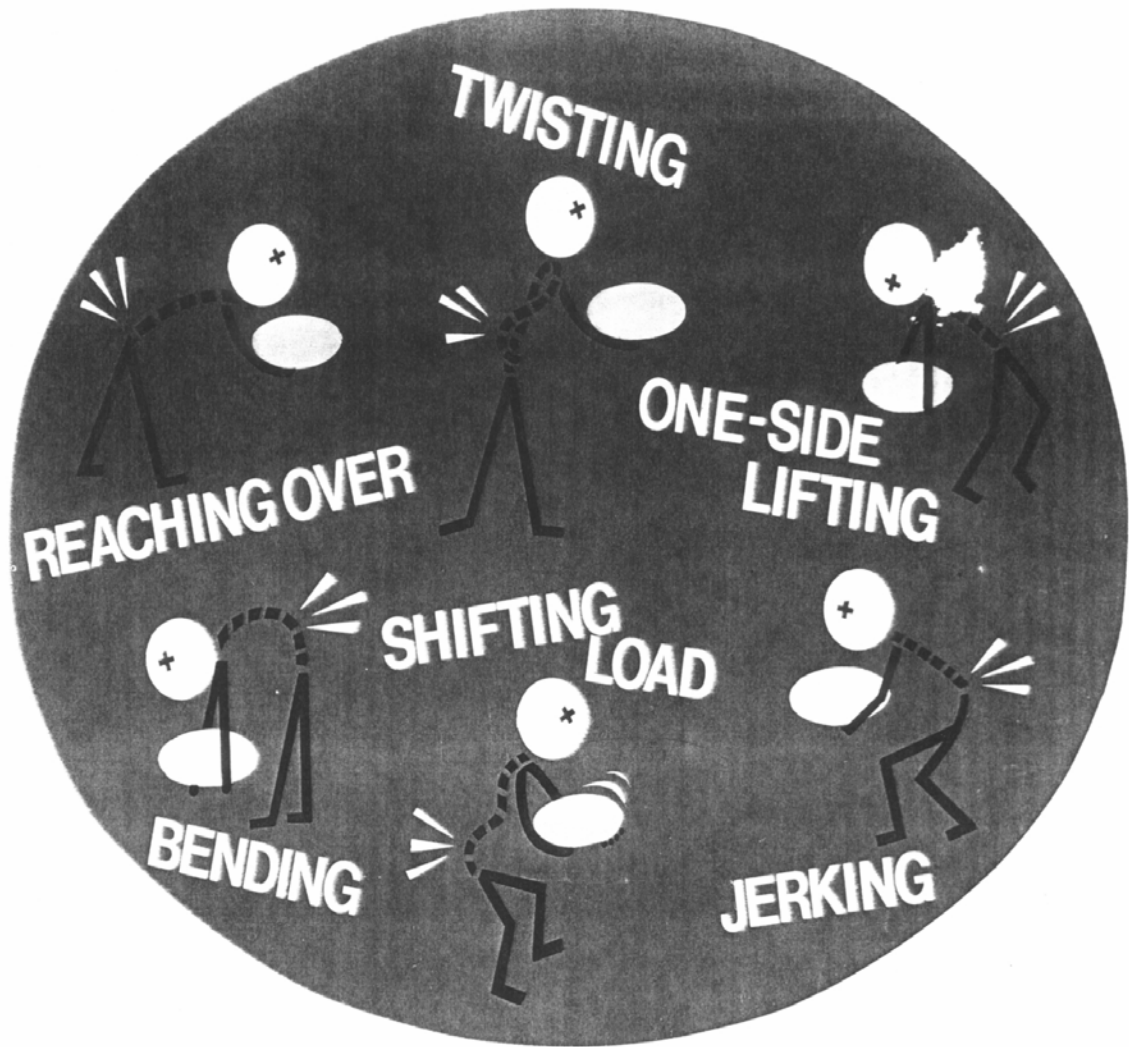
DO NOT hold the child away from you.



DO complete the lift before turning.



DO NOT twist your body while lifting.

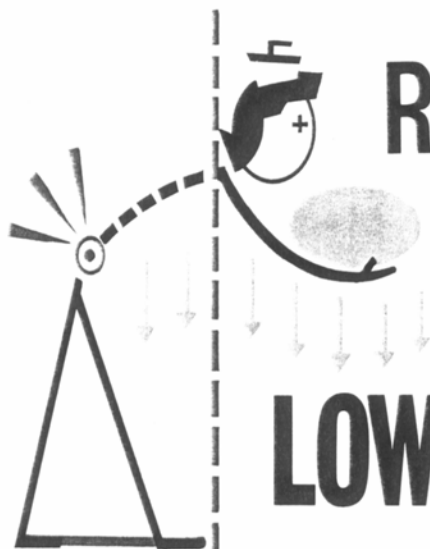
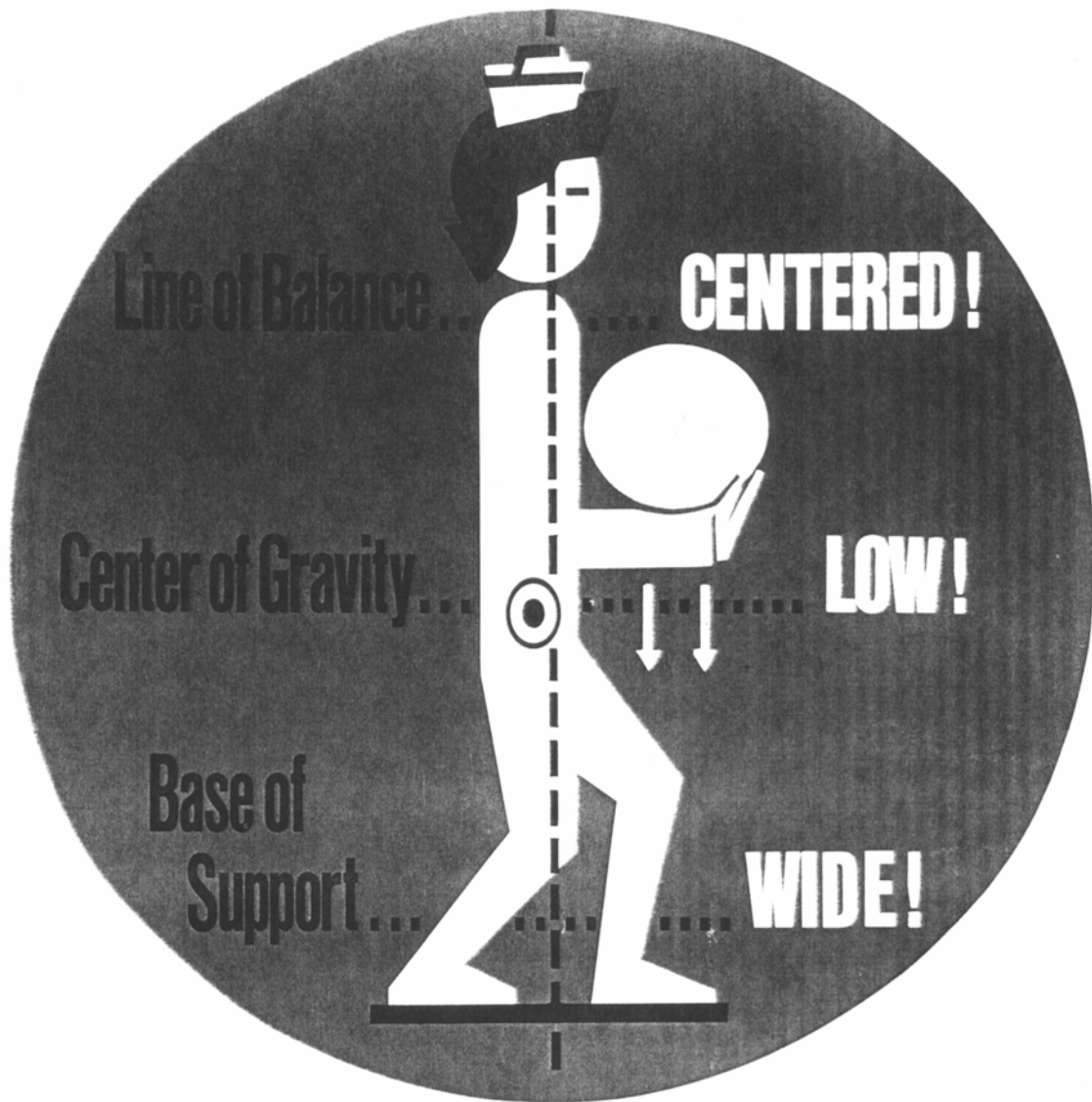


Constant daily abuse

causes bad backs.

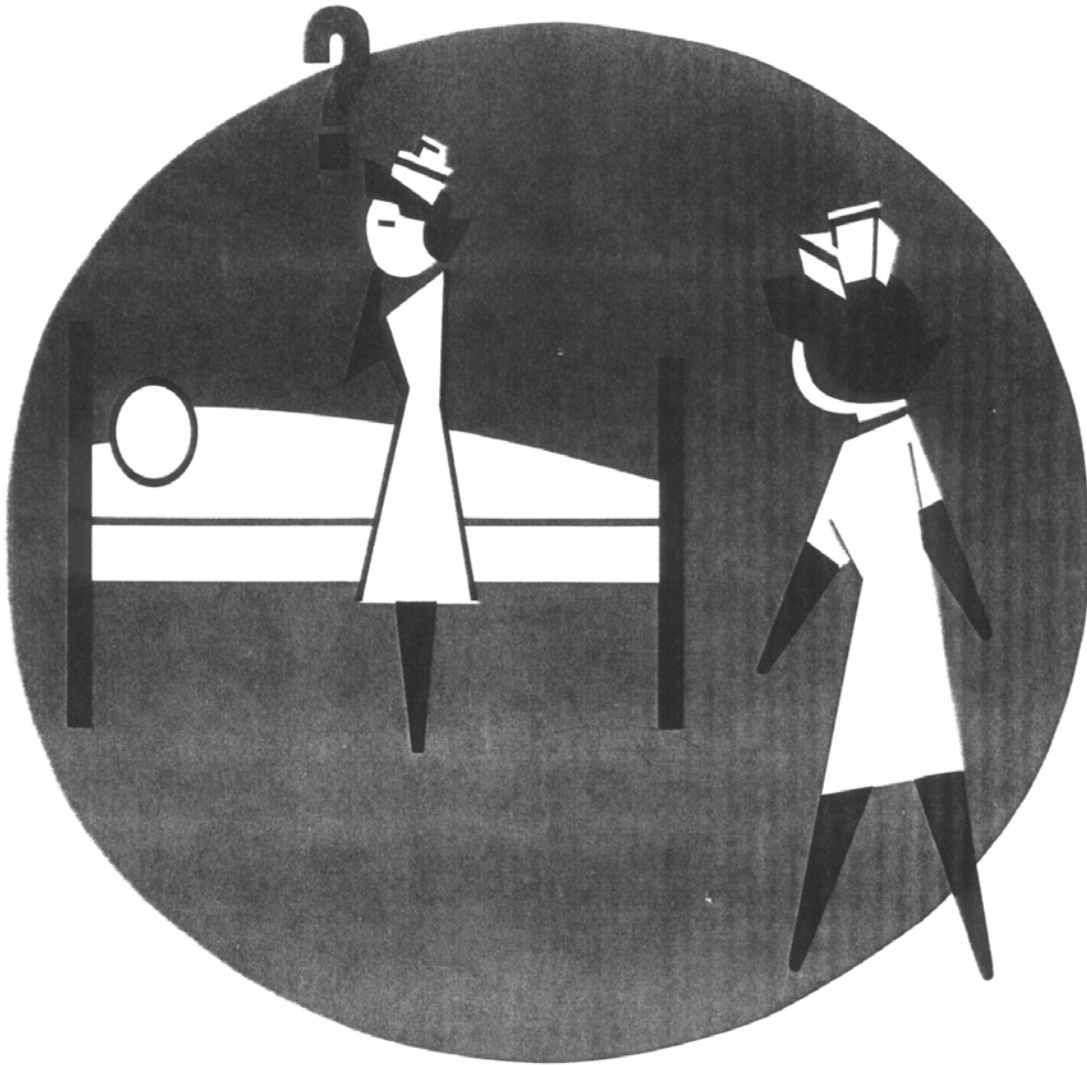


LIFT CORRECTLY!

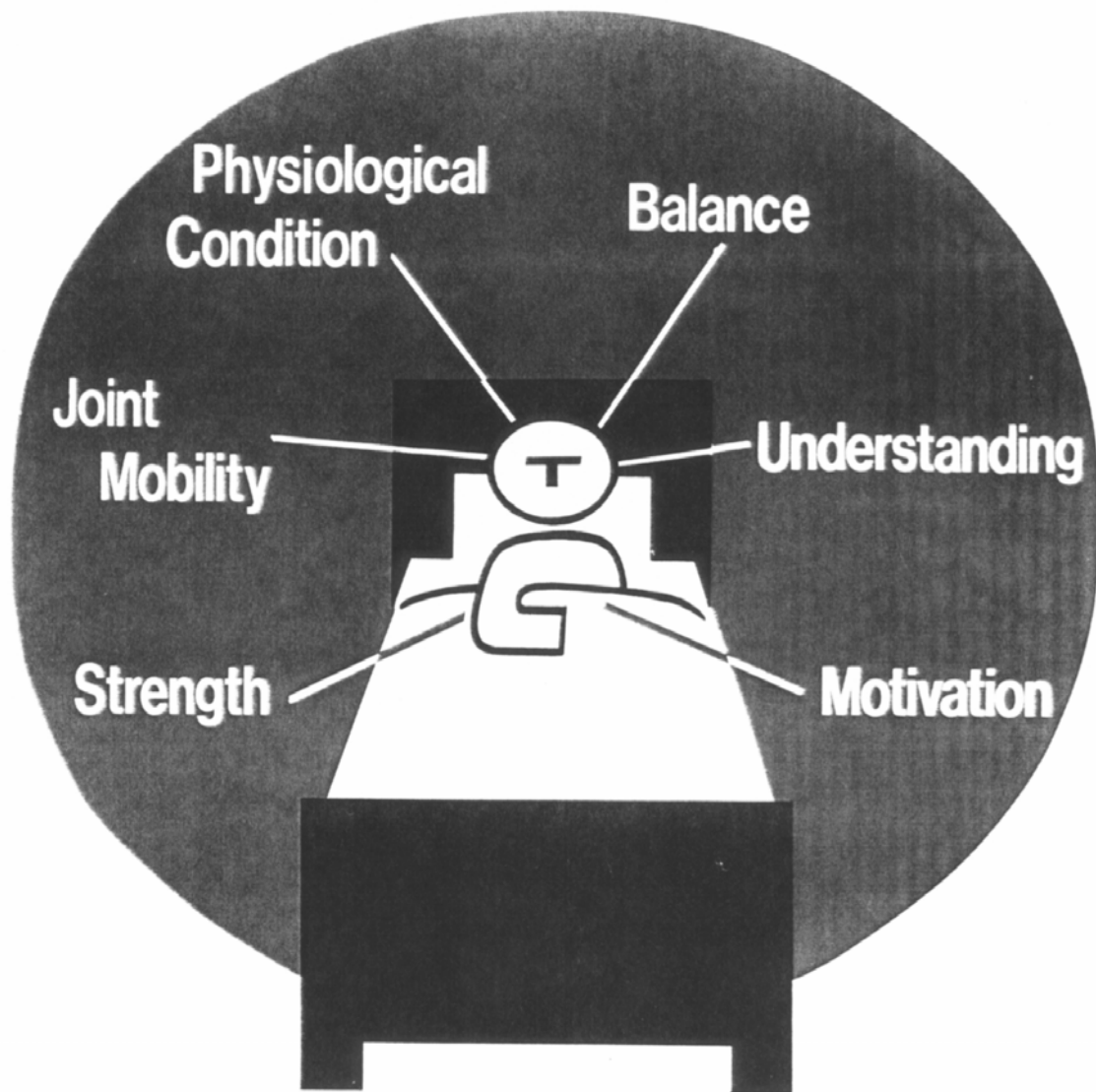


Reaching too far
causes

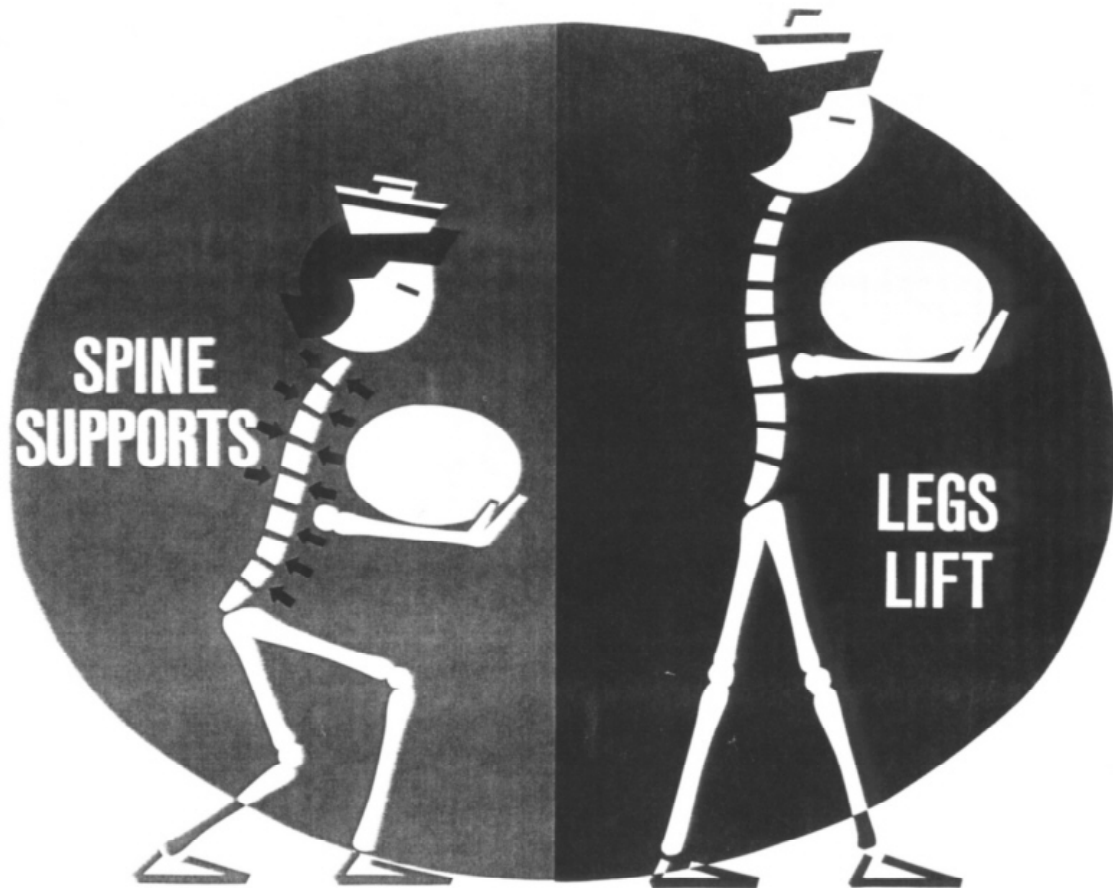
LOW-BACK INJURY



Know your lift limits!
Get help when needed.



Before lifting--
assess patient's condition.

