



**Teaching Infant Massage:
For Babies with
Special Health Needs**

Compendium

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Foreword

From the moment they are born, babies actively seek interaction with others and, through play and just being around people in everyday life, their unique little personalities become increasingly apparent to their parents, who can then tune into their infants likes and dislikes, strengths and sensitivities.

Loving touch from a parent plays an enormous part in establishing physical and emotional connections with an infant and, during the last decade, there has been a huge upsurge in professionals working with parents and infants to offer infant massage to parents who are seeking to learn more about the wonderful benefits.

T Berry Brazelton, child psychologist, believes that touch is central to the development of the bonding relationship between parent and child. Infant massage is a form of positive touch and an extremely important form of communication between parent and baby, therefore aiding the attachment and bonding process. Especially important for parents who may be experiencing guilt and grief over the loss of the birth of a 'perfect baby' (Limbrick 2009). A recent systematic review (Underdown et al, 2006) found that infant massage has beneficial effects in terms of reducing stress hormones (Cortisol), promoting sleep and promoting positive interactions, especially where mothers have been diagnosed with postnatal illness. In addition, Suzanne Zeedyk (2007) states that regular positive touch and infant massage can help with cognitive and brain development. These significant benefits can be experienced not only by a healthy full-term baby, but by babies with some form of special need or disability.

Many Portage service professionals and health professionals, working with parents whose infant has a special need, undertake infant massage teacher training, because they recognise how valuable this service can be. When infant massage is taught sensitively and professionally to parents, it offers them a non-stigmatising, inclusive, and empowering environment in which to learn a new skill. This will enable them to communicate with their infant, understand their baby's body and feel positive that what they are doing is not only safe, but will help their baby. It is paramount that a non-directive teaching style is adopted ensuring that the teacher is hugely respectful of the parent and the infant, so that the experience is a positive one for all.

Commonly, infant massage is taught in a group setting, so that parents can not only learn the skill, but form friendships and network with each other. It is particularly useful for those parents who feel isolated or for mothers suffering from depression. However, it is recognised that working with groups of Portage parents may prove difficult due to the need for numerous hospital/clinic appointments and often parents may not be able to attend a regular course. This does not preclude them from attending a one-to-one course with a teacher so that the programme can be tailored to their individual needs – it just takes a little thought.

Each condition will be different and will require the teacher to consider adaptations to the standard strokes and positioning to accommodate specific medical needs. For instance, a baby with a gastrostomy (Tipping, 2009) or an umbilical hernia (Epple, 2009) may find it difficult to lie in the prone position for a back massage, but suitable adaptations can be made to perform the back strokes without causing discomfort.

Lots of infants with special needs (such as Cerebral Palsy) have sensory issues and it is important when teaching parents to massage their infant that the strokes should be quite firm as otherwise, they may tickle and over-stimulate the baby. This can start with a very few strokes each session, building baby's tolerance, until the point when they are happy to receive a full massage. Regular massage can strengthen the immune

system and studies show that some premature infants, who receive positive touch from their parents in hospital, show greater physical and neurological improvement over those who are not massaged. The infants receiving positive touch generally gain weight more rapidly, reducing their stay in a special care unit (Scafadi, 1990).

Infant massage can also help those families whose babies are terminally ill. This can improve the quality of the remainder of everyday life for the child and enable the parents to remain in touch with their child and communicate their loving feelings (Hubbard, 2002).

Infant massage can be used with infants with many disabilities, however the parent is always asked to check with the baby's physicians to ensure that there are no contraindications arising from a particular condition with regards to massage (Epple, 2017).

As a teacher and trainer of infant massage to health professionals I am convinced that as well as the above, massage can offer so much more for an infant with a disability and their family, giving increased confidence and providing respite from constant trips to appointments.

Anita Thomas-Epple

Author, Lecturer and Director of Touch-Learn International Ltd

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Using the Compendium

This guide is broken into two distinct sections:

- Under-pinning theory
- Practical case studies

The practical case studies section is a comprehensive document; however, it is by-no-means complete. It is the intention that the infant massage teacher will use this compendium as a starting point and add to the case studies to build their own personal and relevant compendium for the needs of their parents and babies.

Terms of Reference

For the purposes of the programme and this compendium the special needs will be grouped as follows:

- Preterm and Sick neonates
- Illness and conditions that may be:
 - Life limiting
 - Life threatening
- Special Situations

The terminology used in the Handbook has been selected to be inclusive, compassionate and instructive to the infant massage teacher.

- The terms *parents* and *carers* are intended to be inclusive referring to any adult who has a responsibility caring for an infant. Sometimes the carer may not be the biological parent of the child. When only the word parent is used in context, it does not exclude carers for the infant. For the purposes of the compendium the word *parent* is used for readability.
- The terms *neonate* and *newborn* are used interchangeably

Teaching Safely and Professionally

Professional Practice

It is important for all baby massage teachers to practice safely, ethically and professionally.

See Touch-Learn's Code of Ethics for its teachers on the website under *Our Philosophy*.

It is particularly important to appreciate that facilitating infant massage is about supporting, teaching and empowering parents and is not a 'hands on' qualification. Remaining 'hands off' also includes situations where a parent may ask you to help them position their baby or their toddler, in this respect.

Preparing to Teach

Scheme-of-Work

Even if you plan to teach the strokes and holds over just a couple of sessions, it is still important to ensure that there is continuity from session to session. A scheme-of-work will help you achieve this as it establishes the framework for the delivery of the content. As with all planning, you still need to be flexible and prepared to adjust if needs be, especially when working with parents and their babies with special needs. Consider that your scheme-of-work is not cast in stone, but a working document.

Lesson Plan

Once the scheme-of-work has been designed, each individual session requires a lesson plan, which is a more detailed document depicting what will be delivered in that particular session. Each individual lesson plan should ideally include the:

- Aims, objectives and learning outcomes
- Time it will take for each activity
- Topics
- Resources

Role-modelling - Using a Realistic Demonstration Doll

The demonstration doll should be a useful and influential tool when teaching baby massage; it can help the parents feel that what they experience and learn during a session is positive and memorable. As the demonstration doll is the Teacher's 'baby', it is important that the doll is handled and treated realistically at all times during each session. The use of a realistic doll allows the Infant Massage Teacher to engage successfully with parents when:

- Demonstrating the strokes and holds correctly
- Demonstrating safe practice
- Encouraging parents to observe and respond to their baby's cues in a non-judgmental manner

To enhance teaching and to role-model effectively, it is important to:

- Use an appropriately-sized demonstration doll so that this is as realistic as possible, especially when teaching parents of a tiny baby
- Always use your demonstration doll to support your teaching
- Give your doll a realistic name
- Handle your doll as you would a baby – during the whole of the teaching session
- Dress your doll in baby clothes
- Always use your doll to highlight important points

Supporting Parents' Learning Styles

The Visual, Auditory, Reading/Writing and Kinaesthetic (VARK) learning styles of the parents you teach will all need to be supported so that you successfully engage with them and they have a positive and effective learning experience.

| Type of learner | Examples of how you can support the parents you are teaching |
|-----------------|--|
| Visual | <ul style="list-style-type: none">• Pictorial handouts may be helpful, particularly to enhance safe practice• The demonstration must be clear• Role-modelling with the demonstration doll is vital |
| Auditory | <ul style="list-style-type: none">• Clear and concise verbal explanations of the massage strokes and holds are essential |
| Reading/Writing | <ul style="list-style-type: none">• Your supporting handouts• (The Pocket Book of Massage) |
| Kinaesthetic | <ul style="list-style-type: none">• Parents need to practise the massage and gentle touch with their baby. So, if their baby is asleep, offer parents a spare demonstration doll to aid their learning |

Tips to Enhance Your Teaching

Once you have considered how to structure your sessions for the parent and the baby with the special need you may find the following reminders useful.

| Tip | Reason |
|---|---|
| Role-model 'checking-in' with your demonstration doll | Parents will follow suit and check-in with their baby or ask their toddler how they are |
| Check-in with the parent regularly so that they ensure that their baby is happy and not over-stimulated | Helps parents to re-focus on their baby/child if they are only focusing on your teaching and learning the strokes and holds |
| Reaffirm cues during the massage session | Serves as a reminder whilst parents are concentrating on learning new skills and strokes |

Teaching Strategies

Consider carefully the strategies that are going to be implemented and be prepared to be flexible.

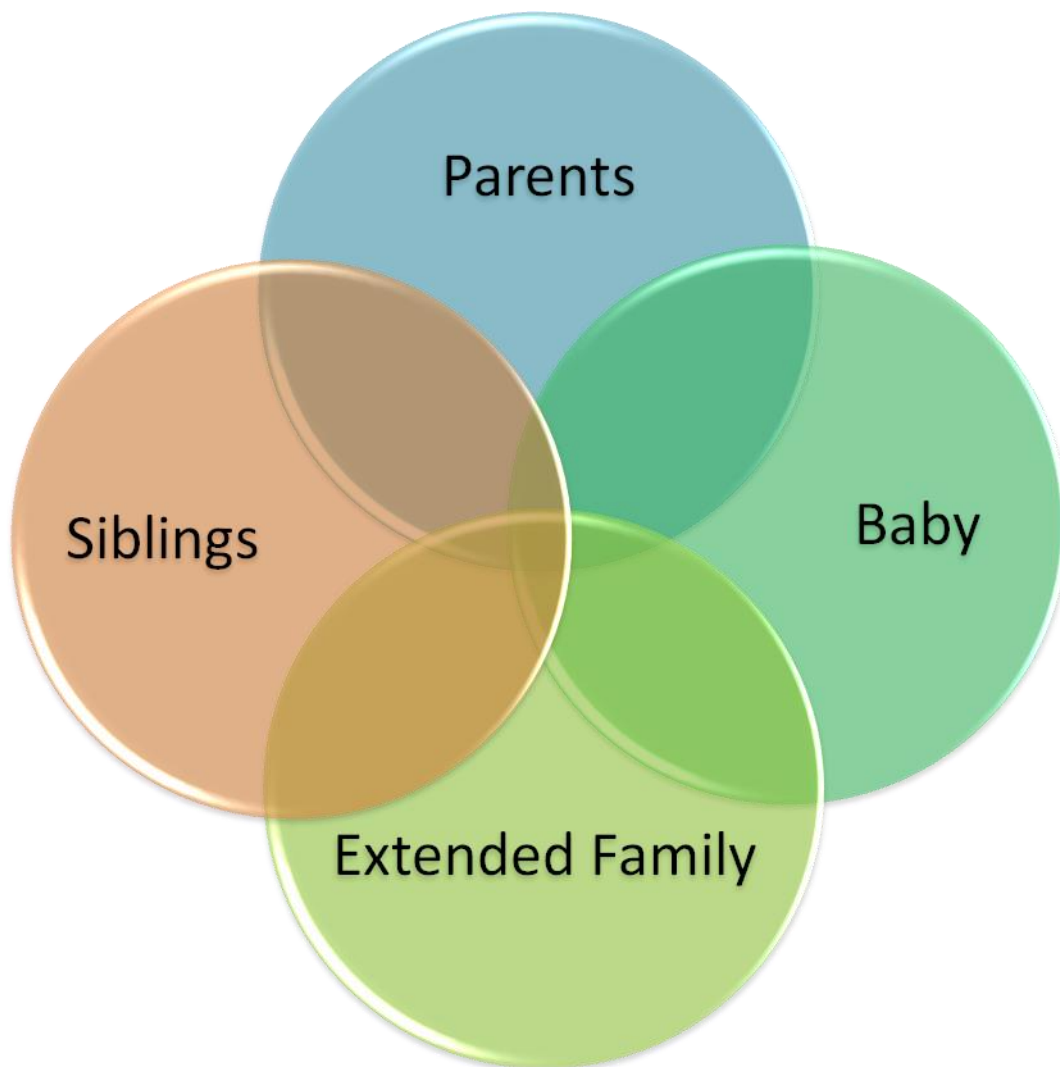
| Considerations: | Suggested strategies: |
|--|---|
| Managing Expectations | It is the infant massage teacher's role to prepare the parents and explain what can be gained from massage, how the massage will be taught, possibly in small stages over a number of sessions working within the baby's tolerance levels. It is advisable to have a pre-meet with the parents to discuss baby's condition and parental expectations. This is a good opportunity to assess the baby for yourself and ask any appropriate questions prior to you tailoring the massage sequence. |
| Group or one-to-one | Empower parents by involving them in the decision as to whether they learn massage on a one-to-one basis, or they join a group. |
| Empowering parents | During the first meeting is it advisable to ask the parents what their baby's physician or consultant believes to be appropriate for the infant. This empowers the parents to be involved in tailoring the massage programme for their baby. This can enhance the parents' feelings of self-esteem as they 'educate' you about the condition and can help them to feel more confident. |
| How will you interact with the parent/carer? | Show confidence when guiding parents through the massage strokes and holds for their baby. |
| What resources will you use? | <p>A suitable demonstration doll is a must, so that you can role-model the holds and the strokes clearly. If you are teaching a parent with a neonate then use a newborn demonstration doll, if the baby is older use your 3-4 month old baby.</p> <p>Cushions, bean bags and props may be necessary for the parents and babies' comfort. Will you ask the parents to bring sheets and blankets for the nest?</p> |
| How will you ensure parents feel confident to carry on with the special massage and holds at home? | <p>By observing that they are carrying out the massage safely and confidently before they leave the session. If you have any concerns, reflect on how you are demonstrating and consider re-phrasing what you say, or repeating the visual demonstration.</p> <p>If their baby is not saying 'yes' to massage then offer the use of a spare doll.</p> |
| Helping parents remember the exercises for when they are on their own? | Using the names of the massage strokes helps parents remember when they are at home. Produce simple, clear handouts for parents to use as a reminder. |

Reflection and Evaluation of Your Teaching Practice

As an infant massage teacher, you are probably already aware of the benefits of maintaining a reflective journal and garnering the views of your parents in the form of parental evaluations. Your own reflections on your teaching and the evaluations from the parents will inform your future practice, helping you make adaptations and subtle changes where necessary.

The reflective practice will also help you to build further case studies to enhance this compendium. It is also good practice to share with other professionals. If you share these with Touch-Learn, your case-studies will be made available to other infant massage teachers that have attended the Special Needs programme.

The Emotional Effects of Having a Special Needs Infant



Parents

Having a baby with a special need can be totally overwhelming for parents and can disrupt family life beyond recognition. The family may struggle to function properly having to juggle time between work, hospital appointments and home life.

As mothers take over the role of the 'expert' nurse, this can lead them to feel empowered, in control and boost their confidence. Conversely it can lead them to feel insecure, inadequate and over-faced with responsibility.

Fathers, particularly, can find the situation difficult; feeling helpless and inadequate. It is historically the father who has the role as 'bread winner' so they will often choose to be at work more as this is a place where they can regain some confidence and competence; it's a place where they can 'do' something and keep busy. If a baby has been in hospital for a while and the caring role has been taken over by the mother, at this point the father can either be 'drawn in' by the mother, or he could be pushed to the periphery. This situation may cause resentment for both partners.

In addition both parents may have similar feelings of:

- Helplessness
- Inadequacy
- Depression (leading to PNI for the mother)
- Grief
- Guilt
- Fear of making things worse
- Financial worries – for example costly travel to appointments, adaptations to the house, unable to work, etc
- Denial

All these feelings, combined with possible lack of support and understanding from extended family, can culminate in the parents being emotionally unavailable for each other and/or the baby. Partnerships can be broken under the stress, but with help can become much stronger.

Parents may have anxiety and lack of understanding of their baby's condition or fear of an unconfirmed diagnosis. However, they can gain emotional and practical help from an established support network, such as The Down's Syndrome Association. Organisations like this understand how parents are feeling and that the parents will no longer be following their expected route, and so help them to feel that they are not alone and that they can celebrate their baby's life.

On a more local level, parents may be able to find a TAC (Team Around the Child), Early Support Programme coordinator or CAF (common assessment framework) leader to support them with liaising with all the professionals they require for their baby's care.

Infant Massage

Classes give parents a chance to bond and 'get to know' their babies and increase their confidence. During the early weeks parents can become increasingly isolated; attending infant massage classes introduces them to other parents in the area.

Some parents may find joining a group difficult for many reasons; they may feel their baby is still vulnerable to infections so have a fear of mixing with healthy, robust babies. If a baby was born very immature or with a physical disfigurement, they will appear different to others, leading parents to feel 'my baby is different', 'I'm different'. However, offering attendance to a group with parents who have been through a similar experience may be useful in helping them to gain confidence in handling and understanding their baby.

Massage will help parents to overcome any feelings of rejection, or guilt often experienced by parents because they may feel responsible for their child's condition or may have aversion to how their child looks.

The massage routine should be tailor-made for a baby's individual needs. A baby who has special needs may tire easily and become rapidly over-stimulated, so massaging in a group may be difficult. Teaching a modified massage routine on a one-to-one basis first, may then give the parents the confidence to join a general massage group later to learn a full routine, and mix with other parents.

Siblings

When an infant with special needs is introduced to the family, it can have long-term and profound effects on the other children. They may suffer from some, if not, all of the following:

- Not feel so special anymore
- Defensive – they may feel that they have to protect against any negativity
- Feel isolated as they slide under the radar; as all the attention is focused on the baby with the special need.
- Feel frustrated and have an inability to communicate their feelings and become withdrawn
- Their needs not met – attendance at clubs or social life
- Confusion about the condition and prognosis
- Suffer throughout life
- Depression
- Attention seeking behaviour
- Anxiety/behaviour -self-harming
- Be overprotective – lack of sleep due to listening out for the sick child at night
- They become Carers – grow up faster
- Grief
- Embarrassed

Using infant massage with the family can not only help the infant with special needs but it can be used effectively with siblings so that they feel loved and nurtured and still an important part of the family. It can be used to eliminate many of the effects listed above. Massage may help them to accept their new baby and become involved with the care.

