

THE MISCARRIAGE ASSOCIATION

ANNUAL REPORT 2007–2008



marking 25 years of support, information and change

**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.**

The Miscarriage Association



acknowledging pregnancy loss

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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 (3779123)

foreword



It is with great pleasure that I introduce this Annual Report, which marks the 25th anniversary year since The Miscarriage Association was founded.

I am sure that those involved 25 years ago would never have dreamt that so much would have been achieved. But they would be proud. Similarly, those who have become involved more recently probably cannot remember what it was like all these years ago. But I do.

I became a registrar in obstetrics and gynaecology in 1980, 28 years ago. At that time we, as junior doctors, admitted women with early pregnancy bleeding, diagnosed “spontaneous abortion” often on clinical grounds, took them to theatre and carried out a D&C. We took pride in doing it efficiently and getting them out of hospital and home as quickly as possible. But each time I did this, the looks in the eyes of the women who had lost their pregnancies told me this was wrong, but that was the way it was done. There was no-one to turn to back then for information or advice.

The Miscarriage Association came and educated us. It provided a source of help and support for the women and for the staff caring for them. The leaflets were wonderful, the telephone contacts invaluable. Their lobbying made people stop and think and it led to the changing of the nomenclature and the setting up of early pregnancy units to support women rather than just process them. They were the voice in the wilderness.

I am proud to have been involved in a small part in these achievements. I have officially been involved with The M.A. for at least 15 years but its influence on me, my thinking and my practice goes back longer.

Happy anniversary M.A!

Professor James Walker,
Department of Obstetrics and Gynaecology
St James University Hospital, Leeds.



1982 Karen Spencer founds the Miscarriage Association

The experience of repeated miscarriage leads Karen to determine to provide support and information for others. Based in Bristol, she gathers a group of people who become the M.A.'s first committee.



1982 Getting established

Press articles promote the M.A. and Karen responds to a deluge of requests for help. She writes the first newsletter, gathers information for leaflets and then hands over the reins to volunteers in Yorkshire. In November the M.A. is registered as a national charity.



support

The loss of a baby in pregnancy can be a very distressing and lonely experience and levels of anxiety in a subsequent pregnancy are often very high. The Miscarriage Association provides support, understanding and a listening ear to anyone affected by pregnancy loss, whenever the need arises.



'You need a huge amount of support in the next pregnancy'

Andrea Pearson

When I was signed off after my miscarriage, what concerned me was the lack of follow-up. Unlike after you've given birth, no one bothers with you and I was sent home unsupported.

I already had a 14-year-old daughter from my first marriage. I fell pregnant just after my wedding to Alan last September. The next month we all went to Greece, and that's where I lost the baby. The hospital treatment was good but it was difficult returning to the holiday when all I wanted was to go home.

Making contact with The Miscarriage Association was wonderful. I received telephone support, read the leaflets and spent a lot of time on the website. It all helped to make me realise that miscarriage was common, that millions of other couples go through it and that we were not alone.

When I found out I was pregnant again I was overjoyed but petrified. Even at 26 weeks' pregnant you still worry. You need a huge amount of support in the next pregnancy because you can't stop worrying until you hold your baby in your arms. The members' forum on the website has a section called *Pregnant After Loss* where I gain and give support.

Alan and I recently set up a Miscarriage Association support group in Doncaster and have so far held three sessions, mostly for small numbers. But if I help only one person every now and again, that's enough. The M.A. was there for me and I am determined to give something back.

Key achievements:

staffed helpline

- a swift, sympathetic and informed response, five days a week, to a total of 8,200 letters, calls and e-mails
- a 23% increase in e-mail requests for help

support volunteers

- 90 telephone contacts and 29 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

miscarriageassociation.org.uk

- a popular and reputable source of support, information and comfort, with personal reflections and poems
- launch of the message-board – 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 9 languages other than English
- venues and facilities for central M.A. events accessible to people with disabilities
- increased distance learning programmes to reduce barriers to volunteering



1984

A new secretary at the helm
Kathryn Ladley volunteers as membership secretary and then general secretary, answering letters and telephone calls from her home near Wakefield. By now there are 65 support groups across the country.



