

THE MISCARRIAGE ASSOCIATION

Listening



and responding

ANNUAL REPORT 2004–2005

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
to those whom it affects.

The Miscarriage Association



acknowledging pregnancy loss

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

Foreword



Most of you reading this report will have first-hand knowledge of the information and support provided by The Miscarriage Association through your own experience of pregnancy loss. Even so, I am sure you will be impressed by the range of needs with which The M.A. can now assist, as well as the extent of the work undertaken in all strategy areas.

This report is structured, as in previous years, to reflect The Miscarriage Association's four key areas of work: providing *support*, providing *information*, promoting *good practice*, and raising *awareness*. In each of these areas The M.A. has clear objectives and a strategy for achieving them. Such clarity is essential for any organisation to achieve its

purpose. It provides a basis for monitoring and evaluation and for planning – in other words, for listening and responding. You will see this clearly illustrated in this year's Report.

As an independent consultant working with voluntary organisations I have been delighted over the last few years to see The M.A. working to develop a really effective structure and processes. It is better placed now than ever before to assess how far it is fulfilling its objectives and to improve the means for doing so. As part of this, The M.A. embarked in 2004/05 on its first external evaluation, with funding from Lloyds TSB and help from our consultancy. Many of you will have seen a questionnaire or the pop-up form on the website. These sought views on all the ways in which The M.A. communicates with members and enquirers.

Completing questionnaires is not everyone's favourite pastime. Over six hundred of you are to be warmly congratulated on letting The M.A. know what you think. The results have provided solid evidence about how far it is meeting your needs, and what changes you would like to see to ensure even better support and information accessible to all. Armed with all this valuable feedback, the Trustees and the National Director will soon start updating the organisation's rolling three-year plan, looking as far ahead as 2009.

This Annual Report focuses on the range and quality of services that The Miscarriage Association provides to those who have suffered pregnancy loss. All this has come as the result of hard work behind the scenes and – perhaps most importantly – The M.A.'s ability to listen to feedback, to hear what you say and to respond.

I warmly commend this report to you all.

Janet Williams
Partnership at Work



Support

Beverly Boyle received no support when she was going through her first three miscarriages. Family and friends said things like: 'It's nature's way', and 'It wouldn't have been a baby anyway'. Joining The Miscarriage Association was 'a breath of fresh air – I got support just by knowing they were there'.

'No one we knew had experienced miscarriage, so we felt terribly alone. When we joined The M.A., it was wonderful to find that other people had experienced the same problems and the same feelings and yet refused to give up hope. They gave us the support we needed to carry on trying

when other people were saying, "it's not meant to be". Even the consultant didn't hold out much hope: he actually said "Any time you fancy a kick in the teeth, have another go"!

'Although I had one further miscarriage, Eleanor Ruth finally arrived in July 2003 and she is our miracle. Part of the healing was writing up my own story in The M.A. newsletter. Even now when I read it, the tears well up – but that is all part of the support process.

'I had another miscarriage last November, and the jury is still out on whether Simon and I will try again. I hope we will gain the courage to do so from The M.A. and its members. When you are in the depths of despair, they give you that spark of hope. In fact, one of the most supportive things that we feel comes through from The M.A. is the work that they are doing with health professionals. Even if things do not change in my child-bearing years, let's hope that they do for others in the future!'

I am finding it very hard to cope. I feel as if there is an empty space in my heart that can't be filled.

Because I have a daughter who is nearly 3, people think that my loss is less painful and because I've put on a brave face with friends and at work, people think I've got over it.

As a grieving prospective father, I found that your website was the only real resource on the web that addressed the emotional needs of men affected by miscarriage. It gave acknowledgement to many of the emotions I have been feeling. I am glad to know that I am not alone and that these feelings and experiences are all normal.

I am so pleased you replied so promptly. I feel as if you were by my side, grabbing my hand.

Beverly's story emphasises the power of shared experiences and feelings in providing support. This is the basis of The Miscarriage Association's support service, which is continually informed by the personal experience of members, support volunteers and users. By listening carefully and responding sensitively we can ensure that we provide a high standard of support, care and comfort to those who experience the distress of pregnancy loss.

Key support services in 2004/2005:

Staffed helpline

- We maintained two helplines five days per week, providing a swift, sympathetic and informed response to 8,500 letters and calls and 3,100 e-mails requesting support and information.

