

communication help  
feelings choices explain  
support comfort talk  
awareness listen  
emotions friend research  
care information  
reactions reflections  
volunteer knowledge  
understanding time

# It's time to start talking about miscarriage



MISCARRIAGE  
ASSOCIATION

The knowledge to help

Annual Report 2012-2013

**Miscarriage can be a very unhappy,  
frightening and lonely experience.**

**The Miscarriage Association acknowledges  
the distress associated with pregnancy loss  
and strives to make a positive difference  
for those it affects.**

**We have the knowledge to help.**



**MISCARRIAGE  
ASSOCIATION**

**The knowledge to help**

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The Miscarriage Association is a registered charity in England & Wales (1076829) and in Scotland (SC039790)  
and a company limited by guarantee, registered in England & Wales, number 3779123



Remember, less is more. That was the guidance I was given when asked to write the foreword for this Annual Report. And it's true. When we look at the power of communication, the need to put a message across, it is often the simplest messages that are the most poignant or the most meaningful.

I am here. I care. I will listen.

We recently suffered bereavement in our family. An elderly lady and not unexpected. It still however brought great sadness to us all. What I noticed more than anything though was the differing reactions from other people. Bear hugs and kind words from the most unexpected. The scurrying away and not knowing what to say from others.

It made something much clearer to me. If people don't know what to say or how to react to a kind gentle release, no wonder they find it so hard to express their sympathy or to say anything at all when a family suffers a pregnancy loss. Just when families need to talk, express their sadness at the loss of the baby, the dreams, the plans for the future they realise what a taboo it is to talk.

This is why I believe communication is key to the Miscarriage Association. Our leaflets are clear and informative. We have support workers and volunteers always ready to listen. We can direct you to the latest research and give you accurate information. We have peer support on the forum and Facebook.

Our awareness campaign in the Spring of 2013 touched so many people. The simplicity of the posters and the 'blue envelopes' reached out and really helped lift the taboo. Communication became conversation.

It's time to start talking about miscarriage.

A handwritten signature in black ink that reads "Penny Kerry".

**Penny Kerry**  
Chair of the Board of Trustees

“ I have found the courage to break my silence.  
Thank you @MiscarriageA for supporting all of us. ”

“Those who've not been touched by pregnancy loss tend to think we'll bounce back after a month or two. But I'm coming up to what should have been a first birthday and realising that our loss is something we never “get over” but we learn to live with.”

The experience of miscarriage, ectopic pregnancy or molar pregnancy can be devastating. Excitement and anticipation are replaced by loss and sadness. Hopes, plans and dreams for the future are suddenly shattered. And it can feel a very lonely place, especially if others don't understand, don't know what to say.



### Cathryn Scott

I will never forget the moment the sonographer told us our baby didn't have a heartbeat. It was our first scan. I was 13 weeks pregnant and my husband and I were excited about seeing our little one for the first time. I had a small bump. I'd been feeling sick. We'd discussed names.

In our minds, we were already a three. We had no reason to suspect anything was wrong. Being told our baby had died five weeks earlier was devastating.

Family and friends told us how sorry they were. They sent flowers and cards. Yet even though most people had the kindest of intentions, some of the things they said were painful to hear. Phrases like “At least you know you can get pregnant”, “You can try again”, “Imagine how much worse it would be if it happened later” offered little consolation.

Actually I didn't know if I could get pregnant again. If I did, would I miscarry again? And yes, it would have been devastating if I'd miscarried later in the pregnancy, but that didn't mean it wasn't devastating now.

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“These forums have been invaluable to me. It's been amazing the help and support I've got from total strangers, more so than people in 'real life'.”

“Just talking to people who understand what I've been through and how I'm feeling makes me feel like I'm not alone.”