Extended Family

Extended family, such as grandparents, aunts and uncles may struggle with congenital or genetic disorders as often they are looking for reasons as to why this happened and perhaps apportion blame to 'the other side of the family'. This can split families, putting added pressure on the parents who feel that they can not approach their in-laws for support. They may also be grieving for the expected child and need time to come to terms with their feelings. They may be grieving twice over – for their own child's loss and for their own hopes for their grandchild. There is often a lack of support, such as counselling, for grandparents who may feel as distraught as their children. Again, as for parents, specific support groups can be an excellent source of support.

Extended family sometimes do not know how to respond and stay away for fear of not knowing what to say, and if a child is extremely disfigured the extended family may feel embarrassed to show them off to others. Siblings of the parents may also feel deep guilt that their own children are fit and healthy.

The Baby with the Condition

Babies are emotional beacons and will always pick up on 'vibes' and emotions from everyone in their environment. If these emotions are continually negative it can have a detrimental effect in that they can feel unloved, insecure and their self-esteem can be affected as they grow. Constant negativity increases Cortisol, the stress hormone, and this is extremely corrosive to the developing, immature brain.

Lack of positive emotions can impede physical development making infants prone to infections. However, using infant massage regularly when the child is receptive and saying 'yes' to massage can reduce Cortisol and increase the hormone Oxytocin. This hormone is responsible for enhancing feelings of love and security and regular massage will help the parents and the baby to bond.

A baby that has a congenital malformation or a degenerative physical illness will have a much more positive self-body image if massaged regularly from birth. This will help with their confidence and self-esteem as they grow older and are trying to understand and come to terms with their illness as they mature.

The Infant Massage Teacher

Whilst practicing as an infant massage teacher working with babies with special needs, you may come across some disorder which you could find distressing. One way to manage your emotions is to research the condition well before you meet the family. That way you will have a better understanding of what the baby/child is likely to look like and less likely to show your emotions outwardly before the family.

Your research may consist of some or all of the following:

- Internet search
- Medical journals
- Colleagues
- Touch-Learn's Special Needs Consultant

If you feel you cannot cope, then it is better to refer on to a colleague than meet the family and have to withdraw your services. Imagine how upsetting it would be for the family to see a negative reaction to their baby. It would only compound any negative feelings they already have about their baby.

It may be that the condition is emotive to you personally and you are not able to deal with it at that time. If this is the case it is most certainly better to refer on.

Working with babies who have special needs can be hugely rewarding especially if you have been able to see an improvement in their condition since introducing baby massage. However, if you have found it somewhat emotional then it is recommended that you share your feelings with a buddy or mentor. This person could be a colleague or a professional counsellor.

Preterm and Sick Neonates after discharge from NICU

Within the confines of the neonatal unit, giving touch to such fragile babies requires sensitivity and mindfulness. Parents may or may not have been given lessons in the unit on how to touch their baby appropriately. The teacher needs to be considerate of the emotional wellbeing of the parent whilst participating in this activity. Often parents lack confidence to touch their babies, so need activities that will encourage touch in a sympathetic and positive way. It is, therefore, important to teach parents about appropriate touch; by observing cues, they will be aware when baby is becoming over-stimulated, helping to reduce stress in both the baby and parent. These cues may be more subtle and not as obvious as with a full-term, healthy baby.

The Neonate Prior to Discharge

Intra-uterine

The uterus provides a stable environment for the growing baby; it has perfect temperature control, and the baby's body systems are regulated to stay 'in tune' with the maternal biological rhythms.

Extra-uterine

When the baby is born early this gentle stimulation is replaced by that of the neonatal unit, which leads to sensory overload for the baby's developing nervous system.

These infants are subjected to prolonged:

- Disrupted sleep states
- Persistent ambient sound
- Supine positioning, often without adequate support for self-regulation
- Routine and excessive handling
- Poorly timed social and care-giving interactions

All these have adverse developmental effects. It has been found that even the most fragile of neonates, when observed, can display behaviours and negative cues which can be very subtle. See negative cues below.

Central Nervous System

For the neonate, negative cues can be categorised as following:

Autonomic

The maturity of autonomic function is noted by the smooth transition from intra to extra uterine life, and is observed by the onset of regular respirations, pink colour and warm skin.

In the preterm infant these functions are not matured sufficiently for unaided extra-uterine life. This immaturity is observed by:

- Respiratory pattern
- Colour fluctuations, eg pallor, cyanosis
- Spitting, gagging, hiccupping, straining (negative cues)



Sensory

The sensory system is developed in utero in a specific order and continues after birth. Touch is the first sense to develop followed by smell, taste, hearing and vision.

Motor

As the infant develops, movement and tone are increased and they begin to demonstrate the development of the sleep/wake states

- Movement patterns
- Posture
- Tone of the trunk, extremities and face either flaccidity or hypertension
- Finger splaying, fisting, arching, grimacing, yawning, fussing, eye aversion (negative cues)



Sleep And Wake States

State patterns after birth are individual and reflect the infant's ability to self-habituate and adapt to their environment. The ability to adjust sleep/wake states shows a maturing of the neuro-behavioural organisation; therefore as the baby matures the transition between the different sleep/wake states becomes smoother. Observing these transitions is the key to understanding the status of the developing brain.

Quiet (deep) Sleep

- Body Activity - Nearly still, except for occasional startle or twitch
- Eye Movements - None
- Facial Movements - Without facial movements, except for occasional sucking movement at regular intervals
- Breathing Pattern - Smooth and regular
- Level of Response - Threshold to stimuli very high so that only very intense and disturbing stimuli will arouse
- Implications for Care-giving - Trying to arouse baby from this state to feed would probably be frustrating. Infants will be unresponsive, even if disturbing stimuli is used to arouse infants. Infants likely to arouse only briefly then return to quiet sleep. Beneficial to wait for baby to move to a higher, more responsive state

Active (light) Sleep

- Body Activity - Some body movements
- Eye Movements - Rapid eye movement (REM): Fluttering of eyes beneath closed eyelids
- Facial Movements - May smile and make brief fussy or crying sounds
- Breathing Pattern - Irregular
- Level of Response - More responsive to internal and external stimuli. When these stimuli occur infants may remain:
 - In active sleep
 - Return to *quiet sleep*
 - Arouse to *drowsy state*

- Implications for Care-giving - Active sleep makes up the highest proportion of newborn sleep and usually precedes waking. Brief fussy or crying sounds are made normally during this state which may necessarily mean that baby is ready for a feed or interaction

Drowsy

- Body Activity - Activity level variable, Occasional mild startles, Movements are usually smooth
- Eye Movements - Eyes mostly open, closing occasionally, Heavy lidded with dull glazed appearance
- Facial Movements - Some facial movements, mostly none, face appears still
- Breathing Pattern - Irregular
- Level of Response - Delayed reaction to sensory stimuli. State change after stimulation often noticed
- Implications for Care-giving - From the drowsy state baby may return to sleep or waken. If stimulation is given baby may arouse to *quiet alert* state. If no stimulation given baby may return to sleep state

Quiet Alert

- Body Activity - Minimal
- Eye Movements - Brightening and widening of eyes
- Facial Movements - Face has bright shining and sparkling look
- Breathing Pattern - Regular
- Level of Response - Baby aware of environment. Focusing on any stimuli present.
- Implications for Care-giving - In this state baby gives positive feedback. Providing baby with something to see, hear or suck will help to keep baby in *quiet alert* state

Active Alert (fussy)

- Body Activity - Body very active. May have periods of fussiness
- Eye Movements - Eyes open with less brightening
- Facial Movements - Much facial movement. Face not as bright as in *quiet alert* state
- Breathing Pattern - Irregular
- Level of Response - Increasingly sensitive to disturbing stimuli: hunger, noise, excessive handling
- Implications for Care-giving - Crying is babies communication signal, a response to unpleasant stimuli eg. fatigue, hunger, discomfort. Crying says baby's limits have been reached. Sometimes they can console themselves (self-regulate) and return to lower states, other times they need help.

Crying

- Body Activity - Increased motor (body) activity with colour changes
- Eye Movements - Eyes may be tightly closed or open
- Facial Movements - Grimaces
- Breathing Pattern - Irregular
- Level of Response - Extremely responsive to unpleasant external or internal stimuli
- Implications for Care-giving - Crying is babies communication signal, a response to unpleasant stimuli eg. fatigue, hunger, discomfort. Crying says baby's limits have been reached. Sometimes they can console themselves (self-regulate) and return to lower states, other times they need help. May need to intervene to console and bring baby back to lower state

(Kenner and McGrath 2004)

The Effects of Stress on the Neonate

Stress can be caused from handling, bathing, noise levels, lighting, etc. The environmental stress can be due to:

- Neurological immaturity
- Physiological instability
- Inability to inhibit stimulation and habituate effectively

Stress can cause:-

- Increased susceptibility to infections
- Inability to self-regulate
- Raised Cortisol levels
- Erratic sleep patterns

Gentle Introduction to Touch for Premature and Sick Babies

The strokes selected are a very gentle introduction to touch for these babies. At all times encourage parents to be mindful of their babies' subtle non-verbal cues and to stop massage if baby becomes distressed, tired or disengaged.

We suggest that the baby is contained in a 'nest' and clothed prior to these gentle strokes to ensure they feel secure.

Teaching parents the containment holds in this routine can help to centre and calm the parent and provides two-way gentle holding contact. The holds can help to settle a distressed and 'angry' baby and promotes self-regulation. These holds are always done with the permission from the baby; by observing their cues.

Sequence of Holds and Strokes (these can be found in the *Massage Sequence Handbook for Special Needs*)

Nesting

Containment Holds:

- No Touch
- Gentle Hold (and asking permission)

Soothing Stroke

Velvet Cloak

Sole Stroke or

Butterfly Hand Stroke

Containment Hold:

- Lazy Lion

Neonatal Babies

An Introduction To Gentle Strokes For Newborns

A full massage routine may be over-stimulating for a newborn baby, so it is suggested that parents introduce their baby to this gentle routine. Initially long, sweeping strokes can be done over the clothes to accustom the baby to massage. The baby may find these strokes soothing and calming, but it is still always important to watch for any display of negative cues.

We suggest that the baby is contained in a 'nest' for these gentle strokes to ensure they feel secure. Once the baby becomes accustomed to this routine with their clothes on, then the massage can be done without clothes and with oil. (Suggest an organic vegetable oil such as Sunflower oil).

Sequence of Holds and Strokes

Asking Permission
The Velvet Cloak
Upward Leg Glide
Sole Stroke
Bubbling Springs
Tummy Circle
Windmill
Butterfly Stroke
Hand Bubbling Springs
Angel Kisses
Gentle Back Soother
The Velvet Cloak

Later a full routine can be introduced gradually when baby is ready for a more stimulating massage.

Contraindications and Considerations for Massage

Contraindications

Massage should be avoided when a baby:

- Is asleep, tired, hungry, crying or fretful. These are all 'no' cues.
- Is unwell, or has a raised temperature and fever. Their immune system needs to be left to deal with the condition and not be over-stimulated by massage.
- Has undergone recent surgery. Refrain from massaging the affected area for at least 8 weeks to allow scars to heal after surgery, however unaffected areas can be massaged if this will not cause discomfort. (Though it is advisable for parents to check with the GP or consultant).
- Has an infectious skin condition. This may aggravate the infected area and there is a risk of cross-infection.
- Is suffering from bruising, sprains or a fracture. It is advisable to refrain from massage until the injuries have healed completely and swelling has reduced. It may be possible for the unaffected areas to be massaged.
- Has open, weeping wounds and rashes. Breaks in the skin may become infected if massaged.
- Has an unhealed naval.
- Is suffering from jaundice; as their liver is not functioning as it should. Refrain from massage until all signs of jaundice have gone. However, massage may help infants with Neonatal Jaundice.
- Has suffered haemorrhaging. (Massage increases the blood flow in the body and there may be a risk of further bleeding).
- Is diagnosed with brittle bone disease - osteogenesis imperfecta. (The bones in children suffering from this disease can be so brittle that they break with normal handling).
- If the baby has been vaccinated within the previous three days.
- Has convulsions as a result of touch or stroking on any part of their body.

Considerations

- **Anaemia** - premature babies are often anaemic prior to discharge from hospital, be aware that these babies may appear well but will tire easily.
- **Constipation** – babies who are anaemic and receiving iron supplements may be constipated and have an uncomfortable tummy. The Tummy Circle and Windmill strokes may help plus any other abdominal strokes from your usual full massage routine.
- **Feeding** – leave at least half an hour after feeding for babies that are having small, frequent feeds before carrying out any massage.

- **Environment** - subdued lighting, gentle music, and a minimum number of strokes may be tolerated and enjoyed by the baby. Eliminate perfumes and artificial smells.
- **Music** – music may be too over-stimulating initially, introduce gradually and be led by baby.
- **Nesting** – use a containing change mat or a ‘nest’ for premature and neonatal babies to maintain boundaries and feelings of security.
- **Security** - maintain one hand in contact with baby at all times.
- **Stability** - only a part of the massage may be able to be performed at a time depending on the stability of the baby.
- **Focus** - keep all attention on baby and avoid conversation with others.
- **Strokes** - use slow, gentle moderate pressure NB: take care not to use very light touch as this induces a tickle stimulus.
- **Touch-averse** - many premature and sick neonates experience invasive procedures during their time on the neonatal unit. For instance, many have to endure the presence of cannulas in their feet and heel prick blood testing. These babies may display negative cues when their feet are being massaged.
- **Vaccination** – after the three days have passed since the vaccination, avoid the injection site when massaging until any bruising or swelling has healed.

Case Studies

A Stay in Hospital

Parents whose children are admitted to hospital for investigations or surgery often feel isolated, scared and helpless, and as though they are losing control.

A gentle massage gives parents the opportunity to give loving touch to their child and these anxieties will start to dissipate. Massage also gives them something that they can feel empowered about and helps them to feel that they are able to do something positive for their child.

It is so important for parents to maintain communication with their child whilst they are in hospital, so talking, smiling and singing nursery rhymes should be encouraged and indeed all of these can be done whilst massaging.



Often on special care baby units, there are specialist infant massage teachers who will show parents how to do positive touch with their baby safely. If the child is too poorly to be touched, parents may be offered the choice of learning the moves on a doll so that when their child is well enough they can then start to do containment holds, gentle stroking and eventually massage them. This also helps parents feel like they are doing something valuable for their critically ill baby and focus on doing something positive.

'Whilst massaging my daughter I felt the happiest of all the time I spent in hospital because of the contact and the fact that it relaxed us both. Apart from the obvious benefits the massage provided some light relief for both my daughter and myself, in what has been a traumatic experience.'

Supplied by Debbie Mills, Hospital Play Specialist

Massage

It is recommended that a full massage is used if a baby child has been admitted for an operation. Follow guidelines in Contraindications post-surgery. For an infant that is premature or a sick neonate then use the gentle introduction to touch routine. As baby becomes more robust progress to the Neonatal Massage routine, always guided by baby's tolerance. This will prepare them for a full sequence at a later time.

Achondroplasia

Achondroplasia is the most common cause of short stature with disproportionately short limbs and is the most common form of dwarfism. The average height of an adult is about 4ft 4in in males, females are generally shorter. Although it is a genetically inherited condition there are about 80% fresh mutations (these occur with normal height parents and no family history). The children will have normal intelligence, but motor milestones may be delayed.

Occasionally in infancy or early childhood there may be problems with:

- Otitis media (middle ear infections)
- Symptomatic airway obstruction
- Thoracolumbar kyphosis - a type of scoliosis (curvature of the spine)
- Symptomatic hydrocephalus

Massage

If there are no airway problems and no Hydrocephalus, having infant massage would benefit the baby and the family both physically and emotionally.

If there are airway problems with some constriction in the size the airways and it is not severe then massage of the chest may be of benefit. If baby is quite breathless then s/he is likely to tire very easily.

If there is any noticeable Hydrocephalus then avoid massaging the soft spots on the head, remembering that they may be enlarged and extending along the sutures of the skull.

The majority of children with Achondroplasia will be able to live an independent and productive life, although in the early weeks there may be issues around acceptance, so infant massage would be a useful tool to aid with bonding and attachment.

References and further reading

<https://ghr.nlm.nih.gov/condition/achondroplasia>

Adoption/Fostering

Touch is a universal language understood by children all over the world. Whether adopting a child abroad or locally, new adoptive parents can express their feelings for their adopted child through touch. Positive touch communicates love, respect, safety and acceptance; all essential for a healthy parent–child relationship and there is no exception for adoptive or foster parents.



Whether for a newborn baby or a slightly older child, massage can really play an important part in successful adoption and fostering. The age and individual case needs to be considered carefully, but massage can help to form trusting relationships and offer adoptive parents or foster parents a way to make up for lost time through quality contact time that promotes closeness, security and love. As bonding involves all the senses, but primarily touch, massage can really help in the bonding process and help the adoptive parent and child to become accustomed to one another. This can help a baby to feel nurtured and loved at a most unsettling time.

Positive touch, especially skin-to-skin contact and containment holding, can help bring a new baby closer to its adoptive/foster parents, especially when the baby will be grieving for the familiar touch, sounds or smells of their birth mother. When fostering, a gentle loving massage after visits to the birth mother in the very early days after separation can help with anxiety for both the baby and the foster parents.

