



**Brave
HeARTs**

This book is dedicated to Edith, Alana and Lilith

With thanks to the women who took part in this project for their strength and courage in sharing their experiences and allowing their work to help others.

This book was created through a series of creative workshops with women in Greater Manchester who have had a stillbirth, researchers from The University of Manchester's Maternal and Fetal Health Research Centre, the Public Programmes Team at Manchester University NHS Foundation Trust and local artists, Chava Erlanger and Jenny Berry.

Copyright © The University of Manchester 2019

Introduction

Bravehearts is a booklet created by three women in the UK whose babies were stillborn. The booklet showcases the artwork, including drawings, collage, clay sculptures and poetry they created whilst taking part in a project called Still Life. The pieces reflect on their own experiences of their bereavement and also the research that is being conducted to help understand why stillbirth happens so that it can be prevented from happening to others.

They hope that through this booklet their work can be used to raise awareness of stillbirth and neonatal death and the importance of the research taking place to prevent it. They also hope it will help other families going through these tragedies to realise they are not alone. The name BraveheARTs was chosen by the women to represent the bravery of families who go through the loss of a baby, and their use of art and creative techniques within the project.

Also included in the booklet are pieces created by midwives, pregnancy researchers and facilitation staff who also took part in the project alongside the women. The midwives and researchers involved were from a research group that works on the topic of stillbirth to understand why it happens, to try to prevent it in future and to improve the care and support families who face the loss of a baby.

How the Still Life Project started

The Still Life project was set-up in September 2018 through collaboration between Europe's largest pregnancy research centre – The University of Manchester's Maternal and Fetal Health Research Centre, based at St Mary's Hospital in Manchester, and the Public Programmes Team at Manchester University NHS Foundation Trust. The Public Programmes Team is a specialist unit working to involve and engage the public in health research.

The original aims of the project were to:

- Raise awareness of stillbirth and neonatal death
- Provide a safe space for women who had experienced the loss of a baby to explore this and help break the taboo around talking about stillbirth
- Provide an opportunity for women who had experienced the loss of a baby to meet with researchers and research midwives to learn from each other
- To provide a space for discussions

Women from in and around Greater Manchester were invited to take part in a series of guided workshops over four weeks. The workshops focused on a different theme each week to help guide the art and the discussions, however participants were free to create pieces that were reflective of what they wanted to focus on. The workshop themes were:

Week 1: The womb (drawing, oil painting)

Week 2: The placenta (collage)

Week 3: Research on the prevention of still birth (clay sculptures)

Week 4: Womb words (poetry)

The pieces created in the workshops were shown at a public exhibition in November 2018 in Manchester. This booklet has been created so that others can see these powerful works of art.

How you can use this booklet

You can use this booklet in any way that is helpful to you. We hope it will help families who have had a loss, but also those who are trying to understand more about the impact losing a baby can have. You can use it to reflect, as a discussion point or as inspiration to try using art and creative techniques in your own life. At the back of the book there is a space for you to reflect on your experiences, and suggestions of things you can do if you want to explore your thoughts and feelings using these techniques. There is also a list of support resources which you may find helpful.

Find out more

If you would like to find out more about this project or the ways in which you can get involved in helping to shape pregnancy research then please contact:

Katharine Cresswell at katharine.cresswell@mft.nhs.uk or call 0161 276 6614.

This work was supported by a Wellcome Institutional Strategic Support Fund award [204796/Z/16/Z] and a donation to the Maternal Fetal Health Research Centre made to commemorate Professor Harold Fox.

Help...how can I help?
Let's work together to make it easier

Engage...we are powerful together

Listen carefully to families

Placentas...

