

TAKE A DEEP

A NICU Soldiers Free Resource, August 2021

BREATH

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A CONCISE GUIDE FOR PARENTS
IN THE NEONATAL INTENSIVE CARE UNIT

By EfiA Akese

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Introduction

HI, my name is Efiya Akese, a mother of two — a boy born in 2017 and a girl born in 2020. Depending on where we meet, you may also know me as “Evelyn” (My official English name).

Interestingly, both of my children were admitted to the Neonatal Intensive Care Unit (NICU) after delivery for different reasons. While the boy was a full-term baby, the girl was a preterm born at 35 weeks.

Having a child at NICU is a difficult experience for every parent, irrespective of the child’s diagnosis or how long he or she would be there.

A few months ago, I started a blog, nucusoldiers.com where I share my experiences from the NICU and that of other parents and caregivers.

Feedback from articles posted on the blog and its supporting social media pages has been amazing. There is the popular assertion that Ghanaians don’t like sharing their personal experiences but my few months working on the blog has proven otherwise.

Most people I have reached out to were more than willing to share and I currently have a backlog of stories which I’m yet to share.

Having been to the NICU twice, I believe there are some guidelines I can share with parents particularly those in Ghana and that led to the birth of this eBook — Take a deep breath.

This eBook is a simple guide on what to expect and how to navigate the NICU journey. Each person’s story is different but I believe this will make your stay easier.

Hopefully, parents or caregivers who currently have children at the NICU as well as those who may go there in future would find these tips useful.

Efiya Akese

The NICU shock

I am tempted to say welcome to the NICU, but on second thought I know this is not a place you want to be welcomed to.

I know this is not how you anticipated your pregnancy journey would end, but here you are standing in a room or cubicle full of babies with different health conditions and you are trying so hard to process what is going on around you.... please calm down and, take a deep breath.

As you may have read earlier, both of my children born three years apart went to the NICU for different reasons and with my second child, one may assume I wouldn't be shocked or scared by the happenings at the unit, but that's not true.

I think my anxiety level was higher compared to my first visit as I knew what exactly happened there and how scary some days were.

I was delivered of a healthy-looking baby girl through an emergency caesarean section but the consultant obstetrician thought it would be good to monitor her for a while because she was still



Picture Credit: PR Unit. Korle Bu Teaching Hospital

classified as a preterm — thank God he did!

My point is, no matter how tough you are, or the condition of your baby, the NICU is not easy and it may take some hours, days or even weeks to come to terms with what happens there.

Whether you are a parent or a caretaker of a baby whose parents are not readily available, a lot will run through your mind. How did I get here? Why me? Couldn't I just go home with the baby after delivery like most people? How long will we be here? Will my baby survive?

You are human and such

thoughts are bound to occur. My first advice; don't overstretch your mind, you will need the energy to run some errands and most importantly you have to be in a good mental condition to understand what is happening to your baby and the treatment plan by the health experts.

Your mental health affects your physical health so don't over think. I'm not sure you want to be sick when your baby is ready to go home.

Here are some tips to keep you going.

Always mask up and keep portable hand sanitizers

Keep an extra mask and a portable hand sanitizer. *PictureCredit: creativefabrica.com*



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LONG before covid-19, health experts at the NICU were extremely careful about parents and caregivers introducing infections to the unit. All the facilities I had seen before Covid-19 had hand wash stations where parents are expected to wash their hands with soap and water before entering the facility.

Some facilities even provide all the essentials baby will need during the period; diapers, wipes, cups for storing breast milk, clothes etc.

No worker at the NICU will allow you into the facility without properly washing your hands and wearing a face mask properly.

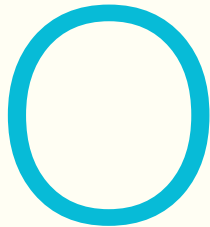
This is done with the intention of reducing the risk of infections from outside.

Today, Covid-19 is here and it has become extremely important to follow all the safety protocols. No worker at the NICU will allow you into the

facility without properly washing your hands and wearing a face mask properly.

