

## The Butterfly project: The Lived Experience of Families Suffering Baby Loss



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## Welcome to the Butterfly Project

Our mission is to better understand the lived experience of families suffering baby loss in a multiple pregnancy by conducting research, raising public awareness of twinless twins, and improving education for healthcare and other professionals.

[About the project](#)



# Introduction – Loss of a Baby in a Multiple Pregnancy

- Qualitative research with bereaved parents & staff
  - Nurses, midwives, ultra-sonographers, neonatologists, parents
- “Co-twin” baby loss: miscarriage, stillbirth, neonatal death – **trigger warning**
- Co-produced guidelines
- Films & eLearning
- Butterfly family follow up
  
- **“The Butterfly Project”**

# 'Traditional' areas - neonatal research

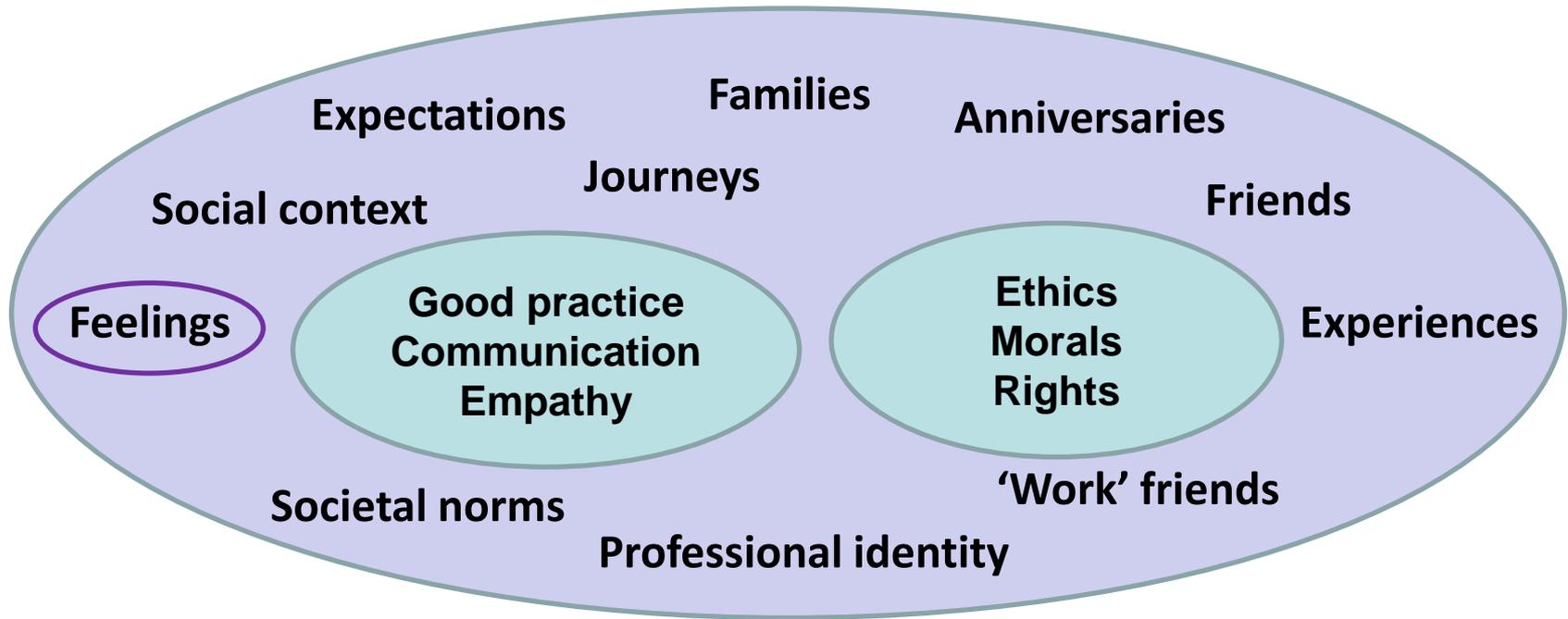
## Practical aspects

**Good practice  
Communication  
Empathy**

## Ethical aspects

**Ethics  
Morals  
Rights**

# Parent & Staff: we live in society, not in a hospital



## Life stories

# Parents feelings & experiences

- Parents were generally 'positive' about staff
- ***It's the little things that count*** – humanity in a technical world
- Remember how we made them feel decades later
  
