

MISCARRIAGE
ASSOCIATION

The knowledge to help

Newsletter Autumn/Winter 2020



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Please note that the opinions expressed in the newsletter are not necessarily those of the Miscarriage Association or of the editor.
 The editor and management of the Miscarriage Association reserve the right to shorten articles submitted for publication, while retaining their original meaning.
 REMEMBER – this is our newsletter – written for and by women and men whose lives have been affected by pregnancy loss and who want each others' support. If you feel the newsletter fails to give you the information or support you need, please let me know and I will do my best to change things.

Office hours: 9.00 – 4.00
Monday – Friday.

Readers' letters are always welcome, as are personal accounts and poems. All letters to the editor will be assumed to have been submitted for publication unless clearly marked to the contrary. Names can be withheld on request.

Please send newsletter copy to:
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All other material should be sent to Head Office.

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EDITORIAL

Hello, and welcome to our Autumn/Winter newsletter.

As the Covid-19 virus still holds the world within its grasp, we now tentatively settle into a 'new normal' way of coping with the day to day routine of living our lives alongside ever changing restrictions.

Life does go on and thankfully, so does the dedication, hard work and commitment of the Miscarriage Association, helping as always, to guide women, men and their partners through the sadness and uncertainty of miscarriage, ectopic and molar pregnancy in a rapidly changing world.

Within the pages of this newsletter, I was particularly interested in the way Miscarriage Support Groups which cannot presently meet face to face, are evolving into Zoom meetings with nine groups presently available. This may not replace the cups of tea and hugs, but the feedback has been really positive. See page 5 for details.

At whatever stage you are in your journey to start or complete your family, stay safe and may I wish you peace, health and happiness for 2021.

Peta.



Peta Harrison, Editor.



LETTER FROM THE CHAIR



Laura Norris, Chair of Trustees

In the Spring/Summer newsletter I talked about how the Trustees had agreed the next five-year strategy at our Annual Planning meeting in March and I promised to share more details with you in this newsletter.

After a long and in-depth planning process we agreed our five key aims are to:

- Provide high quality support & information and make it accessible to all who need it
- Support more health professionals in more settings provide high quality, compassionate care
- Ensure more policy, research & funding decisions acknowledge pre-24 week loss
- Stop pregnancy loss being a taboo so people feel able to talk openly about it if they want to
- Make sure everyone knows about the Miscarriage Association.

Everything we do continues to be underpinned by our values, our culture

and our vision so that 'Everyone affected by pregnancy loss gets the care, support and information that's right for them'.

Over the last 6 months (and likely for the next 12 months), Coronavirus has meant our plans under each of these aims has had to be scaled back slightly as we focus on the increased demand for our services and a reduction in funding. We still have very ambitious plans for the next year and are looking forward to building the longer term plans under each of our aims in the coming months.

We would love to hear your feedback on our strategic aims and please, as always, do let us know what is most important to you.

Thank you for your continued support and please stay safe!

Laura

LETTER FROM THE TERRACE

A warm hello to all our members and supporters from the team at the Miscarriage Association's Wakefield office.

Except, of course, that we're not at the office. At the time of writing, we're all still working from home, with just the occasional days when one or another of us needs to be at our 'real' desk, even if it's only for an hour.

Despite the challenges of working remotely, our helpline team is operating as normal – and coping with a 37% increase in calls, emails, live chat and direct messages since lockdown. While physical support group meetings are still suspended, we now have nine groups meeting via Zoom (see page 5). And despite the cancellation of many mass participation events, especially the London Marathon, which is a significant income generator for us, our supporters have embraced a variety of other fundraising events to help fill the gaps (see pages 14/15/16).

In July we were delighted to welcome a new ambassador for the M.A., former Strictly professional Natalie Lowe (see page 4). We have continued to develop our online resources, with our shareable Virtual Hugs and a host of new stories on our website; and by the time you read this, we'll have officially launched our new resources for employers and employees, Miscarriage and the workplace.

There is no doubt that these are very tough times for all of us as we live through huge changes and disruption to our home, work and social lives, as well as the additional grief caused by illness, loss and isolation. And yet, despite all those challenges, we have also seen great kindness, support and generosity. Our thanks to all of you – volunteers and fundraisers, staff and Trustees, advisors, colleagues and healthcare providers – who are helping us to help people through.

Ruth, Lisa, Ann, Alice, Juanita, Helen, Karn and Vicki.



Q&A WITH OUR NEW AMBASSADOR

Ruth asks the questions and Natalie answers:



Q: Did you use the M.A. yourself or did you find out about us later?

A: I did use it. I called the helpline and I remember what a relief it was to talk to someone who understood and listened.

Q: Do you think it's still difficult for people to talk about miscarriage?

A: I hardly told anyone about my first miscarriage. I felt uncomfortable, embarrassed... I didn't want people feeling sorry for me or to upset anyone or make them feel uncomfortable. When I did tell people, though – and especially when I went public – there was such a lovely response from people, especially other women who had been through it themselves. I'm so glad to have got miscarriage talked about a bit more and that's what I want to keep doing.

Q: So is helping people be more open about miscarriage and raising awareness something that's really important to your work as an ambassador for the M.A.?

A: Yes, it is. Miscarriage is such an awful thing to go through – and not just for women but for our partners too. I want to get it talked about more and to promote the M.A. as a place where people can find support and understanding and really helpful information.

Q: Natalie, we were delighted when you got in touch to say you'd like to support the work of the Miscarriage Association. Can you say something about what led you to do that?

A: It's really because of my own miscarriages. When I got in touch, as you know, I had just decided to speak out publicly about my experiences of miscarriage, about what a dark place I was in at that time and what helped me. I did that because I wanted to reach out to people, to reassure them that they aren't alone. And I wanted to let them know that there is help out there, especially the M.A..

Q: And you're supporting our Miles That Matter fundraising campaign too.

A: Absolutely. I think it's such an important campaign right now, when the pandemic is having such an impact on the work you do and on your funds. You've told me that you're getting far more calls for help since the lockdown in March, but at the same time you've got less income than you'd normally expect, especially with many fundraising events being cancelled. So a campaign to raise funds for staffing the helpline, when people need it more than ever - that really appeals to me.

Q: And the campaign timeframe leads us up to the last day of Baby Loss Awareness Week, on the 15th of October. Do you have any thoughts about that day or week?

A: It's incredibly important. This year more than ever we need to raise public awareness about the facts and feelings of pregnancy and baby loss.

Q: Thinking about all of this, Natalie, what's the most important message that you'd like to get across to people about pregnancy loss?

A: It's okay not to be okay, speaking about it is extremely healing and can help things to eventually get better. Help is there - don't go through this alone.



SUPPORT GROUPS WITHOUT BORDERS

It was a real blow to have to suspend our normal face to face support group meetings in March, but thankfully, some of our volunteers have been able to offer a different kind of meeting, thanks to the wonders of Zoom.

