

Kieron's Story

Week 2

Dedication

To Kieron

Mummy and Daddy's special "Little Man"; a fighter and a hero.

To Our Families and Friends

Thanks for everything we wouldn't have finished this part of the journey without you.

To the nurses and doctors at the Neonatal Intensive Care Unit, Jessops Hospital for Women, Sheffield and Special Baby Care Unit, Bassetlaw Hospital, Worksop

Thank you for all you did for Kieron without you we would never have celebrated the day in September 2000 when Kieron came home.

Foreword

On April 20th 2000 Andrew's (my husband) and my life was turned upside down. Due to complications with my pregnancy at week 24 our son Kieron was born, our lives and that of our families would never be the same again.

Despite being very ill myself, I started to write a diary that took the form of a mothers (and fathers) thoughts and feelings. It was set out as if I was talking to Kieron, which I often did, I told him how he was doing and what was happening around him

The first 6 months of Kieron's life was spent in hospital, this is his story of those days; it contains times of pain and despair but even more times of happiness and hope. For those of you who have or are going through this we hope what follows lets you know you're not alone; for the rest of you all we can say is this is what it was like to be the proud parents of a very premature baby.

Sharon,
Kieron's Mummy

Diary of a Little Man

Friday 28th April

You had a good night; Mummy didn't seem to sleep very well although she probably had 7 hours it didn't feel like it. Mummy was reading some devotional reading this morning and a line said

"Everyone must go through the tunnel of tribulation before, they can travel on the high road of triumph"

Isn't that lovely Kieron? That passage I feel is definitely for Mummy, Daddy and you. Mummy had to rest for an hour before she came up to see you; I got up to you about 10ish after the doctors had done their rounds. You're doing great buddy!

You're now on the right antibiotics for your infection; Your stomach isn't swollen; Your oxygen levels have been taken down and you're breathing at a more regular pace as the doctor showed me on your TV; You can lie on your front which will help expand your little lungs;

"Praise the Lord you're back on Mummy's milk, so I'd better get pumping"

Your skin is a better colour; and the hat Grandma Whybray knitted really suits you. I did your care and Kath left me to it. I had to wait a few minutes just so your breathing could settle. Your eye is opening almost full now. I think you're a little scared to open both eyes at the same time. So you're opening one just to check this big wide world out.

You had filled your nappy for me. Well done! And you continued to poo while I was cleaning you up, you monkey! Mummy put your nappy on the wrong way round and just as I was fastening it up you decided to wee all over it. Kath told me to just fasten it up. So I did. I then rubbed some sunflower oil into your dry areas. Then we just sat and relaxed down with Mummy stroking your little hand and you grabbed Mummy's thumb nice and hard, just to say I'm glad you're here. I smoothed your hand and you dozed off, so Mummy left you to sleep and came back to her room yawning all the way and fell asleep listening to Charlotte Church.

See you later little fellow Mummy's proud of you keep it up! Daddy and Grandma Norton came to see you they were very pleased with you. Daddy is not coming to do your care tonight he's going to stay with Grandma Norton. Grandma has nearly finished your hat while she's been sat here.

Daddy cheered up when he knew you had done a smelly nappy. Daddy will change you he's just nervous about hurting you, but he still loves you and he says he will come and see you later. Please open your eye a little tonight because your Grandma and Granddad Whybray are coming to see you in your hat.

I came up to do your care. You'd pooped that much in your nappy that the midwife couldn't measure your wee, keep it up. She said as you progress and get stronger you will be moved to Bassetlaw hospital which Mummy and Daddy can walk up to from home so work towards that goal little fellow.

That eye is really open isn't it, you behaved really well while I changed you and you're getting better when they suck stuff out of your stomach.

You relax down a lot easier and you held Mummy's hand as though you didn't want to let it go and went back to sleep.

The midwife said you've started taking little breaths for yourself and the ventilator helps you out when you need it. Your chest and lungs were clear on the x-ray and you're still on my milk and from what I've been told you're absorbing it well. So they may up the amount they give to you. Now the breast pump is working properly Mummy will be sending up loads so you keep drinking and enjoying little fellow. See you later,

Love

Mummy

Daddy came up and you'd got your finger stuck to your tape that was holding your breathing tube in. Daddy had to get Sharon (the midwife) to help you out.

Grandma and Granddad Whybray came to see you and you opened your eye for them. Mummy came up later with Grandma

Norton you were very active moving around, but Mummy settled you to sleep by smoothing your hand.

