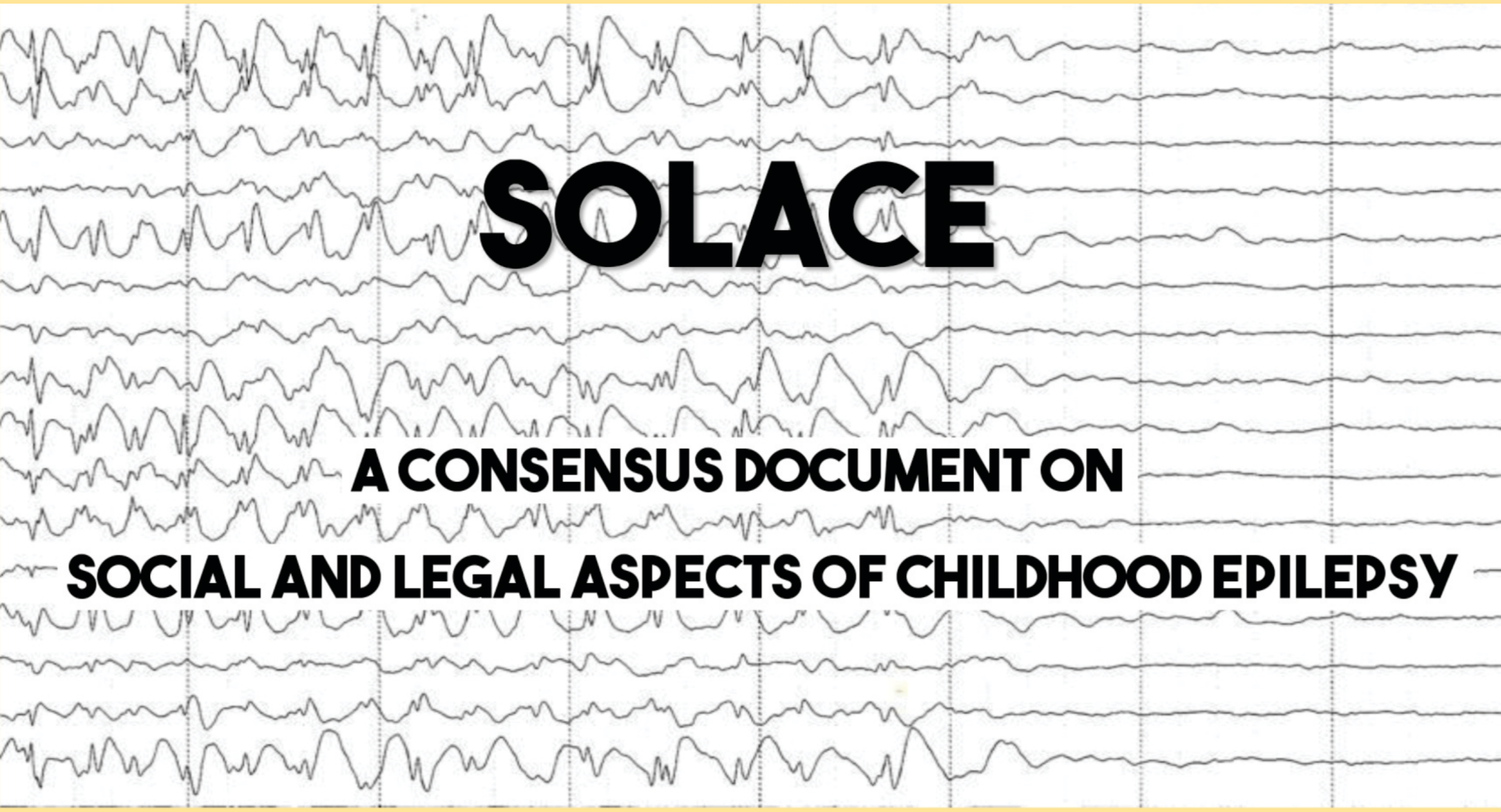
AOCN

INDIAN EPILEPSY SOCIETY



SOLACE

A CONSENSUS DOCUMENT ON SOCIAL AND LEGAL ASPECTS OF CHILDHOOD EPILEPSY

From
Association of Child Neurology (AOCN)
&
Indian Epilepsy Society (IES)

SOLACE
from AOCN-IES:

A Consensus Document
for Guidelines on
***S**ocial and **L**egal **A**spects of*
***C**hildhood **E**pilepsy*

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Disclaimer :

This document is a compilation of resources for different aspects of epilepsy in children and contains information for parents, schoolchildren, school staff and policy makers.

In individual case management, the treating doctor's opinion and directions are final.

Introduction: Need for the Document

The diagnosis of epilepsy in an individual affects the entire family, and there is an urgent need for the individual and family to learn about the disorder and continue seeking information throughout the course of treatment. This helps them to adapt to life with epilepsy helps improve self-confidence and promotes optimal well being and quality of life. (1).

Most parents are extremely upset at the time of diagnosis of epilepsy in their child, mainly because of the stigma associated with the condition. Witnessing their child's seizure may be the most anxiety-provoking experience for them. Most parents go into an anxious withdrawal due to lack of knowledge of this condition. Financial and management difficulties add to their stress (2).

It is important to educate the parents to create a positive and safe family environment, keep the communication channels open with the child and share relevant details with other stakeholders involved in child's care (3,4).

Epilepsy impairs all aspects of quality of life of children and their parents (5). Many parents feel overwhelmed by the new information, hence it is important to apprise them of written and internet links to resources which can help them to access information at their leisure. They should be encouraged to join the local support groups to network with other parents, which will also help in advocating their children's rights in schools etc. Printed handouts giving information about school, travel and other aspects of the life of a child with epilepsy can be given (6, 7).

Apart from routine day to day concerns of seizures and their management, many parents are worried about the future prospects in terms of marriage and employment, the main reason being unawareness of epilepsy as a disorder and the stigma attached to it by the general public. These concerns can be suitably allayed through thoughtful counselling. (8)

Additionally, there may be many legal aspects like discrimination against the child especially in respect of school admissions, treatment in school, examinations, and other aspects of school life. Epilepsy is also often associated with co- morbidities that need to be addressed.

At school, the child is independent of the care of parents and in the care of school staff, who may not be fully conversant with the child's condition and management. Peers may be affected by the attitudes of the school elders and their own parents, and the experiences of a child with epilepsy at school will depend on the attitudes of the elders. Thus, awareness amongst all stakeholders is extremely important in creating an accepting and non-discriminatory environment for the child at school.

Since childhood years are the developing years, a diagnosis of epilepsy at this time and the various experiences the child goes through can affect the self- esteem and confidence, and thus shape the child's personality, and entire future of the child. Hence it is extremely important that all social and legal aspects of epilepsy in children are addressed in a humane and empathetic manner without being overprotective or uncaring.

The legal aspects and relevant social issues that affect adults have been discussed and also documented (*Epilepsy and Law in India by the Indian Epilepsy Society and Indian Epilepsy Association)*. However, the social issues and legal implications of epilepsy in children are different and have not been addressed so far.

The Association of Child Neurology (AOCN), a body of Pediatric Neurologists from all over India, decided to prepare a document to address these issues in children with epilepsy. The Indian Epilepsy Society (IES), a body with membership of eminent epileptologists of India, agreed to join hands with the AOCN in this endeavor. Inputs were taken from parents, social workers, Special educators, lawyers and others to put together this document.The Document was named SOLACE – an acronym for **So**cial and **L**egal **A**spects of **C**hildhood **E**pilepsy.

Mission

To prepare a document on social and legal aspects of epilepsy in children, which can be used by parents and other caregivers, teachers, epilepsy educators, social workers, school health programs, and doctors who are involved in providing social and medical care to children with epilepsy.

Participants:

Members of the AOCN
Members of the Indian Epilepsy Society
Epilepsy social workers and educators
School teachers
Parents of Children with Epilepsy
Lawyers

Conclusion

It is hoped that this Document will go a long way in providing information to stakeholders involved in care of children with epilepsy – both medical and non- medical.

Process

1. Idea mooted by Association of Child Neurology (AOCN) to produce a consensus document along with Indian Epilepsy Society called SOLACE as above.
2. Team and participants
    - Members of the Association of Child Neurology (AOCN): Pediatric Neurologists of repute in India from \ both Private and Government setup
    - Members of the Indian Epilepsy Society (IES)
    - Epilepsy/ Special educators
    - Parents of children with epilepsy
    - School representatives
    - Legal advisors
3. Steps in formulation of the document

(a) Preparation of list of scope of issues to be put into document, based on doctors' experiences was prepared.

(b) All the issues to be discussed were divided into 6 groups. Each group had members of AOCN/IES, Epilepsy / Special educators, legal advisor, and a writer – coordinator of each group (Pediatric Neurologist for compiling all the inputs and coordinating with various members of the group). The 6 groups were:

GROUP I	**Social Benefits**
GROUP II	**Social & Legal Aspects of Epilepsy in infants and preschool children**
GROUP III	**Social & Legal Aspects of Epilepsy in preadolescent school children**
GROUP IV	**Social & Legal Aspects of Epilepsy in adolescent school children (12 Years Onwards)**
GROUP V	**Epilepsy counselling**
GROUP VI	**Epilepsy in children with multiple disabilities**

(c) Preliminary meeting to obtain inputs from epilepsy educators/special educators, parents, legal advisors, school representatives to discuss any further points was held on 07 Mar 2018. It was decided that school representatives would also be included in the relevant groups.

(d) Revised list of scope of issues to be included in the document was prepared, and the final list of scope of issues and the group distribution were mailed to all the participants.

(e) The writer – coordinator of each group prepared the draft of the document on all points of the issues of the group. This activity was carried out online, Whatsapp groups, or by conference calls, as required. Literature search, references in literature, status in other countries were included in the draft. All members viewpoints were considered in giving the existing status and recommendations.

(f) A Draft Document by each group was prepared and compiled sent to all the participants.

(g) A consensus meeting was held on 15 April 2018, where a majority of the participants was present. The writer – coordinator of each group made a presentation of the draft document for consensus. Deliberations were held, and inputs and suggestions by the various participating members were incorporated into the document. ***On the suggestion of all participants, all points from Group 3 and 4 were found to be similar and hence merged to form one group: Social and Legal Aspects of Epilepsy in school children.***

(h) Epilepsy in children with multiple disabilities has its own set of unique problems. Although many requirements and supports available for these children may be same as that for children with epilepsy only, it was decided to retain this as a separate chapter.

(i) The coordinators introduced a special chapter on guidelines for air travel separately as it was common to all children with epilepsy.

(j) The final document was prepared and circulated to all the participating members.

(k) The document was published.

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ACKNOWLEDGEMENTS

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PARENTS
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And all others who have raised questions and given their inputs

1. SOCIAL BENEFITS

1.1 Is Epilepsy Considered as a Disability in Children?

1.1.1 Defintion of Disability

Disability is an umbrella term, covering impairments, activity limitations, and participation restrictions.

A person with a disability is defined as "*a person with long term physical, mental, intellectual or sensory impairment which, in interaction with barriers, hinders his full and effective participation in society equally with others* "(1).

It is important to understand the terms.

Impairment: A problem in body function or structure.

An activity limitation: The difficulty encountered by an individual in executing a task or action.

Participation restriction: The problem experienced by an individual in involvement in life situations.

Disability is thus not just a health problem. It is a complex phenomenon, reflecting the interaction between features of a person's body and features of the society in which he or she lives(2).

Neurological disabilities occur due to the damage to the nervous system i.e., the brain and spinal cord, that results in the loss of some bodily or mental functions. They are unique and affect multiple domains of day-to-day functioning such as mobility, disturbance of cognition and behaviour; they can also cause pain, altered consciousness, bladder and bowel dysfunction, and inability to perform activities of daily living(3).

Disability is an evolving, dynamic, and complex phenomenon. All societies recognise the need to make adjustments, and provide affirmative action for persons with disabilities by providing rights and privileges, including India. There is a paradigm shift from "charity"-based approach to "rights"-based approach for persons with disability.

Rights of Persons with Disabilities Act 2016, India

In 2016, Rights of Persons with Disabilities (RPWD) Act 2016 , a guideline for assessment and certification of a person with a disabilitywas passed(1).

Subsequently, the Central Government notified guidelines for assessment of disabilities. As per these guidelines, there are eight *categories* of conditions that can qualify as disabilities, with overall twenty-one disabilities included, but epilepsy per se was not included under any category (4).

The 21 disabilities are given below :

1 Blindness
2 Low-vision
3 Leprosy Cured persons
4 Hearing Impairment (deaf and hard of hearing)
5 Locomotor Disability
6 Dwarfism
7 Intellectual Disability
8 Mental Illness
9 Autism Spectrum Disorder
10 Cerebral Palsy

11 Muscular Dystrophy
12 Chronic Neurological Conditions
13 Specific Learning Disabilities
14 Multiple Sclerosis
15 Speech and Language disability
16 Thalassemia
17 Hemophilia
18 Sickle Cell disease
19 Multiple Disabilities including deaf blindness
20 Acid Attack victim
21 Parkinson's disease

Drug resistant epilepsy or epilepsy with significant comorbidities can be classified as a disability in the "chronic neurological disorder" category of disabilities under the Act. In other cases, if the existence of epilepsy is causing a significant impact on the quality of life, for any reason (e.g. major side effects of drugs, school attendance, deterioration in scholastic performance and others), temporary disability may be awarded at the discretion of the board.This may be based on inputs from caregivers, school teachers, or school report cards, which may be submitted to the board.

1.1.2 What is the concept of hidden disability

Invisible Disability, or hidden disability, is an umbrella term that captures a whole spectrum of hidden disabilities or challenges that are primarily neurological in nature. Invisible Disabilities are certain kinds of disabilities that are not immediately apparent to others (5).

The majority of disabilities are hidden.

Invisible disability refers to symptoms such as debilitating pain, fatigue, dizziness, cognitive dysfunctions, brain injuries, learning differences and mental health disorders, as well as hearing and vision impairments. These are not always obvious to the onlooker, but can sometimes or always limit daily activities, range from mild challenges to severe limitations, and vary from person to person(6).

Diabetes, epilepsy, heart conditions, mental health conditions, autistic spectrum disorders, chronic fatigue syndrome, irritable bowel syndrome and hearing impairment are just a few examples of disabilities that are usually invisible.Because an individual has a hidden disability they may find that inclusion and requests for assistance difficult to access as other people do not always appreciate the challenges they face.

1.1.3 Current scenario:

Epilepsy is not included in the list of 21 conditions which are considered as disability as per Rights of Persons with Disability Act. The degree of physical impairment caused by epileptic fits based on frequency/ severity has been removed in the Disability guidelines 2016.

However, the bill does have the provision for categorising "**chronic neurological conditions**" as a disability, and

no specific condition has been defined in this group. Thus chronic neurological conditions which is a condition that has its origin in some part of person's nervous system, and lasts for a long period or is marked by frequent recurrence. Many cases of epilepsy would fit into this category.

The bill however fails to specify the duration of illness or defining the frequency of recurrence. This ambiguity may hinder the certification process or may be misused for the purpose of welfare benefits(3).

1.1.4 Status in other Countries

Epilepsy is considered as a disability in all age groups in US, England, Scotland, Wales, Ireland and Canada (7).

GROUP RECOMMENDATIONS

i. As Epilepsy is not just a mental and physical disability but a social disability as well. Epilepsy should be included in " chronic neurological disorders" in the disabilities Act 2016.

ii. However, not all persons with epilepsy are disabled. Hence Neurologists/Pediatric Neurologists should be included in the medical board to assess the severity of epilepsy and the impact of seizures /antiepileptic drugs on day to day life, school performance.

iii. Situations in which Epilepsy may be considered a disability:
  a. when a person has frequent seizures(the frequency of seizures to be decided) which affect mobility, co-ordination, ability to perceive risk of physical danger.

  b. seizures cause pronounced issues after each seizure, which may include phenomena like unusual behaviours, trouble thinking, a lack of energy, difficulty staying awake, or other post-seizure symptoms that interrupt daytime activities.

iv. Once a child with epilepsy is entitled for disability benefits, he/she should be categorised as a temporary disability/permanent disability based on the medical board's discretion.

v. Children with epileptic encephalopathy, epilepsy with intellectual disability, epilepsy with microcephaly, epilepsy with significant behavioural comorbidities, epilepsy with learning disability etc may be categorised as "permanent disability".

vi. All the cases to be revisited after two years as epilepsy in children and its impact is a dynamic phenomenon.Children with age limited epilepsy might no longer come in the disabled category, but definitely require benefits when they have active epilepsy

The AOCN and IES would work towards suitable incorporation into the disabilities act.

1.2 Income Tax Rebate in Epilepsy

1.2.1 Current Scenario in India :

Income Tax benefits are available in Epilepsy in India; however due to lack of awareness it is not availed of by most of the families.

1.2.2 Income Tax Benefits in Epilepsy in India

The Income Tax department allows deductions under section 80DD to individualswho take care of a disabled/ differently abled dependent. The dependent has to be a child/sibling/spouse or parent, provided a certificate is obtained from an authorized Medical Practitioner as prescribed under the Income Tax Act that such a disability reduces considerably the affected person's capacity to normal work or engaging in a gainful employment.

If a person incurred any expenditure for the medical treatment, training and rehabilitation of a dependent with disability, he/she shall be allowed a deduction of Rs.75,000/- from his total income ie if the principal caregiver of the person with epilepsy is a taxpayer, then he/she may claim a reduction in the tax as per the appropriate clause. However, this would be applicable if epilepsy is considered a disability.

A person claiming a deduction under this section, should furbish a copy of the certificate issued by medical authority in the prescribed form 10-IA, along with the return of income under section 139, in respect of the assessment year for which the deduction is claimed (8).

GROUP RECOMMENDATIONS

i. People with Epilepsy to be made aware of this tax rebate by Doctors/ social workers/ support groups and organisations working for people with epilepsy.

ii. All public information literature should include this benefit in their pamphlets.

1.3 Concessions Allowed for Parents

1.3.1 Current Scenario in India :

There is NO provision for any Carers allowance or Disability Living allowance for people with epilepsy or their parents or caregivers.

1.3.2 Status in Other Countries

Status in some other countries is given as an example and familiarisation and sensitisation that a lot more affirmative actions is required in our country than is currently available.

Epilepsy is clearly considered as a disability in USA and UK. The frequency of seizures and the criteria which must be met before one can avail disability benefits are clearly mentioned. Allowances are given to the caretakers of the affected individual as well as there are certain allowances for people with epilepsy if there are significant co-morbidities.For example

Carers Allowance
Disability Living Allowance
Travel Allowance (Rail card and free bus travel)

Carer's Allowance

This is a benefit to help with the extra cost of looking after a child who has a disability or a health condition which requires substantial extra care.

In UK, certain fixed amount is paid per week as Carers allowance(£62.70 a week as on November 2017) to a person who has to look after someone with epilepsy with substantial care needs. A person living in England, Scotland and Walesis eligible for Carer's Allowance if they are 16 years or over, spends at least 35 hours a week caring for someone who is disabled and does not earn more than £120 a week (after taxes and some expenses) and is not in full time education) (9).

Similarly in Australia yearly Child Disability Assistance Payment is given to parents that helps them with the costs of caring for a child with epilepsy (10). An additional fortnightly payment as carers allowance is given if they are involved in **dailycare** of someone with disability (11).

Disability Living Allowance (DLA) for people with epilepsy

In England, Scotland and Wales one can only make a claim for DLA on behalf of a child under 16. They must have had these difficulties for at least 3 months and expect them to last for at least 6 months. Depending on the level of help a child needs the parents receive weekly allowance as DLA.(12) A child is eligible for DLA if their epilepsy or any other disability or health condition needs more looking after than a child of the same age who doesn't have a disability and/or they have difficulty getting about and have had these difficulties for at least 3 months and expect them to last for at least 6 months. If a child gets the middle or higher care rate of DLA along with 35 hours or more a week care, you may be able to get Carer's Allowance.

