

P-04-603 Helping Babies Born Under 22 Weeks to Survive – Correspondence from the Petitioner to the Chair, 11.02.15.

Chair of the Petitions Committee, William Powell

This is my response to the health minister Mark Drakeford's recent letter dated 31/01/15. I will start with saying I agree that this is a sensitive issue and this is the whole reason why I am asking for change. The guideline as it is set is not in the interest of the baby when the baby is born breathing, it is uncertain to say whether or not any baby born before 23 weeks will or will not survive but when it is born independently breathing it should be given the chance and not immediately left to die because of sadistic or seen as a percentage. There is no fact that that baby wouldn't survive, that baby could be the low percentage but no one will know until each baby is given that chance. If each baby born independently breathing at or after 22 weeks they should be seen as a full term baby, just because that baby has sadly been born early at no fault of its own does not mean it has any less right to be medically helped or have its rights taken away from them.

As the health minister has explained resuscitation is set on the guideline as to been seen by medical professionals as when a baby needs support to continue breathing, meaning the baby will need resuscitation to stay alive. If this is true then how long does a baby need to be independently breathing before given help? As the committee know the reason I began this petition was because of my personal loss, my son was born breathing at 22+3 days and breathing, he breathed independently for 83 minutes with no help. We were told he couldn't have any help because of his gestation, the fact that he was breathing was of no interest to them. No higher medical staffs were called apart from the midwives on that ward, no one came and discussed any options or the outcome with me. The midwives just referred to the guideline as it was set in stone.

What are exceptional circumstances? When is a baby seen as valuable enough to be helped? How long before help is given after a baby is born and struggling to stay alive. My son lasted 83 minutes but he was not seen as an exceptional circumstance for even the paediatricians to come down before he finally gave up!

As the minister states in his letter each mother and baby needs to be individualised. This is not the action taken in these hospitals, I was not individualised and neither was my son.

He says the situation will always need to be individualised by clinicians; they should be guided by current guidance. They are not seeing this guideline as guiding them but as a set guideline, they are not using it to make a decision for a baby but as that's how it is and that's its attitude. I know this from not only my own experience in the hospital but from parents contacting me with their stories on how their baby was treated and left to die. Since starting this petition I have been contacted various ways by families who have lost their baby from not being helped after being born before 23 weeks but breathing independently. I have all these saved and have the support of families for this petition. What is going on? How can all these babies before 23 weeks be left to die because of their age. If the baby is fighting for a chance the baby should be given help each time, it is that baby's decision whether or not it'll live not the midwives at that time of labour.

It is frustrating to hear the health minister say the guideline does include 'exceptional circumstances' what do these babies born breathing have to do to be an exceptional circumstance. What qualifies the baby chosen to be helped, to be given the chance that each baby should have. It is as if the guideline is a lucky baby guideline, one lucky baby gets chosen to be given help. My son was not even looked at, so how do we know he wasn't that baby who'd survive out of your percentage! Babies no matter how small should never be seen as a percentage.

For us parents who have suffered the loss of a premature baby in the hands of medical staff are taking a stand and I will not let other parents go through this in the future, our son like many others should not be seen as a possible death but as hope and hope that that baby survives. Until each baby is given that chance is born with signs of life we will not know which baby will pull through or which baby will sadly die but each needs the help to have that chance to be the baby that survives. Leaving a baby breathing to die is not in the best interest of the baby or the mother, the baby fights till the end and is given no hope and the mother will always wish the medical staff there that day helped her baby and why their baby wasn't chosen to be saved. I will be fighting for each baby to be that one baby given the chance of hope and medical assistance he/she needs. Leaving a baby to die is murder and there is no other word than letting a baby die other than that.

Emma Jones