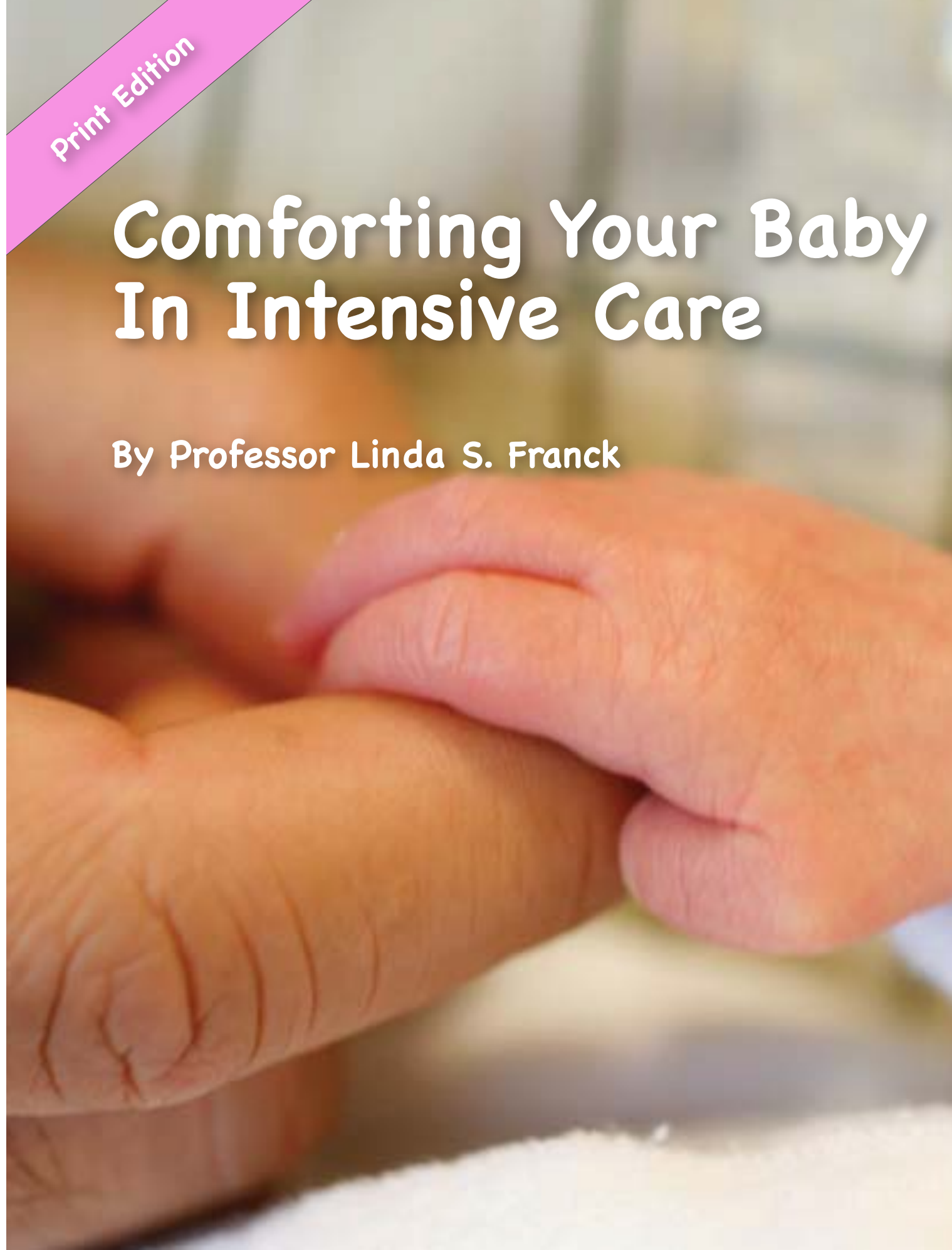


Print Edition

Comforting Your Baby In Intensive Care

By Professor Linda S. Franck





Comforting Your Baby In Intensive Care (Print Edition)

by Professor Linda S. Franck

How to use this book

Welcome to the second edition of *Comforting Your Baby in the Intensive Care*. This multimedia edition provides readers a more interactive experience with the choice of making notes as they read, listening to the content and viewing videos.

This edition of *Comforting Your Baby in Intensive Care* may be useful in any type of intensive care setting such as the cardiac intensive care unit (CICU) and the pediatric intensive care unit (PICU).

If you want to view the booklet on a computer or iPad, please visit:

<http://familynursing.ucsf.edu/resources-parents>

Here is a quick guide in helping you get the most out of this book:

*** Video clips:**

This book contains links to video clips that demonstrate some techniques that you may decide to use when interacting with your baby. There are captions throughout this book (typically underneath or next to a photo) with web links that contain important and helpful information.

To access the videos, simply type the web address (colored in blue) into any web browser. This will take you straight to the desired video. Press the play button when you are ready to watch the video.

Below is an example of how links to video clips are laid out within this booklet:



To learn how to reduce stress noises, visit:

www.vimeo.com/81631747

Introduction

Being a parent of a baby in the neonatal intensive care unit (NICU)/intensive care nursery (ICN) can be an emotional and stressful experience. We know it is very important to you that the treatments your baby receives are as painless as possible.

The clinical team caring for your baby is constantly trying to make treatment for all babies less painful. Our goal is for you to be completely satisfied with how pain was treated during your baby's stay in the NICU.

