Fragile brain, handle with care

Jonathan Dart and Sarah Cumberland report on a form of child abuse that is not instantly recognizable, but the consequences can be dire. In the absence of treatment, Australian doctors are trying to improve diagnosis and agree the focus must be on prevention.

The scenario is all too common. A baby is brought to Sydney Children’s Hospital, Australia, suffering seizures, vomiting, irritability and lethargy. There are no obvious injuries and its mother has no explanation for the child’s symptoms.

The examining doctor may think the baby has a virus. But on closer examination, there may be subtle clues pointing to hidden injuries, such as bruising, retinal haemorrhages or fractures of the ribs or other bones. Tests, such as a computed tomography (CT) scan, may also reveal signs of injury.

If there is no medical explanation for such injuries, the baby will be considered a possible victim of ‘shaken baby syndrome’, a form of child abuse that involves the violent shaking of an infant.

The term ‘shaken baby syndrome’ was first coined in the 1970s, but is no longer used at Sydney Children’s Hospital, although paediatricians still use the term loosely. Terms more commonly used include abusive head trauma or inflicted traumatic brain injury.

According to Dr Kieran Moran, forensic paediatrician at Sydney Children’s Hospital, babies are victims of violent shaking mainly in their first year of life, as that is often when they cry inconsolably and when parents and carers become most frustrated. Indeed, abusive head trauma reaches a peak at ages six to eight weeks, when babies cry the most.

Doctors describe the brains of very young babies as having the consistency of unset gelatin. The rapid acceleration-deceleration forces of violent shaking can cause much more damage to brain tissue and blood vessels than in the Department of Violence and Injury Prevention and Disability at the World Health Organization (WHO). Three months of group rehab is the best these children can hope for.

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Obonyo Tom Fred

And after the three months are up? Where possible, children are returned to their families and communities to begin the long road back to ‘normal’ life. And it is here that many face the biggest challenge. “These children have often lost their families and so have no network of support, no way to make a living, nothing,” says Obonyo Tom Fred, director of the Agoro Community Development Association in Agoro, a war-torn rural community in northern Uganda that has been devastated by 17 years of almost constant civil and tribal conflicts. “It is so hard for them,” says Obonyo. “I have heard some say they were better off in the war zone.”

To point them in the right direction, in 2003 the Agoro Community Development Association started working with RESPECT International, a Canadian NGO that links refugee communities with online volunteers from the United Nations Volunteers programme. One of the fruits of this association is a computer resource centre that today gives IT training to students with a view to creating work opportunities later on.

Encouraging life skills and economic autonomy is also a key aspect of UNICEF’s rehabilitation and reintegration efforts. “We provide support to get these children back to school or into vocational training or work,” says Ironside. These activities take place in local communities and include other vulnerable children, not just former child soldiers, to promote a sense of community and reduce stigmatization.

Children who successfully complete a vocational training receive a start-up kit, for example in dress-making, carpentry or hairdressing, to help them along the long road to recovery, reintegration and independence. A kit to put a shattered life back together? “The kit is but one component of support and follow-up provided to these children. I have witnessed transformations,” says Ironside.
a direct bump to the head caused by a short fall. "Shaking may seem like the option least likely to cause damage, but the opposite may be the case," says Moran. "Babies are especially vulnerable because of the softness of the brain and lack of development of muscles in the neck."

Studies since the late 1970s in the United States of America have shown that between 13% and 30% of babies diagnosed with abusive head trauma die as a result of their injuries, while many of the survivors are left with varying degrees of long-term damage, including learning and behavioural disabilities, blindness, seizures and paralysis.

"Surviving victims usually have terrible outcomes. Even milder cases often experience learning difficulties and have problems concentrating. All these patients need long-term follow-up," says Moran.

In the Australian state of New South Wales (NSW), children suspected of having suffered abusive head trauma are referred to a major paediatric hospital, where a forensic paediatrician is involved in the investigation. Last month, the NSW Department of Health was finalizing new guidelines in the diagnosis and management of these cases, including ways to recognize intentional head injuries and the questions doctors need to ask carers.

"Better training for doctors in the recognition of warning signs will help earlier identification and thus hopefully prevent the severe end of the spectrum," says Moran, who was involved in developing the guidelines.

In NSW – with a population of just under seven million people – less than half of known cases of abusive head trauma in children result in prosecution of perpetrators. "It's usually pretty hard to find a witness to an episode of abuse," says Dr Amanda Stephens, who is writing a doctoral dissertation at the University of Sydney on the issue. "And where a parent is suspected … it can be hard to get an admission [of guilt]."

So while prosecution – or the threat of it – is not an effective deterrent and, given such poor prognosis, the focus has to be on prevention. "It's too late to intervene by the time a kid has been shaken or abused around the head area," says Stephens. "You really need to intervene before this all happens, you need to identify the children who are at risk. That doesn't necessarily mean removing children but it does mean really intense programmes to ensure that a child is not going to be damaged. It's also about broader policy – fixing poverty and drug abuse and so on."

In some countries, primary prevention efforts have proven successful in making parents aware of the dangers of violent shaking of infants and providing them with techniques to cope with crying infants. Such social programmes target the most likely perpetrators of this type of abuse. Studies in Australia, Canada and the USA have found that biological fathers were responsible for abusive head injuries in around 45% of cases, while 25% were caused by the mother's boyfriend, 15% by mothers and 15% by childminders.

In Australia, the Department of Community Services, the NSW government agency responsible for early family intervention, set up the Brighter Futures programmes in 2004 to support and educate new parents at risk, particularly new fathers.

In the USA, abusive head injuries to infants were reduced by 47% over a three-year period after a hospital-based programme to educate parents was introduced in New York state, according to a study published in Pediatrics in April 2005. The programme involved giving parents a simple one-page information leaflet, showing them an 11-minute video and asking them to make a statement confirming they had received and understood these materials. It cost less than USD 10 per infant and was designed to require less than 15 minutes to implement.

"When compared to the initial hospitalization and ongoing medical costs for treatment [of a shaken baby] that can average nearly USD 300 000, this study shows that a small investment of time and money can truly make a difference," says Dr Mark S Dias, paediatric neurosurgeon at Penn State Milton S Hershey Medical Center, USA, and the lead author of the New York state study.

Research from the University of North Carolina School of Medicine, Chapel Hill, USA, suggests that parent education programmes should be considered worldwide. Surveys of parents in low- and middle-income countries suggest that some use shaking as a form of discipline without realizing the serious consequences. "Shaking of young children is reported at 10 or more times the rate in high-income countries, with rates higher still in urban slums," says Dr Desmond K Runyan. "If this is related to shaken baby syndrome in the way that we postulate, it may explain large portions of infant mortality, developmental delay and learning disabilities in low- and middle-income countries."