Do well to keep extra masks, as well as a portable hand sanitiser, they will come in handy.

Speak To The health experts



ON your arrival, the health experts at the unit will give you the schedule for visiting babies

and please note that ONLY parents, that is mother and father of the child will be allowed to attend to baby.

In instances where the mother is still recovering and the father is not available, a family member will be allowed to see the baby.

Your first point of contact at the NICU, I believe will be the nurses. There are doctors at the unit but it's the nurses who are usually in charge and must be your first point of call when you get to the unit. In many facilities, it's the nurses that receive the babies after delivery, prepare their documents (folders) and take their vitals.

The nurses should be able to explain the condition of your child and what treatment plan they are using. If you have to run laboratory tests or get medications and other essentials needed during your stay, they would be the best people to get all the information from.

NICU health workers are some of the best health workers I have come across, but the unit can be on "fire" some days and it may look like no one is paying attention to you. Please don't get upset. There are moments where they are overwhelmed with emergencies but that shouldn't discourage you from asking for details.

Mind you, if you are waiting for a NICU doctor to be free, you may never talk to one as they are



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Of course, some of the health workers can be rude or make comments and faces that may upset you. If you encounter such person(s), express your displeasure to him or her or a superior around. Please don't throw tantrums or make a scene. I understand it can be frustrating when a health worker rubbishes your concern, especially when it is related to the health of a helpless baby.

always busy. They are usually reviewing conditions of babies, writing notes, prescriptions or request forms or discussing

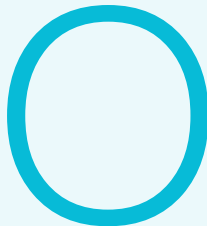
The nurses can give you all the information you need. *Picture Credit: hipaatrek.com*

some cases.

Fact is they are NEVER free. You can simply walk to one of them, introduce yourself, and ask for details or progress on your baby. Usually, they will schedule an appointment with you if they are attending to another issue at that moment and if they are available immediately, trust them to give you all the details.

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Duration in the NICU



ONE of the most asked questions in NICUs is “When are we going home?”. The answer is

simple, on your day of admission, it is difficult for health workers at the unit to predict how long you will spend at the NICU.

The number of days you spend at the facility depends on your baby’s condition and recovery. In 2017, I was shocked when a ‘little’ baby, weighing less than two kg was discharged after spending a few hours at the unit, while my full term ‘big baby’ still needed support to breathe.

After two weeks, when I was discharged, another mother who had

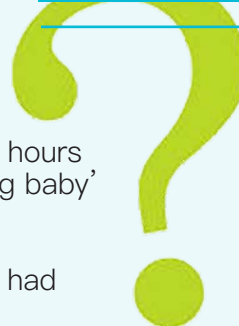


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been there for close to three months saw me carry my boy away and said she wished she was also going home.

My daughter was a preterm baby but she spent only four days at the unit while my son, a full term baby spent three weeks — you see why there is no need to compare your journey with another person’s?

Like I always say, each person’s case at the NICU is different and I’m certain that when baby is ready to go home, the doctors will gladly discharge him or her.



Picture Credit: istockphoto.com

eatwell

I'm sure if you just left the NICU after first seeing your baby, you will roll your eyes at this point but it is very important to eat well. If you are a mother and your baby hasn't started feeding for health reasons, please start eating well as you may soon be asked to express breastmilk or breastfeed your baby.