This booklet has been written to help you learn about pain so that you and the team caring for your baby can work together to **help your baby be as comfortable as possible.**



"I am the baby's parent - I act as an advocate and provider, I play the role of making sure he is comfortable - I respect the role played by nurses and doctors."

After reading this booklet we hope you will know more about:

- * How babies feel pain and how it affects them
- * How to tell if your baby is in pain
- * How to help make a more comfortable environment for your baby
- * Things that you can do to comfort your baby

Key points to remember while your baby is in the NICU:

- * Your baby will undergo procedures and will require treatment that may cause pain. Some of these treatments are: taking blood, giving fluids or medication through a tube in a vein, being connected to a breathing machine, or surgery.
- * The nurses and doctors will do everything they can to prevent pain, look for signs of pain, and relieve pain. They will show you how to tell when your baby has pain or is upset. They will also support you to be as involved as much as you would like in working with them to make your baby comfortable.
- * Please let the nurses or doctors know if you think that your baby is in pain or if you think the pain relief given to your baby is not helping.
- * You can help your baby by learning how to tell when she/he is in pain. Over time, you can become an expert in knowing how your baby shows pain. You can learn different methods of pain relief that best help your baby.
- * Learning the methods shown in this booklet and being involved in comforting your baby may help you as well as your baby.

Chapter 1 – How can pain be prevented and relieved?



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This section will give you information about how your baby can be made more comfortable and how their pain can be relieved. There are five main ways that pain can be prevented or relieved for babies in the NICU.

Nurses, doctors, therapists and parents can all work together to give babies calm surroundings, comforting touch and oral comfort.

- * By creating a calm surrounding to lessen stresses that affect the way babies respond to or cope with pain.
- * By giving comforting touch and handling babies in a way that gives comfort during painful procedures.
- * By comforting sights and sounds, such as your face and voice.
- * By providing oral comfort – sucking, things that taste good.
- * By giving pain medicines.

Section 1: The special role of parents

It is important for you to know that, if you want to, you can be with your baby during most procedures. There may be reasons why it is sometimes not possible, but you should always feel comfortable to discuss your wishes with your baby's nurses and doctors. If you are unable or feel it is best not to be with your baby during a painful procedure, your baby's care team will do everything possible to prevent or relieve your baby's pain.

Seeing your baby in pain can be stressful for you. It can help you to remain calm if you remind yourself that these procedures are necessary for your baby's well-being and that you are doing everything you can to help her/him.



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If you choose to be with your baby during procedures, keep calm by breathing slowly and deeply and relaxing your jaw and posture. You can usually help your baby by talking to your baby in a soothing voice, or providing gentle but firm touch. Your baby's nurses will advise you on your best way to help your baby during painful procedures.

As babies grow and are comforted when they have pain, they can learn to comfort themselves. For example, you can help your baby to learn how to find his/her fist to suck, and then as your baby grows stronger, she/he can comfort themselves by bringing their fist to their mouth and sucking, called 'self-soothing'. As you get to know each other better, you will learn ways to help your baby feel better when in pain.

Things to remember when you are helping to relieve your baby's pain:

- * Be flexible in applying the methods. What might work one day may not work the next.
- * If you try something and it doesn't work the first time, don't give up and give it another try or get advice about trying a different method.
- * It is always important to try only one method at a time in relieving your baby's pain or discomfort and see how your baby likes it. If your baby doesn't like it then try something else.
- * It is important to look at your baby's face, position, and movements to see if they like the method you are using.
- * The more you use these methods the better you will be at doing them and the more your baby will get use to them and like them.

Section 2: Create calm surroundings

Bright lights and loud noises can be upsetting to babies and affect the way they respond to or cope with pain. There are a number of things that you can do to help make your baby's surroundings as calm as possible.

Reduce stressful lighting

- * Ask about dimming the lights or shielding your baby's eyes during periods of quiet rest or sleep. For example, putting a blanket over the top of the incubator or crib may limit some exposure to light.
- * Bright lights (sunlight, overhead lights, phototherapy) may be needed for some procedures; if it hasn't already been done, ask your baby's nurse about shielding his/her eyes from direct light.
- * When you are holding your baby outside the incubator or crib, you may need to use your hand to shield her/his eyes.

To learn how to reduce stress lighting,

visit: www.vimeo.com/81631746



Reproduced with permission from Bliss UK

Reduce stressful noises

- * When you close the door to the incubator, do it quietly rather than snapping it shut.
- * Avoid putting hard objects on top of the incubator, and ask other people not to put things on it or use it as a writing table.
- * Talk quietly around the incubator or crib; move away for conversations, do not be afraid to ask the care team to talk more quietly around your baby – it can be difficult for nurses and doctors to keep their voices low all the time although they know how important it is, and they will not be offended if you let them know your concern.
- * If your baby is on a breathing machine, water in the tubing can sound much louder in the incubator; if you notice this water, please tell your baby's nurse or therapist.



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*If there is a noise that seems to upset your baby, such as a telephone ringing, then you can discuss with your baby's nurses ways of either lessening the noise or moving your baby to a quieter area.



To learn how to reduce stress lighting,
visit: www.vimeo.com/81631747

Reducing stressful touch

- * Some babies, particularly preterm babies, react in a stressful way to light feathery touch and light stroking, so avoid using this type of touch. Ask your baby's nurses or therapists for suggestions on the best ways to comfort your baby with touch.



