Global Best Practices in Care, Rehabilitation and Research
Blood Disorders (Thalassemia, Hemophilia & Sickle Cell Disease)

Dr. J.S. Arora
Thalassemiologist
MSc in Haemoglobinopathy
University College London

General secretary:
National Thalassemia Welfare Society
Federation of Indian Thalassemics

Member Ethics Committee:
BT Delhi
Lady Hardinge Medical College and Associated Hospitals, New Delhi
ITC Dental College Hospital & Research Centre, Greater Noida

Founder Member:
Indian Alliance of Patient Groups

Member Advisory Committee:
- D D U Hospital Govt. of Delhi
- Coordinator Thalassemia Cell Govt. of Delhi

"Life Time Service Award" from PHO Chambers of IAP

Patients for Patient Safety (PFPS) Champion India
Member: Patients for Patient Safety Advisory Group
js.arora.10@alumni.ucl.ac.uk

7% of the world population
Carry Thalassemia/Hb’pathy gene

400 million heterozygous carriers

3,000,000-4,000,000 babies with severe haemoglobinopathies born each year.

INDIA, THAILAND AND INDONESIA
► 50% OF WORLD’S THALASSAEMIA CARRIERS
► 50% OF THALASSAEMIA MAJORS

β Thalassemia

100 million carriers of β Thalassemia.
More than 100,000 Thalassemia Major born/year

India

• βthalassemia: Carrier rate 1% - 17% (mean 3.9%) more prevalent in certain communities. 50 million carriers, Over 12,000 affected born every year.

• Sickle Cell Disease: common in tribes carrier rate as high as 40% in some areas

• HbE: Highly prevalent in West Bengal & North Eastern States.

Complications of Thalassemia

Severe Anemia – Lethargy, Loss of appetite, Malnutrition

Thalassemia faces - Social stigma

Hepato-Splenomegaly – Protruded abdomen, Increased destruction of blood cells

Blood Transfusion Therapy
Scarcity of Blood & Transfusion Centres
Transfusion Reactions & Infections (HBV, HCV, HIV)
Repeated hospital visits

Iron overload
Growth retardation, Delayed/missed Puberty
Endocrine complications, Bone disease
Heart and Liver failure

Chelation therapy - Lifelong, Painful & Costly

Absenteeism from school/college & work place – Loss of education & income

Management of Thalassemia

• Blood transfusion therapy, every 2-3 weeks lifelong
• Iron Chelation
• Splenectomy (in under transfused patients)
• Growth, Puberty and Endocrine complications
• Osteoporosis
• Cardiac complications
• Stem cell transplantation
• Gene therapy
• Psycho-social support
**Sickle Cell Disease**

- Normal RBC’s are smooth surfaced, enabling them to change their shape to flow through small blood vessels.
- Under certain conditions (i.e., acidosis, dehydration, infection, and low oxygen etc.) RBC’s containing Sickle Hemoglobin become rigid, elongated, and sickle shaped.
- Sickled RBC’s can become trapped within the blood vessels and thus interfere with normal blood flow.
- This obstruction can lead to sudden pain anywhere in the body as well as cause damage to body tissues and organs over time.

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**Clinical Symptoms – Sickle Cell**

**Sickle Cell Anaemia - Homozygous (SS)**
- 3-12 months, splenomegaly, Growth retardation, Hand & foot syndrome, Leg ulcers, Abdomen pain, Infections, Gallstones, CV Symptoms etc.

**Sickle Cell Trait – Heterozygous (AS)**
- Mild, may remain undetected

**Sickle Cell Disease – HbS + α/β/C/D/E/Q**
- depends upon combination

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**Crisis in Sickle Cell Disease**

- **Vaso-occlusive** obstruction of microcirculation due to sickling
- **Hand and foot syndrome** between <2-3 yrs of age
- **Bone & joint crisis** >3 yrs, larger bones, spine, rib cage
- **Abdominal** infarcts of mesentry & abd viscera, severe pain (4-5day)
- **CNS (stroke)** ↑ HbF<8%, occlusion (2-15yrs), Haemorrhage (older)
- **Acute chest syndrome** infections ↑ thrombotic disease
- **Haematologic crisis** sudden severe anemia-untreated →death
- **Aplastic crisis** Parvovirus B19→↑Hb, self limiting-recovery 5-10d
- **Splenic sequestration** 4m-24m, ↓HbF→Hypovolumic shock → death
- **Infectious** pneumonia, meningitis, influenza, Osteomyelitis

