Returning to School

# After Encephalitis

ENCEPHALITIS SOCIETY

## Repeating a school year

It is unusual for a child to repeat a school year, but this may be considered in exceptional circumstances such as after very long absence from school following encephalitis. A repeat year may be just right for the occasional child, but if it is being considered, issues to think through include:

- the exact purpose of repeating the school year
- whether the situation could be managed differently
- whether being a year behind will disrupt friendship groups
- whether repeating a year is simply delaying the kinds of support that the child really needs
- the implications of a child being a year behind the age-group over the following years
- the extent to which the arrangement could be kept going throughout the future stages of schooling such as transfer to secondary school, post 16 education and so forth
- the risk that a year may be missed out completely
- the possible implications of reaching school leaving age before reaching the last class
- above all, the extent to which a repeat year will resolve learning difficulties arising from this child's ABI

**In discussion with parents, it is best that specific advice from a psychologist be obtained if a repeat year is being considered.**

# Brothers and sisters of children affected by encephalitis

The wide-ranging impact of encephalitis has a profound effect on other family members and especially on siblings. When a brother or sister is very ill, their parents have to be with their sick child as much as possible. Day-to-day routines are changed. They often have to rely on others to look after their other children. When a child who has been in hospital comes home, they may need much care for a long time, and be the focus of everyone who telephones, writes or visits their home.

A brother or sister who has been very ill may not seem the same as before, and their parents' behaviour with them may have had to change. Some children are born into a family where they already have a sibling who has had encephalitis. For these children, the impact of their sibling's needs may develop over the years, particularly as they go through school.

## Strong feelings

The siblings may be affected in many ways depending on their age, family's dynamics and resilience and the effects of encephalitis on their brother/sister. It is good if school staff can be aware of feelings that naturally result from both major change at home, and with living alongside siblings with various special needs. Strong reactions are understandable.
Children need their feelings to be recognised, and understood.

Siblings may feel:

- loss and feelings of bereavement they cannot understand
- jealousy at the attention their sibling receives
- anger about the attention their sibling gets
- guilty that it may be all their fault
- anxiety that the illness may happen to them
- left out, that they are missing things
- confused because of the changes in their social lives
- frustration when having to play/interact with a child with a brain injury who cannot remember, is tired or displays disinhibited behaviour
- responsibility for their siblings

## What can help?

- Recognise their feelings and the effects.
- Reassure that is not the sibling's fault.
- Provide opportunities to talk things through, as and when appropriate; having someone to turn to can make a big difference.
- Nurture an atmosphere in which the care of others is respected and no adverse remarks from other pupils are tolerated.
- Facilitate access to a support group for brothers and sisters.
- Talk with parents if needed.

**Further Resources**

- The local authority, the local health services or Child and Adolescent Mental Health Services (CAMHS) may be able to provide information about a support group for brothers and sisters in the local area.
- Child Brain Injury Trust (CBIT) (www.childbraininjurytrust.org.uk) provide siblings and family support in most areas in the UK.
- Sibs (www.sibs.org.uk/professionals/supporting-young-siblings) is a charity for the brothers and sisters of disabled children and adults. Their articles on supporting young siblings are strongly recommended.
- The Children's Society Include programme (www.youngcarer.com) has various resources aiming to support young carers.

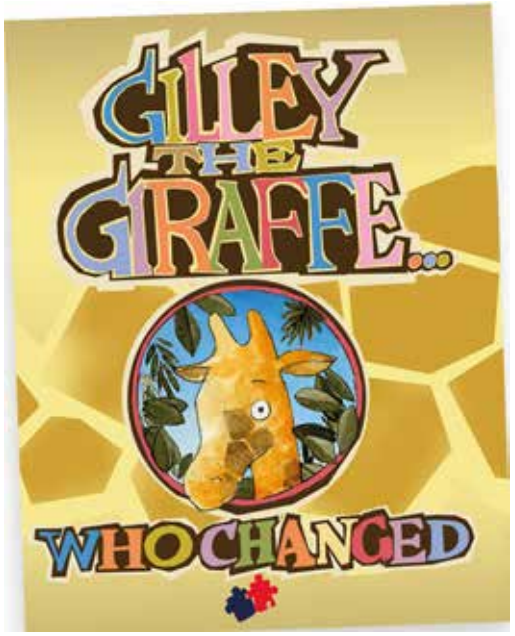
## Useful organisations/websites

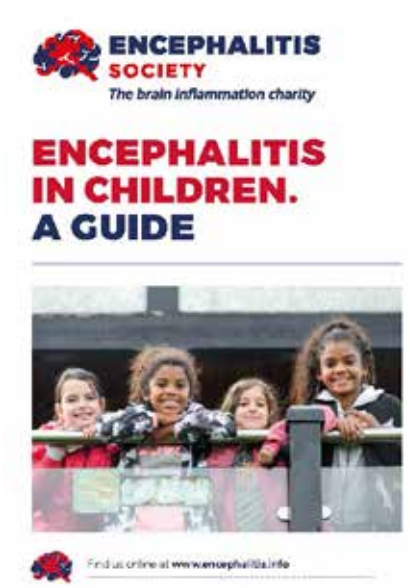
The following resources were consulted in writing this guidance and are strongly recommended for further information and support:

