

Learning from deaths in twin pregnancies



How care could be improved and baby deaths in twin pregnancies prevented

Lay Summary

Around 740,000 babies are born every year in the UK, and 2 out of every 64 babies born are twins. Twins are 2x more likely to be stillborn and 3.5x more likely to die as newborns compared to babies in pregnancies with one baby.

Twin pregnancies have higher risks because women are more likely to have complications, such as high blood pressure and pre-eclampsia, and bleeding before or during childbirth. Babies in twin pregnancies are also more likely to be born preterm (before 37 weeks gestation) and need to be cared for in neonatal units. This report shows that much more could be done to reduce the risks for women and their babies, save lives and prevent physical, emotional and psychological harm for women and their families.

This enquiry looked at 50 twin pregnancies in 2017 where one or both of the babies died. The aim was to review the quality of care, as it was recorded in the medical notes, in a sample of pregnancies when one or both twins died and to determine whether different care may have made a difference for the babies and the mother. The care the babies and their mothers received during pregnancy, labour and afterwards was compared to care outlined by national guidelines for best practice, by a panel of clinical experts including midwives, obstetricians including fetal medicine specialists, neonatologists and pathologists.

The care reviewed included when mothers were pregnant; care during labour and birth; care for their babies once born; postnatal and bereavement care when one or both babies died; and any tests or investigations that took place to understand what happened and where improvements in future care are needed.

The clinical experts looked at whether the care women and babies received may have contributed to the babies' deaths. They also looked at the quality of emotional and psychological help and support provided for women when one or both babies died. This included the offer of post-mortem and the quality of local hospital reviews to understand why the baby or babies died.

Key findings

High quality care was found in a minority of the deaths which were reviewed. Most deaths may have been prevented with better care.

- » The care was assessed by the clinical experts as good in around 1 in 5 deaths.
- » In around 1 in 2 baby deaths, the care was poor. If care had been better it may have prevented the baby from dying.
- » For around 3 in 5 mothers care after their baby/babies died was poor. If it had been better, it may have meant bereaved mothers were likely to have been better supported in their physical and emotional health.

Care in pregnancy (antenatal care)

- » Less than half the women were looked after by a multidisciplinary team of doctors, midwives and sonographers who were experts in twin pregnancies.
- » Only half the women had a discussion with health professionals about their individual risks in their twin pregnancy, particularly the signs and symptoms of preterm birth.
- » Aspirin is recommended for women with a twin pregnancy at risk of pre-eclampsia, but this was prescribed for just under half of the women who needed it.
- » Women with a twin pregnancy where the babies share one placenta (monochorionic) were not always referred to a senior twins specialist when they reported to triage with signs of developing the complication Twin-to-Twin Transfusion Syndrome.

Ultrasound scanning

- » For almost all women the placenta was looked at as part of an ultrasound scan to find out if the babies shared one placenta or were in completely separate chorionic and amniotic membranes around the fluid sacs.
- » However, if a single placenta was diagnosed (monochorionic), most women did not then have the recommended two-weekly scans from 16 weeks.
- » Almost half the women did not have scans to check the growth of their babies as regularly as recommended. For about two thirds of women there was nothing in their medical notes to record if there was a difference in each baby's estimated weight.
- » Women with babies sharing one placenta (monochorionic) were not referred to the highest level fetal medicine centre for specialist input into their care when there were signs of complications.

Care during labour and birth (intrapartum care)

- » For some women their care during labour and birth was not overseen by a senior obstetrician.
- » Neonatal care doctors were not always involved in discussions with parents about difficult decisions and the parents' wishes when one or both babies were at risk of not surviving.
- » Many parents were not asked about their wishes and what they felt was best for their family when one or both of their babies needed resuscitating or stabilising or required further care.

Care after birth and death (postnatal and bereavement care)

- » Many parents were not given any care to help them cope with the death of one or both of their babies, and if they were it was poor quality.
- » Bereavement care was particularly poor when one baby died and the other survived. Communication between obstetricians, midwives and neonatal teams was not joined-up which contributed to poor postnatal and bereavement care.
- » Only half of parents were offered follow-up appointments to discuss what happened and how they were coping. When parents weren't offered a follow-up appointment the reason why was not documented in the woman's medical notes.

Tests and investigations to find out what happened when babies died (post-mortem and hospital review)

- » Where a post mortem was carried out by a specialist doctor (perinatal pathologist) the quality of the report was good.
- » Only 1 in 5 deaths were reviewed by the hospital, and these reviews were poor quality.
- » Where deaths were reviewed, parents were not informed or given the opportunity to ask questions or give their perspective on the care they received.

Call to action

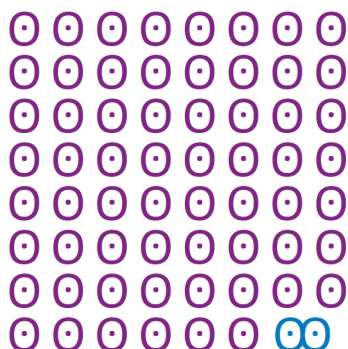
Professionals should read the full report at www.npeu.ox.ac.uk/mbrace-uk/reports, implement its recommendations and follow national guidance. If this were done, it is clear that future lives could be saved and national ambitions to reduce avoidable baby deaths might be achieved.