Involving siblings in the massage can help the new arrival to become accustomed to all their new family members.

'As time went on Chloe became anxious when being taken away from me for visits to her birth mother, whilst this was a positive sign that she was becoming attached to us, it was a difficult time for both of us as I did not like her having to experience such trauma as these visits had to happen. She would return to us quite irritable and massage helped to soothe her and me and we felt connected again.'

Auditory Impairment (Hearing Loss)

Tactile experiences are of great importance for hearing impaired babies as they help them define the world around them. Baby massage can offer a positive tactile experience.

Auditory Impairment Massage

- Lots of eye contact is very important
- Until the baby is used to massage and feels secure, avoid strokes that impede eye contact (such as the back massage)
- Talking and singing rhymes is still important as the baby may still focus on the parents lips moving and may feel the vibrations from the singing and music

Helpful organisations:

<http://www.royaldeaf.org.uk/>

Autism

Pre-autism

Studies in many countries show that Autism appears to present itself in infancy as 'pre-autism'. This is whereby a baby will begin to show a number of recognisable characteristics. These signs of 'pre-autism' have been analysed with the use of video footage dating back to the 1930s.

It has also been recognized that the interaction and the subsequent attachment between parent and 'pre-autistic' baby was clearly different to that of a parent and infant, where the baby did not present with this condition.

A centre in Israel, studying pre-autism, offers support to parents with babies showing signs of pre-autism. They help the parents by teaching them how to improve the interaction and engagement with their babies. One of the tools that is used is baby massage – this helps with the interaction between parent and baby. The centre has been able to establish that intervention at an early stage definitely seemed, in most cases, to prevent the usual recognisable autistic characteristics developing later.

Children with Autism are usually diagnosed at around 18 months of age. They often have difficulty in relating to other people, have a disassociation from their environment and are very sensitive to sound, light, smell and touch.

Massage

Massage may help a child by reducing their stress. It may also improve communication, such as eye contact and vocalisation. As the massage should be tailored to meet the sensory needs of the infant, ask the parent if their child has any self-stimulation behaviours and any displays of touch aversion. Children with autism often are touch-averse and may become aggressive when touched. Also, a light touch can be far too over-stimulating for these babies, so it is recommended that a firmer touch is applied. Always, watch for their individual cues and be patient as they may not respond as quickly to massage as babies that do not have this condition.

Interactive play such as the Yoga Exercises and the Massage Stories can also help some Autistic children too. Shared play experiences can enhance a child's potential in all areas of learning and development. Developing interaction and communication with children using play rather than simply increasing 'play skills' can enhance their learning experience.

Helpful organisations:

www.autism.org.uk

www.autismuk.com

Benign Myoclonus of Infancy

Benign myoclonic epilepsy in infancy is a rare syndrome characterized by non-epileptic spasms occurring during the first or second year of life. The infants have non epileptic twitches and spasms and do not have other seizure types. Usually, these seizures are easily controlled with antiepileptic drugs and are limited to the first few years of life. Developmentally these children do well, but may have impaired cognitive development. Differential diagnosis is West's Syndrome which is a severe type of epilepsy.

Massage

As a precaution, if Epilepsy hasn't been totally excluded, do not use the 'Jelly Roll' as this is quite a stimulating stroke, and observe baby's cues carefully. Take the massage quietly and gently but make sure that the massage strokes are performed with medium to firm pressure, ensuring of course that they are not given roughly, and that baby is happy. If the strokes are too light the stimulation of 'tickle' may trigger a fit. I would suggest that a hand massage given to the parents during your first visit will help to confirm the pressure.

Establish that epilepsy has been ruled out in case baby has a fit during the massage session. If baby does have a fit, the parents should have been shown what to do, so be guided by them, and obviously you will stop the massage. If baby is having frequent attacks, the parents may not be as anxious as you would expect them to be, but you need to be prepared, so that you don't pass on any anxiety to the parents.

References and Further Reading

www.epilepsy.com/learn/professionals/about-epilepsy-seizures/overview-epilepsy-syndromes/infant-benign-myoclonic

Biliary Atresia

Biliary atresia is a serious congenital disorder in which there is a blockage of the ducts that carry bile from the liver to the gallbladder. The atresia (blockage) or Stenosis (narrowing) can lead to damage and cirrhosis of the liver, and is life threatening if untreated. The bile ducts help to remove waste from the liver and carry salts that aid the digestion of fats.

Neonatal (physiological) jaundice develops in the first 2-3 days and is a normal process as baby is born with a high concentration of red blood cells that the immature liver has difficulty breaking down, leading to jaundice. Neonatal jaundice is treated with phototherapy and recently research has shown that massage can be beneficial in lowering bilirubin levels. If the serum bilirubin becomes too high an exchange transfusion can be performed.

Newborns with biliary atresia may appear normal at birth and gain weight for the first month. However, the bilirubin level remains high and by 2-3 weeks baby will lose weight and become irritable, with worsening jaundice. The urine is often dark; the stools are foul-smelling and pale/clay-coloured.

The treatment is surgery to by-pass the atresia (Kasai procedure) this is successful in some cases but most cases require a liver transplant, with more recent advances in treatment, more than 80 to 90 percent of infants with biliary atresia survive to adulthood. If untreated biliary atresia is fatal.

Massage

Jaundice is a contraindication for massage, however clinical trials have demonstrated that massage can help to reduce bilirubin levels, in healthy babies with *neonatal jaundice*. In the case of biliary atresia massage would be contraindicated as the increased blood flow would be a strain on the liver. However, if it is for end of life care then massage would be appropriate as giving comfort, increasing endorphins in both parent and baby. Consultation with baby's physician should be sought before baby-led massage could be given. Start with a gentle introduction to massage and progress from there.

References and further reading

<https://www.niddk.nih.gov/health-information/liver-disease/biliary-atresia>

https://en.wikipedia.org/wiki/Biliary_atresia

Lin et al (2015) *Effects of infant massage on jaundiced neonates undergoing phototherapy* Italian Journal of Pediatrics 41: 94

Chen et al (2011) *Baby massage ameliorates neonatal jaundice in full term infants* Tohoku J Exp Med 223: 97-103

Lei et al (2018) *Effects of massage on newborn infants with jaundice: A meta-analysis* International Journal of Nursing Sciences 5: 89 - 97

Caffey Disease

Caffey disease (Infantile Cortical Hyperostosis: ICH) is a rare and mostly self-limiting condition that affects young infants. It is characterised by acute inflammation of the lining of the bone (periosteum) with soft tissue swelling, fever and irritability. The most common site is the mandible, as well as the long bones and ribs.

During the initial inflammatory phase there is localised swelling with a low-grade pyrexia and tenderness over the area. During this time the baby is restless and irritable (not surprising). It is a self-limiting disease so it will pass. Treatment if any is usually anti-inflammatory such as Ibuprofen.

Massage

Start with the gentle introduction to touch routine during the Initial inflammatory phase. As baby's condition improves, progress to the Neonatal Massage routine, always guided by baby's tolerance. This will prepare them for a full sequence at a later time. Positioning will be whatever is comfortable for the parent and baby and may be a little trial and error. Try lying baby on a large soft pillow between parent's legs to try and cushion the constant discomfort of the limbs. As the spine is never affected the back massage may be possible with baby lying prone on parent's chest.

Strokes that may not be possible:

- Avoid leg massage if lower limbs are painful
- Knee hug
- Chest massage
- Face (if mandible is affected)

Cancer/Leukaemia (Life-limiting disorders)

Leukaemia and life limiting cancers are very rare in the first year of life. Advising and providing infant massage would be complex and if considered must be carefully supervised. Infant massage teachers would need to work closely and take advice from the health professionals caring for the baby.

Massage

Gentle containment holds may help to provide physical contact and comfort without destabilising a fragile and sick baby.

Helpful organisations:

www.lls.org

www.childrenwithcancer.org.uk

Cerebral Palsy

Definition

Cerebral Palsy (CP) is an umbrella term used to describe a group of chronic conditions that affect body movements and muscle coordination that is non-progressive. It is caused by damage to the brain either in utero, during or shortly after birth. Because of the injury to the brain (cerebral) these children are not able to use some of the muscles in their body in the usual way (palsy), so may not be able to walk, talk, eat or play as other children. Cerebral Palsy cannot be cured, but with the help of education, therapy and technology the condition may be improved.



Cerebral Palsy is characterised by an inability to fully control motor function, particularly muscle control and coordination. Some of the symptoms may be muscle tightness or spasm, involuntary movements, impairment of sight, hearing or speech, and convulsions.

How CP affects a child can vary vastly, while one child with severe CP may have a limited life, others may be unable to walk and need extensive lifelong care, but can still go to University, while others with mild CP might be only slight mobility impairment and require no special assistance.

Massage

Check with the parents that they have asked baby's health professionals that it is ok to massage baby, especially if the baby has convulsions. This will help to empower the parents at a time when they may be feeling 'out of control'. Massage will help the whole family, as they will be going through a whole range of emotions including grieving for the 'normal' child they have lost and helping them to re-bond with their baby.

It would depend on the severity of CP as to whether a group or 1:1 would be better; each case needs to be assessed individually. A group may be too stimulating for the baby and too overwhelming for the parents. However attendance at a group may help the parents to build a support network, that doesn't just involve health professionals. In a one-to-one you can work at the parent's and baby's pace, especially if baby can only tolerate very short sessions. Music may or may not be useful during the sessions as it may be over-stimulating, although it may help to relax the baby and carer.

If baby has convulsions it is important to find out from the parents whether the fits are being controlled by medication, how often the fits occur and if they know what triggers the fits. It is important to pay very close attention to subtle cues because of the potential consequences of over-stimulation. Encourage the parents to observe baby very carefully for tiring and/or becoming stressed; also the pressure of the stroke, if it is too light and 'tickly' this may trigger a fit. The parents may know when a fit is about to occur, but if they haven't learnt this yet; by gaining a better understanding of their baby's cues this will empower them to have a much better understanding and the knowledge that they can do something positive to help their child.

If baby starts to fit during the massage, then turn baby into the recovery position on one side and use a containment hold in that position until the fit has passed; this can also be used as an alternative to cuddling if baby becomes tired, it can be less invasive than picking baby up. How baby is massaged will depend on whether the limbs are floppy or stiff. If the limbs are floppy (hypotonic), use a moderate to firm pressure, which will help to strengthen the muscles. If the limbs are stiff (hypertonic), the strokes should be slow to help relax the muscles, as tense muscles can be tender when pressure is applied. Encourage the parents to massage the unaffected limbs first so that baby learns to appreciate how good massage can feel.

Helpful organisations:

<https://www.cerebralpalsy.org.uk/>

<https://dvlcc.org.uk/>

<https://www.actioncp.org/>

CHARGE Syndrome

Definition

CHARGE is a rare genetic disorder and is an abbreviation for several of the features that are common in the disorder:

- Coloboma of the eye and blindness: this is where part of the eye has not developed properly in the womb. It looks a little like a keyhole but gets no worse as the child grows older.
- Heart defects: this can vary but commonly VSD (Ventricular Septal Defect or Tetralogy of Fallot)
- Atresia choanae is present at birth: one or both of the openings at the back of the nose are blocked by bone or tissue. Choanal atresia causes breathing difficulties, as babies cannot breathe properly through their mouth for the first few months.
- Retardation of growth and development: Also they are often late in starting puberty and may require additional hormone treatment.
- Genital and urinary abnormalities: boys often have a small penis and this may also be associated with undescended testicles. In girls the inner lips of the vagina may be very small.
- Ear abnormalities and deafness: Most children have underdeveloped or low-set ears, and the condition is connected with hearing loss, which can vary from mild to profound.

These symptoms are the most commonly seen in children but there can be other problems. A large proportion of children have some degree of learning disability but this can be variable. The facial features can be quite similar even though they are not related and include a small lower jaw and cleft lip and/or palate.

CHARGE syndrome is a recognizable genetic syndrome with known pattern of features. It is an extremely complex syndrome, involving extensive medical and physical difficulties that differ from child to child. Babies are often born with life-threatening birth defects. They can spend many months in hospital, undergoing many surgeries and other treatments. Swallowing and breathing problems make life difficult even when they come home. Most have hearing loss, vision loss, and balance problems that delay their development and communication. Despite these seemingly insurmountable obstacles, children with CHARGE syndrome often far surpass their medical, physical, educational, and social expectations.

What causes CHARGE syndrome?

CHARGE syndrome can be caused by a mutation (change) in a particular gene, usually the *CHD7* gene. Around half of all children with CHARGE syndrome have this gene mutation. Although CHARGE is a genetic condition, it is not usually passed on from parent to child – the gene mutation happens by chance.

Massage

As the symptoms are so variable, each case should be considered individually taking into account the severity of the condition. As baby may have spent a long time in hospital, massage would be a great tool to help the parents bond and come to terms with the condition.

References and Further Reading

www.sense.org.uk

www.chargesyndrome.org

Choanal Atresia

Definition

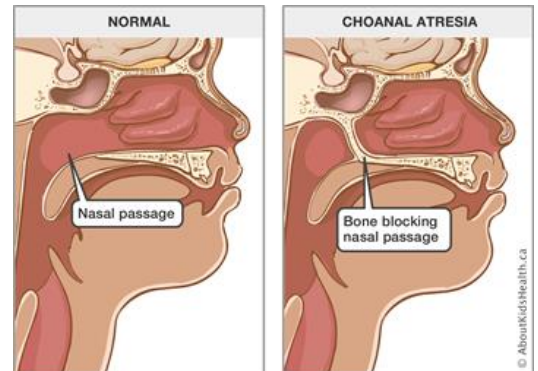
Choanal atresia is a condition that is present from birth, in which the nasal passages are blocked by bone or tissue. This condition can affect one or both nasal passages.

If only one side is blocked there is often a delay in diagnosis. When both sides are affected, baby will have difficulty breathing. Babies are unable to mouth breathe for the first few months of life so the condition is likely to be diagnosed soon after birth.

Choanal atresia is a rare condition affecting about 1 in every 10,000 births. As it can be associated with other problems the baby will be investigated further. It is slightly more common in girls than boys.

The treatment is immediate surgery. Post-surgery baby will have nasal stents (small plastic tubes) stitched in place to ensure the nasal passages remain open. These remain in place for 6-12 weeks, and will need regular suctioning during this time to maintain a clear airway. The parents will be taught how to do this at home when baby is discharged.

The prognosis is good if there are no other health issues.



Massage

It is always a wise precaution to have consent from baby's consultant, especially if there are other health issues. Baby is likely to be quite touch-defensive about the face area, especially if the stents are still in place and they have been having regular nasal suction. It is beneficial to teach parents the face strokes so they can be introduced in time once the stents have been removed.

References

<https://www.gosh.nhs.uk/conditions-and-treatments/conditions-we-treat/choanal-atresia>

<https://medlineplus.gov/ency/article/001642.htm>

Chronic Lung Disease in Neonates

Definition

Chronic lung disease (CLD) is a general term for long-term respiratory problems in premature babies. It is also known as *bronchopulmonary dysplasia (BPD)*. It is more common in infants with low birth weight and those who receive prolonged mechanical ventilation to treat respiratory distress syndrome (RDS).

Treatment of CLD may include:

- Oxygen therapy
- Ventilation initially weaning to Continuous Positive Airways Pressure (CPAP)
- Surfactant replacement
- Medication
- Intravenous fluids and nutrition

CLD can be a long-term condition, some babies requiring mechanical ventilators for several months. Many may also require oxygen once they discharged from the hospital, most are weaned from oxygen by the end of their first year. These babies have an increased risk of respiratory infections which may need further hospitalisation.

If baby requires home oxygen the parents will be confident in caring for their baby prior to discharge, and are aware of any worrying signs to be concerned about.

Massage

Other than the facial strokes, there is no reason why baby cannot have a full massage, massaging the chest and back should help to improve pulmonary function. Baby may be particularly touch sensitive to the feet as they will have had lots of bloods taken by heel prick, whilst in hospital.

Baby is also likely to tire easily so may not complete a whole massage session, so one to one sessions would be better initially, introducing touch must be taken slowly and be baby led.

The parents, especially the mother may have become isolated during the time that baby has spent in hospital, so as baby improves a group session may be possible. As baby is likely to be more susceptible to chest infections the ground rules must reflect this.

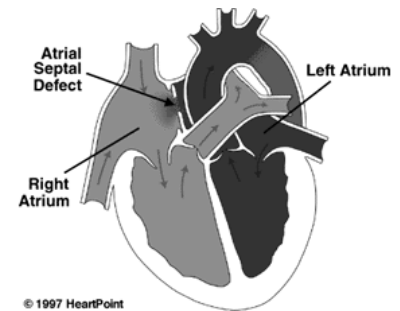
Congenital Heart Defects

There are many congenital heart defects, too numerous to mention individually. However, two of the most common defects are described below:

Atrial Septal Defect

Definition

Atrial Septal Defect (ASD) is a hole in the septum between the upper chambers of the heart. Blood from the left atrium is allowed to pass through the hole into the right atrium instead of the left ventricle, as it should. This means that the oxygenated blood is pumped back into the lungs instead of going to the rest of the body. A small ASD doesn't affect the way the heart works, many close spontaneously as the heart grows; one in four people grow up with a small ASD and never know about it.