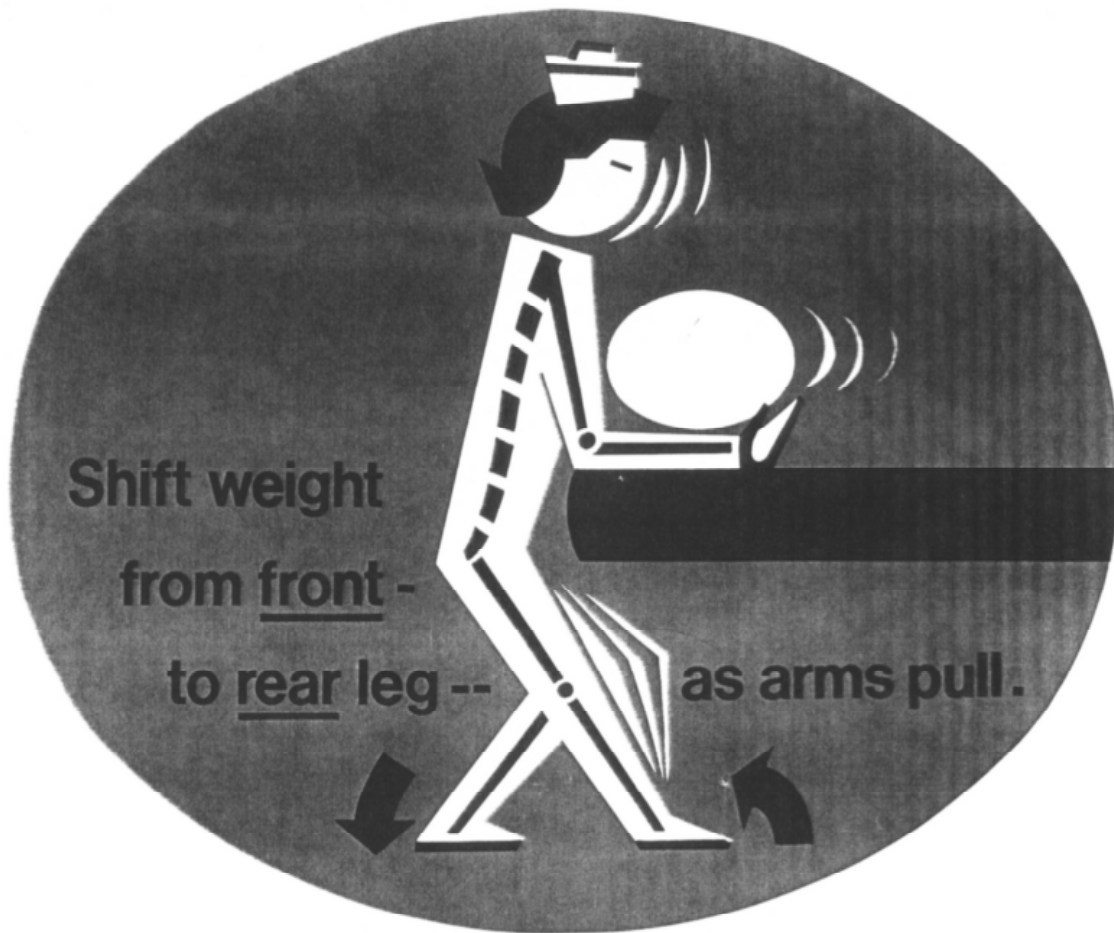


BEFORE LIFT:

Set muscles to
support spine.

DURING LIFT:

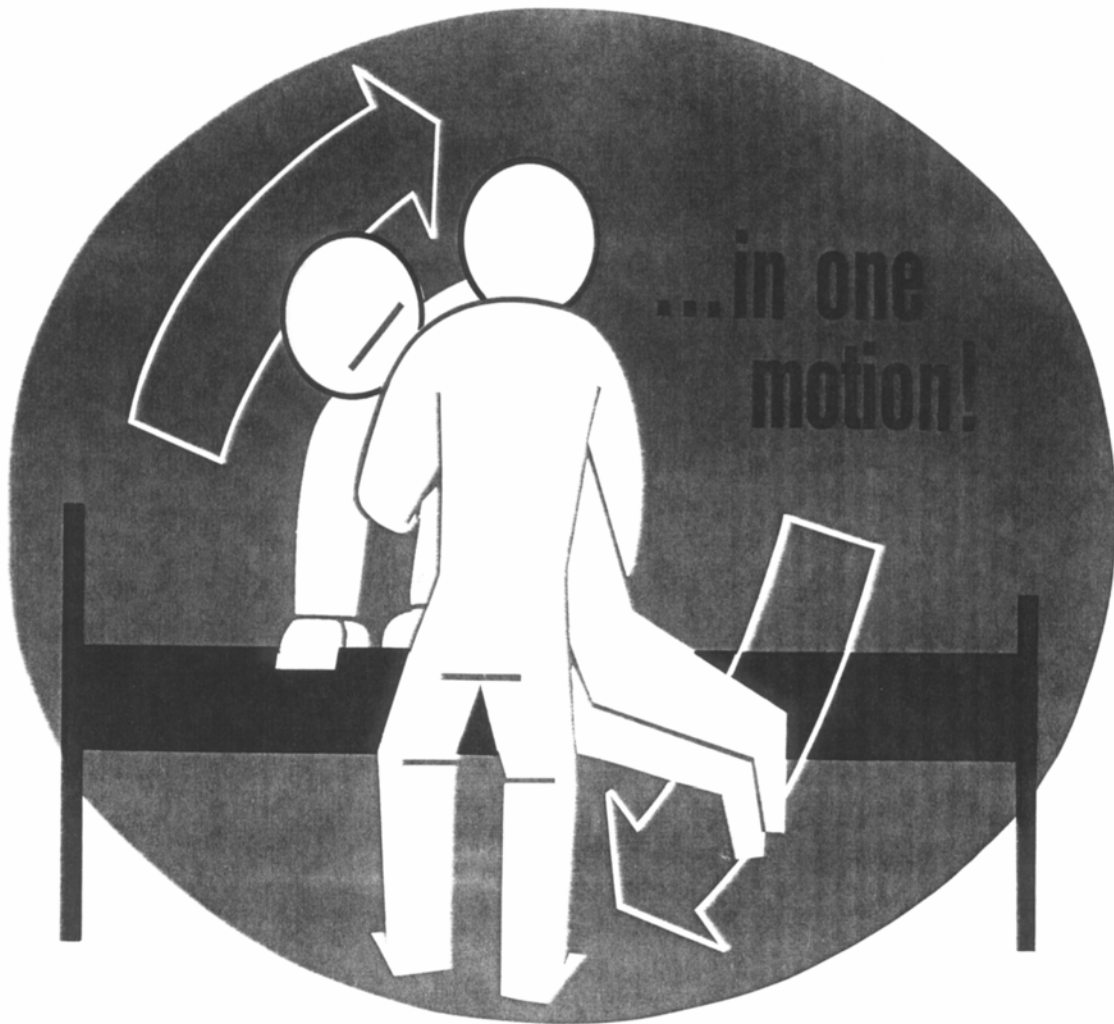
KEEP SPINE
SUPPORTED!



Transfer to SIDE of bed:

Keep your spine 'set'.

Legs and arms pull!



Assist to SIT :

Keep your spine 'set'.

Legs and arms lift!



Assist to STAND:

Keep your spine 'set'.

Legs and arms lift!

- Maintaining the center of gravity of the body close to the center of the base of support
- Keeping the combined center of gravity of the aide and your child centered within the base of support
- Having a base of support that is of the appropriate size and shape

An essential ingredient in maintaining a healthy back for the care provider is proper body mechanics in the various activities of daily life. With regard to the back, proper body mechanics means using the body and the different parts of the body in ways that

are consistent with the smooth functioning of the joints, muscles, ligaments, disks, and other structures of the back. Among other things, this means knowing how to lift and carry heavy objects properly, not holding your back in a fixed position for prolonged periods, and being careful never to twist the trunk when reaching for something. As with proper posture, proper body mechanics can significantly reduce the risk of many back problems. For most of us, body mechanics need to be learned and to make them a habit. Although they represent slightly different ways of thinking, posture and body mechanics are closely related phenomena. Proper body mechanics will allow for smooth functioning of your joints, muscles, tendons, and ligaments.

V. Medical Issues

- A. Your child's level of independence and function** depends in large part on good health maintenance. Your child's energy, strength, weight, and the minimization of any potential circumstances particular to their special needs, all need regular attention. The more your child builds healthy routines in his/her life, the more they become simple habit and the less they seem like work.

The following are the brain regions which control different activities:

- Caudate which governs affect, impulse control, and executive function
- Thalamus which is involved with sensory integration

- Cerebellum which is involved in motor planning
 - Hippocampus which directs memory and attention
 - Superior temporal gyrus which directs language
 - Cerebral cortex which directs goal-directed behavior and working memory
1. **Exercise** to prevent weak muscles, the parts of the body you can control need exercise to stay strong and vibrant; cardiovascular loss -your ability to function depends on the hearts' ability to get healthy blood out to your muscles. A weak heart means early fatigue and long term decline in your level of activity and independence; osteoporosis - your bones lose density from lack of use; weight gain - calories turn to fat when you do not burn them off with exercise. The heavier you get the harder it is to exercise and lose weight. Extra weight adds to the strain on your heart and muscles. In order to control the above four areas, you may need to do the following:
 - a. strength building exercises
 - b. aerobic exercises
 - c. exercise programs
 2. **Diet** - a variety of whole foods with minimal processing is the best source of nutrients needed by the body.
 - a. Vitamin A is for growth and repair of body tissues and maintenance of healthy skin, derived by the body from carotene - carrots, green leafy vegetables and broccoli
 - b. Vitamin B complex produce energy by helping the body to convert carbohydrates to glucose; crucial to the nervous system; found in whole grains, liver, and brewer's yeast; some antibiotics limit the ability of the body to produce B Vitamins in the intestines
 - c. Vitamin C plays a role in the healing of wounds by maintaining collagen, the protein that forms connective tissue in the body; also helps fight bacterial infections; found in fresh fruits and vegetables
 - d. Vitamin D maintains intestinal reabsorption and metabolism of Calcium and Phosphorus levels in the blood and bone; also maintains renal (kidney) reabsorption; essential for normal

development of bones and teeth; can prevent and cure osteoporosis; some antiepileptic, drugs especially Dilantin and Phenobarbital, also have been found to cause Vitamin D deficiency or to interfere with the utilization of Vitamin D. This places nonambulatory children with seizure disorders at increased risk for fractures

- e. Calcium most abundant mineral in the body; it must be accompanied by Vitamin A, Vitamin C and Vitamin D, as well as, Magnesium and Phosphorus; it is crucial to bones and teeth and proper functioning of muscles (including the heart, which can not contract and release without Calcium); best source of Calcium is dairy products, but also found in fruits, vegetables and grains, especially figs, greens, and soy products
- f. Iron exists in every living cell; it works with Protein and Copper to carry oxygen from the lungs to the tissues of the body; found in liver, oysters, lean meat, molasses, and green leafy vegetables
- g. Potassium is involved in maintaining the water balance of cells which is necessary for cell growth and to stimulate nerve impulses to muscles; it also stimulates the kidneys to eliminate toxins from the body; Potassium is found in all vegetables, oranges, whole grains, sunflower seeds, potatoes and bananas
- h. Zinc is a crucial nutrient for wheelchair users because of its importance of blood formation and the skin, particularly in the healing of wounds. It is naturally found in meats, eggs, liver, seafood, legumes, nuts, peanut butter, milk, and whole-grain cereals
- i. Carnitine - a naturally-occurring amino acid found in skeletal muscle, essential for long chain fatty acid oxidation when impaired fat utilization and energy production is present. A deficiency can be caused by the usage of Valproic Acid (Depakote). Carnitor is the medication prescribed to correct this imbalance. Blood work should be done periodically to check the Carnitine level if on this medication

3. **Skin care** to prevent pressure sores which develop from oxygen and blood being restricted in skin tissues by the weight of the body pressed continuously on a small area of skin
 - a. Avoid unnecessary areas of pressure, especially the knees, buttocks, sacral bones (pelvis), ensuring proper fit and contact with braces, catheters and clothing
 - b. Regularly inspect areas that receive pressure
 - c. Use appropriate cushions and maintain them
 - d. Do exercises regularly and movement for pressure relief by shifting position and weight
 - e. Use of tilt or recline system
 - f. Do not wear rough or irritating undergarments
 - g. Do not wear loose undergarments (wrinkles can cause increased pressure in small areas)
 - h. Keep buttocks clean, especially after a bowel movement
 - i. If skin is dry, use moisturizers in areas of regular contact
 - j. Eat a balanced diet rich in nutrients for skin health - proteins, Vitamin A, Vitamin B Complex, Vitamin C, and Zinc; drink plenty of water to keep tissues moist and flexible

4. **Prevent Osteoporosis** - osteoporosis is defined as an increase in porous areas of bone, softening of bone as calcium decreases. Without the regular loading of weight from walking, bones begin to lose Calcium, this leads to osteoporosis in which bones become more brittle and more prone to fractures. The hips are a common site for fracture/dislocation as are the legs, spine, and arms

5. **Bowel & Bladder Management**

- a. Good diet - adequate fluids, wheat or rice bran, vegetables and fruits - especially figs, prunes and dates
- b. Possible use of stool softeners to help relieve constipation
- c. Possible use of foley catheters or condom catheters

- B. **Immobility** - immobility is defined as not mobile, motionless or fixed and atrophy is defined as a wasting away, due to lack of nutrition of any part, therefore reducing the size of the structure, disuse, disease, or interference with nerve or blood supply. Perhaps

the most profound change in human skeletal muscle during immobilization is atrophy of muscles. The degree of atrophy depends on both the duration of immobilization and the position or stretch imposed on the muscle. Muscle fiber types are also affected by position during immobilization. Protein synthesis increases muscle atrophy resulting in a decrease in muscle weight, therefore, muscle loses its ability to generate force and tension. The greatest amount of atrophy occurs within 1 week of immobilization and muscle fiber size decreases by approximately 17% within three days of immobilization.

1. Effects of motion and immobilization on **tendons** are similar to other tissues (cartilage and bone). Overall strength is decreased. Conversely, stress and exercise produce increased strength, stiffness, and increased collagen size. Early motion of tendon injury provides increased motion, but decreased strength. Likewise, immobilization creates improved strength of the tendon, but with less motion
2. Effects of immobilization on **ligament** tissue and associated structures: reduced motion, decreased nerve input, muscular atrophy, ligament shortening, reduction of water content, bone loss, cartilage erosion, reduced ligament weight, reduced ligament size, reduced ligament strength, adhesion formation, increased ligament laxity. and joint stiffness related to synovial membrane adhesions

- C. Bone Healing** - process of bone healing. Bone healing can be characterized by the following sequence of events:
1. Fracture occurs
 2. Bleeding occurs, and a hematoma (a pocket that consists of blood) results
 3. Granulation tissue is formed by the hematoma (soft callus formation)
 4. Osteoblasts (new bone cells) produce new bone, and a bony or hard callus is formed
 5. The callus is gradually reabsorbed, and the anatomic contour of the bone is regained

- a. As with soft tissue, the immediate inflammatory response lasts 24 to 48 hours and is characterized by the development of granulation tissue, blood clotting, and fibroblast and osteoblast proliferation. The repair phase of bone healing signals the development of bone scarring, or callus formation, which usually is detected within the first two weeks after injury. The degree of callus formation depends on the anatomic alignment of the fragments and the degree and quality of immobilization. If motion occurs through the fracture site during this phase, a soft bone callus (primarily of cartilage) will bridge the fragments. This type of callus also forms if the union between the fragments is poor, even when immobilization prevents motion

- b. When a bone breaks - fracture breaks continuity of bone and of important attached soft tissue, including blood vessels which spill their contents into surrounding tissue. Even before treatment, the body automatically seeks to repair the injury. Inflammatory cells rush to destroy, dilute or isolate invaders and injured tissue. Tiny new blood vessels called capillaries begin growing into the site. Cells proliferate. The injured person usually must endure pain, swelling, and increased heat at the breakage site for one to three days.

New tissue bonds the fractured bone ends with a soft callus, a mass of connective tissue and exudate (matter escaped through blood vessel walls). Remodeling begins. Within a few months, a hard callus replaces the soft one. Remodeling restores the inner canal. Once restoration is complete, which may take years, the healed area is brand new, without a scar. Usually thicker, the new bone may even be stronger than the old. If the bone should break again, it is unlikely to be at the same place. Children's bones have a healing boost. They are growing. The growing skeleton is geared to make bone

- c. For bone healing to occur, a major goal is to immobilize the fracture site. However, when bone tissue does not receive physiologic loads (ambulation, vertical loads, and muscle contractions), the normal remodeling processes are negatively affected. The rate of normal bone remodeling changes when immobilization lasts slightly longer than 1 week. The turnover or remodeling of bone during immobilization is characterized by a loss of calcium, resulting in localized bone loss

Immobilization leads to a reduction in the hardness of bone related to the duration of immobilization. By 3 months, bone strength is only 55-60% of normal strength. The relationship between soft tissue structures and bone during periods of immobilization reflects the interdependence of muscular contractions, forces acting on joints, compressive loads, circulation (blood flow affecting nutrition), and motion in maintaining bone remodeling equilibrium

- d. A definite contrast is seen in the care of healing bone tissue. It is necessary to immobilize the fracture fragments so healing can occur, yet minimize the negative effects of immobilization through the judicious application of progressive motion, exercise, and weight bearing. The length of time needed to regain bone strength after immobilization is considered longer than the duration of immobilization. Therefore, the length of the immobilization is an important component in the overall process of healing bone tissue
- e. Occasionally, the process of bone healing leads to three distinct complications:
 - 1. Delayed union - the repair processes of bone healing occur at a slower rate than anticipated (for example - for fractures of the femur and tibia it is 20 weeks and 10 weeks for the humerus). Usually, the cause of the lengthened time for healing is inadequate or interrupted immobilization

2. Nonunion - the healing processes have stopped. It occurs when there is significant and severe associated soft tissue trauma, poor blood supply, and infections
3. Malunion - healing results in a non anatomic position, caused by ineffective immobilization and failure to maintain immobilization for an adequate period of time. For appropriate bone healing to occur, anatomic alignment of fragments, adequate fixation (external or internal), and length of time of immobilization must occur in concert. If these factors are not balanced, the chance of complications is increased

D. Complications affected by immobility - skeletal issues

Joint involvement or ossification is defined as a limb not moving as freely as it once did or should. In the early stages, there may be no visible evidence, just the awareness of a vague abnormality on moving the limb. Swelling may occur within a few days and possibly some erythema (redness and a rash), which can then lead to stiffness of the joint. As the disease progresses, it can be seen on x-ray. Complications may include the following: spasticity, contractures, fractures/dislocations, foot drop, osteoporosis, spinal deformities, scoliosis, pressure sores, pain, dislocations and constipation. One or all of these may become present in many of our children with Batten Disease as the disease progresses.

1. **Spasticity** - As of 1997, medications have shown limited usefulness in improving muscle tone in children with spasticity and rigidity. Spasticity is defined as an involuntary, sudden movement or convulsive muscular contraction causing stiff and/or awkward movements. Rigidity is defined as tenseness, immovability, stiffness or the inability to bend or be bent. The medications most commonly used to control spasticity and rigidity are Valium (Diazepam), Baclofen (Lioresal) and Dantrium (Dantrolene). Valium and its derivatives, Ativan (Lorazepam) and Klonopin (Clonazepam) have been found to be used most frequently. A newer medication called Zanaflex (Tizanidine) has also been used.

These drugs for spasticity affect brain control of muscle tone, beginning one half hour after ingestion and lasting approximately 4 hours. Withdrawal of these drugs should be gradual, as physical dependency can develop. Side effects include drowsiness and excessive drooling, which may interfere with feeding and speech.

- a. Valium depresses the central nervous system (CNS) and has action on the spinal cord to produce skeletal muscle relaxation. It is usually given three or four times a day. Major side effects include drowsiness, sedation, depression, lethargy, fatigue, lightheadedness, disorientation, restlessness and gastrointestinal problems including nausea, vomiting, constipation and diarrhea
 1. Ativan also depresses the central nervous system (CNS). It is usually given three or four times a day. Major side effects include drowsiness, sedation, depression, lethargy, fatigue, lightheadedness, disorientation, anger, confusion, headache, crying, and gastrointestinal symptoms of nausea, constipation, diarrhea, and dry mouth
 2. Klonopin acts by decreasing involuntary leg movements. It is usually given three times a day. Major side effects include drowsiness, ataxia, behavioral disturbances, sedation, depression, lethargy, fatigue, lightheadedness, disorientation, anger, hostility, restlessness, confusion, crying, headache, increased drooling and gastrointestinal signs of nausea, constipation, diarrhea, and dry mouth
- b. Baclofen is a central nervous system (CNS) depressant. Acting as a skeletal muscle relaxant, it reduces transmission of impulses from the spinal cord to skeletal muscles. It is usually given three times a day. Drowsiness, nausea, headache, and low blood pressure are the most common side effects of this oral medication in children. Also, dizziness, weakness, fatigue, confusion, headache, insomnia, nausea, constipation, and urinary frequency are side effects. Care must be taken when stopping this medication, as rapid

withdrawal may lead to severe side effects including hallucinations.