Meeting on Zoom is definitely different. No touching, never mind hugs; no cups of tea to help break the ice; no quiet corner chats or easy eye contact. But there are also no geographical boundaries, no need to leave the house, and the option to take part without using the video link for those who prefer that.

We now have nine groups meeting monthly across the UK, including one for people pregnant after loss. There is at least one group meeting each week so that people have the option of attending more than one group per month.

Dates and times are up on our website and people just need to contact us to ask for the Zoom link to take part.

Feedback has been really positive, as one attendee reported:

"It was the first I attended and words can't begin to describe how incredible I found it. It was good to finally be able to share my experience with another group of women who'd been through similar. I wanted to give each and every one of them a virtual hug! I have woken today feeling the best that I have since the situation began, and finally feel like a weight has been lifted."

Our sincere thanks to all the support volunteers who have made this possible.

Find information about all our support groups on our website www.miscarriageassociation.org.uk/how-we-help/support-groups/

PREGNANCY LOSS DURING THE PANDEMIC

During the last six months, we have been gathering, sharing and updating information with other charities, professional groups and service users, as to how NHS responses to the Covid-19 pandemic would likely affect gynaecology, maternity, fertility and GP services across the UK.

Understanding the impact

All of this means we have a real sense of the impact that Covid-19 has had on people affected by pregnancy loss. Even so, when we were invited to give a report to the All Party Parliamentary Group (APPG) on Baby Loss in August, we conducted a brief online survey, seeking information about their experience from people who sought or were due to have pregnancy/miscarriage care since 1 April.

We had an astonishing 172 responses to our survey in just two hours, so we closed it at that point to allow us time to analyse the results. For that reason we can't claim that this is a representative sample. What's more, changes and restrictions to NHS services varied, as they still do, across the UK and over time. But the survey responses largely confirmed what those people contacting us had been telling us since lockdown.

We should also say that not all of the concerns of survey respondents or helpline users reported below were specifically due to Covid-19 – complaints about lack of information or of compassion or of follow-up happened pre-Covid too. But here are the key issues where the pandemic clearly either caused or exacerbated particular distress.

Reduced access to face to face care

People reported problems in being seen face to face, especially for scans and assessments, whether they were:

- seeking help because of a problem such as pain, bleeding or loss of symptoms
- expecting planned or routine appointments, such as booking-in or 12 or 16 week scans
- expecting and/or had been advised scans due to previous losses, including ectopic pregnancy

Of those answering the survey who were seen or referred when they first sought help, 18% (nearly a fifth) came into hospital via Accident and Emergency. That might have been because they presented in the evening, at night or the weekend, but for some, it was because they saw A&E as their only way to get seen, especially with GP and midwifery services under pressure.

Of those people who were not seen and not offered an appointment, many said they were advised to go home and wait it out, and to come back only if things got very much worse. Some of these did just that, and came back another time, often in increased distress; others miscarried at home.

Investigations into recurrent miscarriage were largely cancelled or postponed, and the same was true for fertility investigations and treatment.

Severely reduced access for partners

The lockdown meant severe restrictions on anyone coming into hospital, so even when women were seen, they were almost always instructed to come alone, without their partner or other key supporter. In most cases, women were also not allowed to call their partner, whether by phone or video link, during their appointment, though this last has eased over time. This resulted in:

- women having to cope with difficult and distressing news (including uncertainty) alone
- women having to hear and absorb information and, in many cases, make decisions about next steps alone
- partners feeling alone, excluded and unsupported.

“Being told I’d miscarried for the 4th time without my husband there was the most awful experience of my life. Walking out into the car park to tell him my body had failed us again was awful.”

Reduced options for management of miscarriage or ectopic pregnancy

When it came to making decisions about management of missed or silent miscarriage or ectopic pregnancy, emergencies were treated as such, but otherwise options were either reduced or different from usual.

With miscarriage, we noted:

- very little access to surgical management, especially under general anaesthetic

- most women miscarrying at home, either after medical management or as a result of being sent home to wait for nature to take its course
- many reported being very little information on what to expect in terms of pain, bleeding or what they might see – and this caused additional distress and trauma. This was also true of those assessed and advised by phone only.

“Not given any choice really. Medical management only option in current COVID climate, so had 2 attempts at medical management which have both failed. Also feel that I was given no information about how unwell I would feel or what to expect re: bleeding.”

With ectopic pregnancy:

- apart from cases where surgery was the only option, practice was very varied with regard to managing, monitoring or following-up medical or expectant management.

With molar pregnancy:

- the specialist follow-up services operated as normal, but we don't yet know if fewer hospital appointments meant that fewer cases were diagnosed in the usual time-frames. If they were diagnosed only many weeks later, that may increase the need for further treatment.

Reduced information, empathy, follow-up

Even while they recognised that NHS services were restricted due to the pandemic, many survey respondents reported feeling rushed, unsupported, uninformed, uncared for and alone.

This wasn't true across the board, however. People also commented on staff who offered kindness, compassion and information despite the limitations of social distancing, PPE and reduced treatment options.

“I felt for the HCP's as they were unable to comfort me as I sat alone in my grief and one mentioned that she felt she was only doing half her job.”

Changes since our survey

There has been some easing of restrictions over time. Some hospitals now allow the use of mobile phones during appointments and some invite partners in if there is bad or unexpected news. While that is good news, the fact that many hospitals are still operating a 'patient only' practice, is still causing great distress and, of course, it also causes confusion when people share their experiences with others.

So what of the future?

The main purpose of the APPG meeting was to highlight the impact of the pandemic across those affected by pregnancy and baby loss. The CEOs of the M.A.,ARC (Antenatal Results and Choices), Sands, BLISS (neonatal care) and the Lullaby Trust (Sudden and Unexpected Death in Infancy), were each invited to report on how our stakeholders and our charities were affected. But we were also asked to name one key concern going forward, and to say if we had any specific calls to action.

Here is what I said on behalf of those affected by miscarriage, ectopic or molar pregnancy:

One key concern for our stakeholders

We are very concerned that current restrictions and reductions in service may be maintained even after the strains on the NHS ease, in order to reduce costs and save on staffing.

Our calls for action

1. We call on healthcare providers to ensure the reinstatement of face to face appointments, inclusion of partners and all options for management of miscarriage, ectopic and molar pregnancy and follow-up, as soon as this is possible.
2. We call on the Department of Health and indeed all MPs to support and enable adoption and implementation of the National Bereavement Care Pathway. We need high quality bereavement care during and after loss - it's what women and their partners want and it's what staff want to provide, so we need to do whatever is possible to support healthcare staff to enable them to provide that care.

PREGNANCY LOSS: MEANINGS AND MARKERS

Earlier this year, pre-lockdown, I took part in a seminar called *Body of Work* – a meeting that focused on experiences of and attitudes to pregnancy and fertility, especially in the workplace.