- Unique bond with staff – ***you knew my baby***
- Don't expect NICU staff to be counsellors, miracle workers etc.
- But parents expect us to “genuinely care”

Challenges where one twin dies, and one survives

# Society is fascinated by twins & multiples



Twinning rates are increasing worldwide – lots of factors

# “Nature versus Nature”

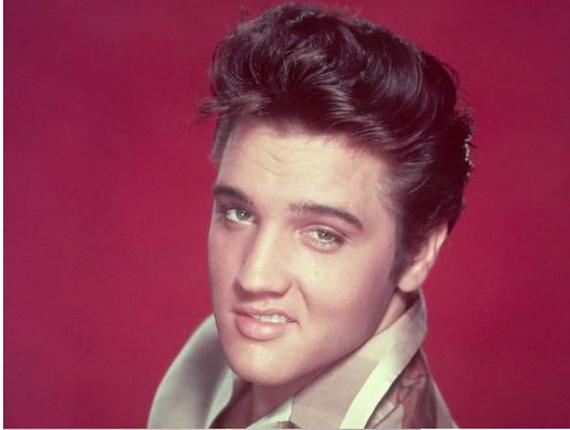


“Three identical strangers”: triplets deliberately separated at birth; Galland committed suicide at 35y age

Twins separated at birth

*Twins & multiples are seen as special – we are fascinated and moved by their stories.*

# Co-twin died at birth

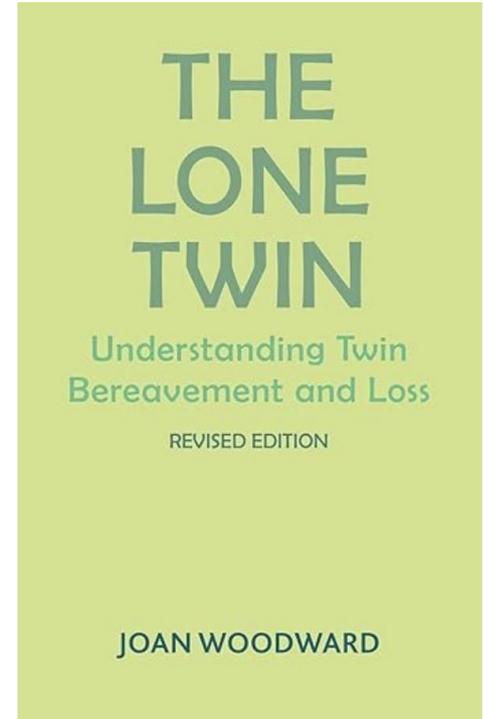


- Jesse stillborn 35 minutes before Elvis
- Elvis visited Jesse's grave regularly
- Defined his life & career
- Liberace encouraged him to be showman
- "Life purpose" to find how to connect with twin again

# Lifelong nature of twin identity?



Is anyone a twin or 'twinless twin'?



200 lone-twin adults interviewed

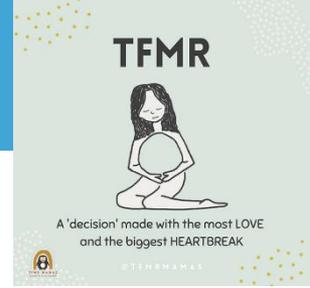
# Losing a baby from a multiple pregnancy

- Early miscarriage
- Pregnancy following assisted reproductive technology
- Termination for medical reason (congenital anomaly)
- Unexpected stillbirth
- Co-twin death on NICU

How do parents cope?

How do our behaviors help or hinder?

How can we best make a difference?