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**Crises Management in SCD**

- Infection
- Fever
- Dehydration
- Acidosis
- Hypoxemia Po2 <75
- Cold exposure
- Exhaustion
- High Altitude
- Avoiding weight bearing in early phases of bone necrosis
- Pneumonia vaccination
- H influenza
- Hepatitis B
- Penicillin prophylaxis 4mth-5yrs
- Folate supplementation
- Splenectomy
- Analgesics Paracetamol (avoid salicylates)

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**Hemophilia**

**Definition**
- A group of hereditary bleeding disorders in which there is a deficiency of one of the factors necessary for coagulation of blood

**Types**
- **Hemophilia A** - absence or deficiency of Factor VIII also known as Classic Hemophilia
- **Hemophilia B** - absence or deficiency of Factor IX also known as Christmas Disease
- Other rare missing clotting factors include factors II, V, VII, X, XI, XIII
Incidence

- One in 7500 live male births
- Affects approximately 17,000 males in the U.S.
- All races and socioeconomic groups are equally affected
- X-linked disorder, females carry gene, males are affected.
- 30% cases genetic mutations

Degrees of Severity

- Normal factor VIII or IX level = 50-150%
- Mild hemophilia - factor VIII or IX level = 6-50%
- Moderate hemophilia - factor VIII or IX level = 1-5%
- Severe hemophilia - factor VIII or IX level = <1%

Hemophilia in India

Hemophilia A
- Observed: 0.9 per 1,00,000
- Estimated (calculated at 4 per 1,00,000 population)
- (1 in 5000 males)
- Year 2014 reported
- Estimated around 50,000 patient

Hemophilia B
- Observed = 0.1/100,000
- (1 in 30,000)

Hemophilia - Joint & Muscle Bleeding

- Joint Bleed – early signs bubbling, tingling and heat at the joint
  (best time to start treatment)
- Swelling and pain set in, feels boggy, motion is limited, not be able to bear weight or move a limb. Very painful in later stages of a bleed
- Knees, Ankles & Elbows most often affected
- Muscle Bleed – leg, thigh, calf, forearm & groin most affected
  – Vague ache, severe pain, swelling
  – Inability to move muscle
  – Tightness & shininess of skin
  – Significant blood loss can happen quickly
- Patient can feel a joint bleed or muscle bleed LONG before anyone sees any outward symptoms

Hemophilia - Bleeding Episodes

Life Threatening

- Head/Intracranial - Nausea, vomiting, headache, drowsiness, confusion, visual changes, loss of consciousness
- Neck and Throat - Pain, swelling, difficulty breathing/swallowing
- Abdominal/GI - Pain, tenderness, swelling, blood in the stools
- Iliopsoas Muscle - Back pain, thigh tingling/numbness, decreased hip range of motion

Other Bleeds

- Mouth bleeding - May cause vomiting, Feces may be black
- Nose bleeding - Sit up, pinch bridge of nose, cool pack on back of neck
- Scrapes and/or minor cuts - Wash, pressure, dressing

Treatment of Bleeding Episodes

The recognition of bleeding episodes and treating bleeds as early as possible prevent complications such as loss of range of motion, arthritis & muscle atrophy

REPLACEMENT OF DEFICIENT CLOTTING FACTOR IS THE SINGLE MOST IMPORTANT STEP IN ANY INTERVENTION

Factor concentrate should be given as close to the time of the bleed as possible

Prophylaxis

- Primary – Usually started in young children to reduce or prevent joint disease and it is continued indefinitely.
- Secondary – Short term and is started when a bleed has occurred and continued on a regular schedule for a defined period of time.

