

www.liv.ac.uk/braininfections

# Long term care of patients with encephalitis – a simple guide for resource poor settings

Some simple & practical tips for long term care and follow up of encephalitis patients to assist clinicians and other health care workers caring for children in resource poor setting

Tom Solomon, Professor of Neurology Juliet Weston, Specialist Neurodevelopmental Physiotherapist Vicky Gray, Paediatric neuropsychologist Frances Carlton, Headteacher and Educationalist Janet Lewthwaite, Occupational Therapist Wong See Chang, General Pediatrician Wendy Blumenow, Senior Specialist Speech and Language Therapist Penny Lewthwaite, Infectious Diseases Research Fellow Mong How Ooi, Pediatrician Research Fllow Rachel Kneen, Consultant Peditric Neurologist

University of Liverpool Viral Brain Infections Group, UK Walton Centre for neurology and Neurosurgery NHS Trust, and Royal Liverpool Children's NHS Trust, UK

# Introduction

This guide has been drawn up at the request of physicians in resource-poor settings in Asia to help them in their follow-up of children that are recovering from Japanese encephalitis. The ideal and full rehabilitation service involves a series of regular assessments by the multidisciplinary team including doctors, nurses, physiotherapists, occupational therapists, speech language therapists, play therapists, nutritionists, psychologists, educationalists and others. Although this full complement of therapists is rarely available, it is not acceptable to declare that "nothing can be done". This guide draws attention to some of the simple measures which can be taken, and directs the reader towards other resources. It is not our aim to attempt to replace the efforts of the multi-disciplinary team, nor to educate people about what they do and how they do it. The reader is referred to some excellent textbooks and web resources, which are referenced in the text, and listed at the end of the document.

#### Approach

There are several ways in which one could consider the rehabilitation issues after acute encephalitis, including::

• the time-frame during which problems present (e.g. acute phase problems, or later follow up problems)

- the system involved, e.g. gross motor problems, fine motor, behavioral problems
- the age-related significance of the problem
- the activities of daily living that are affected, etc
- whether they respond to pharmacological or other measures,
- the main health-care professions involved

In this guide we divide the rehabilitation issues into those which need consideration during the acute illness, and those which become important during longer term care. We consider issues of gross motor, fine motor, communication, memory, behavior, as well as education

# Issues to consider during the acute illness

### **Nursing issues**

A child who has had viral encephalitis may need to be an inpatient for several weeks. For this reason there are several simple things that can be done help a child during this time.

• **Partnership** between parents and nurses: Although it can be frightening for them, parents should be encouraged to be in a partnership with the nurses and learn how to be involved with cleaning, feeding and moving their child from the earliest stages.

• **Primary nurses:** It can be very reassuring to a child to have the same nurses looking after them if this is practical.

• Visiting: Children need to have regular visitors but not too many at a time. Similarly, parents need to be able to visit their other children. Siblings can also help with rehabilitation and should also be encouraged to visit.

• **Reassurance:** Children should have their favourite toy or other item used for comfort (e.g. blanket) brought into hospital for them.

• Coming to terms with their new child: Parents need information and should not expect their child to be 'back to normal' as soon as they start to 'wake up'. Parents need to be given information in a realistic and sympathetic manner. This information is likely to need repeating. Ideally, parents should have the opportunity to talk to a psychologist to help them come to terms with these issues.

• Feeding issues: Feeding is likely to be more difficult and will take longer. Initially a child may require nasogastric tube feeding. See later section for more details.

• **Bedsores** These are especially likely to occur over pressure areas such as the occiput, sacrum and buttocks and ankles (Fig 1)

 $\rightarrow$  Reduce the risk of bedsores by regularly turning the patient

 $\rightarrow$  Even if the mattress is very firm, placing softer materials under the pressure points may help



Fig 1. Sacral bed sore

## Feeding and swallowing difficulties

Swallowing is a highly complex motor process. A child who has had viral encephalitis is more likely to aspirate food and drinks. The following should be considered before reintroducing food and drinks.

To **assess** whether a child is able to start feeding orally again, they should be alert and responsive. They should be in a suitable position (usually sitting in a chair or on a parent's knee), they should be able to swallow most of their saliva and have a cough and gag reflex. Do not try if the child is tired or sleepy. Try to feed the child where it is quiet and there are no

distractions. It can take a long time for a child to re-establish full oral feeding. Patience is needed.

