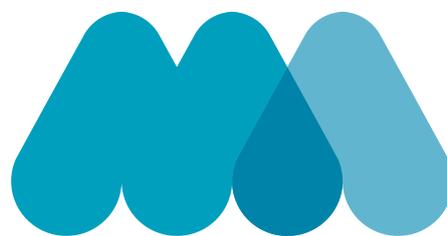


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MISCARRIAGE
ASSOCIATION

The knowledge to help

Annual Report 2013-2014

**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

17 Wentworth Terrace, Wakefield, West Yorkshire WF1 3QW
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



When I think back to 1987 when I had my first miscarriage, I remember thinking; **Why us? What did we do wrong? How can we stop it from happening again? Will we ever be parents?**

When I became pregnant again, I wished more than anything that private scans were available to keep me going between NHS ones, then I wished we could own one of the magic Dopplers which weren't available to anyone but hospitals.

In the late 80's and 90's when I was going through more miscarriages, I did everything I could to talk to people about them and to stop miscarriage being a taboo subject. I was delighted to be asked to talk to doctors and midwives to tell them my personal story. I also worked in a mainly female staff of 22 people. When I came back after one of my miscarriages, the first one while working there, I was astounded to hear that 19 of the staff had lost a baby through miscarriage. No-one had mentioned it before then.

Later in 1987, I got some helpful leaflets from the Miscarriage Association. It was a much smaller organisation then than now. There was a number to call which was manned by a lovely lady called Kathryn.

In 1988, when I realised there was no support available locally, I, and another lady who had received help from Kathryn, set up a support group in Edinburgh. We are no longer involved but I am delighted that, with only a few gaps, the group still meets regularly to offer support to anyone who has gone through the pain of pregnancy loss.

Some things have changed since then. The Miscarriage Association is still small, but now has an amazing team of staff and volunteers, offering support and information on the phone, by email, and online. You can read more about the work they do further on in this Report.

More research has taken place and the M.A. leaflets now carry much more information. The internet is a regularly used source of information for people, which can be a help or cause more distress. The Miscarriage Association website, though, is a reliable source of accurate information and support, while allowing people to share their feelings and stories.

Move along to 2013/14, and despite all the hard work of the M.A. and many individuals, miscarriage is still a taboo subject for many people, the bewilderment, sense of longing, anger and grief are the same and sadly the questions still remain **Why us? What did we do wrong? How can we stop it from happening again? Will we ever be parents?**

It's good to know that the M.A. will be here to help people through.

Morag Kinghorn

Morag Kinghorn
Chair of the M.A., 1992-1994

Why do I feel this way?

“A friend got pregnant recently and it took me days to get over it. It sounds stupid but I cried every night for almost a week.”

The experience of miscarriage, ectopic or molar pregnancy can be devastating, but there's no 'right' way to feel. Women and their partners may be shocked by the emotional impact of their loss – or perhaps worried that it is not hitting them as hard as they expected. They can feel isolated and lonely, especially if others around them seem to have had problem-free pregnancies.

Much as they want a baby, they may feel uncertain about trying again in case they have another loss – or they may face additional hurdles, such as problems conceiving. They may fluctuate between hope and anxiety



Craig Watt

I have two beautiful daughters, but my wife and I have also been through the pain of an ectopic pregnancy and three miscarriages.

We found out Katie was pregnant for the first time only after she had surgery for what turned out to be an ectopic pregnancy. She was in theatre for 5 hours while they diagnosed and removed the ectopic. Until it was over, nobody told me anything and I just waited alone. I was distraught.

We knew about the next pregnancy early on, but had to have two scans before we found out we'd lost the baby. By the third pregnancy, we were anxious from the start. You get used to things going wrong. Again it took two scans to confirm but this time everything looked fine and after a difficult birth, our daughter was born.

Kate had another two miscarriages before I pushed for a specialist referral. Tests showed no major problems and a few months later we were pregnant again. We had excellent care, with scans every fortnight from 6 to 12 weeks. Our second daughter is now nearly 4.

There have been times when I thought 'Why is this happening to me?': when there's another scan with no heartbeat, when you're walking through a waiting-room in tears. But I'm quite a positive, 'glass half-full' person and I've tried to take it in my stride. After the first miscarriage it hit home that we'd had two problem pregnancies and we wondered if we'd ever have a baby. But having our first daughter gave us hope and proof that it can happen.