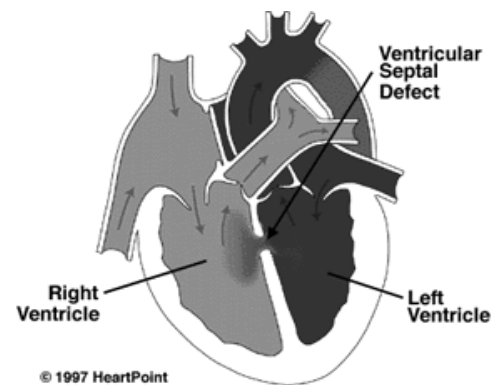
Ventricular Septal Defect (VSD)

Definition

A Ventricular Septal Defect (VSD) is a hole in the part of the septum that separates the ventricles (the lower chambers of the heart). The hole allows oxygenated blood to flow from the left ventricle into the right ventricle instead of flowing into the aorta and out to the body.

An infant who is born with a VSD may have a single hole or more than one hole in the wall that separates the two ventricles. The defect also may occur by itself or with other congenital heart defects.

Small VSDs do not cause problems and often may close on their own. If the VSD is larger, surgery may be required to close it; either by catheter or by open heart surgery.



Massage

Parents must seek medical advice before starting a full infant massage course. If baby has needed open-heart surgery to close or repair a defect, massage will help the parents to accept, look at and touch the scar which may be difficult for them.

The parents will have been told what symptoms to look for if baby's heart is tiring, but generally it will be pallor, or baby has a bluish tinge, especially around the mouth. Also baby may become 'sweaty'; if this happens encourage the parent to stop massaging immediately and quietly cuddle baby before dressing. This must be done in a non-directive, supportive manner.

Helpful organisations:

www.bhf.org.uk

<http://congenital-heart-defects.co.uk>

Congenital Malformation

A baby with a congenital malformation may benefit from receiving a full massage from infancy and into childhood, as it may help them have a positive self-image, as well as helping the parents to overcome their fears and to accept their child's body shape more readily.

This can be said for Cleft lip and palate, hemangioma and any cranio or facial disorder, etc



Hemangioma



Cleft lip

Cystic Fibrosis

Definition

Cystic Fibrosis (CF) is an inherited, chronic disease caused by a defective gene, affecting the lungs and digestive system. Newborns are now screened for CF and diagnosed within four to six weeks, this earlier diagnosis and treatment gives a better long-term prognosis.

The defective gene causes the body to produce unusually thick sticky mucous, the main areas to be affected are the lungs, pancreas, liver, intestines, sinuses, and sex organs. Mucous is normally a slippery, watery substance keeping the linings of certain organs moist, preventing them from drying out or getting infected. Cystic Fibrosis causes the lungs to become blocked, increasing the number of lung infections which can be life-threatening. The sticky secretions block the flow of digestive juices into the gut leading to impaired digestion and poor absorption of food.

Soon after birth the baby may not have passed the first black stools (meconium) and this may lead to surgery to remove the blockage from the abdomen.

As the infant grows intensive chest/lung physiotherapy will be introduced to help remove the sticky mucous from the lungs.

Meconium Ileus

Meconium Ileus is an obstruction of the terminal ileum (the last segment of the small intestine) by abnormally tenacious meconium and can be a complication of Cystic Fibrosis. Symptoms include vomiting, abdominal distension, and failure to pass meconium (the normal sticky black stools of a newborn baby) and occur within the first 24-48 hours after delivery.

Treatment is by an enema but if the obstruction cannot be cleared the baby may need surgery. The surgeon may be able to wash out the meconium, but some babies will need to have a segment of their intestine removed (resection) or they may need an ostomy creating a stoma on the wall of the abdomen. After the blockage is cleared, the surgeon performs another operation to close the ostomy and to sew the open ends of the intestine together.

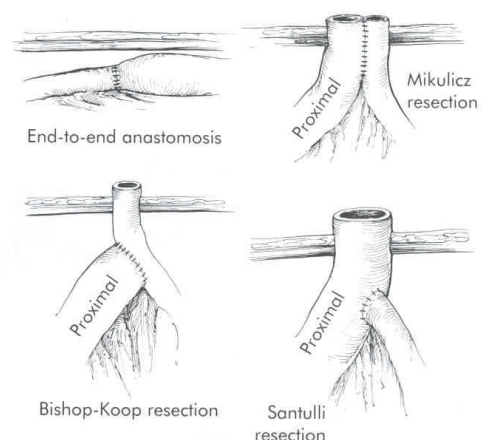


Fig. 69-2 Operative options for the surgical treatment of meconium ileus.

Massage

The build-up of mucous makes it easy for bacteria to grow; this leads to frequent serious lung infections, which can eventually damage the lungs. It is well documented that baby massage boosts the immune system (Diego et al 2001), therefore it would follow that massage can help to build up the babies natural immunity to fight infections

The main focus of treatment for CF is physical therapy, exercise and medications. The parents are generally taught physiotherapy by a professional to aid the loosening of the mucous, but exercise is also recommended, so perhaps rhythm and movement and baby yoga may also be of benefit, always of course remembering that these babies may tire easily because of the lung problems.

The thick sticky mucous also prevents the enzymes in the pancreas reaching the small intestines to aid the absorption of fats and proteins. This can cause vitamin deficiency and failure to thrive; it can also cause bulky stools, trapped wind, and a swollen tummy, resulting in pain and discomfort. As research has shown that massage aids the relief of constipation and colic, it would be a useful tool to teach parents to help empower them with the care of their baby.

CF also causes the excretion of salt through the skin which can cause an imbalance of minerals in the blood; this can cause the baby to become dehydrated. As babies are often thirsty after a massage, it is strongly recommended that these babies, in particular, are always offered a drink after the massage.

It's important to remember that these children can contract chest infections very easily, so parents may be reluctant to join a class, opting for a one-to-one instead. However, the parents may be feeling isolated, and might enjoy the company and support that a group can give; if this is the case then ground rules would have to be very clear about bringing babies to class with colds and snuffles.

Parents should consult their specialist team on the best way to incorporate a full massage into their routine of regular treatment. As the baby's experience of touch tends to be invasive physiotherapy, infant massage offers the opportunity for soothing positive touch.

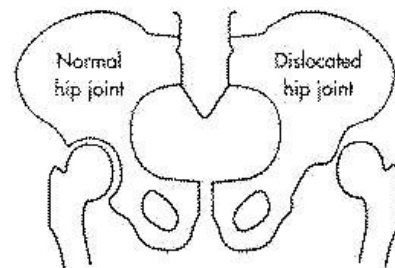
Helpful organisations:

www.cftrust.org.uk/aboutcf/publications/

Developmental Dysplasia of the Hips

Definition:

Developmental Dysplasia of the Hip (DDH) (formally known as Congenital Dislocated Hips CDH) occurs when the head of the femur is unstable within the socket (acetabulum) of the pelvis. The ligaments of the hip joint may also be loose and stretched. It can affect one or both hips. When it occurs in one hip it is easier to diagnose early, as one leg is shorter than the other, the buttocks folds may not be symmetrical with more creases showing on the dislocated side. Bi-lateral dislocated hips can be harder to diagnose, as both legs would be the same length.



All newborn babies are screened for hip dysplasia. If the hips are thought to be unstable, 'clicky,' they will be re-checked at 3 weeks. If the hips have remained unstable at this time baby will be fitted with a Pavlick Harness.



Hip Spica

After a four weeks in the harness, the hips are re-assessed if the head of femur remains unreduced, an abduction splint (hip Spica) is used. At 3 months further checks are given, as surgery may be required. Treatment in plaster will continue for several weeks or months and may be followed by a period in a splint.



Pavlick Harness

Massage

The family may be struggling to come to terms with the condition and caring for their baby may make them feel overwhelmed, so teaching some positive touch techniques and specific massage strokes will help to overcome this.

A full massage is impossible on a baby who is in either in the Pavlick Harness or the Hip Spica, as only a few areas are exposed, but it is important that positive touch is given to help baby feel loved and nurtured. Baby's feet, arms, head and face are fully available, so can receive all the strokes normally given in a full massage; in addition some of the leg strokes can be adapted for the arms. When baby is lying prone an adapted stroke to massage the top of the back and arms may be possible.



Helpful organisations:

www.steps-charity.org.uk

Down's Syndrome

Definition

Down's Syndrome is a relatively common genetic disorder and occurs when the baby is born with an extra chromosome (47 instead of 46.) It usually occurs when there is an extra copy of chromosome 21, and is sometimes called trisomy 21. The extra chromosome causes physical problems and reduced intellectual development.



Whilst Down's Syndrome symptoms vary from person to person and can range from mild to severe; babies do share similar facial features and physical symptoms. They have a flattened nose, which may give rise to sinus and breathing problems, upward slanting eyes with Epicanthic folds, and often they may have smaller ears and mouth. The hands are usually wide and short with short fingers and they generally have a single palmer crease transversely across the palm of the hand. They usually have decreased muscle tone which may give rise to hip problems and risk of dislocation, and their physical development is often slower than normal. Children may also have delayed mental and social development, Down's syndrome is often associated with a heart defect, usually Atrial Septal Defect (ASD) or Ventricular Septal Defect (VSD), see separate sheet on these conditions.

Massage

Poor muscle tone contributes to the tendency of some children with Down's syndrome to be physically inactive. For this reason, their need for physical stimulation and sound is vital. The guidelines for hypotonicity should be taken into account when doing massage. Research has shown that massage given to babies with Down's Syndrome has very positive outcomes, including enhanced motor functioning and increased muscle tone. As many of these children suffer from constipation, which can be long-term and chronic, the tummy routine will be especially helpful. Care should be taken when first doing the head massage strokes as some Down's syndrome babies have widely spaced sutures on the skull (sutures are the joints between the bones).

Most children generally love music, singing and dancing and children with Down's syndrome are no different. Sensory stimulation (eg music) and motor stimulation (eg dance) should form part of their education from a very early age. Movement stimulates the brain and nervous system and music is composed of a highly structured series of sounds and contains most of the elements of language — pitch, rhythm and timbre. Listening to music, singing along to nursery rhymes, and dancing can help a baby with Down's syndrome acquire their language skills. Therefore, singing during a massage is especially important for their speech and language development.

Advice regarding massage should always be sought from a specialist for any children suffering from internal organ defects, such as congenital heart problems.

Helpful organisations:

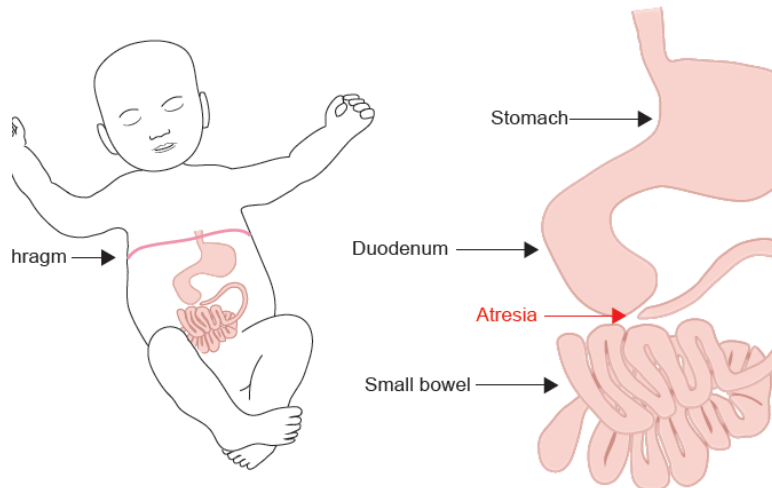
www.downs-syndrome.org.uk

www.nads.org

Duodenal Atresia

Definition:

Duodenal atresia is a rare condition and occurs in about one in 6,000 births, if left untreated it is fatal. The child requires surgery within the first few days of life. It is often associated with Down's syndrome and other congenital abnormalities. It is diagnosed in 80 – 90% of cases during pregnancy at the 7 month ultrasound scan.



The Duodenum is first part of the small intestines starting at the stomach. Atresia is when there is a 'blind' end, so doesn't connect to the remainder of the intestines. This means that food and fluids cannot pass from the stomach into the intestines. Sometimes there is a narrowing of this portion called Duodenal Stenosis. Once treated there should be no long-term effects

Massage:

It should be safe to massage six to eight weeks post-operation once the sutures have been removed and the scar has healed. However, it would be wise for the parents to gain permission either from their consultant or GP to ensure that massage would be safe, especially as there may be other complex health needs.

Abdominal massage should certainly be helpful to ensure good bowel movement but be aware that baby may be touch-sensitive over the abdomen so massage would need to be taken at the baby's pace. One to one sessions may be advisable initially to see how baby reacts.

References:

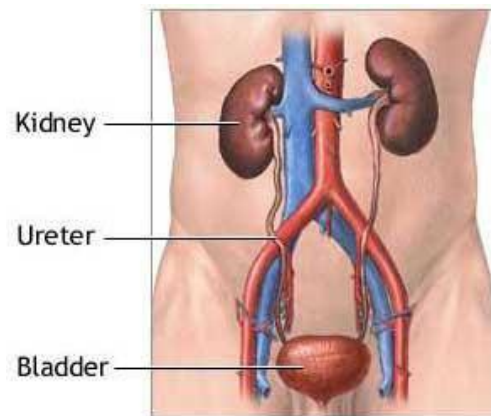
<https://medlineplus.gov/ency/article/001131.htm>

<https://rarediseases.info.nih.gov/diseases/54/duodenal-atresia>

Ectopic Kidney

Definition

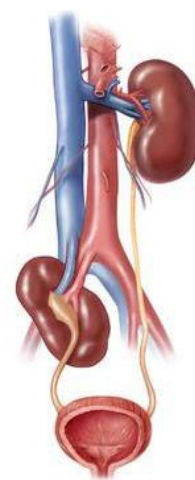
An ectopic kidney is a congenital defect and is defined as a kidney that is not located in its usual position. The kidneys are normally found in the posterior abdomen on either side of the vertebrae in the lumbar region, the right kidney slightly lower than the left due to the position of the liver. An ectopic kidney is most commonly found in the pelvis (*simple renal ectopia*), but may also cross over to the opposite side, in this case the two kidneys may fuse together, (*crossed renal ectopia*). They are thought to occur in 1:900 births but only about 1:10 are ever detected.



Normal kidneys position

Complications:

- Urinary Tract Infections (UTI), caused by stasis of urine in the bladder
- Kidney Stones, caused by the chemicals staying in the urine forming a hard stone
- Infections are frequent or untreated then the kidney can become damaged and could lead to kidney failure
- Hydronephrosis: if there is a blockage the urine backtracks into the kidney causing swelling



Right ectopic kidney

Treatment:

Treatment is only required if there is a problem with the urinary flow, by treating the infection or surgery may be required to remove any blockage and improving the urinary flow. If the kidney is severely damaged it may be necessary to remove the kidney, providing the other kidney is healthy.

Implications for Massage:

There is no reason why baby cannot receive a full massage, but care as always must be taken over the kidneys. It is helpful if the parents know where the kidney is so a lighter touch can be used over this area when performing the back massage. If the position is unknown then a lighter pressure can be used below the waist area.

If the kidney is in the abdomen then a lighter pressure must be used over this side.

Erb's Palsy

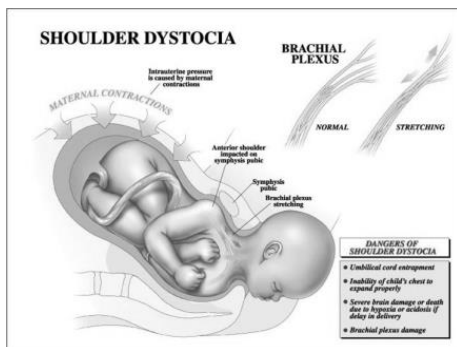
Definition:

Erb's Palsy is a form of brachial plexus injury and is presented by a loss of movement or weakness of the arm, that occurs when the collection of nerves around the shoulder are damaged during a difficult delivery.



The doctor may use different names for this injury, based on where the weakness occurs in the affected arm:

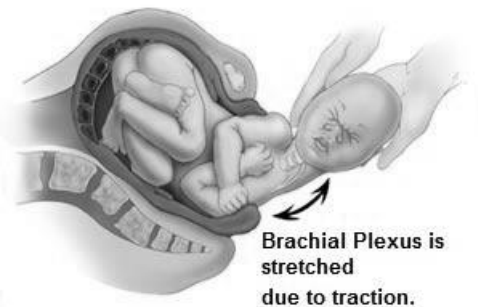
- Erb's Palsy: weakness in the shoulder and upper arm
- Klumpke's Palsy: weakness in the lower arm and hand
- Complete Palsy: weakness in the whole arm



One common reason for Erb's Palsy is shoulder dystocia, after delivery of baby's head; this is when the anterior shoulder gets stuck behind the mother's pubic bone. The incidence of shoulder dystocia rises with many factors, the most prominent of which are the size of the baby. Larger babies, predictably, are often born to mothers with diabetes, or gestational diabetes, particularly if the blood sugars have not been carefully monitored and managed.

The injury usually happens when too much force is applied to the baby's head, while trying to pull out a baby stuck in the birth canal.

The paralysis may be partial or complete; the subsequent damage to each nerve can range from bruising to tearing. The majority of these injuries resolve by three months although some may require specialist intervention. Other problems associated with shoulder dystocia are fractured clavicles and/or humerus; baby may also have had some degree of birth asphyxia if the delivery had been prolonged.



