

MISCARRIAGE
ASSOCIATION

The knowledge to help

Annual Report
2009-2010

**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

c/o Clayton Hospital, Northgate, Wakefield, West Yorkshire WF1 3JS
Tel: 01924 200799 (Helpline); 01924 200795 (Admin) Fax: 01924 298834

info@miscarriageassociation.org.uk

www.miscarriageassociation.org.uk

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

Foreword



‘Those affected by miscarriage deserve the best possible care and support.’

The theme of this Annual Report is moving forward and moving on. Many reading this report will be making or have made their own journey around pregnancy loss, their own personal moving forward and moving on. And the Miscarriage Association itself has been moving forward and moving on, most visibly with its new logo and look.

My first miscarriage was in 1991 and I received a mixture of leaflets from the M.A.. Some were photocopied sheets of paper folded in to a booklet with the lotus flower logo on; others were printed leaflets with the black and white Russian doll image. The lotus flower represented new life growing out of darkness, the flower stretching up from the dark earth to the light above. The Russian doll signified the emptiness associated with pregnancy loss.

In 2000, I was talking to junior doctors at the Royal London Hospital about how women coming to A&E with bleeding in pregnancy might feel, and I was very pleased to be given a Powerpoint slide template to use with the bright new photographic version of the Russian doll.

My final miscarriage was in 2006. I sat in the corridor waiting to go in to the Early Pregnancy Assessment Unit opposite a M.A. poster featuring the familiar yellow and red Russian doll. It seemed ironic that the Chair of the Board of Trustees of the Miscarriage Association was herself having a miscarriage and couldn't make sense of the poorly photocopied and collated hospital fact-sheet.

Instead I relied on the familiar M.A. leaflets for reliable information about medical vs. expectant management. I downloaded the leaflets from the Internet rather than having to wait several days for a large brown envelope to drop through the letterbox. And I chatted on an internet forum rather than waiting for monthly meetings of the North East London support group as I had done in the early 1990s.

Mine has been a long journey and the M.A. has been with me every step of the way, from the lotus flower through the Russian dolls, to the new turquoise M.A.. Does our look really matter? Yes, because it is a visible sign that we are professional. Those affected by miscarriage deserve the best possible care and support and we want our look to reflect that, so when you first pick up a leaflet or see a poster, you are reassured that we do indeed have the knowledge to help.

We thank you for your support during our journey, because miscarriage matters.



Barbara Hepworth-Jones
Chair of the Board of Trustees



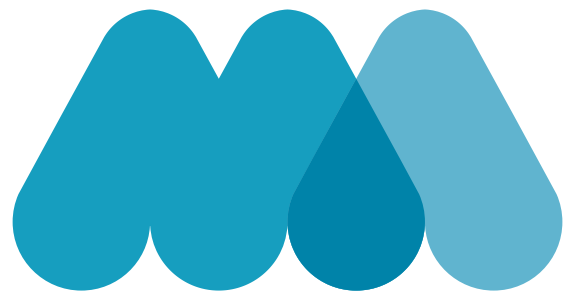
1982



1991



2000



2010

Support

The loss of a baby in pregnancy can be a very distressing and lonely experience and coping with recurrent miscarriage can be particularly difficult. Along with our staffed helpline, support from others who have been through something similar can sometimes be the key to getting through these tough times and moving forward.



‘The support forum helped me through my darkest days’

Madeline Jones

‘I turned to the MA for support on and off for several years, from my first miscarriage in 2002 to the birth of my younger child Oliver last year. In the intervening years I had one successful pregnancy, with Megan, now six, and three further miscarriages.

‘After my fourth miscarriage I remember lying there thinking I had hit rock bottom. It was the most miserable day of my life.

‘I sold all my baby things because I thought I had to move on. But it was my GP who gave me the optimism to try again when he said: “You’ve done it once and you can do it again, but I can’t tell you how many times you will miscarry”.