I was asked to talk about the Miscarriage Association, about our work and our aims, and to say something about the role of markers and memories in coping with pregnancy loss.

Talking about the M.A.'s work and the issues that matter to our service users always starts with something that writer and researcher Christine Moulder impressed upon me many years ago: a reminder of the individuality of pregnancy loss.

While many things are shared, the impact and significance of each miscarriage, ectopic or molar pregnancy depends on this woman or man, on this pregnancy and on this loss. Personalities and personal styles, relationships, social, cultural or religious factors; the significance of this particular pregnancy and its meaning (a first pregnancy, or one after previous loss/es or after fertility problems); the physical and emotional experience of this particular loss - all are unique, each and every time.

That means that we all have to be careful that we don't make assumptions about someone's feelings, about whether they want to create memories or markers in some way, about whether they see such things as comforting or more upsetting or just not relevant for them.

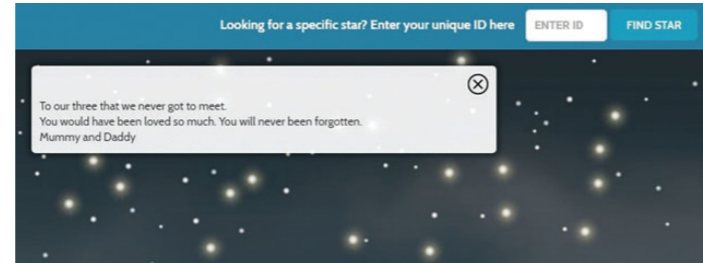
Preparing for the session was an opportunity for me to reflect on just how many different ways people mark or think of their pregnancy loss or losses. For some, it's giving a name, whether a nickname (like 'little bean') or a first name, perhaps one that might suit a boy or a girl.



For some it's some kind of ceremony or ritual, public or private. They include things like the Baby Loss Wave of Light, or remembrance services or memorial walks.

For some people, there are special objects, like an ornament or piece of jewellery, a memory box or a certificate of loss or actions,

like having a tattoo, or planting something in memory. It may be having some kind of memorial, whether physical or online, such as our Stars of Remembrance.



Some people find comfort in sights or symbols that represent their baby, like white feathers or robins; others think of their baby as an angel or cherub or a bird. Religion and culture also play their part – like the tiny Buddhas or Mizuki in Japan which represent lost babies, or the birds in heaven that Susie Kilshaw described in our Spring/Summer issue. Sometimes religion falls short, though and we look for other options, or create them ourselves.

We know too that people take part in activities to help others, in memory of their losses – especially fundraising events, but also in volunteering. And some people write poetry or prose, or create artwork, music, theatre or dance.

What brings comfort or helps people through is thus hugely varied. For some people, it is more about moving on, while for others, an action, object or something else makes a real difference.

It's all about this person, this pregnancy and this loss.



INTRODUCING THE LGBT MUMMIES TRIBE

We are the founders of The LGBT Mummies Tribe & have been together for 13 years. We always knew we wanted children but we didn't know any other same sex families and there was a real lack of information and support for LGBT+ women like us looking to start a family. After five attempts (including a miscarriage at 11 weeks) we had our first child, and our second child on the second round of IVF. We are incredibly lucky that we have both been fortunate enough to carry and so are both 'bio' and 'non-bio' mothers.

In those 8 years, we were consistently contacted by other LGBT+ women & people, or people who had 'friends like us', about how we started our family. It even resulted in a very lovely nurse coming in with a pad & pen in recovery after our first born arrived to ask "I hope you don't mind, but my friends are married & they have asked me how you went about having your baby!" - Which was a funny & surreal moment! If anything, this cemented for us the fact that there was no central point or source of information & support for women looking to start a family. So, we decided to set up the LGBT Mummies Tribe.

What started off as a small Instagram page, has flourished into a full blown business, with 'Meet' events, Support Groups & worldwide coverage, with over 20k+ followers across our social channels.

We have had multiple articles & interviews published; been on the LGBT+ Parenting panel for My GWork's 'WorkPride' Conference & have worked with some amazing brands like The Positive Birth Company & even Stonewall.

We have experienced miscarriage as a couple & at the time, we felt isolated & alone with no one to go to for support, no one fully understanding. Also, being a non-biological mother, I didn't realise the impact our miscarriage would have on me emotionally. Had I had access to the Miscarriage Association all that time ago, I would have had someone to talk

to about my feelings & how our loss had affected me, even though I hadn't carried.

At the time, I didn't know how to support my wife, what to say, how to make things better. I didn't have the physical connection to the loss so I couldn't comprehend her pain, yet I was going through a rollercoaster of emotions & didn't know what I could do to make things ok again.

The fact that we knew we would continue fertility treatment made it all the more painful - knowing that we would have to start the process all over again - so we decided to take a three month break to heal before we tried again.

Women & people we support have come to us before trying, to explain how as 'the other mother' they too felt lost, & that they had no one to turn to to talk through their pain. From supporting our Tribe, it is apparent that as a community we don't openly share or talk about miscarriage & loss. When going through fertility treatment it seems to be 'onto the next cycle we go!' without time to digest what you have gone through, a merry-go-round of medication, scans & waiting rooms.

This is why we have our miscarriage & baby loss support groups, so people can come together to speak openly & get support. It seems that there does not appear to be much support within some NHS Clinics for those who miscarry. Working with the



Miscarriage Association, we hope to help bridge that gap to have open & raw conversations so our women & people can work towards healing by speaking about their experiences, with those who understand.

It is apparent too, that there's a lack of understanding about the dynamics of LGBT+ relationships & how loss can affect each person in different ways.

For us, working with an amazing organisation like the Miscarriage Association is crucial. Having experienced miscarriage ourselves, we know how painful & isolating it can be & there needs to be further support for LGBT+ women including 'non-bio' mothers & parents regarding the aftermath of a miscarriage. More conversations need to be had, more stories shared so that other LGBT+ women & people do not feel alone & working with Miscarriage Association will do just that.

The mental health support that is needed after suffering a loss is monumental in ensuring that you can try to move on to continue to create your family. Wounds take time to heal, but if organisations like ours & the MA collaborate, we can ensure that no LGBT+ woman or person feel they have none to turn to, or that there's a lack of support, & that they can reach out & ask for help.

Laura-Rose & Stacey Thorogood

BABY LOSS AWARENESS WEEK 9-15 OCTOBER 2020

Many of you will be familiar with Baby Loss Awareness Week. A collaboration of around sixty organisations, the Week provides a special time of remembrance, as well as an opportunity to talk about the impact of the loss of a baby during pregnancy, at, or soon after birth, or in infancy.

In previous years, the week has also had a campaigning element, highlighting the need for tangible improvements in bereavement care, research and prevention. This doesn't feel appropriate this year so instead we have chosen to have a general theme for the week – one that is true at any time, but even more so during the pandemic – **Isolation**.