The Miscarriage Association helps by providing opportunities to talk to people who understand, to read or listen to what others have felt, to feel more “normal” and less alone. We made this possible in 2012/13 through:

- a staffed helpline responding to 6,000 calls and emails about pregnancy loss with support, understanding and information
- 93 support volunteers offering peer support by telephone and in support groups
- a safe and secure online forum, with a rapidly growing membership
- developing our Facebook and Twitter accounts so people can connect with others affected by pregnancy loss
- a regularly updated website with easy to read text and leaflets, personal reflections and a place for remembrance; an average of 32,300 visits per month
- an informative members' newsletter, a much-valued source of support and comfort



“ I had numerous tests performed to determine the cause for my recurrent miscarriages but none of them gave me any answers. I found it very hard to accept because if there was a reason, then maybe I could come to terms with it. ”

When things go wrong in pregnancy, there is often a great need for information about what is happening and what is likely to happen. There may be questions about the physical process of loss and the options available; about what happens to the remains of a miscarried baby; about further tests or treatments; and especially about whether there is anything that can be done to reduce the risk next time.



### Victoria Bristow

Following my missed miscarriage, I was not given any information at the Early Pregnancy Unit at which I was seen. I found it incredibly distressing, even more so that I had to ask the registrar who saw me what I should expect. It was devastating after a day of tests, scans and tears.

The question that I had to ask, that haunts me to this day, was ‘Will I bleed?’ I had no idea and I had no idea where to go to find out.

Fortunately a friend pointed me towards the M.A. website. I was relieved to find sensitive information presented in a way that was easy to access and understand at an incredibly difficult and distressing time. Medical information and complicated terminology were all clearly explained so I understood what I was reading. I also appreciated how easy it was to navigate to other information, some of which I had not realised that I needed.

I have since recommended the M.A.’s website to others who have had the misfortune to suffer the loss of a baby.

“ I have just had my miscarriage confirmed after two days of bleeding. Although the hospital staff were kind, they didn’t give me any information or leaflets to take home, so my many unanswered questions have mainly been dealt with by reading info on this website. ”

*The Miscarriage Association consults with experts so that we can provide accurate and understandable information. We support and are actively involved in further research into the causes and treatment of miscarriage, ectopic and molar pregnancy. Key activities and achievements in 2012/13 were:*

- publishing a range of 18 leaflets on the facts and feelings of pregnancy loss, all freely available on our website
- increased use of social media to highlight information available on our website, in print or by e-mail; a 74% increase in visits to the website compared with 2011/12
- representing the patient perspective on steering committees for three clinical research trials and on a specialist Early Pregnancy Clinical Studies Group; and supporting applications for four additional research studies
- 28,000 leaflets ordered by hospitals, health centres and individuals and a further 1,000 leaflets supplied to conference and exhibition delegates

“ I suffered from a ruptured ectopic pregnancy last week after not even knowing I was pregnant. Your leaflet has been a real help and comfort for me trying to piece things together and work out how to move on. The tone and level of information is perfect. ”

*The PROMISE and TABLET trials, two national studies with the aim of reducing the risk of miscarriage, have benefited immensely from the M.A.’s involvement and guidance, from the very early stages of developing the studies to conducting them successfully. The trial findings have the potential to help many women and we look forward to working closely with the M.A. on these and future studies.*

**Professor Arri Coomarasamy, Professor of Gynaecology, University of Birmingham**



“After finding out at my scan I'd had a missed miscarriage, I was sent home and told to go back in 10 days for another scan. I wasn't given any information at that point and miscarried at home after three days. I was then given a leaflet which referred to “spontaneous abortion” rather than miscarriage which was very upsetting.”

The quality of care that women and their partners receive in hospital and general practice can have a significant impact on their experience and memories of pregnancy loss. When processes and findings are communicated clearly and sensitively, it can make a real difference in helping people through.



### Caroline Overton

I am a consultant obstetrician and gynaecologist at St Michael's University Hospital in Bristol and Chair of the Association of Early Pregnancy Units (AEPU).

For me, our biggest achievement has been in driving the change to the term 'Surgical Management of Miscarriage'. This is so much more acceptable than 'Evacuation of Retained Products of Conception'. Using words like 'evacuation' and 'products' simply made a bad situation worse.

I went into medicine to make a difference – we all do – and I'm delighted that we have made this change. And we couldn't have done it without the combined work of all those involved: patients, their supporters, health professionals, the M.A., the AEPU and the Royal College of Obstetricians & Gynaecologists.

I'm glad to see that miscarriage and ectopic pregnancy are increasingly at the top of the agenda for organisations like NICE, the RCOG and the European Society for Human Reproduction and Embryology (ESHRE). Pregnancy loss should be recognised as a health issue that has a huge impact on so many people and I'm delighted that we are working with the Miscarriage Association to make sure that we provide the very best care we can.