Research - Cure for Blood disorders

- Stem Cell Therapy for Thalassemia & SCD
- Gene therapy – Thalassemia, SCD, Hemophilia, research currently underway is encouraging.
- Haemoglobin Enhancers – Thalassemia & SCD
- L Glutamine Powder – Reduces crisis in SCD
- Technically, a liver transplant can cure hemophilia, since coagulation factors are produced by cells inside the liver. However, the risks of surgery and the requirement for lifelong medication to prevent rejection of the transplanted organ may outweigh the benefits.
Socioeconomic Challenges of Persons with Blood Disorders

Thalassemia, Sickle Cell Anaemia and Hemophilia, common in all

- Repeated blood/factors administration for survival/prevention of complications.
- Repeated pricks for investigations and to infuse medicines or blood
- Infections, inflammation and painful episodes
- Transfusion transmitted infections HBV, HCV, HIV
- Repeated hospital visits for treatment or monitoring
- Travel (100 – 500 km) for adequate/proper treatment
- Loss of work days (education, employment or business)
- Treatment is very costly not affordable by even upper middle class family
- Govt policy draft states free for BPL, even they incur a huge expenses on travel and out of town expenses and loss of income.
- Social stigma a big issue
- Life expectancy always hovers the minds of affected persons and family

Measures needed for Rehabilitation of Persons with Blood Disorders

- Public awareness to take preventive measure to reduce the future burden and promote voluntary blood donation
- Sensitization of society specially schools to preclude discrimination.
- Because of anaemia, pain crisis, infections, hospital visits etc. they miss schools (may be exams too) so they can not compete with their peers. They should be given relaxation in attendance and extra time in exams.
- Though in RPWD act 2016, they have been given reservation in higher education, above factors endorse us our petition to provide job reservations to persons with blood disorders. No private establishment will be willing to employ a person who will without fail take 2-4 extra leaves every month. Business is also not a sensible proposition as most of money is already spent on treatment and secondly 2-4 days closer of business every month also spoils the business.
- besides free treatment, financial assistance should be given to affected person/care giver to meet the hidden expenses.
- Income tax deduction on treatment expenses be raised to actual expenditure.
- Income ceiling should be raised minimum to Rs. 5,00,000/annum for all schemes to support affected persons/caregiver.
INTRODUCTION

• The overall burden of neurological disease in society is considerable and complex with individual effects on social functions, employment and health care provision as well as secondary effects on family members and caregivers.
• Among the NCDs, neurological disorders form a significant proportion of global burden of disease.
• Developing countries, including India are passing through a phase of epidemiological transition with increasing burden of non-communicable diseases (NCDs) due to improvement of health care services in preventive and promotive domains.
• The crude prevalence rate varied from 967–4,070 per 100000 population with an average of 2304 per 100000 population. Based on this data it is estimated that the current population of 1.27 billion, approximately 30 million people suffer from neurological disorders in India (excluding neuroinfections, traumatic injuries and neoplasms and metabolic disorders).

CHRONIC NEUROLOGICAL DISEASES

1. EPILEPSY & EPILEPTIC SYNDROMES
2. ANTERIOR HORN CELL DISEASES- ALS, PLS, PMA, SMA, MMA
3. ATAXIA- HEREDITARY & ACQUIRED- SCA, FA
4. DYSTONIA & other movement disorders
5. NEUROPATHIES- HEREDITARY e.g. HMSN
   - CHRONIC ACQUIRED PROGRESSIVE- e.g. CIDP & its variants.
6. POST-TRAUMATIC DISABILITIES- head trauma, spinal cord trauma
7. others - demyelinating diseases e.g. MULTIPLE SCLEROSIS
   - degenerative diseases e.g. parkinsons disease, dementias.

EPILEPSY & EPILEPTIC SYNDROMES

• The global burden shows 50 million people with epilepsy and more than 80% of them are in developing countries.
• The mean crude prevalence rate in India was 5.7 per 1000 population (range 2.5–11.9); 5.3 (2.5–7.5) in urban and slightly higher rate of 5.8 (2.5–11.9) in rural population.
• There is a significant treatment gap in epilepsy i.e. proportion of patients with active epilepsy not receiving treatment in the developing countries is very high ranging from 80–94%.
• In India treatment gap (TG) was determined through prevalence studies and the TG was lowest at 29% among Parus in Bombay,38% in Kerala,50% in Bangalore, Karnataka,65% in West Bengal,75% in Kashmir, and 78% in Yelahur, Karnataka.
• The TG was lower in urban population compared to rural areas perhaps due to better awareness about the disorder and availability of health services in closer proximity.

• Epilepsy is considered a disability because people with epilepsy may face barriers similar to those by people with disabilities in:
  • getting an education,
  • finding employment,
  • gaining acceptance from others due to stigma and existing myths about epilepsy.
• Some of the people with epilepsy or epileptic syndromes have low cognitive ability. Their life is affected with the repeated attacks of seizures and post-seizure deficits.
• These children or adolescents suffering from progressive epileptic syndromes have significant cognitive and focal deficits.
• Some epileptic patients may face severe bodily trauma from ITA or machinery trauma or from burn injuries. They can lead various degrees of additional short-term or long-term disabilities.