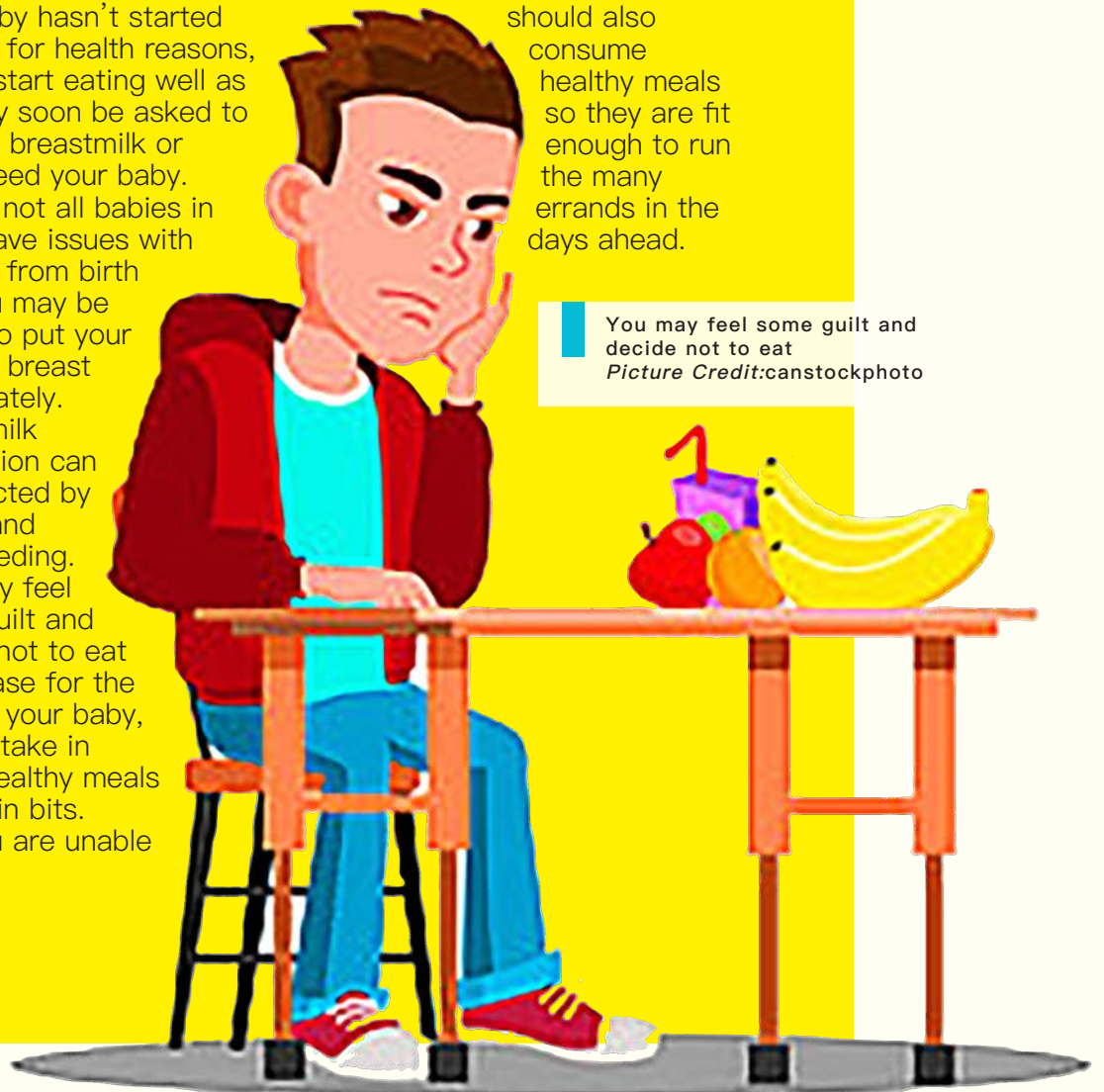
Also, not all babies in NICU have issues with feeding from birth and you may be asked to put your baby to breast immediately. Breastmilk production can be affected by stress and poor feeding. You may feel some guilt and decide not to eat but please for the sake of your baby, try and take in some healthy meals even if in bits.

If you are unable

to provide enough breastmilk for your baby, the health experts will start feeding the baby with infant formula.

Mothers who may not be able to breastfeed, fathers and caretakers should also consume healthy meals so they are fit enough to run the many errands in the days ahead.

You may feel some guilt and decide not to eat
Picture Credit:canstockphoto



Wear

comfortable clothes

THE NICU is stressful and I guess the last thing any parent wants is to be stressed by a choice of cloth. You will be required to be close to the facility throughout the day and an uncomfortable dress, shoe or pair of trousers may make your day worse.