“Thank you all so much for your support and warmth over the last few months, for being a place to come for comfort from women who simply understand.”
(Facebook private group)

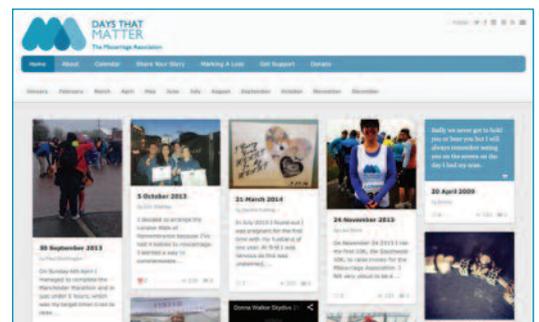
The Miscarriage Association

understands and acknowledges the range of feelings after pregnancy loss. We support women and their partners in coping with their feelings and provide opportunities for them to share those feelings with others who understand.

In 2013/14 we achieved this through:

- our staffed helpline: a compassionate and understanding response to calls, e-mails and online calls for help and support
- peer support from others who have experienced loss, via telephone, support groups, and online
- leaflets that focus on the emotional impact, especially: *Your feelings after miscarriage*, *Partners too* and *When the trying stops*
- sections on our website dedicated to offering support and advising on additional sources of help
- places for remembrance and for marking a loss, including a virtual forget-me-not-meadow and a new 'Days that Matter' website;
- further development of resources for people with hidden needs: partners of women who miscarry and young people.

“So many years I've remembered in my heart and now with a message in the forget me not meadow my remembering will go on long after I'm gone.”



Why has this happened to us?

“Surely we've been punished enough. We don't drink, don't smoke and have a loving relationship so why does this keep happening to us?”

For many women and couples miscarriage comes as a shock. They may have used contraception successfully for many years, conceived easily, done all the right things and assumed that everything would go to plan. A miscarriage – or two, or three, or more – can shake their confidence and threaten their plans for the future.

In this situation it is natural for people to look for answers in the hope that they can prevent it happening again. Unfortunately most couples aren't offered tests unless they have had recurrent losses, and even then there may well be no answers.



Professor Arri Coomarasamy, Professor of Gynaecology, University of Birmingham

When I see patients who have had a miscarriage, they generally have two questions: 'Why did it happen?' and 'How can we stop it happening again?' Those are important questions for doctors too, especially when we sometimes feel powerless to help.

That's why research is so important. Laboratory research, studying blood or tissue samples, can help us understand more about possible causes and may also lead to developing potential new therapies. These then need testing further to make sure that they are safe and to see whether they are of any benefit.

It's a very long process, especially if it means developing a new drug. Even when we test an existing drug, as in the **PROMISE** (progesterone) trial, it can take five or six years, from applying for funding to recruiting enough women to join the trials so that the results are reliable. Not everyone is willing to take part in a research trial of course, but many who do, find it reassuring to have the regular support of the research team.

The M.A.'s involvement and guidance in **PROMISE** and a number of other trials is immensely helpful. We know we can rely on them to provide the patient viewpoint and they also help by supporting and informing women about the research being done. We're all working to the same end – to find more answers and reduce the unhappiness and pain of miscarriage.

“It should have been good news that my blood tests showed nothing was wrong, but I burst into tears. I wanted an answer – something that could be fixed.”

The Miscarriage Association

provides clear, accurate and understandable information about pregnancy loss, helped by experts in the field. We also support and are actively involved in high quality research into the causes and treatment of pregnancy loss.

In 2013/14 we achieved this through:

- a staffed helpline 5 days a week: a swift, sensitive and informed response to calls, e-mails and online queries
- a range of 18 leaflets, regularly reviewed and updated and all freely available online
- 24,000 leaflets ordered by hospitals
- a mobile-friendly website and a new FAQ section, enabling easy links to key information; 727,000 visits during the year: an increase of 87% on 2012/13
- active involvement in research: representing and informing patients on five clinical trials and supporting funding applications for five further research studies
- publication of the medical textbook "Recurrent Pregnancy Loss", with a chapter written by the Miscarriage Association.

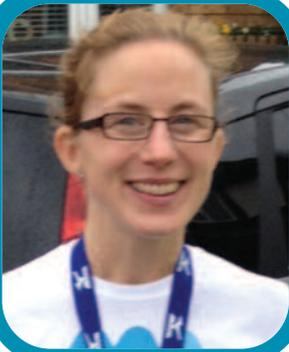
“The clearest info I found on the web.”