Physiotherapists encourage infant massage as an addition to any treatment that they may prescribe. Other suggestions the physiotherapists may give are:

- Protect the arm from hanging down or getting caught in straps
- Avoid lifting baby up from under the arms and avoid pulling the arm
- When dressing, dress the injured arm first

Massage

The parents will have been taught by their physiotherapist a series of exercises which need to be carried out as instructed. As parents are often frightened of touching the affected arm, massage will encourage 'normal' touching and handling, this helps the baby's brain to build up pathways to include the affected arm. In some cases the clavicle may have been fractured during the delivery, in which case infant massage cannot be given to the affected limb until the bone has healed. Baby can still receive the rest of a full massage on the legs, tummy and head, and if it is possible to lay baby in a comfortable position then perhaps the back could also be massaged, but this may not be possible. As always the massage is baby led, never working beyond baby's point of resistance. Take into account that baby may be fractious if there is any pain, so may

only tolerate very short sessions. When the arm can be massaged, encourage the parents to use the same pressure on both arms and treat them both the same, start with the unaffected arm, so baby can feel how good it is. It may be useful to incorporate some of the leg strokes to the arms (avoiding the jelly roll), this will help to develop the neural pathways.

It is important that the parents try to encourage baby to use the injured arm to reach out and explore the environment by using rattles and mobiles, etc. Tummy time is also important to encourage baby to put weight on both arms to strengthen the affected arm and to encourage equal development on both sides of the body.

As with many 'special conditions' parents may be grieving for the 'normal' baby that they were expecting, which can hinder bonding, but also in this group of parents the injury could often have been avoided if the delivery had been managed differently, so they may be angry and may be seeing lawyers regarding litigation. It would be useful in all cases to direct parents to the Erb's Palsy group for help and support.

Helpful organisations:

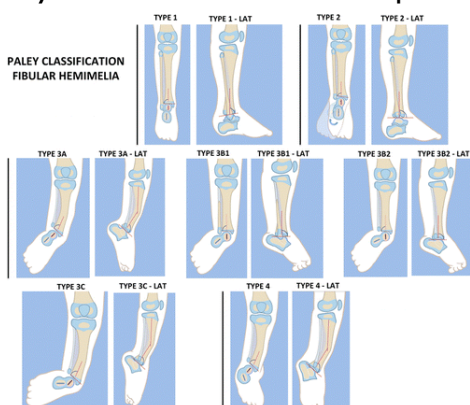
www.erbspalsygroup.co.uk

Fibular Hemimelia

Definition

This is a rare genetic congenital limb deficiency, the cause unknown, appearing in 1:40,000 births. The abnormality is likely to have occurred during the development of the lower limbs during early pregnancy. In the majority of cases the tibia is shorter than normal with the fibula missing completely, but as in many genetic conditions this can vary in severity from one child to the next. There can be associated foot and ankle disfigurement and knee involvement.

In some cases the femur may also be shorter and the hips unstable



Treatment

The treatment is dependent on the severity of the condition. Treatments may include leg lengthening procedures, surgical operations to the feet, and physiotherapy. In very severe cases amputation may be necessary.

Massage

A full massage routine can be offered but with adaptations to the leg massage. The 'Jelly Roll' should be avoided, as the leg is likely to be too unstable for this. The foot strokes may be given. The double leg lift is suitable as this is a gentle move, but avoid the knee hug, as there may be knee and hip involvement. Working 'with' baby and tailoring for his individual needs.

Using massage is a good tool to encourage the parents to touch and interact with baby in a positive way. When a baby is born with a disability such as this it is useful to remember that the parents are in mourning for the loss of the full term healthy baby they were expecting.

As a massage teacher it is important to prepare yourself before meeting the family. It may be a shock to see baby's legs for the first time, therefore research and look at images on the internet. When you meet the family, focus on the positives eg beautiful eyes, but at the same time don't make the deformity the 'elephant in the room', acknowledge but be positive and be parent led.

Resources and Research

<https://www.stepsworldwide.org/conditions/fibular-hemimelia/>

Contact details: info@steps-charity.org.uk Tel: 01925 750271

<https://kidshealth.org/en/parents/fibular-hemimelia.html>

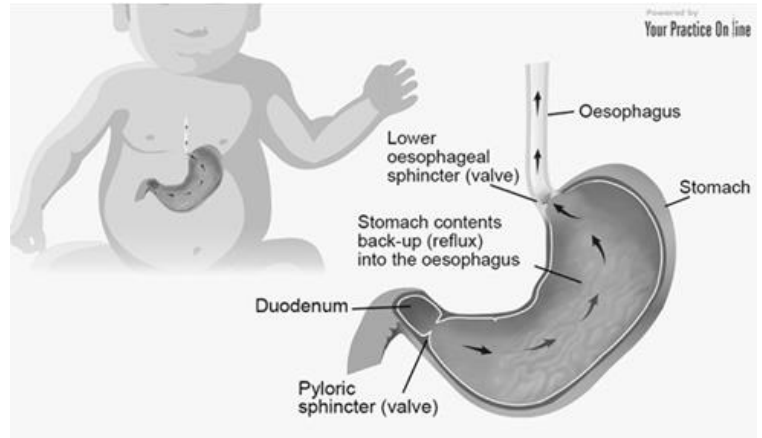
<https://rarediseases.info.nih.gov/diseases/8659/fibular-hemimelia>

<https://www.limblength.org/conditions/fibular-hemimelia/>

Gastroesophageal Reflux

Definition

When food is eaten it goes down the oesophagus and into the stomach, Gastroesophageal Reflux (GER) is a backward flow of milk or digestive juices (which are acidic) from the stomach and duodenum into the oesophagus, and a small amount of feed is regurgitated into the mouth 'possit', this may happen 30 or more times a day.



Reflux usually occurs because stomach muscles and nerves are weak and not fully developed, so is more common with babies who have been born prematurely. It is very common for babies to suffer from reflux during the first few months, and although there may not be an underlying medical problem, it can be quite distressing for the parents, however as baby gets older the occurrence becomes less frequent and usually disappears by 12-18 month old. Because the regurgitated food is acidic, reflux can be painful a bit like heartburn.

Massage

When massaging these babies, follow guidelines for *Gastrostomy*. Offer a full massage to baby with head raised when either supine or prone. Massage has been shown to improve gastric motility (Hernandez-Reif et al 2005) and will help strengthen the abdominal muscles. It is advisable that the parents of babies who suffer from frequent reflux consult their health professional to ensure there is no underlying medical condition.



Guidelines are given to parents regarding the best way to treat and nurse babies with reflux. For the babies who are prone to reflux a lighter pressure should be used across the top of the tummy. Positioning is also important; baby should be massaged with the head raised at about 30% to avoid reflux. When massaging the back it may be advisable to use an alternative position, with baby lying on the right side with head raised or on the shoulder. Another suitable position is for baby to be positioned lying up the thighs as is demonstrated in the picture.

Helpful organisations:

www.livingwithreflux.org

Gastroschisis

Definition

Gastroschisis is a birth defect of the abdominal (tummy) wall. It is a type of hernia where the baby's intestines protrude through a hole in the abdominal wall, usually to the right of the umbilicus. The hole can differ in size from small to large. In some cases the liver and stomach may also be involved.



Research has indicated that there is a higher incidence of gastroschisis in teenage mothers and women that smoke and consume alcohol. Taking folic acid and vitamin supplements before becoming pregnant, and during pregnancy, may help reduce the incidence of congenital abnormalities, also cessation of smoking and drinking alcohol.

Treatment

Soon after birth, surgery is performed to replace the organs into the abdomen. If the lesion is large this may have to be done slowly over a few days, this involves placing a mesh sac over the intestines so they are contained, and then suspended above the baby so the intestines can gradually move back inside the abdomen by gravity, the opening can then be repaired. It may take some time before the bowel starts working properly from a few days to a few weeks, during this time feeding will be via intravenous infusion.

Children who have had a gastroschisis repair may develop hernias, as the abdomen has fewer muscles than normal.

Massage

Massaging the tummy will help to strengthen the abdominal muscles and using sunflower oil will help to heal scar tissue. Once healing has taken place after surgery, the massage routine can be taught as normal, with some caution of the tummy strokes. The **daisy wheel** is quite a deep stroke, so be cautious with this, it may be beneficial to omit this stroke until baby is a few months old and consent has been given from baby's consultant, otherwise a full routine can be taught.

References

<http://www.cdc.gov/ncbddd/birthdefects/gastroschisis.html>

<https://www.nlm.nih.gov/medlineplus/ency/article/000992.htm>

<http://www.gosh.nhs.uk/medical-information/search-medical-conditions/gastroschisis>

Gastrostomy

Definition

A gastrostomy tube is a way of feeding babies who are not able to suck or swallow enough food to maintain good nutrition. A small, flexible, hollow tube with a balloon or special tip is inserted into the stomach through a small cut on the left side of the tummy above the umbilicus. Stitches are used to hold the tube in place initially, once healing has taken place the tube is replaced with a 'button', which is easier for feeding and care. The 'button' is a simple, skin-level device with a one-way valve which is held in place with an internal anchor.



Medical reason

Babies with Oesophageal Atresia require gastrostomy feeding as this is a condition where the oesophagus has a blind end, therefore food cannot reach the stomach. Other reasons are caused by poor muscle tone to the stomach and oesophagus resulting in severe reflux; these are a group of babies where extra precautions for massage are required.

Care

The parents and family are taught the day-to-day care of the gastrostomy, how to care for the skin around the tube how to spot any signs of infection, and to how to observe for any complications, such as infection. They are also taught what to do if the tube becomes blocked or if it is pulled out, how to empty the stomach and to release wind. They soon become 'experts' in managing their own baby.

Massage

A baby with this condition can receive a full massage; however the *Windmill* stroke or other similar downward strokes should be avoided. The position of the tube should give sufficient room to perform the tummy strokes providing care is taken to avoid dislodging the tube. Care also needs to be taken when massaging the chest. It may help to massage the tummy and chest over clothes to avoid this happening. If the baby is not prone to reflux then the back can be massaged as normal, ensuring baby is comfortable and observing cues.

The site of the insertion of the tube or button can become sore, like a 'nappy rash' if this occurs then the area should be avoided.

For babies who are prone to reflux a lighter pressure should be used across the top of the tummy. Positioning is also important; baby should be massaged with the head raised to avoid reflux. When massaging the back it may be advisable to use an alternative position, with baby lying on the right side and head raised or on the shoulder. Another suitable position is for baby to be positioned lying up the thighs as described for '*Umbilical Hernia*'.

Hirschsprung's Disease

Hirschsprung's Disease (HP) is a congenital disorder normally diagnosed during the first few weeks after birth.

Definition:

Hirschsprung's disease is a rare disorder of the bowel that can lead to severe constipation and intestinal obstruction; it can affect one in every 5,000 babies. The nerve cells (known as ganglion cells) that control the peristaltic action of the bowel are missing, which means that the faeces cannot be pushed through the bowel at that point. It can occur at any point in the bowel, the length of the affected part varies from one child to another, but most commonly at the sigmoid colon (the last part of the large bowel) and the rectum.

HP is suspected if baby fails to pass meconium (the sticky black stools first passed by baby). This is diagnosed firstly by x-ray using a contrast medium, followed by a rectal biopsy to confirm that the nerve cells are missing. The cause of HP is unknown but recent research has identified a number of genes which means it *could* run in families.

Treatment

Surgery is generally required to remove the affected part of the bowel and re-join the healthy bowel to the rectum (this is known as a 'pull-through' operation).

They will probably need regular bowel washouts if they have to wait for surgery, a thin tube is inserted into the rectum and warm salt water is then used to soften and flush out the trapped stools. Sometimes a stoma (the bowel is brought through to the abdomen and a bag is attached to collect the faeces) is required until the child is healthier, then the pull through operation can be performed.

Implications for Massage

As always with any condition ask the parents to gain permission from the baby's Consultant/GP. If baby is having bowel 'wash-outs' prior to surgery, teaching the parents a colic routine may help providing baby is generally well and saying 'yes; to massage.

Parents can also be taught a containment holding technique that can be used pre and post-operatively. This is done by placing one hand on baby's head and one hand over baby's legs/feet. Teach the parents to take a few deep breaths first to calm themselves, then to send their love to baby, this will help to settle baby and promote self-regulation.

Many babies with HD suffer with long term problems such as diarrhoea, constipation, soiling and abdominal pain. Massage has been proven to aid constipation so once healing has taken place after surgery, gentle abdominal massage can take place. This will aid bowel movement.

If baby has a stoma prior to having the 'pull through' surgery, there is no problem teaching all body areas (6-8 weeks after surgery) although abdominal massage is difficult because of the position of the stoma, but it may be possible to do the tummy circle and knee hug while baby is clothed as this may help with trapped



wind. When teaching the back ensure baby is in a comfortable position (see picture for alternative position.) It would be useful to teach the parents the full tummy routine so that they can massage this area 6-8 weeks after the next operation, the colic routine could be performed with each nappy change remembering that massage is always baby-led.



References/Useful web sites

<http://www.uhs.nhs.uk/OurServices/Childhealth/NeonatalSurgery/Conditionswetreat/HirschsprungsDisease.aspx>

<http://www.gosh.nhs.uk/medical-information/search-medical-conditions/hirschsprungs-disease>

<http://www.niddk.nih.gov/health-information/health-topics/digestive-diseases/hirschsprung-disease/Pages/ez.aspx>

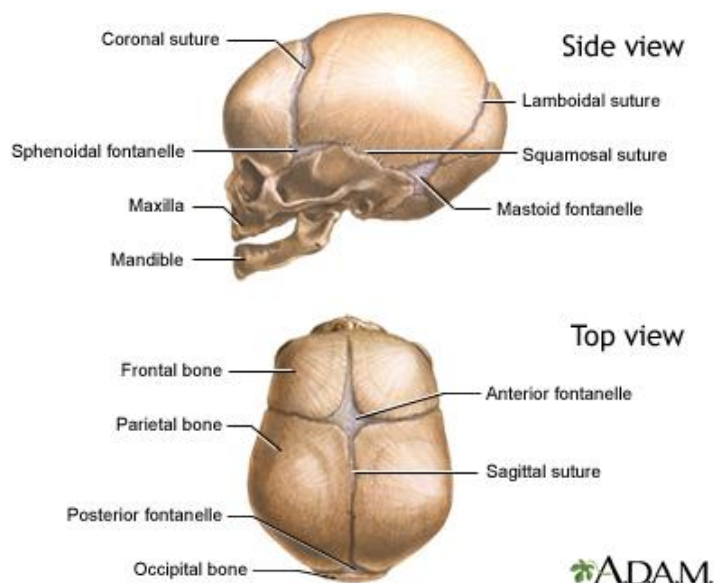
Hydrocephalus

Definition

Hydrocephalus is an excess of cerebrospinal fluid (CSF) surrounding the brain

CSF has three important functions:

- Protects the brain from damage
- Removes waste products from the brain
- Provides the brain with the nutrients it needs to function properly



The brain is constantly producing new CSF around a pint a day; the old CSF is reabsorbed into the body by the blood vessels. If this process is interrupted the level of CSF in the brain can build up very quickly causing excessive pressure on the brain and can lead to brain damage.

To understand the causes of hydrocephalus it helps to understand how CSF circulates through the brain:

- CSF is created in the brain and flows through the ventricles (chambers within the brain)
- Excess CSF moves out of the brain, via specialised tissue (arachnoid villi), to leave the brain and filter into blood vessels while preventing the blood from leaking into the brain and damaging it.

Hydrocephalus can develop if:

- There is a blockage in one of the ventricles so that excess fluid cannot move out of the brain
- There is a problem with the arachnoid villi so that fluid is unable to filter into the blood vessels
- The brain starts to produce too much cerebrospinal fluid (this is very rare)

Congenital hydrocephalus

- May be the result of a brain defect that restricts the flow of CSF. For example, the passages that connect the ventricles in the brain become blocked or narrowed
- A baby born with Myelomeningocele or myelocoele (See Spina Bifida)
- Premature Babies (especially very low birth weight) either pre or post-natal, can bleed into the ventricles, which can block the flow of CSF
- Idiopathic congenital hydrocephalus, the cause is unknown.

To treat hydrocephalus a thin tube known as a shunt is placed in the brain, it works by draining the excessive CSF from the brain to another region of the body where it can be absorbed.

Insertion of a shunt:

- An area of hair on the head is shaved. This may be behind the ear or on the top or back of the head.
- The surgeon makes a U-shape cut behind the ear. Another small surgical cut is made in the abdomen.
- A small hole is drilled in the skull. A catheter is passed into a ventricle.
- Another catheter is placed under the skin behind the ear. It is sent down the neck and chest, and usually into the abdominal area. Sometimes, it stops at the chest area. The doctor may make a small cut in the neck to help position it.
- A valve (fluid pump) is placed underneath the skin behind the ear. The valve is connected to both catheters. When extra pressure builds up around the brain, the valve opens, and excess fluid drains through the catheter into the abdomen or chest area. This helps lower intracranial pressure. (<http://www.nlm.nih.gov/medlineplus/ency/article/003019.htm>)

Indications for Massage

Before a shunt has been inserted a very gentle head massage may still be given providing great care is taken using the palms of the hand instead of the finger tips. The sutures will be widely spaced, so only very gentle pressure can be given to the areas over the bones, the suture lines will feel like baby's soft spot (anterior fontanel) so are treated in the same way.

Post-surgery, once the scar has healed and the shunt is working properly massage can be given as normal, taking care over the shunt. Baby may be wary about the head being touched so massage, as always, is baby-led.

There may also be some tenderness where the shunt tube passes over the clavicle, if this is the case avoid the chest and arm glide, although this could be adapted to avoid the shoulders.

Chest and Arm Glide adaptation:

- Place both flat hands on baby's chest
- Slide hands up the chest
- Pass gently over the shoulders (without cupping the shoulders)
- Gently stroke down the arms to the wrists etc.