# When a twin baby dies



***“I can only hear one heartbeat”***



***“My surviving twin is still sick”***



***“I did not know she was a twin”***



***“I only visit one baby now”***



***“I’m scared to go home”***



***“When do I tell her about her sister?”***

# If you lose a twin, what must it feel like when....

- .. return to antenatal clinic after an in-utero death
- .. stay on a postnatal ward with other sets of twins
- ...return to the same room in NICU where baby died
- ...come to follow up clinic & no one says anything
- Walk down the street, see other twins in a pushchair
- Every birthday, anniversary, first day at school ....
  
- ...and what does the surviving twin think as they grow older?



***You have enormous power - your behaviours & actions affects families for the rest of their lives***

# Key themes from qualitative studies

1. **IDENTITY**: Recognise twin status
2. **ACKNOWLEDGE** the bereavement
3. **SUPPORT** the parents emotionally
4. **INFORM** - provide appropriate information
5. **CONTINUITY** – staffing, information
6. **MEMORY MAKING** – physical, emotional
7. **LOGISTICS** cot occupancy & position on NICU
8. **DISCHARGE** - Prepare parents for going home

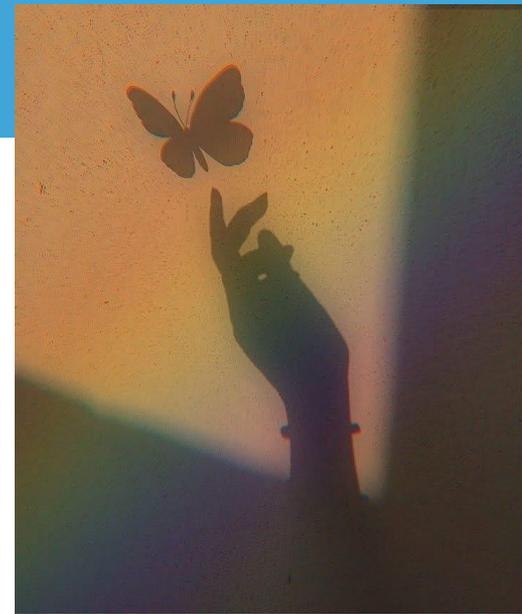
*“it was almost like  
– oh he’s not a  
twin anymore....”*

**ACKNOWLEDGE**

*Many more themes - focus on themes where we could make practical differences*

# Recognise twin status

*‘The nurses would ask ‘How was your pregnancy with him ....they forget about him being a twin and everything like that’*



**ACKNOWLEDGE**

# Recognise twin status

*‘they forget about him being a twin [Father] ’ ‘it’s not just they forget...a lot of them didn’t know’ [Mother]*

## Workshop –

*‘a little blue butterfly.....just put a butterfly on the cot then they know he’s a twin and then it solves the problem’  
[Mother]*

**ACKNOWLEDGE**



# Butterfly symbol





# Acknowledge the bereavement

*‘one of the doctors at the time really quite upset me and she often said to me **“at least you’ve still got one”**.....*

*that was one of the **worst things** that anyone could possibly say’*



**Before you tell a grieving parent to be grateful for the children they have, think about which one of yours you could live without**

**Anon.**

# Provide emotional support



*‘it was just a bit matter of fact (‘normal’) to people’* [Mother talking about the funeral]

*‘one of the nurses that was least thoughtful kept calling him [surviving twin] by his brother’s [dead twin] name’* [Mother]

Practical tip – ask parents to write the name



# Provide continuity



*‘It was really good, we knew the nurse and trusted her’*

*‘a lot of days it was a new nurse....and we had to keep explaining it again’*

- Parents found it painful to retell ‘story’
  - they want to talk about it, but expect staff to know details
- Learn the names of all the babies; offer to talk about it ***if they want***
- Sense of continuity – will they see you again?
  - Doctors & nurses.