‘When I found out I was pregnant once more, all the worry and fear struck again. First the scan didn’t match my dates, then I had a heavy bleed at 10 weeks. And then at 16 weeks, just as I was starting to believe it was going to happen, I was told I had a significant chance of having a Down’s syndrome baby and advised to have an amniocentesis.

‘The members’ support forum was a lifeline to me all the way through that pregnancy. I would post a comment like: “Now eight weeks pregnant and terrified – how do others cope?” and get a lot of support from people who had been in the same place. When I wasn’t sure whether to have the amnio, I found it comforting to hear from people who had been through it and not gone on to miscarry.

‘The support forum helped me through some of the darkest days I have ever known. Ollie was born after a quick, easy labour, but even now, 15 months later, I still can’t believe I have two children.

‘These days I’m a moderator on the messages board, and in May this year I became a Trustee of the MA. It is really nice to feel that I have come full circle and can finally give something back.’

“You feel so desperately empty after the loss, and want to fill that void. But at the same time you’re scared to get the much wanted positive test as that then brings the possibility of another loss.”

Helping people through:

a staffed helpline

- a swift, sympathetic and informed response, five days a week, to a total of 8,500 letters, calls and e-mails

support volunteers

- 89 telephone contacts and 24 local support groups across the UK – all people with personal experience of pregnancy loss
- matched support on 26 specific areas of pregnancy loss (e.g. recurrent miscarriage and ectopic pregnancy)
- an out-of-hours helpline, offering support at evenings and weekends

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- a popular and reputable source of support, information and comfort, with personal reflections and poems
- a support forum – a safe space for sharing feelings and experiences, good news and bad
- a place for remembrance: an electronic forget-me-not meadow and a Lights of Love tree

accessibility and equality

- all support materials available in large print and on our website
- all staff familiar with RNID’s TYPETALK service for deaf and speech-impaired callers
- staff and volunteers able to offer support in 8 languages other than English



A swift, sympathetic and informed response

Information

Those who experience pregnancy loss are often desperate to know why it happened and whether there's anything they can do to reduce the risk next time. They may find it hard to pick up the phone or talk to others, so having written information that's accurate, understandable and easily accessible can make a positive difference.



'The M.A. leaflets make miscarriage less of a taboo'

Rachael Friend

'I don't like to discuss my feelings, and after I miscarried my first baby in 2007 I couldn't talk to people about it. But I had so many questions, like what did I do wrong, how should I be coping, would it happen again, how long I should wait before trying again....

'I was able to find most of the answers in the M.A. leaflets and on the website. The leaflets helped me prepare for what was going to happen when I opted for medical management of my miscarriage and there was helpful information about preparing for another pregnancy too. I had never realised how common miscarriage was, and I felt reassured that I wasn't the only person, it wasn't my fault, it wouldn't necessarily happen again and even if it did, help would be available.

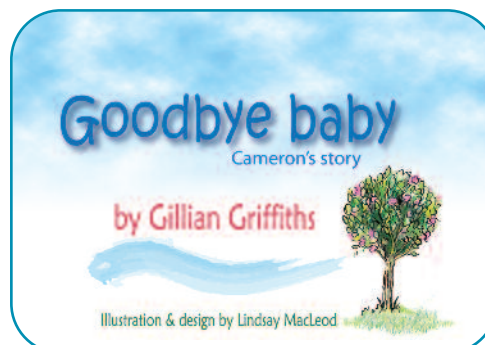
'My husband Richard couldn't even talk about the miscarriage to me. Even now, more than three years later, it's still too raw for him. So I left the leaflets around for him to read and I feel it did help him even though he wasn't able to say so.

'In the end we tried again quite soon and Grace was born in April 2008. I liked being pregnant but because of what had happened before I was never able to relax fully until she was in my arms and I knew she was okay.

'It's only now that I can talk to people about what happened, but I find that when I do, a lot of people say "Oh, that happened to me too!" It's still a taboo subject because pregnancy is meant to be such a happy experience, but the leaflets are a great way to make it less taboo.

'Earlier this year I ran the London Marathon for the M.A. and raised £1,400. I never thought I would be able to raise that much, but people were incredibly generous because of the story I had to tell.'