© Desmond O'Neill

1989

Our first patron

Dame Josephine Barnes agrees to become our patron. A tireless campaigner for women's health, she notes: *The M.A. not only helps sufferers, but it also has an important role in educating health professionals.*



information

Pregnancy loss can be even more distressing when parents are faced with making difficult choices. Clear information, support and time can help them gain some sense of control in stressful circumstances. That's why The Miscarriage Association provides accurate and understandable information about both the facts and the feelings of pregnancy loss.



'Hospital information wasn't very helpful'

Ian Every

There's information and information. When my wife Michelle was admitted at 20 weeks to deliver our fifth baby, who had apparently died some weeks earlier, we were given information about our choices, but it wasn't very helpful.

While going through labour, mostly alone, we were invited to make various decisions – cremation or burial, funeral arrangements, writing in a memorial book – and felt pressured to commit ourselves then and there.

We decided on cremation, with no particular service, and to recognise the death in our own way at home. Now I am not sure we made the right decision. Having learned how our children deal with sadness, a ceremony might be our preference now.

It wasn't until we read The Miscarriage Association's information that we realised it would have been okay to have gone home and made these crucial decisions later. This knowledge would have put us in a stronger position at the time.

I don't think men know how to react after miscarriage and how much they might need to talk. Because I was open about our loss, several blokes took the opportunity to talk for the first time about their own experiences of miscarriage.

Being interviewed for The M.A.'s short film helped me consider not just my own feelings but what other men had gone through and I am now considering joining Michelle as a telephone volunteer for The M.A.

Key achievements:

staffed helpline

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

leaflets

- publishing 25 leaflets, plus fact-sheets and booklets on aspects of pregnancy loss
- over 61,000 leaflets ordered by hospitals, clinics and individuals
- leaflets also downloaded from our website

accessibility

- a new leaflet for profoundly deaf people; and a new illustrated leaflet for people with learning disabilities
- seven bi-lingual leaflets, including a new Polish-English version in response to demand
- all leaflets printed in clear typeface and available in large print and on our website

miscarriageassociation.org.uk

- a well-used resource for those seeking information, support and comfort, recording an average of 16,477 visits per month
- ranked highly on all major search engines
- consistently given high approval ratings by visitors, with feedback informing content and design
- recognising under-reporting of leaflet downloads and incorporating a new tracking system for 2008/09; anticipating 5,000 leaflet downloads per month

research

- producing and promoting a lay-person's summary of research findings on risk factors for early miscarriage



Ruth Bender Atik

1993

A National Director

An external consultant reviews the M.A.'s services and structure. She recommends appointing a full-time National Director to enable the charity to move to a new stage of development and raise its public and professional profile.



1998

Expanding the helpline

Tesco Baby Club supports an additional helpline worker and telephone line, expanding service capacity. They place 75,000 copies of *Someone You Know*, a leaflet for family and friends, across their UK stores.



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 clarify myths and misunderstanding.



‘I want to raise awareness and change attitudes’

Natasha Bailey

When I look back at the seven miscarriages I endured before giving birth to Raya, I still recall the hurtful things people said while trying to be kind.

Things like “it wasn’t meant to be”, or “you can always have another one”, and even “it wasn’t a real baby”! But you still feel you have lost a baby and if people don’t acknowledge that, it can be very upsetting.

I only heard about The Miscarriage Association after my third miscarriage. It was good to know that I was not alone and that many other couples did eventually have a baby. In 2001 I ran the London Marathon, raising just over £1,000 in sponsorship and getting publicity for The M.A. too.

After my fourth miscarriage I was diagnosed with a blood-clotting problem and was treated with aspirin and heparin. But it took three more miscarriages before doctors detected a structural problem in my uterus and I needed three operations to solve the problem.

Shortly before I had Raya, I was invited to become a media volunteer for The M.A.. I appeared in their short film about miscarriage and now I’m willing to tell my story. I want to raise awareness of the suffering that miscarriage can cause and of the help that The M.A. can provide.

But I also want to change attitudes – to make the public and health professionals aware of the need to be sensitive and supportive, to listen rather than comment and to understand that each miscarriage could have been a baby.