# Memory making



*‘the nurses did it, they took footprints and handprints; I find it difficult to look at them....but I’m pleased they did’*

*‘I have got pictures....it’s nice to see that it was both of them together in the incubator’*

Importance of ‘shared’ memories – photos, blankets, toys

# Handle cot occupancy sensitively



*‘it was not nice, putting us on a ward with parents and other twins’*

*‘it was really hard, but you know it has to be done....*

**[admitting new baby into the cot/incubator space of the twin who died]**

# Prepare parents for discharge

*‘it was horrible going home ...when I had to come home that was really hard’*

*‘I thought it would get better when I got home.... but it actually got a lot worse’*

**ACKNOWLEDGE**



# Lots of themes – we can all do better



- Lifelong impact on parents' experience
- 25 years later ... parents remember how we made them feel
- Small things can make a big difference
- Project is 'more than' a Butterfly symbol
  - Think about our words
  - Behaviours in follow up clinic
  - Body language
  - Interactions

**ACKNOWLEDGE**





## Butterfly Cards

When visiting this hospital, either as a patient, partner, relative or friend please be aware of the butterfly symbol which maybe on some cribs or isolates.

This represents a baby that was part of a multiple pregnancy but sadly not all the babies survived and parents have chosen that they wish to make others aware.



Scan for more information

www.theskyehighfoundation.com



**Guida de un embarazo gemelar**  
para profesionales de la salud

## Spanish

*Este manual surgió de una investigación que identificó la necesidad de la salud en la asistencia a los padres tras de la de un embarazo múltiple. Fue desarrollada en colaboración con profesionales de la salud en esta especialidad. El ánimo de estas recomendaciones sin ser obligatorias.*

## German French

**Leitfaden nach einer Zwillings-Schwangerschaft**  
Leitfaden für medizinische Berufe

*Este manual surgió de una investigación que identificó la necesidad de orientación para profesionales de la salud, a fin de que pudiesen ofrecer apoyo a los padres tras la muerte de uno de los bebés en un embarazo múltiple. Fue desarrollado en colaboración con profesionales que trabajan en esta área. Recordamos que su objetivo es ofrecer sugerencias a los profesionales, para ayudarlos a lidiar con el asunto. Agradecemos comentarios y sugerencias que puedan mejorar este manual. Por favor envíenlos para el Dr. Nicholas Embleton (Consultor en Neonatología) nicholas.embleton@newcastle.ac.uk*

## Portuguese

**Perda na gestação gemelar**  
Orientações para profissionais de saúde

*Este guia surgiu a partir de uma pesquisa que identificou a necessidade de orientação para profissionais de saúde, a fim de que pudessem oferecer apoio aos pais após a morte de um dos bebês numa gestação múltipla. Ele foi desenvolvido em colaboração com profissionais que trabalham nesta área. Lembramos que seu objetivo é oferecer sugestões aos profissionais, para ajudá-los a lidar com o assunto. Agradecemos comentários e sugestões que possam ajudar a melhorar esse guia. Por favor envie-os para o Dr. Nicholas Embleton (Consultor em Neonatologia) nicholas.embleton@newcastle.ac.uk*

Atualizações e versões em idiomas estrangeiros podem estar disponíveis em nosso site [www.neonatalresearch.net/butterfly-project](http://www.neonatalresearch.net/butterfly-project)

Estas orientações foram desenvolvidas com o apoio de Sands (Stillbirths and Neonatal Death Charity - [www.uk-sands.org](http://www.uk-sands.org)) e da Fundação Multiple Births ([www.multiplebirths.org.uk](http://www.multiplebirths.org.uk)) e são endossadas pela Fundação Europeia para o Cuidado de Recém-Nascidos ([www.efcni.org](http://www.efcni.org))

## Italian

## Japanese

## Russian

## Romanian

*Not all twins walk side by side;  
Sometimes one has wings to fly.*





[usa@theskyehighfoundation.com](mailto:usa@theskyehighfoundation.com)

# About Us



## ABOUT THE SKYE HIGH USA FOUNDATION

The Skye High USA Foundation was set up to support families during and after the loss of a twin, triplet or multiples.