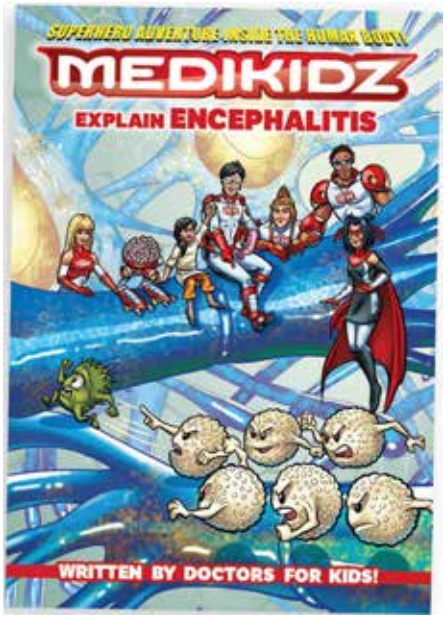
- British Columbia Ministry of Education www.bced.gov.bc.ca
- Children's Trust www.braininjuryhub.co.uk/teacher
- Child Brain Injury Trust (CBIT) www.childbraininjurytrust.org.uk
- Encephalitis Society www.encephalitis.info
- Epilepsy Action www.epilepsy.org.uk/info
- Epilepsy Society www.epilepsysociety.org.uk
- Independent Parental Special Education Advice (IPSEA) www.ipsea.org.uk
- I CAN www.ican.org.uk
- LEARNet www.projectlearnet.org
- Sibs www.sibs.org.uk
- The National Blind Children's Society's www.nbcs.org.uk
- The Royal National Institute for the Blind (RNIB) www.rnib.org.uk
- The Royal Children's Hospital Melbourne www.rch.org.au/kidsinfo/
- The Children's Society Include programme www.youngcarer.com

## Useful information resources

- **Encephalitis in children. A guide**. It follows the child and their family's journey from the hospital ward, to the rehabilitation setting, school and home, hoping to direct them through the maze of health care education and social services.
- **Gilley the Giraffe Who Changed**. An illustrated book aimed at children age 4 to 10 describing the journey of Gilley—a giraffe who had encephalitis and went back to school.
- **Medikidz**. A comic book aimed at children 7 to 14. The Medikidz are superheroes who live on Mediland, a planet shaped like the human body. They are experts in health and illness, and their mission is to teach children about brain and how encephalitis affects it.
- **Encephalitis in children. E-learning**. E-learning modules aimed at parents/carers and children about encephalitis and its consequences. (available only online at www.encephalitis.info/encephalitis—in—children—e—learning).



# Appendix 1

## Difficulties checklist

This checklist can be used by any educational professional in respect of a child's particular needs.

| Area of difficulty | All information and plans are in place | Further information is needed | Further actions are required |
|---|---|---|---|
| Memory | | | |
| Planning and organisational skills | | | |
| Attention and concentration | | | |
| Speech, language and communication | | | |
| Physical skills | | | |
| Hearing perception and sensitivity to sound | | | |
| Visual perception | | | |
| Epilepsy | | | |
| Fatigue | | | |
| Behaviour | | | |
| Social skills | | | |
| Other | | | |

# Appendix 2

## My journey through encephalitis

This form outlines key facts about the child and their needs in order to inform the school staff about the specific needs of the child. It aims to help the child and their families not having to repeat the same information to different people.

This template can be used in this format or adapted to own school practices or pupil's needs. Ideally it should be completed together by the child and parent/carer and given to the teacher who can also make notes regarding their day-to-day management in class.

Name .....

Class .....

History of the illness .....

My difficulties .....

My medication .....

What helps me? .....

What doesn't help me? .....

.....

## Teacher’s notes (Practical steps)

### Do’s

### Don’ts

# Encephalitis Society

The Encephalitis Society is an international charity and the only organisation of its kind in the world dedicated to supporting adults and children affected by encephalitis. The Society provides support and information to all people affected by encephalitis across the globe, and to a variety of professionals and organisations from health, social care and education. The Society works in conjunction with academic and clinical partners to promote and conduct high quality research into encephalitis and its consequences and promote high standards for patient diagnosis, management and care.

## Key services

- **The Encephalitis Society website** which contains information about encephalitis and its consequences www.encephalitis.info
- **Telephone and email Support Line** giving advice, support and information about encephalitis +44(0)1653 699599 or support@encephalitis.info
- **Team Encephalitis Volunteer Scheme** - an expanding network of global volunteers
- **Residential weekends, meetings and events** for all the family
- **Connections Scheme** which puts people affected by encephalitis in touch with each other
- **Seminars, training and education** about encephalitis to health, social care, legal and education professionals
- **World Encephalitis Day** (22nd February each year)

TeamEncephalitis Volunteer Scheme

World® Encephalitis Day 22nd February

**ENCEPHALITIS SOCIETY**

*The brain inflammation charity*


**The Encephalitis Society**
32 Castlegate, Malton
North Yorkshire
YO17 7DT
United Kingdom

www.encephalitis.info

**Social Media**

@encephalitis
/encephalitissociety
/company/the-encephalitis-society
The_Encephalitis_Society
youtube.com/EncephalitisSociety

**Support Team**

+44(0)1653 699599
support@encephalitis.info

**Admin**

+44(0)1653 692583
admin@encephalitis.info



**President**

Professor Barbara A Wilson OBE

**Vice Presidents**

Baroness Anne McIntosh
Richard Lockwood
Kika Markham
Tom Naylor-Leyland
Tiggy Sutton
Robert Sutton

**Ambassadors**

Rebecca Adlington OBE
Mathew Bose
Tonia Buxton
Susannah Cahalan
Aliki Chrysochou
Simon Hattenstone
Charlotte Leeming



Copyright © 2017 Encephalitis Society



Encephalitis Society is the operating name of the Encephalitis Support Group
Registered Charity England and Wales No. 1087843, Registered Charity Scotland No. SC0482010;
Charitable Company registered in England and Wales No: 04189027

Design by eecreative.co.uk