• The need of the hour is to achieve adequate seizure control through various antiepileptic drugs.
• The drugs available –
  1. OLDER GENERATION e.g. PhenitoIn, Phenytoin, Valproate, Carbamazepine etc
  2. NEWER GENERATION e.g. Levetiracetam, zonisamide etc
  3. RESEARCH e.g. Lamotrigine, stiripentol.
• For this, the patients should be followed up regularly with adequate participation of the caregivers.
• The social awareness must be increased to reduce the stigma about epilepsy so that the patients are not discriminated.
• Newer research is underway to determine the genetic basis of epilepsy and individualise the antiepileptic drugs basing on the genetic testing.
### MOTOR SYSTEM DISEASES

- The common motor system diseases in the community are:
  1. ALS
  2. SMA
  3. PMA
  4. PLS
  5. HSP
  6. FOCAL ALS/MMA
  7. POSTPOLIO MUSCULAR ATROPHY(PMA)

- In an Indian study, out of all motor system diseases, amyotrophic lateral sclerosis (ALS) constituted 42.6%, progressive muscular atrophy (PMA) 10.9%, and polyneuropathy muscular atrophy (PPMA) 1.8%, spinal muscular atrophy (SMA) 20%, atypical form Madras pattern of MND (MIMND) 0.9% and monomelic amyotrophy (MIMA) 2.7% of cases.

- The disability in these patients are progressive. In due course there is involvement of respiratory muscles and bulbar muscles causing respiratory distress and repeated aspiration leading to chest infections.

- Median disease duration is 19 yrs in PLS, 5-10 yrs in PPMA, 5-25 yrs in SMA, 12yrs in PMA, 3-5 yrs in ALS.

- Most of these diseases have no definite treatment.

- Research molecules like RILUZOLE and EDARAVONE have been tried and approved by FDA to be used in ALS. But these agents are not able to cure the disease rather they are able to retard the progression (which can be quantified in terms of slowing of the worsening of the ALS FRS score).

- Physical therapy should focus on nonfatiguing aerobic exercise, modest isometric/isokinetic exercise, and range-of-motion stretching maneuvers. The goal should be to maintain exercise in affected muscles but not to the point of overuse, while also limiting the disease of unaffected muscles.

- Low impact exercise in warm water can be particularly helpful and also appears to help control fatigue and pain. In patients with more serious functional decline, prescribe appropriate assistive devices to maintain activities of daily living.

- Pulmonologists must evaluate those who develop respiratory insufficiency to rule out primary pulmonary disease and to prevent/treat chest infections.

- Patients whose employment or lifestyle involves significant physical exertion need to modify their work duties and other activities.

- The motor system disorders comprise of the family of disorders that may affect the upper and/or lower motor neuron system as well as nonmotor systems.

- They present with limb weakness along with spasticity or flailness based on whether the UMN or LMN is affected respectively.

- These group of diseases are progressive and disabling.

- Due to the UMN involvement there is loss of dexterity which manifest as stiffness, slowness and clumsiness of the fingers and hands. It leads to affection of voluntary skillful movements. There is also muscle weakness predominantly in extensors of upperlimbs and flexors of lowerlimbs. The patients also suffer a lot due to the spasticity of the limbs.

- Due to LMN involvement there is flaccidity and dragging as well as weakness of affected limbs.

- Hence there is marked disability in the patients suffering from motor system diseases.

### ATAXIA

- Ataxias are a group of disorders characterized by imbalance and incoordination involving gait, limbs, and speech and usually result from a disorder of the cerebellum and/or its connections.

- The patients of ataxia may have a sense of insecurity while walking, especially when performing acts that require a bit more skill, such as turning or balancing on a narrow ledge.

- The care plan should focus on avoiding fatiguing activities that aggravate symptoms, modifying activities to conserve energy, weight reduction for those who are overweight, and treating underlying medical disorders that reduce overall wellbeing.

- Careful screening and treatment for possible sleep apnea and depression are important. Those patients who have worsening of preexisting ventilatory muscles may require noninvasive positive pressure ventilation (NIPPV) or noninvasive bilevel positive airway pressure (BiPAP) ventilation.
• They may feel incoordination and tremor of the hands leading to clumsiness with activities such as writing, picking up objects and buttoning.