To learn how to reduce
stress lighting, visit:
www.vimeo.com/81631748

- * Sometimes babies do not like to have their belly or chest touched so watch how your baby reacts to touch and stop if she/he becomes more upset.

Providing comforting sights and sounds

- * Talk to your baby in a soothing voice. Say what is happening and how you are helping them. Your baby will not understand the words, but will be comforted and distracted by your voice. Humming or singing softly may also be calming for your baby.
- * There may be an added effect of distracting your baby during blood taking procedures by getting your baby to look at you, talking in a soothing voice, and giving comforting touch (see next section) all at the same time.

You need to check that your baby does not find all this activity too stressful by first trying each type of action (touch, sight, voice) one at a time.

- * Some parents worry that babies will link a parent's presence to the pain. By providing these comforting methods, your baby will associate your present with comfort and relief from pain, not with the pain itself.

To learn how to provide comforting sights and sounds, visit: www.vimeo.com/81631603

Section 3: Comforting touch

Your baby's nurses will help you learn ways of handling your baby until you feel confident to do them yourself. Always check with your baby's nurse before doing these things if your baby is very ill. Always wash your hands first to prevent infection. Be sure you warm your hands before touching your baby. This can be done by using warm water when you wash, by placing your hands in the incubator for a few minutes, or by rubbing them together to increase circulation. Comforting touch can be given by constant contact or active touch.



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Section 4: Constant contact

Swaddling

Swaddling your baby using a blanket provides support for the baby and stops him/her moving around too much. Swaddling will also help to relieve pain through gentle stimulation of the nervous system through the skin. Check to see that this is helping your baby feel secure. If not, check to see if the swaddling is too tight or too loose. When swaddling, gently bring your baby's hands together below their chin.

It is important to leave the hips free to move and not tightly strapped with the legs straight out and together. Let the baby hold his or her hips bent up like they were when the baby was born and allow room for the legs to move freely.

An example of when you can use swaddling to relieve your baby's pain is when she/he is having blood taken, leaving one foot out for the procedure while the rest of the baby's body is comfortably swaddled.



To watch a demonstration of how to swaddle your baby, visit: www.vimeo.com/81631975

Nesting

Nesting is a way to give your baby physical boundaries so your baby feels supported. Nesting also helps to stop your baby moving around too much and using too much energy. Care must be taken so that your baby isn't nested so tightly that their movement is restricted too much. Nesting can be done when your baby is on their back, side or tummy. Special positioning aids can be used and your baby's nurses will show you how this is done. Nesting should only be done in the NICU where your baby is under constant observation. It should never be used at home.

An example of when nesting can be used for your baby is during a painful procedure such as when a cannula (IV line) is placed in a vein in their hand or foot.

To watch a demonstration of nesting, visit:

www.vimeo.com/81631372

Baby nested on her side



Reproduced with permission from Children's Medical Ventures

Baby nested on his back



Reproduced with permission from Children's Medical Ventures

Containment holding

Containment holding is done by cradling your baby's head with one hand, then placing your other hand on their back or bottom. Keep your hands in place for as long as is comfortable for you and your baby, then gently take your hands away. Another way to do this is by holding their arms and legs so that they are gently tucked in close to the body.

Your baby might find containment holding soothing is after a painful procedure.

To watch a demonstration of containment holding, visit:

www.vimeo.com/81631111

Containment holding - head, arms, neck



Reproduced with permission from Dr. Anna Axelin

Containment holding - body, arms, legs



Reproduced with permission from Dr. Anna Axelin

Section 5: Active touch



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Skin-to-skin holding (kangaroo care)

This type of holding is done with your baby skin-to-skin, on your chest, under your clothing. Skin-to-skin holding has been shown quickly to calm babies after painful procedures. It is also a very good way to prevent babies from getting upset during blood taking procedures.

To watch a demonstration of skin-to-skin holding, visit: www.vimeo.com/81631752

Rocking

When your baby is well enough to be out of the incubator, rocking can be soothing. Your baby should be swaddled (see previous page) or held skin-to-skin with their head well supported. Rocking may be most useful after a painful procedure to calm your baby. Rocking can be done in two ways to provide different types of comfort:

- * If your baby is distressed and crying, faster rocking (and patting) is more intense and may get their attention quicker but if you find your baby gets more upset, slow down or stop.
- * Slower, large, smooth movements may, on the other hand, create a steady soothing and often helps get babies to sleep. In time, you and your baby will find your own special rhythm.

To watch a demonstration of rocking, visit: www.vimeo.com/81631751

Massage

Massage is sometimes used to help the general development and growth of babies. Some nurses, doctors and therapists believe that massaging the area before a painful procedure might prevent or reduce pain. There is not much research about this but you can talk to your baby's nurses to see if they think this might be of help to your baby. You will need to carefully watch your baby's responses to massage because it may cause more stress, especially if your baby is very preterm or ill and is very sensitive to touch.



[Click here](#) to watch a demonstration of how to massage your baby

Section 6: Oral comfort

Sucking

Babies can learn to calm themselves by sucking either on a finger, hand or pacifier. You may hear this called 'non-nutritive sucking' and it is a very effective way that babies cope with pain or stress. You can help your baby develop this coping skill by helping them get their hand to their mouth or by offering them a pacifier (as soon your baby's nurses say it okay to do so). Offering your baby a pacifier before, during, and after painful procedures is a very good way to help prevent or reduce their pain. Offering your baby a pacifier only when they have a painful procedure will not interfere with breastfeeding.