< 16 years- Disability Living Allowance (Received by parents/caregivers on behalf of a child)

16-65 years- Personal Independent Payment for People with Epilepsy

GROUP RECOMMENDATIONS

i. Carer's allowance for caretakers is desirable; however it can be taken up only after Epilepsy is accepted as a disability by Govt. of India and other benefits of disability are extended to families.

ii. There are significant limitations in providing carers allowance in India as the health care system in countries where carers allowance is provided completely insured by the government.

1.4 Travel Concessions

1.4.1 Current scenario in India

Epilepsy is not included in the list of conditions entitled for Travel concession given by central and state Govt. for the disabled for travel by rail and for air travel. Concession is available for

a. Blind person
b. Orthopedically handicapped person
c. Deaf and dumb person
d. Mentally retarded person (13)

1.4.2 Scenario in other countries

Free Scotland-wide bus pass

Any child of fare paying age (5-16 years)whoreceives middle or higher rate of DLA and hasat least one seizure in the last 12 months will be entitled to a free Scotland-wide bus pass. The child may also be entitled to a companion card which allows an adult to travel with them free of charge.

Any child aged 16 and over will automatically be entitled to a free bus pass irrespective of any benefits they may get, as long as they have had one seizure in the last 12 months(14).

Disabled Person's Railcard

A child with epilepsy may be entitled to a Disabled Person's Railcard if aged 5-15 years. The card also allows another adult to travel with the child for a third less of the full fare in Scotland(14).

GROUP RECOMMENDATIONS

i. People with epilepsy should also be included among those who receive travel allowance as many persons with frequent seizures are unable to travel alone.

ii. The travel allowance as per the current scenario in the above guideline is entitled for central Govt. and state Govt. employees, should be extended to employees in private sector.

iii. The travel allowance benefits should also include bus travel and metro trains.

iv. Concession benefit should be extended to the affected individual as well as one accompanying person.

1.5 Preference in Government/Corporate Jobs and Postings

1.5.1 Current scenario in India

No provision exists for jobs in Government sector for parents of children with epilepsy

1.5.2 PWD in Central Government

As per the Persons with Disabilities (Equal Opportunities, Protection of Rights & Full Participation) Act, 1995, government provides three percent reservation in jobs for PWDs.Apart from this reservation at the entry stage. DoPT has issued instructions regarding identification of jobs, post-recruitment and pre-promotion training, providing aids/ assistive devices, accessibility and barrier free environment at work place, preference in government accommodation, grievance redressal, and preference in transfer/posting for PWDs(15).

1.5.3 Scenario in other countries

There is no provision for special job opportunities for parents. However working parents of a disabled child is allowed

a) Dependant Leave/ time off emergencies- The employer has a discretion as to whether or not the time off is paid

b) Parental Leave-Employees with atleast one ear continuous service can avail 13 weeks unpaid leave to look after a child < 5years of age and 18 weeks unpaid leave per child to look after a child under 18 years.

c) Flexible working hours – The Work and Family Act 2006 gives employees 26 weeks of continuous employment the right to ask for a change in their working hours(16).

1.6 Schooling

1.6.1 Current scenario

At present, there are no school fees concessions for children with epilepsy in Private Schools. Education is free or subsidized (for all children) in Municipal Corporation schools.

As per the Law, all children till they are 14 years are covered under Sarva Shiksha Abhiyan (SSA) & Right to Education and no child should be denied admission on the basis of child's epilepsy.

1.6.1 Current scenario

For people with epilepsy or their family members, there are special scholarships. Scholarships are offered for any level of education but are generally given for assistance in college or graduate school

GROUP RECOMMENDATIONS

I. Considering the burden of childhood epilepsy and phenomenal cost of most of the long-term antiepileptic drugs, it would be wise to seek for an educational concession even for children with epilepsy alone and include children with epilepsy as one of the beneficiaries in SSA.

ii. School staff and teachers must be sensitized to care of children with epilepsy. School should be equipped with first aid measures to handle seizure. School staff and teachers may be trained to handle seizure, ensure drug compliance, encourage buddy system, and develop liason with local hospital in case of medical emergency.

iii. If the child is forced to leave the school on the basis of his/her epilepsy, there should be an accessible redressal pathway for the family. For example, parents can explore the option of grievance redressal with the disability commissioner.

1.7 Insurance Benefits

1.7.1 Current scenario

Usually epilepsy is not covered by Insurance companies and the expenses incurred during treatment cannot be claimed.

Before understanding the insurance for children/persons with disability, it is important to understand the "exclusions" in Mediclaim insurance policies. Exclusions are conditions that are not paid for by the insurer. These can be :

Pre-existing Diseases are those that exist at the time of taking a policy and are excluded from the cover during an initial waiting period of 2- 4 years. Different diseases could have different waiting periods, depending on the policy type. This is because insurance covers the risk of an uncertain event and not something that is already prevails. The report has recommended that a pre-existing ailment should be defined as an ailment that's diagnosed or for which medical advice or treatment was recommended or received by a physician prior to the effective date of the policy. Just existence of signs and symptoms to identify pre-existing conditions is not allowed.

Waiting period is the time span from when the policy is bought to when the policy holder starts getting coverage from it. A maximum waiting period of 4 years is allowed for any pre – existing condition.

Permanent exclusions are those diseases or types of treatments that are not covered in the health insurance schemes at all.

Scenario up to 02/11/2018

At the time of the meeting, the status of Insurance for children / persons with epilepsy were as follows (as per the Insurance providers and the experience of the clinicians):

1. If epilepsy was diagnosed after policy inception, some insurance companies were denying claims for epilepsy treatment even after policy was taken, under the guise that epilepsy is a permanent exclusion.

2. Epilepsy was included in the list of permanent exclusions for Insurance providers. As a result:

   (a) some insurance companies were cancelling insurance claims of children with epilepsy even after diagnosis was made after policy inception.

   (b) Any child person with an existing epilepsy could not obtain any insurance coverage, even for other illnesses

   As a result, many doctors avoid giving the diagnosis of "epilepsy" and used the term "seizure disorder" instead.

3. According to the new classification of epilepsies, the term genetic should be used to describe certain focal or generalized epilepsies, if that be the case. Also, the term" idiopathic generalized epilepsies" was discontinued and the term genetic generalized epilepsy was used instead.

   As clinicians who are bound to follow international and national guidelines and terminologies for uniformity, it was seen that whenever the term "Genetic" was used for describing the etiology of epilepsy in a particular child, all claims were being cancelled, even though many of the genetic epilepsies could be well controlled by using epilepsy medicines. This was forcing clinicians to avoid using the term "genetic" in their diagnosis.

Overall, there was a lot of confusion and variability in the various Mediclaim policies regarding pre-existing conditions and permanent exclusions, not only for epilepsy but other conditions as well. However, for epilepsy, the conditions seemed particularly harsh as most patients remain well controlled with oral medications.

Present Status

The Insurance Regulatory and Development Authority of India constituted a **Working group for standardization of exclusions in Health Insurance Contracts in July 2018. Their report was submitted in October 2018, and published on 2 Nov 2018 on their website** [https://www.irdai.gov.in/ADMINCMS/cms/Search_Results.aspx : REPORT OF THE WORKING GROUP FOR STANDARDIZATION OF EXCLUSIONS IN HEALTH INSURANCE CONTRACTS uploading date 02/11/2018, Chapters 3 and 4.]

As per these recommendations:

Epilepsy is included in the list of permitted permanent exclusions . (The list has 17 conditions which can fall into the category of permanent exclusions. This list may be changed annually by the IRDAI, depending upon changes in perceptions).

This can impact insurance for children and persons with epilepsy in the following ways:

(a) If epilepsy develops after inception of the policy :

As per the recommendations, all health conditions acquired after policy inception should be covered under the policy and cannot be excluded. Exclusion of diseases contracted after taking the health insurance policy cannot be permitted. Thus if a child develops epilepsy after the policy comes into effect, he/she will be covered fully.

(b) Insurance if a child or person is known to have epilepsy at the time of taking the policy:

Till now a person with epilepsy could not obtain any insurance at all, as any person having a pre-existing disorder which was mentioned in the permanent exclusion list, could not be insured.

However, with the present the IRDAI working group recommendations, health insurance may be obtained by disclosing the epilepsy at the time of taking the policy; treatment for epilepsy would be excluded, as it is named in the list of conditions in the permanent exclusions, but treatment for other conditions can be covered from the day of inception. A written consent of the person with epilepsy or parents of child with epilepsy would be required at the time of enrolling into the plan.

Thus before taking any insurance plan, the parents must go through in detail about the type of policy and the exclusions, so that they are not denied claims later.

However, some insurance companies have started to include epilepsy in the Health Insurance plan:

1) Swavlamban Health Insurance Scheme

1.7.2. Swavlamban Health Insurance Scheme

This prestigious health insurance scheme was initiated on 2nd October 2016 solely for Persons with Disabilities (PwD). It was launched under the power of New India Assurance Company limited with the association with Ministry of Social Justice and Department of Empowerment of Persons with Disabilities(17).

Note: If Epilepsy is associated with mental retardation then the benefits of this scheme can be availed,however the list of disorders does not include epilepsy nor it does not clarify whether it is considered mental illness.

The Mission of Swavlamban Health Insurance Scheme:

- To provide low cost and affordable health insurance to people with Low Vision, Blindness, Leprosy-Cured, Loco-Motor Disability, Hearing Impairment, Mental illness and Mental retardation.
- To improve the quality of life for PwD.
- To improve general health conditions for PwD.

Key Features of Swavlamban Health Insurance Scheme:

- The steady premium of INR 357/- for every PwD living across the country. (10% of actual premium plus Service Tax)
- Sum cover of INR 2 lacs on the family floater for 12 months. Family size up to 1+3, primary member is mostly the person with PwD but in the case of minor being, PwD the parent/guardian of the minor can also be covered under the scheme.
- Age band covered under **Swavlamban Health Insurance Scheme** is 0-65 years.
- To get enrolled in **Swavlamban Health Insurance Scheme** the PwD need to carry the PwD certificate issued by PwD Act, 1995.
- PwD family income not exceeding 3 lacs P.A or below are also eligible.
- No pre-medical tests involved before enrolling into the policy.
- Pre and post hospitalization is covered as subject to limits.
- OPD cover for curative therapy up to INR 10,000/- for 12 months for PwD. For persons with mental disability or mental retardation, OPD covers INR 3000/- P.A.
- Pre-existing conditions cannot be excluded but curative surgery for existing impairment can be done with the consent of insurer/TPA.

Please note: People with multiple disabilities, cerebral palsy and autism are not covered under this scheme (16).

GROUP RECOMMENDATIONS

i. Work towards removing Epilepsy as a whole from the list of permanent exclusions, e.g. certain types of self-limited or well controlled epilepsies may be included as pre - existing disorders, where a waiting period of 4 years may be allowed.

ii. In case where epilepsy can be declared as cured as per definition by ILAE, epilepsy should not be a pre-existing disorder and neither should it be on the list of permanent exclusions.

2 SOCIAL & LEGAL ASPECTS OF EPILEPSY IN INFANTS AND PRESCHOOL CHILDREN

2.1 Introduction

Epilepsy in infants and pre-school children poses distinct challenges, somewhat different from older children.

2.1.1 Recognising the seizures:

Seizures with fever (ie febrile seizures), are common in this age group. These are usually brief, self-limiting and generalised when present in simple form. However, there may be prolonged, repetitive and focal seizures in complex forms (1).

Other seizure presentations include myoclonus, tonic seizures and atonic seizures.

However, non-epileptic events, ie, events that are not seizures but look like seizures, such as startles, shuddering attacks, self-gratification, stereotypies, non-epileptic staring spells and breath-holding spells are also common (2). Therefore, it is sometimes difficult to recognize a true seizure by caretakers, and non-epileptic events have the propensity to be misinterpreted as a seizure.

2.1.2 Association with comorbidities:

Epilepsy in this age-group may be associated with co-morbidities which include complex conundrum of development delay, hyperactivity and autistic features (3). The underlying development and behavioural issues may range from subtle to significant. Many times, these co-morbidities are more important and of a concern than seizures or epilepsy itself.

Conversely, epilepsy is also common comorbidity in children with developmental delay, hyperactivity and autism spectrum disorder. There is scarce published data on the magnitude and burden of co-morbidities in young children from our country. The underlying aetiologies include structural causes such as malformation, hypoxic-ischemic brain injury, hypoglycemic brain injury along with genetic causes which are important determinant for underlying co-morbidities. Overall, it highlights that some children with epilepsy not only need treatment of epilepsy but the management of co-morbidities also.

Thus epilepsy and comorbidities often occur together in this age group, making epilepsy management more complicated in this group.

2.1.3 Aspects of care at home and in day-care centres:

Most of these children are non-verbal, and dependent on all activities of daily living on a care giver, who could be a parent, or non-parent such as domestic worker, elder sibling, grandparent or other relative, or an attendant in a day care centre, depending on the circumstances. All persons involved in the care of the child would need to be familiar with the special care of the child, as well as recognition of the seizures and pre-hospital management of the seizures.

2.2 Problems of Working Parents

As children in this age group require constant supervision, and also have seizures that may be more difficult to control, situations where both parents are working may be especially complex, because of the following reasons:

- Frequent medical visits
- Difficulty in regular administration of medications
- Adverse effects with medications, which may not often be recognised early
- Uncontrolled epilepsy and presence of co-morbidities

Therefore, quality of life is commonly even more compromised in parents of an infant or toddler with epilepsy as compared to older children.

Evidence suggests that psycho-social factors, along with medical factors, also significantly affect the quality of life (4). Mothers often feel increased parenting stress. It is not uncommon to have anxiety and depression symptoms in the parents. The problem is of paramount importance especially when both parents are working.

There are frequent recalls from workplaces for medical reasons of the child with epilepsy and need of frequent hospital visits. Working parents need frequent casual leaves, child-care leave and need a better support system. However, the support facility at work environment is poor.

2.2.1 Laws & Support System in Our Country

Child Care Leave (CCL) is granted to women employees in Central Govt. set up for a maximum period of two years (ie, 730 days) during their entire service for taking care of their minor children (up to eighteen years of age). No extra leave is permitted for children with epilepsy.

There are no additional legal or support systems peculiar for epilepsy in this age-group.

2.2.2 Status in Other Countries

No specific support systems or laws peculiar for infancy and toddler age-group could be found.

GROUP RECOMMENDATIONS

Working parents with infants or toddlers with epilepsy should be provided support for extra casual leaves or child-care leave .

2.3 Day care Centres - Special Requirements

Day care services have a crucial role for working parents. However, there is often denial of admission for children with epilepsy.

Despite the improvement in technology, social media and literacy, there are still significant deficiencies in knowledge, attitude and practices of people towards epilepsy. There are misconceptions that epilepsy is contagious, hereditary, and some sort of insanity (5,6). Thus, it is not uncommon to have social stigma and discrimination towards children with epilepsy, even infants and toddlers. Sometimes, co-morbidities also contribute to social isolation. There is a need to have a special education program aimed at improving knowledge and to dispel these misconceptions through television, social media etc.

2.3.1 Special requirements for day care centres

Day care centres should have a comprehensive facility for

- Administrating prescribed medications
- Feeding special diet (ketogenic or other)
- Administrating prescribed medications
- Feeding special diet (ketogenic or other)
- First-aid services for seizures and
- Escort services to the hospital
- Early intervention therapies : as children with epilepsy often have co-morbidities including developmental delay, certain special day care centres may also provide early intervention therapies.
- Adequate ratio of caretakers : current challenges include an inadequate ratio of caretakers for a large number of children. Furthermore, a child with special needs requires 1:1 caretaker: child ratio. Recruitment of an additional staff for children with disability or epilepsy would result in a hike of fees.

Lack of awareness on first-aid management among caretakers is also needed to be addressed. Concealment of diagnosis by parents is also an important issue and the fear of discrimination of their ward is crucial contributing factor.

2.3.2 Laws & Support System in Our Country

There are no additional legal or support systems peculiar for epilepsy in this age-group.

- The Maternity Benefit Amendment Act, 2017 states that employers with >50 employees need to have a day-care but it has not been implemented properly.

- The Rights of Persons with Disabilities Act, 2016 protects against discrimination

2.3.3 Status in Other Countries

- The Americans with Disabilities Act prohibits discrimination based upon child's disability including all child care programs.

GROUP RECOMMENDATIONS

i. The Maternity Benefit Amendment Act, 2017 should be implemented and there should be day-care facilities.

ii. Day Care Services and pre-schools should not deny admissions to children with epilepsy.

iii. Day Care Services should be able to provide comprehensive services including administrating prescribed medications, feeding special diet (ketogenic or other), first-aid services for seizures and escort services to the hospital. There should be early intervention facilities for needy children in day care services.

2.4 Air Travel Permissions

There are no special recommendations regarding air travel specific for infants and pre-school children with epilepsy Aspects of air travel are discussed in Chapter 6.

2.5 Prehospital Management of Seizure by Caretaker

The knowledge about optimum first-aid for seizure management is poor in the community (5,6). It is important as care providers for children are variable and include parents, family members, domestic workers and crèche staff. An inability of young children to verbalise their problems, hence extra care required in the home management of not only seizures but the child as a whole. Care-takers need to be sensitized about seizure management plan at the respective area. Furthermore, the first aid facility should be available in public transport facilities including flights and trains. Treating paediatricians should form an individualized written plan for first-aid management of such children.

Prehospital seizure management is described in English and Hindi in Annexure 1.

GROUP RECOMMENDATIONS

i. There is a need to arrange training sessions on seizure recognition and first-aid management for preschool teachers and caretakers at day-care centres. There may be incentives or special recognition given to teachers, schools and day-cares who undergo this training.

ii. It should be made mandatory for preschools and day-care centres to be equipped to handle seizures. Midazolam nasal spray and first-aid management should be available in day cares, pre-schools, flights, trains and long-distance buses.

iii. The treating pediatrician/ pediatric neurologist should provide a written plan for emergency seizure management and train the caretakers for the same.

iv There is a need to have epilepsy educators or epilepsy nurses in all hospitals. It is recommended to develop a special training module for special educators and nurses to specialise in epilepsy education. The role of epilepsy educators would be to counsel and guide all those involved in care of the pre-schooler with epilepsy.

3 SOCIAL AND LEGAL ASPECTS OF EPILEPSY IN SCHOOL CHILDREN

The school going period is one where children in this age are expected to attend school, where they are in the care of the school staff, and independent of constant supervision for varying periods.

Schooling for children with epilepsy may be challenging both for the child and the family as well as the school. An atmosphere of trust and understanding is required on both sides, which can only be built if there are guidelines and systems in place for the safety and security of the child, and which cover all aspects of schooling.

This chapter aims to address all of these issues.

3.1 School Admission: Current Scenario

3.1.1 Right to Education: Sarva Shiksha Abhiyan and its role in education of children with epilepsy

Sarva Shiksha Abhiyan (SSA) was launched in the year 2000 – 2001. It is a Centrally sponsored scheme implemented by Government of India in partnership with State Governments. It is India's main programme for universalizing elementary education. Its overall goals include universal access and retention, bridging of gender and social category gaps in education and enhancement of learning levels of children.

SSA also ensures that every child with special needs, irrespective of the kind, category and degree of disability, is provided meaningful and quality education. Hence, SSA has adopted a zero rejection policy. This means that no child having special needs should be deprived of the right to education, and is taught in an environment, which is best, suited to his /her learning needs. [http://pib.nic.in/newsite/PrintRelease.aspx?relid=68106].

Thus, children with epilepsy between 6 – 14 years also have the fundamental right to free and compulsory education like all typically growing children. Children with epilepsy cannot be refused admission under the RTE Act and The Rights Of Persons With Disabilities Act, 2016. These are given in appendices 1 and 2 respectively.

