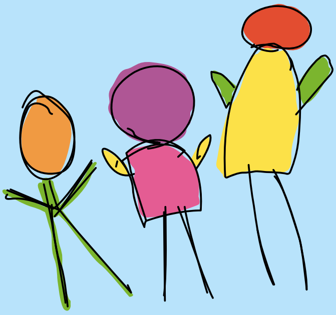
Help for children with brain injuries



Friends of Brain Injured Children

Libby Steeper

A project of Friends of Brain Injured Children ACT Inc

Hands Across Canberra

Cracking Good Time

Preserving farming in the Majura Valley

Funded by Hands Across Canberra and Majura Valley Landcare Group

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Friends of Brain Injured Children

Introduction

When a child has a brain injury parents have a great deal to come to terms with. There will be worry, grief, and concerns for the future. Parents want to find out as much as possible about their child's condition and what to expect in the future. They also want to know how to find the best treatments for their child.

There is some need to find effective treatments as early as possible, as the window between birth and age six is the period of greatest development of the brain and therefore offers great effectiveness in undoing many of the effects of brain injury. The brain continues to develop until adulthood and recovery from brain damage is possible at later ages with treatment.

Friends of Brain Injured Children ACT Inc. has been active in the Canberra region since 1988. Its purpose has always been to assist families who have a child with a brain injury, using the philosophy of early intervention and regular, intensive, frequent therapeutic activity. We believe this level of treatment is necessary to help the brain "rewire" itself and reduce the disabling effects of the injury on the child's body and mobility. The organisation has helped hundreds of children and their families.

Over the years the range of therapies tried and tested by the families of FBIC has grown, adding new therapies as they are developed. The growing understanding in the medical research community about neuroplasticity and the power of the brain, especially a child's brain, to change and develop supports the FBIC approach.

Friends of Brain Injured Children has regretfully closed its doors after nearly thirty years. The FBIC committee decided to use its experience and knowledge for this booklet about brain injury and its treatment as a final gift to families of a child with brain injury. You, as a parent, will need to be in charge of choices of therapies and therapists. Use this information and do your own research, discuss ideas with professionals and be as closely involved with your child's treatment as possible.

Thank you to the kind contributors to this book; Gabi Monus for her expert contribution on Conductive Education; Sirla Jafri who wrote the chapter on the National Disability Insurance Scheme and the inspiring story about her son Kamran; Jody Sliwka for Zac's story; Julie Hodgkinson and Sonia Maginnity for their contributions on Bowen Therapy and Anat Baniel Method respectively; Jane Duncan and committee members Jill Stenhouse and Maureen Bamsey for support, ideas and proofreading; and Mandy Hudson, FBIC's excellent organiser.

Finally, I thank the parents who have joined FBIC over the years and who have inspired us and helped to expand our knowledge of treatment options and in so doing have given their children better futures.

"I have read through the book and it is both compelling and significant with regard to the support of all those caring for and loving a person with acquired brain injury."

Sherry McArdle-English, Majura Valley Landcare Group

"Friends of Brain Injured Children has been a great support to us as we navigate through the world of brain injury. We hope the expertise and help in this book is a steering guide for other families, carers and their children."

Annie and Jim, parents

"I came across FBIC a few years into our journey. FBIC helped us navigate a path through the bewildering maze of early intervention. We found great practitioners, great support and most importantly, hope, for a better outcome for our precious child. Any family raising a child with brain injury would be well advised to read this book!"

Fiona West, mother of a child with brain injury

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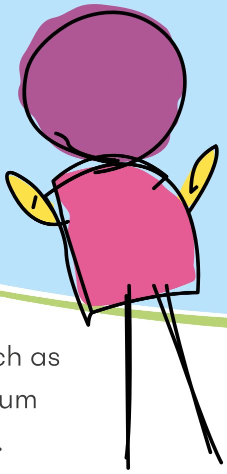
CHAPTER 1

What is brain injury?



Acquired Brain Injury (ABI) can have a number of causes, such as injuries sustained during or after birth, Foetal Alcohol Spectrum disorder, accidents, falls and hypoxic injury (lack of oxygen). Lack of oxygen or bleeding to the brain causes cells to die, and the affected part of the brain is no longer able to perform its function. Brain injury is not the same as intellectual disability.

The example of an airport control tower can be helpful. If part of the control tower is out of action planes do not receive complete messages and those planes cannot follow instructions. Similarly, if a portion of the brain is damaged it cannot send messages through the nervous system to activate movement or cognition. This could mean, for example, that hands don't receive signals to move normally. Without careful treatment the muscle development of the hands doesn't happen and the child could eventually have poor hand use.

The brain itself is divided into two halves, or hemispheres, and each hemisphere has four lobes. Each section is involved with aspects of how people think or move their bodies. In the past people believed that these functions were fixed, and any damage to a particular part of the brain meant a permanent loss of that particular function.

Can anything be done about brain damage?

You will hear about neuroplasticity, a concept behind all effective treatments. Neuroplasticity is the ability of the brain to form and reorganise synaptic connections, especially in response to learning or experience or following injury. Simply put, this means the brain's capacity is not fixed at birth as was once thought. We now know it is capable of change and repair.

Modern research shows there can be redevelopment of function in other parts of the brain, and even cell growth. A child's brain develops rapidly during the first two years. From two to six years there is also good development and synapses continue to form until age eleven, and at a lesser pace throughout life. For this reason parents are always encouraged to make the most of these windows, seek intensive therapies, and provide as much suitable activity, practice and enrichment as they can for their child.

Finding time for appointments becomes more difficult after a child begins school and parents may have work commitments. It is important to maintain as much beneficial therapy and activity as possible to continue improvement as this can prevent deterioration as the child's body grows.

What are the effects of brain injury?

The effects of a brain injury depend on a number of factors, including the severity of the injury and the part of the brain which has been damaged. For instance frontal lobe damage can affect problem-solving skills, thinking and emotions. Damage to the cerebellum can affect muscle coordination and balance. Damage to the occipital lobes can affect eyesight. Sometimes a child will develop epilepsy if there is some damage between the hemispheres.

Although scans can give some idea of future problems it is hard to predict with certainty what effects a brain injury could have on development. The disabling problems than can arise depend on the area of the brain damaged and the severity of that damage. Every child will be differently affected. However, these are the some of the most common disabling effects.

MOVEMENT	Some degree of paralysis of limbs can occur, either both arms and legs (quadriplegia), arms or legs (paraplegia) or one side (hemiplegia). Paralysis may range from total inability to use the limbs to a milder difficulty in walking or using hands.
CONTINENCE	Some children are unable to control bladder and bowel functions because of their brain injury. This can mean using nappies, possibly throughout life. There is assistance available to provide free nappies, and some therapists will offer advice or treatments that may improve results.
VISION	Eyesight can be affected. Some children are helped by glasses or eye exercises, others have more severe vision problems.
SPEECH	The mouth and throat can be affected, leading to difficulties with sucking, swallowing and speech development.
COGNITION	Some children may have difficulty in some areas of intellectual development and in impulse control. In the past people with limited or no speech were assumed to have an intellectual disability, but nowadays we know differently. Better testing, an enriched environment and teaching programs assist children to become their best. Children may receive assistance when attending mainstream schools, or specialist settings within mainstream, special education or independent schools, and have great lives.
EPILEPSY	This can be a complication of brain injury. Not all epilepsy is accompanied by severe seizures that require immediate medical treatment. More commonly it takes the form of “absences” where the person goes very quiet and may be vague when the moment passes. This can be quite difficult to spot, and it is usually a parent’s or therapist’s awareness that something is odd that brings it to light.