Key achievements:

news & features

- seen by the media as an expert resource, providing advice, information, comment and case studies
- responded to 72 media queries, from television (9), radio (11), magazines (22), newspapers (22), web-based media (4) and compilers of fact-based books and journals (4)
- helped by 51 media interviewees who contribute personal reflections and experiences
- advised on storylines for two drama series, on the BBC Asian Network and on BBC2 Wales

profile

- completion of a short film *Acknowledging Pregnancy Loss*, supported by the Media Trust, in time for April 2008 launch
- a rowan tree planted near Loch Lomond to mark 25 years of miscarriage support in Scotland
- public exhibition and coverage of Charlotte Latham’s interactive artwork *Hands of Hope*
- promoting National Babyloss Awareness Week, together with four other baby-loss organisations
- over 80 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



2000

Raising awareness

On The M.A.’s 18th anniversary, we launch Miscarriage Awareness Week. Events include tree-planting, a memorial garden and the release of 5,000 balloons across the UK in memory of babies lost in pregnancy in any week.



2003

Support for all

We produce four new Asian language leaflets, a leaflet on late miscarriage, and one on pregnancy loss and infertility. We develop and deliver new training for support volunteers and study days for health professionals.



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.



'People didn't use to ask what had happened to their babies'

Lesley Allan

'As a newly qualified staff nurse on a gynae ward, I was especially interested in the care that women experiencing pregnancy loss received. It seemed to me that ensuring that sensitive disposal of the pregnancy was offered to all women, regardless of the gestation of their pregnancy, was an important part of that care.'

'Although I felt like a lone voice, I went ahead and wrote a protocol for sensitive disposal and managed to negotiate with my management to offer it at all gestations.'

'I thought that was the end of the story, but then I was invited by the RCN Gynae Nurses Forum to join a committee charged with developing the first national guidelines on sensitive disposal, designed to address inconsistent practices around the UK.'

'Those guidelines were published in 2000, but after that came the real work of making sure they were implemented, and I worked with The Miscarriage Association to promote the guidelines at a series of special conferences for health professionals.'

'I am now involved in revising and updating the guidelines, working very closely with Ruth Bender Atik of The Miscarriage Association. Nurses look after women while they are miscarrying, but The M.A. has contact with them afterwards and we really need to know what women think and feel about their treatment.'

'I hope the work I have been involved with has empowered people to talk about issues previously seen as unmentionable. Now I want to make sure that practice keeps up to date.'

Key achievements:

conferences & training

- presenting our research on risk factors for miscarriage to the European Society for Human Reproduction & Embryology's winter symposium in Brussels
- co-producing a tutorial on *Breaking Bad News* for the Royal College of Obstetrics and Gynaecology's on-line training and tutorial system
- contributing to the launch of the new SANDS Guidelines *Pregnancy Loss and the Death of a Baby* with a presentation on miscarriage
- training sessions for staff at Kings College and Kettering General Hospitals on caring for patients with pregnancy loss
- a training pack for service users – people who want to represent the patient perspective on pregnancy loss in local NHS Trusts

collaboration

- working with the Royal College of Nursing and the Institute of Cemetery and Crematorium Management to revise and update guidelines on the sensitive disposal of fetal remains
- active links with other pregnancy/maternity charities, the Association of Early Pregnancy Units and the Royal Colleges of Nursing and of Obstetricians and Gynaecologists

consultancy

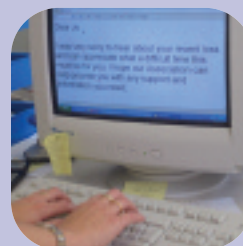
- acted as advisors on five research proposals; advised on three NICE guidance documents and two patient information leaflets; and provided input for two sets of professional guidelines and the Healthcare Commission review of maternity and pregnancy care



2005

A year of partnership

We work with government, professional groups and key charities to develop guidance on the disposal of fetal remains. We run two major conferences for health professionals with a third planned for 2006.



2008

Meeting the needs

Patterns of use are changing and The M.A. continues to respond. We now provide high quality support and information by phone, in print and on-line, with leaflets designed to suit a wide range of needs. We are ready to start the next 25 years.



abridged accounts

1 April 2007 – 31 March 2008

	General funds £	Designated funds £	Restricted funds £	Total
Income:				
Donations & similar income:				
Membership fees & donations	17,923	-	1,046	18,969
Government grants	10,000	-	-	10,000
Other donations & grants	35,061	-	2,918	37,979
Branch income	-	-	12,990	12,990
Activities to further the Charity's objects:				
Sales	47,419	-	-	47,419
Conference & Members' Day fees	390	-	-	390
Activities to generate funds:				
Fundraising activities	52,274	-	-	52,274
Sales	2,946	-	-	2,946
Interest received	12,606	-	-	12,606
Total income	178,619	-	16,954	195,573
Expenditure:				
Cost of generating funds:				
Fundraising	30,220	-	5,615	35,835
Charitable expenditure:				
Service provision	83,196	24,176	21,197	128,569
Governance	36,213	-	174	36,387
Total expenditure	149,629	24,176	26,986	200,791
Net surplus/(deficit)	28,990	(24,176)	(10,032)	(5,218)