“I think the new Molar Pregnancy leaflet is really good. I liked how it explained what 'trophoblastic' and 'molar' meant and the Q and A section at the end. It would have been brilliant to read when I first found out about my molar pregnancy.”



An illustrated e-book for children

Helping to answer the questions

a staffed helpline

- responding to a wide variety of questions on pregnancy loss, providing clear information and clarifying confusion

leaflets

- a range of 28 leaflets on aspects of pregnancy loss, including three that were completely revised
- publishing an illustrated e-book for children by one of our members, prior to its printed publication
- all leaflets available free of charge on our website

accessibility

- one leaflet in seven community languages and in versions for people with learning or hearing disabilities
- all leaflets printed in clear typeface and available in large print
- working towards revision of all leaflets to increase accessibility

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- a well-used resource for those seeking information, support and comfort, recording an average of over 16,000 visits per month
- ranked highly on all major search engines
- an average of 5,900 leaflets downloaded from our website each month

Research

- active involvement in a range of research studies and a member of the Early Pregnancy Clinical Study Group
- responded to 6 requests for expert opinion and/or peer review relating to specific research proposals
- presented the patient perspective in clinical research at one UK and one Europe-wide research meeting

Good practice

The quality of care given to women in hospital and general practice can have a major impact on their experience and their memories of pregnancy loss. The Miscarriage Association offers training and consultancy to healthcare professionals and works with key organisations to promote sensitive care for patients who miscarry.



'I didn't realise how awful it is to have a miscarriage'

Dr Nicola Caplan

'You'd think that being a doctor would be an advantage if you have a miscarriage, but it wasn't for me. After miscarrying my second baby at nearly 18 weeks I had such an awful time on the postnatal ward that I ran out and went home as soon as I could.'

'I had an unsympathetic GP, who wouldn't prescribe drugs to help me when my milk came in. Plus my boss wanted me back at work after three days and grudgingly settled for a week.'

'Everyone assumed I knew about miscarriage, so I wasn't offered any leaflets or explanations. Sometimes being treated as a patient is better.'

'I had previously worked in the hospital where I had my miscarriage and was very aware at the time that I was doing patients with miscarriage a real injustice, but I didn't have the time, didn't know what to say. No-one taught us anything about how to look after the women we were seeing, other than from the medical point of view.'

'I found the MA on the Internet and gained a lot of comfort from reading the leaflets, if only being given permission to grieve. Later when I offered to help I was invited to become a Trustee.'

'I have focused on improving training for doctors and have organised several teaching sessions for GP trainees, which have gone down really well.'

'Doctors tend to get taught about the physical aspects of miscarriage, not how to address the emotional side of things. But I want them to appreciate what a significant event miscarriage can be in someone's life, the turmoil they can go through and the huge variety of emotions they can experience.'

'I've just written an e-learning module and an article for two medical journals; I am on a national working group developing guidelines for pain and bleeding in early pregnancy; and I am determined to help the MA use the new GP commissioning process to advise on developing the best early pregnancy services in all areas.'

'I'm glad to be able to combine my personal and professional experience to improve care for women and couples who go through miscarriage.'

“It made me think about the way I communicate with patients, the importance of giving clear explanations and information when dealing with pregnancy loss, and that each case is individual.”

Encouraging good healthcare practice:

training

- delivered training to gynaecology and midwifery staff and students, fertility nurses, GP trainees and counsellors for the UK's largest police force
- contributed to a new BMJ e-learning module

collaboration

- active executive member of the Association of Early Pregnancy Units; with a presentation to delegates at their November 2009 conference
- active links with other pregnancy and maternity charities

consultancy

- responding to seven requests for advice regarding patient care and support; providing the patient viewpoint on research for the National Perinatal Epidemiology Unit; and assisting two hospitals with setting up support groups
- advising a national charity regarding volunteer recruitment and training; assisting another with a presentation on bereavement through pregnancy loss; planned training for a regional branch of Sure Start