Support volunteers

- We coordinated a UK-wide network of 105 telephone contacts and 39 local support groups.
- Fifty-three contacts provided support on 26 specific areas of pregnancy loss (such as recurrent miscarriage and ectopic pregnancy).
- Twenty-eight volunteers staffed an out-of-hours helpline, offering support at evenings, weekends and Bank Holidays.
- Seven volunteer trainers and 11 regional coordinators helped us

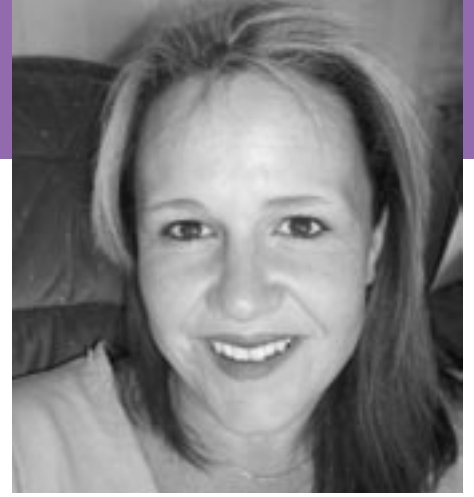
implement a new recruitment, selection and training process for all support volunteers.

Newsletter and website

- We published a quarterly newsletter, a source of support, information and comfort for our members. We posted selected items on the website, which also contains a section called "Reflections on Loss".

Accessibility

- We ensured that venues and facilities for central M.A. events were accessible to people with disabilities; and increased distance learning facilities for potential and established volunteers to reduce barriers to volunteering. All leaflets are available in large print and on our website.



When Debbie Small contacted the Miscarriage Association after the traumatic loss of twins – her third miscarriage – she wrote: ‘After reading your leaflets I know that what I am feeling is quite normal in the circumstances...What a relief to know that I’m not alone in my “weird” moods and behaviour’. Later she put her experience to positive use by helping us prepare our new leaflet Talking to Children about Pregnancy Loss.

‘I lost the first twin in front of my nine-year-old son Joshua and the second on my own in a hospital bed. I was 14 weeks pregnant but didn’t know I was expecting twins. Because it was Christmas, the hospital wouldn’t scan me. If they had, I believe the second twin could have been saved. But they subjected me to four internal and then the inevitable happened.

‘Nobody offered me any information, and when I got home I was completely devastated, depressed and having panic attacks. Luckily my partner Jason saw an article about The Miscarriage Association and contacted them for me. I got a lot of support from The M.A. and the information they supplied was absolutely brilliant. I have since had two healthy boys.

‘I was delighted to help with the new leaflet. When I was miscarrying at home, Joshua was terrified and thought I was bleeding to death. In my next pregnancy, I let him go through everything with me – the antenatal checks, the scan, even the birth – and he was one of the first people to hold Mitchell. If my experience can be used to help other parents, that is wonderful.’

Debbie was one of 64 M.A. members who provided input for the leaflet Talking to Children about Pregnancy Loss, which we produced in response to requests from service users. Those who experience pregnancy loss are often desperate for information on both facts and feelings and we ensure that our leaflets address both aspects.

Key information services in 2004/2005:

Staffed helpline

- Helpline staff responded to a wide range of questions on pregnancy loss, providing clear information and clarifying confusion.

Leaflets

- We produced two new patient information leaflets and revised and updated five others, incorporating findings from our research into risk factors for miscarriage; we now publish 18 leaflets on aspects of pregnancy loss.
- We sent over 80,000 leaflets by request to individuals and to hospitals and clinics and a further 1,800 per month were downloaded from our website.

Accessibility

- We provided our most widely-read leaflet in four Asian languages, all in bi-lingual format, and translated it further into Arabic and Turkish.

- We continued to offer a scripted dialogue about miscarriage on audiotape, in three Asian languages and in English.
- All leaflets are printed in clear typeface and are available in large print and on our website.

Website

- We continued to develop a clear, accessible and informative website, with an average of 24,200 visits per month – an increase of 24% since 2003/04; and we made plans for a major revision in 2005/06 in response to visitor feedback.

Research

- We presented a summary of the findings of our research studying risk factors for miscarriage to a study group convened by the Royal College of Obstetricians and Gynaecologists.

I recently miscarried at 11 weeks. I would dearly love to conceive again but I’m getting conflicting information on how long we should wait. What is the consensus on this? Are there any medical problems if we do not wait at all? I really don’t think I could go through another miscarriage, and want to give our baby the best possible chance.

I have read the "Hidden grief" leaflet – I couldn’t believe some of the quotes were almost word for word what I have been thinking.