Each day during #BLAW2020 we plan to explore a different topic within the overall theme, with the aim of helping people feel less isolated. Our plans for the week's topics are:

Fri 9 October

An introduction to the week with a focus on mental wellbeing, a day for those directly affected

Sat 10 October

A focus on partners, and also including those without partners

Sun 11 October

Considering the wider family, including children, and friends – support for them and how they can support someone they know

Mon 12 October

A focus on the workplace - employees, employers/managers, HR and colleagues

Tue 13 October

Looking at how issues around culture, ethnicity and religion can impact positively or negatively on pregnancy and baby loss

Wed 14 October

Looking at the needs of LGBTQ+ people, including non-biological parents/parents-to-be, male couples, those using surrogates etc.

Thu 15 October

A focus on remembrance, the different ways in which people remember their babies, different cultures and traditions; and the Wave of Light

Throughout the week we'll be inviting people to share their stories and any ways they have found to get through or lessen isolation. We'll also be featuring the groups and organisations that can help.

Getting involved

The pandemic has put paid to many of the activities and events that we would normally see during Baby Loss Awareness Week, especially with social distancing, local infection spikes and lockdowns likely to continue for many months. However, it has also meant that many of us are using online communications more than ever before, so we're hoping to make the most of this in and leading up to 9 October 2020.

We'll be working with our partner charities to share information, images and online resources that you can use throughout the week, and we encourage you to visit www.babyloss-awareness.org where you'll find lots of helpful social media images and messages.

We'll also be posting news and updates on our website and on the M.A.'s own social media spaces, including updates about our Miles That Matter campaign - the wonderful 100-day fundraising challenge leading up to 15 October. Read more about it on page 16!

Raising awareness via pink and blue

We're more than conscious that many of you won't know the gender of your lost babies and that this choice of colours might not feel right for you for that or other reasons. On the other hand, these colours have long been associated with Baby Loss Awareness Week and you may still want to mark your loss/es along with others remembering the babies and children who should have been.

Here are some of the ways you might want to get involved or things to look out for.

Pin badges...

You can mark the week by wearing a Baby Loss Awareness Week enamel pin badge. If you'd like one, you can order them through our online shop, for £3.50 (including p&p): www.miscarriageassociation.org.uk/shop. I'm afraid we can't take orders over the phone this year.



Twibbons

You can also add a virtual ribbon, or 'Twibbon', to your Twitter and Facebook profile pictures. You'll find the link at <https://babyloss-awareness.org/get-involved/>

At home

You might like to think about having some kind of pink and blue display in a front window, or with fairy lights outside. If you're thinking about bunting, you could use the template at www.babyloss-awareness.org/ribbon-remembrance-events/.



Lighting up the UK

It's been lovely to see the year-on-year increase in the number of public buildings and landmarks lit up in support of Baby Loss Awareness Week – from 71 in 2017 to 267 in 2019. Despite the challenges that the pandemic is likely to bring, we're still hoping to get lots of colour out there this year too and we'd be delighted if any of you can help.

Wave of light

At the end of the week, on Thursday 15 October, you might like to take part in the International Wave of Light, where people around the world light a candle or candles at 7 p.m. local time in memory of the baby or babies they have lost. Photos of these candles on social media create a wave of light that spreads across the globe.

You can join this virtual wave of light by adding your photo at 7 p.m. on October 15, with the tag #WaveofLight.

Updates

We'll be sharing updates before and during the week on Facebook, Twitter and Instagram.

If you'd like to follow and take part in the online conversation, make sure you use #BLAW2020.

A LETTER TO THE GRIEVING

In response to the Awareness Week theme of isolation after loss, Lizzie Lowrie writes:

Dear beautifully strong, fragile, grieving parent,

Firstly, you need to know the sadness/confusion/anger/numbness/exhaustion/despair you feel right now is normal and legitimate. The loss of a child, no matter how young or how small, is still a loss and the size or age of your child does not lessen your pain.

Also, you need to know that this mess of emotions you're feeling is grief.

What frustrates me about grief is that you can't hide it away in a box until you feel stronger. Grief will never fade with neglect, it will remain there, angry, confused, sad, lonely, hopeless, guilty, waiting for you to acknowledge it. You see, grief has to be felt. I know it's scary, I know it's exhausting, I know people are probably avoiding you because they're worried you might get upset and they won't know what to say, but you have to feel it. You may believe that if you were stronger you would be able to handle this better, that you would have more control over your emotions, well let me tell you right now. You are strong. For it is the strong who grieve, who cry out, who get angry at injustice, who have red eyes and snot dripping down their noses.

Just because you're struggling right now doesn't mean you're a failure, it means you're human. Grief in itself is meaningless, it contributes nothing to the world. But you have the power to give meaning to your grief in the way you respond to it.

After 6 miscarriages I can confirm I still hate grief, but I am grateful for what it has taught me. I know what it is to love because I have lost what I loved. I know what it is to hope, because I have lost hope. I know what it is to be loved, because I received true love when I was most distressed.

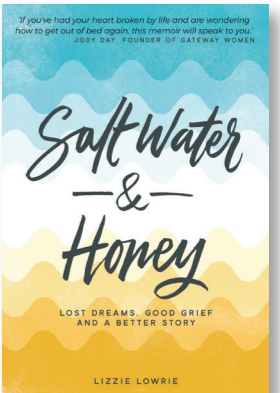
One day, you will come through this, you will stand tall and look back from the green pastures of the other side to see how far you've come and your heart will beat with the same compassion for those beginning their descent down into the pit. You will walk with them, you will cry with them, you will be their guide not because of what you know, but because of what you felt.

Right now you may wonder if the tears will ever end, but I promise you grief is a precondition to joy. You may not believe me, but this truth of death before life, mourning before joy, darkness before light is written throughout the story of this world, each moment becoming even more beautiful and even more welcome because of the darkness that came before them. So take my hand, let's go into the pit. We have to continue this journey towards joy, but the only way to get there is by walking into the darkness first.

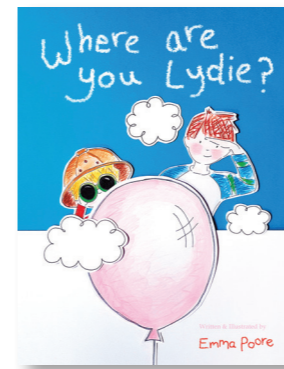
With much love

Lizzie xx

Ed: Lizzie is the author of 'Salt Water and Honey', published earlier this year by Authentic Media (ISBN 9781788930959), Price: £9.99



BOOKS



Where are you Lydie, by Emma Poore

ISBN: 978-1-9162333-0-0

A book which may be particularly suitable for those experiencing late loss or stillbirth, and their families.

