

Kieron's Story

Weeks 3 and 4

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 5th May

Mummy will be up to see you about 10ish to do your care. So see you later little fellow.

Well I came up to change your nappy about 10ish you'd filled it, but this time you didn't put your foot in it. I had to leave about 10.15ish because the doctors do their ward rounds later on a Friday, I was one of the last parents out and one of the consultants jokingly tutted at me. They will ring when I can come back up to you. You're now on just over 4mls a hour of milk.

Well done keep it up.

Mummy came back about 11.15ish and you were on your tummy asleep so mummy just sat and stroked your hand. You're now off your intravenous feeds because you're managing a lot more of my milk. Your little arm that has the tape on with the intravenous drip on will be taken off today so your arm will be free of that tape.

The midwife said the doctors are pleased with you, so keep going mummy's little fighter.

Mummy came up to see you about 1ish you were sound asleep so I sat and held your hand. You didn't even stir, mummy then came down to the ward for a sleep. Like you she had a good hour and a half and woke up very refreshed.

Mummy came up to do your care at 4pm. Your heart rate went down and you had to be reminded to breathe. You've been on this new ventilator a long time and you're getting tired you managed to stabilise yourself and mummy didn't leave you until she knew you were ok.

Daddy and mummy were up again at 5.30 the midwife said you were tired and your heart rate had dropped again. She said that you may go back on the other ventilator for a rest, but that it's nothing for daddy and i to worry about she said it was normal for a baby your size to keep switching their breathing systems.

So keep it up fighter so that your daddy can go home and not worry.

Mummy came up at 10pm to do your care the midwife who was on was lovely talking to you the whole time. No wonder you had problems breathing with all that stuff she sucked out of your nose. She's going to do it again in 3 hours time so be good.

I changed your nappy and did your care you were awake the whole time, I hope this isn't a sign that you'll be awake around 10ish when you come home. The midwife changed your bedding so that you had a nice quilt to sleep on and put piglet by the side of you. You were still awake, well half awake when I left at 10.45pm. This is very late for a little fellow, so I hope you settled down to sleep quickly and were no bother for the midwives.

Saturday 6th May

Well today mummy slept alright and it's 7.45am and breakfast is on it's way round. I'll see you about 10ish little chappy

Mummy was up at 10ish expecting to do your care, but she thought they'd probably changed it to the new times, but the midwife and I decided not to disturb you so I'm coming up at 12ish to do the new times of 12.00 and 6.00 you held my finger and opened your eyes just to check who it was then closed them again and went back to sleep.

Mummy came up at 12.00 to do your care. Your little nose is red and sore with the breathing up your nose. So they put you on incubator oxygen to give your nose a rest. You may be only on it for half an hour, but if you seem to cope with it they will leave you on it for longer. You were wide awake. I think you were wondering why your head felt so free.

What a surprise your mummy had this afternoon when your Granddad Norton poked his head round the door of my room, he'd arrived back today and had come to see me and you. Daddy

brought him up to see you. Granddad Norton thought you were lovely.

Mummy came up at 6.00pm to do your care and daddy arrived not long after we had finished. You were doing very shallow breathing and at one point mummy thought she couldn't see you breathing and called one of the midwives over who reassured me that everything was alright and she turned up your oxygen.

Mummy became upset because she thought she couldn't see you breathing and this got daddy agitated. When Grandma Norton came in she said it was because you were on your back.

Grandma and Granddad Norton came to see you again and they said you were quite active when they were with you. So daddy and I came up to see you about 7.45pm with grandma and Granddad Whybray. You didn't seem so tired, we read you a book called Friend for Lion we've now got four in the series and mummy is going to buy you the other four.

Grandma and Granddad Whybray went in to see you and we sat and talked to Callum's mummy and daddy that's the little boy next to you. You know the one you keep playing see who can turn off their bleeper on and off at night.

Mummy came up to see you about 9ish, but was told they were changing your tube. So please let them be putting you back on the ventilator for a rest. I'm praying that I'm right because it will put your mummy and daddy's minds at rest.

Mummy was back up at 10pm. Tina was on, the midwife that was on last night. You're back on your ventilator, Praise the Lord !You can have a rest, you've been given some morphine and Tina had got a lot of secretions from your nose. She'd done your care early so that you could rest. You opened your eyes a little but because of the morphine you were tired. So mummy let you rest with piglet keeping you warm, sleep well little fellow and be good for Tina.