Miscarriage: Facts, Feelings & the GP

Ruth Bender Atik & Dr Nicola Caplan
The Miscarriage Association

Leeds GP trainees
November 2009

Patients' wants and needs:

- good listening
- acknowledgement of feelings
- clear information
- sensitive language/terminology
- joined-up communication
- support during/after the loss and in the next pregnancy

Awareness

People often under-estimate the emotional impact of miscarriage, especially if it happens early in pregnancy. The Miscarriage Association works with print, broadcast and online media to raise public awareness of the feelings as well as the facts of pregnancy loss, to make sense of news stories and to ensure that bereaved parents know where to turn to for help.



‘Raising awareness is still important’

Christine Moulder

‘I have been working with the Miscarriage Association on and off for over 20 years. In the 1980s I had several miscarriages and was helped a lot by my local M.A. support group. I became a local contact and with other women worked with our hospital to produce a leaflet for miscarriage patients.

‘Talking with other women made me realise how individual our experiences were and yet how there were also common strands. And I got very interested in how healthcare could be improved, especially at a time when information about miscarriage was often hard to find. So to fill that gap I researched and wrote a book about women’s experiences and included guidelines for good practice and care. I later wrote a book for health professionals.

‘In the late ‘80s I represented the MA on a working group of professional and voluntary organisations developing policy on the management of miscarriage, stillbirth and neonatal death. We talked in detail about the care women should have, including the implications of ultrasound, which was relatively new at the time. The guidelines we produced were sent out to every Health Authority.

‘Three years ago, at a different stage of my life and with new skills to offer, I rejoined the Trustee board. Much has changed in terms of openness, patient involvement and consumer rights as well as in the organisation and regulation of healthcare. Yet miscarriage is still taboo and often difficult to talk about and women do not always receive the quality of healthcare they should.

‘The quality of information and support the M.A. provides is high but our presentation was old-fashioned. We needed to make the M.A. and the information and support we provide as accessible and user-friendly as possible – particularly on the website, because that’s where so many people get their information today.

‘The work of raising awareness is still important. What I want is for anyone affected by miscarriage to know about the M.A. and to get what they need from us when they need it. I hope the re-brand will help to get us to that position.’

“ I actually think the logo should stay away from representing the loss of the baby or the emptiness which we feel. It should show how your charity offers a strong support network. ”

Response to consultation on rebranding

Reaching people:

news & features

- seen by the media as an expert resource for advice, information, comment and case studies
- responded to 52 requests from the broadcast, print and online media for expert comment, background information and case studies
- helped by 44 media interviewees who contribute personal reflections and experiences

profile

- recorded 2,100 viewings during the year of our short film *Acknowledging Pregnancy Loss* on the Community Channel and 7,391 on our website
- continued collaborative work with other baby-loss charities to raise awareness of pregnancy and baby loss, especially through the UK-wide Babyloss Awareness Week
- over 125 supporters taking part in a range of fundraising events and raising awareness of the charity as well as funds
- maintaining an excellent internet profile, with links from other websites, so that we feature highly on the largest search engines

“ I am researching a feature on recurrent miscarriages for *Fabulous* magazine.

I’m looking for a couple who would be happy to speak to me about their experiences.

Perhaps they have gone on to have a child or have been left so emotionally drained that they can’t face trying again... ”

Abridged accounts

1 April 2009 – 31 March 2010

	General funds £	Designated funds £	Restricted funds £	Total
Income:				
Donations & similar income:				
Membership fees & donations	14,616	-	982	15,598
Other donations & grants	44,955	-	500	45,455
Branch income	-	-	5,932	5,932
Activities to further the Charity's objects:				
Sales	33,437	-	-	33,437
Training & Members' Day fees	733	-	-	733
Activities to generate funds:				
Fundraising activities	54,243	-	-	54,243
Sales	2,917	-	-	2,917
Interest received	4,291	-	-	4,291
Total income	155,192	-	7,414	162,606

