

THE MISCARRIAGE ASSOCIATION

ANNUAL REPORT 2005–2006



The wider impact of pregnancy loss

**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

c/o Clayton Hospital, Northgate, Wakefield, West Yorkshire WF1 3JS
Tel: 01924 200799 (Helpline); 01924 200795 (Admin) Fax: 01924 298834
Scottish helpline: 0131 334 8883
e-mail: info@miscarriageassociation.org.uk

Website: www.miscarriageassociation.org.uk

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



I have been involved with The Miscarriage Association since the mid 1980s, when I had miscarriages myself. My local support group, in Brighton, proved to be an indispensable source of much-needed understanding, comfort and information.

It was hard then to find out about miscarriage. Few books or articles were readily available and I didn't know anyone else who had miscarried. I desperately needed other people who understood, but I found it difficult to talk about. The Miscarriage Association was a lifeline. It had no office or paid staff back then and the leaflets were copies of typed sheets, but I haven't forgotten them or the people who wrote them and I never will.

Since then The M.A. has developed into a thriving organisation that provides support and information to thousands of people each year. Women going through pregnancy loss will always need support and information about the experience, the physical facts, the feelings, and what will happen next. But their partners are also likely to be affected by what has happened and so too might family, friends and colleagues. As is demonstrated so well in this Annual Report, miscarriage doesn't just affect women going through it themselves but those around us too. The M.A. has always recognised that and provides appropriate information, help and support to anyone who needs it.

The M.A. also understands the importance of good healthcare for women who miscarry and continues to make an invaluable contribution in service and policy development. The conferences and study days provide much-needed support for professionals as well as opportunities to develop understanding, knowledge and skills. It is easy to forget, when you are going through the experience, that health professionals too are often affected by the sadness that miscarriage can bring, especially when they are working, often with little support, in a pressured and changing healthcare system. The M.A. is there for health professionals too.

In commending this report to you I would like to congratulate the Miscarriage Association on another excellent year's work and wish it every success in the future.



Christine Moulder

Professional Advisor and author of *Miscarriage: Women's experiences and needs* and *Understanding pregnancy loss: perspectives and issues in care*

The wider impact of miscarriage

The loss of a baby in pregnancy can be a deeply unhappy experience for the woman and her partner, yet many people fail to recognise their feelings and needs. The Miscarriage Association works to fill the gap by providing high-quality support, care and comfort to anyone affected by pregnancy loss.



The husband: 'I couldn't go through that again'

Paul Williamson supported his wife Karen through a traumatic miscarriage that started when they were on holiday in the U.S.. She is now a support volunteer for the Miscarriage Association.

'At 45, Karen was all set to be our doctor's oldest maternity patient. The pregnancy was not planned,

as we each had 2 children, now young adults, from our first marriages. But by the time we left for a holiday in Florida, when Karen was nine weeks pregnant, I had started to look forward to the new arrival.

'When Karen started to bleed we went to the local hospital, but some of the care we received was quite poor. It was obvious at the ultrasound that something was very wrong but it took another hour for a doctor to come and tell us the bad news: not just that the baby had died but that the pregnancy might have been ectopic and there was a cyst on Karen's ovary.

'It took ages to deal with the insurance paperwork and then we waited hours the next day for a doctor to give Karen permission to travel. He wanted her to have a D&C but we were so desperate to get home that we just flew back to the UK, where she miscarried naturally.

'When our GP asked how I was feeling, it was the first time anyone had seen me as anything more than a spare part doing the rounds with Karen. In fact I felt horrendously sad and hollow to have lost our baby.

'A final scan showed that the pregnancy hadn't been ectopic and the cyst had shrunk. Since then I've made an appointment to have a vasectomy. I couldn't contemplate going through that trauma again, not for Karen or for me.'

I had quite a complicated miscarriage just over 2 months ago. I am still very teary every day, feel very down and cannot see any light at the end of the tunnel. It doesn't matter what anybody says to me, I can't get it out of my head that it was taken away from me as I don't deserve it or I did something wrong. I find it impossible to think positively and that one day in the future we will have our own family.