...together let's learn more about it to reduce stillbirth

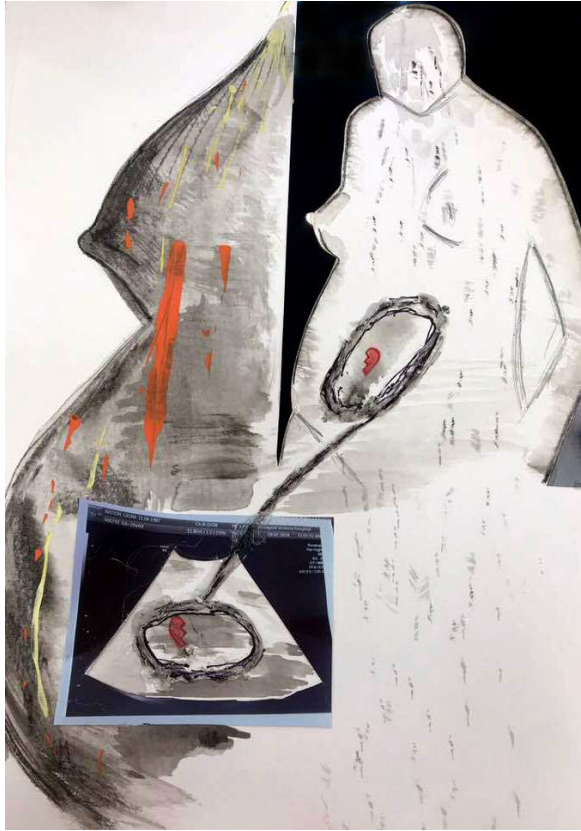
Research Midwife

LONGING

Lost myself in this grief
Or am I with you
Never told you
Goodbye
I don't see it that way
Not giving up hope that I'll
Get to hold you again...one day

Edith's Mummy





NOW and THEN

Two parts of the same image.

A moment captured in a perfect present has now become memory.

A memory of life with her...The warm glow of THEN and a past that held so much promise.

The fragmented greyness of NOW. Without her life is hollow and flat. My future uncertain, forever shaped by the love, the beauty and the loss of my first born child.

Edith's Mummy



“The Beauty”

This piece represents the beauty of my pregnancy. Just because my daughter died and the pregnancy wasn't textbook it does not mean there wasn't happiness or beauty.

The beauty is washing the hand-me-downs that my husband and his siblings wore and tearing up from happiness. Beauty is my husband playing pat-a-cake through my belly with Lilith as I slept. Beauty is craving anything and everything spicy and not even breaking a sweat while eating it. Beauty is Lilith headbanging during her nuchal scan, covering her face every time they looked and turning around when we tried to find out the sex. Beauty is giving Daddy the idea to write an honest guide to pregnancy; “50 Shades of Green.”

Beauty is our daughter and her name is Lilith.

Siobhan Triplett – Mum of Lilith

The Placenta is amazing

But it is also complex

It supports the life of the baby during pregnancy

But it can also be responsible for taking that life away

We expect our baby to be born alive and well

But when a baby is stillborn we ask why?

The placenta is complex

The placenta can fail

Let's try to understand why

Researcher



The placenta is at the centre of the research we are undertaking into stillbirth. Although there are many things we understand about the placenta and how it works, there is still so much we don't know. I have coiled the vessels into question marks to represent all the things we have yet to learn about the placenta, why some placentas don't work as they should and what we can do about it.

Research Midwife



My Placenta

The colours represent all that is beautiful and positive in my pregnancy.

The heart is my baby – but it is empty – I feel empty

The placenta is surrounded – encased in black – grief/sadness/
heartache

It is attached to a question mark – was this what killed my baby?

It is made up of broken pieces – my broken pieces.

Mary – Alana Willows' Mummy

I wish when you'd asked me, you'd mentioned her name.
Yet you simply decided to call her 'all that'
I agree when you told me it just isn't fair.
Yet in the next breath you said 'it's just one of those things'
I love to hear you say you thought about Edith.
Yet when I think about her you say, 'let go, move on, come
back'
I can't come back, because she can't come back.
I know that she's gone, but I won't ever let go.
I'm telling you her spirit forever is in me, so when I start to
move on, she's moving with me.

Edith's Mummy

So why did it happen?

There is not enough known

I want to understand

Let me find out

Let me try!

By doing my

Important job of

Researching the placenta

To help more babies be born alive,

Healthy and well.

Researcher



'Looking closely at the Placenta'

The umbilical cord in the shape of a magnifying glass symbolises how researchers are investigating the placenta to understand how it works and develops and why it can fail.

MFHRC Researcher

What Can I Say?

Help me, help me,

What can I say?

I know you are hurting

But what can I say?

“What did you call her?”

Lilith, Alana and Edith

“Have you got a photo?”

Beautiful, lovely, gorgeous

“How are you coping?”

“What can I do?”

For you and your lovely baby?

Lilith, Alana and Edith

Project Evaluator

How are you?

Shit

Maybe you'll win the lottery?

Great, I'll just buy another baby shall I then!

I'm tired of lugging this weight around

If you don't want them, I'll take them

She's in a better place

If it's so much better then why aren't we all there?