To watch how babies learn to calm themselves by sucking, visit: www.vimeo.com/81631976
Things you can do to help your baby to learn to suck a pacifier are:

- * Gently stroking the side of your baby's mouth until it opens; Don't push the pacifier in if the mouth is not open.
- * Holding your baby's hands so they are tucked under the chin or face.

Breast milk and breast feeding

A small drop of breast milk on the tongue can help babies calm quickly after procedures, but because it is not as sweet as sugar water, the effect is often not as strong. If your baby is able to breast feed, this can be very effective because it gives your baby comforting touch, smell and sounds as well as taste.

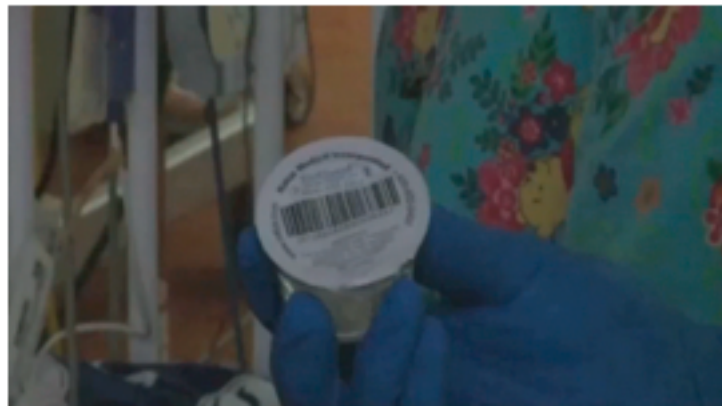


Reproduced with permission from Bliss UK

To watch how to comfort your baby by breast feeding, visit: www.vimeo.com/81631110

Sweet tastes

Giving babies a small amount of sugar water (sucrose) on the tip of the tongue or inside the cheek about two minutes before a painful procedure such as blood taking helps them to calm quickly. Ask your baby's nurse if this could help your baby. Giving your baby a pacifier to suck at the same time may work even better.



[Click here](#) to watch how to comfort your baby with sweet tastes

Chapter 2: How to tell when babies have pain

This section will give you information about how you can be involved in helping your baby be more comfortable and how to tell if your baby has pain.



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Section 1: How to tell if your baby is in pain

When we have pain, each of us responds and communicates in our own way. Your baby does this too. There is no single behavior or sign of pain common to all babies. As a parent, you will get to know your baby better than anyone. Over time, you will become the person best able to tell when your baby is in pain. Listed below are some of the signs of pain that you might see in a healthy newborn baby. If your baby is very ill or born early he/she may not show some of these signs and instead might keep very still, limp or rigid.

It is important to remember that babies may show some of the same behaviors when they are upset, but there is no reason to think they have pain. If you are unsure whether your baby is in pain, you should ask yourself this question: Would this hurt me? If the answer is yes, then it is likely that it would hurt your baby too.



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Section 2: Signs of pain

Crying



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Crying is the main way that babies let us know that they need our attention. You will learn to tell a cry from hunger or wet diaper from a pain cry. Crying in response to a sudden pain may have a high pitch and come in short loud bursts. But if pain lasts a long time, the cries may become weaker or less frequent. If a baby is

on a breathing machine (ventilator), it may not be possible to hear them cry because the breathing tube (endotracheal tube) stops the baby from making any sound, but it is still possible to tell if they are crying by changes in their facial expression. An ill or preterm baby may have a weak cry.

To watch crying as a sign of pain, visit:

www.vimeo.com/81631112

Facial Expression

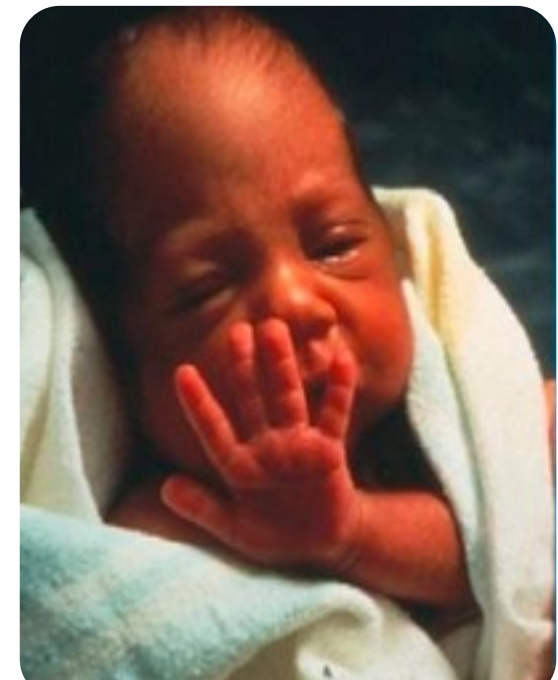
You can usually see when a baby is in pain by looking at their face. Babies in pain often make a 'pain face'. They squeeze their eyes together, have a bulging brow and deep creases between their nose and the corners of the mouth. Their mouth is often open wide and square-shaped and the tongue is cupped.