3.1.2 The type of schooling

Inclusive mainstream or special - shall depend on their intellectual abilities. If there is no comorbidity, then regular schooling is a must. In other children, treating physician and school authorities may jointly decide on this issue.

As far as possible, inclusive education should be the norm, even in children with co morbidities. Exposure to normal school atmosphere by grouping children with epilepsy with normal students improves group behavior.

3.2 Disclosure of Epilepsy

3.2.1 Why there is reluctance to disclose?

Absence of disclosure is almost always linked to stigma and discrimination where the teachers and society have a role. The aim should be to dispel the myths and stigma attached with epileptic fits.

A study from Chandigarh showed that most teachers are aware of the non – contagious nature of epilepsy unlike rural populations. Moreover, epilepsy is still considered as "Oopri Hawa/ Chhayya/ Jadu tona" (i.e. caused by demonic possessions) in many rural populations and managed by folk healers.

3.2.2 Importance of disclosure

Parents must disclose any seizures for the protection and safety of the child in all areas where child is present.

3.2.3 Who all should be informed?

Family, close friends, school teacher, transport teacher, school doctor and nurse. In fact all caretakers of the child should be informed.

The child should also be explained about the condition, depending on the level of understanding of the child and the comfort level of the parents.

Classmates and the child's friends should also be informed, as they may be the first witnesses to a seizure.

3.2.4 How can disclosure help?

- Explaining the epilepsy and the impact it has on the child's life helps people understand and empathize with the child's status.

- When the child needs emergency medication, friends, teachers are aware of Do's and Don'ts and how to administer rescue medication.

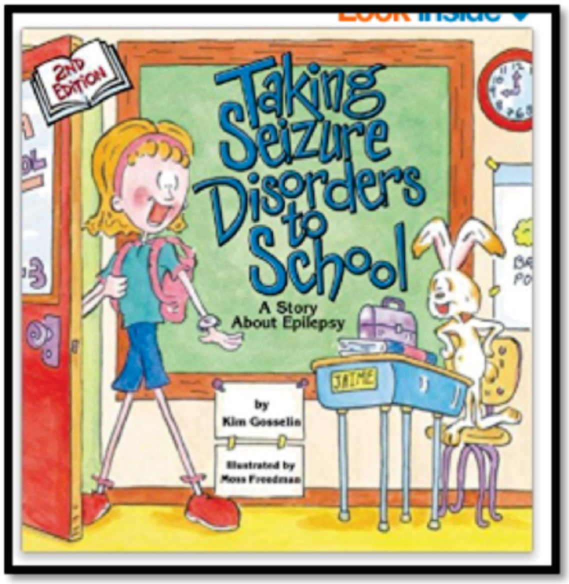
- The child would understand that the majority of people will be very worried and concerned about his/ her problem.

- In case of bullying in any form (hitting, teasing, name calling, spreading nasty stories about the child, stealing or hiding belongings or being ignored), the child can be encouraged to share his/ her feelings with an adult who can be trusted, like parents, older brother/ sister or teacher. They can help in coming out with strategies for dealing with it.

3.2.5 How to disclose about epilepsy?

3.2.5.1 To the child and other school children

There are ways to talk to children about epilepsy in a simple way. Indian literature is, however, is lacking. There are many books available in other countries (like the one given below) to educate children about epilepsy. There is a need to develop Indian material along similar lines.



3.2.5.2 To the school

The principal, class teacher, school transport teacher, school nurse or doctor should be informed about the following:

- Details of the epilepsy,
- What happens to the child during a seizure
- Video recording of the seizure
- First aid of a seizure and rescue medication
- Contacts of parents and hospital
- Doctor's prescription and any certificates

3.3 School Sensitization

As a large part of a child's growing and formative years are spent in school, experiences in school are important in shaping the outcome and personality of the child.

The attitude of the peers is often a reflection of the attitude of not only their parents, but the teachers and staff of the school as well.

Administrative staff, teaching staff, helping staff, student community and parents, all need sensitization and training in first aid.

3.3.1 Problems faced by child with epilepsy in school

3.3.1.1 Teacher and staff related issues

Studies have also shown not only lack of knowledge but also gap in attitude and practice in the teachers regarding epilepsy that is present in most developing counties including India.

Teachers are often apprehensive of handling children with epilepsy if they get a seizure. Multiple issues cause concern such, as

- fear of inability to handle the seizure
- handling other kids and chaos
- running to get help / take child to sick room, call special educator, call parents, hospital etc

3.3.1.2 Peer and friends related issues

Discriminatory attitudes, bullying, fear can develop not only because of lack of awareness in peer group, but also because of prejudice in parents of peers, who may pass these on to their children.

Hence, school sensitization is extremely important for overall comfort level and avoidance of unpleasant and discriminatory attitudes of the child's classmates and teachers.

3.3.2 School sensitization and change in attitudes is possible by

- Including epilepsy training as mandatory in teacher training curriculum.
- Time to time educational and orientation capsules. The initiative may be taken by schools or NGOs working in this area.

3.3.3 Topics to be covered in epilepsy training of teachers and school staff

Following issues need be covered:

3.3.3.1 Types of seizures and their manifestations:

Research clearly highlights that teachers are unaware of the varied manifestations of epilepsy e.g. absence seizures, myoclonic jerks etc. Most only label the generalized seizures with jerking as seizures – other manifestations are often ignored.

Documentation of such episodes (through video recording) can assist the physicians for planning and customizing medications and further investigations (although maybe a sensitive point with some parents). If such episodes are witnessed by the teachers, they may be permitted to video graph them.

The teachers may also be simultaneously educated about the non-epileptic conditions, including syncope. Teachers may often confuse fainting spells with seizures, though the former clearly outnumber the latter. Differentiating points like bradycardia, low BP (using a simple tool of fingertip pulse oximeter, wrist BP monitor to the school nurse and School medical officers) may be explained.

3.3.3.2 Availability of a Medical kit in school, with Nasal Midazolam

a. Medical kit in school should include midazolam nasal spray for use as rescue medication by trained teachers/caregivers in the event of a seizure occurring in school. It must be kept in every activity area of school, including school bus with a school teacher.

b. However, Midazolam should be prescribed only if the child has a seizure. School authorities should not give midazolam for suspected seizure, for a first episode as many non-epileptic events may mimic seizures.

3.3.4 Educational / Resource material

a. Pamphlet regarding first aid and epilepsy should be displayed on school bulletin board so that it can easily be read by teachers, students, parents.

b. Many **First Aid Apps** (First Aid app by Red cross) have an integral components of Seizure management which can be communicated to teachers , parents etc. In addition there are many dedicated apps for epilepsy management - Seizure tracker, young epilepsy app, Smart watch app (detects seizures and issues warning also.

c. Printed Resource material.

The educational material prepared for educational awareness and sensitization of the teachers and school staff should cover different aspects of epilepsy in children.Basic package of printed material has been created by Action Epilepsy India (AEI), which includes -

- First aid
- Epilepsy Management Plan

These resources are given in Annexures 1 and 2 at the end of this booklet, and may be used as guide for first aid (given here in English and Hindi). These can be translated in to local languages wherever needed.

d. Further resources online Epilepsy Action, UK (http://learn.epilepsy.org.uk/classroom-resources/; link for visuals to show students of different ages if there is a child who has a seizure in their classroom).

3.3.5 Medication during school hours

Schools need to be sensitized that they might need to take care of medication of children with epilepsy in school if needed. Though not common, some children with epilepsy may have to take AED during school hours as well. In this regard, a customized healthcare plan as well as form providing instructions regarding medication administration at school should be made available and given to the school.

3.3.6 Exams and tests, and attendance

a. If stress is known to trigger seizures in certain epileptic children, then their exam performance may be compromised. To mitigate such concerns, a proactive and engaging discussion with parents and student regarding need for special arrangements or alteration in timing may be warranted.

b. If the student is absent on account of seizures or doctor appointments, there needs to be a system of extra tutoring and non-penalization for the same, as required by the situation.

At present there is no formal pathway to get extra time for a board examination on account of epilepsy needs, unless epilepsy is considered a disability (see chapter 1)

c. If the student's medication or seizures warrant extra time to complete the Board Exam, it is felt that a system be created whereby a neurologist and the school principal can certify that the student needs the extra time. This will need to be taken up with the CBSE. However, this may be implemented in the in house exams and tests.

d. Benefits during exams and curriculum :

The child with epilepsy may need different support services during his/her educational years such as remediation therapy, shadow teachers and some concessions during exams. These concessions may vary depending on the Central or State Boards such and the National Institute for Open Schooling (NIOS). [Indian Law and Epilepsy]

Certain Benefits for students with disability (and/or epilepsy) are provided under the Govt. of India's Sarva Shiksha Abhiyan (www.ssa.nic.in) or other similar initiatives.

Procedures for applying and concessions vary among different Boards. Most Boards require a disability certificate from a Government Doctor in requisite format and information about the child's requirements from the School Principal.

The type of concessions granted will depend on the needs of the child and the policy of the Board. There are additional guidelines available on concessions for children having different disabilities (including those having epilepsy with disability.

e. The Central Board of Secondary Education (CBSE) is the largest board conducting secondary level examination as at the National Level. It provides several benefits/ facilities to students with disabilities who may appear \ from Patrachar Vidyalayas or as private candidates, like scribe, extra time, exemption from third language. Breaks may be allowed during this time to counter fatigue.

The details are given in the **Appendix 4, which gives Some Relevant extracts from Examination Bye-Laws 1995 (Updated Up to 2017); the website is** [http://cbse.nic.in/newsite/attach/PWD%20 NOTIFICATION.pdf].For the other Boards, the respective Board of Education under which the child is studying can be contacted for availing the special provisions under the Examination Bye Laws.

Following benefits can be made available:

- Provision for special needs of children with epilepsy can be sought if it can be established that a child with epilepsy has certain special needs and can be covered in any of the following 21 categories mentioned below {this is the extract from the SSA Assessment Guidelines for Children with special needs (CWSN)} as “Epilepsy” is neither mentioned specifically in PwD Act nor in SSA guidelines.

- Some children can also be evaluated for special needs under General Evaluation Techniques for CWSN like: Use of technology e.g. computers, tape recorders, voice synthesizers to be allowed as per the needs of the child.

- The special needs of a child with epilepsy should be taken up with the school authorities along with supporting documents.

- The dialogue with the school authorities should be aimed at the identifying the dominant focus related skill in the affected child and its development by specialized trained teachers.

f. Children with epilepsy who may have difficulty in going to school for reasons of distance, terrain etc. should be encouraged to study under National Institute of Open Schooling. NIOS has its Regional Centres and the Study Centres across the country.

3.3.7 Working with computers and lights

Though rare, children with photosensitive epilepsy may have a minor, yet possible, risk of seizure being triggered by flashing or flickering lights or by particular geometric patterns. Even school cultural programs using flickering overhead lights may be potential photosensitive triggers for seizures.

General precautions like using computer in a well-lit room or avoiding programs/games with fast flashing lights may be implemented at school.

3.3.8 Use of additional assets:

a. 'Buddy' system can be very helpful in social acceptance, confidence building and true integration. For this choice of buddy critical.

A friend of the child or a popular student of the child who shows willingness to take on this task may be assigned as a buddy to be a special friend of the CWE, and also be specially trained to help in first aid if old enough to do so.

He can also cover reminding the child to have medication if required or help with school-work as the teacher may direct.

b. Peer Educator in addition to Buddy – Under the Rashtriya Kishore Swasthya Karyakaram the schools are expected to train Peer Educators in first aid and other health issues. These students can be an asset for the school and subsequently society. This programme is being run by the Ministry of Health and Family Welfare. They have an Android based App – Sathiya .

GROUP RECOMMENDATIONS ON THE ROLE OF SCHOOL TEACHERS

i. The school staff and the teachers are an essential component of epilepsy management in children.

ii. A well informed and sensible teacher is the best resource for a child or adolescent with epilepsy, as majority of the child's day is spent at school. This helps, not only in better medical management, but overall educational, social and emotional wellbeing of the child.

iii. Once the diagnosis of epileptic seizures or epilepsy is made, the family should sit down with the class teacher and discuss all aspects of their child's epilepsy. This includes details of types of seizures, medication schedule, potential triggers for seizures, first aid management including rescue medication, activity restriction/participation (if any), any special educational needs and emotional/social aspects including bullying etc.

iv The teacher can help the child/adolescent in handling a seizure calmly and effectively, and can sometimes alert the family about any signs of seizure activity that may have gone unnoticed by others. ▯

v The teacher's observation and reporting of any changes in the child's behaviour can help the family and physician in better management of epilepsy▯

vi Teachers are likely the first people to notice any educational problems the child may develop, and can help in instituting early intervention measures as needed

vii A sensible teacher can also help in sensitizing other children in the class about epilepsy, first aid management and optimal participation of the epileptic child in group activities. This will go a long way in promoting the child's self-esteem, prevent bullying and the damaging social impact of epilepsy, and in turn help in realising his or her academic potential

GROUP RECOMMENDATIONS FOR POLICY MAKERS

I. To include children with only epilepsy also as disability and include it in special needs.

ii. To involve Ministry of Social Justice and Empowerment (Government of India) and the concerned State Governments.

iii. To open special Teachers Training Centers for PWE (CWSN) providing meaningful education to PWE with an aim to raise their confidence levels necessary to lead normal life.

iv. To provide information and links to information regarding currently available concessions in education boards for children with epilepsy.

v. To develop and include in act method of quantifying level of disability in a child with epilepsy (should include comorbidities, difficulties in mobility in addition to number of seizures).

3.4 Management of Seizures in the School
(Classroom, Sickroom, Playground and School Transport)

Introduction: School nurses and teachers must be trained in first aid for epilepsy even if the school has no recorded student with epilepsy because a seizure can occur anywhere, anytime.

Every school **MUST** have a seizure or epilepsy management plan . it should include the following-

3.4.1 Preparation of the school medical aid kit

- The school medical kit should include Midazolam nasal spray and kept in every activity area.

- In school bus, medical kit (first aid box) should include Midazolam nasal spray and the staff member travelling should be taught first aid management including administration of Midazolam nasal spray

  [However, Midazolam should be prescribed only if the child has past history of seizure or definite epileptic seizures (may need educating teachers on identifying common seizure types School authorities should not give midazolam for suspected seizure in 1st episode as many non-epileptic events may mimic seizures]

3.4.2 Seizure management and first aid

The first aid and immediate seizure management training *(including the use of rescue medications)* should be done for the school doctor or nurse as well as ALL staff members, not only those involved with children with epilepsy.

This may be conducted by

- epilepsy educators or doctors at the schools possibly.
- Possibility of parents as people who can train the school in first aid can also be explored.

3.4.3 Post seizure actions

A well defined protocol should be in place to inform the parents and transport the child to the hospital in case of continuing seizures.

It is best if the nearest hospital is earmarked and parents informed beforehand of the place the child will be shifted to in case seizures occur.

3.4.4 Maintenance of records

Maintaining record of doctor's prescription, and advice on acute seizure management in all children with epilepsy in the school is mandatory.

The school should have information on :

- Known triggers for the child's seizures must be noted and avoided.
  The child's medications must be known to the class teacher and the school health personnel, and whether any medications are taken in school.

- Doctors recommendations for acute seizure management

3.4.5 Creation of a buddy system

Here a friend is made aware to look out for the child with epilepsy in whatever way that child requires specifically and informs a school staff member when there is a problem.

The pamphlets prepared by Action Epilepsy India (AEI) can be used as guide for first aid (given below in English and Hindi). Same material can be translated to local languages wherever needed.

3.5 Restriction Of Activities

3.5.1 Introduction

A number of studies over the years have demonstrated the benefits of physical exercise in children and adolescents with epilepsy. The benefits are related to improvement of physical and mental health parameters, better social integration and reduction in markers of stress, epileptiform activity and the number of seizures.

Usually people with chronic diseases like epilepsy are sedentary, overweight and have higher rates of depression. The restriction of physical activity and confinement to studies often results in mood disturbances, low self-esteem, withdrawn behaviour in groups and feeling of isolation.

Literature on sports recommendations has following lacunae:

a. It is scarce

b. Most studies are based on small number of patients.

c. Most studies are based on questionnaires constructed by authors based on qualitative measurements relying on patient's or relative's reports. More robust controlled randomised studies on physical exercise and epilepsy are needed to provide basis for physicians to give informed counselling on this subject.

The general consensus is that

a. There is a definite benefit with regular physical exercise done with necessary precautions like protective gear.

b. For children with comorbid physical disabilities, better access to exercise facilities should be provided.

c. Exercise in groups also reduces stigma associated with epilepsy, improving the quality of life.

However, children and adolescents with epilepsy are often discouraged and barred from participating in many sports, games and physical exercise. The major reasons are: fear of physical injury (and death), overprotective attitude of parents and lack of awareness of benefits and risks associated with these physical activities.

3.5.2 General Principles in Activity Restrictions

3.5.2.1 Activity restriction needs to be noted in the individual management plan because no two children may need the same restrictions.

Also different epilepsy programs and services have slightly varying recommendations for various activities.

3.5.2.2 The decision to permit or restrict various activities depends on the assessment of risk benefit ratio, to the child with epilepsy as well as others, if there is a chance that the seizure might occur during the activity.

Keeping these points into consideration, certificates may be issued. Sometimes, individual sports / activities may require specific certificates.

3.5.2.3 The following factors must be considered:

a. The type of sport/ activity

Types of activities requiring consideration include water sports in general (wearing a life jacket is essential even if medically allowed), swimming (life guard must be aware of the student's seizure type and the first aid for that type and know when to call an ambulance), cycling without a helmet, horse riding, running, trekking, climbing jungle gyms and trees, theme parks, gym activities (if seizure free for 12 months the child should be able to use any gym equipment), squash, yoga, pranayam, boxing, martial arts, team sports, chemistry lab activities, cooking and cutting with knife.

There is no evidence to suggest that team sports (football, rugby, cricket and volleyball) should be avoided as long as safe guard of wearing head protection is followed.

If the epilepsy is caused by a head injury the doctors may ask the student to avoid team sports.

For individual indigenous sports, there is a lack of guidelines, as guidelines are mostly from developed countries with differences in usual sports. In these cases, the treating physician may use his judgment based on the child's epilepsy and seizure type and degree of control.

b. The probability of a seizure occurring –

i.e., duration of seizure freedom, treatment compliance eg in *Controlled epilepsy which means seizures absent for one year*.

c. The probability of a seizure occurring –

eg Children who have seizures only during sleep and are well controlled may not require any restrictions.

Other factories

- Prodromal manifestations
- Seizure triggers
- Past history of seizure related accidents or injuries
- Personal preference

3.5.2.4 The ILAE Task Force on Sports and Epilepsy, 2016, proposed to categorize various physical activity and sports in to three groups based on their potential risk of injury or death should a seizure occur.

Group 1: (no significant additional risk) includes sports in which the occurrence of seizures poses no additional risk of injury for either the person with epilepsy or bystanders (other athletes, referees, or spectators).

Group 2: (moderate risk) includes sports involving a moderate risk of physical injury for PWEs, but pose no risk for bystanders.

Group 3: (major risk) sports entail a high risk of injury/death for PWEs and, for some sports, also risks for bystanders.

The categorization of sports listed in Table 1, and suggestions for restrictions are listed in Table 2.

Table 1. Sports included in the 3 risk groups. Some sports will be in the grey zone, and the treating physician can decide which group to place it in.