 $\rightarrow$  Always introduce a pureed diet, either yoghurt or pureed vegetables, before introducing fluids as this texture is less likely to be aspirated.

 $\rightarrow$  Tastes can initially be given from the finger onto the bottom lip to see how well it is tolerated. The amount can be gradually increased and a spoon introduced.

 $\rightarrow$  A soft shallow spoon is ideal if available. Increased tone can lead to a bite reflex, which if a metal spoon is used can be dangerous.

 $\rightarrow$  Give the child plenty of time to process and swallow the food that is being offered.

 $\rightarrow$  Visual and perceptual difficulties should always be taken into consideration when feeding. A child may need plenty of reassurance and tactile help to make them feel safe when feeding initially.

 $\rightarrow$  Stop if the child shows no interest in the food, or if they become distressed or start coughing.

 $\rightarrow$  When reintroducing liquids, they should be thickened as they will be easier to swallow.

 $\rightarrow$  If there are no signs of aspiration and the child is tolerating the thickened fluids, gradually reduce the amount of thickener added.

 $\rightarrow$  Even if there are no concerns regarding aspiration, you may find that many children cope better with a thickened fluid than without.

 $\rightarrow$  Initially fluids should be given using a spouted cup or bottle.

 $\rightarrow$  As the child progresses, increase the texture of the food, this can be done by adding bread crumbs to a puree or blending food less.

 $\rightarrow$  Foods to avoid would be mixed consistencies, flaky and crumbly foods. For those children where there are concerns of aspiration beware of solids that become liquids when taken in the mouth, e.g. ice cream, some milk shakes and ice lollies.

 $\rightarrow$  In order to maximise the progress to oral feeding, it is important to allow the child some time during the day to develop a hunger pattern. This would involve manipulating their tube feeds to allow regular time throughout the day where the child has the desire to feed orally. This may involve overnight tube feeding.

 $\rightarrow$  As the child progresses into taking most foods orally, their calorie requirements should be calculated. Ideally a dieician would be involved and give this advice.

 $\rightarrow$  The child should be weighed regularly, and monitored with appropriate charts

#### Communication

• Speech and language difficulties are dependent on the size, location and severity of the brain damage caused by viral encephalitis. Recovery is also variable and will also depend on the child's pre-existing learning ability.

• Consider pre-existing communication, behaviour, social skills and general developmental milestones. Take time to ask the family and/or teachers for information.

 $\rightarrow$  Take into account the child's fear and frustration of their new situation.

 $\rightarrow$  There may be sensory deficits that also need to be taken into consideration, including vision, hearing and tactile responses.

 $\rightarrow$  In general, try to keep the child's environment as distraction free as possible, this will help them to concentrate on the task at hand without having to continually block out unnecessary, either visual or auditory stimulation.

 $\rightarrow$  It is very important that you keep to a recognisable routine, and orientate the child in space and time whenever you begin to do anything with them, especially those children where there are visual disturbances.

 $\rightarrow$  Initially the child will be very sleepy. The child's first attempt at communication may well be in response to unpleasant stimuli.

 $\rightarrow$  Initially, keep language short and simple, with frequent repetition. You can always adapt your language to be more complex when you are sure they understand you!

 $\rightarrow$  Try to encourage choices for a child even if they are non-verbal. Establish a reliable method of communication for example using finger pointing, directed eye movements or communication cards which are picture based

• Change can be quite rapid at times, and for this reason, frequent re assessment is important.

 $\rightarrow$  Ask closed questions that can be answered with a 'yes' or 'no' approach, this will only work however, if the child has a reliable method of signalling "yes" and "no".

• Word finding difficulties are common. Naming errors are common. Children may also try and describe what they are trying to say if they cannot find the exact word to use.

 $\rightarrow$  A child with word finding errors may benefit from cues which are either phonemic e.g. sounding similar or semantic e.g. meaning similar. You will soon find which of these is more helpful both functionally and in therapy sessions.

 $\rightarrow$  You can help them by asking them to describe the word: its colour shape, where you find it, what's it made from, what we do with it, where they saw it etc.