- c. Dantrium works on muscle cells directly as a calcium channel blocker to inhibit their contraction to treat spasticity in severe chronic disorders by relaxing skeletal muscles. About half of the children treated with this medication show modest improvement. It is usually given 2-3 times daily. Major side effects include drowsiness, muscle weakness, and increased drooling with dizziness, general malaise, fatigue, and diarrhea as lesser side effects. A rare side effect of this drug is severe liver damage.
 - d. Zanaflex is an antispasmodic, a short acting drug for the acute and intermittent management of increased muscle tone associated with spasticity and acts as a skeletal muscle relaxant. Zanaflex is usually given three times a day. Its major side effects are drowsiness, sedation, dizziness, asthenia, dry mouth, constipation, hypotension, and orthostatic hypotension.
2. **Contractures** occur when your child undergoes prolonged immobility and his or her extremities are not properly cared for and exercised. A contracture is defined as an abnormal condition in which there is a permanent condition of a joint, characterized by flexion and fixation and caused by atrophy and shortening of muscle fibers or by loss of the normal elasticity of the skin. This usually includes muscles that spasm because of the abnormal shortening of muscles that usually results in a deformity of the joint and renders it resistant to movement. Permanent deformity may occur. Usually, there is no pain, but you will notice joint stiffness, immobility caused by shortening of surrounding structures, and deformity with decreased mobility and function of the affected part.
- Foot drop is a frequent complication of children suffering from muscle weakness, and it occurs as a result of a child's inability to maintain the foot in a

normal position. In essence, it is a dragging of the foot. Children suffering from foot drop usually have problems with poor circulation. The Physician usually orders elastic stockings to be worn to enhance venous blood return to the major veins. Removing and reapplying the stockings at least twice a day, changing your child's position at least every two hours, and stretching the heel cords, generally helps to prevent foot drop, as well as, contractures and pressure sores.

- Plasticity (the ability to be molded) - may vary in degree. The increased muscular tension in plasticity can lead to uneven distribution of pressure on joint cartilage. This may result in destruction of cartilage, capsular contractures or partial dislocations of varying degree. Keep in mind the following when considering treatment: fatigue has a depressant effect on plasticity; muscle accommodates to prolonged stretch; posture influences reflexes; and plasticity is influenced by emotional factors. Methods of treatment include passive movements, hydrotherapy, and reflex inhibiting postures, standing and walking, ice therapy, drug therapy or it may require surgical procedures by elongating a tendon or severing a nerve to reduce plasticity.

A. Contractures introduce delays and complications into your child's program of Intervention. It is the direct responsibility of the Physical Therapist and nursing care to lessen their occurrence by instructing parents (unless hospitalized).

1. The causes of contractures -

- a. Positioning in bed or posture in a wheelchair without good body alignment
- b. Inappropriate Physical Therapy regimen to move the joints
- c. Spasticity

It is difficult to separate these three closely linked factors in relation to the formation of a contracture.

Sometimes they will occur no matter what

2. Conservative treatment of established contractures
 - a. Passive movements - passive movements are always given at every treatment in addition to other methods employed. In conjunction with the passive movements a passive stretch is also given in the position of maximum correction
 - b. Prolonged passive stretching - A prolonged passive stretch can be given for flexion contractures of the hips and knees and adduction contractures of the hips by strapping the limbs in the corrected position. The stretch is normally maintained for 20-30 minutes
 - c. Active exercises if able - to where natural movements of the extremities can be done and your child is able to resist movements in order to strengthen muscles
 - d. Splinting - to avoid excessive pressure, it is advisable to make splints and not to try to obtain maximum correction initially
 - e. Passive and active exercises in a heated pool - the hot water aids relaxation, and is especially beneficial if there is severe spasticity
 - f. Ice therapy and ultra-sound - are used as and where suitable. Sometimes they are used in conjunction with the other forms of treatments
 3. Surgical treatment - when no improvement has occurred in spite of intensive therapy, your child may be referred to surgery. Release of a muscle, elongation of the Achilles tendon, or releasing the adductor muscles are useful surgical procedures in cases of severe contractures which have not responded to conservative methods. If your child has strong spasticity, as well as contractures, other surgical procedures may be recommended
3. **Osteoporosis** is defined as a disease in which the bones become extremely porous, a decrease in bone tissue, structural

weakness, and softening of the bone. Symptoms you may see or have: pain is possible because of a fracture or vertebral collapse or may be aggravated by movement; and/or deformity and immobility because of fractures of involved bones; collapse of some vertebrae; or increasing in curvature of the spine. When examined by a Physician, he would possibly recognize a healed fracture, loss of weight, wedging of the vertebrae, and would request diagnostic studies including x-rays and bone density tests.

Research has shown that mineral metabolism associated with atrophy of the muscular and skeletal systems changes as a result of prolonged bed rest. These changes are more prominent when the bed rest is combined with immobilization. Considering the inevitable immobility associated with Batten Disease, it is not surprising that osteoporosis may be present to some degree in all or most children with Batten Disease. The degree of osteoporosis is considerably increased by chronic infection from any cause. Therefore, fractures/dislocations of bones can occur as a result of exceptionally minor injuries. Due to the lack of sensation in some of our children, they may be unaware that a fracture/dislocation has occurred until the area becomes swollen, has a fever, or feels painful. To treat such cases, your child should be turned frequently to aid the circulation and some researchers feel that a diet high in protein with added Vitamin D may be helpful. Exercises whether passive or active may also be done to increase circulation and to minimize further development of osteoporosis.

- 4. Spinal Deformities** - any child confined to bed for some time is in danger of developing contractures and may also develop a scoliosis. Scoliosis is defined as a lateral curvature of the spine, usually consisting of two curves, the original one and a compensatory curve in the opposite direction. Symptoms that may be present include: pain radiating from the back to the extremities; joint stiffness with hip or knee flexion contractures; deformity and immobility; rib cage deformity; or

hamstring tightness (the higher the location of scoliosis, the more severe the deformity); sensory changes with decreased sensation to the lower extremities. A Physician may see a limited spinal range of motion; fatigue or tired back; hair patches, dimples and pigmentation on the back; decreased chest expansion; impaired pulmonary or cardiac function (hypoxia, cyanosis, or possibly a lung disease-refer to glossary); one scapula, breast or flank more prominent than the other; shoulders and hips not level. Diagnostic studies include x-rays.

Children and adolescents are in particular danger because of continuing growth and extreme joint mobility. When a child spends a high proportion of time in an abnormal, incorrect posture for functional activities, for convenience, or for comfort, deformities are likely to develop.

a. **Gross scoliosis or pelvic distortion** will severely hamper your child's Intervention and may prevent him/her from attaining maximum independence or from functional weight-bearing. To minimize or treat such deformities, correction must be made for your child who spends a lot of time in bed or in a wheelchair by: strengthening the weaker or less used muscle groups; stretching the muscles tending to shorten; maintaining a passive stretch in the overcorrected position for the muscles tending to shorten; re-education of posture; corrective sleeping patterns; and the possible use of braces or splints.

1. Surgical correction for scoliosis

The spine is composed of many small bones called vertebrae, which are lined up one on top of another, creating a bony column in which the spinal cord rests. Moving from head to toe, the spine is divided into 4 areas: cervical, which refers to the neck area; thoracic, which refers to the chest area; lumbar, which refers to the lower back; and sacral, which refers to the pelvic area.

In scoliosis, the spine takes on an atypical sideways curve. In Batten Disease, it is usually caused by complication of the neuromuscular tree rather than a congenital issue. Children with a very mild degree of scoliosis most often do not require surgical treatment. However, these children will need regular followup to check whether the curvature is increasing with time. Sometimes electrical stimulation of the back muscles is used. A moderate degree of scoliosis can be treated with bracing (a molded plastic jacket or a chair insert). If untreated, a spinal curvature can interfere with sitting, walking and self-care skills. If severe enough, it can also affect respiratory efforts. Severe scoliosis and gradually increasing scoliosis despite bracing may require surgery, especially if it is affecting the diaphragm and breathing.

If surgery is needed, it is called a spinal fusion where the use of Harrington rods are wired along the spine to maintain proper alignment while bone graft material fuses the spine in position. The goal is to straighten the curve as much as possible and to prevent the vertebrae from shifting further. It is possible a body jacket is worn for 6-8 months after surgery until the spine is completely healed. Care must be taken not to twist or bend the spine following this surgery.

5. Pressure Sores

The direct cause of pressure sores is pressure. It cannot be overemphasized that pressure sores are caused in bed or in a wheelchair through prolonged pressure, which prevents adequate circulation to the area. Symptoms you would see are first redness of the area, followed by blisters and breakdown of skin. If untreated, further development of an ulcer would appear, associated with a possible unpleasant odor and drainage of the wound. Minimal bleeding may also occur. These symptoms are further discussed in the stages of skin breakdown.

a. Contributing factors to pressure sores:

1. Loss of sensation and voluntary movement - the loss of sensation prevents your child from receiving warning of long-standing pressure. He/she is not only unaware of the discomfort normally felt, but due to his/her immobility, he/she is unable to shift his/her position to relieve it
2. Loss of vasomotor control - the impairment of the circulation produces a lowered tissue resistance to pressure. Ischemia, due to local pressure, therefore, pressure sores may occur more readily
3. Effects of posture - sores develop mainly over bony prominences, which are exposed to unrelieved pressure in the lying or sitting position. The most vulnerable areas are the sacrum, hips, knees, fibula, heels and the fifth metatarsal or little toes. The elbows are also at risk in some children. If for some reason your child should end up with a plaster cast, pressure sores readily occur under splints, casts and braces applied over immobile areas

b. The stages of pressure sores are as follows:

1. First Stage

In this stage, skin stays red for 5 minutes after removal of pressure and may develop an abrasion of the epidermis (the top layer of skin). The skin also feels warm and firm. The skin may be unbroken. The sore is usually reversible if you remove the pressure, and the underlying tissues are still soft. The sore will show redness, edema, induration, and epidermal desquamation

2. Second Stage

Breaks appear in the skin, and discoloration may occur. A blister may be present, either broken or unbroken skin. Penetrating to the subcutaneous fat layer, the sore is painful and may be visibly swollen. If pressure is removed, the sore may heal in 1-2 weeks

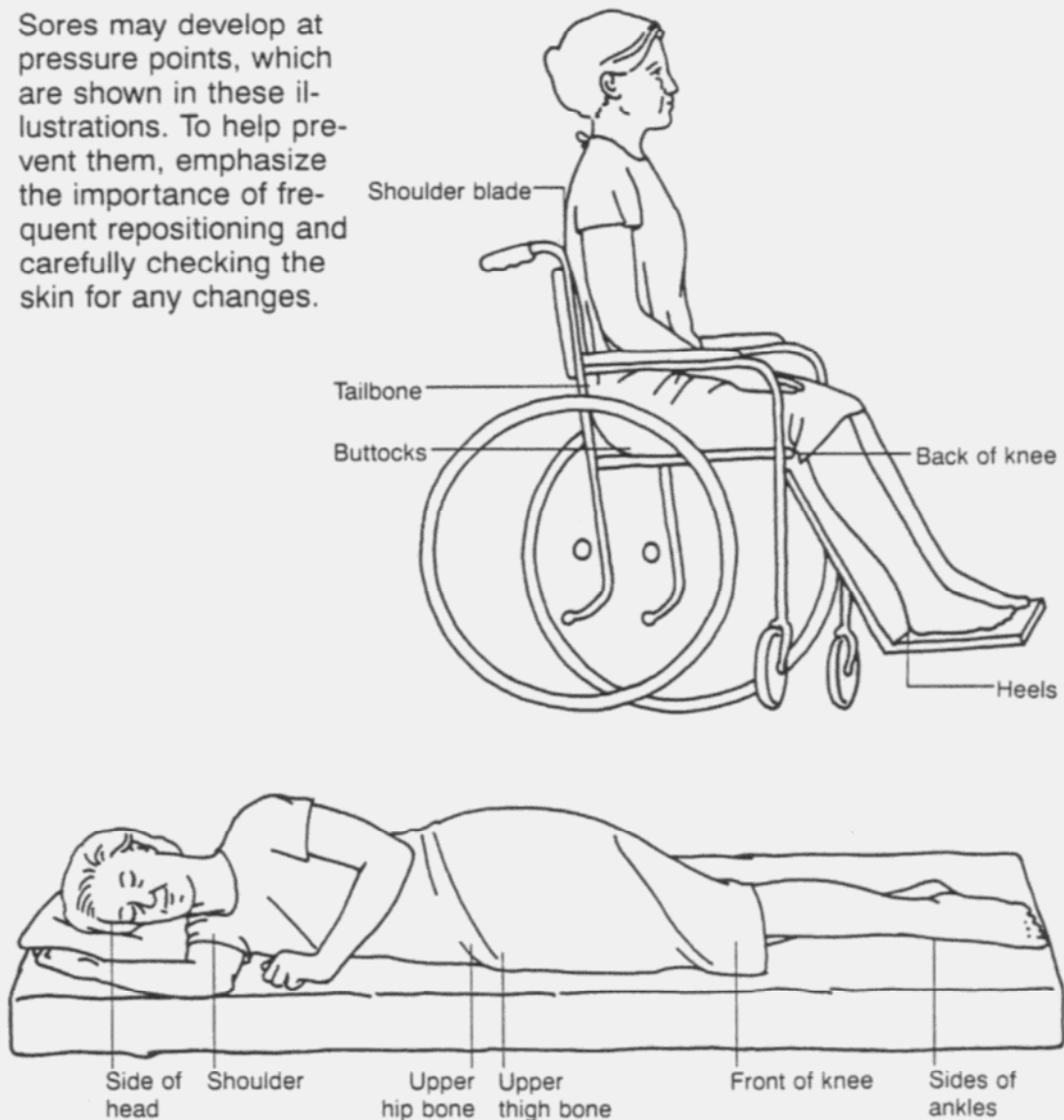
3. Third Stage

A hole develops that oozes foul-smelling yellow or green fluid. The skin becomes necrotic (dead) with exposure of

fat which extends into the muscle; the sore may develop a black, leathery crust or eschar, at its edges and eventually at the center. The sore is not painful because

Pressure points: Common sites for sores

Sores may develop at pressure points, which are shown in these illustrations. To help prevent them, emphasize the importance of frequent repositioning and carefully checking the skin for any changes.

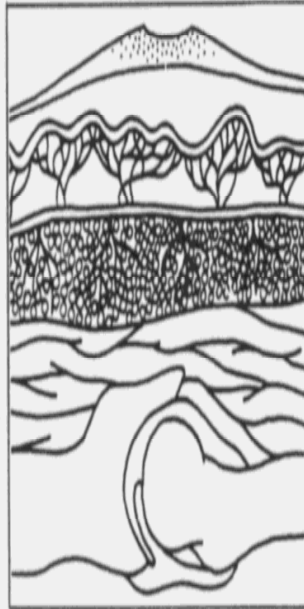


Four stages of pressure sores

Teach your patient the four stages of pressure sores. Advise him to inspect his body daily and to contact the doctor immediately if he spots a new sore, or enlargement or signs of infection in an existing sore.

Stage 1

In this stage, skin stays red for 5 minutes after removal of pressure and may develop an abrasion of the epidermis. (A black person's skin may look purple.) The skin also feels warm and firm. The sore is usually reversible if you remove pressure.



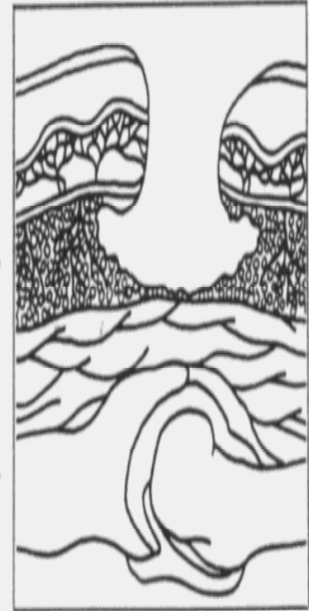
Stage 2

Breaks appear in the skin, and discoloration may occur. Penetrating to the subcutaneous fat layer, the sore is painful and may be visibly swollen. If pressure is removed, the sore may heal in 1 to 2 weeks.



Stage 3

A hole develops that oozes foul-smelling yellow or green fluid. Extending into the muscle, the sore may develop a black, leathery crust or eschar at its edges and eventually at the center. The sore isn't painful. Healing may take months.



Stage 4

The sore destroys tissue from the skin to the bone and becomes necrotic. Findings include foul drainage and deep tunnels that extend from the sore. Months or even a year may elapse before the sore heals.



fat which extends into the muscle; the sore may develop a black, leathery crust or eschar, at its edges and eventually at the center. The sore is not painful because the nerves at the site have deadened. Healing may take months. It is a primary site for a serious infection to occur

4. Fourth Stage

Necrosis extends through the fat layers to the muscles followed by further fat and muscle deterioration to bone destruction with periostitis and osteitis progressing to osteomyelitis with the possibility of sepsis, arthritis, pathologic fracture, and septicemia. The sore destroys tissue from the skin to the bone and becomes necrotic. Findings include foul drainage, and deep tunnels that extend from the sore. Months or even a year may elapse before the sore heals

- a. The surrounding tissues are rapidly involved if infection occurs, and a very small skin opening may be the only visible sign of a deep cavity reaching down to the infected bursa, and usually to bone

c. **The treatment of established pressure sores**

1. Conservative treatment - relieve pressure - the first essential step in treating a pressure sore is to totally and continuously relieve the pressure on the sore. Your child must be turned every two hours day and night to minimize further sores from developing on unaffected areas and positioned in such a way that no weight is thrown onto the sore or sores. Rings around the heels to relieve localized pressure are contraindicated. The area of skin under the ring may receive sufficient pressure to cut off the blood supply to the area in the center, which is the area most at risk. If pressure is not relieved over the sore, any other measures taken will prove unsuccessful
2. General treatment - blood transfusions may be required to keep the hemoglobin level in the upper limits of normal. Because without knowing it as an obvious issue, the pressure sore can slowly lower the hemoglobin (blood count) and result in anemia by oozing small amounts of

blood

3. Local treatment - all slough and necrotic tissue is radically excised by the Doctor in charge of the case. This prevents the toxic effects, which result from the absorption of dead tissue into the blood stream. A wide range of lotions/creams/ointments are used including local antibiotics in solution and many other medicated dressings can be used. The dressing is completely sealed off with wide porous elastoplast tape. The dressings are changed according to your Doctor's directions, usually once or twice a day
4. Surgical treatment - surgery is considered in selected cases. The following procedures being used:
 - a. Excision of the sore and direct suture, with or without excision of prominent bone
 - b. Seed graft used mainly to stimulate epithelialization of the granulating areas
 - c. Split skin graft used to stimulate healing or as a permanent cover
 - d. Flaps are used as a last resort, usually after a sore is healed when the remaining scar is considerably smaller than the size of the original sore

d. The prevention of pressure sores

1. When there is no pressure, there will be no sore. Prevention, therefore, depends primarily upon the frequent relief of pressure in conjunction with the correct positioning of your child
2. Turning your child - children need to be turned every two hours, day and night. The most susceptible areas, that is, where bony points are close to the skin, must be kept free of any pressure by adjusting the pillows accordingly. At each turn, all areas need to be inspected, the skin is checked and all wrinkles and debris are removed from the bed linen. Any evidence of local pressure, however minor, is an urgent warning. Redness, which does not fade on pressure, septic spots, bruising, swelling, induration or grazing indicate an impending pressure sore. All pressure

must be relieved from any area thus affected until it is healed. Regular turning also aids in renal function by preventing stagnation in the urinary tract (bladder). Turning also helps the lung status by simple movement from side to side. Body support systems (speciality beds) are constantly being developed to facilitate the healing of pressure sores. A current example is the low air loss bed system in which the pressure in each of several sections is controlled individually according to the child's requirements

3. Care of the skin - the emphasis is on cleanliness and dryness. Intact skin is kept clean by the normal use of soap and water. Dead epithelial tissue tends to collect through disuse on the soles of the feet and palms of the hands. It can be prevented and removed by thoroughly washing and toweling these areas, and then rubbing in lanolin
4. The use of an inflatable ring is not a good idea to use if the pressure sore is on the coccyx (tailbone). Because, although some pressure is relieved around the specific sore, now new pressure is more pronounced around the rings' edge and can lead to skin breakdown other than on bony prominences
5. Grease Massage - the pliability of the skin is an important factor when excision of a pressure sore is considered. The more pliable the surrounding tissues the easier the approximation of the skin following the excision. When necessary daily massage with lanolin is given to a wide area surrounding the sore, deep finger kneading increases the circulation and improves the elasticity and mobility of the skin and subcutaneous tissues.

If you would like more information on pressure sores, you can refer to the book entitled Pressure Sores at the BDSRA office.

6. **Pain** - pain is defined as a sensation in which a person experiences discomfort, distress, or suffering, and most likely can and will be associated with decreasing mobilization due to

the following reasons:

- a. Due to muscular contractures/fractures (which may be caused by osteoporosis)
- b. By faulty positioning and lack of movement
- c. Nerve root pain may cause an attack of wavelike intensity of pain shooting, stabbing or burning sensations usually in the legs
- d. Referred pain such as pain in one area of the body can cause symptoms in another area - for example - an abdominal issue can cause pain in the shoulder area.