Mummy and daddy are really pleased that you're back on the ventilator because it gives you and your lungs a rest and probably your nose chance to heal. Remember the cherubs are with you.

Sunday 7th May

Well mummy's going home today, but she'll be here to see you everyday. Don't you worry about that little fellow. Mummy came up to see you 10ish and read you Smart Snake. You had to be suctioned again; the midwife laughingly said you're storing it like a hamster.

The paediatrician was round and asked me if I was up to date with what was happening. He was the doctor who had put your tube in. He said "You were shattered" or words to that effect which mummy will not write in this book.

He thinks your doing well, you will also be having a blood transfusion so that your red blood cells can produce more oxygen.

See you for your care at 12ish, have a good rest little fellow.

On the morning service one of the choruses went like this

"You believe in miracles, when you believe, Who knows what miracles you can achieve? When you believe"

'Mummy came up to do your care about 12.15am, you were really moving around. I'm so glad they've put you back on that ventilator for a while. You're a lot more active. Your little pads were changed today because they were losing there stickyness. Mummy came back up about 12.45am because she needed to pump some milk for you little fellow.

Mummy and daddy came up to see you about 2.45pm. You opened your eyes the most we've ever seen. You must have been hearing us calling your name. You're really enjoying your milk and it was going to be changed as we left. You've got some lovely dark hair, you take after your mum for that.

Mummy and daddy will be up later on for your care and we'll say goodnight and read you a story. Mummy and daddy are really pleased with your progress.

Keep it up little fighter.

Mummy and daddy came up to see you after 6pm. The midwife said to change your nappy if it was dirty. It was, so we had to change you. You opened your eyes really wide to say hello to us, we stayed with you longer than we expected. You held my finger and kept opening your eyes to check we were still there. We said goodnight to you at 7.30pm and daddy took me home.

You be good and sleep well little fellow and mummy will see you tomorrow afternoon.

Monday 8th May

Well mummy's at home and is totally disorientated, I'm back to being like an old woman having to think what I'm doing. It's amazing how you get use to a hospital routine.

Daddy rang up to see how you'd been, your blood gases were up and then back to normal what a surprise, but otherwise you'd had a good night, see you this afternoon. Here are the words at last of "When at night I go to sleep." This is mummy's song for her little boy.

"When at night I go to sleep
When at night I go to sleep
Fourteen angels watch do keep,
Two my head are guarding;
Two my feet are guiding;
Two are on my right hand;
Two are on my left hand;
Two who warmly cover; Two who o'er me hover;
Two to whom' its given to guide my steps to heaven."

(Translated from the German by Constance Buche)

Mummy and Granddad Whybray got in to see you about 3.15pm. You were sound asleep. You're on antibiotics for an infection but the midwives are not worried by it. Your little nose looks sore. You opened your eyes just to check who had come to see you then closed them tightly. I'm pleased to see you've got your tape off your arm. You can tell you like it because that arm is very active. About 4pm mummy went down to the ward to have her blood pressure checked. Granddad Whybray came back to see you then he left. Mummy went to express some milk for you. When mummy got back daddy had arrived. I noticed you opened your eyes more for daddy.

The midwife did your care today just to show me about the creams that have to go on your bottom and the stuff they put in your mouth to help you.

You're also having physio because when they x-rayed your chest your lung was cloudy from all the muck that's there. Fiona the nurse who was doing your physio said that you were giving her some peculiar looks while she was doing it.

Mummy and daddy then went for a stroll and when we came back we read you 'A Friend For Lion'. Then we said goodnight and you settled down to sleep.

You'll be pleased to know that we now have the full set of those books to read to you.

Sleep well little fellow, mummy and daddy love you loads.

Tuesday 9th May

Daddy rang in this morning and you'd had a stable night. So mummy will be in to see you about 2.30pm little fellow.

Mummy and Granddad Whybray came to see you about 2.45pm you were back on CPAP which means you're prompted to breathe and you have to work a little harder on this one, but remember little fellow you've got to remember to breathe.

"Please Lord have an extra cherub with Kieron tonight, just so they can whisper to him and remind him to breathe."

You opened your eyes to see who had come to see you. Daddy arrived at 5.15pm and you were having your catheter changed that your antibiotics goes into, it was put in the other arm and because you've got such small veins it's difficult to put it in. Mummy did your care about 6ish after you'd had your suction the midwife noticed your stomach was swollen and asked one of the doctors to look. They felt it and said it felt full of air which can happen when on CPAP.