Written from the point of view of two young brothers, aged about 3 and 6, Where are you Lydie

celebrates the brief life of their baby sister and the continuing love they feel for her.

In thinking of ways to celebrate Lydie's birthday, her brothers explore feelings of sadness and bewilderment, but the main focus of their journey is on having fun and remembering Lydie with love, creating a life-affirming and celebratory tone. The boys switch from expressing feelings of sadness and loss to everyday childish preoccupations, reflecting normal life in an honest and reassuring way.

Most of the book is made up of the thoughts and dialogue of the two boys, but with quotes from their parents who don't appear in the book, weaved in, so the book has the feel of a love letter to Lydie from the whole family.

The illustrations are bright and funny and reflect the children's vivid imaginations.

It is clear from the dedication that this is a true personal story. It has the power to help support families experiencing bereavement and to be a platform from which to explore loss with children of all ages, and perhaps to inspire readers' own ideas of how to celebrate and mark the life of a lost child.

Reviewer: Elizabeth Schofield

NEW GUIDELINES FOR DELIVERING UNEXPECTED NEWS IN OBSTETRIC ULTRASOUND

'We are delighted that the new professional guidelines on the communication of unexpected news in ultrasound, to which the M.A. contributed, were published on 5th August. Here's the post we shared that day.'

Today sees publication of new and very welcome guidelines for the way in which sonographers and ultrasound practitioners deliver unexpected and possibly difficult news when scanning in pregnancy.

That news may be the diagnosis of a miscarriage or ectopic or molar pregnancy; or findings that suggest this may be the case but it's not yet certain. It may indicate something unusual or concerning in the baby's development, or confirmation that a baby or babies has or have died.

The way that this news is delivered is hugely important and we believe that these new guidelines can make a very positive difference to women and their partners facing unexpected, difficult or distressing news, as Amy notes:

Three of my miscarriages were discovered at the scan stage and while some sonographers were kind, others were so clinical and all used the same language which still haunts me: "this isn't a viable pregnancy".

Developed with input from health professionals, women and their partners and charities including the Miscarriage Association, the guidelines provide specific suggestions for words and phrases which practitioners can use in a range of situations and settings.

Behaviours matter as well as words, and the guidelines focus on key aspects of the whole ultrasound experience, from the first hello through to discussing next steps. They emphasise too that it's important not to make assumptions on how patients may feel about the scan findings but to be ready to express empathy.

Specific recommendations include that:

- honest and clear communication should be prioritised, even with uncertain findings;
- technical terms should be used, but these should be written down together with their lay interpretations;
- unless expectant parents use other terminology (e.g. 'fetus'), the term 'baby' should be used as a default, even in early pregnancy;
- at the initial news disclosure, communication should focus on information provision;
- expectant parents should not be asked to make decisions during the scan.

The guidelines were featured on BBC Breakfast on 5 August and the coverage can be seen at <https://www.instagram.com/tv/CDgoOp-hD49/>. Our thanks to M.A. media volunteer Lydia Boyd for sharing her experience on the programme.

You can find the full guidelines at <https://journals.sagepub.com/doi/full/10.1177/1742271X20935911>

[And given that you're reading a printed article, you might like to know that you'll find clickable links in the news post itself on the news section of our website.]

The results, published on 25 August in the Lancet*, showed that the combination of drug treatments was the most effective option. Treatment with mifepristone two days before misoprostol, led to the miscarriage resolving more quickly than treatment with misoprostol alone.

The combined treatment also reduced the need for surgery following medical management, and was less costly overall.

We hope that these results will lead to more consistent practice across the UK for those women who opt for medical management of missed or silent miscarriage. We hope too that it will lead to a change in the NICE guidance, which currently recommends use of misoprostol alone.

*Mifepristone and misoprostol versus misoprostol alone for the management of missed miscarriage (MifeMiso): a randomised, double-blind, placebo-controlled trial: [https://doi.org/10.1016/S0140-6736\(20\)31788-8](https://doi.org/10.1016/S0140-6736(20)31788-8)

MEMORY CARDS AT AIREDALE HOSPITAL



Caroline Hill (L), who designed the card, with EPAU nurse Joanne Bradley.)

Staff at Airedale Hospital have now created special memory cards, to recognise early pregnancies that are sadly lost.

Prompted by a conversation with a patient who had miscarried, the team from the Early Pregnancy Assessment Unit (EPAU) decided to develop a card to recognise first trimester pregnancies that unfortunately miscarry, an idea supported by the Miscarriage Association.

Patients and families are currently supported following miscarriage by the EPAU team and patients are provided with a direct contact telephone number to ring if they have any concerns.

Joanne Bradley, Clinical Sister at the Early Pregnancy Assessment Unit at Airedale NHS Foundation Trust says:

"The cards are designed to help parents with the grieving process at a difficult time and it gives official recognition of a life that has been lost. As a unit we felt that first trimester miscarriages are not always recognised as a loss and the emotional impact is often underestimated."

The cards were created by local personalised card company, Collisons, who are based in Shipley and actively help local charity projects, and in collaboration with the hospital charity, Airedale Hospital & Community Charity.

Joanne continues:

"We are extremely grateful to Collisons for their support in creating the cards. So far they have been well received, although it is appreciated that this type of commemorative token is not for everyone. As a team we are dedicated to supporting ladies who have unfortunately

miscarried in the first trimester of pregnancy and the memory cards are offered to provide an element of comfort and lasting recognition of the loss."

Jo Dawson, Sales and Accounts Executive at Collisons Ltd said:

"I was honoured to have been involved in helping to turn this new idea into reality. When first approached I leapt at the chance for myself and Collisons to help make this happen and even more so when I had the chance to meet with the team who do such an amazing job and are so passionate about this project."

"Miscarriage affects many of us, directly or indirectly, and probably far more people that we know because it can be hidden rather than acknowledged and supported. I hope these cards and the messages they contain will be of some help and comfort to a lot of parents at a very sad time. It's amazing to have had the chance to support the team who support those parents on a daily basis."

The above article first appeared on the Airedale NHS Foundation Trust website and is reprinted with permission.

POEM

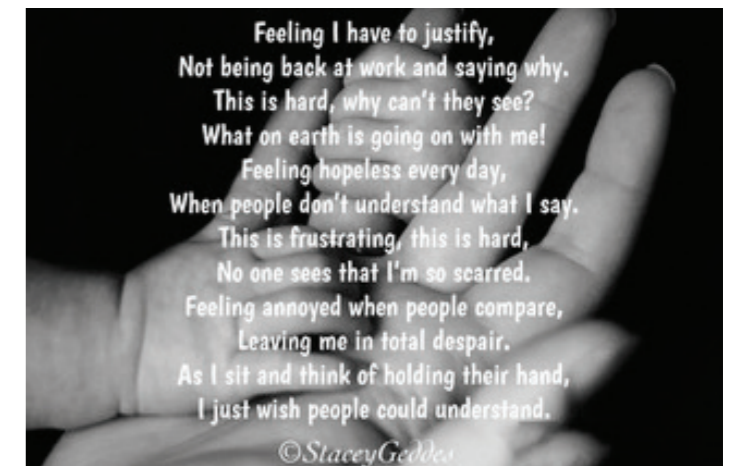
Stacey writes:

After experiencing a miscarriage at the end of January this year, I started writing poems as a way of dealing with my loss. I found that this really helped me to express how I was really feeling - something that I find difficult at times.