As Grandma and I were leaving we met Daddy so we decided to come and say goodnight to you, but you were a naughty little rascal because as Daddy was just about to say goodnight you started bleeping and you put the willies up your Daddy. Sharon had to take some water out that had gone down your tube which it can do and you were fine after that. Kieron darling try not to do that when Daddy's around. Mummy smoothed your hand to relax you down and you closed your little eyes and went to sleep.

"God watch over Kieron tonight and please place your cherubs around his incubator so they can watch over him this night."

Saturday 29th April

Well Mummy's has had a good night's sleep. She decided it was because she took the stronger pain killers last night. Hope you had a good night little fellow. In the reading today it spoke about prayer it said:

He kept praying

The lesson here is that you must keep praying

Three definitions of faith

- 1 *Taking hold of Christ*
- 2 *Keeping our hold on him*
- 3 *Not letting go of him"*

Thank you Lord that every reading I look at there is a small passage that I always find relevant for Kieron, Daddy and me.

WOW! Kieron you've now got both eyes open and this world isn't that bad is it. You're off your morphine which probably means you can feel Mummy's touch more. You had done a lot of wee in your nappy today well done and no other surprises for Mummy perhaps you're saving it for Daddy later on.

You're still having half a millilitre of Mummy's milk and you seem to be getting used to it slowly. You've now got your Grandma Norton's hat on, I'm bringing you some little booties up later. Mary the midwife has said if you keep going the way you are

you'll be on a breathing machine like the little girl opposite you. You breathe by yourself, but the machine will help a little with your lungs. So keep up the fight buddy boy and then you can change machines.

Mummy met another Mummy who's just down the corridor from me on the ward her baby weighed the same as you. So Mummy's got someone to talk to. Anyway you have a rest now and don't wriggle too much I know it must be exciting to be able to feel every movement, but you must rest just like Mummy.

Sleep tight

Love Mummy.

Oh yes, Mummy got a little name label you had when you were born and your blood pressure strap as you've now gone up to a size two with a rabbit on it.

See you later Mummy's little boy.

Mummy came up about 12.45 pm to see you I only stayed for quarter of an hour as you were asleep but I held your hand.

The lady I was telling you about who had a little boy the same weight as you came to see you and her partner asked if he could look at you while I was there it was nice to be able to show you off. I was so pleased to find a baby the same weight as you, I think you're four days older a big boy ain't you.

Daddy will be up later to see you. Your brain scan is clear and the doctor was the one who saw you when you were poorly and he said how much you'd improved since the last time he saw you that is encouraging.

Daddy and I came up to see you about 2.30ish. Daddy was very pleased that you opened your eyes you must stop setting your bleepers off because it unnerves your Daddy. We left you to sleep because you've got a lot of visitors coming to see you this afternoon.

Daddy's Song for his little fellow:

*I do swear that I'll always be there
I'd give anything and everything and
I will always care.
Through weakness and strength, happiness
and sorrow, for better, for worse
I will love you with every beat of my heart.
From this moment life has begun.
From this moment you are the one
Right beside you is where I belong
From this moment on.
From this moment I have been blessed
I live only for your happiness
And for your love I'd give my last breath
From this moment on.
I give my hand to you with all my heart
Can't wait to live my life with you
Can't wait to start
You and I will never be apart
My dreams came true because of you
From this moment as long as I live
I will love you. I promise you this
There is nothing I wouldn't give
From this moment on
You're the reason I believe in love
And you're the answer to my prays from up above
All we need is just the two of us
My dreams came true because of you.
From this moment as long as I live
I will love you I promise you this,
There is nothing I wouldn't give
From this moment
I will love you as long as I live
From this moment on*

(from Shania Twain's Album Come On Over)

More visitors today; Auntie Naomi thought you were wonderful and you opened your little eyes for her I think everyone melts when you do that. You also opened your eyes for Auntie Emma which was a lovely surprise. Emma thought you'd grown. You left your party piece for your Grandma Whybray you opened your eyes when Grandma said "Kieron open your eyes". Grandma says you're getting more like a baby everyday. Mummy's coming up to do your care, Daddy is sorry but all the bleeps unnerve him. But he's promised that he'll change your nappy once you're not on so many monitors. You can do as many sticky, smelly nappies as you like then. So see you later.

Mummy came up to change you, she didn't get very far because they had to x-ray you. You'd got some gases in you. But you were fine.

You're back on your insulin because there's sugar in your blood and you were having some blood put into you. The x-ray showed that the tube in your mouth had gone to the side and needed re-adjusting and that your lung had infected, but not to worry you had to go on some new antibiotics and you were fine. The midwife said the consultant would re-adjust your pipe that takes the oxygen, but put it down your nose if they can rather than your mouth and then they will up your oxygen and massage your lung. So be a good boy it may feel uncomfortable but you be Mummy and Daddy's brave little boy, the doctors and midwife have to change things around until they suit you.