Group 1 sports (no significant additional risk)	**Group 2 sports (moderate risks to the PWEs but not to bystanders)**	**Group 3 sports (high risk for PWEs, and, for some sports, also for bystanders)**
Athletics (except for sports listed under group 2) Bowling Most collective contact sports (judo, wrestling, etc.) Collective sports on the ground (baseball, basketball, cricket, field hockey, football, rugby, volleyball, etc.) Cross country skiing Curling Dancing Golf Racquet sports (squash, table tennis, tennis, etc.)	Alpine skiing Archery Athletics (pole vault) Biathlon, triathlon, modern pentathlon Canoeing Collective contact sports involving potentially serious injury (e.g., boxing, karate, etc) Cycling Fencing Gymnastics Horse riding (e.g., Olympic equestrian events— dressage, eventing, show jumping) Ice hockey Shooting Skateboarding Skating Snowboarding Swimming Water skiing Weightlifting	Aviation Climbing Diving (platform, springboard) Horse racing (competitive) Motor sports Parachuting (and similar sports) Rodeo Scuba diving Ski jumping Solitary sailing Surfing, wind surfing

Table 2. Suggestions of physical activities/sports participation for PWEs or with other seizure disorders

	One or more symptomatic seizures	Single unprovoked seizure	Seizure free (12 months or longer)	Sleep related seizures only	Seizures without impaired awareness	Seizures with impaired awareness	Epilepsy resolved	Medication withdrawal
Group 1	Permitted	Permitted	Permitted	Permitted	Permitted	Permitted at neurologist's discretion, when seizures are precipitated by specific activities	Permitted	Permitted at neurologist's discretion applies when seizures are precipitated by specific activities
Group 2	Permitted at neurologist's discretion, with restrictions	Permitted after 12 months of seizure freedom	Permitted	Permitted at neurologist's discretion, with restrictions	Permitted at neurologist's discretion, with restrictions	Permitted at neurologist's discretion, with restrictions	Permitted	Permitted after appropriate periods following AED cessation
Group 3	Permitted at neurologist's discretion, with restrictions	Permitted after 12 months of seizure freedom	Permitted	Generally barred, but may be considered, with restrictions, at neurologist's discretion, for sports posing no risk to bystanders (see text)	Generally barred, but may be considered, with restrictions, at neurologist's discretion, for sports posing no risk to bystanders (see text)	Generally barred, but may be considered, with restrictions, at neurologist's discretion, for sports posing no risk to bystanders (see text)	Permitted	Permitted after appropriate periods following AED cessation

3.5.3 Group Recommendations

The group suggested certain special precautions to be taken when participating in individual sports and other physical activities, permitted for children with epilepsy, pertaining to the Indian scenario.

GROUP RECOMMENDATIONS		
S.No.	**Activity Type**	**Recommendations**
1.	Swimming and water sports	Swimming can only be permitted in supervised pools with direct supervision of trained professionals (cardiopulmonary resuscitation training), who have been informed of the condition of the sports practitioner. Swimming teacher and life guard should fully understand a child's epilepsy so that if the child is having a seizure in the water, it can be detected quickly. Schools may use a buddy system which pairs up pupils so that everyone has someone to look out for them in water. This may help child to feel that he is being treated the same as other children, as well as increasing everyone's safety in water. A less crowded time for swimming may be safer for the child. Swimming open unsupervised waters is to be avoided. Wearing a life-vest is a must when in a boat, when water-skiing or any other similar sport (sports not to be undertaken alone); also these sports should be avoided in uncontrolled epilepsy.
2.	Sports at heights	Horseback -riding permitted if under supervision as therapy. Risk for certain sports (bicycling, gymnastics at parallel bars or involving acrobatic activities, rock climbing) should be assessed with controlled epilepsy Necessary safety equipment must be provided and not alone.
3.	Motor sports	No formal restrictions in controlled epilepsy according to driving regulations. Not recommended for those with uncontrolled epilepsy.
4.	Shooting sports	The type of seizures and type of weapon to be evaluated for controlled epilepsy. Not recommended for those with uncontrolled epilepsy.
5.	Contact sports	Generally recommended with exception of boxing for which no general consensus has been reached. However appropriate safety gear is to be worn.

6.	Aerobic sports (e.g. running, basketball, stationary bike, aerobics, gymnastics not involving heights)	No restrictions with the use of appropriate safety equipment when advised eg safety harness or helmet as necessary
7.	Cycling	The child should always be accompanied by someone. Helmet should be worn Busy and main roads, and hilly areas should be avoided
8.	Kite flying outdoors	Allowed under supervision in a child/adolescent with epilepsy
9.	Fetching water from well or river side, cooking with *choolha*	Allowed under supervision in a child/adolescent with epilepsy

3.6 School Outings, Trips and Sleepovers

- Student should be allowed to participate in all school outings, overnight trips unless advised otherwise by a doctor.

- When a school trip is being planned the school authorities (teachers and other support staff involved in organizing the trip) should do a risk assessment in consultation with the parents and, if necessary, the treating physician; they should look at what extra help may be required so that the child can participate fully and safely.

- This may involve being flexible and making reasonable adjustments. A list of activities to be done in the trip should be made, and the assessment of risk of injury to the student should be made beforehand.

- Extreme sports during such outings such as bungee jumping, paragliding, parachuting, rock climbing, should be avoided if the seizures are not controlled.

- If the outing is such that the child may not be getting adequate sleep it could trigger a seizure. Such trips are to be avoided. If child is going to stay up late at night, encourage them to sleep during the day. *Avoid sleep deprivation*: Night stays often involve staying up late in to the night. Adolescents with epilepsies that might get triggered with sleep deprivation (most of the primary generalized epilepsies and some focal epilepsies) should take extra care to ensure adequate, timely sleep schedule during the stay.

- If the child has rescue medications prescribed for prolonged seizures, the expiry date should be checked and sent with the child.

Rescue medication: If the child is known to have longer (>3-5 minutes) of convulsive seizures previously, the rescue medication (nasal Midazolam spray) should be kept with the teacher or staff accompanying the child and ensure that he/she is aware of first aid management including administering the rescue medication; A trusted friend or companion can be identified who is aware of the child's epilepsy and first aid management.

- *Medication compliance*: If the trip involves overnight stay, parents should ensure adequate supply of medicines (anti-epileptic drugs), and identify a companion or teacher to ensure administration of medicine during the trip.
- If travelling by plane, the child's medications should be carried in hand luggage in case hold luggage is lost or delayed.
- For liquid medications, check with airlines for rules regarding taking liquids.
- The doctor's letter with details of child's condition and the medication they take and emergency contact numbers preferably translated into the language of the country one is visiting, and must be carried or sent along with the teacher or supervisor.
- A medical alert bracelet with details of seizures would be useful.
- Food and medication as per regular schedule is essential.
- Adolescents should weigh the risks, before giving in to peer pressure, for outings to theme parks, discotheques, crowded places with loud music and noise. Some of these situations can be tiring, stressful and can trigger seizures. Identifying triggers will help make safe decisions on restriction of activities.

3.7 Special Instructions for Boarding Schools

The boarding schools offer some special problems with respect to children and adolescents with epilepsy. The commonest concerns of the family are: compliance of the child with anti-epileptic drugs, ensuring adequate sleep and avoiding other seizure-precipitating measures, and management in case of emergency i.e. convulsive seizures in the hostel.

With cooperation from school authorities and hostel staff, these concerns can be minimized to a large extent.

GROUP RECOMMENDATIONS FOR BOARDING SCHOOL

i. The boarding school staff must be trained and be comfortable in first aid management of convulsive seizures in children; The matron/house mother/hostel-warden should have an emergency plan outlined and available to all hostel staff.

ii. The school should have child's epilepsy card consisting of all epilepsy-related details of the child including: types of seizures child known to get, current medication with dosage, rescue medication and administration, and emergency contact numbers.

iii. The school should identify one teacher/staff member to ensure drug compliance.

iv. The school doctor and/or nurse must have regular contact with the child and parents.

v. The school/parents should identify a neurologist/hospital close by where the child can be taken in case of emergency.

vi. The routine of food, sleep and medication must be seamlessly followed with a designated teacher taking responsibility.

vii. A written outline of the same along with copies of medical records must be given and maintained accessibly by the school.

viii. SUDEP should be addressed with the parents where appropriate so that they can make an informed decision about sending the child to a boarding school.

3.8 Computer and TV Usage

Computers are an essential part of school/college curricula for adolescents now a days. As a general principle, most of the children and adolescents can be allowed to use computer as needed for their school work and home work.

GROUP RECOMMENDATIONS

i. Most children with epilepsy (95%) can watch TV, play computer games and use computers and mobile phones, without any risks. Only a small group, about 5% of persons with epilepsy have photosensitive epilepsy. In these children, their seizures can be triggered by flashing or flickering lights as occurs on putting on the TV or strobe lights in discotheques. Seizures can be triggered by seeing moving patterns like stripes or checks. Consult a doctor, preferably a Neurologist if Photosensitive epilepsy is suspected.

ii. Those children and adolescents with photosensitive epilepsy should avoid flashing lights and images. Patterns on TV screens or computer games can also act as triggers. It is advisable to watch TV in a well-lit room and away from the screen. Keeping one eye closed when the TV is switched on may reduce the impact of the flickering light appearing on the screen. Triggers may differ from person to person. Identifying specific triggers is important to avoid seizures.

iii. Check for warnings on packaging of Computer games with flashing images. Though older TV and computer screens were found to be common triggers for persons with Photosensitive Epilepsy, the newer generation of TVs and computer screens have a very high flicker frequency and are less likely to be a trigger for people with photosensitive epilepsy.

3.9 School Medical Certificate

3.9.1 Situations where it is needed:

1. School admission in a child with known epilepsy
2. Occurrence of epilepsy in a child who is already school going
3. Re - joining school after hospitalization due to seizure
4. Joining boarding School
5. Going for school trips
6. Enrolling in special/extracurricular activities (for example, swimming, dancing etc)

3.9.2 Parts:

1. Description of child's health condition by doctor
2. Child's plan of care including
3. Emergency medication and first aid
4. Schedule of treatment to ensure medication compliance even at school
5. Safety concerns
6. Parent involvement in care
7. Parental consent to administration of emergency medication by school personnel
8. Parental consent to self-provision of medication needed by child to school.

"For format of medical certificate kindly see Annexure 2."

3.10 Adolescent Issues: Driving License

According to the Motor Vehicle Act, 1939, people with epilepsy (or even a single seizure) cannot obtain a driving license irrespective of their age. This applies for both two wheelers (including Scooty) and four wheelers.

The application by Indian Epilepsy Association (IEA) for granting driving licenses to people with epilepsy (with certain riders and regulations) is pending with the government of India since 2005.

3.11 Adolescent Issues: Vocational and Career Counselling

A majority of adolescents with epilepsy will be able to pursue courses or careers of their choice like everybody else. Only a small proportion of people with certain epilepsies and poorly controlled seizures may have limitations regarding the career/ job options.

3.11.1 The main considerations with respect to career options in adolescents with epilepsy are: risk of injury to self and others

Certain occupations/ professions might involve substantial risk of injuries (to self or others) should a seizure occur during the course of the job. These are strictly not recommended for people with epilepsy.

Examples: Driving a commercial vehicle or passenger vehicle, pilots, locomotive pilots, fire fighters, occupations involving working at heights etc.

3.11.2 The other aspect to consider is whether the work involves any potential triggers for epilepsy.

For example, jobs involving frequent night shifts can trigger seizures due to sleep deprivation. The jobs involving flickering lights (DJs) can also trigger seizures in some people (photosensitive epilepsies).

GROUP RECOMMENDATIONS

iv. It is recommended that the adolescents and young adults consult their Neurologist, discuss the careers of their choice, the risks involved (to self and to others) and any potential seizure triggers involved.

v. It is also recommended that people with epilepsy fully disclose the details of their epilepsy to their potential employer. This will ensure safety of the employee and the colleagues

3.12 Grievance redressal

3.12.1 Who to approach in case of discrimination?

- But and if the child is asked to leave school then there should be a guided grievance cell pathway for the family to get help.
- Explore the option of making a complaint with the disability commissioner. Concern would be discrimination against the child in the present school and any other should they choose to leave the current school.
- Each State in India has its own State Commissioner for Persons with Disabilities. In most cases of discrimination in the area of disability, one may go to them first for redressal.
- The pitfall is that it is applicable only to benchmark disabilities having $> 40\%$ disability. Thus the mildly affected ones are unable to seek redressal from disability commissioner.
- In cases relating to Central Government, complain directly to:

Chief Commissioner for Persons with Disabilities

Sarojini House, 6 Bhagwan Dass Road, New Delhi 110001
Phone No : 91-011 - 23386154, 23386054; Fax: 91-011-23386006

3.12.2 How to approach?

One can approach the Chief Commissioner in one of the following ways:

- In Person
- Through a Representative
- Through Registered Post
- By E-mail

Following details need to be given

Name, address & brief description of complainant and the nature of disability.

The name of the person (s) & organization(s) against whom the complaint is being made, together with their address & details, so far as they can be ascertained.

- The facts relating to the complaint
- What happened
- When it happened
- Where it happened
- What sort of relief is being claimed
- Documentation Required
- One must be able to give Documents in support of the allegations contained in the complaint.
- One must enclose a copy of Disability Certificate from a valid authority. Vide Notification No. GSR.2(E) dated 30.12.2009, Ministry of Social Justice & Empowerment, Government of India have amended the provision relating to issuance of disability certificate in PwD Rules, 1996. It requires that the medical authority shall issue a disability certificate in Form II or Form III or Form IV as applicable.

3.12.3 What Happens Next?

- Once the Chief Commissioner has received the complaint, a copy of the complaint will be referred to the appropriate party mentioned in the complaint directing him to give his version of the case.

- If necessary the parties may be heard in person.

- If the complainant or his agent fails to appear on the date, the Chief Commissioner in his discretion may dismiss the complaint or decide on merits.

- Where the opposite party or his agent fails to appear on the date of hearing, the date of hearing, the Commissioner may take such necessary action under section 63 of the Act as he deems fit for summoning and enforcing the attendance of the opposite party.

- The Chief Commissioner may dispose of the complaint exparte, if necessary.

- The Chief Commissioner may on such terms as he deems fit and at any stage of the proceedings, adjourn the hearing of the complaints.

- The complaint is decided, as far as possible, within a period of three months from the date of notice received by the opposite party.

4 EPILEPSY COUNSELLING

4.1 Introduction

When a child is diagnosed with epilepsy, counselling regarding the same is done by the treating doctor. Although counselling is done by all doctors, many aspects of epilepsy remain uncovered in daily practice. Many a times differing inputs are given by different personnel – doctors as well as supportive staff. Also the paediatrician / paediatric neurologist may not be able to give comprehensive advice which would include drug dosages, administration, side effects, home seizure management , precautions, prognosis, follow up, and any benefits, and other aspects. Ideally help of an epilepsy educator should be taken to cover all aspects of epilepsy. Hence there is a requirement to develop standardized counselling parameters, as far as possible, and also a checklist to \ ensure quickly that all points have been covered (1,2,3).

This section discusses the essential information to be included while counselling caregivers of a child with epilepsy. This chapter is divided into 8 subdivisions and has been prepared to be used as is as a **Patient information sheet.** Checklist for elements of counselling for doctors and epilepsy educators are given in Annexures 4 and 5.

4.2 About Epilepsy

1.Seizures and types of seizures (4)

The brain is made up of millions of cells called neurons. They communicate with each other through electrical signals for thinking, planning actions etc.

Sometimes, there is abnormal electrical activity generated in the brain. If it remains confined to an area of the brain, child may get funny sensations or movements in one part of the body. These are called **focal seizures**.

If they spread to the whole brain, the child may develop loss of consciousness and violent limb movements with frothing from mouth etc. These are called **generalised seizures** and can be dangerous if last for long.

There are also other different types of seizures: like sudden falls (atonic) , blank spells (absence), sudden jerking without losing consciousness (myoclonic) etc. A special type of seizure seen mostly in children is called **spasm** (baby suddenly stiffens with crying), these may come in clusters after awakening from sleep.

2. Epilepsy and its causes (5)

Any cause which irritates the brain can cause seizures by altering the electrical activity e.g. low sugar levels (hypoglycaemia), disturbance of electrolytes (like low Calcium) etc. Some other conditions like high grade fever, head injuries (accidents, falls) and brain infections etc. can also irritate the brain to cause seizures. These are called **acute seizures**.

When there is no immediate cause and still there is a repetitive tendency of the brain to develop seizures, it is called **Epilepsy.** Same causes can give rise to both, e.g. when a child gets meningitis- he is admitted with fever and seizures: these are acute seizures which require short term treatment. The same child may return many months or years later with repeated seizures arising from the damaged parts of the brain: these will be called**remote** (cause in past) **symptomatic** (from damaged brain) **epileptic seizures** because there is no immediate cause now. These seizures will require long term treatment for at least 2 to 3 years.

Many times, the brain is structurally normal and there is no prior injury. These are most likely due to inherent (genetic) faults in the electrical networks of the brain and called **idiopathic or genetic epileptic seizures.**In such cases, you may get a history of seizures in the family members.

3. Epilepsy is common.

Out of 1000 population, 3 to 12 people are suffering from some kind of epilepsy. Different causes and names (mirgi/jhatka/fits/aakdi etc.) may be prevalent in different parts of the country.

4. Epilepsy is not limited to a particular age and locality.

Some causes of epilepsy are prevalent at certain ages, e.g. birth related brain injuries in newborn, meningitis in infancy, accident related head injuries in adults etc.

A condition called neurocysticercosis is common in Northern parts of India- wherein water filled cysts carrying larva of tapeworm get trapped in the brain and cause acute as well as epileptic seizures later.

Most genetic (idiopathic) epilepsies are also age related, e.g. some are limited to childhood and resolve by puberty while some start at puberty and may remain lifelong.

5. All funny movements are not seizures.

For each type of seizure, there are similar looking movements which do not require treatment with anti-seizure drugs. A detailed history and a video of event is very useful to rule them out.

4.3 Diagnosis of Epilepsy

1.Diagnosis of Epilepsy is mainly clinical.

Epilepsy is mainly a clinical diagnosis, Investigations are used only to support (6).

Clinical means the detailed description of the events, i.e. what was the person/child doing, what exactly happened, how did it start, how did it progress, how did it end etc. This helps to find out whether the seizures are arising from a particular part of the brain. Many times, the parents or family has not seen the event, then its best to take a first-hand account from a witness to decide whether it was a seizure and the type of seizure. A video record of the event helps, if available.

A detailed history of birth events, development and family members is also asked to arrive at cause. A diagnostic tool for use by general practitioners is available (7).

2. Blood test sare not routinely required.

Blood tests are not routinely indicated; calcium levels may be advised in infancy. **Sugar would be checked.**Your doctor may advise special tests to rule out metabolic, genetic or autoimmune disorders if indicated.

3. Role of EEG in diagnosis of epilepsy.

EEG shows a map of the electrical activity of the brain. Presence of abnormal discharges supports the diagnosis of epilepsy. The distribution and type of abnormalities also helps to classify the type of epilepsy and decide the best treatment. Certain abnormalities can help to predict the further course – "how long will seizures remain?", "Will it affect the intelligence?" etc (8).

4. The EEG procedure.

Electrodes connected to wires are applied on scalp to pick up the electrical signals in the brain, which are fed into a computer. Different states like awake and sleep are recorded, as well as some light flashes are given to stimulate seizure occurrence. Older children are asked to breathe deeply for 3 -5 minutes during the procedure.

5. EEG may be normal even in Epilepsy.

As we record from scalp, abnormalities in deeper regions of the brain may not be detected. Hence first EEG may be normal in up to 50%. Repeated EEGs and EEG done in a sleep deprived state –(e.g. 4 hours at night) may improve the yield. So a normal EEG does not rule out epilepsy (9).

6.We may need to repeat EEG sometimes.

EEG may be repeated if it is normal and there is a strong suspicion of epilepsy. Usually EEG is also repeated before the decision to withdraw treatment after seizure freedom for 2-3 years (10).

7. CT Scan is indicated only in emergency.

In an emergency, CT Scan might be advised to rule out bleeding in the brain etc. But if the child is stable, it is **preferable to do MRI Scan** to look at the structure of brain in detail. It may pick up prior brain damage or developing problems like neurocysticersosis, tumors etc. It also helps to find out a lesion which can be surgically removed to treat the epilepsy (11).