By writing my feelings down, I find that I have been able to be much much more honest and this has helped me with my grieving process.

This poem is the first one I wrote.....

*Feeling I have to justify
Not being back at work and saying why.
This is hard, why can't they see?
What on earth is going on with me!
Feeling hopeless every day,
When people don't understand what I say.*



*This is frustrating, this is hard,
No-one sees that I'm so scarred.
Feeling annoyed when people compare,
Leaving me in total despair.
As I sit and think of holding their hand,
I just wish people could understand.*

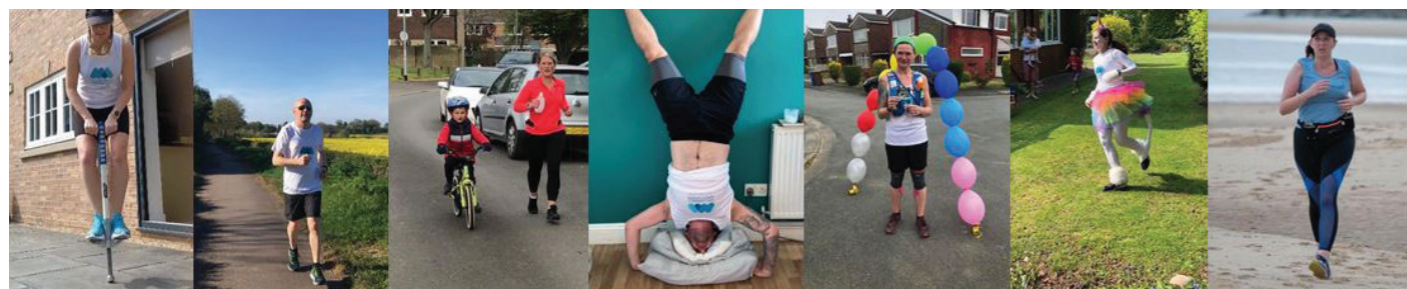
© Stacey Geddes

Research News



Medical management of miscarriage - the MifeMiso trial results.

The MifeMiso trial focused on medical management of miscarriage, investigating whether a single drug treatment (misoprostol) or a combination of drug treatments (mifepristone plus misoprostol two days later) is best for the medical management of missed or silent miscarriage in the first 14 weeks of pregnancy.



FUNDRAISING

The Covid 19 situation, with self-isolation and the impact on charity races and other events, has hugely affected recent fundraising activities at the M.A., and yet our dedicated and resilient supporters continue to find ever more imaginative ways to raise funds and increase awareness of the services we offer!

You probably know that the majority of our income comes from public donations and fundraising activities, money raised by people who have either been through pregnancy loss themselves or care about someone who has, and who want to help others in a similar situation.

If you'd like to join in and help to increase awareness of miscarriage, ectopic and molar pregnancy as you raise money to support our work, then please get in touch!

The wonderful people on the following pages did just that during the spring and summer, and we hope that their achievements will inspire you and give you some ideas of your own.

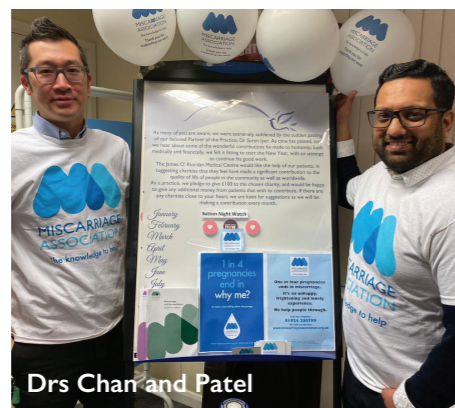
The determination and commitment our fundraisers show in raising money to help us reach and educate more people, and to support those who need our help, is phenomenal. Thank you so very much - we really couldn't do it without you!



Karn

karn@miscarriageassociation.org.uk

MARCH Our March fundraisers did all sorts, from baking cakes to cutting hair, skydiving to cage-fighting and lots of running. Many thanks to Chloe Jones, Fraser Ruthven, Mark Tilman, Karen Hoskins, Lynne Deveraux, Sarah Drysdale, Matthew Deakin, Hannah Pope, Kevin Chan, Danny Fison and Ryan Atkinson



Drs Chan and Patel

APRIL In April, soon after the news that the London Marathon had been postponed for the first time, the race organisers launched a national 2.6 Challenge to help raise vital funds for the nation's charities.



THE 2.6 CHALLENGE

The challenge started on Sunday 26th April and encouraged people of all ages and abilities to take on a 2.6 themed challenge of their own and fundraise or donate to support a charity of their choice.

We had a fantastic response to our appeal for our supporters to get involved, with over 30 individual fundraisers and their families holding their own socially distanced events, including 2.6 mile dog walks, 26 pogo stick jumps, baking 26 cakes, 26 minutes of dancing, leaping over 26 obstacles in the garden, a virtual pub quiz with 26 questions, a garden half marathon, and even running 26 miles on a treadmill.



Alison Mason, 2.6 challenge

Our thanks to all those who made direct donations to the M.A. in support of the challenge and to those who set up an online page and had people sponsor them that way. They include: Hollie Andrews and Canterbury AC, Joanna Bhargava, Jan Birrell, Helena Cheyne, Eliff Corca, Stephanie Daniel, Bethanie David and Sonia Deary; Eleanor Gallon, Andrew Gilroy, Sian Green, Jenny Griffiths, Jade Grosvenor,

MA 26

- 112 feet x26 laps for MA makes 2912feet. M, S, J
- 26 x2 star jumps M
- 26 star jumps S
- 26 x 2 star jumps J
- Bounce the ball 26 time without dropping it. M,S and J.
- Kick the ball against the fence 26 times. S and J
- 26 throws against the fence L.
- 26 successful shots of basketball net.. S and J
- We all walked the dogs through the fields for 2.6 miles.
- A donation will be on it's way soon.

M, S, J & L, 2.6 challenge

Fay Hancock, Heather James, Carrie Jameson, Kelly Jarold and Paul & Marg Jukes; Jennifer Lavender, Tanya Morton, Sinead O'Connor, Claire Potterton, Hannah Ricketts, Vicki Robinson, Nicola Roper, Honour Schram de Jong and Jennifer Schram de Jong; and Philippa Shine, Kate Taylor, Cassie Thomas, Rebecca Timms-Weaving, Alice Weeden, Jennifer Whitmore and Gemma Wright.