“I'm so glad the name will change. 'Evacuation of Retained Products of Conception' makes me think of something unwanted. 'Surgical Management of Miscarriage' acknowledges that it was a baby.”

The Miscarriage Association offers training and consultancy to health professionals and works with key organisations to promote sensitive care for patients who miscarry. Highlights during 2012/13 were:

- helping the Association of Early Pregnancy Units to research and promote an alternative term for the surgical management of miscarriage, approved by patients and health professionals and supported by the RCOG
- contributing to the development of NICE guidance on pain and bleeding in early pregnancy; and providing clear public and patient information when the guidance was published
- providing expert opinion to the Scottish government regarding investigations for recurrent miscarriage; and advising on the sensitive disposal of pregnancy remains
- sourcing “expert patients” as tutors for medical students at the John Radcliffe Hospital in Oxford; and gathering patient views on developing the undergraduate curriculum on early pregnancy
- an invited conference speaker for the European Society for Human Reproduction & Embryology, the Association of Early Pregnancy Units and the RCOG
- contributing a chapter for a book on Recurrent Pregnancy Loss, part of the *Gynaecology in Practice* series; and one of the Trustees contributed to a BMJ podcast for GPs on treating patients with pregnancy loss
- providing expert opinion, advice, training and/or guidance to a range of NHS staff and management, pastoral staff and students



I am bowled over by the commitment, professionalism and skills of the patient tutors. The students give excellent feedback and often comment in their end of course reflections on the opportunity of talking to the women in this way.

Jane Moore, Course tutor in Obstetrics and Gynaecology, University of Oxford

“I've had seven miscarriages to date and still no child. I saw your tweet about the blue envelope campaign and I would like to help. There isn't any mention of the Miscarriage Association in my doctor's, let alone being able to speak about miscarriage to anyone and I really feel it's important.”

Even though miscarriage is sadly all-too-common, it remains something of a taboo and its emotional impact is often unrecognised. Raising public awareness of the feelings as well as the facts of pregnancy loss helps break the silence and increase understanding. It can make those affected, however long ago, feel less alone. And it helps to ensure that bereaved parents know where to turn to for information and support.



### Kathryn Sheppard

I've been a media volunteer since January 2012. I had had four miscarriages by then, including the loss of twins. Our second twin made it to 18 weeks, when we thought we were in the clear, so losing him then really hit us hard.

Miscarriage happens to far more people than you think but people don't talk about it, especially recurrent miscarriage. It can be hard to hold on to hope. You begin asking yourself 'Is it really worth the pain and heartache to keep trying?'

I didn't know if I would ever have a baby but even at the worst times, we realised that there were many good things in our lives and we tried to focus on those. I'm glad I got the opportunity to say that when I was interviewed on **Good Morning, Wales** last year. It would have helped me to hear that despite losses and tragedy, you can still get through and the future can be positive.

Happily for us, our fifth pregnancy resulted in the birth of a healthy daughter in March 2013. But that doesn't mean we have forgotten the babies we have lost, and it certainly won't stop me talking about miscarriage.



M.A. Director Ruth Bender Atik on BBC Breakfast television

The Miscarriage Association is seen by the media as an expert source of information and comment on miscarriage, ectopic and molar pregnancy and we are often called on at short notice. This year we also took the opportunity to begin a series of annual public awareness campaigns. Key achievements in 2012/13 were:

- a high impact awareness campaign, *It's time to start talking about miscarriage*, combining outdoor advertising with “guerrilla” distribution of small blue envelopes in print and online –
  - the online note was read by 328,639 people on Facebook during the campaign
  - 775 mentions on Twitter potentially reached 811,114 people
  - the campaign featured on BBC Breakfast and BBC Radio 5 Live as well as local radio and press
- responding to 74 requests from the broadcast, print and online media for expert comment, background information and case studies, helped by 72 media volunteers; and gained a further 62 volunteers willing to help with future awareness campaigns
- widespread media interest in our response to publication of the NICE guidance *Ectopic Pregnancy and Miscarriage*, including interviews on BBC Breakfast and ITV Daybreak television
- featuring as charity of the year for the President of the National Association of Ladies' Circles, reaching an estimated 8,000 people; and a further 167 people promoting the charity through a range of fundraising events
- maintaining an excellent internet profile and further developing our online presence through social networking sites

“@MiscarriageA – I would love to help. Losing a baby is really hard & having more people understand will really help.”