You'll have more

I might but I still want the child I lost

There's no point sitting in a corner crying about it

No but it's acceptable to cry over car insurance apparently

I've had ten miscarriages and you don't see me complaining

*I'm sorry for your losses but this is different and we are different
people*

I'm sorry, I don't know what to say

Neither do I but thank you for being honest

Siobhan Triplett – Mum of Lilith

It happened for a reason
A baby taken from their mother
It happened for a reason
A lifelong grief we'll suffer

It happened for a reason
All the firsts we'll never know
It happened for a reason
We can never watch her grow

It happened for a reason
The "What-ifs", "Hows" and other questions
It happened for a reason
To some it may seem like an obsession

It happened for a reason
Our beautiful daughter was born still
It happened for a reason
We may never know the answers
Or maybe we will

Siobhan Triplett – Mum of Lilith



“Flat-cake”

The word placenta originates from the Latin “Plakous” (flat-cake) and Greek “Plakount” (flat plate.) The word is based more on how it looks rather than what it does. One of the common words used about the placenta in the workshops was “complex”, and it is. The placenta not only gives life but can take it away. With something so complex it is sometimes probably easier just to look at it.

Siobhan Triplett – Mum of Lilith



'The Tape Measure'

The tape measure became an item that was hated as it showed that the baby was no longer growing.

Sculpture created by Edith's Mummy, description by Workshop Facilitator

'Fail'

This sculpture represents the failure of the placenta.

Sculpture created by Edith's Mummy, description by Workshop Facilitator

Review what's happened

Evidence is what we need

See what we need to do

Ethically

Arrive at a question

Randomise or

Cohort, or ask the Mums themselves

Hope we find an answer

Project Evaluator

“How are you?”

“How are you coping?”

“What was wrong with her?”

“Do they know what happened?”

“You can always have more”

“You’ll always be her Mum”

They see me and turn the other way

“I’m sorry, I don’t know what to say”

“There’s no point sitting in the corner crying about it”

“Just do what you need to”

“At least...”

Just don’t!

Siobhan Triplett – Mum of Lilith



The eternal question

This piece shows both the placenta and the umbilical cord going from a healthy pink colour to a necrotic black. From life to death and all the devastation this encompasses. It is in the shape of a question mark representing all the questions families have when their baby is still born. It also represents all the research questions that need to be answered to help prevent still birth and the huge importance of this work.

Project co-ordinator

Grief

It is true when they say grief happens in stages but there is no linear path that these stages follow. It is like a massive storm in the sea and you are in there, trying to keep your head above the water. Often there are huge waves and you will be drawn under the water whilst they crash down on top of you. You can't breathe. You panic. There is a constant dense, black cloud over your head. You can't see anything ahead of you apart from a dark empty space. You feel hopeless, helpless, weak, broken. Every now and then the water starts to settle and the sun suddenly peeks through a gap in the clouds. You are still working to stay above the water but you don't need to use as much energy. The warmth from the sun feels good... it makes you smile. It makes you remember how life was before this everlasting storm appeared. Your feet still haven't touched the ground but you can see land in the distance and start to swim towards it. However, as quickly as the sun comes the cloud closes in on you and you are once again battling with the fucking storm. Your sense of direction has disappeared. The rain is pelting you in the face, physically hurting you all over... making you ill and run down. If it was only you in the water then you would probably give up but your family are waiting for you on land... your children... they have got everything together to try and save you but the storm is so bad they are unable to get into the water and get close to you. And so you have to find the energy to save yourself for them. It's exhausting. As time passes the sun starts to appear more often and it stays for slightly longer. When it's there you can see clearer and it gives you hope that the storm might start to pass. However... 8 weeks into my journey I'm not being fooled!!! The storm is still there... very much the dominant force in my life. But at least I have hope...

Mary – Alana Willow's Mummy

This represents my placenta at each stage of my pregnancy. I managed to get to the all-important 12 weeks and my baby was fine. We are led to believe that once we reach the 12 week stage then all is well - all is gold. As the weeks go on you can see that my placenta starts to become poorly. It isn't smooth anymore and it is dying. All the while my baby remains the most precious thing throughout. She has been painted gold. My baby died at 37 weeks - right at the end of my pregnancy. I have added wings to represent my angel baby. I have wrapped the cord around her neck as it was when she was born. We don't know if this caused her death yet. We also don't know if it was my placenta. The cord is also attached to my pregnancy journey. It was uneven and overshadowed with blackness - however the gold (my baby) always shines through.

The small gold sculpture represents how a pregnancy journey is generally seen once you hit the 12 week mark. Smooth - without flaws and bright.