What if we don't have a diagnosis?

A diagnosis of brain injury is not always obvious or straightforward. Parents will need to keep a close watch on their child and make regular visits to their doctor and paediatrician.

We would suggest that you keep a journal of your baby's progress and include everything, large or small, that concerns you. This will give better information to the doctor than a short visit can provide. Don't worry about being thought a worrier. Parents' gut feelings are usually reliable, even if you are not sure what you are seeing. Write down your concerns, as specifically as possible.

It can help if you can introduce a simple routine for your child. Playtime on a rug on the floor is great, tracking toys, reading stories, gentle tickling games, singing and talking are all part of good parenting, and will enrich your child's world. Join a playgroup. You may find one for children with disabilities.

Your observation of your child's vision is important, as you may pick up difficulties early. At the earliest stage you can watch for tracking of toys moved past their eyes and responses to mobiles overhead, responding to faces, grabbing at toys and colour preferences, among other ideas. Ask for testing if you become concerned at any stage.

Artist
Felicity, aged 9

CHAPTER 2

Diagnosis and getting started

Is diagnosis easy?

It isn't always easy to diagnose a brain injury unless it is quite obvious. Your doctor or paediatrician will diagnose and assess your child, and this may be done over a period of time. It will probably involve brain scans to find out about the extent of the damage and what part of the brain is affected.

You may have a diagnosis of brain injury but still be uncertain about how this might affect your child. You will be advised to keep a close watch on your child and pay particular attention to the usual developmental milestones, such as speech development, rolling over, crawling and walking. Of course, children reach these milestones at different rates. That is quite normal, so don't compare your child's progress with other children completely. Just be aware of your child's progress and listen to your gut feelings.

Once you are told your child has a brain injury, like most parents in this situation, you may have feelings of grief and worry about your child's future. Give yourself some time to get used to this new future, but please believe there is help out there and many treatments for your child.

Your job is to love your child and choose a path through the information available to arrange the best help and support for your particular situation.

Delayed diagnosis

Sometimes a diagnosis can take months or years. Parents may feel there is a problem in development but are unable to find a useful diagnosis. In this case you need to find out about developmental milestones. Remember that these are only averages, so children reach them at somewhat different ages. But if a milestone is considerably delayed you can take that information to a doctor for discussion.

If you are still concerned you could try other doctors and reach out through the internet, friends and parents with children with disabilities. A diagnosis and assessment is important, as you then know what you are dealing with and you can set up your child's treatment program. You may only have suspicions that all is not well but you can begin a program of therapies that seem sensible and doable. Try some of the everyday suggestions in later chapters. These will help brain and physical development while you are waiting for the situation to become clearer. The earlier you are able to start the better.

What can be done? Getting started

The best results for repair and development come from early intervention, regular, intensive and frequent therapeutic care, as well as care provided at home. Frequent treatment doesn't mean you will have to take your child to therapists for several hours every day. You can supplement at home what those therapists are doing for your child.

For example, your physiotherapist will suggest exercises and movements you can do at home, your Conductive Educator will offer lots of advice about home therapy, or your masseur can teach you simple things you can do while you are changing nappies, after the bath and before bed. All these activities contribute towards the development of your child's brain and body.

Use every opportunity you can to interact with your child, if only for a few extra minutes at a time. These short periods can add up over the day to a really effective home therapy schedule. All these activities can be part of your regular day. Remember that all the early progress your child makes may reduce future disability – for life.

What therapies are available?

You will be offered a range of medical mainstream treatments at various stages: Paediatrician and General Practitioner care; physiotherapy; occupational therapy; speech therapy; Botox therapy; ankle-foot orthotics; dietician; surgery; equipment (wheelchair, hoist, walker etc.).

Your doctor and paediatrician are a very important part of your child's care. They will keep a close eye on development and be alert for signs of difficulties. They will also recommend any therapies they think will be of benefit. It is a really good idea to take a written list of your concerns when you visit your doctor, as your observation is crucial. Without your list you may forget to mention something important.

Can I use a combination of therapies?

Yes, you can. In fact, you will find combining therapies may achieve the best overall results.

To arrive at the best treatment program you will need to research for yourself. Therapists are expert in their own discipline of course, but may know little about other therapies. Doctors and physiotherapists certainly have knowledge of a range of other therapies beyond their own expertise but may be uncomfortable with some complementary therapies, especially those emerging after their medical education. It is quite right that they advise caution, just as we do. However, the careful selection of a wider range of therapies and trusted therapists by FBIC parents has produced impressive results.

Neuroplasticity is the concept behind all effective treatments. Neuroplasticity is the ability of the brain to form and reorganise synaptic connections, especially in response to learning or experience or following an injury. Simply put, this means the brain's capacity is not fixed at birth as was once thought. We now know it is capable of change and repair.

We recommend a three pronged approach:

- The first prong is your medical professionals, doctors, physiotherapists, speech therapists, occupational therapists, and treatments offered by major children's hospitals.
- For the second prong use the philosophy in the chapter on Conductive Education and your own research to choose suitable complementary therapies.
- The third vital prong is good mothering and fathering. Think about how babies are usually cared for. They are cuddled, tickled, played with, placed on the floor to explore movements, admired by family and friends. All this helps a baby develop and we do it naturally.

As far as possible, consciously do the same with your baby with a disability. Talk while you are feeding, changing, bathing, use lots of touch and cuddles, be proud of your baby and invite others to cuddle and chat, too. This is wonderful brain development. Nasogastric tubes can be rolled into a baby bootie and tied to a bib for daytime and playtime. Play peekaboo, sing nursery songs, read stories, do everything you can to enrich the baby's environment. Enjoy your baby.

As parents you will also become therapists, using ideas you learn from the paid professionals.

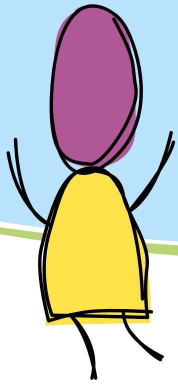
A typical program could include regular visits to the general practitioner and occasional visits to the paediatrician. There could be weekly visits to a physiotherapist, and possibly visits to a dietician, speech therapist and occupational therapist. The baby might have visits to an osteopath and masseur to soothe any discomfort.

As the baby grows therapy needs could change. You might try a toddler gym class, hydrotherapy or playgroup.