• Patients of cerebellar ataxia usually have slurred speech and abnormalities of pitch and volume control (scanning speech). Dysphagia can result from incoordination of swallowing muscles, and patients report strangling and choking.

• All these features makes a person disabled in absence of weakness.

• They may be inherited or acquired.

Among all ataxias the hereditary ataxias are progressive and don’t have any curative treatment.

The common are: AR- Friedreich’s ataxia, Ataxia telangiectasia etc

AD – Spinocerebellar ataxia 1-31

They run in families affecting more than one members.

In addition to ataxia, they can have other less common features like neuropathy, motor weakness, gaze abnormalities, seizures, low cognitive ability.

• They may be inherited or acquired.

ACQUIRED CAUSES OF ATAXIA
Congenital: “ataxic” cerebral palsy, other early insults
Vascular: ischemic stroke, hemorrhagic stroke, AVMs
Infectious/Transmissible: acute cerebellitis, postinfectious encephalomyelitis, cerebellar abscesses. Whoop disease, HIV, Lassa fever
Toxic: alcohol, anticonvulsants, mercury, 5FU, cytoxins salvadorensis, lithium
Neoplastic/compressive: gliomas, ependymomas, meningiomas, brain meningial carcinomatosis, craniovertebral junction abnormalities
Inherited: MSA, paraneoplastic syndromes, anti-eti, gluten ataxia
Deficiency: hypothyroidism, vitamin B, and B12, vitamin E

GENETIC CAUSES OF ATAXIA
Autosomal recessive: FA, AT, AVED, AO1, AO2, MIRAS, ATNSAGS, others newly defined autosomal recessive ataxias
Ataxia in other genetic diseases not traditionally classified as an “ataxia”

Autosomal dominant: SCA types 1 through 31, episodic ataxias types 1, 2, others
X-linked, including fragile X tremor/ataxia syndrome (FXTAS)
Mitochondrial: mtDNA, MELAS, MERRF, others including Kearns-Sayre syndrome

DYSTONIA & OTHER MOVEMENT DISORDERS

• Movement disorders are a group of disorders in which the patients suffer from the involuntary movements of part/whole of the body or limbs.

• They are classified into hypokinetic (paucity of movements), or hyperkinetic (excess movements).

• Hyperkinetic movement disorders are subdivided into:
  1. tremors
  2. dystonia
  3. athetosis
  4. chorea
  5. ballism
  6. tics
  7. stereotypy
  8. akathisia

• The most distinguishing feature of hyperkinetic movement disorders is bradykinesia, typically present in Parkinson’s disease and other parkinsonian disorders.

• Dystonia is a syndrome consisting “of sustained muscle contractions, frequently causing twisting and repetitive movements, or abnormal posture.”

• Tremor is an unintentional, rhythmic muscle movement involving to-and-fro movements (oscillations) of one or more parts of the body.

• Chorea is an involuntary, semipurposive, improbable body movements ranging from minor movements, such as fidgeting, to severe uncontrolled movements of the arms and legs. It can also interfere with speech, swallowing, posture, and gait.

• Myoclonus is a symptom which refers to sudden, involuntary jerking of a muscle or group of muscles.

• Ballism or ballismus consists of repetitive, but constantly varying, large amplitude involuntary movements of the proximal parts of the limbs.
• All these movement disorders can be short lasting when they are secondary to some other metabolic (KWS,OKA), infectious (viral, bacterial), vascular (CVS) or structural (CSSL) causes. In those scenario they are adequately treated by eliminating the underlying causes.
• But most of the inherited dystonias, ataxia and some of the secondary dystonias are resistant to drugs and persist. They can affect the quality of life and professional (e.g. writer’s cramp).
• INHERITED DYSTONIA:
  1. Autosomal dominant, such as DYT1, DYT5, DYT6, DYT11, rapidly progressive dystonia-parkinsonism (DYT12), neuroferritinopathy (NFB3), dentatorubral-pallidolysian atrophy, and Huntington disease.
  2. Autosomal recessive. Willi syndrome, PKAN (NBA1), PLAN (NBA2), and type 2 juvenile Parkinson disease (PASH).
  3. X-linked recessive. LUBAG (DYT3), Lesch-Nyhan syndrome.
  4. Mitochondrial. - Leigh syndrome or Leber optic atrophy and dystonia.