• Children might also present with perseveration, this is when they frequently repeat the

same word/phrase long after it has been used appropriately. It is best to try to ignore this and not perpetuate its use.

 $\rightarrow$ Dysarthria, dyspraxia and non-fluency of speech is common. Give the child plenty of time to complete what they are trying to say. Do not answer questions for them.

Repetition will help with receptive language problems. Try exercises such as asking the child to select a target picture/object from a choice presented using the reliable method of communication mentioned above.



Fig 2. A bell attached to the arm, for attracting attention

• Even though a child has severe physical disability, cognitive function may be relatively well preserved. Although a child cannot speak, it may be able to communicate its needs

 $\rightarrow$  For example a bell attached to the wrist can be rung to indicate the child needs something (Fig 2)

# Rehabilitation during follow up

### Gross motor problems

• **Spasticity** is increased muscle tone and is a common consequence of encephalitis. If this is untreated it becomes fixed as a **contracture** (a muscle/tendon shortening which stops the joint moving through its full range). Ultimately it may result in a joint **deformity**.

• Contractures can affect many joints in viral encephalitis. Common problems include plantar flexion of the ankle to give equine feet, hyperextension of the knees, and fixed flexion deformities of the upper limbs (Figs 3 & 4). Hypersensitivity of the sole of the foot can trigger extensor spasticity and make things worse

 $\rightarrow$  During the acute stage of the illness, encourage family members to apply gentle passive stretching to the joints (especially dorsiflexion of the ankle joints) to reduce the chance of contractures.

 $\rightarrow$  Simple splints can be applied to limit contractures, such as splints to prevent ankle plantar flexion (Fig 5)

→ Dealing with flexion deformities of the upper limb is a difficult and specialized area. However, it is possible to carefully splint the elbow, ensuring that it is not put under too much pressure; the wrist and fingers should be splinted in slight extension, using a paddle type splint (which looks like a paddle to keep all the fingers extended. (Fig 6)

 $\rightarrow$  If a patient is in a chair, making sure their feet rests flat on a surface (rather than dangling in the air) will reduce the risk of contractures at the ankle.

 $\rightarrow$  If a child is placed in a chair, use pillows and cushions to support the body. Checking alignment and symmetry of the trunk and pelvis can help determine that the child is positioned properly.

 $\rightarrow$  Even if the child cannot walk, wearing a supportive shoe when sat out in a chair can reduce the risk of hypersensitivity to the sole

and support the foot. This may have an effect on the development of spasticity

 $\rightarrow$  Do not leave a child in a seated position all day, because of the risk of hip and knee contractures and pressure sores. If they cannot stand, you should





Fig 3. Fixed flexion deformities of the arms, and



Fig 4. Adduction and flexion of the right leg, hyperextension of the left legs, and



Fig 5. Ankle Foot Orthosis



Fig 6. Paddle splint for the hand



Fig 7. Assisting the child to maintain a prone position

alternate sitting with assorted lying positions, eg prone lying (on the child's tummy)

→ Children can be placed in prone lying for short periods. This helps to strengthen their upper trunk and improve head control. It also facilitates a prolonged stretch to the hips. A small roll under the chest (or rolled up towel) or wedge can be used to assist with the position (Fig 7). The child can be encouraged to reach for toys and play in this position, however if they find this too hard, they can be encouraged to weight bear through their forearms/ extended arms to look at a book.

 $\rightarrow$  Lying the child on their side (side lying) is a useful position because it aligns the body (trunk and head), brings their hands together, and into the eye-line (ie the child can see their hands), which can facilitate play.

• **Night-time** is an especially important time in terms of positioning. It is a time when spasticity is naturally minimized because the child is at rest and relaxed, and so the child can be positioned effectively. However, if their position is not correct, and they are left in this position for many hours this can lead to the formation of contractures and deformities

→ When putting the child to bed at night do not leave them on their back. Supine lying provokes the development of extensor spasticity. Side-lying is preferable, ensuring that the child has sufficient support with pillows. Curl them forwards "hugging" a pillow (if needed to maintain position), with another pillow between their legs (Fig 8). Avoid any stimulus to the back of the head, which provokes extensor posturing. The child should be alternated between right and left "side-lying" at least every four hours.