Older children can add new therapies to their mix, or beneficial mainstream activities, such as music, bike riding, gym training, dancing or hobbies if they are suitable.

CHAPTER 3

Mainstream medical therapies



Finding the best therapies for your child can involve trialing a number of different treatments and possibly changing them as your child grows. It usually takes a combination of therapies and treatments to achieve the best possible outcomes.

Every child is different and a therapy that works well for one may not have the same impact for another. We emphasise that the selection of the therapist is even more important than the choice of the therapy. Careful checking of a therapist's qualifications and relevant experience in treating children with brain injury is important.

Some useful questions to ask when selecting a particular therapist:

What benefits can we expect for our child?

Have you training and experience treating children with brain injury?

Are you treating any children at the moment with brain injury?

Do you measure progress with regular assessments?

Do you have evidence that your treatment is safe and effective?

What are the costs?

Can we use the NDIS for payment?

Can you show us what we can do at home to help our child?

Does your therapy fit with the science of neuroplasticity?

Paediatrician and General Practitioner

Your doctors are the front line for on-going care, including general health care needs and observing developmental progress. They will also suggest various treatments, including specialist care. As well as medical care you will probably be offered a range of medical mainstream treatments at various stages by your doctors; physiotherapy; occupational therapy; speech therapy; Botox therapy; ankle-foot orthotics; dietician; surgery; equipment (wheelchair, hoist, walker etc.).

Physiotherapy

Physiotherapists assess and provide treatment to increase mobility, reduce stiffness and pain and help overcome movement disorders. They will work with your child to help develop new motor skill functions, improve your child's existing and growing abilities and functions, and help your child engage in various physical activities. They develop exercise programs for your child and use techniques including massage, hydrotherapy and joint mobilisation.

Some physiotherapists specialise in working with children with various disabilities. Others work in areas like sports treatment or adult injuries.

Their approach may suit some adolescent children.

Physiotherapists are important for NDIS planning as their recommendations are usually needed for equipment, continence aids, speech therapy, occupational therapy and other aspects of a child's plan.

Speech therapy

A speech therapist works with people who have difficulty with speech, eating, drinking and swallowing. Some of the strategies used include developing different ways your child can communicate and be understood, helping to reduce problems with reflux, and offering strategies for eating and swallowing food. Sucking and swallowing are an important forerunner to speech development.

Botox treatment

Botox is used by specialists in major hospitals. It is injected under gas and with numbing cream into selected muscles, weakening them for several months, and giving the surrounding muscles the opportunity to build up and strengthen. Botox treatment programs are most effective when used with appropriate exercise and rehabilitation programs.

Occupational therapy

Occupational therapists help children participate in everyday activities, ranging from being able to hold a fork to being able to walk independently. They use a number of methods, including making changes to the person's environment, providing assistive technology, and providing useful strategies for doing the things the child needs to do. This can include working on strategies to improve necessary skills such as fine motor skills, gross motor skills and core strength. It can also include providing equipment to help your child, such as a hand splint. They can also help with modifications to improve your environment, for example, to help a person in a wheelchair use the bathroom unassisted.

Zac's Story

In the early hours of December 5th, 2011, a month after celebrating his 2nd birthday, our youngest son Zac stopped breathing for no apparent reason. Zac's dad performed CPR until the ambulance arrived; however his heart had stopped beating and had done so for approximately 20 minutes. He had suffered a cardiac arrest. Zac was resuscitated and taken by ambulance to the The Canberra Hospital where he was stabilised. He was then transferred by helicopter (NETS) to the Sydney Children's Hospital in Randwick. He spent the next 11 days in an induced coma, MRI and CT scans confirmed that he had suffered brain damage from the lack of oxygen to his young brain. This resulted in a diagnosis of Dyskinetic Cerebral Palsy, leaving him unable to walk, talk or undertake any basic motor skills. Up until then he had reached all the age appropriate milestones for a toddler.

After 3 long months we were discharged from the hospital with an extremely poor prognosis. As very strong-willed parents we were determined to give Zac every chance possible to regain the independence he had lost. Through a series of events (and a case of divine intervention), we connected with Gabriella (Gabi) Monus, Conductive Educator. Gabi connected us to Friends of Brain Injured Children (FBIC), who provided us and other families of children with brain injuries much needed support through advocating for grants, providing financial assistance where possible, providing seminars around alternative therapies, toileting, nutrition. They offered peer support which was invaluable to our family new to the disability scene and trying to make sense of what had happened and trying to find their way.

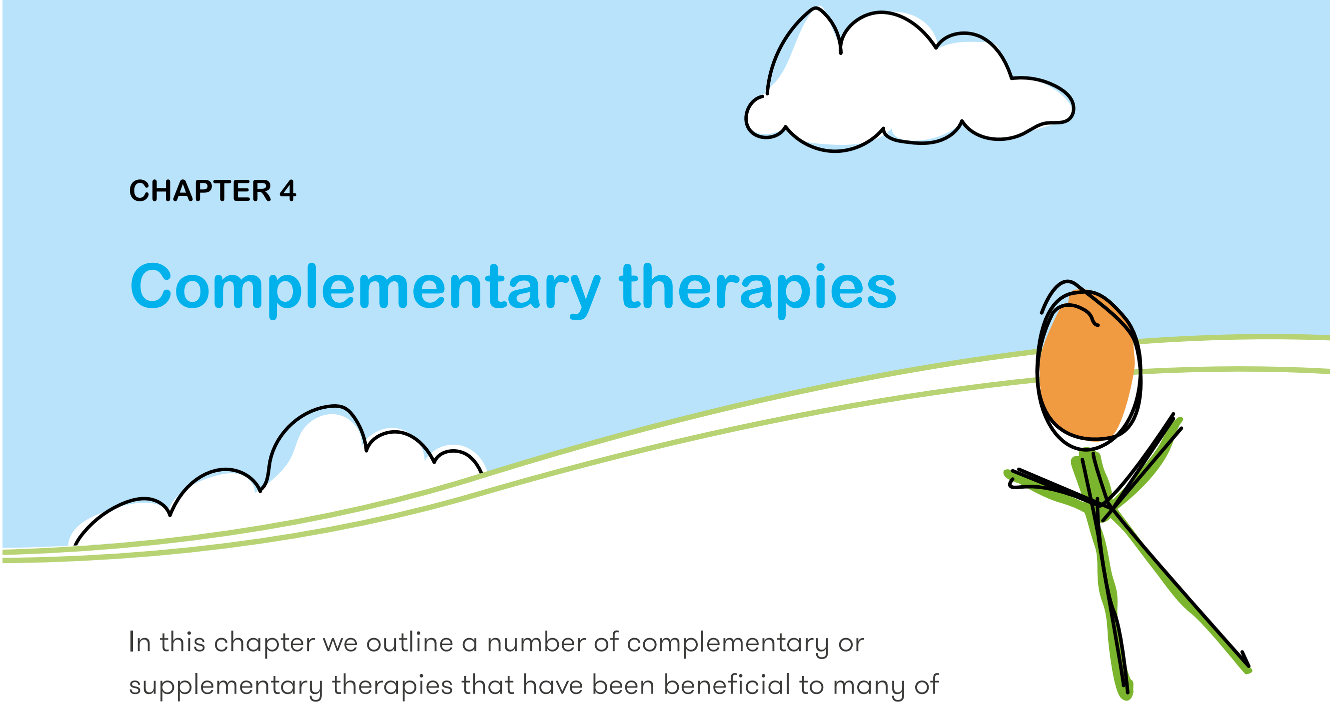
Zac has had regular and on-going therapy supports including; Conductive Education, Occupational Therapy, Speech Therapy, Physiotherapy, Chiropractic (Spinal Network Analysis) and Osteopathy, hydrotherapy, Feldenkrais, Second Skin suits, Orthotist, Podiatrist, Cold Laser Therapy, Naturopaths and Nutritionists. He also had more regular appointments with pediatricians, respiratory specialists and cardiologists.