Expenditure:				
Cost of generating funds:				
Fundraising	31,575	-	-	31,575
Charitable expenditure:				
Service provision	81,895	28,695	12,332	122,922
Governance	40,624	-	23	40,647
Total expenditure	154,094	28,695	12,355	195,144
Net surplus/(deficit)	1,098	(28,695)	(4,941)	(32,538)

BALANCE SHEET

Fixed assets	438
Current assets	217,887
Total liabilities	(11,687)

Net assets	206,638
Represented by:	
Brought forward from 2008/09	239,176
Net surplus/(deficit) 2009/10	(32,538)
Balance carried forward	206,638

This financial statement has been agreed by Mazars LLP as being consistent with the full financial statements for the year ending 31 March 2010. 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, c/o Clayton Hospital, Northgate, Wakefield WF1 3JS.

The full accounts were approved on 6 November 2010 and have been submitted to the Charity Commission and the Office of the Scottish Charity Regulator.



Signed: Barbara Hepworth-Jones (Chair)

Auditors & accountants

Mazars LLP
Mazars House
Gelder Road
Leeds LS27 7JN

Bankers

Cooperative Bank
Providence Street
Wakefield WF1 3BG

CAF Bank
Kings Hill
West Malling
ME19 4TA

Birmingham Midshires
Pendeford Business Park
Wobaston Road
Wolverhampton WV9 5HZ

Yorkshire Bank
Northgate
Wakefield
WF1 1TA

Reviewing our finances

The Miscarriage Association continued its policy of managing its resources wisely in the year ended 31 March 2010, prioritising the need to maintain high-quality services.

We had anticipated a challenging financial climate in 2009/10 and were therefore not surprised to see overall income drop by 15% compared with the previous year.

There were several key reasons for this. Although we worked hard to maximise the value of our funds, the overall fall in UK interest rates resulted in a significant drop in investment income from reserves. Changes in government funding led to the ending of long-running funding from the Department of Health. In addition, income from bulk sales of leaflets to hospitals dropped, reflecting budget cuts across the NHS.

We would have seen a much greater reduction in income were it not for the efforts of our individual supporters. We were delighted that income from public donations increased by over 20% in comparison with 2008/09, and pleased too that fundraising income, particularly from the London Marathon, remained steady. We wish to thank all those involved in fundraising events, both for the funds that they raised and the publicity that they engendered.

While income from companies and trusts was lower than in the previous year, we received significant gifts in kind from two corporate partners who assisted us with the M.A.'s re-branding. Their support has enabled us to apply some of the funds designated for this project for core expenditure.

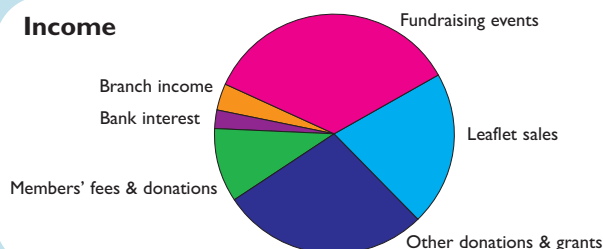
Overall expenditure reduced by 5%, though branch expenditure exceeded income, as one branch left the umbrella of the Association during the year. We report branch funds in our accounts, but they are held as a restricted fund, used by those branches alone. As always, the generously donated services of all of our volunteers enabled

us to keep the costs of providing direct charitable support relatively low, saving an estimated £56,928 over the year.

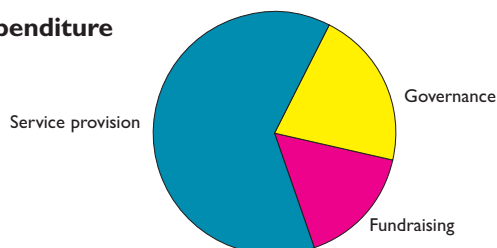
In the years leading up to 2009/10, we were able to build up our general reserve fund, creating a financial safety net against future downturns. This proved crucial during the year as we were able to use some of those reserves, as planned, to subsidise some of our core costs. It does mean, however, that our reserve fund dropped by the year end.