Many children with Batten Disease will complain of eyes hurting, legs aching or painful at times or arms hurting. This is due to the disease process and will usually subside in a week or two, but may return at a later time as the disease progresses. There are many pain medications for children with Batten Disease. If your child/children complains of pain, please do not hesitate to ask your Doctor for pain medications. Pain medications come in different forms to accommodate your child's level of taking medications for example, other than pill form, there are sprinkles, liquid, patches, or rectal suppositories.

1. Considerations to ask when deciding on therapy in regards to pain issues.
 - A. Pain intensity
 1. He/she can tolerate the pain without having to use pain medications
 2. The pain is bad but he/she can manage without taking pain medications
 3. Pain medications give complete relief from pain
 4. Pain medications give he/she moderate relief
 5. Pain medications give very little relief from pain
 6. Pain medications have no effect on the pain and he/she does not use them
 - B. Personal care
 1. He/she can look after himself/herself normally without causing extra pain

2. He/she can look after himself/herself normally but it causes extra pain
3. It is painful to look after himself/herself and he/she is slow and careful
4. He/she needs some help but manage most of their personal care
5. He/she needs help every day in most aspects of self care
6. He/she does not get dressed, washes with difficulties and stays in bed

C. Lifting

1. He/she can lift heavy weights without extra pain
2. He/she can lift weights but it gives extra pain
3. Pain prevents him/her from lifting heavy weights off the floor, but he/she can manage if they are conveniently positioned, like on a table
4. Pain prevents him/her from lifting heavy weights but he/she can manage light to medium weights if they are conveniently positioned
5. He/she can lift only very light weights
6. He/she cannot lift or carry anything at all

D. Walking

1. Pain does not prevent him/her walking any distance
2. Pain prevents him/her from walking more than a mile
3. Pain prevents him/her from walking more than $\frac{1}{2}$ mile
4. Pain prevents him/her from walking more than $\frac{1}{4}$ mile
5. He/she can only walk using a cane or crutches
6. He/she is in bed most of the time and has to crawl to the toilet

E. Sitting

1. He/she can sit in any chair as long as he/she likes
2. He/she can only sit in his/her favorite chair as long as he/she likes
3. Pain prevents him/her from sitting more than 1 hour

4. Pain prevents him/her from sitting more than $\frac{1}{2}$ hour
 5. Pain prevents him/her from sitting more than 10 minutes
 6. Pain prevents him/her from sitting at all
- F. Standing
1. He/she can stand as long as he/she wants without extra pain
 2. He/she can stand as long as he/she wants but it gives him/her extra pain
 3. Pain prevents him/her from standing more than 1 hour
 4. Pain prevents him/her from standing for more than 30 minutes
 5. Pain prevents him/her from standing for more than 10 minutes
 6. Pain prevents him/her from standing at all
- G. Sleeping
1. Pain does not prevent him/her from sleeping well
 2. He/she can sleep well only by using sleeping medications
 3. Even when he/she takes sleeping medications, he/she gets less than six hours of sleep
 4. Even when he/she takes sleeping medications, he/she gets less than four hours of sleep
 5. Even if he/she takes sleeping medications, he/she gets less than two hours of sleep
 6. Pain prevents him/her from sleeping at all
- H. Social life
1. His/her social life is normal and gives him/her no extra pain
 2. His/her social life is normal but increases the degree of pain
 3. Pain has no significant effect on his/her social life apart from limiting his/her more energetic interests such as dancing
 4. Pain has restricted his/her social life and he/she does not go out as often

5. Pain has restricted his/her social life to his/her home
6. He/she has no social life because of pain

I. Traveling

1. He/she can travel anywhere without extra pain
2. He/she can travel anywhere but it gives him/her extra pain
3. Pain is bad but he/she manages journeys over two hours
4. Pain restricts him/her to journey of less than one hour
5. Pain restricts him/her to short necessary journeys under 30 minutes
6. Pain prevents him/her from traveling except to the doctor or hospital

7. **Fractures/Dislocations** - A fracture is defined as a sudden breaking of a bone, an injury in which the continuity of the tissue of the bone is broken. A fracture is classified by the bone involved, the part of that bone, and the nature of the break. A dislocation is defined as the temporary removal of a bone from its normal position in a joint.

Symptoms you may see include: pain and tenderness - intensity increases until fractures are set; joint stiffness may be present with a fracture near the joint; swelling and redness with varying degrees of swelling and bleeding into the tissues (skin discolored-black and blue); deformity and immobility especially if the bone has punctured the skin and also loss of function of the fractured part; sensory changes - if nerves are severed, bleeding and swelling can cause pressure on the nerves, if large vessels are severed - blood loss to the fractured limb; numbness and tingling or muscle spasms may be present.

A Physician will see decreased range of motion, altered joint configuration, changed extremity length, and abnormal bone motion. Diagnostic studies include x-rays of the affected limb or part. Many children with Batten Disease do not even realize

when or how they have broken a bone or dislocated a joint, especially if there is some degree of osteoporosis.

If a fracture/dislocation has occurred in an arm, it should be placed in a sling. If any part of the leg has suffered a fracture/dislocation, it should be immobilized and no attempt of walking should be done. The only way to positively diagnose a fracture/ dislocation is by x-ray. So a trip to the Doctor or Emergency Room will be in order. If you have an Orthopedic Doctor, he will guide you as to what positions of the affected limb, length of immobility, and/or exercises to do for your child. The hips are probably the most frequent joint that becomes dislocated. Depending on each child, the parents/Doctor may decide not to repair the dislocation. Then you need to find out if there are any exercises you can do for minimal circulation for the limb

8. **Constipation** is defined as having infrequent bowel movements that are hard and painful. Constipation means that a child has three bowel movements or fewer in a week. Some people think they should have a bowel movement every day. That is not really true. There is no "right" number of bowel movements per day. Each person's body finds its own normal number of stools. Constipation is a symptom, not a disease, and may be caused by many different disorders. Children with Batten Disease have a huge problem with constipation - the two biggest reasons are side effects from medications and the inactivity of motor skills as the disease progresses.

Constipation can be a common problem for infants and children. Warning signs that may indicate a more serious condition causing your child to be constipated include vomiting, weight loss, poor weight gain, fever, abdominal distention or having a poor appetite. Constipation may be difficult to treat but having painful bowel movements is not something that your child has to "learn to live with" - proper diet and medical intervention should help your child have regular bowel movements. You may need to be referred to a specialist if

your child has any warning signs of a more serious condition or if he/she is not improving with your current therapies.

a. **Causes of constipation in children** can be many fold. It can be caused from: developmental issues where cognitive reasons play a part; situational issues where possibly toilet phobias, school bathroom avoidance or excessive parental intervention; depression; low fiber intake; dehydration; side effects from medications; or many other causes

b. **Why do children become constipated?**

1. Each child has his/her own specific dietary needs
2. Having infrequent bowel movements - usually happens after a child has had a large and painful stool - he/she may associate a bowel movement with pain, therefore he/she will try and hold the stool, which creates a vicious cycle. Many parents mistake the behaviors that children develop to hold in stool as straining to have a bowel movement, but they are usually stiffening their muscles or fidgeting as an attempt to hold their stool in and avoid a painful stool
3. Having a bad experience with potty training
4. Found in children with special needs and also as a side effect of many medications
5. Dietary factors, physical inactivity, mechanical obstruction, numerous drugs, metabolic factors, endocrine abnormalities, and psychogenic disorders (depression and the drugs used to treat it)

c. **Treating children with constipation**

Younger infants and children with constipation should be carefully evaluated by your Doctor. Poor feeding can lead to dehydration and constipation, so it is very important to make sure that your child is gaining weight normally.

1. The ultimate goal in treating constipation is for your child to have a soft bowel movement each day or to his/her specific needs

2. One of the main ways to prevent constipation is modifying your child's diet by decreasing foods that are constipating including cow's milk, bananas, yogurt, cheese, cooked carrots, and other foods that are low in fiber. Soy milk is a good alternative, since it is less constipating
3. Increase the amount of fiber in your child's diet - a daily recommendation is that your child receives 5-6 grams of fiber plus their age
4. Read nutritional labels to choose foods that are high in fiber. Good choices include:
 - A. Fruits - apples, peaches, raspberries, and tangerines
 - B. Vegetables - raw squash, broccoli, brussel sprouts, cabbage, carrots, cauliflower, zucchini, cooked spinach, black-eyed peas, baked beans, kidney beans, navy beans, pinto beans, lima beans, sweet potatoes, peas, turnip greens, and raw tomatoes
 - C. Vegetable soups (lots of fiber and extra fluid)
 - D. Popcorn
 - E. Extra bran can be helpful - including Bran cereals (All-Bran, Total, Bran Flakes, Bran muffins), shredded wheat, graham crackers, whole wheat or 7-grain bread, and whole grain cereals (oatmeal or wheatena)
 - F. Increase the amount of fluids that your child is drinking - minimum of 2-3 glasses of water and juice each day; apple, pear, or prune juice or other juices high in sorbital are good choices. Caffeine tends to dry out the system
 - G. Get enough exercise - regular exercise helps your system stay active and healthy. You do not need to become a great athlete
 - H. Allow your child enough time to have a bowel movement - sometimes we feel so hurried and we do not pay attention to our body's needs. Make sure you do not ignore the urge to have a bowel movement

- I. Use laxatives only if your Doctor says you should
- J. Check with your Doctor about any medications you give your child
- K. Understand that normal bowel habits are different for everyone

d. Medications to treat constipation

Dietary changes take time to become effective, and until they do, your child may need to be on a stool softener. These are often used long-term as maintenance therapy and are considered to be safe, effective, and non-habit forming or addictive. You do want to avoid chronic use of stimulate laxatives, such as Bisacodyl, Exlax, or Castor oil. An osmotic type laxative, which works by pulling extra fluid into the colon to soften the stool, is usually safer for long-term use.

1. Milk of Magnesia - an osmotic laxative with a chalky taste that some children may not tolerate - mixing it with 1-2 teaspoons, of tang, nestle quick, or a milk shake may help (1-12 teaspoons 1-2 times a day)
2. Mineral Oil - a lubricant that you can mix with orange juice; may cause leakage and staining of underwear (1-2 teaspoons 1-2 times per day)
3. Docusate - Colace or Surfak - a lubricant laxative - also available as a stimulant laxative in the combination medicine Peri-Colace (1/2 - 6 teaspoons 1-4 times per day)
4. Malt Soup Extract - Maltsupex - (1-6 teaspoons 1-2 times per day)
5. Senokot - a stimulant laxative day.
6. Bisacodyl - a stimulant laxative - Correctol and Dulcolax
7. Lactulose - an osmotic laxative, by prescription (1-2 ml/kg, 1-2 times per day)
8. Miralax - a tasteless osmotic laxative

In addition to a stool softener, it may also help to give added fiber by mixing Metamucil or Citrucel (1-3 teaspoons, 1-3 times per day) with 8 ounces of water or juice, or another bulk forming laxative or fiber

supplements. All of the above dosages will depend on your child's age and weight, but consult your Doctor before starting them or changing dosages.

The main mistake parents make in treating their children with constipation is stopping the medication once their child begins to have soft stools. If stopped too early, your child is likely to relapse and become constipated again. Instead of stopping the medication, decrease the dosage by 25%. Do not make too many changes based on a single stool. Once your child is having *regular soft stools*, you can then talk with your Doctor about decreasing the dosages of the laxative that you are using.

Constipation can also cause problems with feedings. Work with your Doctor on a plan for keeping this under control. You can start with things like prune juice. Fiber additives, suppositories, enemas and manual removal are steps, which may need to be added. (Do not forget that extra water and/or fluids may help). Preventing constipation is better than treating it, once it occurs, so do not hesitate to be aggressive. You may also find the use of an antacid, such as Maalox, (which combines a little Milk of Magnesia with a little Aluminum Hydroxide) will help soften the stool as well as cut down on some of the acidity. Try one that only has Aluminum or Calcium Hydroxide. Caretakers get to be a real expert at juggling the two of them. If there is an episode of diarrhea or fever, you may want to switch to clear liquids for 12-24 hours, and then work your way back up from dilute to full strength formula again. Many antibiotics have the side effect of wiping out the "good" bacteria in the intestines. You can ask your Doctor about how you can replace these. (There is a medication called Acidophilus that you can buy over the counter at any Pharmacy, crush it, give with food or dilute with water or formula. Yogurt is also a good source of acidophilus).

e. Treating acute constipation or disimpaction

Because there is often a large, hard mass of stool that has “backed up” in your child’s rectum, your child often has to have a “clean out” or disimpaction. Fortunately, this is rarely done manually; instead it is usually done (with your Doctor’s approval) using an enema and/or suppository, or sometimes it can be done with Mineral Oil (or Miralax), up to 1 ounce per your child’s age in years up to 8 ounces per dose for 2-3 days. Children under 18 months can be given a glycerin suppository, between 18 months and 9 years, you can give a pediatric fleet enema or $\frac{1}{2}$ of a dulcolax suppository, and older children can be given a regular fleet enema or a whole dulcolax suppository. You should avoid regular usage of enemas or suppositories.

f. Behavior modification

Once your child’s stools have become soft and regular, it is important to modify his/her behavior and encourage him/her to have regular bowel movements

1. Have him sit on the toilet for 10-15 minutes after meals once or twice a day
2. Keep a diary or sticker when he/she tries, takes medicine or has a stool.

g. Complications of constipation

The one thing you need to be aware of as an acute situation where you need help is a bowel or intestinal “blockage”. Constipation can lead to anal fissures or rectal tears in the skin around the rectum, bleeding hemorrhoids, rectal prolapse, and impaction. Encopresis (incontinence of stool or the inability to know when a child has to have a bowel movement) can lead to involuntary leakage of stool secondary to the impaction of large masses of stool.

9. Nerve Blocks, Motor Point Blocks, Botox Injections, and/or Surgery

In contrast to medication therapy, which has both systemic effects and side effects, several injectable agents are available that can be used to target spasticity in particular muscle groups. Local anesthetic agents injected into the nerves that supply spastic muscles produce a temporary, reversible conduction block and are used for diagnostic purposes. More long-lasting effects are achieved by injecting chemical agents, such as diluted alcohol or phenol, which denature muscle and nerve protein at the point of injection. Direct injections of denaturing agents into motor nerves, called nerve blocks, are sometimes used, but carry the risk of sensory loss due to damaged sensory nerves fibers that are bundled together with motor fibers. A motor point block effectively interrupts the nerve supply at the entry site to a spastic muscle without compromising sensation. The main side effect of the procedure is localized pain that may persist for a few days after the injection. Inhibition of spasticity lasts for 4-6 months, and the procedure can be repeated after the initial effect has worn off. This temporary reduction of spasticity allows for more effective application of Physical Therapy to improve range of motion and function and may make it possible to postpone orthopedic surgery when this is desirable.

- a. Injectable Botox has been introduced as an alternative to motor point blocks. Botox is produced by the bacteria which causes Botulism and is among the most potent neurotoxins known. It works by irreversibly blocking the nerve-muscle junction. When the toxin is absorbed into the general circulation (as with Botulism), death may result from paralysis of respiratory muscles. **However, small quantities can be safely injected directly into spastic muscles without significant spread into the bloodstream.** This results in weakening of the muscle and reduction in spasticity for 3-6 months. The main advantage of Botox over motor point blocks is its relative

ease of administration with less pain and discomfort. The main disadvantages are the cost of the drug and the lack of information regarding the long-term benefits of treatment, and the efficacy and potential toxicity of repeat doses.

- b. Neurosurgery can be performed where a rhizotomy is done. In spasticity, the deep tendon (or stretch) reflex is overactive. This reflex has a motor (efferent) component and a sensory (afferent) component. When a muscle is stretched rapidly, special sensory organs in the muscles (called muscle spindles) send nerve impulses via the afferent nerve fibers to the spinal cord. Impulses are then directed from the spinal cord through the efferent nerve fibers, which end in the muscle and stimulate it to contract, thus completing a feedback loop and counteracting the original stretch. Another way to do a rhizotomy is the dorsal approach. The specific afferent fibers (or rootlets) that make the greatest contribution to spasticity are discerned by observing that these rootlets, when stimulated directly with electrical current, result in the largest spastic motor response. These rootlets are cut. Because only carefully selected rootlets are cut, touch and position sense remain intact. Spasticity is reduced and is associated with variable degrees of weakness. Functional improvement in sitting, standing and walking has been reported.
- c. Another method or procedure allows for the direct delivery of antispasticity medication into the spinal fluid (intrathecal) space, where it can inhibit motor nerve conduction at the level of the spinal cord. A disk-shaped pump is placed beneath the skin of the abdomen, and a catheter is tunneled below the skin around to the back, where it is inserted through the lumbar spine into the intrathecal space. The intrathecal medication most often used is Baclofen, which is stored in a reservoir in the disk and may be refilled with a needle inserted into the reservoir through the skin. The medication is delivered at

a continuous rate that is computer controlled and adjustable. Because the drug is delivered directly to its site of action (the cerebrospinal fluid), much lower doses may be used to achieve benefit, with less risk of systemic side effects. The main benefits of this method are dramatic reduction in spasticity and adjustable dosing. The main disadvantages are complications related to mechanical failures, infection, and the need for intensive and reliable medical follow-up. Refer to the side effects of Baclofen on page 86.

D. Orthopedic surgery

Because of the abnormal or asymmetrical distribution of muscle tone, children are susceptible to the development of joint deformities. The most common of these result from permanent shortening or contracture of one or more groups of muscles around a joint, which limits joint mobility. Orthopedic surgery is done to increase the range of motion by lengthening a tendon, by cutting through a muscle or tendon ("release"), or by moving the point of attachment of a tendon or bone. A partial release or transfer of the hip adductor muscles may improve your child's ability to sit and walk and may lessen the chances of a hip dislocation. A partial hamstring release, involving the lengthening or transfer of muscles around the knee, also may facilitate sitting and walking. A lengthening of the Achilles tendon at the ankle may improve walking. All of these procedures require the use of a cast or splint for 6-8 weeks after surgery and a brace at night for at least several more months.

VI. Adaptive Devices/Selected Assistive Technology

A. What is an Assistive Device?

An assistive device is an aid used to help a person with an activity - a tool used to make life easier. Assistive devices are used to make changes in the physical environment or to serve as an extension of the person's body.

When an assistive device is used, tasks are generally easier to perform. It can provide a feeling of security, for example, a walker gives the person better balance and is more comfortable than using crutches to walk. The reason why children do not use assistive devices may be that parents do not receive proper instructions in its use, loss of the device, failure of the device to accomplish the desired task, feelings of embarrassment at using an aid, or a poor fit leading to discomfort. Local hospitals, home health care agencies, long term care facilities, and assisted living facilities can refer you to Physical and Occupational Therapists and to Orthotic technicians, who specialize in making the devices to meet an individual's needs. Your Doctor can tell you how to locate professionals in your community who sell or rent assistive devices.