Seven years on and Zac is attending a mainstream school in a mainstream classroom. He is walking with assistance (he is extremely close to fully walking independently) and uses a communication device to speak, read and access the curriculum at school. Doing pretty well considering we were told that we may need to turn off life support, and if he did happen to pull through he would be a vegetable and have no quality of life.

The best advice I can offer to any family having to navigate through this unknown territory is to trust your instincts. The doctors/specialists are not always right. Have the confidence to trust in yourself and your child, you just need to pave the way…

CHAPTER 4

Complementary therapies



In this chapter we outline a number of complementary or supplementary therapies that have been beneficial to many of the children in the Friends of Brain Injured Children group over the years. Some, like Chinese acupressure and acupuncture are very old, others are quite new.

All the therapy modes we discuss have been tried by FBIC families and found to be of some benefit. Of course, each family has made its own choices of both therapy and therapist and provided useful feedback to other families. Before making a decision they undertook their own research, including word-of-mouth recommendations. Sometimes they would discontinue with a therapist if not satisfied.

It’s very important that you make your own assessment of each therapy, and even more importantly, each therapist. A particular therapy by itself will not be helpful unless that therapist has skills and experience in treating children with the various symptoms of brain injury. Use the list of questions in the previous chapter to help you assess a therapist.

As well as the therapies your doctor or paediatrician recommends, such as physiotherapy, speech therapy or occupational therapy, there is a wide range of supplementary therapies that can offer great potential for your child’s recovery and pain relief.

There are a number of therapies for you to consider, with a brief description of each one of these:

- Conductive Education
- Acupressure and acupuncture (Point Percussion Therapy)
- Anat Baniel Method
- Bowen Therapy
- Chiropractic treatment
- Hydrotherapy
- Osteopathy
- Riding for the Disabled
- Therapeutic Massage

Conductive Education

We include a lengthy description of Conductive Education, as it expresses the FBIC philosophy in practical terms. It sees the child as a whole and works with the child to achieve as much recovery as possible. It does not accept the disability or adjust the child to live with that disability. Other therapies can be used within the Conductive Education framework.

If you can't find a Conductive Education therapist, we recommend that you learn as much as possible about the philosophy and use it when you are designing your child's therapy program.

It is not so much a single therapy as a philosophy and framework for a child's development and works towards the reduction of future disability. Developed in Hungary in the Second World War, the Peto Institute, with little available funding, developed simple and practical ways for children with disabilities to overcome their problems, working with what the child can do, rather than focusing on the disability. Results were excellent and now the Institute trains its educators from all around the world.

History of Conductive Education

Dr. Andras Peto, a physician and educator, developed Conductive Education in Hungary during the Second World War. His method pioneered a new way to rehabilitate children and adults with physical disabilities. While others learn and develop through stimulation and integration within their peer groups, adults/children with disabilities must be taught how to develop these skills. Dr. Peto believed that difficulties of development were due to lack of opportunity to learn, not only due to the actual medical diagnosis. Conductive Education always believed that despite damage to the central nervous system, the nervous system still has the ability to create new neural connections and, through a proper guidance and learning process, this capacity can be realized. That is why Dr. Peto termed this learning process "conductive". [from Latin- with guidance]

> *'Ask me not what I can do for children with cerebral palsy, but ask me what they can learn to do for themselves'*
>
> Andras Peto

Conductive Education (CE) is an educational program created to teach children and adults with physical disabilities such as, but not limited to, cerebral palsy, chromosome disorders, multiple sclerosis, Parkinson's disease, stroke and brain injury. Conductive Education encompasses the elements of traditional therapies, such as speech, physical and occupational therapy and early intervention. It is a holistic, educational approach, aiming to achieve results through creative problem solving, active learning, repetition, and with a strong focus on developing self-esteem and self-confidence.

Conductive Education is based on the theory of brain plasticity. By repetition of tasks and combining intentional movements with learning, the brain develops an alternative pathway and is able to send messages to the muscle groups and thus create desired movements like walking, standing, sitting and so on. The independence gained through the teaching of Conductive Education is not just limited to physical achievements but includes communication, academic, social and emotional development. Conductive Education finds ways to develop conscious movement in each person with a disability, based on the premise that even though the human body may have limitations the mind does not.

A conductive educator will “orchestrate” [guide] the person’s learning by integrating movement, communicative, cognitive and sensory learning. Using music, games and apparatus that aid movement and the student’s desire to achieve, develop and maximize functional independence through goal-directed activity, verbal cues and group dynamics. It aims to inspire the participant to become an active participant in the learning process, to build self-esteem and self-sufficiency and strive to achieve their highest potential.

Key principles

The child is a unified whole

The detrimental effects of a brain injury may impede the development of the individual, therefore practitioners of Conductive Education practise a holistic approach that considers the individual as a unified whole and provides an overall, holistic intervention. A holistic approach will consider all aspects of life; physical, social, emotional and educational development of the individual. Personal development and social organisation is seen as interdependent, interconnected, multi-leveled, interacting and cohesive. This idea of “whole” underpins the principles of Conductive Education.

Targeting the whole personality

Conductive Education attempts to create and establish the self-esteem and self-belief of all individuals who participate in the Conductive Education program. It also aims to shape a healthy self-image and body awareness. Confidence, self-esteem and self-belief are essential to achieve one’s highest potential. In Peto’s system the individual is not a recipient of treatment; she/he is an active participant in the learning process. Conductive Education is a partnership between educator and learner to create circumstances for learning - it is an all-day learning process.

An interdisciplinary model

Peto believed that, to provide a unified, holistic treatment, an interdisciplinary model is vital to achieve a desired outcome. Instead of a multidisciplinary approach, Peto applied an interdisciplinary approach, where conductive educators are a holistically trained group of professionals, responsible for the planning and implementation of a holistic, individualised program. This program looks at the overall development of an individual and it aims to shape a congruent and able person. Conductive Education will always focus on ability, and aims to build on existing skills to encourage the achievement of the individual’s highest potential.