	General funds £	Designated funds £	Restricted funds £	Total
<b>Income:</b>				
<b>Donations &amp; similar income:</b>				
Membership fees & donations	11,126	-	729	11,855
Government grant	-	-	36,000	36,000
Other donations & grants	70,854	-	-	70,854
Branch income	-	-	4,570	4,570
<b>Activities to further the Charity's objects:</b>				
Sales	26,531	-	-	26,531
Training & consultancy fees	450	-	-	450
<b>Activities to generate funds:</b>				
Fundraising activities	83,983	-	2,226	86,209
Sales	573	-	-	573
<b>Interest received</b>	<b>3,156</b>	<b>-</b>	<b>-</b>	<b>3,156</b>
<b>Total income</b>	<b>196,673</b>	<b>-</b>	<b>43,525</b>	<b>240,198</b>
<b>Expenditure:</b>				
<b>Cost of generating funds:</b>				
Fundraising	27,970	-	476	28,446
<b>Charitable expenditure:</b>				
Service provision	92,200	-	39,230	131,430
Governance	40,578	-	2,007	42,585
<b>Total expenditure</b>	<b>160,748</b>	<b>-</b>	<b>41,713</b>	<b>202,461</b>
Net surplus/(deficit)	35,925	-	1,812	37,737

## BALANCE SHEET

Fixed assets	1,633
Current assets	243,487
Total liabilities	(9,915)

<b>Net assets</b>	<b>235,205</b>
<b>Represented by:</b>	
Brought forward from 2011/12	197,468
Net surplus/(deficit) 2011/12	37,737
Transfer between funds	1,734
<b>Balance carried forward</b>	<b>235,205</b>

This financial statement has been agreed by Mazars LLP as being consistent with the full financial statements for the year ending 31 March 2013. These were prepared in accordance with the Statement of Recommended Practice Accounting by Charities (revised 2005) and receive an unqualified audit opinion.

These summarised accounts may not contain sufficient information to allow for a full understanding of the financial affairs of the charity. For further information, the full annual accounts, the auditor's report on those accounts and the Trustees' annual report should be consulted. Copies of these can be obtained from the Miscarriage Association, 17 Wentworth Terrace, Wakefield WF1 3QW.

The full accounts were approved on 15 September 2013 and have been submitted to the Charity Commission and the Office of the Scottish Charity Regulator.



Signed: Penny Kerry (Chair)

### Auditors & accountants

Mazars LLP  
Mazars House  
Gelderd Road  
Leeds LS27 7JN

### Bankers

Cooperative Bank	CAF Bank	Yorkshire Bank
Providence Street	Kings Hill	Northgate
Wakefield WF1 3BG	West Malling	Wakefield
	ME19 4TA	WFI ITA

# REVIEWING OUR FINANCES

The Miscarriage Association continued its policy of managing its resources wisely in the year ended 31 March 2013, prioritising the need both to maintain and to further develop high-quality services.

The charity enjoyed a high public profile during the year, both due to our publicity campaign and as the President's Charity of the year for the National Association of Ladies' Circles. We continued to make maximum use of use social media to further increase awareness and fundraising.

General expenditure decreased during the year 2012/2013, partly due to a reduction in staffing costs; and we also spent less on generating funds. We did note a significant, although still relatively small, increase in the cost of governance. Much of this was due to legal expenses incurred in guiding us through the staff reduction we reported on last year.

An analysis of income streams shows the continuing trend of higher income from fundraising events: an increase of £26,400 in this financial year. We received £17,500 more from the London Marathon than in the previous year, in addition to first-time income from Nightrider and the Big Give. Ladies Circle members and groups raised over £12,600 for the charity by the year-end with a further £6,000 to follow.

We noted a reduction in income from leaflet sales and training, reflecting budget constraints in the NHS, and from sales of fundraising items, particularly greeting cards.