Providing support in 2005/2006:

Staffed helpline

- We provided a staffed helpline five days per week, providing a swift, sympathetic and informed response to 9,800 letters, calls and e-mails requesting support and information.

Support volunteers

- We coordinated a UK-wide network of 91 telephone contacts, including 21 new volunteers, and 34 local support groups.
- Fifty contacts provided support on 24 specific areas of pregnancy loss, such as recurrent miscarriage and ectopic pregnancy.
- Twenty-four volunteers staffed an out-of-hours helpline, offering support at evenings, weekends and Bank Holidays.
- Ten regional co-ordinators helped us select, support and monitor all support volunteers.

Newsletter and website

- We improved the design of our quarterly newsletter, a source of support, information and comfort for our members. We posted selected items on the website, which also contains personal reflections

Accessibility

- We ensured that venues and facilities for central M.A. events were accessible to people with disabilities; and secured a grant to develop leaflets for people with learning disabilities and for deaf people whose first language is sign language. We continued to develop distance learning facilities for potential and established volunteers to reduce barriers to volunteering. All leaflets are available in large print and on our website.

Those who experience pregnancy loss are often desperate to know why it happened and the risks of recurrence. It can be hard to make sense of the conflicting information available in print and on the Internet. The Miscarriage Association provides accurate, up-to-date and understandable information about both the facts and the feelings of pregnancy loss.



The mother: 'I felt responsible for my daughter's miscarriages'

After her daughter Sue's repeated miscarriages, Renee Campbell was shocked to discover that she had passed on the chromosomal abnormality that caused the losses.

'Dealing with the miscarriages was bad enough. After Sue had her first baby, Jack, she had three miscarriages before having Kate. Each loss was harder than the one before, and at one stage she was quite ill with depression.

'Never have I experienced such feelings of helplessness and uselessness as when I saw my child suffer. And the worry was constant. Once she came with me for a walk and I was terrified all the time that even walking might cause a miscarriage. Then she *did* miscarry shortly afterwards and I was devastated.

'After her third miscarriage, the doctors discovered that she had a chromosomal disorder. Then they asked to test the rest of the family and we were shocked to find out that I and my youngest daughter had it too. My oldest son and middle daughter are clear but my youngest son has refused to be tested.

'For me the main feeling was guilt because I have passed this terrible problem on to two of my daughters and I feel responsible for everything Sue has been through.

'Thankfully she and her husband have decided to stop at Kate. They would have loved another but couldn't go through the distress and worry – and I said I didn't need any more grey hairs!'

“ Thank you for asking my opinion on the draft leaflet on Antiphospholipid Syndrome & Pregnancy Loss. I couldn't find one thing to add or change. I found it to be incredibly helpful, informative and reassuring. Thinking back to the time of my own diagnosis, I like many others searched the web for answers and scared the living daylights out of myself. I know that this leaflet would have been a huge relief to me had it been available back then. ”

Providing information in 2005/2006:

Staffed helpline

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

Leaflets

- We produced a new patient information leaflet on Antiphospholipid antibody syndrome, a significant cause of recurrent miscarriage and completely revised the leaflet *Men and Miscarriage*; we now publish 19 leaflets on aspects of pregnancy loss.
- We sent over 60,000 leaflets by request to individuals and to hospitals and clinics and a further 30,000 were downloaded from our website.

Accessibility

- We provided our most widely-read leaflet in four Asian languages and Arabic, all in bi-lingual format, and a Turkish-English version was completed in 2006. We provided a scripted dialogue about miscarriage on audiotape, in three Asian languages and in English.
- We began research into producing a leaflet for people with learning disabilities and one for deaf people whose first language is British Sign Language.
- All leaflets are printed in clear typeface and are available in large print and on our website.

Website

- We recorded an average of 29,700 visits per month to our website – an increase of 23% since 2004/05; and prepared new content and design for its re-launch in June 2006, incorporating RNIB accessibility guidelines.