To watch how facial expression can be a sign of pain,

visit: www.vimeo.com/81631113

Movement

Babies usually react to painful procedures with increased activity of their arms and legs, wiggling their body, clenching their fists, or spreading and stiffening of the fingers (splaying). If pain is severe, your baby may also have jerky movements or become stiff, or go limp.



Reproduced with permission Children's Medical Ventures

To watch how movement can be a sign of

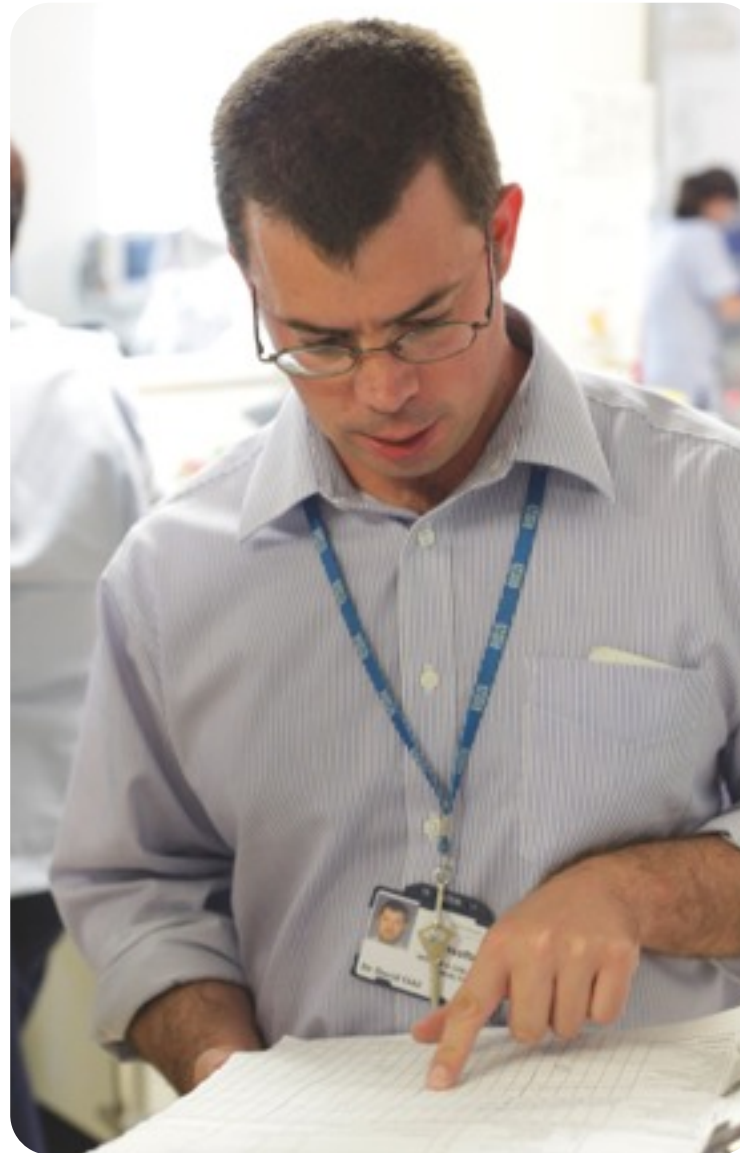
pain, visit: www.vimeo.com/81631370

Altered Sleep and Feeding Patterns

When babies are in pain they may have restless sleep and wake up more often, or they may sleep more of the time and are drowsy when awake. They might also be too tired or upset to feed or want constant suckling without seeming to be satisfied.

Pain Rating Scales

The nurses, doctors and therapists are trained to look for signs of pain in ill babies. They may use pain rating scales to help measure pain in babies. The pain rating scales are based on the signs listed above and other physical signs, such as heart rate, breathing, blood pressure, and oxygen levels.



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It is important to remember that all of these signs occur naturally at times when babies are not in pain. It is the amount, timing and pattern of the signs that tell us whether babies are having pain. Each baby is different and finding out if a baby has pain can take some good detective work.

Chapter 3: What is pain and how can it affect babies?

This section will give you information about what pain is, and why we must try to relieve it in babies. The next section gives you information about how to make babies more comfortable and how you can help your baby by becoming more involved.

After reading the booklet you may have more questions. Your baby's nurses and doctors can help you find answers to your questions, so please ask them.