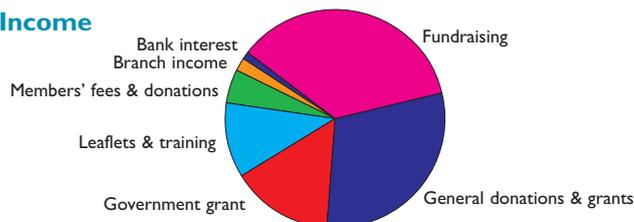
It is important to note the costs which were saved. The generously donated services of our volunteers enable us to keep the costs of providing direct charitable support relatively low. Gifts in kind, from meeting rooms to web-hosting, also combine to save funds. We are also exceptionally fortunate in the continued expert help of digital media, marketing and PR companies LIDA and Pumpkin in promoting our awareness campaigns.

All these gifts are greatly appreciated, along with the financial and moral support provided by our donors, members, supporters and friends. We are fortunate too in the dedication of staff and Trustees who manage the Association's limited resources with great care. It is this sound financial management that enables us to hold down costs without compromising our services.

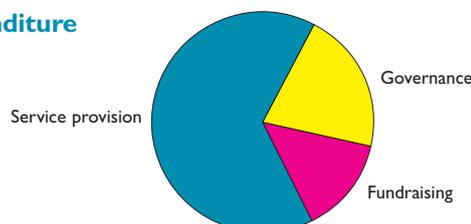
The Trustees work to a three-year budget plan which is carefully monitored and, where appropriate, adjusted during the year. This ensures that we can track financial trends and try to anticipate their effect on the finances of the Miscarriage Association.

We reported last year the need to make one post redundant. As anticipated, the full effect of this will not be seen until 2013/14 but we believe this forward planning is important for the security of the Miscarriage Association. We anticipate in the coming year, therefore, our policy will remain one of careful budgeting and fiscal monitoring as well as striving towards generating more income to sustain and develop the charity's work.

## Income



## Expenditure



## ...AND THANKING OUR SUPPORTERS

The Miscarriage Association would like to express our thanks to all those who have contributed to our funds this year. Grants, individual donations or the proceeds of fundraising events – every contribution, large or small, is greatly appreciated. While we don't have space to list all our donors here, we would like to express special thanks to the following supporters who helped us maintain and develop our services in 2011-12:

### Individuals...

Marjory Aird  
The Beadle family  
Gary Brown  
Catherine Crespin  
Tessa Goring  
Elizabeth Seamons  
Paul and Sarah Sweet  
Daniel Tunney

### ...and groups

National Association of Ladies Circles  
Our Marathon runners  
Our Nightrider team  
Jo Cameron's Achievers Academy for Women

### Government

Department of Health

### Charitable trusts & companies

Barclays Bank plc  
Bramcote Waters Golf Club  
Carillion plc  
Duncan Norman Charitable Trust  
Loch Fyne Financial Management  
News International  
The Reed Foundation  
Sabic UK  
Stella Symons Charitable Trust

### Gifts in kind

Activ Computer Services  
i2i Events Group, via Stuart Thomas  
Landau Morley LLP  
LIDA  
Pumpkin  
Rap Spiderweb

# MAKING A DIFFERENCE 2012-2013

The Miscarriage Association would like to thank all those who have been involved in providing our services during the year.

We are very grateful to our volunteer telephone contacts and support group organisers and helpers. Women and men with personal experience of pregnancy loss, they help to provide comfort and support to others in a similar situation.

Our thanks also go to the people who help to select and support volunteers; our media volunteers; those who help us raise funds; and all those who have informed and contributed to our printed and online information.

Our advisors and other volunteers who provide specialist advice and help are also indispensable. They help us answer medical queries, update our leaflets, develop our reach and plan for the future. Their contribution is strengthened by the support and commitment of the Trustees and our staff team.