The good news is they will probably increase your milk, keep it up remember we love you.

"Dear Lord, be with Kieron while this pipe is re-adjusted, just keep him calm Lord and relaxed, so that when we see him later he will be used to it."

Kieron darling, Mummy and Daddy and your visitors Auntie Denise and Uncle Paul (Mummy and Daddy's friends) will be up to see you later around 8:00 so that you have time to get use to your pipes and everything else. So see you later little fellow and enjoy your milk. Whoops! Mummy forgot to clear up.

We came up about 8 pm, Daddy and Mummy came in first to see you. You seem to love having your mouth free you were opening it and yawning away.

You're on your side to help your lung expand. Everyone said you were stable and they didn't seem worried. They will massage your lung a little for you.

Auntie Denise was overwhelmed by you and felt very privileged that we had let her see you. She was amazed at how well you were formed. Uncle Paul came in with Mummy and you opened your eyes as if to say hello.

We all prayed for you in the waiting room which was lovely because we were closer to you. Mummy prayed that Daddy wouldn't worry so much if your bleepers went off, but good boy you showed Daddy how sometimes you stop it bleeping yourself. Your doctor saw Daddy and Auntie Denise in the waiting room and said how well you looked and he didn't seem very concerned about your lung he said it was stable. Come on Mummy's little fighter let's have that lung inflated by tomorrow morning.

Sunday 30th April

Well today you're 10 days old. Mummy prayed all night. She had a lovely dream and saw quite clearly you in your incubator and one of the little cherubs massaging your lung and the second blowing into your poorly lung with a straw of all things. God said that they will keep this going. To help you here is a hymn Mummy thought of:

*"Breathe on me breath of God
Fill me with life a new
That I may love what thou dost love
And do what thou dost do"*

Mummy came up about 10:00 I sat stroking your back while Marie the midwife was busy with another baby, you were so relaxed. I can see that you love having your mouth clear of that tube and well done little fellow you switched your own bleepers off. Your milk is now up to one and a half millilitres. Once Marie had done your suction etc Mummy got cracking on your care and

by now you were wide awake and watching my every movement. You did an enormous poo in your nappy. Thank you very much. But you were very well behaved and relaxed considering your poorly lung. Marie and I changed your bedding; she lifted you up while I put the new bedding underneath you and took out the old one. Marie also pulled you out on your little tray so that I could kiss you.

I read The Itchy Elephant to you. I think we'll get Daddy to read it to you at night and Mummy read it in the morning. You'll know it off by heart by the time you come home.

Marie said you can hear and see both Daddy and I, so when you're awake we'll talk to you a lot. Daddy will be up later to see you. See you later little fellow keep fighting.

Daddy came up to see you about 12.30 and you opened your eyes to say hello to him. He is very pleased to see that you are switching off your monitors by yourself.

Mummy came up to see you about 1.30 pm you were very relaxed and asleep, Mummy stroked your little head you opened your eyes a little but dozed off again, so Mummy left you to sleep.

Grandma Norton and Grandma and Granddad Whybray are coming to see you. We'll not come up so that you can relax. Mummy and perhaps Daddy will come up later to do your care. Your Daddy and Grandma Norton came up to see you about quarter to four while Mummy pumped some milk for you; boy it looks lovely and creamy. Daddy said hello to you and you opened your eyes. Daddy was really impressed again with you turning off your own beepers.

Grandma and Granddad Whybray came to see you by themselves they commented that you were definitely more active. Mummy is coming up to do your care and the when we come to say goodnight Daddy will read you the story of the Itchy Elephant. Old Bear is a little to old for you yet and the pictures are not so bright.

Mummy, after having yet another sleep, came up to do your care. You're always awake when your care is being done and you had really filled your nappy thank you very much! When Mummy tried to settle you down to sleep you were quite certain that you were not going to, you had your eyes open checking I was still there. I'm sure you keep looking at that little red light on your hand it must be fascinating.

Mummy and Daddy came up early tonight so that Daddy could go home early for an early night you did excellent switching off your beepers. Daddy read you a story about The Itchy Elephant and you settled right off to sleep. Daddy is really pleased so keep it up little boy get that little lung inflated. Mummy will come up later to bring some more milk.

Mummy came up to see you at about 9 pm; bad time change over for the night shift but Mummy sat talking to a lady called Nicola who's from Worksop and she had her little boy last night and he's in NICU.

When I went to see you, you were relaxed Mummy stroked your head as you still had no hat on that must be a good sign. You were dribbling on your bedding; Mummy wiped some of it with her finger and then had to wash her hands.