CORRECT



Fig 8. Side lying

• Foot drop. Children that are able to walk but have a foot drop should be ideally be provided with a flexible foot splint; if this is not available a supportive shoe is better than nothing because it facilitates a heel strike. "Disabled Village

Children" by David Werner (see below) (http://www.dinf.ne.jp/doc/english/global/david/dwe002 /dwe00201.htm) has details of how to make a foot splint.

• Sitting Some children do not have the ability to sit unaided, however sitting balance may be improved with practice. It may be appropriate to start the child in a long sitting position on the floor (with legs slight apart and outstretched), giving them just enough support to maintain their balance, but allowing them to be active in working for their balance. (you would need to sit behind them to proved this support) If their balance improves it may be possible to lower your trunk support, so that they can work to maintain their upper body and head control. An alternative way to achieve this long sitting position is to place the child against the corner of a room with their back against the 2 walls for support (Fig 9).

Some children with very stiff legs find it difficult to maintain their legs outstretched in a long sitting position. For these children it may be necessary to work on improving their sitting balance on a small box or stool (fig 10) A therapy ball could also be used if available.

Another sitting position that can be useful for working on



Fig 9. Sitting in a corner for extra support



Fig 10. Sitting astride a box – useful for children with stiff legs

trunk control is sitting astride a small roll. This is especially useful if the child if the child has strong adductor spasticity. Both feet need to be able to reach the floor.

Once the child has sufficient balance to maintain this position statically, they can be encouraged to reach to each side. Introducing rotation at the trunk is an important way to reduce stiffness and improve balance.

For a child sitting in a chair, a pelvic strap may be important to secure the child in a chair and ensure they remain in a flexed position, rather than extension

#### • Standing

Some children do not have the ability to stand, but can still benefit from stretching exercises.

→ A therapy ball can be a cheap and useful tool to stretch out a child and support in a standing position for a child who may not have standing balance. (Fig 11) The child can initially be laid on top of the ball to relax and stretch, and then taken into a more upright standing position using the ball in front of the child for support ensuring that the feet are flat to the floor. This can be a useful way to work on improving head and upper trunk control, and also stretch out the hips and legs.



Fig 11. Stretching with a therapy ball

 $\rightarrow$  A child that has some standing balance, but still needs some support (due to weakness or poor balance) can be stood against the back of a chair (ensuring it does not tip), or hold onto wall bars (Fig 12) and encouraged to stand in an upright aligned position straightening their legs, and tucking in their bottoms. It may be necessary to assist them to get their feet flat to the floor, and this may be easier with shoes or splints on rather than in bare feet.

Once this is achieved the child should be encouraged to shift their weight between their left and right sides to further improve their balance in preparation for walking.



Fig 12. Encouraging standing

A child who puts more weight through one leg and the other should be encouraged to shift their weight over the side they are reluctant to bear weight through This can be done through play, by asking

reluctant to bear weight through. This can be done through play, by asking them to reach for toys, or bat a balloon.

 $\rightarrow$ Some children lack muscle strength in their legs (especially in their antigravity muscles eg; quads / gluts). This makes them stand in a crouched, flexed position. It is possible to build up their lower limb strength through practicing sequences of movement for example repetition of sitting (on a chair or bench) to standing, encouraging them to slow and control the movement. The higher the chair the easier the movement is.

#### Skin calluses

If a child is dragging themselves round on their elbows or knees, this will result in calluses (Fig 13)

 $\rightarrow$  If elbows, knees or hands are being used for mobilization, they should be protected with pads made from goat-skin, leather or something similarly hard-wearing



Fig 13. Skin calluses from dragging

### Fine motor problems

• A child with proximal balance difficulties ie; poor trunk control and sitting balance will have difficulty with distal activities including many fine motor skills eg; feeding, writing.

 $\rightarrow$  For a child to use their hand function to their optimum ability it is therefore important to ensure that they have sufficient support to maintain a an aligned, secure sitting posture. This is more easily achieved when both feet are flat to the floor (Fig 14).



Fig 14. Seating position with both feet flat

• Sitting in a chair. Ideally the child should be matched with an appropriately sized chair. However, even a chair that is too large can be adapted so that it is

fit for purpose.