We also want to say a very special thank you to all of our 2020 London Marathon team, who had been training hard and fundraising just as hard in the months leading up to that iconic international event. Despite their disappointment at the LM's postponement (later to become a cancellation), many of them used the 2.6 challenge to keep topping up both their funds and their mileage. So a rousing cheer to them all:

Kerrie Aldridge, Gary Ashley, Terry Axon, Emma Barringer, Sarah Bryden-Smith, Anna Buthee and Jo Buttolph; Ruth Caddy, Aaron Carlin, Gregg Chapman, Chelsea Connelly, Mike Corr, Tim Coupe, Katie Craven and Jason



Andie Ford, 2.6 challenge

Cuthbert; Simon Dykes, Luke Eastwood, Lisa Mia Edwards, Carl Ellis, Andrea Ford, Eleanor Gallon, Ben Gregory and Akhil Gupta; Paul Harrison, Lukaz Im, Joanna Jones, Antony Josif, Nicola Kelly, Jasmine Maddison, Ian Marchant and Alex McDonagh; and Ali Roberts, Rob Smith, Lisa Southworth, Tess Taylor, Dominic Woolard, Amanda Woolaston, Katherine Wynne.



Antony Josif, still training

Other supporters who had arranged to complete fundraising challenges during April but were unable to complete them due to the pandemic were: Scott & Nicola Kelly (Glasgow Kiltwalk), Louise Flisher (Manchester Half Marathon), and Melissa Stevens (Peterborough Marathon), and I know that they are all excited to complete their challenges as soon as the circumstances allow!

MAY We had more wonderful supporters out in force in May – running, climbing, skydiving and trekking amongst other things. Our thanks to Jessica Caswell, Kim Burnett, Bobby Coello, Neil Hopkins, Karen Hoskins, Bethany Josh, Amy Moore, Antonia Painter, Caroline Stevens and Crystal Twinn – and a special thank you to Erin Sharkey's three mini Sharks who completed an exhausting obstacle course for us. Emily Snipe and Ross Mann were unable to take part in the postponed Edinburgh Marathon, while Ben Usher should have joined in with the Paris Marathon, but all will run for us as soon as the events are rescheduled.

JUNE June saw people finding ever more creative ways to raise funds and join in during the

lockdown. Our thanks to Sophie Bourne, Polly Churchman, Bethan Cousins, Sarah Coyle, Nina Crannage, Dawn Feazey, Paul Galloway, Katie Illingworth, Jade Meakin, Toby O'Brien and Barry Wilkinson who all participated in socially distant events.

JULY, AND AUGUST

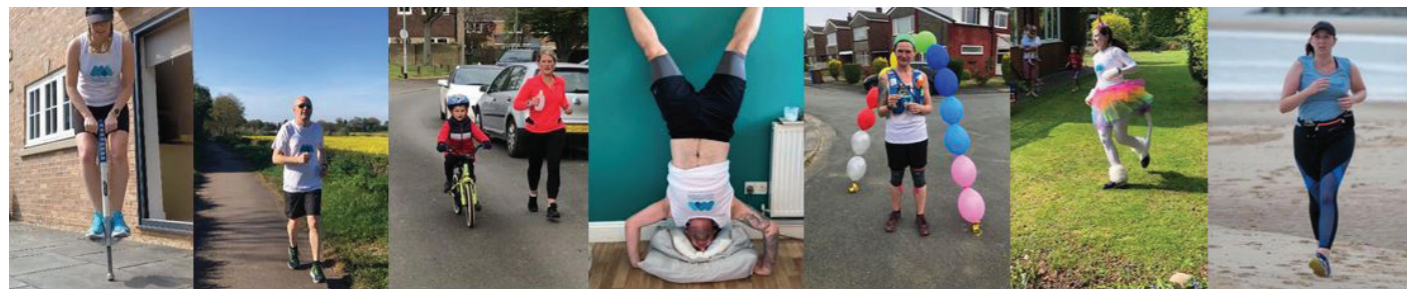


July saw the first ever M.A.-organised virtual event, Miles That Matter. Launched on 8th July, the 100 day event, due to end on 15th October, the final day of Baby Loss Awareness Week, encourages fundraisers to help reach a team target of £25,000, to fund the cost of running our helpline services during the same period.



Helpline Team

It also signposts people to the M.A.'s services, highlighting those provided by our fabulous Helpline staff, Lisa, Helen, Juanita and Ann.



F u n d r a i s i n g



Niki Kelly, Marathon & Miles That Matter

That's been especially important during the pandemic, due to the distress caused by restrictions and reductions in NHS care.



Kerry Drinkwater, Miles That Matter.

Bex Austin, Leigh Ballantyne, Charlotte Blake, Angela Bruce, Ashley Burke and Sophie Burt; Jessica Carr, Holly Chandler, David Cornwell, Rob and Amy Craig, Matthew Crisp and Alice Crisp; Helen Dearn, Jonathan Doyle, Will Doyle, James Doyle, Alexandra Draper, Kerry Drinkwater and Liz Ellis; Hannah Farthing, Lynda Favour, Katie Finney, Sarah Fletcher, Alice Foster, Camille Frank, Julia Godwin



Jess Herring, Miles That Matter.

and Jessica Graham; Judith Hadfield, Amy Hancock, Jessica Herring, Sarah Hirst, Beth Holder, Catherine Hudson, Kate Hutchins and Tanya Ingram; Billie James, Paul Jukes, Sarah Keyes, Lorna Lawrence, Tess Mackean, Laura MacLennan, Lyndsey McDaid, Annette Miles, Gemma Morgan Rawes and Tanya Morton; Rebecca Oakes, Ella Palmer, Lauren Parkin, Hannah Parsons, Charlotte Pearson and Mark Pendleton; Sarah Raiton, Jennifer Ramage, Lucy Ransley, Miriam Ridgeway,

Jan Robertson, Ruth Salt, Ellie Shaw, Lauren Sluz, Jess Stanard, Angela Sturch and Marisa Symond; Claire Totten, Emma Tulloch, Rachel Webster Oldham, Leanne Whiffen and Vixie Williams.

There's still time to support Miles That Matter before the 15th October deadline. See www.miscarriageassociation.org.uk/get-involved/fundraising/ for details of how to get involved!

And still more in July.

We're very grateful to Libby Clark, Kirsty Sims, Elaine Chambers, Brett Robinson, Elaine Reddell, Alitia Plattern, and Jenny Nash for their amazing fundraising efforts, which included the Race to the Stones event, a pier to pier wild swim and even a sponsored beard shave.