The Skye High Foundation was established with one main mission: to offer support and care to families who have experienced the loss of a twin, triplet, or multiples by providing clinical resources and bereavement support.

Founded by bereaved parents who have faced similar heartache, they understand the devastating journey that parents, siblings and extended family members navigate during these difficult times. While already in use in every neonatal unit in the United Kingdom, the foundation now aims to expand these resources to hospitals and other institutions in the United States and later, around the world. Their goal is to provide opportunity for enhanced clinical support, remembrance of loss and for families to be supported, whilst avoiding unnecessary and avoidable comments.



- ‘Struck’ by the power of **hearing parents speak directly**
- Film project with ethnographic film maker: families & staff



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About the project



## Parent experiences



1. Feeling special about having twins



2. When parents lose a twin baby



3. Acknowledging bereavement and twin-ship



4. Coping with trauma and putting grief on hold



5. Demonstrating emotion to parents



6. Providing parents with continuity of information



7. Continuity of Staffing & Trust



8. Location of Care



## Loss of a Baby in Multiple Pregnancy: Supporting Grieving Parents

We have produced a 4-hour eLearning course aimed at health care professionals but may also be of interest to families and friends.

This course can be accessed for **free** by **NHS** and **affiliated staff**. Non-NHS staff can access the course for free for a 2-week period, or longer by paying a small upgrade fee.

[Find out more](#)

### Resources

[4-hour Future Learn Course](#)

[Guideline downloads](#)

[Clinical practice points](#)

[Advice for family & friends](#)

[Links & support groups](#)

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## Advice for family & friends

**We know that many family members and friends struggle to know what to say or do. Here are some suggestions to help you offer support.**

We will add more resources over the next few months. If you have ideas you want to share please [get in touch with us](#).

Every situation is different, every mother and every family are different, and what 'works' for some parents may not work for others. Don't pre-judge or assume. No one can be prescriptive about what to say or do, but here were some phrases and behaviors we heard about that were typically either helpful or not helpful.

### Phrases that were un-helpful

- At least you still have one
- You can try again (for another pregnancy)
- It wasn't meant to be
- Maybe you weren't ready; maybe [twin's name] wasn't ready
- Why don't you stop thinking about or forget about [twin's name] and just focus on the other twin?
- You'll get over it

### Resources

[4-hour Future Learn Course](#)

[Guideline downloads](#)

[Clinical practice points](#)

[Advice for family & friends](#)

[Links & support groups](#)

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- 4 hours CME/CNE learning with peers
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- Upgrade for certificate on completion
- Endorsed by >20 advocacy & professional organisations



Free to access online course  
[www.futurelearn.com](http://www.futurelearn.com)



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## Introduction

In this opening activity, our lead educators and experts outline why this course is so important, and invite you to reflect on personal and professional approaches to twin loss.



- [1.1 Introduction to twin loss](#) AUDIO
- [1.2 Approaching the topic as a caring professional](#) ARTICLE
- [1.3 Starting the conversation](#) DISCUSSION

## Twins, triplets and more

In this activity, we'll be looking at the different types of multiple pregnancies, when and how they occur and the typical timelines of early pregnancy.



- [1.4 Glossary](#) ARTICLE
- [1.5 Early pregnancy: how twin pregnancies occur](#) ARTICLE
- [1.6 Pregnancy timelines, miscarriage and stillbirth](#) ARTICLE
- [1.7 Feeling special](#) VIDEO (03:14)
- [1.8 Pregnancies with multiples: what's different?](#) ARTICLE

## Loss of a baby from a multiple pregnancy

In this activity, we explore parents' experiences when complications arise during pregnancy, or after the babies are born, and reflect on what it feels like to lose one or more babies, but still have at least one surviving baby.