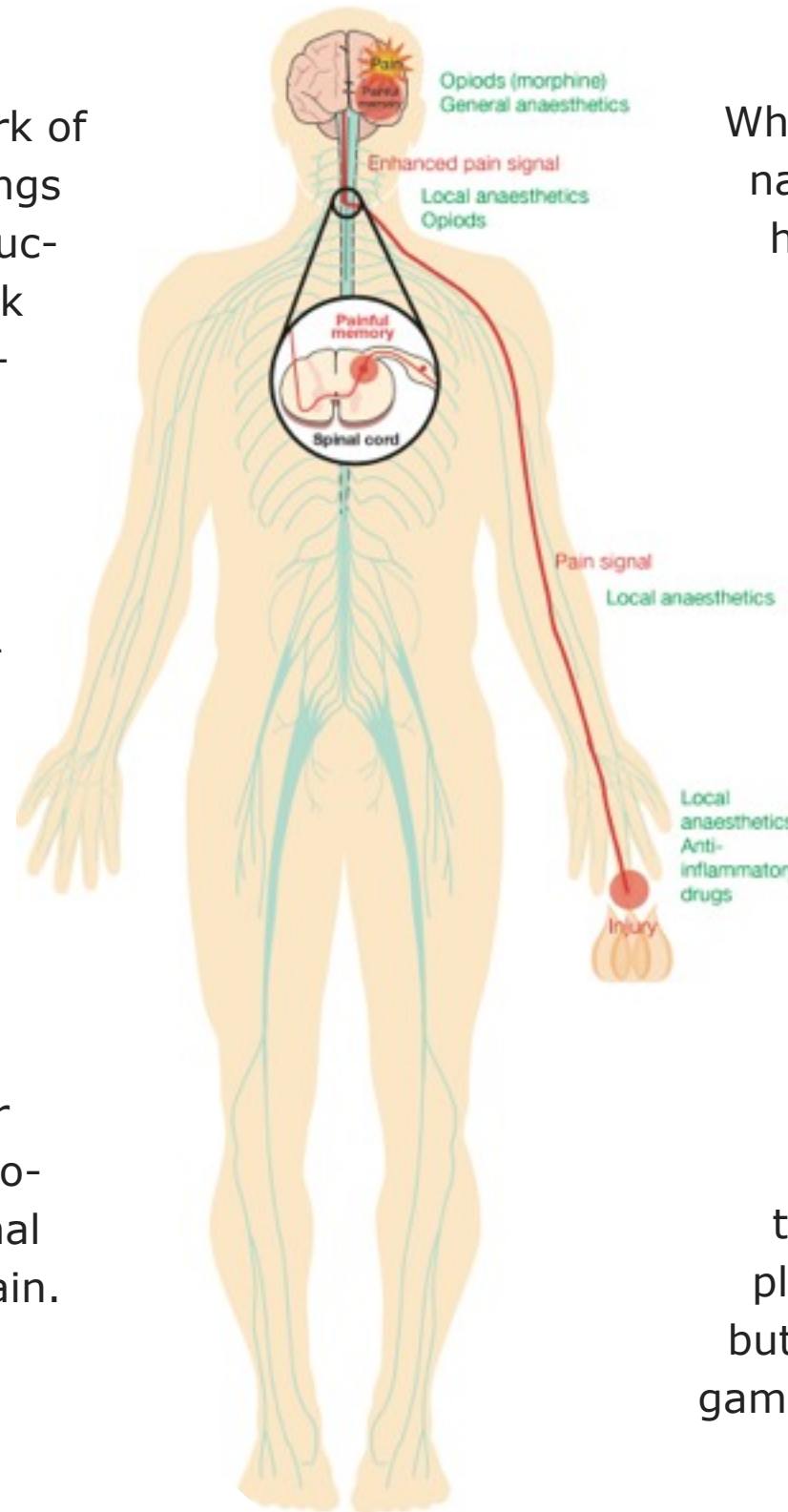
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Section 1: What is pain?

The nervous system is a network of nerves that allows you to do many things – to store information, send out instructions to your body, to breathe, to think and to have feelings and sensations – including pain.


Pain is usually caused by injury or other damage to the body and is the body's way of warning us that something is wrong. The degree of pain can be mild, often called discomfort, or it can be very intense.

Research has helped us to understand how pain works. For example, when we touch something hot, chemicals from the damaged skin on our finger trigger special nerve cells called 'nociceptors' to send messages to the spinal cord and on to the brain.



When the pain message reaches the spinal cord, we automatically move our hand away. This reflex response is our body's way of protecting us from greater injury. It is only when the pain message reaches the brain that we feel the pain and say 'ouch'.

Not all pain messages get through to the brain. Sometimes, nerves carrying non-painful messages, such as touch block pain messages in the spinal cord. That is why it sometimes relieves pain to rub near or on the sore area. Special chemicals released from the brain, called 'endorphins', block painful messages and allow you to ignore the pain for a short time. For example, being injured in a game of sport, but only feeling the pain when the game is over.



At other times, chemicals in the brain and spinal cord strengthen pain messages and then we feel worse pain. Feelings such as anxiety or fear can trigger the chemicals that make the pain worse. The way pain messages are strengthened or blocked by the brain depends on many things: how bad the injury is, our previous experience with pain, what we are thinking about and our feelings.

Section 2: New facts about pain in babies

Much has been learned in the last 20 years about how babies feel pain. Before then, it was often thought that babies did not feel pain, or felt less pain than older children or adults. We now know that babies do in fact feel pain, even if they are born early. Here are some of the facts, as we now know them:



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- * The nervous system develops early in pregnancy. Babies born as much as 3 months early will be able to feel pain.
- * Babies can feel as much pain as adults, perhaps even more. Babies' nerve endings are closer to the surface of their skin, making them more sensitive to touch.
- * Because the nervous system is still developing, babies are unable to block pain messages in the same way that adults can, making babies more sensitive to pain.
- * No one (baby or adult) becomes 'used to' pain. Repeated pain can be very stressful to babies.
- * Babies respond well to a range of pain treatments, which can help in their recovery.