In the coming year, therefore, we will continue to work towards increasing all income strands as well as continuing to manage our resources with great care. We anticipate that with the continuing support of our friends and the positive impact of our re-branding on fundraising, the Miscarriage Association will be able to weather the economic downturn and remain a strong organisation, ready for future challenges.

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, sponsorship, individual donations or the proceeds of fundraising events – every contribution, large and small, is greatly appreciated. While we are unable 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 2009 – 2010:

Individuals and groups

Timothy Apps
Vivienne Armstrong
Bridgwater College Student Union
David Horspool
Paul and Sarah Sweet
Jan & Kai Nicholls
Dan Savage
Ian Skirrow
Neil Stride & Peter Crammer
Liz Watson and family
Our London Marathon teams

Charitable trusts & companies

Duncan Norman Charitable Trust
GlaxoSmithKline
Miller Insurance
News International
Stella Symons Charitable Trust

Gifts in kind

Activ Computer Services
Blueleaf
Landau Morley LLP
LIDA
Pumpkin
RAP Spiderweb
Sterling Events



David Horspool

Making a difference 2009-2010

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 a national network of 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; all those who help us raise funds; and those who have informed and contributed to our leaflets.

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

We are very grateful to all those who provided feedback regarding the Association's visual image, which was the basis of our rebranding project. And we especially appreciate the contribution and commitment of PR, media and marketing company Pumpkin and direct and digital agency LIDA, who provided their expert services completely free of charge.

We would like to express particular gratitude to the following people for generously sharing their time and skills:

- Sarah Owen, Partner/Owner of Pumpkin
- Lisa Thomas, CEO of M&C Saatchi Group
- the members of our Professional Advisory Board
- our patrons
- Peta Harrison, editor of our members' newsletter
- Nigel Wood, our webmaster



M.A. advisor Ms Diana Hamilton-Fairley

Patrons:

Tania Bryer
Nigel Martyn
Anna Raeburn

Professional advisors:

Dr Christopher Everett
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 2010

Barbara Hepworth-Jones
Kerry Addison
Beverly Boyle
Penny Kerry
Julia Bueno
Nicola Caplan
Alison de Verteuil
Clare Hobro
Sheila McPherson
Christine Moulder

Ex-officio:

Morag Kinghorn

Chair

Vice-chair

Vice-chair

Hon Treasurer

Co-ordinator for Scotland

Staff:

at 31 March 2010

Ruth Bender Atik
National Director

Lisa Bruce
Senior Support Worker

Sarah Pugh-Wales
Support Worker

Andrea Allen
Volunteers Manager



M.A. patron Nigel Martyn



Dr Rosemary Fisher (left) and Dee Short, advisors for the leaflet Hydatidiform Mole



The Trustees and National Director

Planning for the future: 2010-2011

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, treatment and prevention 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 UK network of trained volunteers
- open our online support forums to all service users
- roll out and promote a new image for the charity: a new logo and strap-line; the revision of all leaflets; and the redesign of our website
- develop new print and online information for teenagers and young adults
- further improve our online presence through appropriate social networking sites
- continue our project to raise the charity's profile amongst primary care professionals; and further develop consultancy and training for health professionals
- implement a three-year project to develop and pilot tailored packages of support, information and training with areas served by specific hospitals and GP practices
- further develop consultancy and training for health professionals and for other support and counselling organisations
- continue active involvement with the Association of Early Pregnancy Units and maintain positive links with all the relevant professional organisations, government departments, charities, 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 UK-wide volunteer network and volunteer your time and skills
- 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



“ I’d very much like to run the London Marathon for the Miscarriage Association.

I have experienced two miscarriages, losing three babies, before my beautiful children came along.

I sought help and advice from the M.A. to help me through the tough moments. I attended my local group regularly and found the comfort to help me keep trying for a baby.

I want to give something back to this charity and say thank you for the invaluable support it provides to everyone affected by miscarriage.

I’ll be running with my lost babies in mind and for every lost baby and every mum and dad dealing with a loss. ”

Claire Cartwright-Clamp