Good practice



Angela Whitton is a gynaecology nurse specialist with a keen interest in miscarriage and played a key role in producing the Royal College of Nursing's guidelines on sensitive disposal of fetal remains. She has spoken on this topic at several Miscarriage Association study days and helped plan two major conferences on the subject in 2005, funded by the Department of Health. She believes such events are crucial to improving care.

'As a miscarriage nurse specialist for seven years at Coventry's Walsgrave Hospital, the main part of my work was supporting couples through pregnancy loss. I gave M.A. leaflets to every patient coming through the unit and helped to set up a local support group.

'It was while doing this job that I got involved with producing the RCN guidelines on disposal of fetal remains, which recommended that all fetal remains should be disposed of sensitively in cemeteries and crematoria rather than treated as clinical waste. Since we published the guidelines in 2000 there have been vast improvements in practice and all the M.A. conferences have helped to accelerate the process.

'I saw the evidence for this at the most recent conference, with a presentation by two nurses on how they had implemented the guidance. They first learned about sensitive disposal at an M.A. conference in 2001 and were inspired to develop an excellent new policy. Now they were able to encourage others to implement positive changes. This is a very sensitive area of work and the fact that we have come so far in five years is amazing. The M.A. can take a large part of the credit for this.'

After speaking to you I contacted the hospital, who have since apologised to me. I have seen my baby, they gave me photos of him and are arranging for him to be buried. If it wasn't for you, I would be just sitting here crying and wondering what they did to my baby.

I found this study day very helpful. I am taking back some very useful information to help improve the care we give to our couples.

Thank you very much for coming to speak at the Bereavement and Loss course last week. Your talk opened the eyes of the students to the reality and scale of miscarriage and I am sure they will have gone away better able to care for and support those they meet who suffer the pain of miscarriage.

Collaborative work with health professionals and government enables us to be more effective in promoting sensitive care for patients who miscarry. We plan our conferences so that we can respond positively to the needs of both patients and health professionals. Working cooperatively with other charities and organisations maximises the impact of our shared expertise.

Key collaborative work in 2004/2005:

Study days and courses

- We ran two study days for health professionals in Glasgow and Belfast in association with the Royal College of Nursing.
- We contributed to two conferences run by the Royal College of Nursing and to three Bereavement and Loss courses run by and for the Armed Forces.
- We planned two major conferences for 2005.

Consultancy

- We advised ten NHS Hospital Trusts on the management of services for patients with pregnancy loss.
- We provided expert opinion for government and Royal College consultations, especially on sensitive disposal of fetal remains and the registration of stillbirths; and contributed to information subsequently produced by the Department of Health and

the Royal College of Obstetricians and Gynaecologists.

- We gave the patient viewpoint for a research proposal on recurrent miscarriage; and provided support and information for 6 volunteers representing the patient perspective on pregnancy loss in local NHS Trusts.

Collaboration

- We worked collaboratively with the Royal Colleges of Nursing, of Midwives, and of Obstetricians and Gynaecologists; with the Department of Health and the Office for National Statistics; with the Association of Baby Charities, the Association of Early Pregnancy Assessment Units and the charities ARC and Lifeblood.
- We supported the Department of Health's Healthy Start initiative to provide free milk, vitamins, fruit and vegetables to low-income pregnant women.

Awareness



Nikki and Matt Kruczek, both Church Ministers, were offered all the usual tests after their third miscarriage. But they made the active choice to simply stop trying to have a child. They are both keen to highlight the 'alternative view' that there is more than one way forward after miscarriage.

Nikki says: 'I had three miscarriages in 18 months and then suffered a serious depression that needed some treatment. At the root of it was grief for the babies and feeling a failure because I was "not fulfilling my destiny as a woman".

'The decision to stop trying was to protect my sanity and our marriage, and we were well supported by The Miscarriage Association in making it. As a Trustee of The M.A., I have tried to get across the need for this alternative view of life after miscarriage. I would never suggest that people don't keep trying if that's what they want, but they don't always realise how high the cost can be.'

Matt says: 'So many losses don't just give rise to feelings of bereavement but to questions about whether you have succeeded as a human being. But to me the view that you must 'plug away' until you get a healthy child devalues the lives of the babies you have lost.

'Our decision was partly to do with honouring those lives but it was also about honouring ourselves and refusing to judge our worth according to our ability to have a healthy baby. Our experience of bereavement not only as Christian Ministers but also through other people taught us that a healthy child would never take away the pain of our loss. By choosing to mourn our three babies we felt we could move on with our lives.'