Activity and intention

Peto asserted that restoring the interrupted learning process is not possible without the active participation of the individual, and, consequently, passive exercises or patterns cannot change or improve the functional state of the individual. The individual must focus and be fully present. It is the conductive educator’s role to engage and hold the attention of the individual so learning can occur at its best.

Consistent learning

In Conductive Education, continuity of learning and practice is considered necessary to reinforce a new skill. In order to achieve ongoing learning, Conductive Education turns any given part of an individual's day into a learning situation, a learning opportunity. All learned skills are to be used and regularly practised till they become well established.

Parents are involved at home at every step of the way.

Acupressure (point percussion) and acupuncture

This ancient therapy comes from China and is widely used throughout the world. Acupressure is suitable for babies and young children as it involves gentle pressure on various points on the body to aid healing and reduce pain.

Acupuncture, for older individuals, involves fine sterile needles placed on particular meridians for a wide range of healing purposes and pain relief.

Some extra questions for an acupressure or acupuncture therapist.

- *Where did the therapist receive training?*
- *Is the therapist experienced treating children with disabilities?*

Advanced Biomechanical Rehabilitation (ABR)

ABR is a therapy specifically aimed at children and young adults with Acquired Brain Injury. ABR's focus is working at correcting distortions in the musculoskeletal system, which helps facilitate the development and recovery of motor functions. ABR uses a hands-on method of manual application of pressure to the child's body with some simple apparatus.

Families are trained at several workshops a year to use the method at home and to adjust treatment as the child progresses.

For more information visit Advanced Biomechanical Rehabilitation at **www.blym.com**

Anat Baniel Method® NeuroMovement®

Anat Baniel's studies with Moshe Feldenkrais, followed by decades of her own transformational work with children and adults, led to her development of the Nine Essentials and the evolution of the Anat Baniel Method® NeuroMovement®.

Humans are complex information systems controlled by the brain, which learns and develops through movement. In a NeuroMovement® lesson, an adult or child is guided through specific, slow, gentle movements, paying close attention to what they feel (the first Essential). The Nine Essentials provide the ideal conditions for the brain to learn. When combined with the movements, the brain can use the information to grow new and elaborate neural connections, producing physical, cognitive and emotional improvements.

Even when portions of the brain have been damaged or are missing, NeuroMovement® can help the brain to "rewire" itself to bypass these damaged areas and create or recover function. This offers enormous possibilities for children with cerebral palsy, autism or genetic disorders, as well as those struggling with pain or recovering from injury or stroke.

It is a gentle, thoughtful therapy and engages the child completely. All Australian ABM therapists are trained in the US.

More information at **www.neuromovement.com**

Bowen Therapy

Bowen Therapy (also known as the Bowen Technique or Bowenwork) is a gentle form of bodywork where light moves are made over muscles, tendons, nerves and connective tissue ('fascia') ,which may provide sustained improvements in sleep, muscle tension and coordination, communication and general wellbeing.

For children and babies, the level of touch used in a Bowen Therapy session should be very gentle, with pauses between each series of moves to allow them time to integrate the work.

As the skills and training of Bowen Therapists can vary greatly, when you choose a therapist check that they are registered with one of the two Bowen Associations in Australia, their experience working with babies, young children with neurological disorders, and whether they undergo regular training. You may also like to ask if discounts apply for long-term or semi-regular care.

Chiropractic treatment

This treatment is based on the theory that the body has the ability to be able to heal and regulate itself, with the brain, spinal cord and nervous system controlling this process. It can help the body to function more easily and be more resistant to ill health, pain and disease.

Some chiropractors offer a neuroplastic treatment, called Spinal Network Analysis which accesses the brain's ability to change itself to reduce pain and improve health, performance and quality of life.

Hydrotherapy

Hydrotherapy involves movement in very warm water. Parents or a therapist spend time in the hydrotherapy pool with the child, benefitting from the warm pressure of the water over the body or exercising in the weight-free environment. Benefits include improvements in lung and digestive system function, relaxation, muscle development and the joy of water.

Osteopathy

This is a gentle hands-on approach, focusing on the relationship between the body's structures and the way the whole bodily system functions. Osteopaths focus on the relationship between muscles, nerves, circulation, joints and skeleton, and how they all work together to maximise your child's overall health and well-being.

Riding for the Disabled

Sometimes called hippotherapy, riding for the disabled is a specialised therapy. Horses are carefully selected and trained, and trained volunteers lead the horses and ensure the safety of riders.

Apart from being fun, riding helps improve coordination, balance, muscle development and fitness. It also boosts confidence, self-esteem, communication skills, leadership skills and trust.

To find Riding for the Disabled near your home visit: **www.rda.org.au/what-we-do.aspx**

Therapeutic Massage

When done well, massage stretches tight muscles, corrects imbalanced muscle groups, relieves the pain of sore muscles, provides brain stimulation through the nervous system, removes lactic acid and improves body awareness.

To find a good masseur ask the basic questions about their experience with children with brain injury. Few masseurs are experienced with children with your child's needs. You are not seeking a relaxing massage. You want one that can help develop your child's muscles, reduce pain and send messages back to the brain to improve the brain/body connection.

If possible offer your child a professional massage at least once a week, or even more. Learn to give basic massage yourself, best used after the hot bath each day, by asking your masseur to show you some simple things you can be sure will be beneficial.

Ideas you can use at home

Simple ideas that work at home include nutrition, constant awareness and correction of problem posture, and use of warmth and massage to ease stiffness or pain.

Good nutrition is an important part of caring for any child, and particularly when treating brain injury. Some ideas which may help;

- Breast milk is beneficial as long as possible, and can result in better immunity and some increase in IQ.
- Try to provide a diet rich in fish oils, folate, and vitamin C.
- If an older baby is not gaining weight, add some whey powder, butter, milk powder, cream or protein powder to the diet for weight gain.
- And it hardly needs to be said that fast food, soft drinks and other foods with little nutritional value should rarely be offered. Try to make sure everything your child eats or drinks is of the greatest benefit.

Be watchful for developing problems of posture and movement. If nerves and muscles are not receiving messages from the brain to generate movement they gradually lose strength and the ability to move properly. They can contract and become tight. Over time this can settle into awkward movement, stiffness and awkward posture, or even paralysis.

Learn about the stages of development and work within this framework. The usual progression is rolling over, crawling, using furniture to stand, supported walking, then walking solo. Children with brain injury are often slower to reach each milestone, but they still need to follow the basic pattern.

Correct posture problems early. Really observe your child closely for problems like fist clenching or an arching back. For example, you could place a small soft toy in baby's hands at night while asleep to keep them from clenching, or place a pillow between the knees to aid hip development and correct alignment. You can gently push arms to the side when hands contract under the chin.

Heat treatments can be used to relax tight muscles, release lactic acid, and relieve pain. You can use very warm baths with Radox or epsom salts, hydrotherapy, wheat bags and warm clothing to keep your child warm and relaxed.

You can think outside the square, too. Some FBIC parents have used early childhood gym groups, horse riding, ballet lessons, special playgroups, swimming lessons, or a suitable personal trainer and gym for older children. All these ideas offer therapeutic advantages while having fun.