- [1.9 Loss of a co-twin fetus or baby](#) ARTICLE
- [1.10 Supporting parents for the future](#) DISCUSSION
- [1.11 Personal experiences of twin loss](#) VIDEO (05:08)
- [1.12 Professional approach to acknowledging twin loss](#) AUDIO

## Acknowledging bereavement and twin status

Here we will learn more about the importance of recognising twin status, acknowledging grief and loss, and the importance of remembering the name of the baby who died.



- [1.13 Baby names and twin identity](#) DISCUSSION
- [1.14 Acknowledging twin identity and loss](#) AUDIO
- [1.15 Butterfly symbol and cot cards](#) ARTICLE

## Coping with trauma and putting grief on hold

In this activity, we consider the range of emotions experienced by parents suffering co-twin loss, and discuss how they try to balance the conflicting emotions of joy for the surviving baby, and grief for the baby who died.



**1.16** How do you process grief? [DISCUSSION](#)

**1.17** Parent stories of loss and grief [VIDEO \(04:39\)](#)

**1.18** Differences in the experience of grief [ARTICLE](#)

## Baby loss in multiple pregnancy

In this activity, we learn how parents feel with the additional challenges that arise in a twin pregnancy, and identify actions that can improve parents' experiences.



**1.19** Your reflections on the challenges [DISCUSSION](#)

**1.20** Looking forward: demonstrating emotion [ARTICLE](#)

## The lifelong nature of twin loss

Parents never forget about their babies. In this activity we think about the challenges parents face in the first few weeks and months, the challenges of birthdays and anniversaries, and how wider family and friends can help.



**2.14** Coping with the lifelong nature of twin loss [ARTICLE](#)

**2.15** Acknowledgment and support from friends and family [DISCUSSION](#)

**2.16** Siblings, stories and families [ARTICLE](#)

**2.17** Moving forwards [VIDEO \(03:58\)](#)

## Wrap up and connect

In this activity, we will reflect on how best to support parents in different settings and understand how families grow to develop positive memories of their lost twin.



**2.18** Resources and networks [ARTICLE](#)

**2.19** Helping parents tell their story [AUDIO](#)

***“This course is outstanding, so much information to help others & raise awareness”***

***“This is a really powerful, relevant and important course.”***

***“Such great tips ....Even after a long time in nursing we can improve on how to deal with loss.”***

***“What an amazing resource to allow us as professionals to take a little time to understand”***

***“It’s so true that it’s the little things. I have taken away so much from this course and hope to implement service improvements.”***





# Indebted to parents who felt able to share their experiences with us

[www.neonatalbutterflyproject.org](http://www.neonatalbutterflyproject.org)

# Compassionate leadership

- Live in someone else's shoes
- Not just a 'cot card' – **behaviours & actions**
- **It's the little things that count** – never under-estimate your 'power'
- Act as a **leader** – demonstrate to others this is important
- Learning, reflecting and acknowledging makes your job more rewarding

**ACKNOWLEDGE**

# Key themes



1. **IDENTITY**
2. **ACKNOWLEDGE**
3. **SUPPORT**
4. **INFORM**
5. **CONTINUITY**
6. **MEMORY MAKING**
7. **LOGISTICS**
8. **DISCHARGE**

- Recognise twin status
- the bereavement
- the parents emotionally
- provide appropriate information
- staff & communication
- twins together; start early
- cot occupancy on NICU
- prepare parents for going home

Many more themes

**ACKNOWLEDGE**

# Research 2024 – family life & growing up



- Collaboration with networks & families
- 203 families
  - *How do you remember the baby who died?*
  - *What do you say, if asked “how many children do you have”?*
  - *What do you do on anniversaries, birthdays?*
  - *Do you feel triggered when you see other twins/triplets?*

# Tell me about you

*I am a lone twin, my identical twin died at 5 days old...I've always felt that there was some part of my life missing....*

*....being a lone twin affected me growing up, I never felt like I fitted in anywhere, I've always had a feeling of loneliness which I can't explain*



# When did you tell your other children?

*My survivor has always known she's a twin & we have talked about this in different ways as she & her older brother grew up.*