Nikki and Matt's story highlights the range of ways in which people react to pregnancy loss. The Miscarriage Association works hard to raise public awareness of the facts and feelings of pregnancy loss and to provide a balanced view of the personal impact of miscarriage and ectopic pregnancy. With the help of our team of media volunteers, we worked with print, broadcast and online media throughout the year. We provided expert comment wherever we could on news reports of possible causes and treatment of miscarriage and we worked to ensure that bereaved parents know where to turn for help.

Key awareness initiatives in 2004/2005:

Expert comment

- We responded to 23 media requests for expert comment and opinion on a wide range of research and news stories, from studies to individual cases.

Features and storylines

- We provided background information for 79 media articles, programmes and features, with help from 55 media interviewees who contribute personal reflections and experiences
- We advised on storylines for three television dramas and a stage-play. We were pleased to see that the M.A.'s poster is a regular background feature in the BBC hospital series *Holby City*.

Profile

- We worked with four other organisations to promote National Babyloss Awareness Week, with remembrance events across the U.K. and wide media coverage.
- We maintained a high profile for The Miscarriage Association on the largest internet search engines.
- We completed a two-year period of monthly advertising in *Pregnancy & Birth* magazine



Babyloss remembrance service 2004

I contacted The Miscarriage Association after being commissioned by Woman magazine to write an article about coping with different experiences of miscarriage.

I had quite a detailed brief about the sort of case histories I needed: early and late miscarriage, recurrent miscarriage – and I also wanted to include someone who hadn't gone on to have a baby after her miscarriage because not everyone has a 'happy ending'. I found Ruth extremely helpful and informative, not only in putting me in touch with most of the case histories that I used in my article, but as an "expert" explaining why miscarriages happen.

All of the women I spoke to had obviously found great support from The M.A. throughout their time of loss. With their and The M.A.'s help I feel that, hopefully, I put across a very sensitive subject in an informative and interesting way.

Sue Cocker, freelance journalist

Abridged accounts 1 April 2004 – 31 March 2005

	General funds £	Restricted funds £	Total £
Income:			
Donations & similar income:			
Membership fees & donations	19,338	1,299	20,637
Government grants	13,000	29,255	42,255
Other donations & grants	35,802	19,940	55,742
Branch income	–	4,591	4,591
Activities to further the Charity's objects:			
Sales	49,255	–	49,255
Conference & AGM fees	5,256	–	5,256
Activities to generate funds:			
Fundraising activities	41,012	–	41,012
Sales	3,702	–	3,702
Interest received	5,793	–	5,793
Total income	173,158	55,085	228,243
Expenditure:			
Cost of generating funds:			
Fundraising	25,118	1,215	26,333
Charitable expenditure:			
Service provision & support costs	76,136	39,884	116,020
Management & administration	41,752	1,688	43,440
Total expenditure	143,006	42,787	185,793
Net surplus	30,152	12,298	42,450

BALANCE SHEET

Fixed assets	3,294
Current assets	229,810
Total liabilities	(9,187)

Net assets	223,917
Represented by:	
Brought forward from 2003/04	164,694
Net surplus 2004/05	30,152
Transfer between funds	(580)
Balance carried forward	194,266
	29,651
	223,917

This financial statement has been agreed by Mazars LLP as being consistent with the full financial statements for the year ending 31 March 2005. These were prepared in accordance with the Statement of Recommended Practice Accounting by Charities 2000, 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 18 September 2005 and have been submitted to the Charity Commissioners.



Peter Wright (Chair)

Auditors & accountants

Mazars LLP
Mazars House
Gelder Road
Leeds LS 27 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 wisely in the year to 31 March 2005, enabling it to maintain a high level of service provision and to make provision for the future.

In common with many charities, The Association has long been largely reliant on grants and donations but we have continued to work successfully to raise funds from other sources in order to develop a more sustainable funding base. In the year to 31 March 2005 we maintained a sound level of earned income, largely through bulk sales of leaflets to hospitals and clinics. We also raised funds by running Study Days for health professionals and through fundraising activities, particularly the London Marathon which carries the added benefit of raising the charity's profile. The combination of earned income and fundraising constituted well over half of our general (unrestricted) income for the year. The Trustees noted that despite the anticipated reduction in grants from charitable trusts, unsolicited donations – including those made online – nearly doubled, accounting for 15% of general income.

The financial statements show a surplus of both general and restricted funds for the year. The surplus in general funds has enabled us to increase our General Reserve Fund, while restricted funds are for use for specific projects only. In an uncertain funding climate, building up reserves will help us ensure that we can both continue and develop our core services and maintain some key projects once their limited funding ends. It should be noted that branch funds, which are incorporated into these accounts, are held and used by those branches alone.