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Baby deaths in twin pregnancies

2 in every 64 babies are twins



Twin pregnancies are higher risk

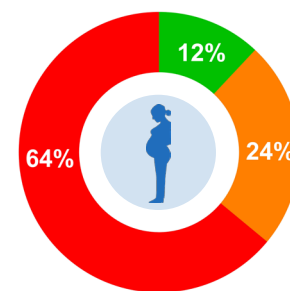
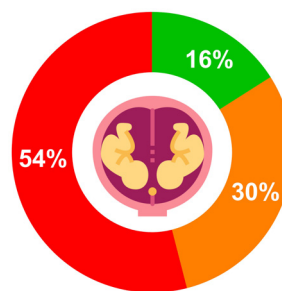
2x
higher risk of stillbirth

compared to pregnancies with one baby

3.5x
higher risk of neonatal death

Baby deaths in 50 twin pregnancies reviewed

Care relating to the babies Care relating to the mother



Good care Poor care which didn't affect the outcome Poor care which may have affected the outcome



There were problems with communication in almost **three-quarters of baby deaths**.

All types of communication, whether verbal, written or electronic, between parents and all health care professionals needs to be improved.



Less than half of women with a twin pregnancy were seen by a specialised team of different health professionals, and **almost none** were seen by a specialist midwife and a specialist sonographer.

NICE Guidance ensuring all women are cared for by a specialist multi-disciplinary team should be fully implemented.



The quality and frequency of ultrasound scans was an issue for **nearly half of the women**.

All women should receive high quality ultrasound from a dedicated team who are trained experts in multiple pregnancy.



There was evidence that professionals had discussed the risks of preterm birth before 24 weeks in a twin pregnancy with **only half the women**.

All women must be told about the risks of preterm birth and the reasons why they might come into the unit for monitoring, ideally by 16 weeks.



When women attended maternity triage because of an acute problem before 27 weeks of pregnancy, they were **not referred** for a specialist review of their care.

All women who attend maternity triage should be seen and assessed promptly by an obstetrician with expertise in multiple pregnancy.



Not all parents were involved in decisions about resuscitating, stabilising and on-going care for their baby or babies.

All parents should be given the opportunity to be fully involved in decisions about all aspects of their babies' care.



Bereavement care was poor and disjointed for **most parents**, particularly when one baby survived.

Family-centred bereavement care, in line with the National Bereavement Care Pathway, should be offered to all parents.



Baby deaths were usually **not reviewed**, and if they were it was often not in any formal or structured way.

All deaths should be reviewed in a standardised way using the Perinatal Mortality Review Tool, to ensure lessons are learnt to prevent future deaths.



When a review did take place **parents were not given the opportunity** to be engaged in the process.

Parents should be engaged in the review process to ensure they receive answers about why their baby or babies died.



Half of parents did not have a follow-up meeting with their consultant to review their care, and **even fewer** had a letter summarising findings.

All parents should have a follow-up meeting (jointly with their obstetrician and neonatologist, if appropriate) to review their and their babies' care, and a clear and personalised summary should be given to the parents.

Messages for women and families expecting twins

A twin pregnancy is potentially more complicated than a pregnancy with one baby, so it is important that your care is overseen by a specialist team of midwives, doctors and sonographers. They will ensure that you receive the right care for you and your babies, and if there are any problems they are picked up as soon as possible. The midwives and doctors should always explain your care plan and involve you in all decisions. You can ask to be referred for a second opinion if you are concerned you aren't getting the right care for you.

What you should expect from your care – a checklist

- ✓ You should be seen in a specialist twins clinic run by a team of doctors, midwives and sonographers who have training and experience in twin pregnancies.
- ✓ You should be given a schedule of the appointments and scans at your first appointment. The importance of each one should be explained to you.
- ✓ The team should explain to you what to look out for if you go into labour early and what to do about it.
- ✓ If you think there is a problem during your pregnancy, or think you might be going into labour, you should be seen by a doctor experienced in the care of twin pregnancies. They should review you and are likely to scan your babies to check they are well.
- ✓ If you give birth and your babies are small or poorly, you and your partner should be asked about the care you would like them to be given, with advice from a neonatal care doctor. You should be involved in all decisions about what happens to them.
- ✓ If one or both of your babies sadly dies, you and your partner should be offered bereavement care and a referral for specialist support.
- ✓ If one or both of your babies sadly dies, you should be given clear information about consenting to a post-mortem and how it might help you understand why they died.
- ✓ If one or both of your babies sadly dies, a hospital review of what happened should take place, with input from all the hospitals where you and your babies received care. This is a review of whether your care was adequate for your circumstances. You should be informed and asked if you have any questions or would like to provide your perspective of your care.



Further support

- » If you have a concern about your care, raise it with the team looking after you.
- » Every hospital has a Patient Advice and Liaison Service (PALS) who can help you if you do not feel you are being listened to.
- » If you want independent advice about your care, these charities have helplines and support teams you can contact and information and resources you can use:

Twins Trust supports families with twins, triplets and more: www.twinstrust.org

Multiple Births Foundation supports families with twins, triplets and more: www.multiplebirths.org.uk

Bliss supports families whose baby is born sick or too soon: www.bliss.org.uk

Sands is a charity supporting families whose baby has died: www.sands.org.uk