Mummy and daddy went off for some dinner, when we came back they were looking at your stomach it had gone down since we'd left you they were going to do a x-ray. So we said goodnight to you and came home. The doctor said it's probably wind and you probably (excuse the term) need to fart, but they were going to x-ray you .We'll find out the results tomorrow.

Sleep tight little fellow and don't be any trouble for the midwife and try and keep those secretions down when they need to suction you.

God Bless Kieron
Goodnight.

Wednesday 10th May

Daddy and I were really pleased to hear that you've had a stable night. You're back on your ventilator because you were getting tired. Mummy and daddy are pleased that you've put on two and a half ounces in weight.

We'll see you later buddy boy.

Daddy and mummy came to see you at about 2.45pm, you were asleep and you opened your eyes when we came in to stroke you to say hello.

Mummy then went to express some milk and daddy went downstairs for a drink. We then went to the ward to have mummy's blood pressure checked, it was fine. We then caught the tram into Sheffield where I got Granddad Whybray's birthday present. We then came back to see you, you were very active all arms and legs that you kept setting your alarms off, but you were

happy. When your care was done you were really wide awake your eyes were wide open which was lovely to see and you filled your nappy for me, Thank you very much. Daddy and I had to go out while the midwife took your cannular where your blood transfusion was being taken out. When we came back you were still wide awake so we read you Duck's Birthday and you were wide awake throughout. Daddy and I then came home.

See you tomorrow little fellow sleep well see you tomorrow love mummy and daddy.

Thursday 11th May

When mummy rang up you'd had a stable night and you'd been a good boy keep it up little fellow. Mummy and daddy will see you later.

Mummy and daddy came to see you at 3.30ish you opened your eyes really wide to say hello to us. They had to change your cannular that your antibiotics were going in to. So mummy and daddy went for a cup of tea. When we got back mummy went to express some milk while daddy read you a story and just sat and looked at you. He said you kept opening your eyes to check he was still there.

When I came back daddy said the consultant wanted to speak to us both this put mummy and daddy on edge. We went into the quiet room where we were told that on your brain scan you had some cysts which he said was normal for a baby of your age. They were very close to the part of the brain that controls movement and vision. They "COULD" effect both your movement and vision or just one of these or "NONE." Daddy and I listened, daddy said after seeing those big blue eyes he couldn't let anything happen to them or those long legs. We did your care well mummy did daddy filled your little pot with water and put things away when mummy had finished with them. Daddy said a pray for you and we said goodnight. When we caught the tram back down to the station we sat outside the cathedral and prayed that God would have his healing hand on you. Mummy had a cry

and so did daddy we couldn't let anything happen to our little fellow as I said to daddy you're our little miracle and your mummy's little fighter.

We rang both your grandparents and asked them to pray for you in church, so you've got loads of people praying for you Kieron. So keep fighting and remember mummy and daddy love you and want you to grow big and strong so that you can come to Bassetlaw Hospital and then finally home.

Take one day at a time buddy boy and remember your loved and being prayed for by many people.

Goodnight little fellow, sweet dreams.

Friday 12th May

Mummy and daddy had a lay in this morning. We rang and you were put on CPAP for 5 hours good boy every little helps. Mummy and daddy are pleased that you've been a good boy and you're absorbing all your milk so that you can grow big and strong.

Mummy and daddy are catching the 3.15pm train so we'll be there about 4ish this is because grandma and Granddad Whybray are coming to see you and they are giving us a lift home. So see you later buddy boy.

Mummy and daddy came to see you about 4pm. You opened your eyes when we came into stroke you and say hello. Then to our surprise your auntie Emma had come over from work to see you and you opened your eyes to say hello to her. After she had left we did your care, daddy did the top and I did the bottom. Daddy made a lot better job of putting the sponges in your mouth they didn't dribble all down your chin. Mummy did your nappy and put some oil on your dry skin. Gosh you do like the freedom of not having your nappy on; your little legs were kicking all over the place. But your nappy had to be done up, perhaps tomorrow you can have that freedom again.

Grandma and Granddad Whybray came to see you they said you were on your side and you were all arms and the one leg that was free was moving all over the place.