NEUROPATHIES - HEREDITARY-
• Hereditary neuropathies are a group of inherited disorders affecting the peripheral nervous system.
• The hereditary neuropathies are divided into four major subcategories:
  1. hereditary motor and sensory neuropathy,
  2. hereditary sensory neuropathy,
  3. hereditary motor neuropathy, and
  4. hereditary sensory and autonomic neuropathy.
• The most common type is Charcot-Marie-Tooth disease, one of the hereditary motor and sensory neuropathies.
• The symptoms of hereditary neuropathies may be apparent at birth or appear in middle or late life. They can vary among different family members, with some family members being more severely affected than others. The hereditary neuropathies can be diagnosed by blood tests for genetic testing, nerve conduction studies, and nerve biopsies.
• There’s no cure for hereditary neuropathy. Instead, ongoing treatment needed to manage symptoms.
• Common treatments include:
  • pain medication
  • physical therapy
  • corrective surgery
  • therapeutic shoes, braces, and supports
  • Eating a balanced diet and getting regular exercise is also recommended.

• Symptoms of the hereditary neuropathies vary according to the type.
• Some of the most common symptoms include:
  1. Sensory symptoms: Pain, tingling, or numbness, often in the hands and feet.
  2. Motor symptoms: Muscle weakness and muscle atrophy, often in the feet and lower legs.
  3. Autonomic symptoms: Impaired sweating, or low blood pressure after standing up from sitting or lying down.
  4. Physical deformities: High foot arches, hammer-shaped toes, or a curved spine (scoliosis).

CHRONIC ACQUIRED PROGRESSIVE NEUROPATHIES
CIDP & its variants
• Chronic inflammatory demyelinating polyneuropathy (CIDP) is an acquired immune-mediated inflammatory disorder of the peripheral nervous system.
• Patients usually present with a history of weakness, numbness, tingling, pain and difficulty in walking for more than 1 week. Some patients may have sudden onset of back pain or neck pain radiating down the extremities, usually diagnosed as radicular pain. These symptoms are usually progressive and may be intermittent.
• Autonomic system dysfunction can occur. The patient may also present with a single cranial nerve or peripheral nerve dysfunction.
• On examination the patients may have weakness, and hypo/anreflexia. There may be wasting of muscles and loss of sensation.
• Variants of CIDP may be —MADSAM, DADS, MMNCB.
• It is a progressive disorder unless treated at right time with right drug.
• Mainstay of treatment of CIDP is steroids (inj or oral long term). Other effective modalities are PLEX, IVIG, Immunomodulators e.g. AZT, CPA, MMF.
• As the disease progresses there is LMN type of weakness. So rehabilitative measures.
• During treatment in acute stage appropriate care for DVT prevention must be taken.
• During the recovery stage, approach to Plan of Care in this manner:
  • Expand activities gradually.
  • Increase repetitions before resistance in order to avoid injury to muscles, tendons and joints. Use of proprioceptive neuromuscular facilitation (PNF) techniques may be helpful.
  • Teach energy conservation (e.g. pacing and breaking tasks into steps).
  • Train caregivers in proper body mechanics for transfers, positioning, etc. to decrease the risk of injuries to themselves and the patient.

Once sufficient return of power has been achieved,

1. Customize exercises to strengthen weak muscles and watch for muscle substitution. For example, a patient may demonstrate hip-hiking and a circumduction gait pattern as a consequence of substitution for weak hip flexion.
2. Plan multiple rest breaks during therapy if fatigue occurs. Exercising to exhaustion will require recovery time that can delay resumption of therapy.
3. Establish a home program that fits the patient’s current activity level as soon as they and/or their caregivers have demonstrated a thorough understanding of the exercises.
4. Assure that family members are aware of the increased risk of falling as a result of their decreased strength.

POST-NEUROTRAUMATIC DISABILITIES

• Secondary to head trauma and trauma to spine, there may occur post-trauma weakness and/or spasticity which reduces the quality of life of the patients. Some patients are bedridden for a prolonged period due to para/quadriplegia/plegia.
• In these situations there is less role of medications. However the antispastic medications e.g. tizanidine, baclofen, benzodiazepines are effective to some extent.
• The most important part of the recovery or maintenance of quality of life of these patients depend on the degree of rehabilitative care they get.
Parkinson’s Disease in the Light of Global Best Practices in Care, Rehabilitation and Research.