Assistive devices for walking can be purchased at medical equipment stores, rented from community agencies, or supplied by an agency providing home care. Some pharmacies provide assistive devices for rent or sale. If an assistive device is ordered by your Physician, Medicaid will generally cover at least 80% of the cost. Devices to use for moving in and out of bed, chairs, or cars can be developed with the assistance of Physical and Occupational Therapists. Physical and Occupational Therapists can identify the best devices to use, are skilled in adapting equipment and supplies, and can teach people how to use and care for the assistive device prescribed. Examples of assistive devices include:

1. Walkers, standers, wheelchairs
2. Also, by modifying standard accessories for infants and children - walkers, high chairs, swings, jumpers, etc.
3. Recreation - hand powered tricycle, sports wheelchairs

B. What is adaptive equipment?

The term adaptive equipment refers to devices that help people to overcome in some way the limitations caused by their special needs/disabilities. Assistive equipment such as walkers and wheelchairs that support or hold an individual and adaptive technology such as electronics, programs, and computers used to perform tasks (like environmental control or communication) are examples. Types of adaptive equipment include the following:

- Positioning/postural support devices - bolsters, modified types of furniture, sidelyers (example - foam wedges), corner seats, standing devices, cut out tables to accommodate wheelchairs, braces
- Transportation aids - car seats, and travel chairs, wheelchair restraints
- Daily living skills - velcro closures for clothing, adaptive clothing, automated feeding devices, hand-held shower head, long handled comb, bath chairs, cooking or eating utensils that can be used with one hand, knives, forks, and spoons with larger blades or handles, bath seats, lifts
- Communication devices - scanners, pointers, nonoral communication systems and artificial voices, language boards, synthesized speech, alternative computer keyboards, talkers
- Individualized seating systems
- Modified tools, utensils, and work surfaces
- Environmental control - switch-operated lights or appliances, canine companions, reachers, ramps, grab bars, automatic door openers, adjusted height counters and cabinets
- Educational aids - automatic page turners, calculators and spell-checkers, adapted pencil grips
- Recreation - switch operated toys
- Vision aids - magnifiers, large print or talking books, braille readers
- Supportive aids - traction, casts, splints, braces or splints for ankles, feet, knees, hips, cables, standing frames, special shoes, braces like a corset for scoliosis, total support systems, proper fitting and prescription of braces
- Ambulation aids - parallel bars, crutches, canes
- Adaptive equipment for fine motor control - equipment to position arms and head, modifying objects for grasping
- Adaptive switches - electrical or battery operated household items and toys

- Modifying equipment to improve the line of sight - by adjusting the height and angle of lap-boards, chairs, tables, beds, TV's, etc.
- Clothing modifications - snap fasteners, velcro, zippers, larger clothing with loose openings
- Mealtimes - special utensils, water repellent eating surfaces and floors for easier clean-up
- Bathing - bath or shower chairs, lifts, lounge chairs, foam cushions
- Transfer and transportation devices - lifts, transfer boards, car seats, travel seats
- Toilet-training aids - elevated toilet seats for the older children, potty seats with high backs, side supports, and desk-like front supports

1. Why is assistive/adaptive equipment needed?

Participation in daily routines and community activities may be difficult or nearly impossible for children with significant physical special needs. However, although a child with a special need may have differing abilities from those of his or her playmates or siblings, your child's curiosity and desire to participate may be quite similar. All children can benefit from a variety of experiences, and all children should have opportunities to be involved in enjoyable events. Children with special needs can delight in their achievements and independence, but achieving success often takes considerably more effort and persistence than most people without special needs realize. Adaptive equipment can help children with special needs to improve control of body movements, increase self-reliance, and make daily routines easier. It can also improve the quality of your child's life by expanding opportunities for growth, satisfaction, and learning.

2. Different areas of the body to consider when thinking about assistive/adaptive equipment:

- a. Adaptive equipment for body control, posture, movement and balance - like problems with the nervous system which controls all of the body's movement and posture by sending

- messages via the nerves to specific parts of the body
- b. Muscle tone which refers to the degree of tension or slack in the muscles, or the way muscles feel - hard, stiff, firm, soft or floppy
 - c. How muscles react to the brain's signal to work - you may see profound weakness or some degree of paralysis if these muscles are not working properly
 - d. Muscles or groups of muscle cells may be attacked by an illness and cause muscle wasting and weakness
 - e. Possibly a malformation in the muscle fibers causing poor posture, balance and coordination which will lead to restricted patterns of movement
 - f. Bones and joints - if contractures or scoliosis become a problem, then the muscles attached to the bone may become in poor alignment which will limit the ability of joint motion, maintain body symmetry and balance
 - g. A temporary muscle problem such as in a cast or traction which would cause a lack of activity, therefore temporary stiffness in joints and a loss of some flexibility and strength in the muscles

- 3. When to consider assistive/adaptive equipment for your child** when problems in body control and effective, independent movement becomes too difficult for your child to master on his own. In Infantile Batten Disease two things to consider are first - the age of your child - adaptive equipment will be most helpful when your child is able to sit up by himself usually by 6-8 months of age, and second - consider the sequence in which a child gains motor control - like lying on their back to flipping over to their tummy, rolling, crawling on their belly, sitting, propping up on their hands and knees, creeping, standing, etc. When your child seems ready, like when he/she can walk holding on to things, he/she may be ready for a stander or if your child becomes extra tired while walking through a mall, it might be time to have a wheelchair available for those times, etc.

4. Assistive/adaptive equipment to improve your child's attitude and interest.

By allowing your child to acquire some form of independence, such as if he/she has a strong interest in a particular skill but cannot seem to master it, he/she may be ready for a different device to gain more independence.

5. What kind of equipment do you need?

By carefully noting what seems to be different about the way your child tries to sit, reach, creep, or accomplish other motor tasks, you may identify areas in which help may be useful. For instance, if your child falls backward, a higher backed chair may be better, or if your child falls forward, a tray or harness may be more useful. Before you buy any item, look into whether borrowing a device is a possibility through local organizations or through Batten Disease Support & Research Associations Equipment Exchange program. When problems arise as your child changes and grows, it is important to make necessary modification one at a time, instead of several, so you will be able to see how each change has made or not made a difference for your child.

a. The walker is a mobility aid that provides a portable base of support. With the correct walker, children can often stroll along at the same pace as siblings or parents. Today, walkers are available in a variety of styles and colors and have numerous accessories. The ultimate selection of a walker will depend on a cooperative effort between the Physical Therapist and the medical equipment supplier. Before you purchase a walker for your child, be sure to test it out to be sure it is the right one for your child. Moreover, the Physical Therapist should demonstrate the proper gait for walking. The proper gait to use with a walker involves moving the walker forward first, followed by one foot and then the other foot to promote safe mobility and protection from physical harm. However, the gait will depend on each individual child for their specific problems.

Walkers are used to enhance balance and to reduce weight bearing fully or partially on a lower extremity. They provide a wide base of support or stance, improve anterior and lateral stability, and permit the upper extremity to transport body weight to the floor. Selecting the right size of a walker is a critical decision. Although most are height adjustable, adequate width and depth are important considerations for proper support. The height of the walker should come approximately to the greater trochanter and should allow 25-30 degrees of elbow flexion. There is a version of walkers that can fold up for easier transportation, but please be careful that when using the walker, that you have done what is required for stability, once the walker has been opened up again.

b. Standers

The physical benefits of standing programs have been long proven. Some of the changes noted in children on a standing program have been improvements in bone density, respiration, bladder and bowel function, digestion, and social interaction. Children who are placed in a stander are often able to perform functional tasks that they otherwise would not be capable of doing. There are many different types of standers, from one for standing only to a multipositional stander.

c. Child Wheelchairs

Because children's bodies are growing and changing, choosing chairs for children and adolescents require consideration of factors not a part of the adult wheelchair selection process. One of these is the frequency with which a chair must be changed or replaced. Because of the high cost of replacing a chair, and because insurance providers often place limitations on the frequency of chair replacement, purchasing a new chair each year can be financially difficult to do, if not impossible. Most insurance companies will not replace wheelchairs before 5 years. They will replace seating more often. A proper cushion is very

important for your child. Depending on your child's specific problems, a cushion can be made to fit any wheelchair, for example, if your child has scoliosis and the spine curves enough to where the hips are at different levels, then a cushion can be made to support the change in the curvature of the spine and hips.

Growth chairs or chairs with growth kits offer an alternative by allowing adjustments to be made to the existing chair to accommodate a growing child. This may include utilizing replaceable components or designing the chair with features that can be converted from a smaller size to a larger one. Manufacturers also respond to the needs of children in having chairs that fit more easily into their environment and social situations. This may be accomplished with a more streamlined appearance and/or a selection of upholstery and/or frame colors.

d. Home modification and repair includes adaptations that can make it easier and safer to carry out activities such as bathing, cooking, and climbing stairs and alterations to the physical structure of the home to improve its overall safety and condition. Home repair and modification can help prevent accidents such as falls. It can also accommodate lifestyle changes and increase comfort. Examples include: ramps, lower kitchen counters, sinks and tables, beds, doorways, hallways or grab bars.

1. Fundamental needs in your home for your child:
 - a. Privacy - space of his/her own and a chance to be left alone
 - b. Belonging - ability to share spaces with family - to be able to join in preparing meals and social activities
 - c. Control - ability to go where he/she wants and do what he/she wants
 - d. Safety and Security - ability to open doors and escape in an emergency

2. Typical problems your child may encounter include:
 - a. Difficulty getting in and out of a shower/tub
 - b. Slipping in the tub or shower
 - c. Difficulty turning faucet handles/doorknobs
 - d. Access to your home - wide enough doors and hallways
 - e. Inadequate heating or ventilation
 - f. Problems climbing stairs or steps up or down to other rooms of the home, or in and out of the home

3. Possible solutions include:
 - a. Install grab bars, shower seals, or transfer benches
 - b. Place non-skid strips or decals in the tub or shower
 - c. Remove glass shower doors
 - d. Hand held shower head
 - e. Lower handles
 - f. Install ramps
 - e. Install insulation, storm windows and air conditioning
 - f. Install handrails for support

- e. **Safety** - providing a safe environment - is everyone's responsibility. It is necessary to prevent accidents. Most common are falls (providing grab bars, handrails, removing foreign objects, mopping up spills, assisting those with poor vision, being careful with scatter rugs or clutter), cuts, burns (test temperature for bath water, soaks or packs and heating devices, inspection of electrical plugs and cords, safe use of oxygen tanks, responsible smoking habits and fire safety), bruises, altercations with others, loss of personal possessions, choking, and electrical shock.

Children have a tendency to climb, touch, taste, and eagerly explore their environments. They need special protection to prevent their curiosity from causing injury.

6. **Good positioning does not always require commercially made adaptive equipment** - for example, to help in sitting - sandbags,

towel rolls, paint rollers, bean bag chairs, swim rings, rubber tubes; to help crawling and standing - slings, putting wheels on a frame to allow creeping; or the use of a hammock to relax muscles; ramps; ride-on toys, etc.

7. **Measuring your child for assistive/adaptive equipment** - determine your child's height, weight, and rate of growth. Your Physical Therapist or a representative from a specific company can give you suggestions in measuring your living space including doorways, halls, and kitchen counter heights.

8. **How to obtain and finance assistive/adaptive equipment** - find out whether a Doctor's prescription is needed and whether it is covered by your insurance. If your child's needs are short termed for a particular item, consider making it yourself, borrowing, or renting one. Ask your Social Worker or Physical Therapist for advice. Equipment can be obtained through medical supply companies. Some items can be ordered from the manufacturer - make sure you ask how long will it take to be delivered. Order whatever accessories you think you may need down the road rather than getting them later - the cost may be lower and you will be assured to have everything you need to provide the proper help later on in the disease process. Governmental assistance programs - Social Security Income, special waivers, or Medicaid, but each has their requirements and limitations. Again, your Social Worker or Physical Therapist may be of great help on this issue. Support groups such as BDSRA, which has an equipment exchange program may also be an option. Some insurance companies will cover items if it is associated with a hospitalization for your child.

VII Positioning and Exercises

In this section we will be talking about specific positions. To make it easier for you, the following definitions will be helpful:

Abduction - movement of the limbs away from the center of the body

Adduction - movement of the limbs toward the center of the body

Alignment - arranged in a straight line

Dorsiflexion - bending or flexing, as in the upward bending of the hand on the wrist or the foot on the ankle

Eversion - turning outward

Extension - the movement of certain joints of the skeleton to increase the angles of two bones - straightening out a joint like the knee

Flexion - the act of bending or condition of being bent, in contrast to

Extending - as in the elbow

Inversion - turning inward

Plantarflexion - contraction of the toes in a downward motion, opposite of dorsiflexion

Prone - lying horizontal, with face downward

Protracted - to draw out or lengthen, prolong

Retracted - to draw back or in

Sidelying - lying on the left or right side

Supinated - the position of lying on the back, face up; one of the kinds of rotation allowed by certain skeletal joints, as by the elbow and the wrist joints, which allow the palm of the hand to turn up

Supine - lying on the back or with face upward

You should turn your child a minimum of every two hours.

A. Correct positioning of the child in bed is important in order:

1. To obtain correct body alignment
2. To reduce the risk of or minimize contractures
3. To prevent or minimize pressure sores
4. To inhibit the onset of severe spasticity

Correct Positioning:

Supine lying - lower extremities

Hips - extended and slightly abducted

Knees - extended but not hyperextended

Ankles - dorsiflexed

Heels - position to keep heels suspended off bed with a pillow, heelbos, etc.

Toes - extended

1 or 2 pillows kept between the legs to maintain abduction and prevent pressure on the bony points

Supine lying - Upper Extremities

Shoulders - abducted and in mid position or protracted, but no retraction

Elbows - extended

Wrists - dorsiflexed to approximately 45 degrees

Fingers - slightly flexed

Arms are placed on pillows at the sides. Pillows should be high enough under the shoulders to ensure that the shoulder is not retracted. If necessary 2 pillows should be used under the forearms and hands as it is important that the hands are kept higher than the shoulders to prevent gravitational swelling in the limbs.

Side lying - Lower Extremities

Hips & knees - flexed sufficiently to obtain stability with a double pillow between the legs and with the upper leg lying slightly behind the lower one

Ankles - dorsiflexed, with use of pillows

Toes - extended

Side lying - Upper Extremities

Lower arm - shoulder flexed and lying in the trough between the pillows supporting the head and thorax to relieve pressure on the shoulder

Elbow - extended

Forearm - supinated and supported by a pillow

Upper arm - as in the supine position, but with a pillow between the arm and chest wall

Always keep the head of your child turned to one side or the other to prevent aspiration of vomitus or secretions. By keeping the head turned, secretions can drool out of their mouth at will. You can use a towel roll or small pillow by the head to keep it turned. You may want to have a towel or chux under the side of their face to collect the secretions.

B. Turning your child from his back to his side

When sheets or blankets are used for turning, they should not be

tightly tucked in at the foot of the bed, as this may contribute to decreased ankle dorsiflexion motion. Footboards are occasionally used to maintain the foot in its neutral or anatomically correct position. Footboards are often ineffective, though, since the children tend to push against the board, placing the ankle again in plantarflexion. For some children, stimulation to the sole of the foot causes a reflex that will also result in ankle plantarflexion. It is important that you position yourself on the side to which you will be turning your child. If your child has control of his/her head, chances are that he/she will be able to assist in turning both his/her head and neck in the direction of the roll as it is initiated. If your child does not have this control, you must be aware that his/her face will be subject to some rubbing on the mattress or mat during the roll.

When you are ready to initiate the movement, tell your child what you are going to do. Tell him/her you will begin on the count of three. Place one hand on your child's shoulder and the other hand on the hips to begin the turning, or if you are using a blanket or turn sheet, grasp the sheet at approximately the shoulder and hip areas. If your child is bigger (adult size), it may be helpful to bend the knee away from the side you are rolling them toward and pull gently on that leg with your hand on the hips to turn. Once your child reaches the halfway point, he/she may finish the roll uncontrolled as a result of the pull of gravity.

Once the roll has been completed, the first body segment to be repositioned is the head. It must be placed in a comfortable position, facing to one side, to decrease chances of aspiration and where drooling can run out of your child's mouth onto a towel or plastic lined pad. There should be no pressure on the eyes, nose, or mouth. Finally, the feet should be uncrossed and placed approximately 6-8 inches apart. The knee on top or both knees should be slightly bent to help balance your child's weight. Pillows can help support the hands to avoid swelling by hanging down, in between the knees and ankles to avoid skin to skin contact, and at the back for support.

C. Turning your child to his stomach or the prone position

You can also turn your child to his/her stomach for awhile. Move your child to one side of the bed, first moving the upper trunk, then lower trunk and legs to the side of the bed. Place the arms at his/her sides to roll the body in one continuous motion. Grasp your child at the shoulder and hip areas and turn your child over. The use of a draw sheet to turn to the stomach may be helpful. Position the head to one side or the other. The arms can be left at the sides or the one arm to which his/her face is turned can be bent and elevated on a pillow. His lower legs (calf and ankles areas) can be supported with a pillow, as well, for comfort.

D. Different Types of Exercises

- 1. Chest Therapy** - to maintain good ventilation. All forms of immobility, whether it be due to pressure sores, fractures, or inability to move, need prophylactic chest therapy as all are subject to pneumonia. To understand how this may happen, it is important to understand that the diaphragm is the principle muscle for respiration. The diaphragm aides in sneezing, coughing, laughing etc. The height of the diaphragm varies with different positions of the body.

Supine - the diaphragm is highest and performs the longest movements with normal breathing.

Standing - the dome of the diaphragm falls and the respiratory movements become smaller

Sitting - the dome of the diaphragm falls lower still and yet smaller movements are performed.

- 2. Active Range of Motion Exercises** - what your child can do by himself/herself, however, he/she may or may not be able to comprehend what you want done. Assess the ability of your child and willingness to perform the movements requested, the range of active movements available, and your child's ability to produce the muscle forces required for active movement. These movements are also used to determine the region of the body from which the symptoms (any degree of immobility that you want treated) are originating, and to determine which

movements and muscles to examine. Progression is made to unassisted active exercises, and your child is encouraged to move his/her arms independently and functionally. Active, resistive movements can be gradually introduced as indicated.

- 3. Passive Range of Motion Exercises** are given to the immobile limbs to improve the circulation and to prevent contractures, when your child can no longer get enough exercise on his/her own. Sometimes after surgery, passive exercises are done to begin an exercise program as soon as possible. Passive movements to the lower limbs are started after surgery when the surgeon considers it advisable. Initially, very gentle movements are advised. The range of any movement, which looks potentially dangerous, is increased with extreme caution to avoid breakdown of the skin. Your child may or may not be able to tell you when pain is provoked.

Passive movements are used to assist the circulation and to ensure full mobility of all body structures. Passive movements of the immobile limbs are essential to stimulate the circulation and preserve full range of motion in joints and soft tissues. Treatment should be started as soon as decreased mobility is evident in the course of the illness. Exercise the limbs and trunk daily or 2-3 times per day for 2-5 minutes as tolerated. A high proportion of this time is given to moving the limb as a whole to improve the circulation. In addition, move each joint, including the metatarsal and metacarpal joints, several times through its full range. Appropriate movements are given to prevent muscle shortening and joint tightness. The movements are performed slowly, smoothly and rhythmically to avoid injury to the sensitive, unprotected joints and immobile structures.

If and when reflex activity returns, the limb must be handled with extreme care, so as not to elicit spasm and reinforce the spastic pattern. If a spasm occurs during a movement, the Physical Therapist, or family/careprovider, holds the limb firmly and waits for the spasm to relax before completing the movement. Forced passive movements against spasticity may

cause injury or even fracture of a limb.