The wider impact of miscarriage

The distress of pregnancy loss can be compounded by conflicting information about causes and treatment. The Miscarriage Association works with print, broadcast and online media to provide clear information, to make sense of news stories and to promote a balanced view of the personal impact of miscarriage and ectopic pregnancy.



The best friend: 'I felt privileged'

Jen Winter (left) supported her best friend Romy Rawlings through an ectopic pregnancy and four miscarriages before the birth of Aden, now aged 6.

'Romy and I have been best friends since we were seven and are

extremely close. Because the quest to have a baby became the most important thing in her life, it also became the most important aspect of our friendship. There must have been about five years when all I could do was give her someone to talk to and share her frustrations with.

'With each miscarriage it got harder for her and Dean. During those years I got much closer to him too.

'I'm an acupuncturist and during one of Romy's pregnancies I tried to do something to help her sickness. When she lay down I somehow knew she had lost the baby. I then spent eight days waiting for the phone to ring and thinking I was going mad. Then it did – and I had been right: one of the worst moments of my life.

'I felt desperately sad for her, but guilty too. With my second child Eve I had picked a date when I wanted to have her, then conceived and delivered almost bang on schedule. Romy lost a child while I was pregnant, which made her visits to my new baby distressing, though she hid it well.

'I can't describe how I felt when Aden was born, but when Dean rang to tell me I just couldn't stop crying.

'As for Romy and me, I can only say that I felt immensely privileged to be trusted to share this time with her, and that I came away in awe of both her resilience and her courage.'

Raising awareness in 2005/2006:

Expert comment

- We responded to 19 media requests for expert comment and opinion on a wide range of research and news stories, from scientific studies to individual cases.

Features and storylines

- We provided background information for 59 media articles, programmes and features, with help from 55 media interviewees who contribute personal reflections and experiences.
- We advised on a storyline for a television drama and noted that The Miscarriage Association'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 through the largest internet search engines.



Miscarriage has touched the lives of many of the Practical Parenting team, which is why we want to show our support and commitment to helping other women and families through this devastating and confusing experience. Those of us who've suffered the loss of a baby will never forget the emotional and physical pain, and the feelings of helplessness and despair. Supporting The Miscarriage Association is the least we can do to help others through an experience we wouldn't wish on our worst enemy.



The quality of care given to women by hospital and community health professionals can have a major impact on their experience and their memories of pregnancy loss. The Miscarriage Association promotes sensitive care for patients who miscarry, highlighting not only the varied needs of patients but also professionals' own support and training needs.



The health professional:

Clinical nurse specialist Carol Holborn has devoted much of her professional life to helping women and their partners cope with pregnancy loss. Three years ago she set up Southend Hospital's Early Pregnancy Unit, which she still runs.

'I had three late losses myself when I was younger and despite being in

a very distressed state my husband and I were offered no support or information. Therefore when I ended up working on the gynae ward I gravitated naturally towards women with miscarriage because I had such a strong empathy with them. I have made it my mission to give people the kind of help that wasn't around when I lost my babies.

'In the EPU I see women with any problems before 17 weeks of pregnancy. The women are assessed following a scan, either being given reassurance when experiencing problems in a viable pregnancy or supporting them through a pregnancy loss caused by miscarriage or an ectopic pregnancy.

'I feel I can make a real difference to women who miscarry. I sympathise with them and, once the couple are calmer, discuss the loss, probable causes of miscarriage and hopefully help them to look forward.

'Due to the high numbers of pregnancy losses seen on the EPU it can be very difficult experiencing all this sadness and I can feel stressed. Often there is often no one to talk to, so on days like that I go home and try to release the stress by walking the dog or playing badminton. I think it is even harder for younger staff on the gynae ward because you need to acquire the skills and experience to deal with these problems.

'What keeps me going is knowing that after years of practice I can take a really bad situation and turn it around for many women.'