Parkinson's disease (PD) is a debilitating neurological condition affecting all facets of life. A diagnosis of PD demands lifelong management and rehabilitation. In India, the concern is right from the stage of diagnosis, where a lack of awareness and a skewed patient to neurologist ratio (1700 Neurologists for the 1.3 billion population of India) causes the condition to often go undiagnosed. At the treatment and rehabilitation stage, the awareness of and accessibility to allied healthcare fields is limited.

Even though classified as a movement disorder, with symptoms such as tremors, rigidity, slowness of movement and postural instability, Parkinson’s manifests itself in several other ways. Difficulties with speech, depression and anxiety, constipation and urinary troubles, sleep anomalies, memory loss, are some of the other common symptoms. Loss of independence, fear of social stigma and embarrassment often change interpersonal relationships with the condition affecting not just those diagnosed, but also the family.

Renowned Neurologist Dr. B.S. Singhal founded the Parkinson’s Disease and Movement Disorder Society (PDMDS) a ‘not for profit’ organization in 2001, with the vision to improve the ‘Quality of life’ of people with Parkinson’s (PwP’s) and their families and to increase public awareness about the condition.

The first initiatives of the organization was reaching out to PwP’s to understand their needs, interacting with Medical and allied health professionals to obtain their perspective, and networking with international Parkinson’s organizations to learn about Global best practice.

Based on this need analysis the PDMDS adopted a multipronged approach, initiating community based support groups, developing programs, and raising awareness amongst the medical and allied health professionals and the general public.

Programs were initiated in the community to serve the dual purpose of making it accessible to people living with a debilitating condition as well as to reintegrate them into their community.

These programs provided information about Parkinson that was scientific yet non-technical for a better understanding of the condition. Therapeutic intervention included physiotherapy, speech and occupational therapy, counseling, dance and movement therapy etc. The focus was to integrate the strategies into their Activities of daily living. Additionally, therapeutic strategies used simple innovative aids thus eliminating the need for specialized equipment as well as the practicality of continuing their use at home.
The positive response to the program was the driving force for the PDMDS to undertake an Action Research Study to develop and document the program into a ‘Multidisciplinary Model of Care’. Information for the development of this model was obtained from medical and allied health professionals, from the experience of the PDMDS in the field and from PwP’s and carers who were part of the ongoing programs.

To reach out to PwP’s living in rural and tribal areas where people had not even been diagnosed, new strategies were developed. These included sensitizing the community through street plays and awareness programs, training of grassroots workers to conduct identification door to door surveys, organizing medical camps and setting up programs in the community.

A new dimension is the development of programs for the increasing number of young onset people with PD who have been reaching out to the organization. Many are in the workforce and often have to give up employment. Parkinson’s Disease being recently included in the Right to Disabilities Act will hopefully work in their favor to retain employment. However much needs to be done to make them aware of their rights and to simultaneously educate their employers and organizations. Strategies have also to be developed to deal with the emotional and psychological issues related to living with this condition at a young age.

Continuing Medical Education (C.M.E) programs, workshops and seminars for medical and allied health professionals is an ongoing process. These programs raise awareness about PD as well as about the services being offered by the PDMDS.

PwP’s are constantly updated on clinical research in the field of Parkinson’s as well as given the opportunity to learn from national and international experts in the field through talks and seminars. The organization also undertakes action research studies on quality of life issues. New intervention strategies identified and evaluated through these studies are being implemented through its programs.

The success of any program is its ability to collaborate with organizations including Government, Non-Government and the private sector. Each support center that has been developed has used different models of collaboration that include utilizing existing networks, exchange of information, sharing of infrastructure and personnel, financial support etc.

The PDMDS continues its journey to improve the quality of life of people with Parkinson’s. It currently runs over 55 centers in 11 states in our country. It works to develop a National Parkinson’s Resource and Training Centre in Mumbai through which it will continue to sustain existing centers and develop centers in all parts of the country. It firmly believes in making the Motto of one of its members the motto of all people living with Parkinson’s and their families - “YES, I may have Parkinson’s but Parkinson’s will not have me.”
What is Multiple Sclerosis (MS)?