Recommendations:

- When doing passive range of motion exercises, move only to the point of resistance. Do not force movement.
- Support joints to prevent excessive motion. Move in a straight line from the starting position to the ending position.
- Move slowly, avoiding rapid or abrupt motions.
- Avoid putting pressure on the ball of the foot or palm of the hand. Pressure on these areas will produce abnormal reflexive movement.
- Move slowly and consistently. Do not start and stop mid-range. If the muscle seems especially tight, slowly pull against it. Gentle, continuous stretching on a muscle will relax it, especially when spasticity is present.
- If the initial movement sets off a clonus (a rapid movement at the joint, such as a "toe tapping" movement at the ankle), or if the movement is difficult to initiate, slightly bend the next joint. For example, to help relax the ankle muscle, bend the knee: to relax the wrist, bend the elbow.

a. Passive range of motion exercises to the upper extremities:

1. Wash your hands
2. Explain to your child what you will be doing
3. Position your child on his/her back, close to you
4. Adjust his/her pajamas or sheet to allow easy movement of his/her head and arms. Do not have clothing too tight.
5. Slowly turn your child's head side to side (rotation)
6. Slowly bend your child's head toward the right shoulder then the left shoulder (lateral flexion)
7. Bring your child's chin toward his/her chest (flexion)
8. Place a pillow under the shoulders and **gently** support the head in a slight backward tilt (hyperextension). Return to the straight position. Adjust the pillow under the head and shoulders

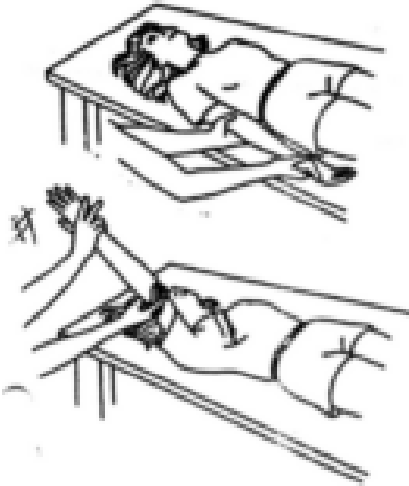
9. Supporting the elbow and wrist, exercise the shoulder joint by bringing the entire arm out at a right angle to the body (horizontal abduction) and returning the arm to a position parallel to the body
10. Abduct the shoulder out to the side, flex the elbow to 90 degrees, putting the palm of the hand to the bed, then the back of hand on the bed (like swimming in position).
11. With the shoulder in abduction, flex the elbow and raise the entire arm over the head (shoulder flexion)
12. With the arm parallel to the body (palm up - supination) flex and extend the elbow
13. Flex and extend the wrist. Flex and extend each finger joint
14. Move each finger and also the thumb, in turn, away from the middle finger (abduction), and toward the middle finger (adduction)
15. Abduct the thumb by moving it away from the extended fingers and palm of hand
16. Touch the thumb to the base of the little finger, then to each fingertip (opposition)
17. Turn the hand palm down (pronation). Then turn it palm up (supination)
18. Grasp your child's wrist with one hand and your child's hand with the other. Bring the wrist toward the body (inversion) and then away from the body (eversion)

Try to do 10 repetitions of each movement if tolerated and as time permits. **Do not hurry!**

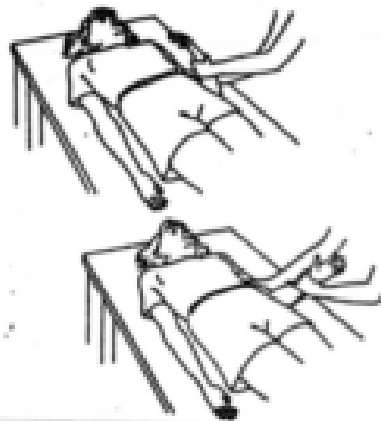
Refer to pictures on the following four pages

UPPER EXTREMITY PASSIVE RANGE OF MOTION

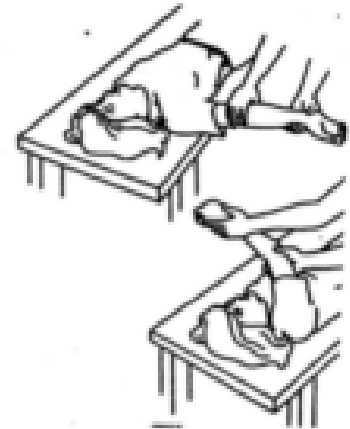
Shoulder Flexion



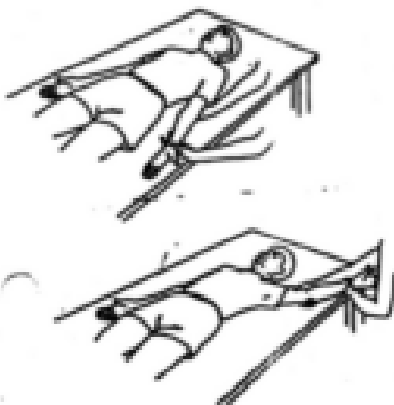
Shoulder Medial and Lateral Rotation



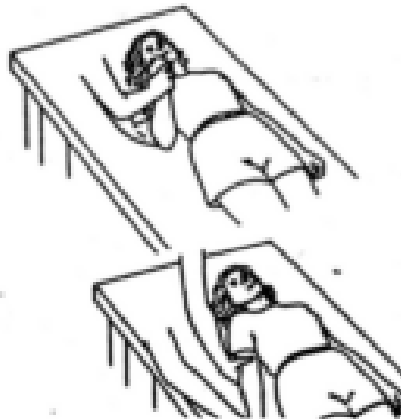
Horizontal Shoulder Abduction & Adduction



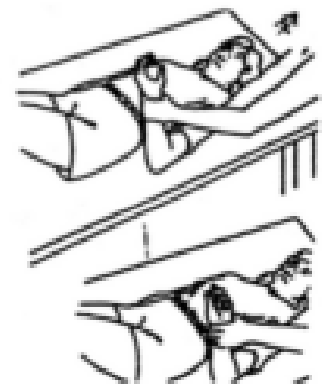
Shoulder Abduction and Adduction



Elbow Flexion and Extension



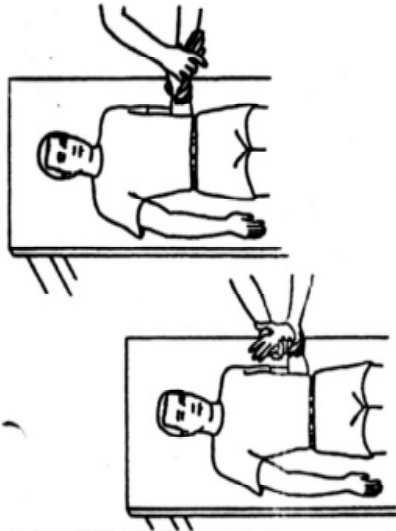
Forearm Pronation and Supination



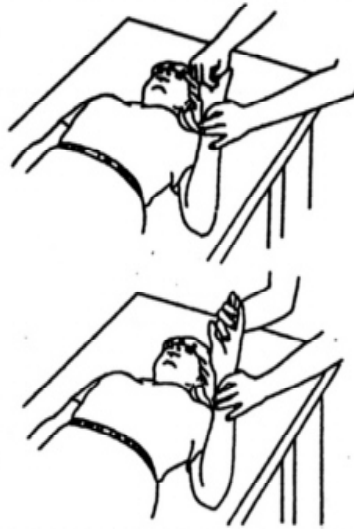
UPPER EXTREMITY

CONTINUED

Wrist Flexion and Extension



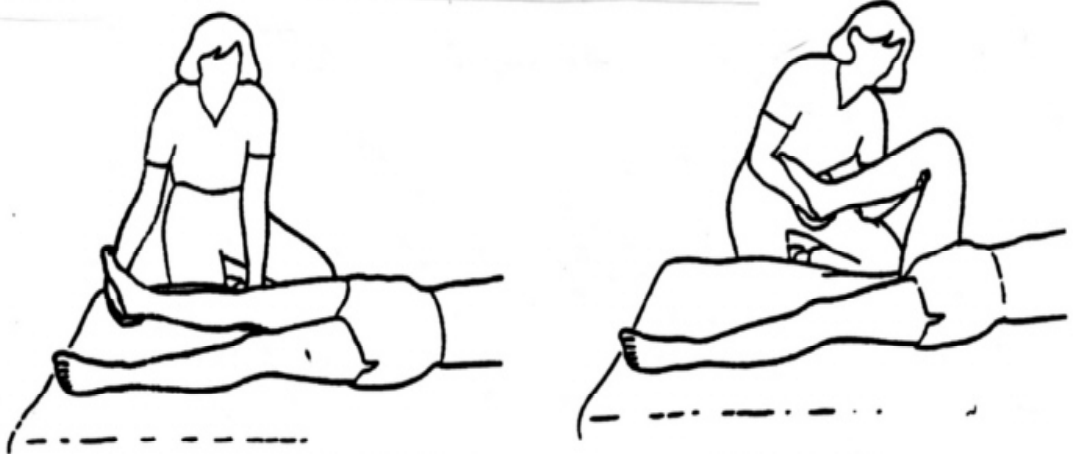
Finger Flexion and Extension



LOWER EXTREMITY

Passive Range of Motion

Hip Flexion/Extension

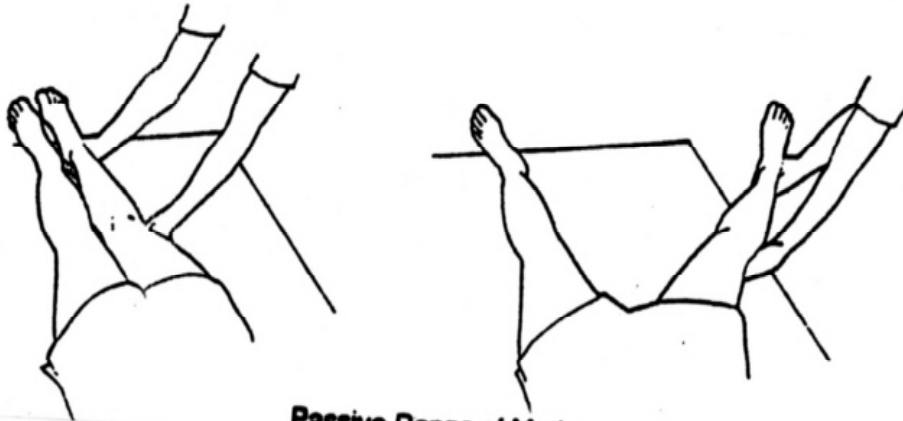


b. Passive range of motion to lower extremities

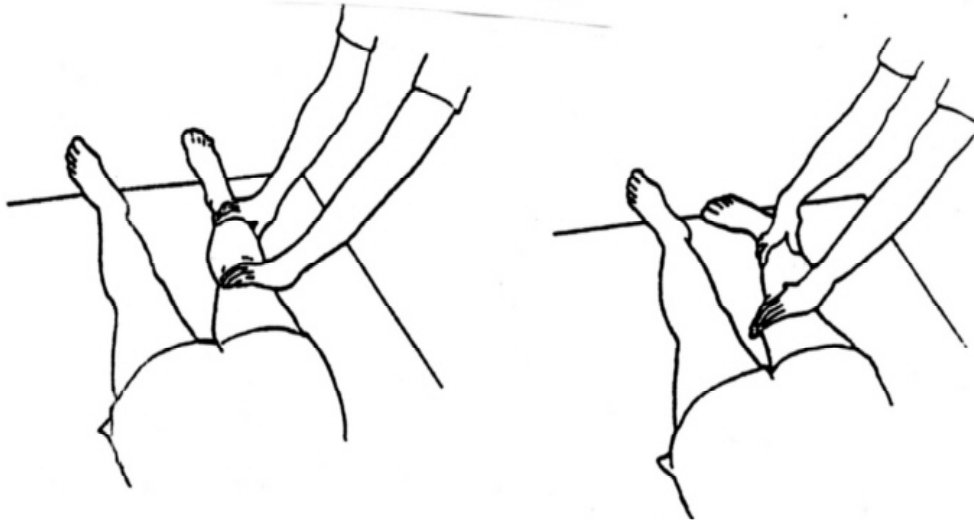
1. Wash your hands
2. Explain to your child what you will be doing
3. Adjust the bed clothing or sheets to expose the area which you will be working. If wearing pajamas, have them loose enough to allow sufficient movement of the extremity
4. Supporting the knee and ankle, move the entire leg away from the body center (abduction) and toward the body (adduction)
5. Supporting the knees in a bent position (flexion), raise the knee toward the pelvis (hip flexion). Straighten the knee (extension) as you lower the leg to the bed
6. Supporting the leg at the knee and ankle, roll the lower leg out to the side. Continuing to support the leg, roll the leg in the same fashion toward the body (medial hip rotation)
7. Grasp your child's toes and support the ankle. Bring the toes and foot toward the knee (dorsiflexion). Then point the toes/foot toward the foot of the bed (plantar flexion)
8. Gently turn your child's foot inward (inversion) and outward (eversion)
9. Place your fingers over your child's toes. Bend the toes away from the second toe (abduction) and then toward the second toe (adduction)
10. For trunk rotation, have your child lying face up with arms relaxed at the sides. Bend your child's legs at the hips and knees and place the feet flat on the bed or supporting surface. Grasp your child's knees and slowly move them from side to side, going only to the point of resistance.

Try to do 10 repetitions of each movement if tolerated or as time permits. **Again, do not hurry!**

**Passive Range of Motion
Hip Abduction/Adduction**



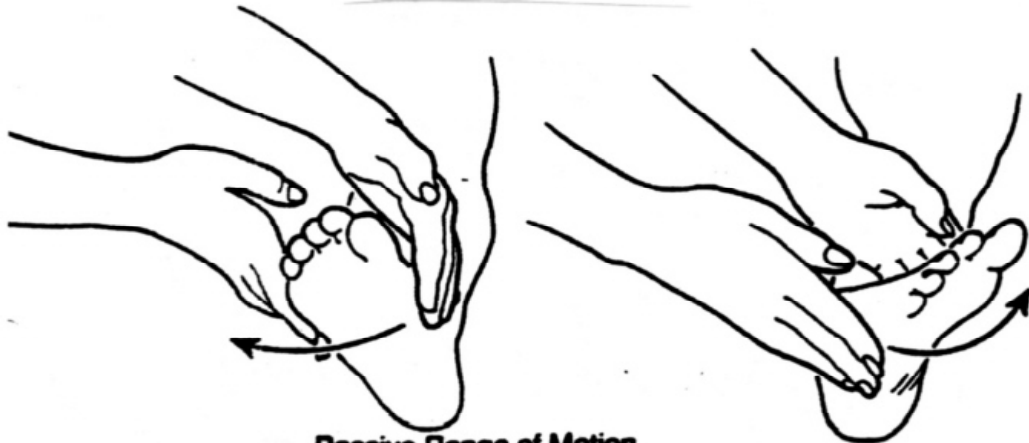
**Passive Range of Motion
Internal/External Rotation**



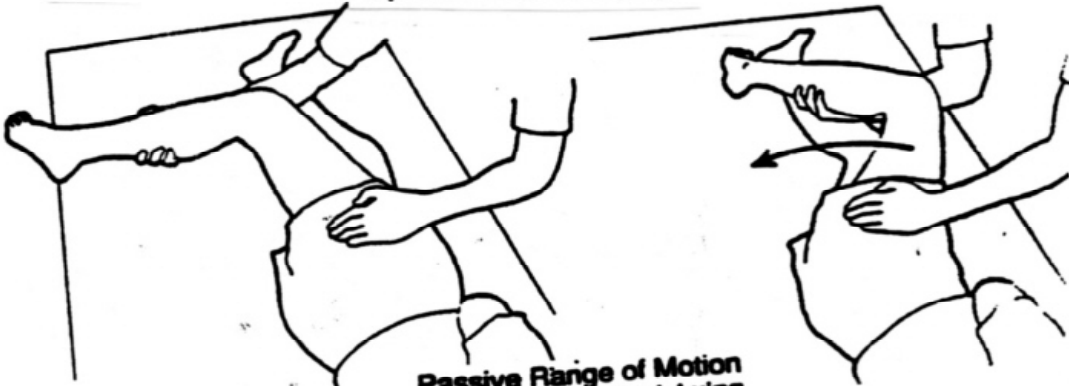
**Passive Range of Motion
Dorsiflexion/Plantarflexion**



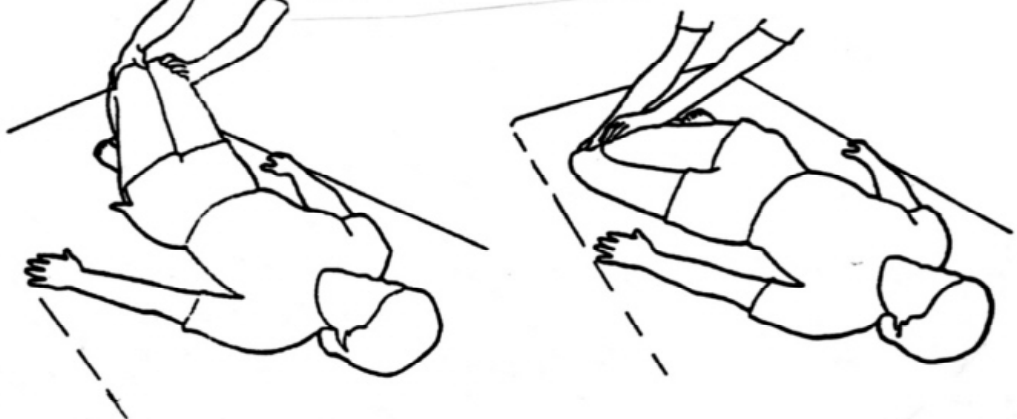
**Passive Range of Motion
Foot Inversion/Eversion**



**Passive Range of Motion
Hip Extension, Side Lying**



**Passive Range of Motion
Trunk Rotation, Back Lying**



4. Transfers - when transporting, remember to cover your child appropriately, lock the brakes when stopped, use a mattress pad or cushioned seating, use safety belts and added equipment when transferring to a chair or wheelchair (head rests, footrests, chest harness, or hand restraints).

a. Transfer from lying down to sitting to standing to wheelchair

Have your child practice push-up exercises in the wheelchair or lying down on the stomach, to strengthen his/her arms. Place the side of the wheelchair as close to the bed as possible and lock the brakes. The parent/caregiver should move the head and shoulders, then the legs and feet to the edge of the bed. Move the hips to the edge of the bed. The caregiver should lift your child's shoulders with one arm and swing his/her legs over the edge of the bed with the other arm (gravity pulls the legs downward, which aids in raising your child's trunk). Allow a few seconds for your child to gain his/her balance of sitting up before proceeding. Place your child's feet well under him/her. If your child can help, it is best to transfer toward their stronger side. The caregiver faces your child with hands firmly grasping each side of your child's rib cage, one knee of the caregiver should be against the knee of your child for stability. Rock the child forward as he/she comes to a standing position with the knee of the caregiver still intact with the knee of your child. Ensure that your child's knees are locked (fully extended) as a safety measure for those who are weak or have been in bed for a period of time. Give the child enough time to balance him/herself, then pivot your child to position him/her to sit in the chair. Parents/caregivers need to watch their own body mechanics while transferring their child.

If your child is too weak, a board may be used to bridge the gap between the bed and the chair. Your child can then slide across it to transfer to a chair, toilet or bathtub. When first done, the caregiver should demonstrate the process to the child to show them what they want them to do.

Name _____ Date _____

HOME INSTRUCTIONS
**Supine to Sit over Edge of the Bed
With Assistance**



Assist the child to bend the knees as needed. Grasp the child's shoulders and knees, and assist the child to roll to one side.



Assist by lowering the child's legs off the bed while the child pushes the trunk up with the arms.

OR



If the child can lower the legs independently, assist with the child's upper trunk.

OR

If needed, assist with both the legs and the trunk.



Special Instructions

The specific technique for each child should be determined by a physical therapist after thorough evaluation.

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S-2

HOME INSTRUCTIONS
Assisted Standing Transfer
Preparing the Child



Prepare the wheelchair (as described in S-3). Unlatch the seat belt.

Note:

In the illustrations that follow, the arms of the wheelchair are not pictured in order to show the activity more clearly. When using this transfer, *do not remove the arms of the wheelchair.*



Move the child forward in the chair by holding under the shoulders and assisting the child to shift weight to one side and move the opposite hip forward.



Repeat the movement, alternating hips, until the child is sitting at the edge of the chair.

Caution

The child should not begin standing until at the edge of the chair with the feet properly placed.

Special Instructions

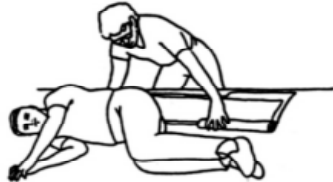
The specific technique for each child should be determined by a physical therapist after thorough evaluation.

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S-4

HOME INSTRUCTIONS
Mechanical Lift — Bed to Wheelchair

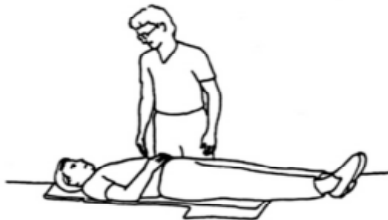
If the lifting support is one piece, the bottom should be at the knees; if the lifting support is two pieces, the narrow piece should be at midback and the wide piece under the thighs.



Roll the child to the side away from you.
Place the support behind the child. Roll up half of the support against the child's back.



Roll the child onto the support and toward you.
Then unroll the support behind the child's back.



Roll the child into a backlying position.



Position the lift and attach the lift chains to the support
with hooks facing outward.



Position the wheelchair parallel to the bed. Lock the
brakes and remove the armrest on the side of the bed.

Crank up the lift to clear the bed.

The specific technique for each child should be determined by a physical therapist after thorough evaluation.

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M-1

HOME INSTRUCTIONS

Mechanical Lift — Bed to Wheelchair (continued)



Move the lift to straddle the wheelchair, and guide the child to center on the wheelchair.



Pull the child's hips back into the wheelchair.



Lower the lift.

**Unhook the lift chain and remove the lift.
Be sure the child is well positioned in the wheelchair.
Attach the seat belt.**



Special Instructions

The specific technique for each child should be determined by a physical therapist after thorough evaluation.

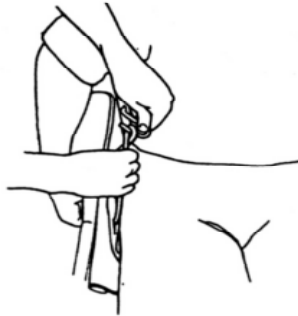
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M-2

HOME INSTRUCTIONS
Mechanical Lift — Wheelchair to Bed

Place the wheelchair parallel to the bed. Lock the brakes and remove all positioning devices.
Unlock the seat belt.

Connect the supports to the lift chain with hooks facing outward.



Remove the armrest closest to the bed.



Stabilize the lift and crank it up.



The specific technique for each child should be determined by a physical therapist after thorough evaluation.