Kamran’s Story

I hope this story will give other parents and caregivers strength and hope to do everything they can to assist their child achieve their greatest potential, regardless of what doctors and other professionals have said the prognosis is.

I am the mother of a 23 year old severely disabled young man, Kamran. Kamran, suffered oxygen deprivation at birth and within a few days his life had been written off by the medical profession. As new parents to our first born we were told he would most likely die within a few days. We were also told that if he survived he would never breathe independently (he was connected to an oxygen tank), eat independently, walk, talk or indeed do anything. It was a very difficult and challenging time in our lives but we were lucky to receive support and education from other sources.

Kamran’s main challenges have been severe low muscle tone in his upper body, cerebral palsy, epilepsy, incontinence, and limited communicative abilities. At the age of 23, while he does require assistance with all aspects of daily living he is also very healthy and happy, can eat, breathe independently, communicate both verbally and non-verbally and is an absolute joy in our and other people’s lives.

The main therapies that have assisted Kamran include:

- Acupuncture and acupressure massage – these assisted Kamran learn how to breathe independently and also stimulated muscles that led to his ability as a baby to independently suck from a bottle and eventually learn how to eat and swallow. Today Kamran can eat independently and enjoys his food – although food needs to be blended to a consistency that makes it easy for him to chew and swallow.
- Hydrotherapy (conducted by mum since Kamran was 2 months old and continues weekly till the present). This has assisted mobility and bowel function, toned low muscle tone, strengthened his body, assisted him to learn how to control his head and prevented contracted muscles. It has also aided independent movement, muscle growth and enhanced his lung function and capacity.

- Remedial massage therapy conducted by a qualified masseur who comes to the house once a week – this has assisted in his overall physical well-being, bowel function, minimised muscle contraction and prevented his scoliosis from progressing – his scoliosis remains as a flexible scoliosis that can be corrected via a second skin suit and with correct positioning. It also relieves tension in specific parts of Kamran's body that occurs through routine positioning including back pain, neck stiffness and tightness in legs and ankles. It assists in relaxing and aligning muscles.
- Osteopathic care - Kamran has been receiving weekly osteopathic care since he was a couple of months old. This has assisted lung function, bowel function, structural corrections, including adjustments to cranial, hips and scoliosis. Osteopathy helps to minimise recurrent shoulder dislocations due to muscle weakness.
- Conductive Education - Kamran received twice weekly physical therapy sessions that were intensive, from the age of a few months up until the age of 22 years. This greatly assisted with brain patterning, muscle memory, strength, and taught him resilience and how to focus on a task until it is achieved. It also assisted in education, muscle maintenance and development – primarily through weight bearing exercises, eye/hand coordination, brain function and communicative abilities (both verbal and non-verbal).
- Cold Laser therapy – this is a relatively new therapy which Kamran has received from a qualified therapist twice a week from the age of 22. Kamran's carers have been trained in how to use cold laser therapy on him and he receives this twice a week. It is targeted to his tight Achilles tendons, shoulders (which are prone to dislocations and knees – which click.

On a needs basis:

- Homeopathic care – approximately every 2-3 months this has greatly assisted with Kamran's Epilepsy and he has gone from being on very heavy anti-convulsants to nil medication. He has had prolonged periods in his life where he has been entirely seizure free. It primarily assists in Epilepsy management but also assists in stimulating appetite, bowel function, muscle tone and other aspects of his well-being.
- Kamran also wears a second skin splint. The splint is hand made by the Second Skin clinic in Sydney. It puts pressure on the muscles which stimulates the brain and enhances the body mind connection and awareness. It also gives him support and corrects his scoliosis. It assists his breathing, lung function and bowel function and it enables him to sit with support and feel more connected to his body.

Kamran's Story (continued)

What difference have these therapies made?

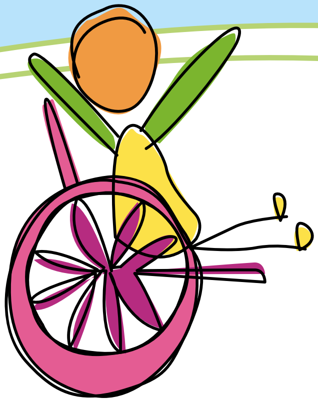
To date, Kamran remains in optimal physical condition despite his severe disabilities and this is entirely and directly attributable to the rigorous therapy program we undertake and maintain with him. Kamran can eat, say a variety of words including yes, no, I know, don't, go, hurt, hug, love, cold. He also uses non-verbal methods to communicate his needs including finger squeezing and nodding. He can move all the parts of his body. He can hold his head independently. He can sit with support and independently for a few minutes. He can weight bear on land and walk in the pool. He can hold things for a few seconds. He has never been hospitalised and can breathe independently. He is healthy and happy despite his disability.

Kamran also has minimal physical contractions in his musculature which is quite remarkable given he cannot walk and has very limited movement and mobility. In addition, his scoliosis remains a 'flexible' one as opposed to being 'fixed' and has not worsened in the last 12-14 years despite his growth. Similarly, his epilepsy, which at one point in his life was severely debilitating, is entirely controlled by homeopathic medication.

What this means in a practical sense is that organs in his body are not impacted by heavy medication and his cognitive abilities are optimised, because many anticonvulsants have the down side of causing drowsiness. To date all of these therapies continue to be an integral part of Kamran's daily care and have enhanced and assisted him to maintain optimal well-being.

CHAPTER 5

National Disability Insurance Scheme



The National Disability Insurance Scheme (NDIS) is a Commonwealth Government plan to assist people who have a serious disability. It also offers early intervention to children, particularly between birth and five. It is being rolled out to cover all Australian states and territories. The National Disability Authority (NDIA provides the policy and development role.

Eligibility

Your eligibility for access to the NDIS will first be determined by the NDIA. Children diagnosed with brain injury, cerebral palsy, and many other brain conditions may be eligible for NDIS funding. The best way to find out if you are eligible is to:

- Visit the NDIS website, **www.ndis.gov.au**
- Click on the Home button and
- Select the State or Territory you reside in

You will find a range of supports to assist you to determine eligibility and apply to the NDIS for support.

Early Childhood Intervention

The NDIS provides tailored and specific support for Early Childhood Early Intervention – children under the age of 6 years. The NDIS has engaged Early Childhood partners around Australia who are experienced in providing early childhood intervention. You can contact the NDIS on 1800 800 110 to find out more about this aspect.

How the NDIA determines your NDIS funding

Once you have contacted the NDIS and they have confirmed that your child is eligible to receive funding through the NDIS, the NDIA will ask you to identify goals for your child. These goals will be based around a 12 month plan and depending on your child's disability may include goals around health and well- being, communication, community and social goals, educational goals, behavioural goals etc. The NDIA will then organise an interview with you to discuss these goals. They will take all of the information you provide to come up with a 12 month figure of funding to assist your child achieve these goals. It is therefore critical that you thoroughly prepare for this interview.