- **MS** is the most common neurological disorder diagnosed in young adults.
- **MS** is a chronic disabling disease that attacks the central nervous system (CNS), which is made up of the brain, spinal cord, and optic nerves.
- **Symptoms**: numbness in the limbs, loss of vision, tingling & fatigue, and pain & spasms, balance problems, bladder issues, etc.

**FOR MORE:** [www.mssocietyindia.org](http://www.mssocietyindia.org)

**The MS Society - Why?**

**MS stops people from moving.** The MS Society exists to make sure it doesn’t.

The MS Society is a group of passionate volunteers who want to move together towards a **world free of MS**.

**Vision of MSSI**

**Raising the bar for global best practices in care & rehab of persons with MS**

**Focus:**

- **National Registry**
- **Rehabilitation**
- **Mobility**
- **Accessibility**
- **Research & Cure**

**What does MS Society do...**

**Our main projects are:**

- **Chalte Raah:** Keep moving - Home Physiotherapy for home-bound.
- **Vidya:** Education Scholarship
- **Sevika:** Home Attendant for bedridden
- **Salah:** Home Visit for free counselling
- **Utkrisht Seva:** Day Care-Quality of Life program to assemble MS person with access to information.
- **Swayam:** An effort to promote talent of MSPs

**Infrastructural for the disabled is missing nation wide, it is premature to list Global Best Practices in care, rehab and research.**

People with MS are living the challenge on a daily basis.

But if we did not hope and dream, there would have been no Disability Act of 2017 ....
WHAT DOES MS SOCIETY DO…

OUR PROJECTS ARE:

- ANAND- ENTERTAINMENT of MS PERSONS
- PRACHAAR: AWARENESS- through various social media, print and electronic media,
- SWASTH- Priority basis access to medical facility
- DAWAI- Monthly free health boosters
- SAHAIITA: Providing FREE MOBILITY AIDS:
- VAAHAN:-TRANSPORT FOR needy MS patients.

We reach out and respond to individuals and families living with Multiple Sclerosis, MS.....

WHAT MSSI DOES....

SOCIAL INCLUSION
Get groups of MS persons together.
2. Get doctors involved with the groups, each with their own speciality...from dental to urology.
3. Run medical camps – one place – lots of special

FINANCIAL AID for WEAKER SECTIONS
1. Scholarships subsidised uniforms/textbooks.
2. Free diapers.
4. Vitamins and supplements.
5. Free Entertainment – movies in cool, cool malls!

ACHIEVEMENTS

CREATE AWARENESS / NETWORKING
1. Create a web-site and a helpline
2. Create awareness among doctors to recognise alarm bells.
3. Use every forum... World MS Day, India MS Day.

NETWORKING
1. For priority doctors’ appointments in crisis.
2. For Disability Certificates.
3. For Fund Raising

MSSI HELPS WITH

AID to CAREGIVERS
Nurse/attendant home visits.
2. Regular Home Visits to assess financial status/condition of MS Person/update addresses, etc.
3. Increase MS Person’s independence –advice on railings, ramps & lifts.
4. Family counseling.

MORALE BOOSTERS
1. Tie-ups with local beauticians/hair-care, laughter clubs stand-up comedians

MOST IMPORTANT OF ALL
1. FREE OR SUBSIDISED HOME PHYSIOTHERAPY- if you don’t use it you lose it.

OPPORTUNITIES

YOUTH GROUP-YMSG
A close knit young-persons group connected on the mobile phone Apps.

EARNING PROSPECT
Self respect by earning for one’s self. Taking part in Fairs/Stalls for handicrafts, homemade pickles, artwork, etc.

FREE HOME PHYSIOTHERAPY, HOME NURSING, HOME VISIT, YOGA, RECREATION AND SCHOLARSHIP BENEFICIARIES
Awareness Projects: Through Media Interaction, World MS Day Programmes, Exhibitions, Walks & Marathons.

All MSSI services are offered free to those who need them.
We are a voluntary organisation and depend entirely on donations.

We receive no government funding; MSSI is registered as a non-profit society.

All donations are exempt from tax under section 80G of the IT Act. We have FCRA permit.

Improve the quality of life by caring enough.

MSSI Delhi Counseling Center
87A, DDA Flats, Shahpur Jat,
New Delhi-110049
Ph No.+91-11- 26490087 (10 am-5 pm)
Help Lines: 011-41745069 / 41829219
Email ID: mssidelhi2@gmail.com
www.mssocietyindia.org

Donations are exempt under Section 80G of the IT Act 1961.