As always, the generously donated services of all of our volunteers enable us to keep the costs of providing direct charitable support relatively low – an estimated saving of 53% of service provision and support costs. We greatly appreciate the financial and moral support provided by our donors, members and friends. We are fortunate too in the dedication of staff and Trustees who manage the Association's limited resources with great care.

The Miscarriage Association continues to develop its services in response to growing and ever-changing needs for support and information in the sensitive area of pregnancy loss. It is crucial that we maintain and increase our efforts to secure the funding which will support The Miscarriage Association for as long as it is needed.

...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 2004 – 2005:

Statutory funding

The Department of Health

Special funding

The Community Fund

Charitable trusts & companies

The Goldsmiths' Company
Leeds Hospital Fund Charitable Trust
Marsh Christian Trust
Penguin Book Charity
Percepta UK
Seagram Distilleries
Sir Jules Thorn Charitable Trust
F J Wallis Charitable Trust

Individuals and groups

The Ladies Festival of the
Goff's Oak Lodge, no. 7169
Bev Lancaster
Paul & Sharon Raymond
Our London Marathon team

Gifts in kind

Activ Computer Services, for e-mail and website hosting

BP, for providing facilities for Trustee meetings, organised by BP employee Rick Anderson

RAP Spiderweb for their skill, support and unfailing good humour in answering our design and print needs



Making a difference 2004–2005

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

We are deeply 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, providing a national network of comfort and support to others in a similar situation.

Our thanks go too to those 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, cope with 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 say a special thank-you to the following people for generously sharing their time and skills:

- the members of our Professional Advisory Board
- the speakers and helpers at our Professional Study Days
- our patrons
- Peta Harrison, editor of our members' newsletter
- Nigel Wood, our webmaster



Carolyn Basak from the RCN, chairing our Study Day

Patrons:

Tania Bryer
Nigel Martyn
Anna Raeburn

Professional advisors:

Ms Anne Jackson-Baker
Dr Christopher Everett
Mr Roy Farquharson
Ms Diana Hamilton-Fairley
Dr Sheila Kitzinger
Dr Marjory MacLean
Ms Christine Moulder
Prof Lesley Regan
Mr Naren Samtaney
Prof Gordon Stirrat
Prof James Walker

Trustees:

from November 2004

Peter Wright
Alison de Verteuil
Nikki Foster-Kruczek
Usha Harte
Barbara Hepworth-Jones
Gillian Lamb
Sheila McPherson
Mr Roy Farquharson
Ex-officio:
Morag Kinghorn

Chair
Vice-chair
Vice-chair

Co-ordinator for Scotland

Staff:

Ruth Bender Atik
National Director

Anne Walker
Senior Support Worker

Lisa Bruce
Senior Support Worker

Anne Woodhouse
Support Worker

Andrea Allen
Volunteers Manager

Kathleen Smith
Administrative Assistant



Volunteer webmaster, Nigel Wood



A Trustee meeting



Advisor Dr Marjory Maclean

Planning for the future: 2005–2006

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 will continue to offer a sensitive, knowledgeable and responsive support and information service, developing our services in line with users' feedback and increasing the range of ways in which people can access those services. We will continue to work with health professionals to enable and encourage them to provide sensitive and high-quality care for those who experience miscarriage, ectopic or molar pregnancy. We will maintain our links with government and with professional organisations to ensure that the patient perspective is taken into account in developing policies and guidelines. We are equally determined to maintain the public profile of pregnancy loss and not to allow the discomfort which it can cause to keep it a hidden grief.

Despite 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 want to ensure that The Miscarriage Association continues to be responsive to their changing needs and expectations, maintaining and developing high quality services. We need to remain open to the need for change, whether in the kind of services we offer or the ways in which we provide them. Above all, we need to keep listening and responding positively to those who experience pregnancy loss.

Our plans...

- maintain two high-quality helplines five days a week, backed by a network of trained volunteers
- develop our services to improve access for all, including people with disabilities
- publish and promote a leaflet on Antiphospholipid Syndrome and pregnancy loss; and complete and publish leaflets in Arabic and Turkish
- work to publish further papers on the key findings of our research into lifestyle and miscarriage
- support volunteers who want to represent the patient perspective on pregnancy loss
- run two conferences for health professionals, addressing difficult issues in caring for patients with pregnancy loss
- 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
- become a Trustee of The Miscarriage Association
- 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



We would like to express our sincere thanks for listening to our comments and for taking the time to revise the leaflet "We are sorry" – you have really done a fantastic job.