Section 3: Why we must try to relieve pain in babies

We are only beginning to learn about how pain in early life may affect a child's later development and there is much that we do not yet understand. Babies' nervous systems continue developing during the time they are being cared for in the NICU. We don't yet know if this gives them some protection or if it makes them more likely to have problems later. Here are some of the findings from research in this area:

Short-term effects

The body's normal "stress response" to a painful injury usually causes a rapid heart rate and breathing, increased blood pressure and blood flow to the muscles, and decreased blood flow to the bowel (intestines). These responses can be harmful to an ill baby who may have difficulty coping with the added stress of pain.



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Babies who are in a lot of pain may need more intensive medical care such as help with breathing or controlling their blood pressure. With good pain prevention and treatment, babies can use all of their energy toward healing and growing.

Long-term effects

Some research studies carried out on animals and humans found that untreated pain in early life caused the animals to feel pain or respond to stress differently when fully grown. However, more research is needed. Because of the possibility that pain or stress responses in later life

might be affected by early pain experience, every effort will be made to tell if your baby has pain and to treat it quickly.

Section 4: Whose job is it to make babies comfortable?

Whose job is it to make babies comfortable and help relieve their pain?

The answer is that it is everyone's job. Nurses, doctors, therapists and parents all have important roles in comforting babies, including: preventing pain, finding out when babies have pain, and relieving pain.



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How nurses, doctors and therapists help:

*** Preventing pain from starting**

This means only doing procedures that are needed for your baby to get well, preparing your baby by making them as comfortable as possible before procedures or by giving them medicine to block pain.

*** Monitoring for signs of pain**

This means regularly looking for your baby's signs of pain. They may use pain rating scales to help them tell how much pain your baby has.

*** Relieving pain**

This means keeping your baby's surroundings as calm as possible, giving your baby comforting touch and if needed pain medicine.

* Teaching parents about pain and how to relieve it

This means helping you learn how to tell when your baby is in pain and how best to comfort your baby.

* Supporting parents

This means listening to any worries you may have about your baby's pain, taking your concerns seriously and helping you to cope with the stress of having an ill

Parents:

You have a very important role in your baby's comfort because, over time, you will become more expert than anyone else in knowing about your baby's behavior. It will be helpful if you become involved in comforting your baby as soon as you are able. You can do this by getting to know your baby's signs of pain and by becoming involved in decisions about how your baby's pain is relieved.

You should also feel free to ask questions and to offer your opinions or ideas, even if you are not asked.

This is a new thing for many parents, and for all first time parents.

With time you will become more comfortable talking with nurses, doctors and therapists about your baby's care. You may be particularly worried about how you can help when your baby has a procedure. Our research has found that some parents want to be with their baby when they have painful procedures, and that some prefer not to be present but would like to help comfort their baby afterward.

Let your baby's nurses and doctors know how you feel. Be sure to also let them know when your feelings change and you wish to be more (or less) involved.



To learn how parents play key roles in their baby's comfort, visit:

<http://vimeo.com/81631604>

Chapter 4: What if I feel that not enough is being done to relieve my baby's pain?



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As a parent of a newborn baby, you probably expected you would learn how to tell when your baby was in pain, but you probably didn't think you would have to learn so quickly or that the kind of care your baby would need might cause pain. This can be very stressful for parents; you may even feel that you are letting your baby down somehow – even though you know the procedures are only being done to

baby. Please don't keep these feelings to yourself. Share your worries, fears, and questions with your baby's nurses and doctors. They can help you cope with these feelings and find ways to help you to help your baby and to feel like the parent you want to be.

Parents are advocates (someone who speaks on behalf of another) for their children. Parents have the right and the responsibility to make sure their baby's pain is noticed and relieved. This may mean that you sometimes have to speak up on behalf of your baby. Your baby's nurses, doctors and therapists would like you to discuss your ideas and suggestions about pain relief with them. In particular, if you see that something is not working, make sure that you let someone know. A good person to talk to first is one of your baby's nurses, since they are the members of the care team that spend the most time with your baby. If you feel that your concerns have not been listened to or acted on, you should talk with a Charge Nurse, your baby's doctor, Nurse Practitioner or Social Worker. If you still have concerns, you should speak with someone from the hospital



administration or patient relations department.

Here are a few general tips on how to make sure that you get the information you need about your baby's care:

- * Write down the questions you want to ask as soon as you think of them, as it is sometimes difficult to remember everything without a list.
- * If you don't understand an answer, ask your question again. Someone else on the care team may be able to explain it in a different way.
- * If you don't think you can handle any more information, take a break. You may be able to cope or understand better in a day or two.

Don't worry about asking for information to be repeated many times. Your baby's care team know you are given a lot of information and do not expect you to remember it all. They need you to tell them whenever you want to hear things again or when you want more information.

Section 1: Medicines used to relieve pain

The nurses and doctors will sometimes use medicines to relieve pain in babies. These can be given by mouth (or feeding tube), as a suppository (in the bottom) or intravenously (through a vein). All medicines have disadvantages as well as benefits. Different NICUs prefer different medicines. Some of the commonly used medicines are listed below. Your baby's nurses and doctors will tell you about the pain medicines they might use if your baby has pain. Although your baby may be getting pain medicines, they still need a calm surrounding and your comforting touch.



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Opioids (morphine and fentanyl)

Morphine and fentanyl are the most commonly used pain relieving medicines in the NICU. They work by reducing the pain messages sent to the brain and changing the way the brain reacts to these messages. They work like the body's own pain relieving chemicals, the endorphins. They can be used for severe pain, to prevent pain during procedures and to relieve pain after surgery, usually given through an intravenous drip into a vein. Both medicines can help to settle your baby if she/he is on a breathing machine. Each of the medicines works slightly differently and each person responds differently to them. Depending on the situation, and how your baby reacts, the health care team will decide which opioid is best for your baby at that time.