When mummy and daddy came in you were wide awake and you stayed awake while mummy read you 'A Surprise For Horse'. When we said we were going you kept your eyes open and wouldn't settle to sleep. I think you wanted to check to see if we had gone or not, we find it hard to leave when you do that. Anyway sleep well little fellow, mummy, daddy, grandma and Granddad Norton will be in tomorrow morning, so we'll see you then.

Mummy and daddy's little fighter, sleep well.

Saturday 13th May

Daddy rang up to see how you are you've been a good boy and your oxygen is up to 25. We'll see you later this morning.

We arrived to see you about 11.40am. Daddy and Granddad Norton came to see you first. Silly mummy had fallen over and tore her jeans at the knee and bruised and cut her knee well crazed it and it was bleeding. So mummy called in at the ward to get a plaster.

Daddy and Granddad were taking photos of you and because they have the same camera daddy borrowed from Granddad a lens which magnifies his normal lens. So daddy got some lovely close ups of you with your eyes open. Daddy decided to take them into one hour photo processing because you're changing everyday and we want up to date photos of you.

Mummy and Grandma Norton came in to see you, you were "all arms and legs" and very active. You would open your eyes for a while then screw them up tight. You looked so relaxed and you held my hand well my finger anyway.

Mummy and daddy then just sat and watched you. You would open your eyes just to check we were there you only

seemed to open one eye, it's very difficult to open the one you're leaning on. We read you 'Miserable Monkey'.

Grandma Norton then came in to see you with daddy and daddy took some more photos.

Then mummy and Granddad Norton came in and Granddad took some more photos of me holding your finger, your little knuckles were white when you were holding my finger.

We then left about 1.30pm, when we rang to see how you had been in the afternoon we were told you'd been a good boy and that your ventilator had been changed so that you had to some work on your breathing, but not as much as with the CPAP, this is the in between stage. So you try your hardest. Daddy and mummy love you and know that you're their little fighter. See you tomorrow little fellow.

Sunday 14th May

Today is Granddad Whybray's birthday, you were fine when we rang up you need some more of my milk so I'll bring some in today. See you later little fellow behave yourself.

Mummy and daddy arrived to see you about 10 to 4 you were very active. Mummy went to express some milk for you, daddy sat and watched you kicking and waving your arms around. You're looking more like a baby everyday.

When it was time to do your care daddy did your mouth and rubbed oil on you, by this time you were wide awake and watching his every move. Mummy changed your nappy, you really love the freedom of no nappy, and your little legs were bending and stretching. Mummy had just lifted your legs up to clean underneath your bottom and you decided to wee straight up your stomach, it went and splashed on your face so you closed your eyes fast I can tell you but mummy dried you off. We did laugh though. You kept your legs straight so mummy found it

difficult to do your nappy up because you wouldn't bend your legs, you did it at last and mummy quickly fastened your nappy.

We said a prayer for you and mummy read you 'Itchy Elephant' which you went to sleep to probably because you've heard it that many times. Anyway sleep well little fellow and be a good boy, see you tomorrow mummy and daddy love you.

Monday 15th May

Well you've been on CPAP since 8pm last night. Well done little fellow, keep it up.

Mummy will be in to see you later and daddy will be in to see you after work. Granddad Whybray is bringing me in to see you.

Well done little fellow you were still on CPAP when Granddad and I arrived. You've been on it a long time well done. You were awake when we arrived; after Granddad had taken some pictures you went back to sleep and seemed very restful.

When mummy came up after having a cup of tea with Granddad she just sat with her hand on your nappy and smoothed your back with her thumb which made you relax and go to sleep. Around 5ish just before your daddy came you woke up and opened those big blue eyes really wide you stayed awake though your care. Mummy had just taken your old nappy off and folded it underneath you and you pooped everywhere.

But the best bit was after your care when we were able to hold you. You stayed awake in daddy's arms, but once in mummy's arms you fell asleep. You were out of your incubator for 20 minutes, if you're still on the CPAP tomorrow we'll see if we can hold you again. When you were put back in your incubator you went straight to sleep. Mummy and daddy said goodnight, so sleep well little fellow you've got world wide prayer being sent for you, Granddad Norton got some Emails today. We'll save them all for you.

Sleep well remember the cherubs are with you.