Preparing for the NDIA interview

In order to prepare for the interview (which may be over the phone or face to face at home or office), you will need to have a very clear idea of what sort of supports you or your child require.

Supports may include things like:

- personal care (toileting, showering)
- social and community access (shopping, going out into the community, participating in community activity and sports, support working)
- attending medical appointments
- occupational therapy and/or physiotherapy
- health and well-being activities – such as hydrotherapy, remedial massage
- capacity building – such as learning a new skill to assist independence
- behavioural support – such as learning how to behave appropriately in different social settings
- continence aids
- domestic support – to assist with keeping your house and garden tidy
- equipment support and maintenance

Once you have clearly identified all the supports you require, you will need to work on a budget so you can cost how much funding is needed for 12 months to fund all of these supports. You do not need to share your budget with the NDIA, it is really to assist you to understand how you can cover all of the costs associated with the supports you are seeking for your child. For example, if you determine that your child requires assistance with showering daily then you need to cost out this figure. If the cost of having a carer come and shower your child is $47 per hour, then you will need $47 x 365 days = $17,155 of personal care funding. Please note that there are different price rates that apply on weekends and public holidays as well, so when costing out this figure you also need to be aware of the NDIS price list for goods and services for these times.

The NDIA will take all the information you provide around supports, and using the **NDIS price list** (the market price of the goods or services you have identified), and cost the supports to arrive at an overall figure to fund your child for 12 months.

It is worth putting effort into this stage and seeking advice from people with experience in developing a plan, as it can be more difficult to change it later if you leave out some assistance you hadn't thought of.

Self–managing the NDIS funding

You will have a choice around whether you as a parent will self-manage the NDIS funds or have the NDIS manage the funds for you. Self-managing the funds gives you flexibility and choice to decide what supports to buy to meet the goals in your plan. Self-managing the funding gives better control and independence over the funds and flexibility in arranging and paying for supports. Importantly, you will have the choice of which therapist you want to use. If you want to self-manage part or all of the NDIS funding you should speak to the NDIA about this when your plan is being developed. The NDIA has developed an **NDIS guide to self management** which can better assist you to understand how to do this.

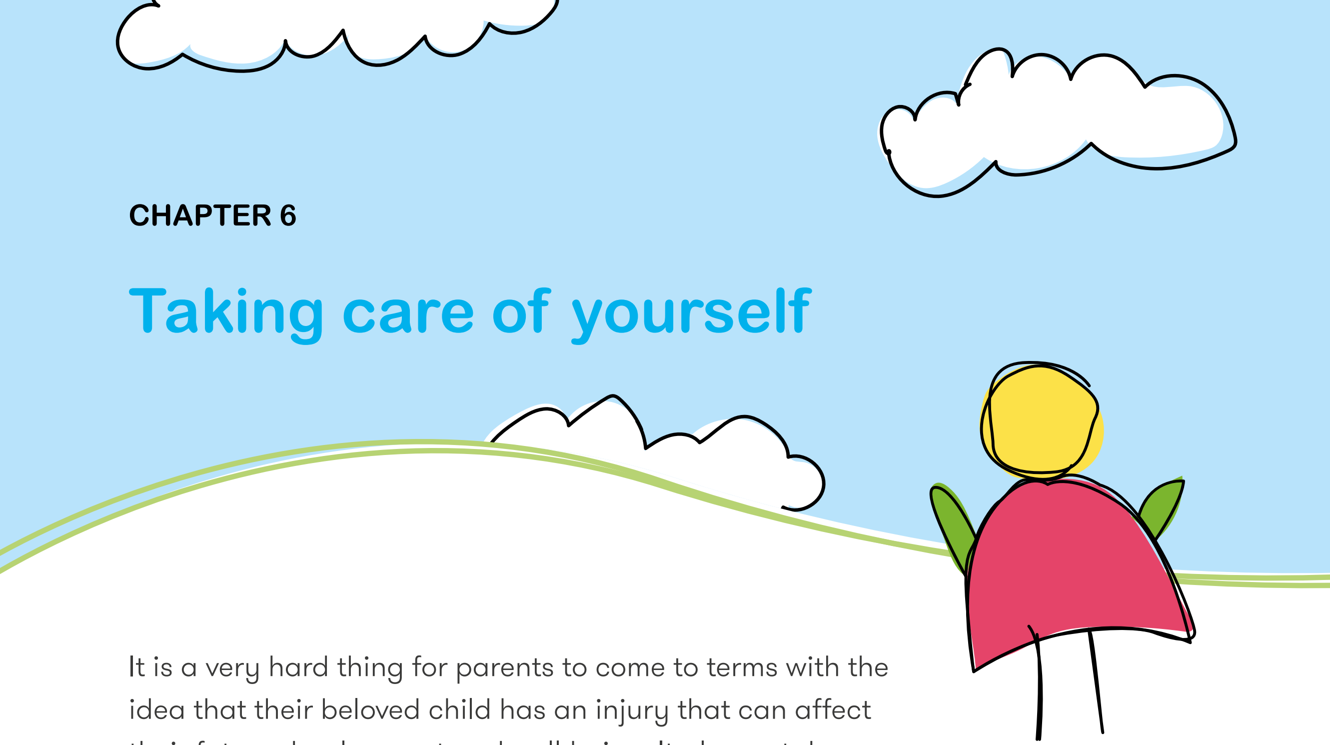
Self-management does require considerable work for parents, so you will need to be organised about invoices and receipts and keep a consistent record of the details of the claims you make. You can find people who can help you manage your plan and NDIS finances for a fee. Your funding package can have the capacity to employ or contract staff to assist you in managing your child's supports.

NDIA Plan Management

Under a plan where the funding is being managed on behalf of the person receiving the support, a person will be identified as the manager of funding for supports for that person. This person may be a registered plan management provider, the NDIA or someone else who has been nominated by the person with a disability to manage the plan on their behalf. Under an arrangement of this nature, there is less flexibility around what supports the funding can be used for. For example, when the NDIA manages the plan, it will directly pay the support providers on behalf of the person receiving the supports. In addition, in receiving supports and services, you can only use NDIS registered service providers, whereas if you self-manage your plan you can use any service provider, whether they are registered NDIS providers or not.

CHAPTER 6

Taking care of yourself



It is a very hard thing for parents to come to terms with the idea that their beloved child has an injury that can affect their future development and well-being. It always takes time to accept the situation and the accompanying grief and uncertainty. It is indeed the beginning of a long journey.

It is important to realise at the beginning that this will be a marathon, not a sprint. This means that you will need to pace yourself, look after yourself and to plan the race.

The FBIC families have shared a number of ideas that help them cope and develop a satisfying family life. Here are some of their ideas. Take what you like and leave the rest. They may help you later.

Learn as much as you can about your child's condition – ask your doctor, therapists, other families in a similar situation, search the internet. Keep learning, as knowledge changes and research brings new ideas and therapies to assist brain injury treatment. Every year we learn about a new therapy or medical breakthrough.