 $\rightarrow$  Ensure it fits the child appropriately; take measurements of hip to knee, and knee to foot and ensure the corresponding dimensions in the chair are the correct length.

 $\rightarrow$  If the chair is too large pillows or cushions can be used to shorten the seat depth.

 $\rightarrow$  The feet should not dangle. Foot supports are important and can often be adjusted to the right height, or boosted with blocks.

 $\rightarrow$  A lap-strap is important to ensure the child does not fall out, and to ensure the hips are held back in a nice position.

 $\rightarrow$  If the chair does not have a specific pressure relieving cushion, the child should have regular periods out of the chair

 $\rightarrow$  Providing a tray across the lap gives a surface for play and feeding. arm rests provide lateral and forearm support.

#### • Wheelchairs.

 $\rightarrow$  The dimensions of the chair, and foot supports need to be adjusted as described above for chairs

 $\rightarrow$  Children with good upper limb function, can be given chairs with large wheels, so that they can mobilise independently.

 $\rightarrow$  Make sure the wheels are fully inflated to ease mobility. (see <u>www.novita.org.au</u> – fact sheet on 'positioning tips for wheelchairs' for further details)

• **Handling pens**, pencils and eating implements can be especially difficult because of weakness, dystonic posturing and poor coordination.

 $\rightarrow$  fattening a pencil with rubber bands to thicken it and improve the grip makes it easier to hold. Alternatively a plasticeine or putty ball will have the same function

• **Tremors** these are common following some forms of encephalitis, particularly Japanese encephalitis

→ Adding a weight to the bottom of a drinking vessel reduces the tremor and makes it easier to drink

• **Continence**. Do not necessarily wait until children are asking for the toilet. If toileting becomes hurried and stressful, spasticity may increase, and there may be difficulty relaxing. Children with spasticity can have problems with constipation because of their reduced mobility, dehydration and poor diet.

 $\rightarrow$  Children should regularly be toileted, e.g. before meals

 $\rightarrow$  A convene/sheath or continence pads may be necessary for urinary incontinence

• **Diet.** Children with acute brain injury are at risk of malnutrition, because of poor feeding, and constipation because of their reduced mobility, dehydration and poor diet.

 $\rightarrow$  Ensure that children have appropriate diet. This may include thickened fluids, because of worries about swallowing difficulties; adequate hydration.

#### • Drinking

Some children are limited by weakness of the neck, which means the chin rests on the chest. This makes drinking from a cup difficult, because the child's nose gets in the way.

 $\rightarrow$  A "nosey" cup can be easily made by cutting down one side of the cup, so that it can be tipped back to drink from it, even if the head cannot be tipped back (Fig 15)

→ The use of a straw can make drinking from a cup easier.



Fig 15. Cup modified for children with weak neck extension

### Cognitive and memory problems

Memory problems are common following encephalitis, this is especially true for herpes simple encephalitis, but is also seen in Japanese encephalitis

 $\rightarrow$  Simple measures may aid the memory. These include a notebook that reminds a child what they need to take to school, a simple diary of what a child did in the day

 $\rightarrow$  Ensure the child is focussing on the speaker and not distracted when instructions or information are being given

 $\rightarrow$  Repeat information or ask the child to repeat back to you in order to help consolidate information and learning.

 $\rightarrow$  Provide information in spoken and written form as memory may be better for things that are heard or for things that are seen.

 $\rightarrow$  Provide frequent prompts and reminders

 $\rightarrow$  Memory difficulties may affect the child's ability to learn and acquire new information. School and parents will need to monitor a child's progress over time and be realistic about the educational expectations.

 $\rightarrow$  A child may be frustrated if they are unable to do things as well as before the illness. This will need to be monitored.

 $\rightarrow$  Age at injury will have a significant impact on the child's cognitive recovery. Some difficulties may not become fully apparent until later in childhood if skills fail to develop.

 $\rightarrow$  An understanding of the child's previous cognitive abilities and personality traits is helpful.

 $\rightarrow$  Physical problems with vision, hearing or fatigue will need to be considered in the classroom and at home.

 $\rightarrow$  The child may be less able to concentrate for long periods or need help when switching to a new task. They may need prompts to stay focussed on tasks.

 $\rightarrow$  The child may benefit from more time to process and understand information.