8. MRI scan may be normal in epilepsy

MRI may be normal if there is only electrical disturbance and no structural problem, i.e. in genetic/idiopathic epilepsies. Your doctor will decide whether a scan is required at all (11).

4.4 First Aid for Seizures

1.Recovery position when a child gets a seizure.

Most seizures are of short duration and will stop by themselves.

Hence one should not panic and remain calm. The child should be brought **away from any danger**(e.g. on road, on edge, near any sharp objects etc.).

The child/person should be put in **recovery position**, i.e. the child is turned to one side gently so that whatever froth / saliva comes out from the mouth gets drained by gravity and is not inhaled into the lungs.

No attempt should be made to hold down a seizing child (12).

Recovery position (courtesy Action Epilepsy India)

2. The mouth should not be opened forcibly.

Sometimes teeth may be tightly clenched and tongue may get bitten. However, during the seizure, if one tries to open the mouth forcibly or insert a finger into his mouth, it might cause further injury.

Only if the child was eating something prior to the seizure, and the mouth is full of food, the finger can be inserted between the cheeks and teeth and any food particlesgently removed (12).

3. Nothing should be put in the mouth, like water, tea, milk.

4. If possible, a video recording of the event should be taken.

5. First aid medicines to stop the seizure.

There are different ways to give medications to abort the seizure. A **Midazolam nasal/buccal spray** is available and easy to use. Your doctor will demonstrate how to use it, how many puffs are to be given. This can be used if the seizure does not stop by itself within3 minutes. (13)

[redacted]

Midazolam nasal/ buccal spray is available,

It can be used in an approximate dose of 2 (e.g. 1 spray in each nostril) for every 5 kg body weight.

e.g. In a child weighing 10 kg, 2 puffs in each nostril can be advised.

The nozzle can also be directed towards inner wall of cheek (buccal use) if not possible to give in nose.

Other rescue medications include Diazepam suppository, rectal injection of diazepam solution etc.

It is important to shake the spray bottle before use. The base around the nozzle needs to be pushed downwards to release the spray, depicted by the arrows in the picture. Before spraying into the nose or buccal area, 3 puffs have to be sprayed into the air, away from the patient, to prime the dispenser.

The rescue medication should be stored in such a way that it is readily accessible in case of a seizure- e.g. in custody of school nurse.

However, it should be ensured that it is not readily accessible to children as there is a potential for misuse. Prior demonstration should be given to the nurse and teachers about how to use it in case of prolonged seizure till help arrives. The expiry date needs to be periodically checked (usually 2 years from the date of manufacture) and replaced when expired.

4. Call an ambulance or shift to nearby hospital if prolonged seizure

If the seizure is prolonged, i.e. lasting five minutes or two minutes longer than their usual seizure, if child is unconscious for a prolonged period after the seizure, has got injured badly, or has trouble breathing, you should take him to the nearest hospital (rather than the best, if far) (12).

5. Sometimes, patients may be able to feel the warning signs- aura.

If seizures are arising from a particular part of the brain, some children/persons can feel the onset of the seizure before becoming unconscious. This is called an **aura**, which includes tingling, flashes of light or darkness, vomiting, pain in tummy, headache, sudden crying etc. If the seizures cause unconsciousness from the onset, child may not feel the aura.

6. Most seizures are short lived. They are dangerous if prolonged.

Most parents have this question at the back of their mind. Although seizures are very frightening events, most are short duration. However, prolonged seizures or accidents such as burns, drowning etc. during a seizure can cause death (14).

7. All caretakers should be well versed in first aid.

People in child's contact- family members,school teacher, personnel ferrying him to school etc (15).

8. Measures to prevent seizures.

Adequate sleep is important. Avoid TV, flickering lights if EEG shows increase in abnormal discharges during light flashes. If child is put on medications, he should be supervised to never miss them. If seizures occur only during fever, medicines are prescribed to be taken during fever (16).

9. Myths: Use of onion, shoe, keys etc. to stop the seizure.

These measures waste precious time. **Bringing patient to recovery position is most important**. Most seizures may stop by themselves, hence it appears that these measures have helped. Putting hard objects forcibly into the mouth to 'break' the seizure may be harmful and can break the teeth or cause oral soft tissue injuries (17).

10. Treatment for febrile seizure

Most febrile seizures are brief and stop by themselves.

The child should not be covered as this may cause a further increase in fever. If the child has high grade give anti-fever medications like paracetamol according to dose prescribed by your doctor- every 6 to 8 hourly to make the child comfortable.

Use first aid if seizure is prolonged (18).

4.5 Treatment of Epilepsy

1.Does the child need treatment?

Treatment in epilepsy is given to prevent seizures. Depending on the type of epilepsy your child has, your doctor will decide if your child needs medications.

2. How long should the child be treated

Anti-epileptic therapy is for a prolonged duration.

Anti-epileptic medications are the main stay. Your doctor will decide the duration of treatment needed.

Anti-epileptic therapy is given usually for a period of 2-3 years of seizure freedom. Anti-epileptic medications are the main stay. The doctor decides the duration of treatment needed- it varies according to cause of epilepsy and ease of control of seizures.

Certain type of seizures may not require prolonged treatment

Some seizures like febrile seizures happen only during fever and may need no additional treatment. Certain types of epilepsies where seizures are infrequent and the chances of child getting a seizure again are very low also might not need prolonged treatment.

Prolonged treatment is usually not required for febrile or very infrequent seizures.

Febrile seizures happen during fever, so these children are usually prescribed medications only during fever. Prolonged treatment may be required if the seizures are frequent or prolonged.

3. Medications are chosen by the Doctor on the basis of seizure type on history and EEG.

There are multiple anti-epileptic drugs available. Which drug is right for your child is decided by the type of seizure - i.e. according to clinical details and EEG findings.

4. Treatment should not be stopped during other illnesses.

Children frequently suffer from cough, cold, fever, diarrhoea etc. The anti-epileptic medicines should be continued even during the illness. If the child is not accepting anything orally due to sickness, consult your doctor immediately.

5.Drugs should not be stopped without consulting the doctor.

The doctor is the best judge to decide when the medicines should be stopped . in your case. The medicines are mostly given for 2-3 years seizure free period, but the duration could be shorter or longer depending on the type of seizures and epilepsy. The treatment should never be stopped on your own. Antiepileptic drugs are usually tapered slowly and then stopped under the supervision of the doctor.

Follow up at least every 3 months is needed, while child is on antiepileptic drug therapy to monitor forside effects, drug dose titration, seizure control, decision regarding stopping/tapering of drug, etc.

6. The dose has to be titrated till seizures are fully controlled.

The doctor chooses the drug according tothe seizure type. Initially, low doses are tried to minimize side effects. Many children may be well controlled on low doses. Some may throw a brief seizure, which will prompt the doctor to increase the dose. The dose can be gradually increased to a level where seizures are controlled without causing any significant side effects.

7. First medicine is effective in 60% patients.

Due to the nature of epilepsy, the first drug may not work even if carefully chosen, in upto 40% of children. Then the doctor will choose another suitable drug. The chances of response become lesser as more drugs need to be tried to control epilepsy.

8. Cure of epilepsy is variable. Some patients may relapse after stopping treatment.

60-70% of children become seizure free with 1-2 anti-seizure medications. After a period of 2-3 year seizure-free period, the drugs are tapered off and stopped. The majority of such children remain seizure free however, some may relapse and would need to be restarted on anti-seizure drugs. Some patients may require very prolonged periods of treatment - e.g. in children with severe brain damage. Some types of epilepsies that start in adolescence- e.g. Juvenile myoclonic epilepsy (JME) may require lifelong treatment. They are easily controlled on low doses, but seizures reappear as soon as drugs are stopped (19).

9. These medicines alter the electrical activity of brain.

These medicines are chemicals which block certain electrical discharges in the brain.

10. Some basic knowledge regarding these drugs is essential.

They should be given regularly, which common side effects to watch for etc. This is discussed further under next section.

4.6 Anti-epileptic Drug Therapy

Precautions while giving anti-seizure medicines.

The doctor will prescribe the generic name, brand, dose, timing and expected side effects.

While buying it must be ensured that the drug matches the prescription exactly. It is not advisable to change the brands frequently as they may lead to change in the blood levels to higher,(causing side effects) or lower (causing loss of control of seizures). If the prescribed brand is not available, please verify with your doctor (20).

Medicines must be purchased in the prescribed form-**plain tablets**or **sustained release**(which can be given once or twice a day).Please note that the chrono/SR_ sustained release formulations have to be swallowed whole, as if they are chewed, they will lose efficacy. If child vomits within half an hour of taking the dose, it should be repeated.

Timing of the medications should be strictly adhered to.As it might be difficult to remember whether medication has been taken or not, it is advisable to mark on a calendar as soon as dose is taken.

For **Syrup** preparations, dose is in millilitres (mL). It is advisable to use a calibrated syringe or medicine dispenser to measure the dose exactly in ml. Plastic caps have only 2.5 and 5 ml markings, leading to inaccuracies. The bottle should always be shaken before use.

Common side effects should be discussed and reported.

Each drug has its own set of acute (seen within hours to days) and chronic (takes days to months) side effects.

Some drugs may cause sleepiness, vomiting etc. These can usually be controlled on reducing the dose and increasing gradually.(21)

Some people have a genetic tendency to develop severe reactions in the form of **skin rash**, extensive skin peeling with affection of mouth and eyes.This is called **Stevens-Johnson syndrome**, which can be life-threatening. Hence, any drug should be stopped if any rash is noticed and the doctor should be consulted immediately.

Genetic test to detect HLA B1502 mutation is available, your doctor may advise you regarding this if using particular drugs. However, this mutation is rare in India, and the side effect can be seen even without this mutation. This test is also very expensive, and is not advised routinely.

In the long term, most will reduce Vit D in body causing weak bones, hence routine Vit D and Calcium supplements may be required. Many drugsmay cause slowing of thinking processes.

Please ask regarding any specific side effects to be watched for the drug prescribed to your child.

Follow up is required at frequent intervals.

Usually, the first follow up should be after 15 days to a month after starting the medication, to look for any acute side effects. After that, 3 monthly follow up will be good to assess seizure control as well as monitor for side effects. Your doctor will ask you to maintain a seizure diary.

Other options are available if medications fail.

In some rare cases, special treatments like Ketogenic diet and Steroids (e.g. for spasms) may be prescribed. The doctor will usually investigate further to rule out metabolic/genetic conditions.

Sometimes, surgery may be suggested.

Surgery may be advised if there is a specific abnormality in the brain structure picked up on MRI scan, seizure frequency is high and child is not responding to anti-epileptic medication.

4.7 Issues in School

1.Epilepsy and anti-epileptic drugs may affect child's learning at school.

If previous brain damage is the cause of epilepsy, e.g. due to meningitis, the child/person may have pre-existing intellectual deficits.

Untreated seizures for prolonged periods may also affect development of the child and have a negative effect on his learning.

Most brief seizures do not affect intelligence. Many anti-epileptic drugs also have effect on higher order thinking skills, but that risk is minimal with newer drugs.

2. Help is available for improving the school performance.

Learning difficulties are commonly seen and need remedial guidance. This is best done by interventional psychologist, school counsellor, taking school authorities into confidence.

3. Schools cannot discriminate against a child with epilepsy.

Nobody can expel a child from school for epilepsy, under the Right to Education Act. Discriminating against anyone on the basis of epilepsy is an offence.

4. Social and financial resources are available.

Financial implications of treatment, help with NGOs, funding agencies etc. are covered in other groups, will be added in brief after their inputs.

5. The school should be adequately informed about the child's epilepsy and first aid.

The school should be explained about the the first aid to control seizures for the child's safety.

The Midazolam spray should bekept in the school with school teacher or in the sick roomwith the number of puffs to be given and your number written on it prominently for contact in emergency. You can co-ordinate beforehand with a hospital near the school, so the school authorities can take the child there if the need arises. They should be assured that they have your consent and will not be blamed as acting in the best interest of the child.

You can take a letter from your doctor to your school class teacher and Principal to allow him in the school and for any reassurance needed.

6. Precautions to be taken during outdoor activities.

If the seizures are well controlled, they should be encouraged to participate in all extra-curricular activities. All regular medications should be taken on time, avoid sleep deprivation and carry the first aid medications. Pre-identify nearby hospital for emergency treatment, if the need arises.

7. No blanket restriction of activities is advisable.

There is no blanket restriction on activities, but if the seizures are not well controlled, it is best to do cooking and swimming under supervision.One on one supervision by one of the parents or a coach in the pool with the child is best.Cycling on the roads may be avoided.

4.8 Special Issues

1. Activities which may need to be restricted on case to case basis.

Teenage children with uncontrolled seizures should not be allowed to drive two wheelers, Everyone should be encouraged to use a helmet (as recommended for everyone else).

Those children/people with abnormal discharges provoked by flashing lights or patterns (on EEG) should avoid exposure to flickering lights e.g. Discotheques , night driving etc.

For driving cars, regulations vary from country to country.

2. Some jobs may be unsuitable for patients with photosensitive epilepsy.

Except for some jobs like pilot, running heavy machinery, firefighting etc. which can be a threat to them and others in the situation of a seizure, most jobs are available for people with epilepsy. Those children/people with abnormal discharges provoked by flashing lights or patterns (on EEG) should avoid exposure to flickering lights e.g. Discotheques, etc.

3.Special issues in females with epilepsy.

Each person with epilepsy is different. Some epilepsy types like Juvenile Myoclonic Epilepsy need treatment all though the productive and reproductive years. Due to the stigma associated with this condition, many people hide the fact from their spouses which complicates the situation. This leads to increased rates of divorce later. It is best to be honest to avoid such complications.

Females may have additional issues of reproductive health- e.g. choice of contraception, choice of anti-epileptic drugs during pregnancy etc. They can have uneventful pregnancy and healthy child under expert guidance. It is important to make them self-sufficient and educated so that they are not exploited later.

Sanvedana Foundation provides matrimonial servicesand support for people with epilepsy. They can be contacted at - www.sanvedana.org.

4. Even if genetic, there may be no family history of epilepsy.

Even in genetic epilepsies, family members may not be affected at all, or have different types of seizures. These abnormal genes may also remain silent in few generations.

5.Some prevalent myths regarding epilepsy in our society.

Not all funny movements are fits or seizures. Epilepsy does not spread from person to person. Epilepsy is not due to prior sins/ black magic/devils etc.As epilepsy was poorly understood in the past, many myths are prevalent. Epilepsy is controllable by drugs when chosen scientifically.

7. Role of alternative therapies like homeopathy, Ayurveda, Unani , and others is not well established.

8. Vaccination should be done routinely, except in specific conditions like West Syndrome

A child with epilepsy should be vaccinated like any other child. However, if your child has uncontrolled seizures or on multiple anti-epileptic medications since infancy, your doctor may decide to avoid certain vaccines like Pertussis (the 'P' in DPT)

9. Leisure activities e.g. swimming should be done under supervision e.g.Buddy system can be followed where every child is being watched by someone- this helps them feel as equal to others, as well as increases everyone's safety in water.

4.9 Family Issues

1. Epilepsy may be associated with behavioural, mood and depressive disorders.

Many children with epilepsy suffer from low self-esteem. They should be encouraged to speak about their concerns. Counsellors at Child Guidance Clinic and school can also help. Some anti-epileptic drugs can cause depression, mood disturbances and even suicidal tendencies. The doctor should be apprised in case these issues arise. Child may be referredto a Psychiatrist, if required.

2. Avoid overprotection.

Parents of children with epilepsy should avoid being overprotective, as this might give rise to more behavioural problems. The child should be cared for and disciplined like any other child. Parents have to be strict regarding medications and appropriate attention should be given to his/ herstudies. Good physical exercise, exposure to sunlight and participation in family functions, and social gatherings must be ensured to prevent feelings of loneliness and isolation.

3.Will his brother/sister also get epilepsy?

Epilepsy does not spread from person to person. Some types may have a genetic basis but the siblings may not have inherited the genes predisposing to seizures. Even if they have inherited, it is not necessary that seizures will occur in everyone who carries those genes.

4.Please do not victimize the siblings.

Sometimes, the child with epilepsy may be getting more attention, thereby neglecting the other kids. This may create frustration in them. Also, they may have some unspoken anxiety and concerns about their sib with epilepsy. It is important to talk to him/her in detail what the concerns; they can be involvedin the care plan, and be taught first aid in the event of as seizure if old enough to understand. Help of school counsellor and psychologist may be taken.

5.Epilepsy, cerebral palsy, autism etc. are not the same.

All these are different manifestations of brain dysfunction. Cerebral Palsy mainly affects muscles thereby affecting a child's mobility, posture etc. Cerebral palsy is usually associated with structural brain problems.

Autism is diagnosed when a child has difficulty in interaction and communication. Usually they do not have any structural brain issues.

Both these conditions have a higher prevalence of epilepsy. Both of them may also be associated with intellectual disability.

6.Some causes of epilepsy can be prevented.

By preventing some causes of brain damage: Wearing helmets(reduces severity of head injury in accidents), Washing fruits and vegetables thoroughly (Prevents Neurocysticercosis), Vaccinating children against brain infections (HiB, Pneumococcal, Japanese encephalitis, BCG)

7. Death due to Epilepsy

Rarely, there may be sudden death in sleep, especially if seizures are not well controlled. The causes are still being investigated.

5 EPILEPSY IN MULTIPLE DISABILITIES

5.1. Children with Multiple Disabilities

Children with multiple disabilities have impairment in cognition, motor or sensory function. Cognitive impairment results in difficulty in learning, and abstract thinking. Motor difficulties result in limitation in mobility, sitting or standing. From child's aspect there are four needs: medical, physical, learning and social emotional needs. Social emotional needs pertain to relationship and membership in community.

5.1.1.Epilepsy in children with multiple disabilities

a. Burden of epilepsy in children with multiple disability.

In a community based survey in rural and urban areas of Lucknow, 4801 children aged 6 months to 2 years were screened for epilepsy, global developmental delay, motor, vision and hearing deficits. (1) Among the 196 screen positive children, 40 children were screened positive for epilepsy. On detailed examination of these 40 children, 11 had single seizure, 11 had febrile seizure, and in rest there were no seizure. Global developmental delay was detected by screening in 43 children, of whom 2 children had GDD with epilepsy and one child had GDD with motor deficit and epilepsy. This yields a prevalence of 6.42 per 1000 children.

In another population based study among individuals in rural and urban districts of Bangalore, prevalence rate of neurological disorder among children aged less than 15 years was 2653 per 1,00,000 population. (2) Crude prevalence rate of epilepsy was 883 per 100000 populations. Among 3206 individuals screened positive, 228 (7%) had more than one neurological disorder. However data on prevalence of epilepsy in multiple disabilities has not been mentioned. In a study from Pakistan, prevalence of disability in children less than 2 years and 2-5 years is 5.5 (3.9-7.3) and 5.4 (4.5-6.4) out of 1,000 children respectively. (3) In this study, prevalence of epilepsy was seen as 1.09 out of 1,000 children in age less than 5 years.

6.1.2 Types of seizures and its inherent refractoriness

Seizures in children with “multiple disabilities” are often of different types, prolonged seizures leading to status epilepticus. Types of seizures include myoclonic seizure, spasm, by doctors, social workers and educators is to achieve adaptation to daily functioning, to allay fears and negative reaction, to improve intrafamilial relation, integration in school and finally ensuring good compliance towards drugs.