Louise is looking after you over night and she says you've been fine. You opened your little eyes when you heard Mummy's voice then you dozed back off again with your free hand up on top of your head you did look funny. You're back on half a millilitre of milk every hour; let's see if you can get it up again. I left you sound asleep, so sleep soundly my little fellow and remember the cherubs are with you at all times.

Monday 1st May

Well Kieron today is your auntie Emma birthday. I'm assuming you've had a good night because I wasn't called. Well done buddy boy. In my reading it talks about faith:

“Faith is not conjuring up, though an act of your will, a sense of certainty that something is going to happen.

No it is recognising God's promise as an actual fact, believing it is true, rejoicing in the knowledge of that truth and simply resting because God said it”

“Kieron mummy came up about 10ish to see you I'd had to have my blood pressure taken and the breast feeding lady came to see me. I lent her your diary to lean on and she walked off with it by mistake, so mummy panicked a little I felt I'd lost part of you. The staff bleeped her and she brought it back being very apologetic, anyway when I got up Louise had finished her part of your care. So I was straight in. I think you were having a lay in as it's bank holiday. No poo today, but a lot of wee. Louise had put you a hat back on, you woke up a little while mummy read to you, but decided that you were going back to sleep.

Mummy left you to sleep and will see you after dinner. I'm having a rest too. Let's see if you'll open those eyes for auntie Emma as it's her birthday.

Mummy came up to see you about quarter to one your being very lazy today but you have every right to be. You opened your eyes a little and then just held my hand and dozed back off again. While I was talking to another mum I noticed one of the doctors taking some blood from your heel. I'll get daddy to ask what that was later.

Your ventilator is down so you're breathing a little for yourself and your morphine is down and you're off your insulin. Well done don't forget to open your eyes for Auntie Emma this afternoon. See you later mummy's little boy.

Daddy and Grandma Norton came to see you about 2.25pm, daddy said you were all arms and legs but you looked restful and you slept well. Your little ear was squashed hopefully the midwife will have flattened it out.

You got two new books today Eeyore's birthday from your Grandma Norton and Mr Small from your daddy.

Mummy came up to do your care. You were asleep most of the time you were then turned onto your stomach, which I know you find more comfortable. Let's hope that there is no sugar in your wee otherwise you'll have to go back on the insulin.

Keep going little fellow your doing great.

Mummy and daddy came up about 7ish to say goodnight. You were having your pipes changed which your daddy didn't like. He did very well though. He read you a story and you opened your eyes and then shut them quickly. Mummy said goodnight and daddy and I came down just before 7.30pm. Mummy will have to get use to it because when she's goes home that will be the time mummy and daddy will be leaving. So be a good boy tonight so that when daddy rings up in the morning he can go to work without worrying.

Sleep tight mummy's little boy see you tomorrow.

Tuesday 2nd May

"Well today everyone in the family is going back to work. So mummy will be up to see you this afternoon see you later little chappy.

Well done Kieron you've had another good night. They've put your ventilator down again and if you carry on you may go onto a different one but they're not going to rush you. You're down to a low bit of morphine and your milk is up to 1ml and you seem to be absorbing it well, your secretions were good too. So all in all well done little fellow, you've still got to keep up the fight you've a long way to go, but mummy is really pleased with you at the moment.

You've got such a huge nappy on you it drowns you, I think they've run out of the little ones you woke up while I was changing you and the nurse turned your temperature down in your incubator. You dozed off to sleep while mummy read you Eeyore's birthday and then you opened your eyes to check that I was still there and then dozed off again.

Sleep well remember the cherubs are with you. Mummy came up to see you about 3.20pm. Mummy had a good sleep after dinner and then one of the chaplains came to see me. He was very pleased to hear of your progress. Mummy read you Mr Small you were very dozy let's hope that your sleeping pattern is as good when you come home. I'm sure you were trying to suck your fingers. Your little arms were all over the place, so you must have been having a good dream. I stayed with you about 20 minutes and then came down and expressed some milk for you. See you for your care about 5.30pm.

Daddy came up with mummy to do your care. Daddy stayed in while Louise was getting the muck out of your mouth. This is a great milestone for daddy. Mummy did your care and you opened your eyes. You love having water in your mouth. When mummy put your new nappy on you proceeded to wee everywhere. You're doing grand little buddy keep it up. Kieron darling here's a verse from a card that I thought you would like.