We would like to make special mention of the following people for generously sharing their time and skills:

- Sarah Owen, Partner/Owner of PR, media and marketing company Pumpkin
- Lisa Thomas, CEO of M&C Saatchi Group
- the LIDA 'blue envelope' team
- Andy Clark, IT volunteer
- Neil Hepworth, for research support
- the members of our Professional Advisory Board
- our patrons
- Peta Harrison, editor of our members' newsletter
- Nigel Wood, our webmaster



## Patrons:

at 31 March 2013

Nigel Martyn  
Anna Raeburn

## Professional advisors:

Mr Roy Farquharson  
Ms Diana Hamilton-Fairley  
Dr Sheila Kitzinger  
Dr Marjory MacLean  
Prof Lesley Regan  
Prof Gordon Stirrat  
Prof James Walker

## Trustees:

at 31 March 2013

Penny Kerry  
Kerry Addison  
Nicola Caplan  
Karen Dalton  
Alison de Verteuil  
Lisa Dixon  
Sarah Dunnett  
Barbara Hepworth-Jones  
Karen House  
Sheila McPherson

Chair & Hon Treasurer  
Vice-chair  
Vice-chair

## Staff:

at 31 March 2013

Ruth Bender Atik  
Lisa Bruce  
Ann Collier  
Elizabeth Stelmach  
Fiona Marshall

National Director  
Senior Support Worker  
Support Worker  
Support Worker  
Development Worker

## RAISING FUNDS AND AWARENESS



The Holbeach runners



Claire Biggs at the London Marathon



Ladies Circle President Marjory Aird, Ruth Bender Atik and Mirren Aird

# PLANNING FOR THE FUTURE: 2013-2014

The Miscarriage Association is a small organisation with a very big mission: to ensure that everyone who experiences the loss of a baby in pregnancy receives the support, information and care which she or he needs.

We are committed to offering accessible services that are sensitive, well-informed, user-friendly and relevant to the range of people who are affected by miscarriage, ectopic or molar pregnancy. Working to meet their needs will always be our priority.

We will continue to work with health professionals, supporting them so that they can provide good and sensitive care for those who experience pregnancy loss. Along with this, we will pursue our active involvement with high-quality clinical research into the causes and treatment of miscarriage.

We will maintain our links with government and with professional organisations to ensure that they consider the patient perspective when developing policies and guidelines. And we will strive to increase public awareness of the facts and feelings of pregnancy loss, ensuring that it is recognised as a significant health issue rather than a hidden personal grief.

Despite some advances in medical research and treatment, miscarriage is still likely to affect hundreds of thousands of women and their partners in the foreseeable future. We must ensure that the Miscarriage Association continues to respond to their changing needs and expectations, maintaining and developing high-quality services that make a positive difference. We hope you will want to support us in this.

## OUR PLANS...

- maintain our staffed helpline five days a week, backed by a network of support volunteers
- create a new leaflet on the management of pregnancy loss, in line with new NICE guidance
- develop new resources for teenagers and young adults
- continue our active involvement in high-quality research
- continue to improve our website so we reach and serve a wider audience
- further improve our online presence and the use of social media
- develop online training packages for health professionals working in the field of pregnancy loss
- develop a series of awareness campaigns, beginning with a focus on the needs of partners
- continue our active involvement with the Association of Early Pregnancy Units; and maintain positive links with all relevant professional organisations, government departments, hospitals and health centres to improve care for couples who experience pregnancy loss
- maintain and promote our reputation as an expert source of information on the facts and feelings of pregnancy loss

## ...AND HOW YOU CAN HELP

- become a member of the Miscarriage Association
- join our online forums and help to support others
- talk to family, friends and colleagues about our work
- take part in one of our fundraising events – or organise your own
- become a Friend of the M.A. with a regular monthly or annual donation
- sign a Gift Aid declaration and make your gift go 25% further at no cost to you
- encourage your employer to implement payroll giving and join in to enjoy tax relief on your donation
- persuade your employer to become a corporate supporter, through corporate donations or gifts in kind



This is a note to anyone who's been affected by miscarriage in any way. And we know there's a good chance you will have been, as it's how 1 in 4 pregnancies end.

We're not asking for money, or for you to run a marathon. Just for you to help us break the silence surrounding miscarriage.

If there's one thing we've learned over the years, it's that talking helps. And we want to get everyone talking a lot more about miscarriage – however difficult that may sound – because it really does make a difference.

If you'd like to talk with one of us, please call on 01924 200 799. And you can join the conversation online @MiscarriageA, and at our Facebook page.



P.S. Please dispose of this note carefully, or feel free to pass it on to someone else.

“ Reflecting the random nature of miscarriage, we addressed the notes ‘To anyone’, as it’s not always just the person who suffers the miscarriage who is affected.

Inside was a short note encouraging people to open up.

And they did. ”