BALANCE SHEET


Fixed assets	1,468
Current assets	265,291
Total liabilities	(12,568)

Net assets	254,191
Represented by:	
Brought forward from 2006/07	206,837
Net surplus/(deficit) 2007/08	28,990
Transfer between funds	(99,303)
Balance carried forward	136,524

This financial statement has been agreed by Mazars LLP as being consistent with the full financial statements for the year ending 31 March 2008. 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 September 2008 and have been submitted to the Charity Commissioners.



Barbara Hepworth-Jones (Chair)

Auditors & accountants

Mazars LLP
Mazars House
Gelderd 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

reviewing our finances...

The Miscarriage Association continued its policy of managing its resources carefully in the year to 31 March 2008, enabling it to maintain and develop high-quality services and to make provision for the future. This was achieved both through the support of our donors, members and friends and by managing The M.A.'s limited resources with great care.

We were pleased to see significantly more income from sales of leaflets to hospitals and clinics this year, especially since this means that more patients are receiving our leaflets. Donations from M.A. members also increased while income from fundraising activities, particularly the London Marathon, remained steady. In contrast, income from government grants, membership fees, grants and non-member donations was less than in 2006/07.

We continued to maximise the value of all of our funds with a mix of instant access and high interest savings accounts. The combination of earned, investment and fundraising income made up nearly three-quarters of The Miscarriage Association's general (unrestricted) income for the year.

The majority of restricted income during the year was raised by and for M.A. support groups, legally branches of The Association. We report those funds in our accounts, but they are held and used by those branches alone. Other restricted income was for sponsorship of two new leaflets and a local initiative for miscarriage patients in Nottingham.

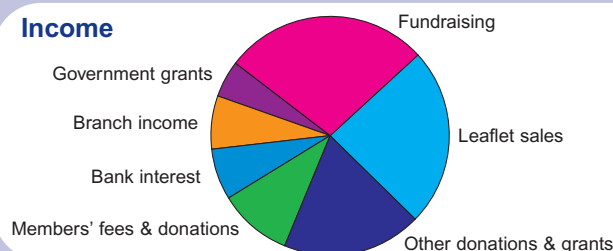
As always, the generously donated services of all of our volunteers enabled us to keep the costs of providing direct charitable support relatively low – an estimated saving of £55,425 during the year. As a result, service provision accounted for less than two-thirds of our total expenditure. Spending on fundraising was similar to the

previous year as were the costs of governance, including legally required meetings, reports and accounting.

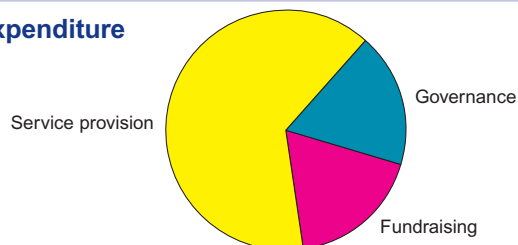
The accounts show a surplus of general (unrestricted) funds for the year, which has enabled us to increase our General Reserve Fund and to designate more of these General Reserves for two key programmes over the next three years. The restricted fund reserve constitutes branch funds only.

The Miscarriage Association continues to develop its services in response to both continuing and changing needs for support and information relating to pregnancy loss. We need to be equally responsive to the changing and more challenging economic climate, developing a more sustainable income base from a mix of earned, investment, fundraising and donated income and ensuring that we have sufficient reserves to enable us to cope with the uncertain funding futures faced by many charities. This is the way to secure the future of The Miscarriage Association for as long as it is needed.