Mary – Alana Willow's Mummy



“Daddy Doesn’t Matter”

He didn’t carry you for nine months
He would have carried you a lifetime

He wouldn’t have breastfed her
He would have had tea parties and teddy bear picnics with her

He would have been at work full-time
He would have appreciated every moment he spent with her

He didn’t feel them kick inside
He played pat-a-cake through Mummy’s tummy as she slept

He didn’t give birth
He watched the woman he loves give birth to their sleeping
daughter

He doesn’t matter
He is her Daddy

He doesn’t matter
He was half of her whole world

He doesn’t matter
He is Lilith’s Daddy and she is his daughter

Daddy does matter

Siobhan Triplett – Mum of Lilith



Precious

I created this piece after listening to the amazing women in the workshops. The bronze colour represents the preciousness of their babies, nestled next to the placenta providing life.

Project Co-ordinator

Try it yourself:

- Why not try creating some of your own pieces at home. You do not need to be an artist or creative in order to benefit from this activity.
- You just need some paper or a sketchbook and a pen or pencil to start. Starts by just drawing or creating whatever feels natural, it can help to focus on a topic to start such as how you feel about your body, how you feel about your baby.
- You could also try experimenting with water colours, oil pastels, charcoal, (which you can often buy at pound/bargain shops) or making pictures from old magazines and materials
- It is not about the quality of work, it is about using art and writing as a non-verbal expression of what you are feeling and what you have experienced.
- All you need is 5 minutes a day (you may end up spending an hour) to put on paper what you are feeling.
- There is no right or wrong, it is yours, your partner's and your baby's story.
- You don't need to show it to anyone, but it may be helpful to take along to your counselling session, or to share with loved ones and at support groups etc.
- Putting your thoughts and feelings on paper is a great way to 'see' your emotions and feelings, and might help you to start to understand your grief.
- Understanding and accepting your loss and grief is one of the first steps to healing and acceptance.

This page is a space for you to draw for yourself, or write your baby's name:

This page is a space for you to draw for yourself, or write your baby's name:

This page is a space for you to draw for yourself, or write your baby's name:

The Maternal and Fetal Health Research Centre

Experiencing the loss of a baby is something no-one should have to go through, however, we know that in the UK, nine babies are stillborn every day.

In Manchester the Maternal and Fetal Health Research Centre (MFHRC), a team of around 50 doctors, midwives, researchers and research students are working on understanding the reasons why stillbirth and neonatal death happens and how they can be prevented. A lot of the work they do focuses on the placenta, the organ that is formed in the womb when a baby grows that is shared between a Mum and her baby.

Are you interested in helping improve research?

When researchers design and run research projects they often need to work alongside members of the public with experience of what they are researching to ensure what they are doing is being done in the best way for current and future patients. Getting involved with research in this way is known as Patient and Public Involvement (PPI).

The MFHRC has a Patient and Public Involvement group which you can join. When you have joined this group you will be invited to take part in activities about different research studies. This may include coming along to meetings face-to-face or doing activities over the phone or by email. Once joined you are under no obligation to take part in any activity you do not wish to.

The kind of activities you may be asked to take part in are:

- Helping researchers understand what topics are most important to research next
- Helping researchers understand whether patients/parents would take part in the research they are proposing
- Looking at information that will be given to patients to explain a research study to make sure it makes sense

If you would like to join the MFHRC PPI group, or would like some more information, please contact Katharine Cresswell on Katharine.cresswell@mft.nhs.uk or call 0161 276 8943.

Information and support available:

Tommy's

Tommy's is the largest UK charity funding research to prevent stillbirth

Speak to midwife on Tommy's free Pregnancy Line: 0800 0147 800, Open 9-5 Monday to Friday

www.tommys.org

Midwives Clinic

Saint Mary's has a dedicated team of bereavement midwives able to help at this very difficult time.

Bereavement.midwives@mft.nhs.uk

Family support: 0161 701 8700

Rainbow Clinic

The Rainbow Clinic is a specialist service for women and their families in a subsequent pregnancy following a stillbirth or perinatal death. We care for families from the time of the postnatal appointment to discuss investigations onwards and into a subsequent pregnancy.

Contact details: 0161 701 0866

Sands

Stillbirth and neonatal death charity. The Sands National Helpline provides a safe, confidential place for anyone who has been affected by the death of a baby. Whether your baby died long ago or recently, we are here for you.

Helpline: 0808 164 3332 / helpline@sands.org.uk



Tommy's
Funding research
Saving babies' lives

*CHAVA
ERLANGER*

MANCHESTER
1824
The University of Manchester



Public Programmes
People | Research | Dialogue
at Manchester University
NHS Foundation Trust