Tuesday 16th May

Well you've been on your CPAP all night well done you dipped a bit this morning but that was because your nose was full of secretions you've had those removed so hopefully now you will not struggle on CPAP. See you later little fellow keep going on CPAP because mummy and daddy are so proud of you. Remember if you stay on CPAP mummy and daddy can hold you. So keep it up buddy boy.

Granddad Whybray and mummy were pleased to see that you are still on CPAP even if your oxygen levels are higher than normal. You were awake when we arrived, but you dosed back off when I stroked your back you seem to relax. After Granddad Whybray had gone mummy just sat stroking your back which you love.

When daddy arrived you woke up and all during care you were wide awake. You were on your back and very active with your arms and legs.

Once your care had been finished you settled down and with both arms above your head you went to sleep. We said a prayer for you and then left to go home.

So you be good little fellow and tomorrow if you're on CPAP we'll see if we can hold you.

“Please Lord be with Kieron and place your cherubs with him so he'll feel safe and secure
Amen.”

Wednesday 17th May

“Well you were a little naughty boy last night letting you heart rate drop it's all those boggies up your nose, once they were cleaned out you seemed alright and you blood gases were fine. Try and stay on CPAP then mummy and daddy can hold you.

Grandma and Granddad Norton are bringing mummy over today so see you later.

Grandma and Granddad Norton came to sit with you for a bit. They said they could watch you for hours.

Mummy then sat with you. You had a few drops in your heart rate while mummy was there but you picked yourself up. By the time daddy arrived you were behaving yourself and we were able to hold you again. Daddy had the longest hold and mummy loves holding her little fellow.

Mummy and daddy then had to go and talk to Mr Mike Smith the consultant that's a big doctor about your brain scan. He told us that the cyst on your brain had got worse and that you would have some form of cerebral palsy. How much he doesn't know, but it will affect those little legs. Mummy and daddy were shocked and upset, but everyone world wide is praying for you that it will be very mild. Mummy and daddy are too.

We came to say goodnight we couldn't leave without doing that.

You don't realise this yet but you be the best loved child ever, you're our little miracle.

You're doing alright though you're on 4.5mls of milk an hour and you're putting on weight 1lb 9ozs now. So keep it up buddy! Mummy's going to find out if there's a support group or write to the association at sometime because that will help.

Thursday 18th May

Grandma Whybray came to see mummy this morning and we just sat and talked. You've got a surprise this afternoon daddy will be coming too and tomorrow, work have sent him home so that he can be with mummy and little fellow.

So see you later and be a good boy love mummy.

You've been dipping on CPAP and you'd had a big one before mummy, daddy and grandma arrived if you have another one you've got to go back on the ventilator. You did have another one while mummy was expressing, so you were put back on the ventilator and your colour looked a lot better and all in all you looked a lot better in yourself. Mummy and daddy did your care then we left you to rest, mummy put your lilac booties on that matched your hat you looked very smart. Sharon the midwife commented on how smart you looked.

We came home and when mummy rang later on you were being a good boy and a lot calmer on the ventilator.

Friday 19th May

“You were a good boy last night. Daddy's been given the day off so he'll be coming to see you with me, today we are coming on the train so we'll be there about 4ish so you have a rest until then. See you later little fellow love mummy and daddy. We arrived at 4pm you were dozing when you realised we were there you woke up and started setting all your alarms off by wriggling around you moved your self so that you were totally laying diagonally. You'd pushed your feet into your snugly and lifted up your stomach. Mummy managed to calm you down by massaging your back with her thumb.

Once your care was done you were wide awake and kicking your little legs and stretching your arms. Grandma Whybray arrived and came to watch me finish off your care. She was amazed at how active your legs were. Mummy then went into the waiting room and Granddad Whybray came in they said they could have watched you for hours you were very active and wide awake. Daddy read you A Friend For Lion and then we settled you down to sleep which was hard because you were so wide awake, but you did go to sleep and mummy and daddy left and said goodnight.

Saturday 20th May

You're a calendar month old today. Mummy and daddy arrived about 11ish but had to wait an hour because of ward rounds and because they were sorting out your machine. You woke up when daddy came in to see you. When mummy came in too you were wide awake and very active with your arms, you were having some blood and the midwife put your milk up to 4.2mls per hour. Your little duct hasn't closed in your heart yet, but you're having antibiotics for it. Mummy and daddy stayed with you until 1.30pm.

We got you settled down before we left. See you tomorrow afternoon little fellow.