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 2007 – 2008:

Statutory funding

The Department of Health

Individuals and groups

Babyloss
Helen Carnell
Nigel & Amanda Martyn
Cathy Midgley
Plough Lodge
Matthew & Jill Walters
Our London Marathon team

Charitable trusts & companies

Hewitt Associates
IPC Media: *Practical Parenting*
JAH Norman Trust
St James' Place
Stanley Grundy Foundation
Stella Symons Charitable Trust
Vitabiotics

Gifts in kind

Activ Computer Services, for e-mail and website hosting
Marks & Spencer plc, for providing facilities for Trustee meetings
RAP Spiderweb, for support in design and print

making a difference

The Miscarriage Association would like to thank all those who have been involved in providing our services during this, our 25th anniversary year. We are conscious too of our founders and the many people who have contributed their support, time and skills since The M.A.'s earliest days in 1982.

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 are the backbone of The Miscarriage Association, as they have always been, providing a national network of comfort and support to others in a similar situation.

Our thanks also go to the people who help to recruit, train and support volunteers; our media volunteers; those who review books for the newsletter; and those who help us raise funds.

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

- the members of our Professional Advisory Board
- our patrons
- Peta Harrison, editor of our members' newsletter
- Nigel Wood, our webmaster



M.A. patrons Tania Bryer and Anna Raeburn

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
Ms Christine Moulder
Prof Lesley Regan
Prof Gordon Stirrat
Prof James Walker

Trustees:

at 31 March 2008

Barbara Hepworth-Jones	Chair
Alison de Verteuil	Vice-chair
Sheila McPherson	Vice-chair
Penny Kerry	Hon Treasurer
Kerry Addison	
Beverly Boyle	
Sue Gillham	
Clare Hobro	
Anne Walton	

Ex-officio:

Morag Kinghorn	Co-ordinator for Scotland
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Staff:

Ruth Bender Atik
National Director

Lisa Bruce
Senior Support Worker

Anne Woodhouse
Senior Support Worker

Sarah Pugh-Wales
Support Worker

Andrea Allen
Volunteers Manager



Volunteer training day



Chair of the Trustees:
Barbara Hepworth-Jones



Trustee Sheila McPherson:
Hands of Hope

twenty-five years

Some anniversaries are a cause for celebration, some for sad memories and yet others are bitter-sweet. So it is with The Miscarriage Association's 25th anniversary year.

We have reason to celebrate the continuing development of our support and information services since those early days, thanks to the support of so many people. We have stayed true to the aims of our founders while responding to the changing wants and needs of our users. We have reached out in innovative ways to those whose circumstances make it hard for them to access our services. We have had a positive influence on government policy and NHS practice and The Miscarriage Association is both well respected and increasingly well known.

We look back with sadness at the deaths of our founder, Karen Spencer; of our first patron, Dame Josephine Barnes; and of our long-time advisor, Nancy Kohner. We are always aware of the losses that members, service users, supporters and staff have experienced: so many babies who died before they were born.

And of course this anniversary is bitter-sweet, since we would rather The Miscarriage Association were not needed at all. We cannot prevent every loss, but we will work to reduce their number by supporting high quality research and providing reliable information. We will also continue to raise awareness and promote good care until everyone who experiences pregnancy loss receives excellent medical care and complete understanding and support from those around them. We hope you will help us achieve our goals.

our plans...

- maintain our high-quality helpline five days a week, backed by a network of trained volunteers
- produce a leaflet for people who are considering stopping their attempts to have a baby and another, for employers, on miscarriage and the workplace
- continue to address gaps in accessibility of services and further develop electronic, telephone and text-based support and information
- launch a project to raise the charity's profile amongst primary care professionals and develop targeted in-house training in hospitals and in primary care
- continue work with the Royal College of Nursing to revise and then launch joint national guidelines on the sensitive disposal of fetal remains
- begin a project to raise awareness of pregnancy loss and The M.A. in general practice and community healthcare
- continue working with all the relevant professional organisations, government departments, hospitals and charities to improve care for couples who experience pregnancy loss
- work collaboratively with other charities to raise awareness of pregnancy and baby loss
- maintain 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
- talk to family, friends and colleagues about our work
- become a Friend of The M.A. with a regular monthly or annual donation
- 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
- take part in one of our fundraising events – or organise your own
- sign a Gift Aid declaration and increase your donation at no cost to yourself

“I would like to take this opportunity to thank the Miscarriage Association and in particular Lisa, at your office. She has been very helpful and understanding in our e-mail exchanges and has always responded promptly to my questions.

“I found the guidance and compassion shown by your Association invaluable at a time when it was most needed.”