“Just close your eyes
and open your heart
And feel your cares
and worries depart
Just yield yourself to the father above
And let him hold you
secure in his love”
(Helen Steiner Rice)

'Grandma and Granddad Whybray came up to see you about 7.17pm they said you were all arms and legs. But you kept the big surprise for mummy and daddy you'd progressed to the next ventilator which just reminds you to breath, it looks a very funny

contraption, but well done little fellow. Louise told us not to worry if you're back on your old one when we next see you it's only to give you a rest.

"Congratulations" Kieron you're doing really well keep it up buddy boy.

"Dear Lord be with Kieron tonight as he's trying out his new ventilator, please still keep your cherubs round him. Thank you so much Lord for his progress.

AMEN"

Wednesday 3rd May

"Well, good morning little fellow I'm assuming you had a good nights sleep.

Today's visitors are Grandma Norton, daddy, great Auntie Yvonne and great nanna so it would be nice if you opened your eyes. Mummy is sorry that she missed your 4.30 am expression of milk my clock had stopped.

Mummy got up to do your care about 10.15 am. She was so glad to see you on the new ventilator still and doing well. Mummy did your care and you slept all the way through it. You'd done an enormous poo thank you so much, but also well done. Mummy read you The Itchy Elephant then you were turned onto your stomach your favourite position. You're off morphine which is good and I assume you're still on 1 ml of milk a hour. See you later little fellow love mummy.

You've got another Tigger from Ian, Bryony and Callum. Nanna came to see you and you opened your eyes for her.

Auntie Yvonne took a video of you and you really showed off opening your eyes.

Your changing times have changed now to every 6 hours 10 am, 4 pm and 10 pm, but the nurse said they can be changed to suit daddy and me once I go home. Mummy hired a pump and the nurse suggested a steam steriliser at home. You've got two new books by Beatrix Potter which mummy will read to you sometime.

We've got a surprise for daddy when he comes in, haven't we. I know he will be so happy. Mummy and daddy came up and held you, you were so small and light we held you for what seemed ages. All daddy could say was WOW!! You opened your eyes when your daddy held you and you looked as though you were going to do the song "If I were a Butterfly". For mummy you looked as though you were doing Spanish dancing. We were amazed, oh you're so wonderful. I love you to bits Kieron and daddy loves his little fellow too.

Mummy came up to do your care at about 10 pm Kath was on and it was nice to see her. Your bedding was changed and you settled down to sleep really well. I think you're getting use to your suction now. See you in the morning little fellow sleep tight remember the cherubs are with you."

Thursday 4th May

"Well today you're a fortnight old, you've got visitors tonight grandma and Granddad Whybray and mummy and daddy's friend auntie Sarah is coming, but unfortunately she won't be able to see you. I'll be up at 10 to do your care see you later buddy boy. Mummy came up to see you about 10ish you've got a nurse called Fiona from Bassetlaw SCBU looking after you that's the hospital near mummy and daddy so if you carry on being a little fighter you will move over there. You had done an enormous poo in your nappy thank you very much. You were awake the whole time I was changing you, keeping an eye on me were you. You then dozed off while mummy read you a story. Oh yes well done little fellow your up to 3mls of milk an hour keep it up buddy boy. Mummy came up to see you just after 1 pm. You just felt my hand and slept and mummy sat and watched you. You'd been a little sick Fiona said, but they were monitoring you, you're off your antibiotics well done little fellow. Mummy stayed with you for about 20 minutes then she walked slowly downstairs for some exercise and had a sleep for 30 minutes. See at 4 pm Kieron keep fighting.

Mummy came up at 4 pm to do your care and you were already you'd done an enormous poo in your nappy and just to add to the

fun you stuck your foot in it then all over your snuggly. So the midwife changed it and you're now wearing booties that Dorothy made for you. The midwife suggests that the next size up. Boy! you must be growing little fellow. You were turned onto your tummy which you love because you woke up. Mummy left you to rest, daddy will be up later. Mummy has some pumping to do.

Mummy and daddy came up to say goodnight about 8ish you were sucking your finger and daddy says he thought he heard you cry.

Your wonderful Kieron and mummy and daddy love you to bits. Grandma and Granddad Whybray went in to see you and they couldn't get over the change in you. They told Auntie Emma that she would notice a big change. Mummy will be up about 10ish to do your care so see you later mummy's little fighter.

You were awake when mummy came up to you. It's way past your bedtime little fellow you should be asleep. You stayed wide awake all the time I was doing your care. You didn't even settle to sleep before I left.

Mummy is going home on Sunday it will be hard, but she feels that she may recover better in familiar surroundings. So they will probably change your care to 6 am, 12.00 and 6 pm that means I can get in for the 12.00 and then daddy and I can do the 6 pm care.

But you've got to be mummy and daddy's little fighter and keep up the fight and remember those cherubs are with you.