“ I guess I keep hoping that there will be national guidelines or better still directives to make our jobs easier and to achieve what parents and their babies deserve – respect and proper choices. I have to say though, it was very reassuring to meet others in the same boat and to discover that everyone else is struggling with similar obstacles. ”

Promoting good practice in 2005/2006:

Conferences and courses

- We ran two major conferences for health professionals in association with the Royal Colleges of Nursing, of Midwives and of Obstetricians and Gynaecologists, the Nursing and Midwifery Council and the charity Antenatal Results and Choices, and funded by the Department of Health.
- We prepared a further conference for health professionals in 2006 in association with the Royal College of Nursing.
- We contributed to a specialist meeting of the European Society of Human Reproduction and Embryology; and to three Bereavement and Loss courses run by and for the Armed Forces.

Consultancy & collaboration

- We provided expert opinion to eleven NHS Hospital Trusts on the management of services for patients with pregnancy loss, and on policy and practice regarding the sensitive disposal of fetal remains; and provided advice to other UK health, education, government and charitable organisations.
- We advised on establishing local support services for miscarriage patients in Denmark, Gaza and Poland.
- We provided training and support to volunteers who want to represent the patient perspective in local NHS Trusts
- We peer-reviewed draft guidelines on the management of early pregnancy loss for the RCOG; and also worked collaboratively with the RCN, the RCM, the Department of Health, the Office for National Statistics and the charities ARC and Lifeblood.

Abridged accounts 1 April 2005 – 31 March 2006

	General funds £	Restricted funds £	Total £
Income:			
Donations & similar income:			
Membership fees & donations	23,320	1,167	24,487
Government grants	15,000	8,200	23,200
Other donations & grants	33,957	21,676	55,633
Branch income	–	15,571	15,571
Activities to further the Charity's objects:			
Sales	41,946	–	41,946
Conference & AGM fees	4,215	–	4,215
Activities to generate funds:			
Fundraising activities	42,707	–	42,707
Sales	3,572	–	3,572
Interest received	8,464	–	8,464
Total income	173,181	46,614	219,795
Expenditure:			
Cost of generating funds:			
Fundraising	26,907	4,521	31,428
Charitable expenditure:			
Service provision	82,153	55,313	137,466
Governance	35,660	212	35,872
Total expenditure	144,720	60,046	204,766
Net surplus/(deficit)	28,461	(13,432)	15,029

BALANCE SHEET

Fixed assets	3,047
Current assets	244,131
Total liabilities	(8,232)

Net assets			238,946
Represented by:			
Brought forward from 2004/05	194,266	29,651	223,917
Net surplus/(deficit) 2005/06	28,461	(13,432)	15,029
Transfer between funds	(1,105)	1,105	
Balance carried forward	221,622	17,324	238,946

This financial statement has been agreed by Mazars LLP as being consistent with the full financial statements for the year ending 31 March 2006. 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 10 September 2006 and have been submitted to the Charity Commissioners.



Peter Wright (Chair)

Auditors & accountants

Mazars LLP
Mazars House
Gelderd 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 prudently in the year to 31 March 2006, enabling it to maintain a high level of service provision and to make provision for the future.

Our total general (unrestricted) income was almost exactly the same as in 2004/05, despite some changes in where the money came from. Increased donations from companies, groups and individuals, including a continuing increase in Internet donations made up for a reduction in income from charitable trusts. However, we noted a 15% drop in income from sales of leaflets to hospitals and clinics, possibly due to NHS financial constraints, though orders began to improve in April 2006.

We continued to promote a range of fundraising activities, from strawberry fundraisers to the London Marathon, which also benefit us by raising The M.A.'s profile. We increased the value of our reserves by opening a new charity savings account, which helped to raise investment income by 46%. The combination of earned income, investment and fundraising constituted well over half of The Miscarriage Association's general income for the year.

Restricted income during the year was for specific projects, including leaflet sponsorship. It also included branch income, which was significantly higher than in previous years, partly due to fundraising activity. This was offset in part by increased branch expenditure, especially the costs of fundraising. It should be noted that branch funds, which are incorporated into these accounts, are held and used by those branches alone.