Morphine and fentanyl are very good at relieving severe pain, but they do have side effects such as lowering blood pressure and breathing rate, sleepiness or constipation. If your baby develops any of these, then the medicine may be changed. If your baby has a

severe reaction, then another medicine can be given to quickly reverse the effects.

Some people worry that giving babies medicines like morphine may cause them problems in later life. Very little is known about this, and it is possible that the risks of not treating the pain are worse than the risks from giving pain relieving medicines. Your baby's nurses and doctors will give your baby no more than is necessary of the strong pain medicines to relieve their pain.

We do know that when anyone is given morphine or fentanyl regularly for a long period (greater than a week), their body gets used to the medicine and they may develop physical withdrawal symptoms if the medicine were to be reduced too quickly or stopped suddenly. To prevent this, the health care team will reduce the dose of these medicines slowly and monitor your baby's reactions. This side effect of withdrawal is different from 'addiction', which is an emotional craving for drugs that babies do not get.

Acetaminophen (paracetamol)

Acetaminophen is good for relieving mild to moderate dull and achy pain. It is most commonly given by mouth (feeding tube) or in a suppository (in the bottom).

Anti-inflammatories

Ibuprofen or indomethacin may be given to some babies to help close a patent ductus arteriosus. These medicines also reduce pain due to inflammation but they can cause more side effects than other pain killers.

Local anaesthetics

Local anaesthetics numb the skin. They can be given as a cream for a small area or by needle to numb a larger area of the body (epidural or nerve block).



Other medicines

Sedatives (midazolam, lorazepam) may also be given to help babies sleep, stay calm, or be still for procedures. These medicines do not provide pain relief and your baby's nurses and doctors may give pain relieving medicines as well.

Muscle relaxants (pancuronium, vecuronium) may be given to help your baby when on the ventilator (breathing machine). These medicines do not provide pain relief and your baby's nurses and doctors may give pain relieving medicines as well.

Acknowledgements

The content of this booklet was developed as part of research projects supported in part by funding from **Bliss**, the special care baby charity, London, UK; The **March of Dimes**, USA, and the **UCSF School of Nursing** and **UCSF Benioff Children's Hospital**.

Many dedicated neonatal intensive care professionals from around the world generously provided their expert advice on the many drafts of this booklet, as did many caring parents whose babies were cared for in NICUs in the UK and US.

We are grateful to Sandra Weiss, RN, PhD and Emily Roberts, RN PhD(c), UCSF School of Nursing, for their assistance with the video script and voiceover narration, as well as to Dr. Joan Smith and the Empower™ Program team at St. Louis Children's Hospital Newborn Intensive Care Unit for the video footage.

The electronic booklet was designed and produced by Fion Ng and Kathy Keihl in consultation with Dylan Romero.

Thank you all.

Bliss

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

Bliss is the UK charity working to provide the best possible care and support for all premature and sick babies and their families.

March of Dimes

www.marchofdimes.com/baby/inthenicu_program.html

The March of Dimes has developed NICU Family support to provide information and comfort to those families in crisis.

The potential of this booklet to help parents and their baby's health care team to provide better pain care was evaluated and reported in the following research articles:

Franck LS, Oulton K, Bruce E. Parental involvement in neonatal pain management: An empirical and conceptual update. *J Nurs Scholar* 2012 Mar;44(1):45-54. doi: 10.1111/j.1547-5069.2011.01434.x

Murdoch M, Franck LS. Gaining confidence and perspective: A phenomenological study of mothers' lived experiences caring for infants at home after neonatal unit discharge. *J Adv Nurs* 2012 68(9):2008-2020. doi: 10.1111/j.1365-2648.2011.05891.x

Franck, LS, Oulton, K, Nderitu, S, Lim, M, Fang, S, Kaiser, A. Parent involvement in pain management for NICU infants: A randomized controlled trial. *Pediatrics*. 2011 Sep;128(3):510-8. doi: 10.1542/peds

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About the author



Linda S. Franck

My first job after earning a bachelor degree in nursing in 1980 was in a intensive care unit where I cared for ill and preterm babies. At the time, it was uncommon for these babies to receive any pain-relieving medicines, even for major surgery. This was because the prevailing medical view was that these young babies did not feel or remember

pain and doctors feared the side effects of the medicines. Watching, day-in and day-out, what appeared to be clear signs of pain and not knowing how to help, was a very distressing part of the job and prompted me to pursue advanced degrees to study the new field of pain management. In the mid-1980's I published one of the first ever studies to measure infant pain responses to heel puncture. Since that time, I have continued to study how to measure, monitor and treat pain in infants and children in hospital settings and at home.

For the past decade, a main focus of my work has been on understanding the very important role that parents have in comforting their babies and how nurses and other health care providers can better support and engage parents so that babies consistently receive the best care available to prevent or relieve pain. This booklet is the result of those years of study and of my experience working with many babies, and their families and health care teams in neonatal intensive care units in the United States and United Kingdom.

If you would like to make a gift to support our research and improve the health of babies and families, please contact: Lynette Teti, Director of Development: LTeti@support.ucsf.edu

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