Mothers who are recovering from caesarian sections should wear clothes that are comfortable. A caesarian section can leave your abdominal area feeling sore and sensitive, so it's best to wear clothes that are comfortable and loose. Your high waist maternity jeans or loose maternity dress can help you cruise through the day easily.

Also, be minded that you may be asked to breastfeed the baby so choose clothes that will make breastfeeding easier.

Fathers and caretakers must choose comfortable shoes as there may be a lot of running around.

Parents whose babies are very small and have low birth weight may be required to start Kangaroo Mother Care (KMC) when the baby is clinically stable before discharge. Kangaroo mother care is a method of care of preterm infants. The method involves infants being carried, usually by the mother, with skin-to-skin contact.



Mothers can still wear their maternity clothes for comfort.
Picture Credit:canstockphoto

Parents who are to do KMC may be given or asked to buy a specially designed wrap from the unit. They may also need a shirt that can be buttoned. It is, therefore, advisable to keep a shirt in your handbag as it may come in handy. You don't want to feel bad when you are asked to start KMC and cannot because you didn't prepare for it.

Have a plan for *emergencies*

IN the last few months, I have shared a number of success stories from the NICU but there are days when things get bad. The



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Such emergencies come with extra costs so please have a financial plan for emergencies

condition of your baby may deteriorate or you may need to be moved to a facility that is more equipped or may need an assessment which will require moving him or her with an ambulance.

Such emergencies come with extra costs so please have a

financial plan for emergencies. Most public hospitals accept the National Health Insurance but cost of labs, certain drugs (in fact most drugs) are not covered by the NHIS, so plan for emergencies.



Have a support system

THE NICU is stressful and you will need someone or a group of people you can confide

in. Sharing some of your experiences may help relieve you of some stress.

Currently, there are a number of support groups for parents in the NICU on social media

platforms where you will find useful resources throughout your journey.

If you are not comfortable sharing or seeking help from “strangers”, you can talk to a close friend or relatives you trust and their words of encouragement and prayers may keep you going.



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Picture Credit: christiancoachinstitute.com

Keep a diary

WHEN I decided to blog about my experiences at the NICU, I realised I struggled with some dates and turn of events. I

remembered most parts of our journey but I struggled with some important details.

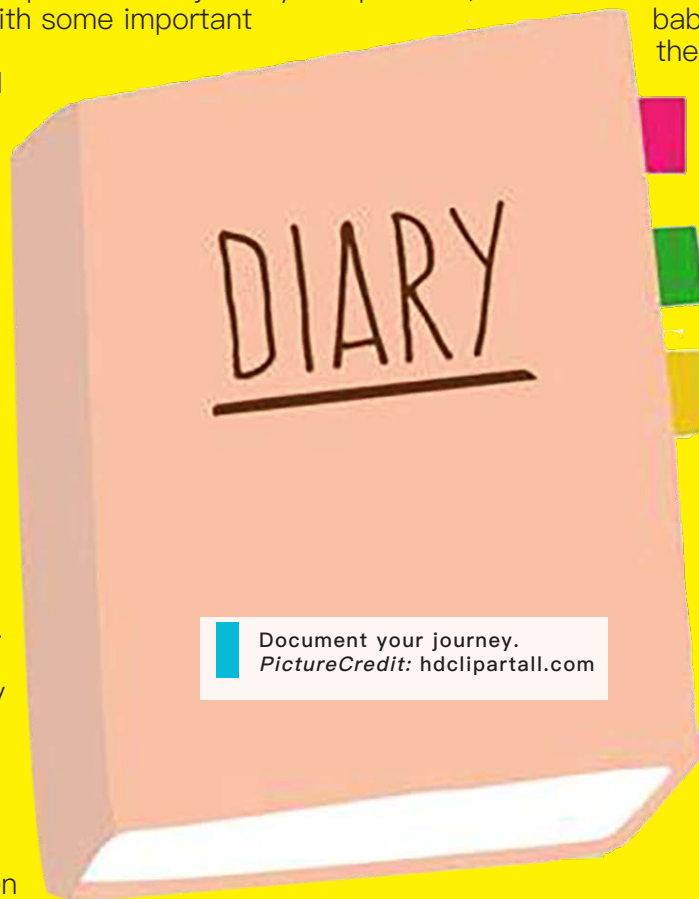
In June, when I asked my husband to share his experience as part of a series I was running to celebrate fathers, he called me several times asking for clarity on some of the details. He couldn't recollect some of the details after three years.