The financial statements show a surplus of general funds for the year, which has enabled us to increase our General Reserve Fund. There is a net deficit in restricted funds, which reflects the expenditure of restricted funds received in the previous year. The restricted fund balance carried forward at the year-end is for specific projects only.

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 41% 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 changing needs for support and information in the sensitive area of pregnancy loss. We need to be equally responsive to changing financial climates, developing a more sustainable income base from a mix of fundraising, donated and earned income. This is the way to secure the future of 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 2005 – 2006:

Statutory funding

The Department of Health
Congleton Ladies' Circle

Special funding

The Big Lottery Fund

Charitable trusts & companies

The Goldsmiths' Company
Great Midlands Fun Run Ltd
IPC Media: *Practical Parenting*
Leeds Hospital Fund Charitable Trust
Masterfoods (Mars UK Ltd)
JAH Norman Trust
Skala Marketing

Individuals and groups

Babyloss

H & I Bartlett and M Stripp
Tanya Crickmore & Sally Roberts
Lifeblood
Our London Marathon team

Gifts in kind

Activ Computer Services, for e-mail and website hosting

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



Jack, after completing the Great Wee Scottish Walk

Making a difference 2005-2006

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 also go 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 express particular gratitude to the following people for generously sharing their time and skills:

- the members of our Professional Advisory Board
- the speakers and helpers at our conferences and especially the late Nancy Kohner
- our Patrons
- Peta Harrison, editor of our members' newsletter
- Nigel Wood, our webmaster



Conference speakers Dr Caroline Gannon and Joanie Dimavicius get to know two of the delegates

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:

at 31 March 2006

Peter Wright
Alison de Verteuil
Barbara Hepworth-Jones
Dee Inott
Sheila McPherson
Anne Walton

Ex-officio:

Morag Kinghorn

Chair

Vice-chair

Vice-chair

Co-ordinator for Scotland

Staff:

Ruth Bender Atik
National Director

Lisa Bruce
Senior Support Worker

Anne Woodhouse
Support Worker

Andrea Allen
Volunteers Manager

Kathleen Smith
Administrative Assistant



Newsletter editor, Peta Harrison



Chair of the Trustees, Peter Wright



Advisor, Professor Lesley Regan

Planning for the future: 2006-2007

The Miscarriage Association is a small organisation with a very big mission: to ensure that everyone who is affected by 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 and knowledgeable support and information service for anyone affected by miscarriage, ectopic or molar pregnancy. We will continue to develop services both to meet the needs of existing users and to reach others who have difficulty accessing our current services. We will further develop the use of electronic services while maintaining our traditional telephone helpline and volunteer support network. We will continue to work with health professionals to support them in providing sensitive and high-quality care for those who experience pregnancy loss. 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 will continue working to raise the public profile of pregnancy loss. No-one should feel their grief has to remain hidden because of social discomfort with this subject.

Despite advances in medical research and treatment, miscarriage is still likely to affect hundreds of thousands of women and their partners every year 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 – and this means ensuring that we have the financial resources and the people to do so.

Our plans...

- maintain our high-quality helpline five days a week, backed by a network of trained volunteers
- produce a leaflet for people with learning disabilities and one for deaf people whose first language is British Sign Language
- produce a leaflet for people who are facing a future without children after experiencing pregnancy loss
- implement a three-year plan to develop audio versions of our leaflets, both on CD and downloadable from our website
- launch our re-designed website, with extensive new content and improved accessibility
- work to publish further papers on the key findings of our research into lifestyle and miscarriage
- run a further conference 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
- 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 just lost my pregnancy and although only six weeks in, I am completely devastated. The person I spoke to last week was incredibly helpful and the information you sent was just what I needed. There's comfort in sharing other people's experience and knowing people move on.

Keep doing the good work you do and helping more people like me. It is completely invaluable.