Try not to worry about the future. It will happen anyway and you will have more energy to handle it if you worry less. When you feel a worry coming on get out a pen and paper and start to plan for that situation instead. Do what you can and leave the rest until later.

Live one day at a time. Or one hour at a time if things are really tough.

Keep activities in your life you enjoy. It is vital that you look after yourself, and this also means having some balance and pleasure in your own life. It's not selfish. Everyone in the family will benefit if you are feeling less stressed. Extra vitamin B complex is good for stress and extra chelated magnesium can help with anxiety.

Your Team will include your doctors and a number of therapists. Another important part of your team will be your family and friends. Try to include them in your goals, even just as cheer leaders. The more they know about what you are doing the more they can help. It is hard to keep up with your friends when you are so busy, but try. Most want to help you but aren't sure how to. You may need to

ask.

Make new friends who have children in a similar situation. They are great allies and you can help each other with ideas and understanding.

Some ideas parents have found helpful include having friends over for an easy barbeque, gardening (they call it the outdoor therapy room), set time aside to read or just have a cuppa, watch a movie (the funnier the better), take it in turns to go out if you don't want to leave your child.

Don't worry too much about a perfect house. Nothing is more important than caring for your child, any other children and yourselves as parents.

Get the basics done, such as cleaning up the kitchen, doing the washing – skip ironing and fold straight off the line instead. Ask the rest of the family to be responsible for their own rooms and possessions and create a roster for everyone to help. Even young children can set the table.

Focus on the positive is the mantra that kept one family going. Every day look for something that makes you feel good. It could be a sunset, a baby's smile, a phone call to a friend.

Keep your paperwork organised. Have one place where the invoices and receipts always go. Use a labelled concertina file or even a handy shoebox. Use Google drive to create files for therapists and the NDIS and coordinate with others using Google calendar or a big whiteboard in the kitchen to keep track of schedules for the rest of the family.

Your mobile phone is a useful tool for busy families for reminders, appointments, your Google drive, and keeping in touch wherever you are.

Seek professional counselling, or talk with Lifeline, a friend or support group if you are feeling overwhelmed by grief, depression and stress. Free counselling may be offered by your local branch of Carers Australia or health centre, or you can speak to your doctor about a free mental health plan. Remember that these resources are there to help you and your family.

And finally, **take very good care of yourself.**

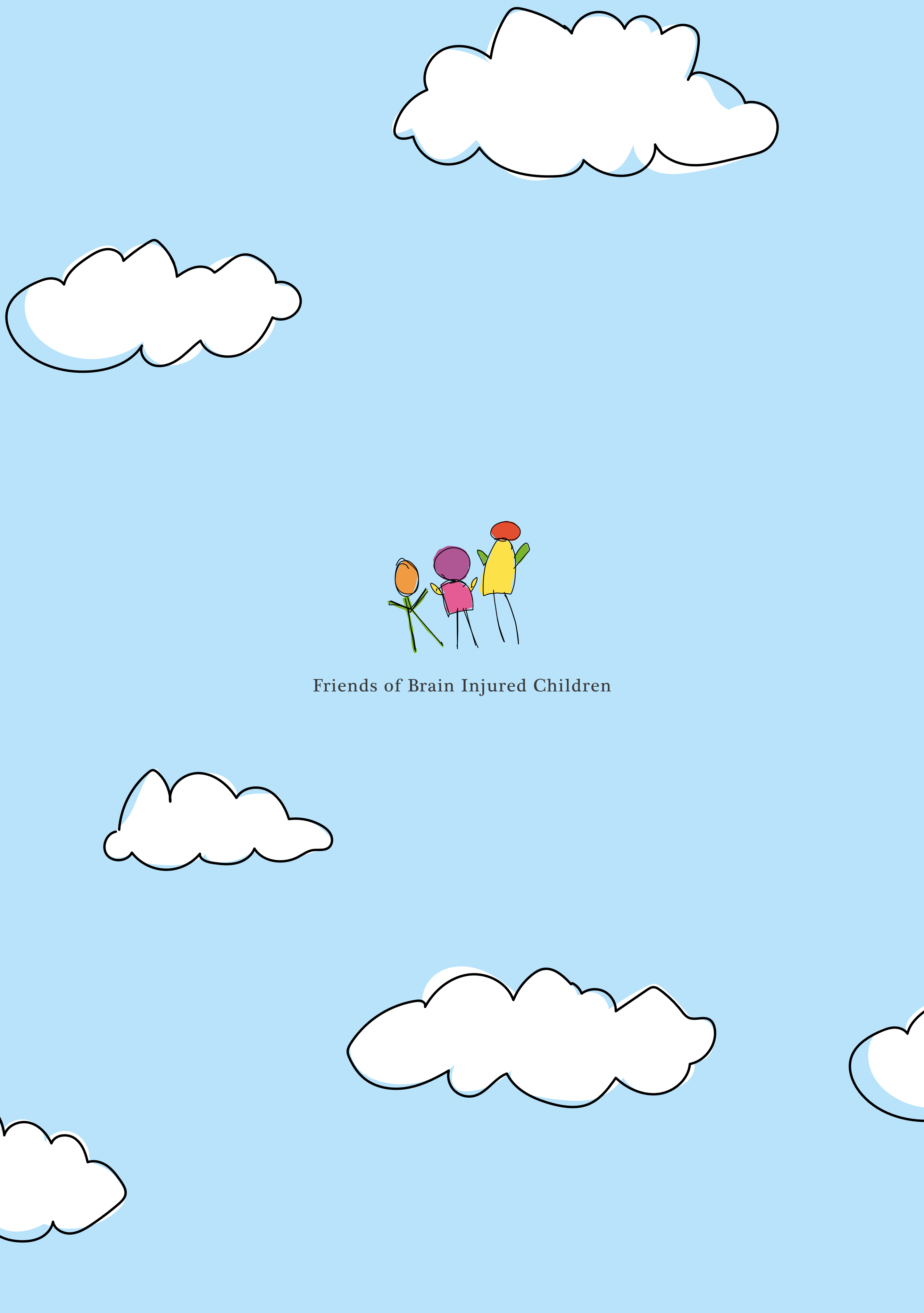
Further information

Websites

- Cerebral Palsy Alliance
  www.cerebralpalsy.org.au
- Association for Children with a Disability
  www.acd.org.au
- Carers Australia
  www.carersaustralia.com.au
- Carers ACT
  www.carersact.org.au
- ACT government assistance
  www.assistance.act.gov.au

Extra reading

- *The Brain's Way of Healing: remarkable discoveries and recoveries from the frontiers of neuroplasticity*. Norman Doidge MD, Scribe Publications, 2015.
- *The Brain That Changes Itself: personal triumph from the frontiers of brain science.* Norman Doidge MD
- *Acquired brain injury – The facts The practical guide to understanding and responding to acquired brain injury and challenging behaviours.* 2016. synapse.org.au
- *Rescuing Brain Injured Children*, Keith Pennock, Ashgrove Publishing Ltd 1999



Friends of Brain Injured Children