Box 1

Co-morbidities of children with epilepsy and multiple disabilities

1.Sleep problems: Insomnia, sleep apnea, poor sleep quality, daytime hypersomnia
2.Gastrointestinal: GERD, GI side effects of AED
3.Urological: Repeated UTI
4.Psychiatric comorbidity: ADHD, anxiety, depression, psychosis
5.Non epileptic event masquerading as epilepsy
6.Risk of injuries, physical abuse and child neglect

5.1.2 Existing Recommendations by experts/committees

- Guidelines for management of epilepsy in adults with multiple disabilities have been published by international association of scientific study of intellectual disability. (5)

- Consensus guidelines for management of epilepsy in adults with intellectual disabilities. (6)

- Scottish guidelines for people with profound and multiple disabilities (7)

- Indian epilepsy society: Epilepsy and law (8)

5.2 Need of the Hour

a. There are no guidelines for management of children with multiple disabilities to the best of our literature search. Hence we need to frame these guidelines to standardize the procedure for best possible care to children with epilepsy and multiple disabilities.

b. ***Step 1***: We need to identify the terminology for population under study like “children with multiple disability-epilepsy” or “children with epilepsy and multiple disability”

c. ***Step 2***: Define “Children with epilepsy and multiple disability” defined as “Children aged 1-18 years with two or more than two disability as notified by government of India along with presence of epilepsy (ILAE definition).

d. ***Step 3***: Identify the challenges faced by this group of children in terms of physical, psychosocial, educational challenges

e. ***Step 4***: develop recommendations for essential components of care to be provided to children with epilepsy and multiple disability. Essential component of medical care includes responsibilities of doctors, social workers and parents.

5.3 Certification of Multiple Disabilities Including Epilepsy

Formula for combining multiple disabilities

Total disability= a + b(90-a)/90

(a=higher score; b=lower score) [maximum score cannot exceed 100%]

In case of multiple disabilities, it will be arranged from highest to lowest and disability score calculated using above formula in sequence. in. It is essential to realise that epilepsy adds to multiple disabilities. **Box 2** outlines the disability scoring for epilepsy under the earlier Persons with Disabilities Act. However, this act has been replaced by Right of Persons with Disabilities Act 2016, which does not include epilepsy as a separate disability and the scoring for epileptic convulsions has been removed.

Box 2: Indian gazette notification (June 2001) outline procedure for disability certification for convulsive seizures and post head injury fits

Frequency of convulsion	Severity	Percent disability
Only one convulsion	Mild	Nil
1-5 convulsion per month on adequate medication	Moderate	25%
6-10 convulsion per month on adequate medication	Severe	50%
More than 10 convulsions per month	Profound	75%

5.3 Elements of Counselling by Doctors

5.3.1 Counselling

Counselling is a formal procedure in which both counsellor (doctor) and parents aims to find a mutually acceptable plan of adjustment. It is a continuous process and not a onetime event. Counselling is the support provided to the family when diagnosis is delivered. Parents of children with multiple disabilities are stressed about the future of their child. Studies have revealed that higher behavioural problems and care giving demands of children with disability were associated with lower level of physical and psychological wellbeing of the caregiver (6). There is a strong relationship between caregiver's health and degree of disability (7).

5.3.2 Counselling regarding diagnosis

Majority of parents (more than three fourth) come to resolution or acceptance of diagnosis by 18 months of their child age. Unresolved reactions of parents were significantly more among those with severe motor disability. Parents often experience great difficulty in obtaining information about the condition creating a feeling of helplessness. Owing to lack of adequate information, parents often end up fishing search engines like Google to retrieve information regarding the diagnosis. Barriers to delivery of complete diagnosis include lack of sufficient time spent per patient, lack of written hand outs for reference, and prevailing ambiguity in diagnosis.

Recommendations for breaking of news

1. Know all facts about the patient record and investigations before you begin
2. Ensure privacy, encourage presence of both parents to counselling session.
3. Understand what and how much they want to know, use simple language
4. Accept parent's reaction, Allow denial, often the parent's reaction to diagnosis of disability is denied; empathize their feelings
5. Go slow, explain step by step, pause, let parents speak, deliver only when they want to know more
6. Allow time for parental concerns, encourage ventilation of their feelings
7. Outline plan of treatment, follow up plan, need for further investigations if necessary

5.3.3 Why did it all happen?

Determining the etiology and explaining to parents in a clear and unambiguous manner is essential to initiate meaningful efforts in rehabilitation. It is quite natural for parents to look for cure, shunting from one physician to another physician. Explaining the etiology for the disability is quite challenging. At times, the answer could be straight forward as in perinatal asphyxia, prematurity or kernicterus. Etiology could be determined in only 54.1% of children presenting with intellectual disability with majority of them resulting from perinatal/neonatal causes. Yield of diagnosis in children with intellectual disability was shown at 82.1% using algorithmic approach. (9) Among the neonatal-perinatal insult, care should be exercised to avoid blame on obstetrician or neonatologist. Avoid words like “defect is there right from the womb” [This leads to blame on mothers].

Few neurological conditions remain undiagnosed despite extensive work up. This should be openly discussed with parents that it is still unclear as to why it all happened. Genetic conditions where available should be offered to parents explaining the cost, limitation and utility of such investigation in management of index case and predicting the recurrence risk in future pregnancy. The term 'genetic conditions' often results in confusion in parents as the word 'genetic' in lay man language refers to “defect in parent so baby is abnormal”. This often results in denial as they perceive that all their family members are healthy.

5.3.4 Understanding the pathogenesis

One of common encountered question in children with refractory seizure is “I am giving medicines for seizure, why is not controlled? Explanation of types of seizure, nature of seizure, and underlying mechanism of seizure often helps educated parents to understand the underlying mechanism. This will help them comply with medication. Most of the seizures are self-limited, last for few minutes and are not life threatening. “Your child might have different types of seizures. Some of them have just a head drop, some might result in sudden fall”

5.3.5 Planning investigations

Cost, intentions, utility, limitation and need for further testing must be emphasized at the time of planning investigations. It would be good to provide a handout of what, how and why of electroencephalography (EEG) as an investigation. This might take care of common misperceptions like EEG will read your thoughts; EEG recording might give electric discharges and so on.

5.3.6 Disability is a life long journey

The most difficult question to answer is “when will my child get alright?” It is rather difficult but essential to explain that disability is a lifelong journey. Development of local parent support group for each condition could alleviate the fear and provide comfort. Motivated parents with higher experience could encourage the parents of new cases. This parent to parent counselling, sharing of their experience could help them sail through this life ling journey.

5.3.7 Delay in diagnosis and early intervention

Early intervention programme have shown benefit in cognitive and motor outcomes during infancy and long term IQ scores. In a study by Jain et al., (10) it was shown that children with spastic quadriplegic cerebral palsy, hearing impairment, vision impairment and multiple disabilities have an early presentation rather than late presentation. Despite such evidence, large number of children with multiple disabilities has a time lag of 6-12 months before reaching the final diagnosis. This window of missed opportunity should be handled with care to avoid guilt, blame and resultant parental dispute.

5.3.8 Terminology

Few words like 'mental retardation', 'handicapped child', 'permanent problem', 'no available treatment or cure' are strongly discouraged during the conversation with parents of children with multiple disabilities. Few phrases that help parents sail through this journey include 'the problem does improve with time and therapy”, “medicines work to control the seizure” “better is the seizure control, better does his brain functions”

5.3.9 Resource material

Provide written information pertinent to the condition. Providing condition specific resource material as patient information sheet would help parents go through relevant literature rather than building knowledge through stray or anecdotal experience shared in public domain.

5.3.10 Handling parental reaction

Parents go through stages of grief: shock, denial, numbness, depression and finally adjustment. Continued contact is essential rather than single visit and counselling sessions. Coping strategies for parents: spiritual support, medical support (learning more about the condition), social support (support from spouse, family, friends, neighbours). Child's adjustment and rehabilitation is dependent on family strength, weakness and emotional reactions.

5.3.11 Transferring from Pediatruc to adult medical care

Majority of hospitals in India have continued pediatric care till 14-18 years. Transition to adult medical care beyond the age of 18 years of children with multiple disabilities is quite challenging. Timing of transition could begin early among children with chronic and severe epilepsy like Lennox Gestaut syndrome.

In a study, it has been shown that nearly 22% of these young adults were still in pediatric care and 22% had no care coordinators. (11) Hence, transfer of care is essential to ensure smooth transition without drop outs. Transition clinic in adult neurology has been suggested by few authors where both the pediatric neurologist and adult neurologist address their issues. Large numbers of adult neurologist are rather uncomfortable with intellectual disability patients. Involvement of nurse specialist during transition would be beneficial considering better approachability of nurse when compared to physician. Involvement of social worker could address the psychosocial problems for patients and relatives. Early start, information provision, and joint consultation between pediatric and adult care could be of major help.

A joint consultation between pediatric and adult neurologist with paediatrician/pediatric neurologist providing a written complete transfer summary of the patient with multiple disability would be useful. As majority of the Indian patients are under follow up of multiple physicians it rather becomes very difficult to establish this transition. It would be good if general practioner or paediatrician who knows the family best coordinate with specialist as and when required. It would be good if transition happens to someone who is locally available for best continuity of care.

5.3.12 Daily household activities

There are few strategies that have been shown to facilitate participation in family activities of children and adolescents with profound intellectual and multiple disabilities (PIMD). The activity planned for the child should be physically adapted, and attractive. They should be planned considering the abilities of the child, interpreting child's signal, positive attitude of people close to child, giving a sense of belonging, and having encouraging attitude.

5.3.13 Sports activity

Participation of children in physical activity and community sports is essential for inclusion in society. However, large number of factors that determine participation of children with multiple disabilities in sports: GMFCS functional status, type of seizure, medication side effects and his ability to follow instructions in the sports. Despite motivated parents, children with disabilities often face barriers like lack of trained instructor, negative societal attitude, lack of opportunity and high cost. PIMD children are at high risk for injuries with outdoor sports activity. Swimming is often discouraged among those with poorly controlled seizures. Playing with friends under supervision of caregivers is acceptable. Wearing head gear helmets made of soft material would enable PIMD children with refractory seizures to participate in supervised outdoor activities.

Recommendations: Supervised outdoor and indoor sports activity should be encouraged. Special precautions include wearing additional protective devices like head gear helmet especially among those with refractory seizures.

5.3.14 Parent support group

Impact of diagnosis on family includes stress, depression and anxiety levels. These factors often lead to parental reluctance to seek professional help. (12) Creation of parent support group and interventions targeted at parents of disabled children to manage their child's behaviour have shown promising results and is cost effective especially resource limited setting. Parent to parent counselling session enabling parents to help other parents in analysing the ability rather than disability

5.3.15 Domiciliary management of seizure

Children with multiple disabilities are more likely to have medically refractory epilepsy, and required to be counselled as such. Domiciliary management of prolonged seizure includes use of midazolam nasal spray. Explanation of recovery position during seizure needs to be explained. Reassurance that most of the seizure are self-limited and does not impair the brain further. Importance of drug compliance needs to be ensured. Non compliance should be dealt with pragmatic, non incriminatory approach. Few antiepileptic medications related FAQs that need to be addressed especially among children with multiple disability. [see section on counselling]

a. Risk of sudden drug withdrawal needs to be emphasized to children/parents

b. Drugs especially in polytherapy needs to be adjusted according to the school timing with parents

c. One can choose to avoid drugs with sedative side effects according to school timing

d. If sustained release tablets are available and feasible, can reduce the daily schedule to twice a day

e. If child is unable to swallow and parents are crushing the tablet, then it is a better idea to give syrup rather than breaking enteric coated tablets

f. Drugs with behavioural side effects should be used with caution especially among children with multiple disabilities

g. FAQs can be added to patient information booklet being provided to patients.

h. Prefer monotherapy over polytherapy. Decrease the number of medication to two to three if possible. Drug that did not work, can be tapered.

i. Time gap between the medicines can be decided with parents based on parents feasibility

j. Possible effect of antiepileptic drugs on menstrual cycle

5.3.16 Academic expectations

Majority of children with multiple disabilities including epilepsy need individualized special education program. Individualized program should be designed with involvement of parents. Regular appraisal of school performance is essential to note the progress. If there is a recent onset of deterioration in school performance following commencement of any antiepileptic drug, the implicated AED could be replaced.

Educational challenges among children with multiple disabilities include difficulty in ability to communicate with peers, teachers, and support staff, and limited capability to function in classroom. They often need compensation for visual and hearing impairment.

5.3.17 Disclosure

Many parents have disclosure fears at the outset. Disclosure of multiple disabilities could lead to their ward being isolated, discriminated from other children. Privacy should be respected, if parents wish not to inform the relatives or school authorities. This is often decided considering that disclosure might lead to societal discrimination and stigma. However, it is quite difficult to do the same among children with evident multiple disabilities.

5.3.18 Use of assistive devices:

There are large number of assistive devices like self-help devices (e.g., bath chairs and feeding tools), special toys and switches, assistive listening devices (e.g., hearing aides), augmentative communication devices (e.g., picture communication boards or computer driven voice output devices), and mobility (e.g., power wheel chair, walkers) and positioning devices (e.g., standers). Prohibitive cost and poor access to these assistive devices among children with multiple disabilities is a major hurdle. Availability across the government centres would probably help these children with better adaptive skills.

5.3.19 Care in nuclear family

Respite is required among parents of children with multiple disabilities in nuclear families with working parents. Social worker would immensely benefit and help parents in providing continued care of their child even during their working hours and absence. They could coordinate with agencies/ non-governmental organization/crèche services who could render their help for working parents.

5.3.20 Economic burden

Care of children with multiple disabilities would impose a major financial burden on families. Majority of children with ID-epilepsy are on multiple antiepileptic drugs that are often not available even from government hospitals and pharmacy. There must be provision to procure these medications for those with multiple disabilities.

5.3.21 Risk assessment

All children with epilepsy and multiple disabilities must have a risk assessment depending on each individual, effect of epilepsy on cognition, risk of injury, severity of epilepsy, quality of life and environment surrounding them. This might help them have improved quality of life. For example, a child with infrequent and well controlled seizure who has good motor and cognitive abilities can be classified as at "low risk"

5.4 Elements of Counselling by Social Worker

Social worker must be appointed in each hospital both government and private sectors to ensure smooth functioning of epilepsy services to children with multiple disabilities. Focus of social worker would be to integrate the child in society. Integration in the community would require access to rehabilitation services, certification of disability, ability to avail the government benefits pertaining to disability. Community based rehabilitation is required for children with multiple disability. Integration and acceptance into society and their family is their main goal. Discrimination is often faced by children with disability. It has been shown that boys with epilepsy had limited peer group activities, and parents conferred fewer responsibilities to them. Children with better cognitive functions can feel shame and embarrassment in society. It is important to analyze his adaptive functions so as to find social opportunities where the child can fit in.

Functions of social workers

1. Reinforcement of the doctor's advice, regular therapies and medication
2. Demonstration of first aid for seizure. It could be a preprepared video that could be displayed while patient is waiting for his turn to meet the social worker.
3. Provision of information on special schools, government benefits, day care centres, support groups, contact persons for availing benefits to the parents
4. Explain the procedure for certification
5. Address concerns on disclosure, discrimination, school admissions.
6. Help create buddy system in schools
7. Orientation of social workers towards special requirement of these children

5.5 Instruction to Parents, Teachers and/or Caregivers

Many of these points are also common to children with epilepsy alone.

1. Physical safety: Ensuring physical safety of the child is essential. Removing physical barriers and making the classroom disabled friendly. Teachers should be explained regarding the chances of recurrence of seizure. They should be explained about the recovery position during seizure and use of intranasal midazolam during the seizure (Prehospital seizure management). They often refuse considering risk to life. It is important to convince them that majority of seizures are self limited and does not lead to threat to life.

2. Educating the school teachers regarding the epilepsy. Removing the stigma associated with epilepsy and multiple disability. It is essential to sensitize them that it is not a contagious disease. Other parents might raise an objection to sending their child to a school where children with multiple disabilities are taught. They perceive that their child might start behaving like him.

3. Involvement of non-governmental organization in implementing integrated education system for children with disability.

4. Capacity building to train teachers to work in inclusive setting with involvement of parents and the community person to improve their education.

5. Designing infrastructural facility accommodating to the needs of children with disability.

6. Setting up curriculum and educational material for children with disability and to look for alternative system of examination.

7. Vocational training, life skill training and recreational activities are essential for children with disability.

8. Awards for special educators and teachers involved in improving education for children with disability. This acts as an incentive to perform higher.

9. Educating the society through media and removing the common notions pertaining to epilepsy and multiple disabilities.

10. School authorities could retain a list of mainstreamed children with their contacts so that parents can interact.

11. Infrastructure enhancement: Availability and use of assistive technology, Augmentative and alternative communication method tends to compensate for limited verbal communication. It includes photographs, symbols, letters to speech technology like read aloud documents with use of laptop, computer, use of sign language.

12. Priority seating, alternative books like audio/Braille for children with disability based on his adaptive functioning.

13. It would be ideal if the teacher set in short term goals for individual child.

14. There should be an effective system of recording and maintaining progress report of child, infrastructural improvement, etc.

6. AIR TRAVEL FOR CHILDREN WITH EPILEPSY

6.1 Air Travel Permissions

6.1.1 Introduction

Air travel is now increasingly used in our country, and there is often a concern by parents regarding safety and feasibility of air travel for a child having epilepsy.

In a 2002 study, seizure was the second most common inflight neurological incident following dizziness and vertigo (1).

6.1.2 Safety of Air Travel

2 important issues are:

Can flying precipitate seizures?

Currently, there is no evidence that air travel increases any risk of breakthrough seizure.

There is no correlation of increased seizures with either of total distance travelled, time zones crossed, duration of flight and direction of flight. Air travel promotes an increase in seizures only for those with a relatively high baseline seizure frequency and a prior history of flight related seizures (2).

However, some people's seizures are precipitated by
- Fatigue – which may occur because of long journey or jet lag.
- Excitement, worry or anxiety. Some people may have these when they travel by air.
- Delayed or irregular meals
- Potential hypoxia

Thus, parents need to be made aware of the factors which can lower the seizure threshold, and try to avoid them as best as they can.

As a precaution,

- Parents should notify the flight attendants during boarding that their child has a seizure disorder.

- Antiepileptic medication should be readily available (i.e., in carry-on luggage). Air travel and children's health issues(3).

What happens if seizures occur during the flight

According to the***Aerospace Medical Association Medical Guidelines for Airline Travel (4)on neurological conditions: Epilepsy (seizure disorder, convulsive disorder)*** themajor risk consideration of inflight seizures, especially generalized tonic clonic seizures, in confined aircraft cabin conditions,are:

- compromised airway maintenance
- risk of fractures and dislocations.
- risk of status epilepticus

Since anticonvulsant medication is not a common component of airline medical kits, emergency aircraft diversion may be necessary.

6.1.3 Laws and Guidelines in Our Country

There are no additional legal or support systems, or special guidelines peculiar for children with epilepsy in this age-group regarding air travel; the guidelines applied are the same as for adults.

Since children are usually accompanied by parents who are familiar with emergency seizure management for the child, it is likely safer as compared to adults travelling unaccompanied.

For children travelling alone under care of flight attendants, disclosure about the child's condition and emergency management must be explained to the airline staff on the flight before travel.

International Air Transport Association (IATA) guidelines regarding air travel in persons with epilepsy (5).

The airlines in India comply with the IATA guidelines, which recommend that

- If a person had a tonic-clonic seizure less than 24 hours before your flight, he would need medical clearance to be allowed to fly.

- If seizures are generally well controlled, with or without medication, usually medical clearance is not needed.

6.1.4 The following recommendations are made by the group

A. For well controlled seizures:

Patients with complete seizure control prior to flying are unlikely to have seizures during or after flying.

However, parents' education should include:

- Information about lowered seizure threshold due to fatigue , irregular meals and jet lag [Para 4.2(a)]

- Strict medication compliance. Alarms may be set to ensure that the medications is being given at correct intervals rather than according to time zones.

- For long distance travel an adequate supply of medication should be assured along with accessibility during flight, and should be sufficient to cover the duration of travel as well as a few extra days

- Rescue medication for acute seizures should be carried along

- Doctor's latest prescriptions must be carried along to avoid problems at customs

B. For uncontrolled seizures

Persons with frequent, uncontrolled seizures should be advised against air travel(1,6,7).

For persons experiencing one or more seizures in theprevious month, it is likely that there is only incomplete control, and air travel is not recommended.