If possible, keep a hard copy journal and write down your challenges, baby's condition and other happenings. When you are finally out of the NICU, you will be amazed at how far

you have come and be thankful for your journey. If you are not a "pen and paper" person, you can also download a digital journal on your App store, there are many free journals.

If your NICU allows parents to take pictures, take as many pictures as possible,

soon, the tiny little baby you see in the cot will start running around. You may also decide to keep their first clothes, socks or baby hats.



Document your journey.
PictureCredit: hdclipartall.com

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Faith

I COULD write a whole book on the importance of faith in the NICU. In 2017, the second day in the NICU was extremely tough for me. My boy had started having seizures and the doctors were concerned about the rate at which it happened.

I remember I walked into the NICU that afternoon and the nurse on duty said to me plainly, “Madam pray hard ooh, the seizures are

not getting any better and it’s not a good sign”. I later asked to speak to the doctor and he was blunt with me. He said the seizures could result in other serious complications. He also mentioned that we should keep

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In tough moments when everything seems dark and you see no end to your journey, pray and keep the faith. I have seen miracles in the NICU and I know they still happen.

praying so the seizures cease.

I always describe my son’s complete recovery as a miracle from God and the doctors who attended to him in his early days agree too.

Yes, I cried but I kept praying and believing that he will be completely healed. I called my pastor, some church leaders I trusted to support me in prayer and my family also kept praying for us.

I am a Christian so I believe in God, Jesus Christ and the power of the Holy Spirit. Whatever your religion is, I believe you appreciate the power of prayers, so in tough moments when everything seems dark and you see no end to your journey, pray and keep the faith. I have seen miracles in the NICU and I know they still happen.



Plan an activity

It is difficult to keep your mind off happenings at the NICU. It is normal to keep searching online for similar diagnosis, reading about treatment plans and searching for effects of medications, etc.

There's so much information online that if you are not careful, you may end up stressing about a problem which is nonexistent. Add an activity to your schedule which takes your mind out of the NICU. It could be reading a book, listening to a podcast, listening

If you love social media, visit pages that has exciting content and be cautious of posts that may trigger certain emotions.

to a playlist or anything that gives you good energy. If you love social media, visit pages that has exciting content and be cautious of posts that may trigger certain emotions.

Even if this activity lasts for only 15 minutes, it can relieve some of your stress.



Add an activity to your schedule which takes your mind out of the NICU.
Picture Credit: dreamstime.com

Celebrate *little wings*

ONE afternoon, after attending to my boy who had then been

taken off oxygen at the NICU, I walked down to the car park in search of “abro ne nkatie” (roast corn and groundnut) as I was still struggling with breastmilk production.

I walked to the car park only to meet a lady I attended prenatal sessions with sipping a chilled bottle of soft drink while she waited for the Khebab seller to prepare two sticks for her.

This lady had delivered two weeks before I did and her baby had been on admission at the Child Health Department. “How can she be sitting here so relaxed and even chewing khebab”? I asked

myself as I drew nearer.

She said her baby had finally started suckling after almost two weeks on

admission and so the “Malta Guinness and khebab” was her celebration party.

I only smiled, bought my “abro ne nkatie” and left. But that evening, I thought about what the lady had told me earlier in the day and realised it was

important to celebrate every win. I became a regular customer at the khebab joint (for obvious reasons).

When the level of oxygen that a baby depends on is reduced,

celebrate; when a baby eats without throwing up, celebrate, when a baby finally has his or her first bath or goes through the night without pulling out the feeding tube, celebrate.

Well, your celebration may not necessarily be with “Malta Guinness and khebab” just count your little blessings and be thankful.



I would love to hear from you



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