References

<http://www.nlm.nih.gov/medlineplus/ency/article/003019.htm>

<http://www.shinecharity.org.uk/hydrocephalus>

<http://www.ninds.nih.gov/disorders/hydrocephalus>

Hypertonicity

Babies that are hypertonic have very tense muscle tone and can appear stiff and may lack flexibility.

Massage

- Initially concentrate on the unaffected areas of the body, so that the baby learns to appreciate how good massage can feel
- Start with gentle massage on the affected areas of the body; tense muscles can be tender when pressure is applied to them
- To avoid discomfort, do not force tense muscles beyond their capacity
- Continually reassure the baby during the massage
- Massage strokes should be slow

Hypotonicity

Babies that are hypotonic have poor muscle tone and can appear floppy.

Massage

- To help improve muscle tone:
 - Massage strokes should be brisk and stimulating
 - Massaging the chin and cheeks can help support the tongue and help with speech

Laryngomalacia

Definition

Laryngomalacia is the most common cause of stridor (noisy breathing) that occurs in the first few weeks of life. 45-75% of infants who present with a stridor are found to have Laryngomalacia. The cartilage in the larynx is underdeveloped and 'soft', this causes the larynx to collapse after exhalation causing the 'noise' during inhalation.

In most cases the stridor is mild and has normally resolved by the time the infant is 1-2 years old. Occasionally the Laryngomalacia is more severe and requires treatment.

The inspiratory stridor usually presents during the first few weeks of life, it's a sound which becomes worse when baby is feeding or becoming agitated and crying, peaking at 6-8 months. These infants may also be more prone to gastroesophageal reflux.

Unless the condition is severe there is no treatment necessary and baby should be treated and handled normally.

Massage

All areas can be massaged, perhaps with emphasis on the chest area, as this will help to open the airways. From experience it helps to extend the chest over the parent's legs, with the head slightly lower than the chest whilst massaging the chest, this position seems to open the airways and ease the stridor. Be aware that baby may be easily tired so observe cues very carefully.

References/ Further Reading

<https://ukhealthcare.uky.edu/wellness-community/health-information/laryngomalacia>

Liver Disease

Liver Failure is a serious condition occurring when liver function is impaired. Acute liver failure has a rapid onset, commonly caused by toxins or virus that damages the liver's ability to clear toxins from the blood, or producing bile. Chronic liver failure, is also known as end stage liver disease and has a slow onset, developing over a period of months/years. This may be caused by Biliary Atresia, Hep B or C, Cirrhosis of the liver, or Metabolic liver disease.

Most cases will need a liver transplant, although some cases recover spontaneously. Nurses rated the most important goals as managing pain, maintaining the child's quality of life, and improving communication. Generally research has found massage to be beneficial in reducing stress in both the caregivers and the child with many other well documented beneficial effects. Baby will obviously tire easily so remember it is baby led. Start slowly by putting one hand on baby's head and the other on baby's tummy and suggesting to the parents that they send their love to baby, this is a way of asking permission, then the velvet cloak, you may be able to introduce a hand or foot stroke, then finish with the same hold you started with. The parents are obviously under a great deal of stress, so it is important that they try to relax as much as possible before starting contact with baby. Taking three deep breaths or a relaxation meditation may help.

Massage for children with liver disease

- Dependant on cause, diagnosis and prognosis
- Is it treatable/reversible/requires surgery/transplant

Acute Stage

- Gentle Introduction to Massage, this will help both parents and child in this acute situation and help to maintain bonding.
- Seek permission from Consultant before starting Neonatal Massage
- As baby improves and becomes more active introduce Neonatal Massage but exclude the windmill.
- Keep Tummy Circle with gentle pressure, as this could be quite soothing without increasing blood flow

Transplant

- Gentle Introduction to Massage, this will help both parents and child in this acute situation and help to maintain bonding
- Seek permission from Consultant before starting any massage techniques, and start with Touch-Learn *Gentle Introduction to Touch for Premature & Sick Babies*
- As baby improves and becomes more active the Touch-Learn *Neonatal Massage* can be introduced
- Exclude tummy strokes until the wound has healed.

References/Resources

Tubbs-Cooley HL, Santucci G, Kang, TI, Feinstein JA, Hexem KR, Feudtner C, Pediatric Nurses' Individual and Group Assessments of Palliative, End-of-Life, and Bereavement Care (2011) *Journal of Palliative Medicine* Vol 14: 5, 632 - 637

Hughes D, Ladas E, Rooney D, Kelly K. (2008) Massage Therapy as a Supportive Care Intervention for Children With Cancer. *Oncology Nursing Forum* Vol 35: 3, 431-442

www.childrenshospital.org/conditions-and-treatments/conditions/l/liver-failure

Multiple Births

Trying to incorporate baby massage into an already hectic daily routine for parents of twins or multiple births can be rather challenging, however, the following approaches will help to find a way to achieve this.

- It may be a good idea to involve both parents, a willing grandparent, an aunt or uncle, or even older sibling, should the babies be ready for a massage at the same time
- Being aware the babies will be completely different – they will display different cues, have different self-calming techniques, will enjoy different strokes and have different needs
- Being aware that the babies may wish to be massaged at different parts of the day, for instance one may prefer to be massaged in the morning whilst another prefers a massage after a bath and before bedtime



Muscular Dystrophy (Duchenne)

Definition:

Duchenne is the most common and severe type of chronic and progressive muscular dystrophy. It is characterized by increasing weakness in the legs and pelvis, shoulders, arms and neck, the muscles especially the calf muscles become swollen with deposits of fat and fibrous tissue (pseudohypertrophy). It is an inherited disorder, as it is an x-linked disorder it is males that are most commonly affected. It is a life-limiting disorder with an expected life span approx 20 years. As technology and management has improved life expectancy has also increased. Eventually as the weakness progresses it affects the heart and lungs.



Symptoms usually appear about 4-5 years but may appear in early infancy. The symptoms show as muscle weakness, fatigue, enlarged calf muscles (which feel spongy), difficulty with motor skills (running, hopping, jumping) frequent falls. Later muscle contractures occur, scoliosis, cardiomyopathy and congestive heart failure, there is sometimes a degree of mental retardation

When the symptoms begin to manifest themselves between the ages of 2-6 years the child will be have a blood test, diagnosis is suspected when high levels of the muscle protein creatine kinase (CK) have been found, a muscle biopsy may also be taken. Diagnosis is confirmed by another blood test for genetic testing.

If the diagnosis has been made in a baby, it is likely that there is a family history of the disease, which may be an older sibling or cousin. There could be two or three siblings all diagnosed at the same time, understandably the parents are going through a tumult of emotions, and need lots of help and support.

Massage

There is no reason a baby cannot be massaged with DMD, just be aware that as the child gets older, any muscles that have become enlarged (hypertrophy) may become sensitive eg. calf muscles.

With an older child who is showing signs of muscle weakness it may be advisable to avoid the jelly roll and possibly the knee bend. The pressure may also have to be adapted as the muscles become more sensitive.

The family will be getting lots of information from different health professionals and support groups, so teaching the parents massage techniques will give them a positive tool to help empower them at a time when they feel 'out of control'. It will be particularly important to re-affirm bonding, and to help calm the emotional turmoil. The techniques taught can then be adapted for any older siblings so the whole family can enjoy a special time together.

References and Useful Resources

www.parentprojectmd.org

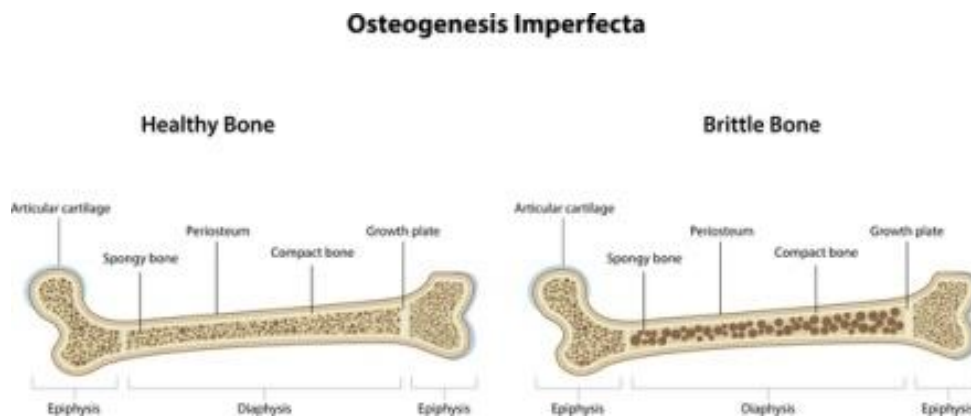
www.dfsg.org.uk

www.muscular-dystrophy.org

Passamano L et al (2012) Improvement of survival in Duchenne Muscular Dystrophy: retrospective analysis of 835 patients. *Acta Myologica XXXI*: p. 121-125

Osteogenesis Imperfecta (Brittle Bone Disease)

Osteogenesis Imperfecta (OI) is a rare genetic disorder affecting about 1 in 5000 births. There are different types from mild to severe. It is a genetic mutation that affects the production of collagen. Collagen is needed to produce strong bones and teeth. In 25% of cases where there is no family history it is likely to be a fresh mutation.



OI exhibits a wide variety of symptoms from very mild to very severe.

Type I: is the mild form with normally no outward signs but they will have bone fragility, so breakages may occur when the child starts to walk. The ligaments may stretch more easily causing joint hypermobility, this may contribute to weakness and fatigue in many muscle groups so may affect quality of life. Other symptoms may include hearing loss, curved bones, scoliosis (curvature of the spine) brittle teeth and short stature, blue sclera is often present.

Type II: is the most severe form, babies are born with many fractures and a misshaped chest, this may cause breathing difficulties. The babies are very small, and some may not survive the delivery, or the neonatal period.

Type III: this is the most severe of those infants who survive to neonatal period. They are born with multiple fractures of the long bones and ribs. They may have breathing difficulties and sucking and swallowing difficulties. The head is often large compared with the rest of the body. Care for these infants is difficult as fracture can occur so easily. Parents will need emotional support as well as medical support and will need genetic counselling before any future pregnancies.

Type IV: This form is a moderate form and comes between mild and severe.

Implications for Massage

As in all cases the parents should gain permission from baby's consultant, but they would need to explain that it would be positive touch rather than massage.

Some sort of touch is so important both for the parents and for the child. In the severe form it is likely to have been diagnosed during the pregnancy so parents will have had time to digest the information. In the mild form because a diagnosis wasn't made the parents are likely to be in shock, and grieving for the full term 'normal' baby they were expecting. In both cases the parents need time to bond with their baby. In the severe type they may be terrified of touching their baby for fear of causing a fracture and frightened of

getting too close emotionally for fear of losing them.

Types II and III and possibly IV massage would be contraindicated as any pressure may be likely to cause fractures. A containment hold to give the baby some comfort should be possible, laying one hand on the head and one on the tummy.

In the mild form a gentle introduction to massage may be possible starting with a containment hold to ask permission followed by a soothing stroke down the whole body, including the velvet cloak, the sole stroke, ensuring that the foot is well supported. It may also be possible to progress to include the upward leg glide, sole stroke, then light circles around the solar plexus area, tummy circle and windmill strokes and end with a gentle back soother, for this stroke position baby along the parent's chest (chest to chest)

As always the touch is baby led and would be given on a one to one basis.

References and Further Reading

www.brittlebone.org

Oxygen Therapy – Nasal Cannulas

There have been many queries to the Touch-Learn Head office over the years about using oil for massage when babies are receiving oxygen therapy via nasal cannula. There is no definitive answer and appears to be quite controversial, with each health authority having their own policy. Some hospitals use fractionated coconut oil as that is stable in warm temperatures but many use sunflower oil as this is closest to the natural sebum in the skin and is therefore unlikely to cause a reaction with the babies skin (research shows that it can increase skin barrier in pre-term babies).



One argument against oils is that it may suddenly combust! There is no evidence to prove or disprove this, unless you are massaging so fast that it causes sparks to fly... The other argument is that the oil will melt the plastic, Helms et al 2010 have demonstrated in their research that this is not the case, although as a precaution we suggest that the face strokes are omitted. Touch-Learn Baby Massage Teachers teach face and head massage without the use of oil so there is no contra indicator.

At Christie Hospital in Manchester they have been using grapeseed oil for foot and hand massage, for over 15 years (now in excess of 10,000 treatments a year) – many of these patients have been receiving oxygen therapy and Dr Peter Mackereth (Clinical Lead for Complementary Therapies at Christie Hospital, Manchester, lecturer at Salford University) has advised that they have never had an adverse event. Given that oils are used in a lot of body products the risk would be extremely low compared with other sources of risk. The bigger concern is people smoking while oxygen is running which has resulted in many injuries/deaths worldwide.

Research/further reading

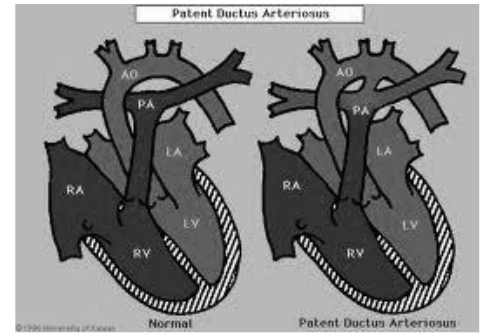
Cooke A, Cork MA, Danby S, Lavender T (2011) *Use of oil for baby skincare: A survey of UK maternity and neonatal units* British Journal of Midwifery June Vol 19, No 6

Darmstadt GL, Saha SK, Ahmed AS et al (2008) *Effect of skin barrier therapy on neonatal mortality rates in preterm infants in Bangladesh: a randomized, controlled, clinical trial.* Pediatrics 121(3): 522–9

Helms RA, Hill DM, Storm MC, Tillman EM. (2010) *In vitro stability of polyurethane and silicone feeding tubes exposed to fish oil.* Am J Health-Syst Pharm—Vol 67 Dec 1

Patent Ductus Arteriosus

In the uterus it is unnecessary for blood to flow through baby's lungs for oxygenation as oxygen is obtained through the placenta. Therefore the normal blood flow bypasses baby's lungs by having a blood vessel (Ductus Arteriosus) that connects the Pulmonary Arteries to the Aorta. This connection allows blood to be pumped from the right side of the heart straight to the aorta, bypassing the lungs for oxygen.



After birth, the baby is no longer connected to the mother's bloodstream, therefore the blood must now go to the lungs to be oxygenated. Normally, when baby starts breathing after birth, the pulmonary artery opens to allow blood into the lungs, and the ductus arteriosus closes. When this blood vessel remains open this is called a Patent Ductus Arteriosus (PDA).

This opening allows oxygen-rich blood from the aorta to mix with oxygen-poor blood from the pulmonary artery. This can put a strain on the heart and increase blood pressure in the lung arteries. Many people live with a small PDA without knowing they have one, but a larger one is more likely to cause problems and may need treatment, either by medication, a catheter procedure or surgery. It affects girls more often than boys and is more common in premature babies. PDA is often associated with other congenital heart defects.

Massage

As infant massage increases the circulation, it is important that parents seek advice from the cardiac specialist before starting infant massage classes.

The parents will have been told the signs to look for that show baby's heart may be working hard, these may include:

- Fast breathing, working hard to breathe, or shortness of breath
- Poor feeding and poor weight gain
- Tiring easily
- Pallor and/or mottled skin
- Sweating with exertion, especially whilst feeding

As an infant massage teacher it is useful to be aware of these signs so that appropriate action can be taken to ensure parents are reading their baby's cues. (Use all-inclusive, empowering and non-directive teaching strategies).

If the consultant has given the go-ahead for massage, a full massage routine can be taught, tailoring sessions appropriately, should baby tire easily.

Helpful organisations:

www.littlehearts.org

Preterm and Sick Neonates

Premature babies usually experience many invasive procedures and live in a highly technical environment in the early days and/or weeks of their lives. These babies may find touch far too overwhelming, so it is important to be mindful when introducing positive touch of any description. These very young, fragile babies are generally far too sensitive to receive a full massage from their parents, as even light stroking can be extremely irritating and stressful.



Massage

Introduce the Touch-Learn *Gentle Introduction to Touch for Premature Babies* sequence whilst a baby is on the neonatal unit. This gives parents the opportunity to start to understand their baby's non-verbal cues.

It can be an extremely positive interaction for both the baby and the parents, if the neonatal staff encourage parents to practise the gentle stroking and containment holds. Research shows that many premature babies who receive positive touch from their parents in hospital can improve physically and mentally and may gain weight more rapidly.

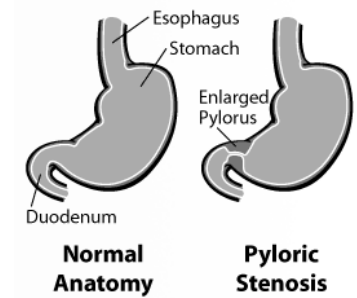
Helpful organisations:

www.bliss.org.uk

Pyloric Stenosis

Definition

The pyloric valve is found at the base of the stomach where it enters the duodenum; it regulates the emptying of stomach contents into the intestine. For an unknown reason it sometimes becomes enlarged during the early weeks of life, causing an obstruction. It is the most common cause of intestinal obstruction in infants and occurs in 1 in every 200-300 live births and is four times more common in males.