6.4 Status in Other Countries

- There are general guidelines by Epilepsy Action on air travel for persons with epilepsy. In general, epilepsy is not considered as a barrier to air travel.

- The following link is provided for detailed information:
  https://www.epilepsy.org.uk/info/daily-life/travelling-abroad. (8)

GROUP RECOMMENDATIONS

i. The airline services should be equipped with Midazolam nasal spray/first-aid management of a prolong seizure.

ii. The airline staff should be trained for first-aid for seizure management.

iii. Airlines medical policy should be checked,and airlines informed of epilepsy status before and during travel.

Appendix 1

Right to Education Act

The **Right of Children to Free and Compulsory Education Act** or **Right to Education Act** (**RTE**) is an Act of the Parliament of India enacted on 4 August 2009 by 86th amendment in Indian constitution; and came into force on 1 April 2010.

It is a fundamental right for children that describes the importance of free and compulsory education for children between the age of 6 to 14 years in India under Article 21A of the Indian Constitution.

'Free education' means that no child, other than a child who has been admitted by his or her parents to a school which is not supported by the appropriate Government, shall be liable to pay any kind of fee or expenses which may prevent him or her from pursuing and completing elementary education.

'Compulsory education' is a paradigm shift that makes an obligation on the appropriate Government and local authorities to provide and ensure admission, attendance and completion of elementary education by all children in the 6-14 age group rather than the onus being on parents.

The provisions in the RTE Act enable out-of-school children from disadvantaged communities to be admitted to an age-appropriate class and complete elementary education upto class eighth. The Act facilitates a child admitted to an age appropriate class to be given Special Training to enable him or her to be at par with other children.

Appendix 2

RTE for Children with Disabilities

The Right to Education of persons with disabilities until 18 years of age is laid down under a separate legislation- the **chapter 5 of Persons with Disabilities Act, 1996** (Equal Opportunities, Protection and Full Participation) Act. The provisions in chapter 5 of this act are described as under:

I **Appropriate Governments and local authorities to provide children with disabilities free education, etc**.

Accordingly, Appropriate Governments and the local authorities will-

a. ensure that every child with a disability has access to free education in an appropriate environment till he attains the age of eighteen years.

b. endeavor to promote the integration of students with disabilities in the normal schools;

c. promote setting up of special schools in Government and private sector for those in need of special education, in such a manner that children with disabilities living in any part of the country have access to such schools;

d. endeavour to equip the special schools for children with disabilities with vocational training facilities.

II. **Appropriate Governments and local authorities to make schemes and programmes for non-formal education, etc.-**

The appropriate Governments and the local authorities shall by notification make schemes for-

a. conducting part-time classes in respect of children with disabilities who having completed education up to class fifth and could not continue their studies on a wholetime basis;

b. conducting special part-time classes for providing functional literacy for children in the age group of sixteen and above;

c. imparting non-formal education by utilizing the available manpower in rural areas after giving them appropriate orientation;

d. imparting education through open schools or open universities;

e. conducting class and discussions through interactive electronic or other media;

f. providing every child with disability free of cost special books and equipments needed for his education.

III. Research for designing and developing new assistive devices, teaching aids, etc.

The appropriate Governments shall initiate research by official and non-Governmental agencies for the purpose of designing and developing new assistive devices, teaching aids, special teaching materials or such other items as are necessary to give a child with disability equal opportunities in education.

IV. Appropriate Governments to set up teachers' training institutions to develop trained manpower for schools for children with disabilities.

The appropriate Governments shall set up adequate number of teachers' training institutions and assist the national institutes and other voluntary organizations to develop teachers' training programmes specializing in disabilities so that requisite trained manpower is available for special schools and integrated schools for children with disabilities.

V. Appropriate Governments to prepare a comprehensive education scheme providing for transport facilities, supply of books, etc. –

Without prejudice to the foregoing provisions, the appropriate Governments shall by notification prepare a comprehensive education scheme which shall make Provision for-

a. transport facilities to the children with disabilities or in the alternative financial incentives to parents or guardians to enable their children with disabilities to attend schools;

b. the removal of architectural barriers from schools, colleges or other institutions, imparting vocational and professional training;

c. the supply of books, uniforms and other materials to children with disabilities attending school;

d. the grant of scholarship to students with disabilities;

e. setting up of appropriate fora for the redressal of grievances of parents regarding the placement of their children with disabilities;

f. suitable modification in the examination system to eliminate purely mathematical questions for the benefit of blind students and students with low vision;

g. restructuring of curriculum for the benefit of children with disabilities;

h. restructuring the curriculum for benefit of students with hearing impairment to facilitate them to take only one language as part of their curriculum.

Appendix 3

THE RIGHTS OF PERSONS WITH DISABILITIES ACT, 2016 (NO. 49 OF 2016) [27th December, 2016]

This is an Act to give effect to the United Nations Convention on the Rights of Persons with Disabilities and for matters connected therewith and lays down the following principles for empowerment of persons with disabilities,—

a. respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons;

b. non-discrimination;

c. full and effective participation and inclusion in society;

d. respect for difference and acceptance of persons with disabilities as part of human diversity and humanity;

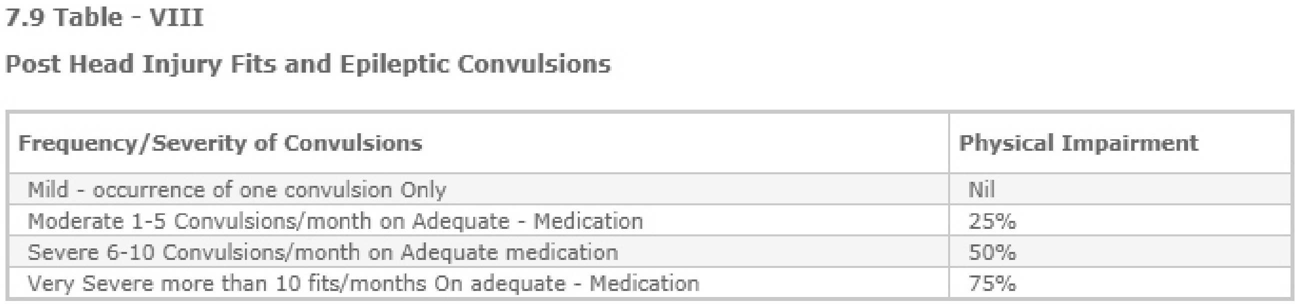
e. equality of opportunity;

f. accessibility;

g. equality between men and women;

h. respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.

Epileptic convulsions are recognised as a disability in this guidelines under the evaluation of physical impairment in chronic neurological conditions.



7.9 Table - VIII

Post Head Injury Fits and Epileptic Convulsions

Frequency/Severity of Convulsions	Physical Impairment
Mild - occurrence of one convulsion Only	Nil
Moderate 1-5 Convulsions/month on Adequate - Medication	25%
Severe 6-10 Convulsions/month on Adequate medication	50%
Very Severe more than 10 fits/months On adequate - Medication	75%

The matter concerning education are included in chapter III of the disabilities act 2016 and are as under:

I.The appropriate Government and the local authorities shall endeavour that all educational institutions funded or recognised by them provide inclusive education to the children with disabilities and towards that end shall—

- admit them without discrimination and provide education and opportunities for sports and recreation activities equally with others;

- make building, campus and various facilities accessible;

- provide reasonable accommodation according to the individual's requirements;

- provide necessary support individualised or otherwise in environments that maximise academic and social development consistent with the goal of full inclusion;

- ensure that the education to persons who are blind or deaf or both is imparted in the most appropriate languages and modes and means of communication;

- detect specific learning disabilities in children at the earliest and take suitable pedagogical and other measures to overcome them;

- monitor participation, progress in terms of attainment levels and completion of education in respect of every student with disability;

- provide transportation facilities to the children with disabilities and also the attendant of the children with disabilities having high support needs.

I.The appropriate Government and the local authorities shall take the following measures for the purpose of section 16, namely:—

- to conduct survey of school going children in every five years for identifying children with disabilities, ascertaining their special needs and the extent to which these are being met:

- to establish adequate number of teacher training institutions;

- to train and employ teachers, including teachers with disability who are qualified in sign language and

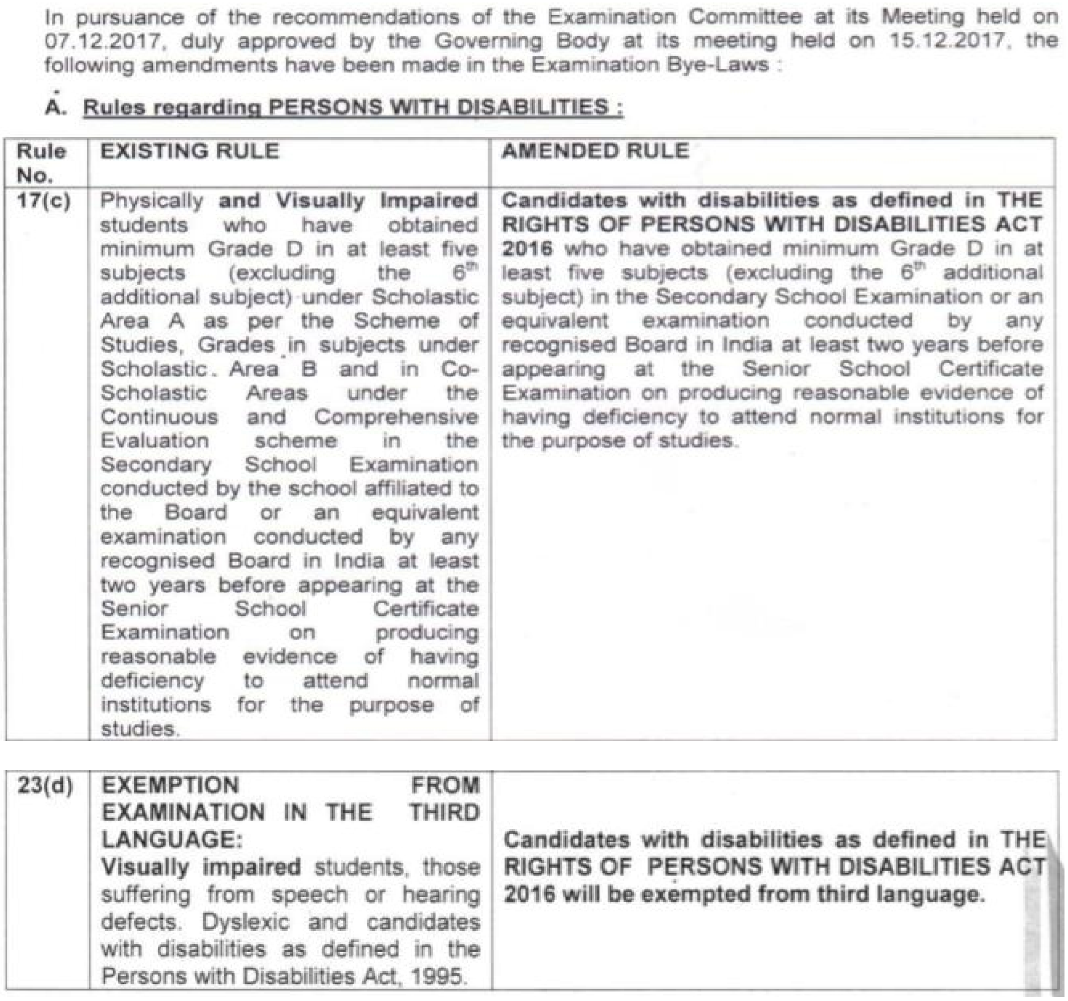
Braille and also teachers who are trained in teaching children with intellectual disability;

- to train professionals and staff to support inclusive education at all levels of school education;
- to establish adequate number of resource centres to support educational institutions at all levels of school education;
- to promote the use of appropriate augmentative and alternative modes including means and formats of communication, Braille and sign language to supplement the use of one's own speech to fulfill the daily
- communication needs of persons with speech, communication or language disabilities and enables them to participate and contribute to their community and society;
- to provide books, other learning materials and appropriate assistive devices to students with benchmark disabilities free of cost up to the age of eighteen years;
- to provide scholarships in appropriate cases to students with benchmark disability;
- to make suitable modifications in the curriculum and examination system to meet the needs of students with disabilities such as extra time for completion of examination paper, facility of scribe or amanuensis, exemption from second and third language courses;
- to promote research to improve learning; and
- any other measures, as may be required.

III.The appropriate Government and the local authorities shall take measures to promote, protect and ensure participation of persons with disabilities in adult education and continuing education programmes equally with others.

Appendix 4

Some Relevant extracts from Examination Bye-Laws 1995 (Updated Up to 2017)

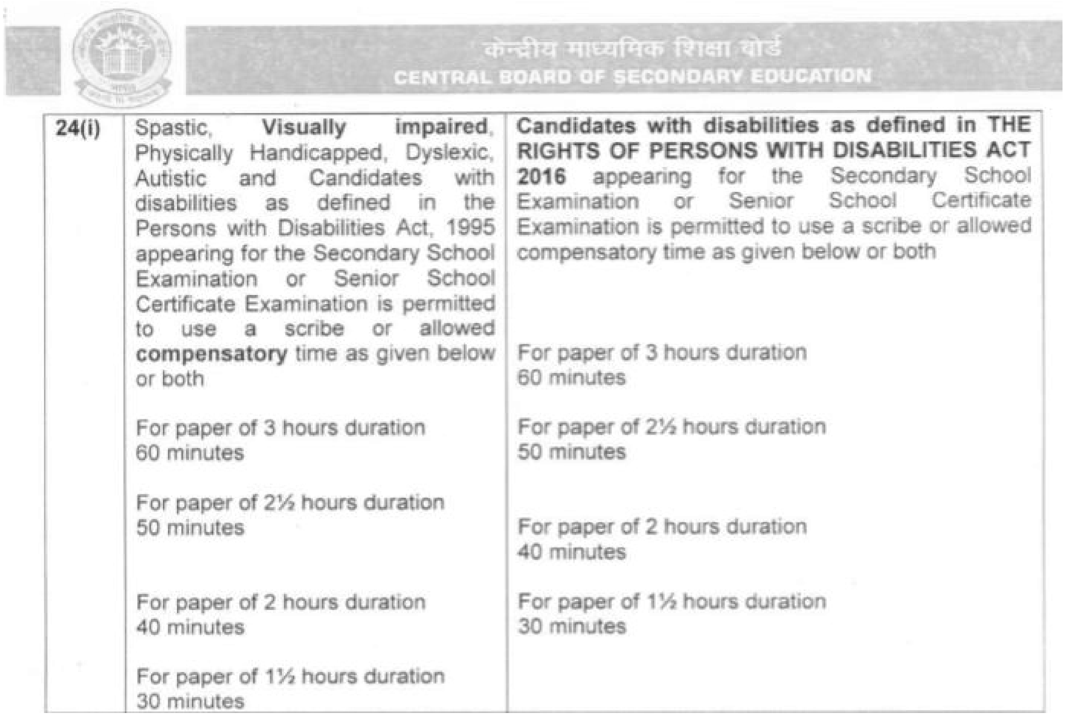


In pursuance of the recommendations of the Examination Committee at its Meeting held on 07.12.2017, duly approved by the Governing Body at its meeting held on 15.12.2017, the following amendments have been made in the Examination Bye-Laws :

A. Rules regarding PERSONS WITH DISABILITIES :

Rule No.	EXISTING RULE	AMENDED RULE
17(c)	Physically **and Visually Impaired** students who have obtained minimum Grade D in at least five subjects (excluding the 6th additional subject) under Scholastic Area A as per the Scheme of Studies, Grades in subjects under Scholastic Area B and in Co-Scholastic Areas under the Continuous and Comprehensive Evaluation scheme in the Secondary School Examination conducted by the school affiliated to the Board or an equivalent examination conducted by any recognised Board in India at least two years before appearing at the Senior School Certificate Examination on producing reasonable evidence of having deficiency to attend normal institutions for the purpose of studies.	**Candidates with disabilities as defined in THE RIGHTS OF PERSONS WITH DISABILITIES ACT 2016** who have obtained minimum Grade D in at least five subjects (excluding the 6th additional subject) in the Secondary School Examination or an equivalent examination conducted by any recognised Board in India at least two years before appearing at the Senior School Certificate Examination on producing reasonable evidence of having deficiency to attend normal institutions for the purpose of studies.

23(d)	**EXEMPTION FROM EXAMINATION IN THE THIRD LANGUAGE:** **Visually impaired** students, those suffering from speech or hearing defects. Dyslexic and candidates with disabilities as defined in the Persons with Disabilities Act, 1995.	**Candidates with disabilities as defined in THE RIGHTS OF PERSONS WITH DISABILITIES ACT 2016 will be exempted from third language.**



केन्द्रीय माध्यमिक शिक्षा बोर्ड
CENTRAL BOARD OF SECONDARY EDUCATION

24(i)	Spastic, **Visually impaired**, Physically Handicapped, Dyslexic, Autistic and Candidates with disabilities as defined in the Persons with Disabilities Act, 1995 appearing for the Secondary School Examination or Senior School Certificate Examination is permitted to use a scribe or allowed **compensatory** time as given below or both For paper of 3 hours duration 60 minutes For paper of 2½ hours duration 50 minutes For paper of 2 hours duration 40 minutes For paper of 1½ hours duration 30 minutes	**Candidates with disabilities as defined in THE RIGHTS OF PERSONS WITH DISABILITIES ACT 2016** appearing for the Secondary School Examination or Senior School Certificate Examination is permitted to use a scribe or allowed compensatory time as given below or both For paper of 3 hours duration 60 minutes For paper of 2½ hours duration 50 minutes For paper of 2 hours duration 40 minutes For paper of 1½ hours duration 30 minutes

24(iii) & 46	Candidates with visual and hearing impairment, Spastic, Dyslexic, Autistic and candidates with disabilities as defined in the Persons with Disabilities Act, 1995 have the option of studying one compulsory language as against two. This language should be in consonance with the overall spirit of the Three Language Formula prescribed by the Board. Besides one language any four of the following subjects be offered: *Mathematics, Science, Social Science, another language, Music, Painting, Home Science, Foundation of Information Technology, Commerce(Elements of Business), Commerce(Elements of Book Keeping and Accountancy),* ***E-Typewriting(English), E-Typewriting(Hindi), Introduction to Computer Technology, any out of Retail(NSQF) and Information Technology(NSQF)***	**Candidates with disabilities as defined in THE RIGHTS OF PERSONS WITH DISABILITIES ACT 2016** have the option of studying one compulsory language as against two. This language should be in consonance with the overall spirit of the Three Language Formula prescribed by the Board. Besides one language any four subjects from amongst the following groups can be offered: ***Group 1*** *Mathematics, Science, Social Science, another language, Music, Painting, Home Science, Commerce (Elements of Business), Commerce (Elements of Book Keeping and Accountancy)* ***Group 2*** ***Any one of the following:*** *e-Publishing & e-Office, Introduction to Computer Technology, Foundation of Information Technology*

केन्द्रीय माध्यमिक शिक्षा बोर्ड
CENTRAL BOARD OF SECONDARY EDUCATION

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		Group 3 *NSQF Subjects for Regular Candidates Only (except Automobile Technology):* Dynamics of Retailing, Information Technology, Security, Introduction to Financial Markets, Introduction to Tourism, Beauty & Wellness, Basic Agriculture, Food Production, Front Office Operations, Banking & Insurance, Marketing & Sales, Health Care Services. Note: Information Technology from Group 3 cannot be offered if any subjects from Group 2 is opted.