In August, Vicky Treherne's friends took part in another wonderful Strut Your Songs event in the UK and far beyond it. Kirsty Nichol staged a birthday fundraiser, Lucy Devany ran a virtual half marathon, Naomi Lutman chose the M.A. as one of a number of charities to say 'thank you' to and

Steve McNeil donated funds raised from streaming his WiFi Wars comedy game show.

Thank you all!

CHRISTMAS ALREADY?

It really isn't, but this is the newsletter issue in which we tell you about this year's Christmas card designs. They are so lovely, you might want to go ahead and order early anyway!

We have five Christmas designs this year, all with the greeting 'With Best Wishes for Christmas and the New Year' and all containing 10 cards and envelopes::

Carrying the presents	160 x 116 mm	£4.00
The tree	160 x 116 mm	£4.00
Christmas pudding	140 x 140 mm	£4.00
Christmas dove	140 x 140 mm	£4.00
Three kings	110 x 110 mm	£3.50

Postage and packing (UK only): 1 pack = £1.20; 2-10 packs = £3.00

Please be aware that your order may take up to 10 working days to reach you, though we will aim to get it to you sooner.

You can order the cards online at www.miscarriageassociation.org.uk/get-involved/shop/. Working from home means we're unable to process telephone orders this year.



Rachel's story

Having three miscarriages and two chemical pregnancies within the past 18 months, it's hard to think of a more physically and emotionally draining period in my life.

My first miscarriage was confirmed at a nine-week scan following some spotting. While the pregnancy had ended almost as soon as it had begun, it was nevertheless devastating and shattered my simplistic view that because I was healthy, I would therefore have a healthy pregnancy. I opted for medical management and my body returned to normal a few weeks later. Despite that early blow, my husband and I were encouraged by stories from friends and family who had also had first time miscarriages and gone on to have healthy babies. Perhaps it was a rite of passage, I wondered.

I fell pregnant within two months after the miscarriage. This pregnancy felt different from the first. My symptoms were more unmistakable, which I took as a positive sign. The weeks passed without incident save some spotting around the nine-week mark.

While it seemed to take an eternity, we finally reached the all-important 12-week scan. After seeing the baby bounce around on the screen, we both breathed a sigh of relief. I started to believe this pregnancy would go the distance, so we began telling family, friends and colleagues.

At around 16 weeks, I started bleeding at work. Panicked, I told my boss and rushed to the nearest hospital emergency room. They didn't offer a scan but a speculum examination showed

the cervix was still closed, (as it should be) and a Doppler revealed the baby's heartbeat loud and clear. Despite the reassurance, I remained on edge. My pregnancy was under threat-I just knew it. The following day, more heavy bleeding and cramping and another trip to the hospital concluded with hearing the baby's heartbeat once again. I was told to go home and just rest until the bleeding settled.

“My husband and I were encouraged by stories from friends and family.”

I still couldn't help but think something was being missed. Surely this isn't how a normal pregnancy is meant to go. My worse fear was realised later that evening when my waters broke and I delivered my baby in the toilet at home. I was completely shell shocked. I just remember crying out 'no' 'no' 'no', as though to convince myself this horrible nightmare just couldn't be real. I was still actively miscarrying by the time I reached A&E and leaving a trail of blood in the reception. The trauma of that night still visits me from time to time.

After this loss, I began having therapy sessions, although they were short lived for me. What I really wanted was answers. How on earth could I lose a seemingly healthy pregnancy with next to no warning? Through our health

insurance, I was able to have various investigations done privately; testing my antibodies, possible clotting disorders or infections etc. All thankfully came back negative but still no concrete answers.

The brilliant consultant who carried out the tests concluded it was possibly caused by a problem with the placenta which triggered a very early labour. She encouraged me to try again as soon as I was ready and agreed to take over my care from her NHS clinic once I was pregnant again. We took a break from trying to conceive so we could indulge over Christmas and have a couple of months of normality.

In late January, I discovered I was pregnant for the third time. There was no fanfare. I jealousy wished we could be those couples who assumed a positive test equalled a baby at the end. True to her word the consultant who had supported me following my second miscarriage offered me first rate care with this pregnancy. She booked me in for early scans, prescribed me progesterone to support with placental development as well as baby aspirin and extra folic acid. Unfortunately, the pregnancy still wasn't meant to be. Another missed miscarriage was diagnosed at nine weeks after the familiar spotting.

It all felt so routine now.

This time I had reached the 'magic' number of three miscarriages in a row which triggered further investigations via the NHS. I opted for an operation to remove the pregnancy just a week before the country went into lockdown. Hospital procedures were already tightening up. I was the only patient in

Outpatient Care that day allowed to have my partner accompany me in the pre-op suite. I was extremely grateful for that compassionate dispensation.

I once again dabbled with therapy but found it didn't work for me. I know it does for plenty of others though. For me the healing process is helped by getting answers, even if those answers raise more questions. Like many couples on a fertility journey, the pandemic has cruelly interrupted any progress in the quest to have a family.

Following delays in the Karyotyping tests due to Covid, I eventually found out that our baby boy (they unexpectedly reveal the sex in the post-mortem report) was missing a chromosome 21. This I'm told is extremely rare and almost certainly resulted in the miscarriage. It also raised the question as to whether my husband or I have a chromosomal translocation that could be contributing to the miscarriages. Equally, the miscarriages may have been a series of terrible coincidences especially as the second

miscarriage at 16 weeks was the outlier and had been a viable pregnancy. At the time of writing this, we face a couple more months of waiting for the results of those genetic tests.

“Recurrent miscarriage for me has caused pain and grief I could never imagine, but it's made me draw from a deep well of resilience and strength I didn't know I had.”

The bad days can be very dark, leaving me feeling hopeless, anxious and angry.

Angry that after multiple pregnancies, I've not been able to take even one of my babies home. Angry that my chance of motherhood might be slipping away, and terrified that I don't have a Plan B that involves a future without a family.

The good days however can feel all the more special. Time spent enjoying the company of my family, friends and my beloved cats, reminds me that I am still capable of experiencing joy, and that my life is valuable and very much full of purpose even if parenthood eludes us for now. Whatever happens next, I know I won't be facing it alone.

Rachel
August 2020



DONATIONS

We are very grateful to all those who have made a grant or donation to the Miscarriage Association during the last six months. In addition to those named below we acknowledge with thanks those who have made a donation via our website, all our Facebook fundraisers, those who give regularly via direct debit, or support us via a workplace payroll scheme, as well as those who choose to donate anonymously.

Individuals

- | | |
|----------------------------|-----------------|
| Jill Bender | Morag Kinghorn |
| Lindsay Dixon, c/o Lycetts | William Madill |
| Karn Dyson | James O'Riordan |
| Dr Roy Farquharson | |

Companies, Trusts and groups

- | | |
|--------------------------|----------------------|
| Duncan Norman Trust Fund | St Denys the Minster |
| Norton Rose Charities | Wakefield MDC |
| Pears Foundation | Warminster Church |