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M-3

HOME INSTRUCTIONS
Mechanical Lift — Wheelchair to Bed (continued)



When the child's buttocks are high enough to clear all objects, move the lift to the bed.



Guide and position the child over the bed.



Crank down the lift and place the child safely on the bed.



Unhook and remove the support.

Special Instructions

The specific technique for each child should be determined by a physical therapist after thorough evaluation.

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M-4

b. Transfer from a wheelchair to the bed

Place the side of the wheelchair as close to the bed as possible and lock the brakes. The caregiver should put one knee against your child's knee for stability. Grasp your child around the rib cage and gently lift up to a standing position, then pivot your child to sit on the edge of the bed. Move the wheelchair out of your way if possible. With one arm under your child's shoulders and the other arm under the legs, in one movement, swing your child's legs onto the bed while lowering the shoulders. Then position properly.

c. Transfer from a wheelchair to the bathtub

It will probably be easiest if a bath chair or stool is available for use. Place the wheelchair beside the tub and lock the brakes. Stand your child and pivot around to the edge of the bathtub or to a chair/stool. Move the wheelchair if possible. Then swing your child's legs around into the tub.

d. Transfer from a bathtub to a wheelchair

Place the front of the wheelchair toward the side of the bathtub as close as possible and lock the brakes. The caregiver should make sure his/her hands are dry. Support your child's trunk to a standing position, pivot around to sit in the wheelchair, then swing his/her legs around to be supported by footrests and/or leg rests.

e. Transfer from a wheelchair to the toilet

Depending on space, place the wheelchair to the side of the toilet as much as possible and lock the brakes. Grasp your child around the rib cage, stand and pivot him/her around to the toilet and sit him/her on the toilet seat.

f. Transfer from the toilet to the wheelchair

Place the wheelchair as close to the side of the toilet as possible and lock the brakes. Grasp your child around the ribcage and stand him/her. Pivot around to the

wheelchair and sit him/her in the seat of the wheelchair.

g. Transfer from a wheelchair to a car

Open the car door as far as possible. Place the wheelchair along the side of the car, then lock the brakes. The caregiver should grasp your child around the rib cage and stand your child, pivot around to the seat of the car and lower. Then swing his/her legs into the car.

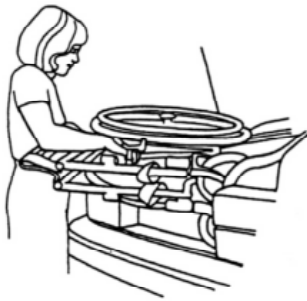
h. Transfer from a car to a wheelchair

Place the wheelchair alongside the car and lock the brakes. Swing your child's legs to the outside of the car and scoot to the edge of the seat. Grasp your child around the rib cage and stand him/her, then pivot around to the wheelchair and sit them in the chair.

See pictures on the following two pages

HOME INSTRUCTIONS
Lifting the Wheelchair into the Trunk of a Car

Remove the wheelchair parts. Fold the wheelchair and lock the brakes.



Bending at the hips and knees, grasp the wheelchair frame with one hand and the handles with the other hand. Turn the wheelchair on its side and place the wheels on the edge of the car trunk.



Move the wheelchair into the trunk by lifting and moving one end at a time.

Special Instructions

HOME INSTRUCTIONS

Lifting the Wheelchair out of the Trunk of a Car



Move the wheelchair out of the car trunk as far as possible by lifting and moving one end at a time.



Grasp the wheelchair frame and handles. Lift the chair out of the trunk and lower the large wheels to the ground.

Unfold the wheelchair and replace the parts.



Special Instructions

5. **Resisted movements** - these are resisted isometric contractions with the limb segment near the mid-range. These movements assess the tension-producing capabilities of specific muscle groups. Isometrics are one form of resisted movements where no motion takes place.
6. **Mobilization** is a passive movement test performed to a joint. It is one step below manipulation.
7. **Manipulation** is a sudden movement or thrust of a joint when referring to Physical Therapy, performed at a speed that makes your child unable to prevent the motion.
8. **Therapeutic massage** involves the mobilization of the soft tissue structures of the body to prevent and alleviate pain, discomfort, muscle spasm and stress; and to promote health and wellness. Massage therapy improves functioning of the circulatory, lymphatic, muscular, skeletal, and nervous systems and may improve the rate at which the body recovers from injury and illness.
 - a. **Massage therapy** is proving to be an effective therapy for children and adolescents with medical and psychological problems. When parents are the massage therapists, the children can be massaged daily, and the parents can feel less helpless and more involved in the child's care. Parents' involvement in their child's treatment is often negative because they must give shots or monitor dietary compliance. Being involved in a more positive treatment such as massage therapy can be very helpful to your child/children.
 - b. **Massage therapy** has generally resulted in lower anxiety levels (both self-reported and observed), lower levels of stress hormones, and better mood (less depression). Other findings were unique to specific conditions. Massage therapy may work by increasing vagal activity, slowing down the nervous system to a more alert, relaxed state in which children characteristically feel better, perform better, are

able to sleep and are less likely to get sick. Enhanced attentiveness or decreased off-task behavior may relate to increased vagal activity. Lower heart rate and greater heart rate variability generally accompany attentiveness. Increased quiet sleep may derive from increases in vagal tone and parasympathetic dominance. Enhanced quiet sleep might also relate to the reduction in anxiety and depression levels. The reduction in pain could relate to the "gate theory" of pain. The theory states that because touch or tactile nerve fibers are longer than pain fibers and because they are more myelinated, their transit time to the central nervous system is shorter and they "close the gate" to the slower moving pain signals. An increase in serotonin also may contribute to these effects (serotonin being the base of many pain medications and antidepressants).

c. People have reported that therapeutic massage can help with a wide range of medical conditions, including:

1. Allergies
2. Anxiety
3. Arthritis
4. Asthma and bronchitis
5. Carpal tunnel syndrome
6. Chronic and temporary pain
7. Circulatory problems
8. Depression
9. Digestive disorders including spastic colon, constipation and diarrhea
10. Headache, especially when due to muscle tension
11. Insomnia
12. Reduced range of motion
13. Sinusitis
14. Stress

Many parents with children with Batten Disease have found that massage therapy before bedtime promotes better sleep.

d. Potential physical benefits of therapeutic massage

1. Helps relieve stress and aids relaxation
2. Helps relieve muscle tension and stiffness
3. Fosters faster healing of strained muscles and sprained ligaments
4. Helps relieve pain and swelling; reduces formation of excessive scar tissue
5. Reduces muscle spasms
6. Provides greater joint flexibility and range of motion
7. Enhances athletic performance
8. Promotes deeper and easier breathing
9. Improves circulation of blood and movement of lymph fluids
10. Reduces blood pressure
11. Helps relieve tension-related headaches and effects of eyestrain
12. Enhances the health and nourishment of skin
13. Improves posture
14. Strengthens the immune system

e. Massage Therapy and well-being: potential mental benefits

1. Fosters peace of mind
2. Promotes a relaxed state of mental alertness
3. Helps relieve mental stress
4. Improves ability to monitor stress signals and respond appropriately
5. Enhances capacity for calm thinking and creativity
6. Emotional benefits
7. Satisfies needs for caring nurturing touch
8. Fosters a feeling of well-being
9. Reduces levels of anxiety
10. Increases awareness of mind-body connection

VIII Advocacy - there are several things to consider when advocating for your child.

A. You are the expert on your child - his/her interests, abilities,

potentials, and needs. You have the information that will help the professionals provide the most accurate supports for your child, and you also have the greatest motivation to see that your child's needs are met. Use that knowledge and motivation to your advantage in a positive, productive manner.

- B. Learn about your child's illness** and about the services that are available to you and your child. This will make you an informed advocate who can collaborate with the health professionals. This will also allow you better understand different perspectives and the full range of options available to you and your child.

- C. Foster a positive partnership with professionals** through open and honest communication. You can learn about the supports that are available to your child and family, and professionals will learn about your child's needs. Communication helps you to learn, to share, and to clear up misunderstandings.

- D. Learn to network with other parents and professionals** who are experienced and knowledgeable. Seek information that might be useful to you, and do not be afraid to ask questions. Documentation is especially important when decisions are being made to keep everyone on the "same page" and avoid misunderstandings. Create a file for documentation. Keep it organized in chronological order, up to date, and in a handy location

- E. When rights and needs are not being met**, you can always ask for an informal mediation and voluntary compliance. Make sure that all people with an interest in or an obligation to your child are present during mediation. If this does not work, you can file a formal complaint following the grievance procedures of the program. In this proceeding, you have the right to legal counsel. From there you can file a complaint with the federal agency responsible for administrative oversight of the rights being violated (U.S. Department of Justice for civil rights discrimination, U.S. Department of Education for IDEA violations,

the Social Security Administration for SSI violations, and the Health Care Financing Administration for Medicaid violations).

IX Federal Programs

With the passage of the Individuals with Disabilities Education Act in 1975, children with special needs began to be integrated into public schools and those systems were required to provide services. Intervention for children, therefore, was delivered through the school systems. Physical Therapists would now work with special needs children at the schools. Equipment and medical services continued to be supplied by charitable organizations. However, what happens when children become adults? Once children with special needs leave the school system where they were receiving medical and therapeutic services, they need to establish a relationship with Physicians and facilities qualified and equipped to address their needs. New issues also appear in adulthood, such as weight gain and living independently and people in such transition need a specialized set of services that the family Doctor is not in a position to provide to them.

When children turn eighteen where do they go? Hopefully, the children's Doctors refer them to an Intervention Doctor, but this does not always happen. They may get assigned to a primary Physician who does not know about their special needs, such as equipment needs or their needs for ongoing therapy. The primary Physicians do not always know what questions to ask, and the parents do not always know how to become advocates. People need to know the services they can ask for. They need to say, "My wheelchair is falling apart because I am 60 pounds heavier" or "I am an adult now and still on this pediatric cushion".

A. Specific federal programs that offer support to children with special needs and their families, focusing on the rights and benefits that your child and family are entitled to under each program.

- 1. Rehabilitation Act and Amendments** - a civil rights law to protect people with special needs from discrimination in areas such as employment, architectural accessibility, and

transportation.

2. **Developmental Disabilities Assistance and Bill of Rights Act and Amendments** (amended in 1999) - promotes the independence, productivity, and inclusion of people with special needs into all facets of community life.
3. **Americans with Disabilities Act** - a civil rights law designed to protect people with special needs from discrimination in employment, public services and accommodations, public transportation, and telecommunications.
4. In 1990 Education for all handicapped Children Act and Individuals with disabilities Education Act Amendments - now known as **IDEA-Individuals with Disabilities Education Act** - supports your child's developmental and educational experiences - focuses on children 0-21 years of age who experience physical or mental conditions that result in developmental delays in cognitive, physical, communicative, social or emotional which includes: mental retardation, hearing, visual, or speech impairment, deafness, blindness, emotional disturbances, orthopedic impairment, autism, traumatic brain injury, or other health impairments. Its objectives are:
 - a. To strengthen the role of parents
 - b. To ensure access to the general curriculum to the extent appropriate
 - c. To facilitate interactions with students without special needs
 - d. To focus on teaching and learning
 - e. To be responsive to the growing needs of an increasingly diverse society
 - f. To ensure that schools are safe and conducive to learning
 - g. To encourage parents and educators to work out differences using nonadversarial means

5. **SSI - Supplemental Security Income** - can provide your child and family with financial support if you can demonstrate that your child meets the standard of disability and your family meets the established income and asset requirements specified by the Social Security Administration.
6. **Medicaid** - a needs-based program that provides children with special health care needs access to important health services.
7. **Consolidated Omnibus Budget Reconciliation Act - (COBRA)**
- to provide health care support to your child and family in the event that you or your spouse experience a change in employment status that would otherwise result in a loss of group health insurance coverage provided by an employer.
8. **The 1990 Omnibus Budget Reconciliation Act PL 101-508, Medicaid Waiver** established that each state can apply for up to 200 waivers each year. This has helped but not completely solved the funding problem. Because the waiver program limits the number of people who can be funded by each state, some states have long waiting lists and some home health care providers are reluctant to accept the relatively low reimbursement rates that the waiver program offers.
9. **Hospice Programs** (not really a Federal program) are available usually when it is believed that there is approximately 6 months left of a person's life. Hospice is available in almost every community. They offer medical care as well as emotional and spiritual care to the child and the family. They have all of the necessary medical equipment, including medications that may be needed at this time.

The federal programs listed above are designed to ensure that your child's rights are protected and that education, health care benefits, and financial support are provided. In spite of the intent and protection offered by these federal programs, you may find

yourself at odds with your local, state, or federal service system at some point. Conflict between parents and professionals can sometimes be the result of intentional efforts to ignore federal requirements. More typically, however, conflicts are a result of honest mistakes, a lack of sensitivity to or understanding of needs, a lack of knowledge about federal requirements, different interpretations of federal requirements, or differences in opinion regarding options and strategies for meeting your child's needs. All of these situations can be addressed through open communication, the sharing of information, and a willingness to learn about and explore options.

Most likely, when you apply for a specific program, the first time you will be denied. This is just the way the system works. Reapply or appeal and appeal and do not give up. It takes some hard work, but it will be worth it in the end.

PHYSICAL THERAPY

MOTOR DEVELOPMENT AND RELATED TOPICS

GLOSSARY

A

ABDUCTION - pertaining to movement away from the midline of the body, as in moving the arms straight out to the sides

ABRASION - a scraping or rubbing away of tissue by friction, like a skinned knee

ACETABULUM - the cup-shaped cavity of the hip bone that holds the head of the femur in place creating a joint

ACTIVE RANGE OF MOTION - muscular action at a joint owing to voluntary effort without outside help, doing exercises or movement by oneself

ACQUIRED CONDITION - pertaining to a characteristic, condition, or disease originating after birth and caused, not by heredity or developmental factors, but by a reaction to environmental influences outside of the body

ACUPUNCTURE - a method of producing analgesia or altering the function of a system of the body by inserting fine, wire-thin needles into the skin at specific sites on the body along a series of lines, or channels, called meridians. The needles are twirled or energized electrically or warmed.

ACUTE - a disease or disease symptoms beginning abruptly with marked intensity or sharpness, then subsiding after a relatively short period of time

ADAPTIVE - an alteration or adjustment to improve a condition in relation to the environment. A device that helps people to overcome in some way the limitations caused by their special needs/disabilities, such as electronics, programs, computers

ADDUCTION - pertaining to movement toward the midline of the body, as in bringing the arms back to their original position

ADHESION - a band of scar tissue that binds together two surfaces which are normally separate from each other

ADVOCATE - to speak, plead, or argue in favor of, one that argues for a cause, one that pleads in another's behalf

AEROBIC CAPACITY - an exercise regimen designed to strengthen the cardiovascular system by mild to moderate muscular exertion below the level that produces an acidosis

AFFERENT - the neural signals sent from the peripheral nervous system to the central nervous system

AGGRESSION - a forceful, self-assertive action or attitude that is expressed physically, verbally, or symbolically. It may arise from the innate drives or occur as a defense mechanism and is manifested by either constructive or destructive acts directed toward oneself or against others

ALIGNMENT - the positioning and supporting of the body in such a way that all body parts are in correct anatomical position

ANAL FISSURES - an ulceration or laceration of the skin around the rectum

ANALGESIA - absence of normal sense of pain, an analgesic is a drug that relieves pain

ANALYZE - medically speaking, where the needs of the child are identified and goals of care are selected

ANATOMICAL - a position of the body in which a person stands erect, facing directly forward, feet pointed slightly apart, arms hanging down at the sides with palms facing forward. This is the standard neutral position of reference to describe sites or motions of various parts of the body

ANATOMY - the study, classification and description of structures and organs of the body

ANEMIA - a disorder in which the blood has either too few red blood cells or too little hemoglobin

ARTERIOLES - one of the blood vessels of the smallest branch of the arterial circulation. Blood flowing from the heart is pumped through the arteries to the arterioles to the capillaries into the venules and veins and returned to the heart.

Arterioles play a big role in the regulation of the blood pressure

ANTERIOR - referring to the front

ARTICULATION - pertaining to the place of a union, as in the union of a joint

ASPIRATION - to draw in or out as by suction, where foreign bodies may be aspirated into the nose, throat or lungs on inspiration

ASSISTIVE - a device used to help a person with an activity to make life easier, as a wheelchair

ASTHENIA - the lack or loss of strength or energy, weakness, debility

ASYMMETRICAL - a part or parts of the body which are unequal in size or shape

ATAXIA - having an unbalanced gait caused by a disturbance of the cerebellar control

ATONIC - absence of normal muscle tone

ATROPHY - pertaining to a wasting or decrease in the size of a muscle when it cannot be used

ATYPICAL - deviating from the normal

AUDIOLOGY - a field of research devoted to the study of hearing, especially impaired hearing that cannot be corrected by medical means

AUDITORY - pertaining to the sense of hearing

B

BEHAVIOR - the manner in which a person acts or performs, any or all of the activities of a person, including physical actions, which are observed directly and mental activity which is inferred and interpreted

BIOMECHANICS - the study of mechanical laws and their application to living organisms, especially the human body and its locomotor system

BODY MECHANICS - a term used to refer to the way in which the body moves and maintains its balance by the most efficient use of all of its parts

BOLSTERS - a long narrow pillow or cushion

BONY PROMINENCES - the part of the bone that is easy to feel, like the elbow, hip, knee, or ankle

BURSAE - a fibrous sac between certain tendons and the bones beneath them, they are lined with a synovial membrane that secretes synovial fluid to act as a small cushion that allows the tendon as it contracts and relaxes to move over the bone

C

CALLUS - a disorganized network of bone tissue formed around the edges of a fracture

CAPILLARIES - one of the tiny blood vessels joining arterioles and venules where blood and tissue cells exchange various substances including oxygen

CARDIAC - pertaining to the heart

CARDIOPULMONARY - pertaining to the heart and lungs

CARDIOVASCULAR - the network of structures, including the heart and blood vessels, that pump and push the blood throughout the body

CARTILAGE - a nonvascular supporting connective tissue composed of various cells and fibers, found chiefly in the joints

CAUDATE - a portion of the brain which is at the end or tail like of the important areas of the brain

CENTRAL NERVOUS SYSTEM - the portion of the nervous system that consists of the brain and the spinal cord. It is primarily involved in voluntary movement and thought processes

CEREBELLUM - the part of the brain located behind the brain stem with functions of coordinating voluntary muscular activity

CEREBRAL CORTEX - a thin layer of gray matter on the surface of the cerebral hemisphere that integrates higher mental functions, general movement, visceral functions, perception, and behavioral reactions

CERVICAL - pertaining to the neck

CHRONIC - a disease or disorder developing slowly and persisting for a long period of time

CIRCULATION - movement of an object or substance through a circular course so it returns to the starting point as in the circulation of blood through the cardiovascular system

CIRULATORY - the network of channels through which the nutrient fluids of the body circulate

COGNITIVE - the developmental process by which an infant becomes an intelligent person acquiring with growth, knowledge and the ability to think, learn, reason, and abstract

COLLAGEN - a substance consisting of bundles of tiny fibers which combine to form the white, glistening, inelastic fibers of the tendons and ligaments

COMPENSATORY - to make up for, to counter balance

CONDOM - a soft, flexible sheath used to cover the penis to be able to collect urine in a bag and avoid urine on the skin

CONFIGURATION - arrangement of parts or elements

CONGENITAL - originating prior to birth

CONSTIPATION - difficulty in passing stools or an incomplete or infrequent passage of hard stool

CONTRACTURES - a tightening or shortening of a muscle, an irreversible shortening of the muscle fibers that causes decreased joint mobility

CONVULSIVE - incoordinate contraction of muscles, as in a spasm

COUNTERINTUITIVE - contrary to what intuition and common sense would indicate

CPR - cardiopulmonary resuscitation - a procedure used after cardiac arrest in which cardiac massage, artificial respiration and drugs are used to restore circulation

CRANIAL NERVE - meaning nerves nearest the head

CUTANEOUS - pertaining to the skin

CYANOSIS - bluish discoloration of the skin and mucous membranes caused by an excess of carbon dioxide in the blood, with too little oxygen

D

DEBRIDEMENT - the surgical removal of dead tissue (like after a burn or infection)

DEGENERATIVE - a deterioration of the structure or function of a tissue

DEHYDRATION - excessive loss of water from the body tissues accompanied by an imbalance of the essential minerals in the body to maintain health, maybe caused from fever, diarrhea, vomiting and any condition where there is a rapid depletion of fluids