25(i)	**Use of Scribe and Appointment of scribe** (i) **Scribe** may be allowed in the following cases; (a) To a **Visually impaired**, Physically Handicapped, Spastic and candidates with disabilities as defined in the Persons with Disabilities Act, 1995. **Autistic candidate is permitted to use the services of a Scribe or an Adult Prompter** (b) On sudden illness rendering the candidate unable to write as certified by a Medical Officer of the rank not lower than Asstt. Surgeon. (c) In the case of an accident rendering the candidate unable to write the examination as certified by a Medical Officer of the rank not lower than Asstt. Surgeon.	Use of Scribe and Appointment of scribe (i) Scribe may be allowed in the following cases; (a) To a **Candidate with disabilities as defined in THE RIGHTS OF PERSONS WITH DISABILITIES ACT 2016**. Autistic candidate is permitted to use the services of a Scribe or an Adult Prompter. (b) On sudden illness rendering the candidate unable to write as certified by a Medical Officer of the rank not lower than Asstt. Surgeon. (c) In the case of an accident rendering the candidate unable to write the examination as certified by a Medical Officer of the rank not lower than Asstt. Surgeon

25(ii)	**A person to be appointed as scribe should not have obtained his/her qualifications in the same subject(s) in which the candidate shall be appearing for the examination**	**There will be no restriction on educational qualifications, marks scored, age or scribe/reader/ lab assistant/adult prompter.**

25(iii)	**The candidate shall have the discretion of opting for his own scribe and shall have the flexibility in accommodating change in scribe in case of emergency. Candidate shall also have the option of meeting the scribe a day before the examination.** The Centre Superintendent of the examination centre concerned shall forward to the Regional Officer concerned of the Board, a report giving full particulars of the candidate and of the scribe.	NO CHANGE
25(iv)	The Superintendent shall arrange a suitable room for the candidate for who as **scribe** is allowed and appoint one special Assistant Superintendent to supervise his examination.	NO CHANGE
25(v)	The services of amanuensis shall be provided free of cost.	NO CHANGE
25(vi)	The **scribe** shall be paid by the Board remuneration as prescribed from time to time.	NO CHANGE

The contact details of CBSE Headquarter of Open School are as under:

A-24/25, Institutional Area, Sector - 62, NOIDA Distt. Gautam Budh Nagar, Uttar Pradesh - 201 309.

Toll Free: 1800-180-9393

Chairman: Tel: 0120-2403173, 0120-4089802

Fax: 0120-4089813

Secretary: Tel: 0120-2402889, 0120-4089809

Fax: 0120-2403172

Appendix 5

Summary of legal provisions for persons with disabilities including Autism Spectrum Disorder [Adapted from article: Barua M, Kaushik J S, Gulati S. Legal Provisions, Educational Services and Health Care Across the Lifespan for AutismSpectrum Disorders in India. Indian J Pediatr 2017; 84: 76-82.]

Acts and rules on disability and mental health	Key objectives
Mental Health Act,1987 (21)	An act to consolidate and amend the law relating to treatment and care of mentally ill persons to make better provision with respect to their properly and affairs and for matters connected therewith or incidental thereto”
Rehabilitation Council of India Act (RCI), 1992 (22)	RCI was set up to regulate training policies/ programs and standardization of training courses in field of rehabilitation of persons with disabilities.
Person with Disabilities (Equal Opportunism, Protection of Rights and Full Participation) Act, 1995 (23)	An Act to give effect to the Proclamation on the Full Participation and Equality of the People with Disabilities
Office of the chief commissioner for persons with disabilities (PWD) (1995)	It was set up under section 57 of PWD act, 1995 to safeguard the rights of persons with disabilities including their education, employment, creation of barrier free environment and social security. The chief commissioner is authorized to monitor the utilization of funds issued by central government. He also can act on complaints concerning non implementation of laws and instructions issued by appropriate authorities protecting the rights of persons with disabilities.

National Trust for welfare of persons with Autism cerebral palsy, Mental retardation and multiple disabilities act, 1999	Aim of the National Trust is to provide an inclusive society which values human diversity and enables and empowers full participation of PWD to live independently with dignity, equal rights and opportunities
National Policy for persons with disabilities, 2006	It deals with Physical, educational and economic rehabilitation of persons with disabilities. In addition the policy also focuses upon rehabilitation of women and children with disabilities, barrier free environment, social security, research etc
United Nations convention for rights of persons with disabilities (UNCRPD) (2006)	The convention marks a paradigm shift in respect of disabilities from a social welfare concern to a human right issue. It ensures and promote the full realization of all human rights and fundamental freedoms for all Persons with Disabilities without discrimination of any kind on the basis of disability.
The Rights of Persons with Disabilities (RPWD) Bill (2014)	The bill was drafted to codify India's obligations under UNCRPD. The bill recognizes the equality of persons with disabilities and prohibits direct or indirect discrimination on the basis of disability

Government of India initiatives to provide education for children with special needs including those with autism spectrum disorder (ASD)

[Adapted from article: Barua M, Kaushik J S, Gulati S. Legal Provisions, Educational Services and Health Care Across the Lifespan for AutismSpectrum Disorders in India. Indian J Pediatr 2017; 84: 76-82.]

Government of India initiative	Principle objective in education sector
Rehabilitation council of India (1992)	RCI was established to standardize and monitor the training of special educators and other rehabilitation professionals of the country. It is also involved in training of special educators and resource teachers that can offer support services to children with disability in regular schools. Diploma in Special Education (Autistic Spectrum Disorders); B.Ed* Special Education (Autistic Spectrum Disorders) are courses recognized by RCI.

Persons with Disabilities (Equal opportunities, protection of rights & full participation) PWD Act, 1995	The act states that Government and local authorities shall ensure that every child with disability has access to free education, integrate students with disabilities in normal school, promote setting up of special schools in government and private sector and ensure development of vocational training facilities. As per the act (1995), It covered seven disabilities and did not include ASD. Scheme for implementation of person with disability act (SIPDA) has been launched to ensure implementation of objectives of PWD act.
National trust for persons with autism, cerebral palsy, mental retardation and multiple disablities (1999)	National trust was formulated to protect the rights of persons with multiple disabilities. Although it does not deal with education directly, it fosters inclusion and developing functional skills of disabled. State Nodal Agency Centre (SNAC) and State Nodal Agency Partners (SNAP) have been conducting training on inclusive education for private school teachers.
Sarva Shiksha Abhiyaan (SSA) (29)	Universalization of elementary education with access, enrolment and retention of all children 6-14 years with zero rejection policy. It aims at combining all the existing laws and provisions for children with special needs. It includes early identification, educational placement, aids and appliances, teacher training, individualized education plan (IEP), parental training, strengthening of special schools, removal of architectural barriers and research
Right to education (RTE) Act, 2009	Right to free and compulsory elementary education for children 6-14 years of age has been incorporated as a fundamental right (86th amendment of constitution of India). This ensures enrolment, attendance and completion of primary education of children. It also protects children from "disadvantaged group" including children with "disability" (including autism) from discrimination and ensures completion of their primary education.

Inclusive Education for Disabled at Secondary Stage (IEDSS) (2010)(31)	It replaces the earlier scheme of Integrated education of disabled children (IEDS). It provides assistance for the inclusive education of disabled children of Classes IX – XII. This program enables students with disabilities to pursue further four years of secondary education after completion of eight years of elementary schooling in inclusive and enabling environment. This scheme is now covered under Rashtriya Madhiyamik Siksha Abhiyan (RMSA) (2013). It provides support like books, stationeries, uniforms, assistive devices, appointment of special education teacher to name a few.
National Scholarship for PWD (32)	National Handicapped Finance and development Corporation, MSJE provides scholarship to Indian students with at least 40% disability for pursuing post-matric, post secondary technical and professional courses

B Ed.: Bachelors in education

Schemes of National trust for children with Autism, cerebral palsy, mental retardation and multiple disabilities. Available from URL: http://thenationaltrust.gov.in/content/innerpage/schemes.php

Schemes of National trust (25)	**Objectives of the scheme**
Disha (Early intervention and school readiness)	Scheme aims at setting up Disha centres for early intervention of person with disability in 0-10 years of age. The centre will provide therapies, training and support to family members. In addition, the centre must provide at least 4 hours of Day care facility.
Vikaas (Day care)	Scheme aims at setting up Vikaas centre for welfare of PWD for providing day care facility for at least 6 hours a day with provision of age specific activities. This facility is intended to provide parents time to take care of their other responsibilities.
Samarth (Respite Care)	To provide respite and residential care for persons with disabilities (PWD) abandoned or orphaned.

Nirmaya (Health Insurance)	The scheme provides health insurance to PWDs with cover up to one Lakh. It will cover medical and surgical expenses for prevention and reducing the impact of disability. Beneficiaries will include those certified with valid disability certificate.
Sahyogi (Care Associate training scheme)	The scheme creates Care Associate cells (CACs) for providing adequate and nurturing care of PWDs. They undergo primary training (three months) followed by advanced training (six months) and internship. They can work with families or NGOs working with PWDs to provide nurturing care.
Gyan Prabha (Educational support)	Scheme encourages by providing financial support to PWDs to pursue higher educational courses including graduation, postgraduation and vocational training courses.
Badhte Kadam (Awareness, community interaction and innovative project)	It aims at community awareness, sensitization and mainstreaming of person with disabilities.

Some of the other central government schemes include:

1.Assistance to disabled person for purchase/fitting of aids and appliances

2.DeenDayal Rehabilitation Scheme

3.National Awards for People with Disabilities

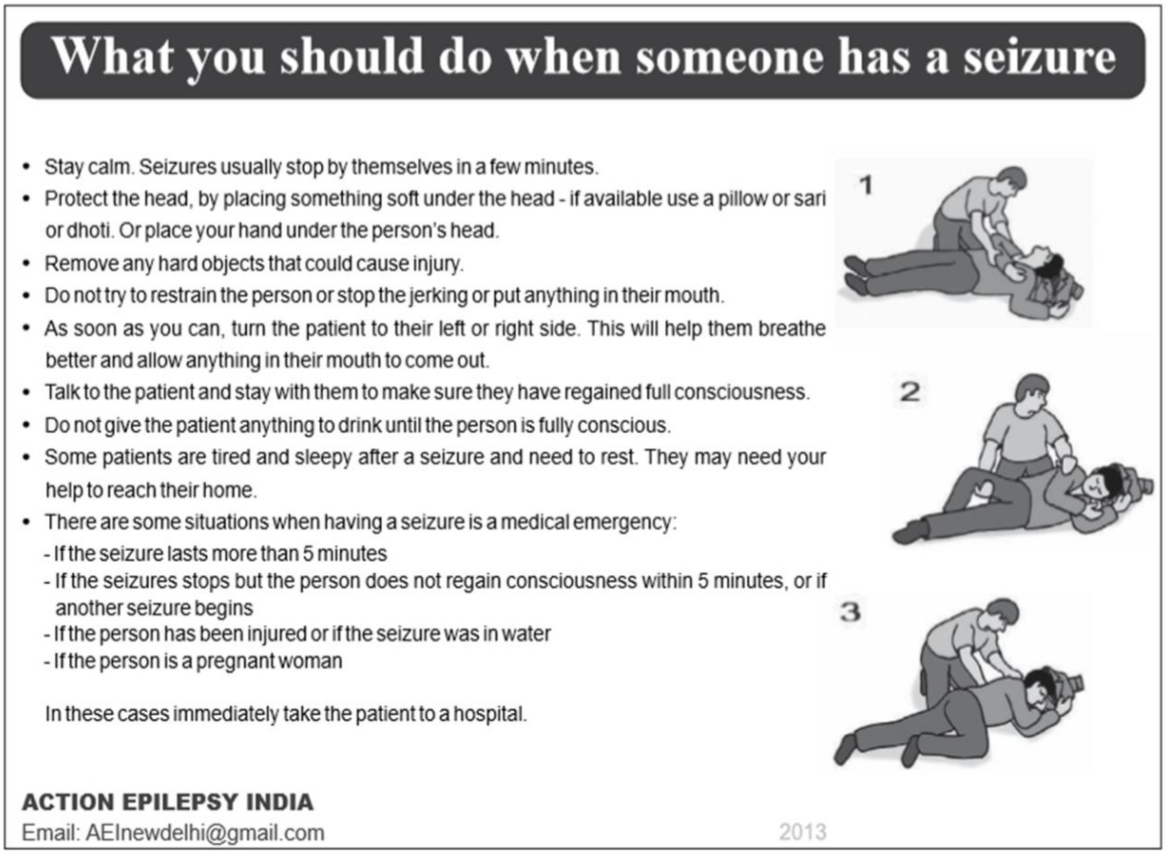
4.An Integrated Programme for Older Persons

5.Vocational Rehabilitation Centre

6.Incentives to Private Sector Employers for providing employment to persons with Disabilities

Annexure 1

Seizure First Aid Resources From Action Epilepsy India



What you should do when someone has a seizure

- Stay calm. Seizures usually stop by themselves in a few minutes.
- Protect the head, by placing something soft under the head - if available use a pillow or sari or dhoti. Or place your hand under the person's head.
- Remove any hard objects that could cause injury.
- Do not try to restrain the person or stop the jerking or put anything in their mouth.
- As soon as you can, turn the patient to their left or right side. This will help them breathe better and allow anything in their mouth to come out.
- Talk to the patient and stay with them to make sure they have regained full consciousness.
- Do not give the patient anything to drink until the person is fully conscious.
- Some patients are tired and sleepy after a seizure and need to rest. They may need your help to reach their home.
- There are some situations when having a seizure is a medical emergency:
  - If the seizure lasts more than 5 minutes
  - If the seizures stops but the person does not regain consciousness within 5 minutes, or if another seizure begins
  - If the person has been injured or if the seizure was in water
  - If the person is a pregnant woman

In these cases immediately take the patient to a hospital.

ACTION EPILEPSY INDIA
Email: AEInewdelhi@gmail.com
2013

जब किसी को दौरा पड़ता है तो आपको क्या करना चाहिए

- शांत रहें। दौरे को अपने समय से ठीक होने दें। व्यक्ति की हो रही हरकत या दौरा रोकने अथवा होश में लाने की कोशिश न करें।
- मरीज़ के आस–पास अगर कोई भी चीज़ हो जिससे उसको चोट लग सकती है तो उसको हटा दें।
- मरीज़ का सिर बचाएँ। सिर के नीचे तकिया या कोई साड़ी या डुपट्टा लगा दें। कुछ न हो तो अपना हाथ रखें जिससे की मरीज़ बार–बार ज़मीन पर सिर न पटके। दौरे पड़ते समय मरीज़ को जकड़ कर न पकड़ें।
- उन्हें आराम से दायें या बाएं करवट दिलाएं। इस तरह उन्हें साँस लेने में आसानी होगी।
- मरीज़ को कुछ भी खिलाने पिलाने की कोशिश न करें और मुंह में कोई वस्तु न डालें।
- मरीज़ को दिलासा दिलाते रहें कि वह ठीक हो जाएगें।
- यदि दौरा पाँच मिनट से अधिक चले या तुरन्त ही दुबारा हो जाए या मरीज को चोट लगी हो या वह गर्भवती महिला हो तो अस्पताल ले जाएँ या डॉक्टर को बुलाएँ।
- कुछ व्यक्तियों को दौरे के बाद थकान होती है जिस के करण आराम या नींद ज़रुरी है।

ACTION EPILEPSY INDIA
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2013

Annexure 2

Medical Certificate and Plan for Epilepsy

Name of the child:... Age: .... years. Gender : ....

Mother's name:...................................... Phone no: ....

Father's name:...................................... Phone no: ....

Residential address:...

....

Physician's Name: ....Phone no: ....

Contact in emergency

Hospital: .... Phone no: ....

Physician's Name: ....Phone no: ....

Epilepsy details

Diagnosis: ....

Type of seizures and duration: ....

Last seizure: ....

Seizure triggers: ....

Current medication (with dose)

1...

2...

3...

4...

5...

Any associated/additional concerns and intervention needed

1...

2...

3...

Danger Signs

Treat the student's seizure as an emergency if

1. Whole body jerks lasting longer than 3 minutes
2. Has a cluster of seizures
3. Has injured himself
4. Has had a seizure in water
5. Has had another seizure without recovering
6. Is having difficulty in breathing
7. Seizure does not stop with midazolam nasal spray or recurs after stopping

What my child's seizure looks like

....

....

....

First aid management

- Do not panic.
- Put the child on his/her side
- Do not restrain the child, Do not crowd around the child
- Do not put anything in the mouth
- Note the time and video record the event, if possible
  In case the seizure does not abort by itself by3 minutes, give Midazolam Nasal Spray intranasally to the child. Spray 3 puffs in the air, away from the child, then spray the dose in the nose, half on each side
- Dose of Midazolam spray....................... puffs in each nostril (Total puffs)
- Need rest after a seizure: Yes/ No (If yes, duration of rest: .... hours)

Special instructions for school

Warning signs to observe: ....

Specific triggers for seizures: ....

Activities restricted: ....

School trips: Permitted/ Not permitted / to be decided after discussion on nature of activities ....

....

Any other instructions: ....

....

Child needs revaluation every _______months. The medical care plan may change on revaluation*

....

Signature of parent   Signature of Physician

Date   Date

Annexure 3

PARENT/GUARDIAN CONSENT:

I certify that I have legal authority to consent to medical treatment for the student named above, including the administration of medication at school.

I consent for my child to be evaluated for a health care plan, consent for the placement outlined, and request designated school personnel to follow this plan as it is written.

I understand that if I disagree with this plan, I have the right to request a hearing by filing a written request.

I understand that this health care plan, including the medical treatment/medication orders provided, must be renewed and reviewed annually.

I understand that my child will be re-evaluated every three years to determine if my child continues to qualify for a school health care plan.

I understand that the school may share this care plan with emergency responders if student requires emergency services.

If medication is prescribed within this plan, the medication is to be furnished by me in the original container, and brought to school by an adult.

I understand medication may be administered by non-licensed trained designated staff members.

I understand that at the end of the school year, an adult must pick up any medication, otherwise it will be discarded.

Father's signature: ______________________________ Mother's signature: __________________________

Date:____________________________ Place: ____________________________________

Annexure 4

Checklist for Counselling: For Doctors

1. What are seizures, what is epilepsy and its causes
2. Diagnosis of epilepsy- mainly clinical, with support from EEG and MRI.
3. Procedure of EEG, role in diagnosis
4. CT/MRI: how do they help in diagnosis and management
5. First aid for seizures: recovery position, Dos and Don'ts, rescue medications, when to take to hospital
6. Prolonged duration of therapy, monitoring and need for follow up , importance of compliance, following exact instructions
7. Expected side effects, even life threatening adverse events, need to be careful- should stop immediately if rash etc. .
8. Learning, mood, behaviour and school performance may be affected, remedial help is available. Screening for co-morbidities
9. Which activities are permissible without and with supervision, Special advice regarding swimming, exams, photo-sensitivity, pregnancy in females.
10. Aim is to normalize the life of child/person with epilepsy & the family as far as possible

Annexure 5

Checklist for Counselling: For Epilepsy educators

1. Diagnosis of epilepsy- what it means to the child and parents
2. Ensure First aid for seizures have been explained, who all need to be trained in its use-e.g. school transport personnel, teacher, sibs at home.
3. Ensure the parents have understood the doses, and treatment protocol, increasing and decreasing doses, and side effects to watch out for.
4. Prolonged duration of therapy, importance of compliance and regular follow up.
5. Need to balance control of seizures with quality of life, each person's epilepsy behaves differently- some may get controlled on first drug, some may require multiple drugs.
6. Learning, mood, behavior and school performance may be affected, remedial help, rights and resources available for help in school, exams.
7. Most activities like driving, sports, outdoor treks etc. are permissible with precautions in well controlled patients.
8. Need to tackle any prevalent myths regarding cause and treatment of epilepsy
9. Aim is to normalize the life of child/person with epilepsy & the family as far as possible. Any other fears/apprehensions/anxiety in the child/parents etc.
10. Need to address their concerns regarding education prospects, job, marriage, pregnancy etc.
11. Parents should be motivated to create a positive environment at home, join any support groups available to help each other overcome the stigma associated with epilepsy

Stress on the fact that Epilepsy should not define the person!

During follow up visits

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