 $\rightarrow$  The child may need help to organize their time, set goals and initiate activities.

### **Behavioural issues**

These are common following encephalitis. Parents often report that although a child has recovered physically, they are irritable and easily get into fights with their siblings, or at school

 $\rightarrow$  Try to ensure that those the child encounters understand that s/he has been ill. A letter to be shown to new school teachers may be helpful. Encourage those around the child to avoid unnecessary confrontation if possible. Simple adaptations in the behaviour of others may make things better for everyone

 $\rightarrow$  A sensible and practical guide to some common behavioural problems in brain injured patients, and how to deal with them is given on the Brain Injury Resource Foundation website (http://www.birf.info/home/library/behavioral/beh-manag.html)

 $\rightarrow$  Provide simple but clear rules about what behaviors are expected and acceptable.

 $\rightarrow$  Be consistent with behavioral requests to help the child understand what is expected of them.

 $\rightarrow$  Children may be more impulsive or less able to problem-solve in difficult situation. It is important that they are supported in re-learning appropriate social rules.

→ Routine will help with a child's behaviour and following a daily timetable if possible

 $\rightarrow$  Changes can be the result of an emotional reaction as well as the illness and hospitalization.

 $\rightarrow$  Look for 'triggers' to behaviour to gain an understanding of why the behaviour is being displayed.

 $\rightarrow$  Give calm and clear instructions of what behaviour you would like to see.

 $\rightarrow$  Provide somewhere quiet for the child to go to calm down if they feel overwhelmed.

 $\rightarrow$  If a child is becoming anxious or angry try changing activity or giving them something different to focus on.

 $\rightarrow$  It is important to remember that siblings may also feel worried or excluded and they will also need time with parents and reassurance.

### Educational considerations

• A child who has an acquired neurodisability may not be able to go back to school when they are discharged from hospital. However, it is worth giving the following advice to the parents or other family members.

• As the condition of each affected child, both cognitively and physically will vary widely, as will socio economic backgrounds, it is only possible to set out the broadest possible guidelines.

#### Set realistic goals

→ It is important to ascertain the skills and knowledge the child possessed before the onset of illness. There is a tendency to have a concept of a 'normal child', whereas, in fact, a pupil may have been exceptionally bright or have had difficulty in learning. It may be revealing to find out what sort of personality the child had prior to being ill. The child's teacher is often the best source of information as their assessment will be more dispassionate than that of a family member. As soon as the child is medically well enough, establish the current cognitive functioning.

→ A programme should be worked out for regaining these skills. For example, in the case of numeracy, maybe a child can now only count up to 3, whereas previously, in day to day life, they could mentally add and subtract within a 100. The next aim might be to count up to 5. Generally, repetition and encouragement will help progress. It may be that the process of regaining skills may require breaking down the process into very small steps. Setting realistic targets will be helpful to the 'teacher', whether that is a member of the family or a whether education takes place in a formal setting. It will also prevent the pupil from being discouraged.

→ In the early stages of recovery pupils may not be able to hold more than one or two ideas in their head at once, as their short term and working memory has been affected. This is likely to improve in time. Break down information into small units. For example, only give the child one or two pieces of information, such as 'Find the yellow car.' It may be necessary to repeat the information and processing is likely to be slow, so patience will be required. The difficulty of the tasks set, will change as the learner improves.

 $\rightarrow$  Simple tasks, which appear to be play, such as colouring in pictures with crayons will help fine motor skills and concentration, as well as providing a sense of achievement.

→ The rate of recovery will vary and extend through time. Often, the greatest recovery takes place in the first months. This is because, unsurprisingly, physical recovery impacts on cognitive recovery. However, there are no hard and fast rules where brain injury has occurred and recovery may continue through many years.

→ Unfortunately, it is not true to say that the young recover better than the older patients. If a child finds it difficult to retain any new information, then they may well not progress in terms of mental development, much beyond the achievements which they had acquired prior to injury. Consequently, a six year old may not develop, mentally, much beyond the achievements one could expect of a six year old. A fifteen year old, however, has a much bigger bank of old learning and knowledge to reacquire. Often, skills and information will be reacquired relatively easily. It may be just a case of revisiting an area of knowledge for that knowledge to be re established.