As the pylorus becomes blocked baby starts vomiting usually after feeds, a common symptom is 'projectile' vomiting as the stomach contracts, forcing the feed out of the stomach. If the vomiting is persistent and the condition undiagnosed, baby may become dehydrated (when the amount of water leaving the body is greater than the amount being taken in) and lose weight or 'fail to thrive'. Treatment is a relatively small operation where the pylorus is partially cut to release the stricture.

Massage

Pre-surgery see *Gastroesophageal Reflux*. Once the wound has healed post surgery, a full massage can take place as normal.

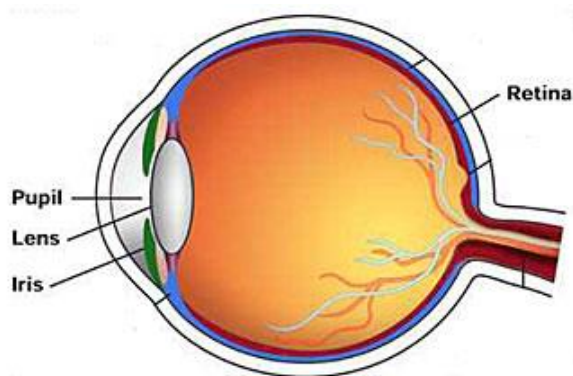
Retinoblastoma

Definition

Retinoblastoma (RB) is a cancer of the retinal eye tissue, and is the most common eye cancer in children. It affects approximately 1:20,000 live births. It is usually detected and treated early in the UK, which is why over 98% of children with retinoblastoma are successfully treated.

One or more tumours may be found in one eye (unilateral) or in both eyes (bilateral). The tumours grow on the retina; the light sensitive part of the eye. Some children are born with the tumours but they can develop up to the age of five years.

There are two types: hereditary and sporadic. If the tumours are multifocal in one eye, or bilateral, then they are heritable. Unilateral tumours are usually sporadic.



Treatment

Early-stage retinoblastoma

Treating a small tumour that is completely inside the eye usually involves one of the following treatments:

- Laser treatment to the eye (photocoagulation)
- Freezing the tumour (cryotherapy)
- Applying heat to the tumour (thermotherapy)

Treating larger tumours

Larger tumours will be treated with one or a combination of the following treatments:

- **Radioactive plaque:** if the tumour is not too large, a small radioactive disc is stitched over the cancerous cells and left in place for a few days to destroy the tumour, before the disc is removed.
- **Chemotherapy:** usually six cycles of anti-cancer drugs are given to eradicate the cancer cells. Sometimes, these anti-cancer drugs are injected directly into the blood vessel supplying the eye.
- **Surgery to remove the eye:** this is necessary if the tumour is large and the eye can no longer see. A prosthetic eye will be fitted.
-

It is useful to have an understanding of the signs of RB as you may be the first to notice the condition or the parents may confide they have a concern.

The signs to look for

- **A white reflex:** A white eye, white pupil or white reflection can be seen in a photograph where the flash has been used. Often one eye will have "red eye" which is normal, but the other eye may look white, yellow or orange. This may be seen in just one or many photographs of the child. A white 'reflex' or white eye/pupil may also be seen when the child is in artificial light or a darkish room. Some parents say that it looks like a cat's eye caught in light or that they think they can see the back of their child's eye, other parents say it looks like jelly. This white reflex may only be seen every so often but in some cases it is present all the time.



- **An absence of "red eye" in flash photographs:** In a photograph where one eye has "red eye" (which is normal) the other eye may look black or looks "wrong". This can also be a sign that something is not right.



- **A squint:** A squint can be a sign of retinoblastoma, although a squint can also be nothing more than a squint. It is always worth having it checked out quickly just to make sure. Some people call a squint a "lazy eye"; it is where one or both eyes look in or out.



- **Red, sore or swollen eye without infection:** A child's eye may become very red and inflamed for no reason. This sign is usually linked with other signs.



- **A change in colour to the iris:** The iris, the coloured part of the eye, can sometimes change colour in one eye, sometimes only in one area.



- **Deterioration in vision:** A child may have deterioration in their vision or they may have had poor vision from birth. You may notice that your child does not focus or fix and follow as well as other children or babies of the same age.

(<http://www.chect.org.uk/cms/index.php/signs-and-symptoms>)

If one or more of these signs are noted, advise the parents to contact their health professional.

Massage

If baby has had treatment for early stage RB, then once the Consultant is happy, then massage can be given as normal. It may be better to avoid the face strokes as baby may be touch-sensitive in this area, but be led by baby.

If baby is having Chemotherapy, massage can take place providing consent has been given, but there are precautions. During chemotherapy the immune system is low so it is advisable for massage to be offered on a one to one basis, also baby may tire easily so the routine can be tailored specifically for their needs. Chemotherapy is given via a central intravenous line, which will stay in for the duration of the treatment; this is usually situated on the chest so the chest strokes must be avoided.

Legs and tummy can be massaged as normal. As the chest is to be avoided perhaps some of the leg strokes can be adapted for the arms if baby is happy – the upward (arm) glide and the gentle (arm) knead are perfect. Angel kisses and ear massage are good but avoid the face strokes, as baby may be touch-sensitive in this area. When positioning baby prone for the back strokes ensure the central line is not caught in any way, otherwise all back strokes can be given. Perhaps the positioning for the back stroke can be adapted, baby could be on the parents chest, ensure the parent's back is supported.

References

Carter, J (2009) Recognizing the signs of retinoblastoma *Practice Nursing* Vol 20, No 8
www.chect.org.uk/cms/index.php/signs-and-symptoms
www.macmillan.org.uk
www.nhs.uk/conditions/retinoblastoma

Russell-Silver Syndrome

This is a very rare genetic disorder; most cases of Russell-Silver syndrome are sporadic, which means they occur in people with no history of the disorder in their family.

Russell-Silver syndrome is a growth disorder characterized by slow growth before and after birth. Babies with this condition have a low birth weight and often fail to grow and gain weight at the expected rate (failure to thrive). Head growth is normal, however, the head may appear unusually large compared to the rest of the body.

Affected children are thin and have poor appetites, and some develop low blood sugar (hypoglycaemia) as a result of feeding difficulties.

Adults with this syndrome are short; the average height for males is about 4ft 11in, for females about 4ft 7in.

Many of the children have a small, triangular face with distinctive facial features including a prominent forehead, narrow chin, a small jaw, and down-turned corners of the mouth. Other features of this disorder can include an unusual curving of the fifth finger (clinodactyly), asymmetric or uneven growth of some parts of the body, including scoliosis (curvature of the spine) and digestive system abnormalities.

Russell-Silver syndrome is also associated with an increased risk of delayed development and learning disabilities.

Massage

Baby would benefit from a full massage, however each case should be assessed individually as the other features of the disorder may require caution, such as gastro-oesophageal reflux requiring positional changes. There may be issues around acceptance, so infant massage would be a useful tool to aid with bonding and attachment.

References and Further Reading

<https://rarediseases.info.nih.gov/diseases/4870/russell-silver-syndrome>

www.magicfoundation.org

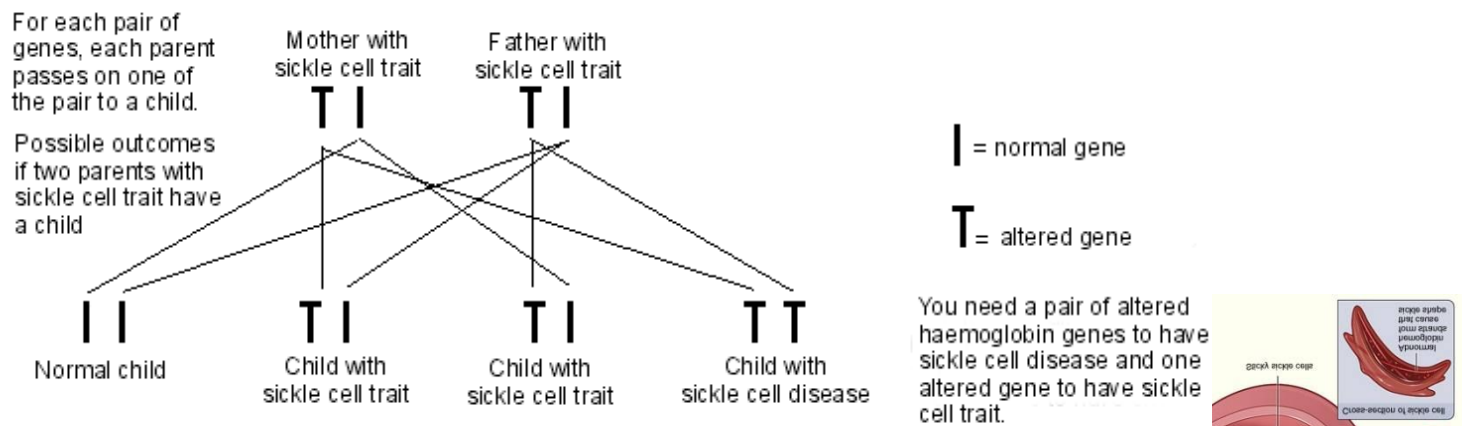
<http://www.childgrowthfoundation.org/>

Sickle Cell Disease

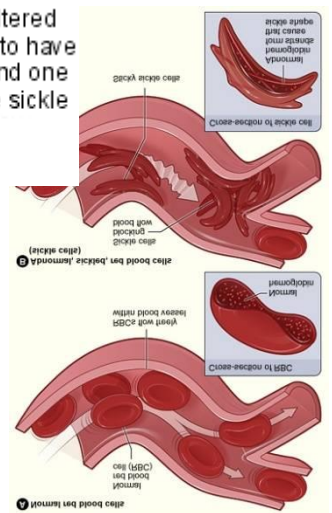
Definition

Sickle cell disease (SCD), often referred to as sickle cell anaemia, is caused by an abnormal type of haemoglobin called 'haemoglobin S', and is inherited from both parents. If you inherit the haemoglobin (S) gene from one parent and normal haemoglobin (A) from your other parent, you will have a sickle cell trait. These people do not have the symptoms of sickle cell anaemia but are carriers of the disease.

Sickle cell disease is much more common in people of African and Mediterranean descent. It is also seen in people from South and Central America, the Caribbean, and the Middle East. 6 in 100 pregnant women may carry the gene for sickle cell trait with 1 in 300 newborn babies having SCD.



Sickle cell anaemia is a disease passed down through families in which red blood cells form an abnormal sickle shape (like a crescent), normal blood cells are disc shaped. The red blood cells contain iron rich protein called haemoglobin (Hb), which carries oxygen from the lungs to the rest of the body. Normally these cells move easily throughout the blood vessels, but in SCD these sickle shaped cells are stiff and sticky. They are also fragile and deliver less oxygen to the body's tissues. They can become stuck in small blood vessels, and break into pieces this interrupts healthy blood flow, and may cause a stroke.



If there is a chance that the baby could inherit SCD, parents will be offered counselling to discuss whether they would like to have a further test pre-natally for the unborn baby.

Symptoms

Symptoms don't occur until after the age of 4 months. Almost all patients with sickle cell anaemia have painful episodes (called crises), which can last from hours to days. These crises can affect the bones of the back, the long bones, and the chest.

Crisis can vary from occasional, every few years to frequent, some can be severe enough to require hospitalisation.

Common symptoms include:

- Attacks of abdominal pain
- Bone pain
- Breathlessness
- Delayed growth and puberty
- Fatigue
- Fever

- Paleness
- Rapid heart rate
- Ulcers on the lower legs (in adolescents and adults)
- Jaundice

Other symptoms include:

- Chest pain
- Excessive thirst
- Frequent urination
- Painful and prolonged erection (priapism - occurs in 10 - 40% of men with the disease)
- Poor eyesight/blindness
- Strokes
- Skin ulcers

Treatment

The goal of treatment is to manage and control symptoms, and to limit the number of crises.

Patients with sickle cell disease need on-going treatment, even when they are not having a painful crisis.

- Folic acid supplements should be taken to help make red blood cells.
- Pain medication
- Plenty of fluids
- Blood transfusions (may also be given regularly to prevent stroke)

Infant Massage

It is important for the parents to consult with medical staff regarding when infant massage is suitable. It is unlikely to be recommended during a crisis when baby will be unwell and in severe pain, during this time gentle holding techniques are recommended. In between crises, massage has been shown to help reduce pain and to help with muscular cramps. Massage is also a positive interaction that a parent can do for their baby.

Research has demonstrated that regular massage, decreased depression, and increased function. The research found that over time the parents/caregivers experienced a sense of control over the disease, in reducing pain and reducing negative emotions. Many research papers have demonstrated the positive effects of reducing stress and aiding relaxation.

Joining a support group where members share common experiences can relieve the stress related to caring for someone with a chronic disease.

References

Beider S, Mahrer NE, & Gold JI. 2007 *Pediatric Massage Therapy: An Overview for Clinicians*. Pediatric Clinics of North America. 54 1025-1041

Horowitz S. 2007 *Evidence-Based Indications for Therapeutic Massage*. Alternative and Complementary Therapies. 13(1) 30-35

Lemanek KL, Ranalli M, & Lukens C. 2009 *A randomised controlled trial of massage therapy in children with sickle cell disease*. Journal of Pediatric Psychology. 34(10) 1091-1096

Organisations

www.sicklecellsociety.org

Sickle Cell Society 54 Station Road, London, NW10 4UA UK Tel 020 8961 7795

Spherocytosis

Spherocytosis is a disease of the blood, characterised by the production of red blood cells that are sphere-shaped, rather than bi-concave disc shaped. Although the damaged red blood cells, characteristic of this condition, have a smaller surface area than healthy ones, oxygen and carbon dioxide are exchanged well enough to maintain healthy oxygen supplies to the body. However, as the spleen recognises these as 'damaged' it actively destroys them, causing anaemia, hyperbilirubinemia and subsequently jaundice are common. In these cases, treatment usually requires a blood transfusion.

Massage

Massage should only be carried out after treatment has successfully relieved the hyperbilirubinemia and jaundice. However, although massage is contraindicated whilst symptoms persist, parents can use the Touch-Learn *Gentle Introduction to Touch for Sick Babies*. Also, if the baby is responding and engaging well without being unduly over-stimulated with normal interactions, the parents could be encouraged to sing nursery rhymes (choosing the ones that accompany the massage strokes, so that if and when the massage commences there is a familiarity to the process for the parent and the baby). Hopefully there will be periods of 'wellness', when the parent may be able to progress to the Touch-Learn *Neonatal Massage* and even a full massage at a later time.

References & Support

<https://patient.info/digestive-health/spleen-pain/hereditary-spherocytosis>

<https://kidshealth.org/en/parents/hereditary-spherocytosis.html>

Hereditary Spherocytosis (HS) Support Group

Spina Bifida

Definition

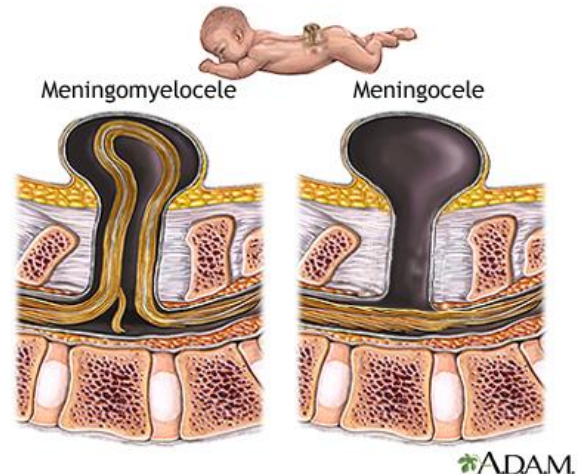
The literal translation of Spina bifida is 'split spine'. When the embryo is developing the spinal column that protects the nerves does not fully close. The exact cause is unknown. Spina bifida is a fault in the development of the spine and spinal cord which leaves a gap in the spine. There are different types of spina bifida, the most serious being myelomeningocele, but there are also Meningocele and Occult types.

Myelomeningocele (meningomyelocele)

The most serious and is said to affect one in every 1,000 pregnancies Britain. The outer part of the vertebrae has not closed completely so both the covering of the spinal cord (the meninges) and the spinal cord itself are pushed out into a sac containing cerebro-spinal Fluid (CSF) that is normally covered by a very thin membrane. This can leave the nervous system vulnerable to infections that can be fatal.

In most cases surgery can be carried out to close the defect, however, damage to the nervous system will usually already have taken place, resulting in a range of symptoms, including:

- Partial or total paralysis of the lower limbs
- Bowel and urinary incontinence
- Loss of skin sensation
- Talipes
- Most babies with a myelomeningocele will also develop hydrocephalus (See Hydrocephalus)



Meningocele

In this form, the sac contains meninges (tissues which cover the brain and spinal cord) and CSF. Development of the spinal cord may be affected, but impairment is usually less severe than myelomeningocele.

Spina Bifida Occulta (hidden form)

This is a mild form of spina bifida, which is more common. Estimates vary but between 5% and 10% of people may have spina bifida occulta. Often people only become aware that they have spina bifida occulta after having a back x-ray for an unrelated problem. However, for a few (about 1 in 1,000) there can be associated problems.

Treatments may include (depending on the severity of the Spina Bifida)

- Surgery at birth to repair the spine, and possibly more corrective surgery later in life if necessary
- Surgery to place a shunt to treat hydrocephalus
- Therapies to help improve day-to-day life and boost independence – such as physiotherapy and occupational therapy and **infant massage**
- Treatments for bowel and urinary problems especially if there is bowel or urinary incontinence

Massage

Although massage is recommended, parents should seek permission from baby's health professional before commencing massage, and to liaise with baby's physiotherapist.