DENATURE - subject to having the nature of a substance changed

DESQUAMATION - scaling of the skin

DIAPHRAGM - a dome-shaped musculofibrous partition that separates the thorax (lungs) and the abdominal cavity. It rises and falls with breathing in and out

DIARTHROSES - pertaining to a freely movable joint

DIATHERMY - the therapeutic use of a high frequency current to generate heat within some part of the body

DISLOCATION - a derangement of the parts of a joint, a displacement of a bone out of a joint space

DISTAL - pertaining to being farthest from a point of reference

DISTENTION - to stretch out or become inflated as in the abdomen due to gas build up

DISTORTION - a twisting or bending out of regular shape, a deformity in which the part or structure is altered in shape

DORSAL - pertaining to near the back of the body

DYSFUNCTION - absence of complete normal function

DYSTONIA - a disorder of the basal ganglia associated with altered muscle tone leading to contorted body positioning

E

ECTOPIC BONE - a bone situated in an unusual place away from the original or normal location, or a protrusion that is abnormal

EDEMA - an abnormal accumulation of fluid in the tissues of the body

EFFERENT - an impulse that goes to a nerve or muscle from the central nervous system (CNS)

EFFICACY - producing a desired effect, effective
ELASTICITY - the ability of tissue as in muscle, to regain its original shape and size after being stretched, squeezed or otherwise deformed
ELECTROTHERAPY - the transmission of an alternating electric current through the body tissues, used in physical therapy; the use of electricity to treat disease
ELONGATING - the process of lengthening
ENCOPRESIS - psychically caused incontinence of stool, incontinence not due to illness or organic defect.
ENDOCRINE - pertaining to an organ, gland, or structure that secretes a substance, as a hormone into the blood or lymph for specific effect on another part or organ
EPIDERMIS - the superficial layer of skin
EPIDURAL - an area between the skull and the outer (dura) membrane of the brain
EPITHELIALIZATION - the regeneration of cells to protect, absorb, secrete and other specialized functions
EPITHELIUM - pertaining to skin cells
ERGONOMICS - a scientific discipline devoted to the study and analysis of human work, especially as it is affected by individual anatomy, psychology, and other human factors
EROSION - the wearing away or gradual destruction of a surface
ERYTHEMA - redness or inflammation of the skin or mucous membranes, like a rash
ESCHAR - a scab or dry crust resulting from a burn, infection or possibly a skin disease
EVERSION - pertaining to turning the sole outward, away from the body
EXCISION - to remove completely as in a surgical procedure
EXCITABILITY - the capacity of a muscle to respond to stimuli
EXERCISE - the performance of any physical activity for the purpose of conditioning the body, improving health, or maintaining fitness or as a means of therapy for correcting a deformity or restoring the organs and bodily functions to a state of health
EXTENSION - a straightening motion that increases the angle between bones, as in straightening the fingers in order to open the hand
EXTERNAL - being on the outside or exterior of the body or an organ
EXUDATE - fluid, cells, or other substances that have been slowly discharged from cells or blood vessels through small pores or breaks in cell membranes

F

FACILITATE - to make easy or easier; to assist
FASCIA - a fibrous membrane covering, supporting, and separating muscles; also unites the skin with the underlying tissue
FEMUR - long bone in the thigh connecting the hip to the knee
FIBROBLAST - a cell from which connective tissue is developed
FINE MOTOR SKILLS - the ability to pick up fine, small objects, using fingers separately to accomplish tasks
FIXATION - the act of holding or fastening in a fixed position
FLANK - the part of the body between the ribs and the upper border of the hip bone

FLAPS - a mass of partly detached tissue attached at the base of the surgery
FLEXIBILITY - quality of being bent without breaking
FLEXION - a bending motion that decreases the angle between the bones, as in bending the fingers in order to close the hand
FLUENCY - flowing smoothly and naturally
FOLEY - a catheter inserted into the bladder for the control of urinary incontinence
FOOT DROP - a falling or dragging of the foot from paralysis of the flexors in the ankle
FORAMEN - a natural opening or passageway, used as a general term for describing a passage into or through a bone
FRACTURE - a break, usually referring to a break in a bone
FUNCTIONAL - an act, process, or series of processes that serve a purpose

G

GASTROINTESTINAL - GI - pertaining to anything from the mouth to the rectum and the digestive system
GENETICS - the study of heredity and its variations; pertaining to or produced by a gene
GERIATRICS - the branch of medicine dealing with the physiology of aging and the diagnosis and treatment of diseases affecting the aged
GEROUS - bearing or characterized by something specified
GRANULATING - any soft, pink, fleshy tissue that forms during the healing process
GRAZING - to touch or scrape lightly in passing; to feed or grow
GROSS MOTOR SKILLS - the ability to hold larger objects, doing activities that require the whole hand to accomplish rather than the fingers only, sometimes with difficulty
GUARDIANSHIP - one that guards or protects; one legally responsible for the care and management of the person or property of an incompetent or minor

H

HABILITATION - the teaching of new skills to children with developmental disabilities. It is called habilitation rather than rehabilitation because these children did not possess these skills previously
HALLUCINATION - sensory perceptions without a source in the external world. These most commonly occur as symptoms of psychosis or seizure
HEMATOMA - a collection of blood collected in the tissues of the skin or in an organ usually resulting from some form of trauma
HEMOGLOBIN - a complex compound in the blood that carries oxygen to the cells from the lungs and carbon dioxide away from the cells to the lungs
HIPPOCAMPUS - a thin sheet of fibers consisting largely of gray matter lying close to the temporal lobe; controls memory but if damaged or traumatized, may result in seizures
HUBBARD TANK - used for underwater exercises usually of the trunk and lower extremities

HUMERUS - the long bone of the upper arm
HYDROTHERAPY - scientific application of water in the treatment of disease
HYPOTENSION - a decrease or lower blood pressure possibly resulting in faintness

I

INHIBITION - the act or state of being restrained, prevented or held back
IMMOBILITY - the decrease or inability to move the trunk and the extremities
IMPACTION - tightly or firmly wedged in a limited amount of space, as in stool
IMPAIRMENT - diminished, weakened; functioning poorly or incompetently
IMPART - to grant a share of; to make known, disclose
IMPEDE - to retard or obstruct the progress of
IMPULSIVITY - inclined to act on impulse rather than thought; spontaneous
INCLUSION - being enclosed or included
INDURATION - an area of hardened tissue
INFLAMMATORY - a tissue reaction to injury whether it be the skin or an organ; it may appear reddened, swollen and tender to touch
INFRARED - invisible heat rays beyond the red end of the spectrum close to the microwave rays
INNATE - existing in or belonging to a person from birth, inborn, heredity, congenital
INNERVATED - stimulation of a part through the action of nerves
INOCULATION - intentional introduction of a virus into the system as a preventive against the acquisition of certain diseases
INSOMNIA - chronic inability to sleep
INTEGRETION - the act or process of being together
INTEGUMENTARY - pertaining to the skin; a covering
INTERDISCIPLINARY - of or involving two or more distinct disciplines of learning
INTERNAL - within or on the inside
INTERVENTION - to come or occur between two things, events, or points of time
INTRATHECAL - intraspinal; with in the spinal cavity; of or pertaining to a structure, process, or substance within a sheath
INTREPRET - to help understand the results of tests or the procedure with which something is to be done
INVERSION - pertaining to the act of turning the sole inward so that it faces the opposite foot
ISCHEMIA - decreased blood flow to an area of the body; leads to tissue death
ISCHIAL TUBEROSITY - an elevation or protuberance of a bone of the lower portion of the hip bone
ISOMETRIC CONTRACTION - contractions in which there is no change in muscle length, but there is a great increase in muscle tension

J

JOINT - an articulation or area of junction or union between two or more bones

K

Kyphosis - humping deformity of the spine, hunchback

L

LAXITY - being lax, not wanting to work correctly

LETHARGY - the state or quality of being indifferent, apathetic, or sluggish; stupor or coma resulting from disease

LIGAMENT - a band of fibrous tissue connecting bones

LIGHT THERAPY - the use of light rays in the treatment of disease

LIMITATION - the point, edge or line beyond which something cannot or may not proceed

LUMBAR - pertaining to the lower back

LUNG DISEASE - any disease resulting in the decrease of exchange of oxygen and carbon dioxide resulting in a difficulty in breathing

LYMPHATIC - a vast complex network of capillaries, thin vessels, valves, ducts, nodes and organs that helps to protect and maintain the internal fluid environment of the body by producing, filtering, and conveying lymph and by producing various blood cells; the system also transports fats, proteins, and other substances to the blood system and restores 60% of the fluid that filters out of the capillaries during metabolism

M

MALAISE - a vague feeling of bodily weakness or discomfort, often marking the onset of an infection or disease

MALFORMATION - an abnormal structure in the body

MANIPULATION - any treatment or procedure involving use of the hands

MASSAGE - the manipulation of the soft tissue of the body through stroking, rubbing, kneading, or tapping to increase circulation, improve muscle tone, and relax the person

MATURATION - the process or condition of attaining complete development; the unfolding of full physical, emotional, and intellectual capacities that enable a person to function at a higher level of competency and adaptability with the environment

MEDIAL - pertaining to near the midline of the body

MEDIATION - to cause a change to occur; to settle a dispute

METABOLIC - the chemical processes that take place in living organisms, resulting in growth, generation of energy, elimination of wastes, and other bodily functions as they relate to the distribution of nutrients in the blood after digestion

METACARPAL - pertaining to the bones in the hand

METATARSAL - pertaining to the bones in the foot

MINERAL - an inorganic substance occurring naturally in the earth's crust; plays a vital role in regulating many bodily functions

MOBILITY - state or quality of being mobile, to move

MODALITIES - a method of application or the employment of any therapeutic agent; a form of sensation, such as touch, pressure, vision, or hearing

MUSCLE TONE - refers to a partially contracted state of the muscles that is normal even though the muscles may not be in use at the time.

MUSCULAR - pertaining to the muscles

MUSCULOSKELETAL - pertaining to the muscles and the skeleton

MYELINATED - a coating called myelin around an axon, (which is a part of the nerve fiber), this quickens neurotransmission

N

NECROSIS - death of tissue

NECROTIC - relating to the death of a portion of tissue

NERVOUS - characterized by the instability of nerve action; excitability

NEUROLOGIC - pertaining to the study of nervous diseases

NEUROMUSCULAR - containing both nerves and muscles

NEURON - the basic nerve cell of the nervous system, containing a nucleus within a cell body and extending one or more processes. Neurons are classified according to the direction in which they conduct impulses and according to the number of processes they extend. Sensory neurons transmit nerve impulses to the spinal cord and the brain. Motor neurons transmit nerve impulses from the brain and the spinal cord to the muscles and the glandular tissue

NEUROTRANSMITTER - a chemical released at the synapse that permits transmission of an impulse from one nerve to another

NONANATOMIC POSITION - not in proper body alignment

NONCONTRACTILE - the inability to contract or shorten

O

OCCIPITAL - concerning the back part of the head toward the base of the skull

ORTHOPEDIC - the study or branch of medicine or surgery that deals with the treatment of disease and deformities of the bones, muscles, and joints

ORTHOSTAIC BLOOD PRESSURE - a quickly lowered blood pressure upon standing causing lightheadedness or faintness

ORTHOTIST - a professional trained in the fitting and construction of splints and braces

OSSIFICATION - formation of bone substance - conversion into bone

OSTEITIS - inflammation of the bone

OSTEOBLAST - a cell involved in the production of bone

OSTEOCLAST - a large cell involved in the absorption and removal of bone

OSTEOMYELITIS - inflammation of bone marrow, or of the bone and marrow

OSTEOPOROSIS - a disorder caused by the abnormal density of the bone where the bones become increasingly porous; a decrease in bone tissue resulting in structural weakness

P

PAIN - an unpleasant sensation caused by the stimulation of the sensory nerve endings. It is a cardinal symptom of inflammation/infection and is valuable in diagnosing many disorders. Pain may be mild or severe, chronic or acute, cutting or tearing, burning, dull or sharp, precisely or poorly localized, or referred

PARALYZED - an abnormal condition characterized by the loss of muscle function or the loss of sensation

PARASYMPATHETIC NERVOUS SYSTEM - part of the autonomic nervous system that involves many different nerves. It can be responsible for slowing down the heart rate, stimulating a bowel movement, promote the secretion of saliva, release insulin and bile, and constrict the pupils, esophagus and lungs

PARIETAL - pertaining to the parietal bone of the skull which is located from the top of the head to below the ears

PARAFFIN - a treatment in Physical Therapy usually associated with arthritis where they dip the hands in paraffin wax and let it hardened

PARALLEL - being an equal distance apart everywhere and never intersecting

PASSIVE - receiving or subjected to an action without acting in return

PASSIVE RANGE OF MOTION - the moving of parts of the body by an outside force without voluntary action or resistance by the individual

PATHOLOGIC FRACTURE - a fracture of a bone resulting spontaneously from weakened bone tissue due to disease without external force

PERCEPTUAL - the conscious recognition and interpretation of sensory stimuli through unconscious associations, especially memory, that serve as a basis for understanding, learning, and knowing or for the motivation of a particular action or reaction

PERIOSTITIS - inflammation of the fibrous tissue covering and protecting all bones

PHYSICAL THERAPY - treatment by physical means such as heat, cold, water, massage, and electricity, exercises

PHYSIOLOGICAL - concerning normal body function

PIGMENTATION - any organic coloring material produced in the body, as skin color

PLANTAR FLEXION - the normal response seen by stroking the outer surface of the sole of the foot from heel to toes, characterized by the flexion of the toes

PLASTER CAST - a liquid and powder mix that hardens when dry, to support a fractured bone as it heals, as plaster of paris

PLASTICITY - the ability to be molded

PLIABILITY - capacity for being bent or twisted easily

PNEUMONIA - inflammation of the lungs caused by bacteria, virus, chemical irritants, vegetable dusts and allergy. Symptoms include fever, increased congestion, possibly shortness of breath and difficulty breathing, pain, and increased sputum which may be thick yellow/brown or may be bloody. Treatment is antibiotics

POSTERIOR - referring to the back

POSTURAL - pertaining to or effected by posture, position of the body

PRESSURE SORES - a sore caused by pressure as from a splint or other appliance or from the body itself when it has remained immobile in bed for extended periods of time

PROCESS - referring to a prominence or part extending from an organ

PROGNOSIS - prediction of course and end of disease and outlook based on it
PROLIFERATION - reproduction rapidly and repeatedly of new parts; rapid and increased production
PRONATION - the act of turning the palm down or backward, face down
PROPHYLACTIC - any agent or device that prevents or helps to prevent the development of disease
PROTRACTED - a muscle that draws a part forward
PROXIMAL - nearest to a point of reference
PSYCHOGENIC - concerning the development of the mind
PSYCHOLOGICAL - measures the intellectual capacity, motivation, perception, role behavior, values, level of anxiety or depression, coping mechanisms, and general personality integration
PULMONARY - pertaining to the lungs

Q

QUALITATIVE - pertaining to the quality, value, or nature of something

R

RECTAL PROLAPSE - a dropping of an internal organ (rectal mucosa) through the anus or opening
RECTAL TEARS - tearing of the rectal mucosa
REFLEXES - an involuntary response to a stimulus. The function or action occurs immediately, without the involvement of the will or consciousness
REFRACTION - the change of direction of energy as it passes from one thing to another of different density
RENAL FUNCTION - how the kidneys function
RESPIRATION - the act of inhaling and exhaling
RESPIRE CARE - an organization in most communities that offer home care help to families in need of medical care or assistance by a medical person
RHIZOTOMY - an operation that deals with roots of nerves
RIGIDITY - a condition of hardness, stiffness, or inflexibility
ROM - range of motion

S

SACRAL - pertaining to the sacrum which is the large triangular bone of the pelvis inserted like a wedge between the two hip bones
SCAPULA - the shoulder blades
SCOLIOSIS - curvature of the spine
SEED GRAFT - a small piece of a material used by the Doctor, inserted in an ulcerated wound to promote or stimulate healing or growth of tissue
SEPSIS - bacterial infection spread throughout the blood stream; also called blood poisoning

SEPTIC SPOTS - inflamed areas or ulcerations caused by an infection or virus/bacteria as in the throat

SEPTICEMIA - a condition of the blood caused by virulent microorganisms

SEROTONIN - a naturally occurring product found in platelets and the cells of the brain and intestines. In the central nervous system, it acts as a neurotransmitter

SEVERED - cut

SKELETAL - pertaining to the skeleton

SLOUGH - to shed or cast off dead tissue cells, the tissue that has been shed

SORBITAL - used as a diuretic or a vehicle for medicinal preparations - to mix with a powder or liquid medicine

SPASTIC - increased muscle tone so that muscles are stiff and movements are difficult, caused by damage to the pyramidal tract in the brain

SPASTICITY - abnormally increased muscle tone

SPINAL DEFORMITY - an abnormal deviation of the spinal column (bone structure) from its normal position

SPLINTING - an orthopedic device used for immobilization, restraint, or support of any part of the body. It may be rigid or flexible.

SPRAIN - pertaining to an injury of a joint with stretching or tearing of the ligaments

STAGNATION - cessation of motion as in the stoppage of motion of any body fluid

STASIS - stagnation of normal flow of fluids as in the blood, urine or intestines

STIMULATION - irritating action of agents on muscles, nerves, or sensory end organs by which activity in a part is evoked

STRAIN - pertaining to an injury caused by excessive stretching, overuse, or misuse of a muscle

SUBCUTANEOUS - beneath or to be introduced beneath the skin

SUBLUXATION - partial dislocation

SUPERIOR - meaning above, or being in a higher position

SUPINATION - the act of turning the palm up or forward

SUPINE - lying flat on the back with the face upward

SUPPOSITORIES - usually a cone-shaped medication to be given rectally for absorption within the intestines, taking effect fairly quickly

SYNAPSE - the minute space separating one neuron from another, neurochemicals breach this gap

SYNAPSE - the passage of a nerve impulse transmitted across the synapse from one nerve fiber to another by a neurotransmitter

SYNARTHROSES - pertaining to an immovable joint

SYNOVIAL - a joint lubricating fluid

SYSTEMIC - involving the whole body

T

TEMPORAL - part of the brain located just above the temples. It contains the auditory receptive areas of the brain

TENDON - a fibrous cord that attaches a muscle to a bone

THALAMUS - one of a pair of large oval organs located in the third ventricle in the brain. Its purpose is to relay sensory impulses to the cerebral cortex. It translates

impulses from appropriate receptors into crude sensations of pain, temperature, and touch. It also participates in associating sensory impulses with pleasant and unpleasant feelings and in the mechanisms that produce complex reflex movements

THERAPEUTIC - beneficial as in relating to a treatment

THERAPY - pertaining to treatment of a disease or disorder, as in physical therapy

THERMAL - pertaining to the production, application, or maintenance of heat within the body

THORACIC - pertaining to the chest

TIBIA - the inner and larger bone of the leg between the knee and the ankle

TORSO - the trunk of the body

TOXIC - pertaining to, resembling or caused by poison

TRANSIENT - present for only a short period of time, temporary

TRIAGE - the process of sorting the degree of injury or sickness on the basis of urgency and type of condition presented, so they can be properly routed to the proper station/Doctor

TROCHANTER - one of the two bony projections located on the femur that serve for the attachment of various muscles

U

ULTRASOUND - a piece of equipment that uses sound waves as treatment

ULTRAVIOLET - a light beyond the range of human vision. It occurs naturally in sunlight, it burns and tans the skin and converts precursors in the skin to Vitamin D

V

VAGAL - pertaining to the vagus nerve, the pair of cranial nerves essential for speech, swallowing, and the sensibilities and functions of many parts of the body

VASCULAR - pertaining to a blood vessel

VENOUS BLOOD RETURN - return of the used blood to the lungs for reoxygenation via the veins

VENTILATION - the process by which gases are moved into and out of the lungs

VENTILATORS - a machine that mechanically is used to assist in respiration

VENULES - any one of the small blood vessels that gather blood from the capillaries and form the veins

VERTEBRAL - refers to the spinal column

VIRULENT - pertaining to a highly pathogenic or rapidly progressive condition

VISCERAL - pertaining to any of the large internal organs contained in the abdominal, thoracic, or the pelvic cavities of the body

VITAL CAPACITY - a measurement of the amount of air that can be expelled after a maximum inspiration, representing the greatest possible breathing capacity

VOMITUS - the expelled contents of the stomach

W

WATER THERAPY - a modality of physical therapy for a treatment with the use of water or under water

WEDGES - a piece of material tapered to insert as a wedge for splinting, securing or levering a position

X

Y

Z

PHYSICAL THERAPY MOTOR DEVELOPMENT AND RELATED TOPICS

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