#### The Learning Environment

 $\rightarrow$  Generally, children who have undergone brain trauma, recover better if their environment is free from too much noise or too much visual distraction. In a classroom, they may be better placed near the front of the class so that they are not distracted by fellow pupils. A clearly defined structure and expectations benefit pupils with neurological damage.

→ Primary aged children often progress better for this reason, not least because there are often fewer people involved during recovery, so that they are better understood and they are likely to feel more secure.

 $\rightarrow$ Pupils may not be able to concentrate on one task for long, so that changing activity, when restlessness sets in, may be helpful.

 $\rightarrow$ Children recovering from neurological damage tire easily. Once they have begun to tire, they should be allowed to rest. This may mean only remaining in a learning environment for an hour or less, at first.

#### The Social Environment

 $\rightarrow$  At first children will be welcomed back by their old friends. It may be that the child has changed both in terms of what they can do and in terms of their personality. Old friends may not wish to engage with a child that has changed. Both the child and the child's parents will need sympathy and understanding if this is the case.

 $\rightarrow$  The parents will need to mourn the loss of the child which they have lost and come to accept the new child. For this they will need support.

 $\rightarrow$  It may be that the child will benefit from being taught with slightly younger children, or children who have similar problems. Each circumstance is individual.

 $\rightarrow$  It is important not to treat a child who has acquired neurological damage in the same way as a child who has been developmentally delayed from birth. The two conditions are not the same. The pupil should be spoken to in an age appropriate manner and when possible material that is age appropriate in style, if not content, should be used.

→ Loss of cognitive functioning may be patchy in the case of neurological damage. Computing numbers, may return relatively quickly, whereas language based tasks, requiring even the simplest deduction, may return very slowly. It is therefore possible to formally test a pupil with a chronological age of fifteen, who has a Number Age of seventeen ( where a test only requires computing numbers and does not deal with problem solving), but a Reading Comprehension Age of nine years.

 $\rightarrow$  Language problems affect all areas of achievement. The work of a teacher and a speech and language therapist often overlap in the early days. Similarly, tasks that an occupational therapist would recommend are often broadly the same as those that might be employed by a teacher. In cases, where there groups of professionals involved, it is important to establish communication, to promote the best interests of the child.

 $\rightarrow$  Previously routine tasks (or new skills that are age appropriate) may appear difficult and care should be taken to establish how and why that is : look at the sequencing, organising aspects of the task and whether or not extra prompts/guidance are necessary to complete the tasks safely.

# Some useful websites and other resources

 The Brain Injury Resource Foundation (<u>http://www.birf.info</u>) exists to support those affected by brain injury (among other functions). Its website has some excellent resources, including:-Behavioral Issues – handling troubling behaviour (a sensible practical guide to some of the common behavioural problems and how to cope with them) <u>http://www.birf.info/home/library/behavioral/beh-manag.html</u>

It also has excellent sections on Communication, Memory and Rehabilitation

# 2. Disabled Village Children - A guide for community health workers, rehabilitation workers, and families

This excellent reference book written by David Werner is to aimed at helping meet the needs of disabled children, especially in resource poor settings It is available on the web <a href="http://www.dinf.ne.jp/doc/english/global/david/dwe002/dwe00201.htm">http://www.dinf.ne.jp/doc/english/global/david/dwe002/dwe00201.htm</a>

**3. Management of Brain Injured Children**, 2<sup>nd</sup> edition, Appleton and Baldwin, OUP This textbook gives a standard Western Industrialised Nations outlook on the multidisciplinary team approach to brain injured children.

4. Child Brain Injury Trust (www.cbituk.org) has lots of useful information and other links

**5.** The Encephalitis Society (<u>www.encephalitis.info</u>) is a UK charity with good information, particularly on memory and behavioural problems.

**7. Wheelchair usage** (<u>www.novita.org.au</u>) Fact sheet on 'positioning tips for wheelchairs', and other aspects of wheelchair usage

# Acknowledgements

We thank our many colleagues for sharing their ideas on rehabilitation with us, and the children and their families for permission to sue the photographs. Funding was provided by the JE program at PATH, Seattle, with additional support from the Wellcome Trust, and the United Kingdom Medical Research Council.