*However, I have still been unable to tell them I had TFMR for Susan, just that their sister died in the womb.*

*Now they are grown up I wish I'd told them before because now it feels a huge deal.*

# How many children do you have?

*If it's someone who I am going to have a long conversation with or someone I will see again (ie not a complete stranger) then I say that I have two children but that Kai is a twin and that his brother died aged 12 hours from a heart defect.*

*It's only if I'm having a fleeting conversation with a stranger, I don't mention it. But then I do feel guilty afterwards.*

# Talking about the twin

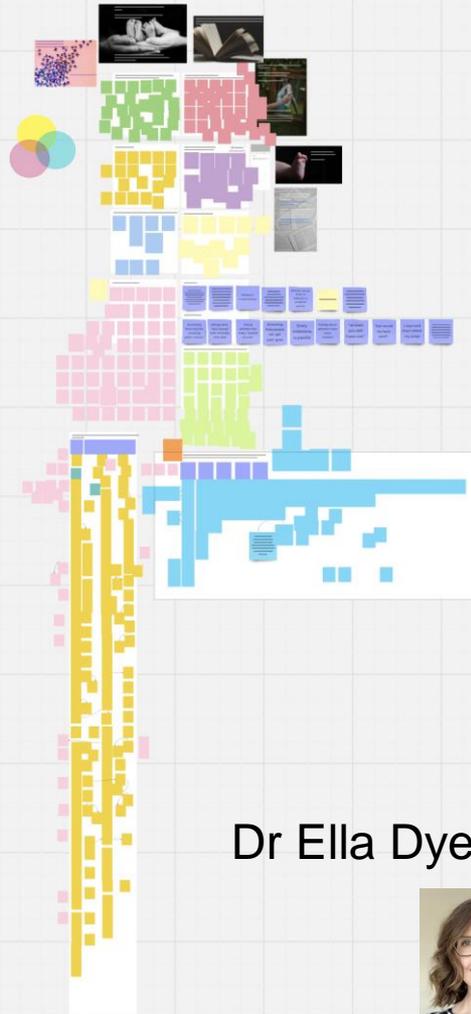
*I feel as though no one mentions it or asks so I feel awkward bringing it up*

*I just want it to be acknowledged. I feel like no one else remembers my loss baby or how sad it is that she's not here alongside my survivor.*

# Seeing other twins

*It feels like an exciting club that I never quite got access to...I never got the opportunity to feel like a twin mum and it seems such a special thing that I missed out on. It makes me feel sad for Kai that he will never know that bond*

# Qualitative analysis



Dr Ella Dyer



# Wrapping up

## Acknowledgment is key

You have the power to make a lasting difference to families' lives

## Acknowledgements

Many amazing parents  
NICU team  
Research team

The Newcastle upon Tyne Hospitals NHS Foundation Trust  
Newcastle University

### Loss of a Baby in Multiple Pregnancy: Supporting Grieving Parents

Gain a deeper understanding of what parents go through when losing a baby in a multiple pregnancy and how to support them.

★★★★★ 5.0 (3 reviews) 619 enrolled on this course

- 2 weeks
- 2 hours per week
- Digital certificate when eligible
- Intermediate level

[Join course](#)

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Online Courses / HealthCare & Medicine  
The Newcastle upon Tyne Hospitals NHS Foundation Trust  
Newcastle University

### Lactation After Loss: Choices for Bereaved Parents

Help bereaved parents understand their lactation choices following pregnancy and baby loss.

- 2 weeks
- 1 hour per week
- Digital certificate when eligible
- Intermediate level

[Join course](#)

[Find out more about how to join this course](#)

The Newcastle upon Tyne Hospitals NHS Foundation Trust  
Newcastle University

### Managing Uncertainty in Perinatal Medicine and Palliative Care

Support families through uncertain perinatal journeys with holistic care and communication strategies.

- 4 weeks
- 1 hour per week
- Digital certificate when eligible
- Intermediate level

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