The parents may need encouragement to touch and handle baby's legs as they may appear wasted with no movement if the lesion has been severe. Massage may help the parents to overcome this. When the lesion on the back has been repaired, again parents may be reticent to touch. Massaging may give the parents confidence.

Thought needs to be given as to whether a group or one-to-one environment would be best. After surgery on the back and a shunt has been inserted for hydrocephalus and all has healed, a group environment may help the parents integrate with other parents, but this must be parent-led, just as massage is baby-led.

If there has been a repair to the back lesion, then six weeks should be left for healing to take place. Once baby is receiving physiotherapy then massage can be incorporated into the routine too. Baby may not feel comfortable lying supine especially if the head is enlarged from hydrocephalus, so it may be necessary to massage with baby lying on his side in a lateral position. When baby is lying supine the back and head must be supported, with a soft cushion/pillow. When massaging prone, make sure the head and body are supported especially if the head is enlarged.

There is likely to be a lack of sensation in the lower body therefore care must be taken with the amount of pressure used, it should be deep enough to stimulate the nerves and muscles to help with movement and strength. As there will be a lack of stability in the hips due to the paralysis of the lower limbs avoid the Jelly Roll and Knee Hug and take care with the Double Leg Lift.

References

www.nhs.uk/Conditions/Spina-bifida

www.shinecharity.org.uk

www.aboutkidshealth.ca

Strawberry Birthmark

Sometimes called a Strawberry Haemangioma or Strawberry Nævus

Definition

A strawberry birthmark is a collection of tiny blood vessels that produce a bump in the skin; they are most commonly seen on the head or face but can be found anywhere on the body. They may be present at birth, but usually start to appear during the first few months of life and are more common in females, and premature babies; about 1 in 20 babies will have this type of birthmark. During the first few months the haemangioma will go through a period of rapid growth. After this time they should start to fade and become flatter in appearance and will often have disappeared between 5-9 years of age. They don't normally leave any mark or discolouration. As this type of mark generally disappears spontaneously no treatment is given unless they appear in a place that could impair vision, or for any other medical reason.



The psychological impact of this type of birthmark may have on a family, can be quite devastating, especially when it is on baby's face. Tanner et al (1998) suggest that parents may go through such emotions as disbelief, fear and mourning, they may feel stigmatised when confronted by strangers whose reaction may cause distress. A research study by Sandler et al (2009) found that parents often blamed themselves and felt embarrassed, they had concerns that their child may be bullied at school, which may have a lasting effect on their child's self-esteem. There is a suggestion by Weintein and Chamlin (2005) that unattractive children may grow up to be aggressive, and develop antisocial behaviour if they have been bullied and teased at school.

Massage

As this is a vascular lesion and massage increases circulation, it is recommended that the area be avoided, however as parents are generally asked to keep the haemangioma moist to prevent it becoming dry and ulcerated, organic vegetable oil, may be applied very gently.

As the psychosocial impact can be great in some cases, it is really important to develop a strong parent-infant bond. Research found that parents would go through stages of grief (shock, denial, sadness, anger and finally acceptance/adaptation), parents also had fears of not becoming attached to their babies and subsequently failing to care for them appropriately. Acceptance and adaptation was often connected to support and acceptance from the extended family.

We know that infant massage has a positive effect on both attachment and bonding, so teaching a full massage will really help to overcome some of these emotions, and strengthen the parent-baby bond.

Helpful organisations:

www.birthmarksupportgroup.org.uk

Substance (Drug)-Exposed Infants

Definition

Babies suffer withdrawal symptoms when they have been exposed to drugs in the womb, due to the mother taking medicines, alcohol, and/or illegal drugs. It can take weeks or even months for a baby to fully withdraw from a substance.

Symptoms include:

- High-pitched piercing cry
- Irritability and restlessness
- Tremors
- Feeding difficulties (the baby is often keen to feed but cannot suck or swallow properly)
- Sleeping difficulties (the baby cannot settle or sleep after a feed)
- Vomiting and/or diarrhea
- Fever
- In severe cases convulsions



Fetal Alcohol Syndrome

Alcohol abuse in the mother can cause life-long physical and behavioural problems in children, including fetal alcohol syndrome. The damage to the baby occurs before they are born and there is no cure.

This group of babies can suffer from:

- Mental retardation
- Birth defects
- Abnormal facial features
- Growth problems
- Problems with the central nervous system
- Trouble remembering and/or learning
- Vision or hearing problems
- Behavioural problems



Massage

Bonding may be difficult for the parents because the baby is so unresponsive and difficult to settle when distressed, they may also have feelings of guilt knowing that their 'habit' has caused baby to be like this. In the hospital, mothers are encouraged to breastfeed their babies as a small amount of the drug is passed through the milk which helps to 'wean' baby off the drug dependency.

Initially baby will be suffering from many of the above symptoms so may tolerate very little touch; therefore massage must be introduced very gently. Start with the *Gentle Introduction to Massage*, baby will need to be contained in a nest and additionally may benefit from being swaddled, exposing the hands/feet when necessary. It has been shown that cocaine-exposed babies may be unable to respond to the human voice and face, and to interact with others. As these babies can startle or cry at the gentlest touch or sound, the room needs to be very quiet with subdued lighting. Massage with baby lying on their side to limit eye contact in the early stages. As baby improves, the neonatal massage can be introduced before progressing on to a full massage. Be guided by the baby to ascertain when it is suitable to introduce music and nursery rhymes

Helpful organisations:

www.steps2rehab.com

Talipes: Clubfoot

Talipes is a congenital deformity of the foot, which is twisted out of shape or in the wrong position, it is also known as clubfoot (Dorland's Illustrated Medical Dictionary 28th Edition). There are many different types, but the one most commonly associated with clubfoot is Talipes Equinovarus, with this type the heel is turned inwards and the whole foot rolls inwards with the toes pointing upwards. Flat feet are also a type of talipes known as talipes planus.



Clubfoot affects one in 10,000 births and boys are more commonly affected than girls, and in 50% of cases both feet are involved. There are two main types of talipes, positional which is often mild and structural which can be more severe and may require surgical intervention when the baby is older.

Positional Talipes: is generally caused from the foot being in an abnormal position in the womb while the baby is developing. Oligohydramnios is a condition in pregnancy when there is insufficient amniotic fluid around the developing baby, this can predispose talipes as it causes abnormal pressure on the foot/feet as they are developing.

Structural talipes: is much more complex and is caused by abnormal growth of the foot. This type often runs in families. The foot is often smaller with poor development of some of the bones, and some of the muscles and tendons are shortened and tightened causing the abnormal positioning of the foot.

Treatment:

In the milder positional cases, very little treatment is needed. Physiotherapists will teach parents specific exercises and the foot may also be strapped with elastoplast from below the knee to maintain the correct position. In more severe cases of structural types, specialists generally use the Ponseti method of treatment which is a combination of treatment using manipulation and casting in plaster. Treatment starts as soon as possible after birth while the tissues are still soft. This treatment is given over the first months then the foot/feet will be placed into special boots to maintain an effective position. In some cases surgery is necessary to correct the position of the foot/feet, but this is done if the manipulation has not been effective.

Massage

If the foot is not in plaster there is no reason why a full massage cannot be given, providing that the physiotherapist or consultant treating the baby has given consent. If the parents are regularly manipulating the foot, providing that the techniques being used are not painful to the baby, then this could be introduced as part of the massage routine and made into a fun game using nursery rhymes.

If surgery has been necessary the feet cannot be massaged until the wounds have healed, although the feet will probably be encased in plaster during this time. After the splints have been removed and the wounds have healed massage may be gently re-introduced, always observing baby's cues and never working beyond the point of resistance. Consent from the physiotherapist who will be working closely with the family at this time, should be sought before re-commencing massage. It should be noted that if baby has had a lot of manipulations and surgery, they may be very touch defensive on the foot, so it may take time and patience before the parents can massage the feet.

Support Group

<https://www.stepsworldwide.org/conditions/talipes-clubfoot/>

Tracheo-Oesophageal Atresia and/or Fistula (TOF)

Definition

This is a rare condition where the top part of the oesophagus doesn't join onto the bottom half of the oesophagus. The top part ends with a pouch so food and oral secretions cannot reach the stomach, often associated with this, the bottom half of the oesophagus connects to the trachea with a fistula (Tracheo-oesophageal fistula –TOF). If this has occurred the air from the lungs enters the stomach and gastric juices can travel to the lungs, causing pneumonia. New non-invasive techniques are used to repair this soon after birth. The cause is unknown, but has been found to be more common in mothers who have too much amniotic fluid (polyhydramnios), and is associated with babies with problems with the heart, kidneys and spine.

Treatment

Until surgery can be given baby requires a suction tube (Replogle tube) to remove secretions, intravenous fluids are given. Surgery is given soon after birth to repair the oesophagus and join the two ends together. If the distance between the two ends is too great the repair will need to wait until baby is older and the oesophagus has had time to grow. In this case the top end of the oesophagus is brought to the surface, usually the side of the neck so secretions can drain away harmlessly and a gastrostomy tube is placed for feeding baby. Occasionally if the gap is very large then the oesophagus may need to be lengthened before the repair can be performed. Once baby is feeding and tolerating feeds then they can be discharged from hospital.

Possible longer term problems:

- Narrowing of the oesophagus, causing difficulty in swallowing (dysphagia)
- Gastro oesophageal reflux disease (GORD)
- Coughing and wheezing
- Recurrent chest infections
- Occasionally the trachea is floppy where the fistula was (tracheomalacia) causing difficulty breathing

Implication for Massage

Any scars must have healed before massage can take place, usually 6-8 weeks. Ask parents to contact their consultant especially if there are any other problems such as heart defects and scoliosis.

At all times massage will be baby-led.

Because of the possibility of gastric reflux baby should be massaged with head raised at approx. 45° angle (see paper on reflux)

- Legs: no problem
- Tummy strokes: no problem unless there is a gastrostomy (see separate paper)
- Chest and arms: all strokes but baby may be touch-defensive and parents may be touch averse
- Head and face: again no problem but baby may be touch-averse especially the face strokes.
- All back strokes may be given, unless if baby has scoliosis, ask parents to speak to baby's consultant, and/or physiotherapist for advice about massaging the back.

References

<http://www.nhs.uk/conditions/oesophageal-atresia>

<http://www.gosh.nhs.uk/medical-information/search-medical-conditions/oesophageal-atresia-tracheo-oesophageal-fistula>

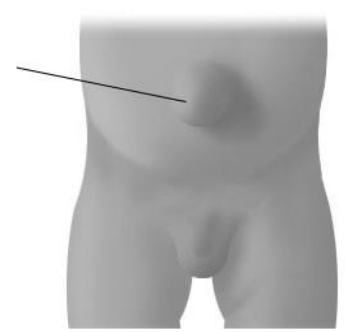
www.tofs.org.uk/

Umbilical Hernias

The condition

An umbilical hernia is a small, soft lump or protrusion and is usually found near the tummy button area. It develops in a weakness or gap in the muscle wall of an infant's abdomen. Around one in three babies are born with an umbilical hernia. It is more prevalent in premature babies and affects more girls than boys; and in about 10 per cent of these cases, the condition is hereditary.

Umbilical Hernia



During pregnancy, the foetus receives all its nourishment from its mother through the umbilical cord which is attached through an opening in a baby's abdominal muscles. After birth, this opening is normally covered by muscle. In the first few weeks of gestation, the gap is quite large, to enable the intestines to develop outside the body. By the end of the first trimester, the intestines have moved back inside the abdomen and the muscle wall closes up, allowing just enough space for the umbilical cord to extend through the opening. A hernia occurs when layers of tissue, fluid or, if the hole is big enough, even organs, such as the intestine, protrude through the gap, causing a soft lump preventing the gap from closing.

After the birth, the region around where the umbilical cord was attached is called the umbilicus. The protrusion is therefore known as an 'umbilical hernia' and appears as though the 'belly button' has popped 'outwards'.

Umbilical hernias do not usually present a problem and they usually heal without treatment. A parent should seek advice from their GP if they have any concerns and perhaps discuss whether any treatment is required.

Massage

There is no reason why a baby cannot receive a full massage. However, it is advisable to exercise caution when massaging directly over the protrusion as this may cause discomfort or exacerbate the condition. Abdominal strokes are generally fine; they help to move the waste in the colon and may even strengthen the stomach muscles.



In severe cases a baby may need surgery if the hernia becomes large or causes discomfort. As there will be pain, bruising and minor swelling in the lower abdomen for a week or two, guide parents to refrain from massage over the abdomen for a minimum of two weeks, until the sutures have dissolved or been removed and the bruising has subsided. Massage can then be introduced slowly. As with all infant massage the parents should be guided by their infant's cues.

Also, parents whose babies require surgery for a hernia may find it difficult to lay baby in the prone position, for the back massage, as this may exacerbate the condition. It might be advisable to suggest an alternative position for the back massage. The second image shows an excellent alternative position for a slightly older baby, where the parent sits with their back supported and knees bent. Baby can then lean on the thighs facing outwards for the massage. If the legs are slight parted then this will ensure that there is no pressure exerted on the hernia.

Ureteropelvic Junction Obstruction (UPJ) – Neonatal

Definition

Ureteropelvic junction (UPJ) obstruction is defined as an obstruction of the flow of urine from the renal pelvis (part of the Kidney) to the ureter (the tube connecting the kidney to the bladder), and usually occurs while baby is growing in utero. It is often associated with hydronephrosis (which means 'water inside the kidney').

Although a congenital disorder, adults may also present with UPJ obstruction following surgery or illness that causes inflammation of the upper urinary tract.

This blockage causes urine to build up and if left this can damage the kidney. During pregnancy an ultrasound may reveal kidney problems in the unborn baby, or postnatally by an abdominal mass, urinary tract infection or abdominal pain.

There may not be any symptoms, but when symptoms occur, they may include:

- Abdominal, back or side pain
- Haematuria (blood in the urine)
- Abdominal mass (lump in the abdomen)
- Urinary tract / kidney infection
- Failure to thrive
- Vomiting

Treatment

Some cases may improve spontaneously but surgery provides the greatest long-term success for severe cases of obstruction. Surgery involves removing the abnormal part of the ureter and reconnecting it to the kidney to permit normal urine flow. The procedure is called pyeloplasty either by incision or laparoscopy - this is less invasive and the recovery faster. Treatment options provide good long-term outcomes.

Massage

Massage is the same as for any baby/child following a surgical procedure. The parents need to ask their Consultant for advice to massage and if there are any areas to avoid or contraindications.

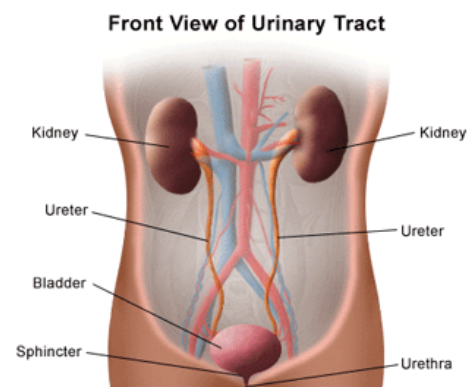
Baby may tire easily and may not be able to cope with a full session, so it is important to manage parental expectations.

- Keep the back massage to just over the ribs, observing baby for any negative cues.
- Avoid any pressure over the bladder (as we do normally)
- Omit the 'tummy hug'
- Before 8 weeks avoid the scar but after 8 weeks massage gently as this will help with any scar tissue. This will also help the parents to 'touch' the scar if they have been nervous about doing this.

References and Useful Resources

<http://www.nlm.nih.gov/medlineplus/ency/article/001267.htm>

<https://kidshealth.org/AllegroPediatrics/en/parents/az-up-junction.html?WT.ac=ctg>



Visual Impairment (Blindness)

Tactile experiences are of great importance for the visually impaired baby as they help them define the world. Baby Massage can offer them a positive tactile experience.

Massage

- Talking gently and singing to the baby during the massage sessions is important
- Describing the area of the body that is being massaged can promote body awareness
- Holding and cuddling frequently gives reassurance and makes the baby feel secure
- Parents can help their baby feel contained by putting a towel rolled up like a sausage around them, giving an added sense of security, during the massage
- Reduce the noises in the immediate area to a minimum
 - So that the baby is more likely to stay focused on the parent and will not be distracted
 - So that the baby feels secure
- If baby has tunnel vision, then parents should massage directly in front of them and if the baby has peripheral vision then parent should be seated to the side to make eye contact with baby.

Helpful organisations:

www.rnib.org.uk

Bibliography and Further Reading

Research Massage for Neonates

Research on touch through massage has shown benefits for infant development, stress reduction, state organisation, weight gain, and earlier discharge from hospital. Care that respects developmental limitations and is responsive to the infant's behavioural cues is likely to be more effective.

Infant massage has been the subject of numerous controlled trials showing positive results (Field, 2000). Mathai et al (2001) supporting the theory that massage has beneficial effects on growth and behavioural development. There were no adverse effects of touch or massage reported in the Cochrane review (Vickers et al 2001).

Recent research has shown that as well as increasing weight gain in neonates there were positive results showing increased vagal activity and gastric motility. It was interesting to note that the same massage strokes were used in both groups, but the control group received light pressure massage and the massage group received moderate pressure massage. This suggests the involvement of the pressure receptors in the skin, which activates the vagus, and ultimately releasing food absorption hormones (Diego et al 2005).

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Other Useful Organisations

Team Around the Child - <http://www.tacinterconnections.com/index.php>

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Touch-Learn International Ltd www.touchlearn.co.uk

Touch Research Institute – <http://pediatrics.med.miami.edu/touch-research>

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