The screenshot shows the Miscarriage Association website. At the top, there is a navigation bar with links for Home, Information, Support, For health professionals, Forum, Get Involved, and About us. A search bar is also present. The main content area is titled 'Information' and lists several categories: 'Frequently asked questions', 'Signs and Symptoms', 'Ultrasound scans', 'Management of miscarriage', and 'Causes, tests and'. Each category has a corresponding link to a page of frequently asked questions. The 'Frequently asked questions' section is expanded, showing a list of questions such as 'I'm bleeding/spotting. Am I miscarrying?', 'When can I have a scan? / Why do I have to wait for a scan? / Why do I have to have a repeat scan?', and 'What's a fetal pole?'.

Why don't people understand?

“People keep telling me I should be grateful because I already have children, but I don't feel my family is complete and no one seems to understand.”

Even though miscarriage is common, many people don't know how to react to someone going through it. Some people feel uncomfortable and avoid saying anything, while others stay silent for fear of causing more upset. Some hope to make people feel better by finding something positive to say. Many fail to consider the needs of partners and may assume that they are less affected. Even when they mean to help, they may unwittingly hurt.



Claire Guile

After having two little girls, I was delighted to find I was pregnant again and looked forward to completing our family. When the 12 week scan showed that the baby had died weeks earlier, I was in shock and completely devastated.

Family and friends were sympathetic but while they meant well, the things they said hurt: 'It wasn't meant to be', 'There was

obviously something wrong', 'At least you have your girls'. Of course I felt blessed to have the girls but the pain of my loss was still there.

People said 'At least you were early on in pregnancy'. They all had stories to tell of people losing babies later on in pregnancy and babies who were stillborn. Awful stories that were heart-breaking but didn't help how I was feeling. They just made me feel guilty for feeling such a huge sense of loss when I already had children.

When I fell pregnant again I was terrified. People said that it would be fine this time but a scan showed that the baby had died at about 8 weeks. My husband and I grieved together.

The third miscarriage was painful and prolonged. I had no more energy to grieve and felt empty and sad. I was desperate to talk about my losses, but each time I spoke about it, I was met with awkward responses. Nobody knew what to say and I had no idea what I wanted them to say. But I did want them at least to acknowledge my loss and my feelings of grief.

Claire photographed after completing the Reading Half-Marathon for the M.A..

“When I'm having a bad day this is my saviour!!! Thank you to everybody behind the forum and all the people on it who are always there to give us inspiration, help and kind words even in their own times of grief and struggle.”

The Miscarriage Association

uses print, broadcast and social media to raise awareness of the emotional impact of miscarriage and to increase understanding. As well as providing support, we raise awareness of the M.A. as a source of help so that people know they have a place to turn.

In 2013/14 we achieved this through:

- our staffed helpline, backed by a UK network of volunteers who have experienced pregnancy loss themselves and offer support by telephone and in support groups
- an online forum: a safe, secure and friendly place for people to share their thoughts and feelings
- the leaflets *Someone you know* and *Miscarriage in the workplace*, which aim to help people understand the experience of miscarriage and find the right ways to respond
- increasing use of social media to drive campaigns and highlight awareness of pregnancy loss
- cementing our reputation as a reliable and expert source of information and comment for the media, responding to 70 requests from broadcast, print and online media.



'I know from the problems readers send me that family and friends often under-estimate the distress a miscarriage causes – to both the would-be parents. I am always very grateful that the Miscarriage Association is there for support, as I know readers will find genuine understanding.'

Deidre Sanders,
Agony Aunt, The Sun newspaper

Why couldn't it be different?

“It may have been cells to them but we had dreams and aspirations for that little life.”

The quality of care that women receive in hospital and general practice can have a significant impact on their experience of pregnancy loss. Even when facilities are less than optimal and staff time is limited, good communication, sensitivity and kindness can make a real difference in helping people through at a critical time.



Erin Sharkey

I've lost four babies in three miscarriages.

I am in a same sex relationship so I conceived using IUI (intra-uterine insemination) with donor sperm. The chances of pregnancy with IUI are quite low so when we got the positive pregnancy test we were delighted. We had perfect scans at 6, 10 and 12 weeks and felt we were out of the danger zone.

At 13 weeks I felt different. Despite my bleeding and begging for a scan we didn't find out for days that our baby had died and that his twin had died earlier.

I heard all the clichés: 'At least you know you can get pregnant', 'There's always next time', 'Just think of it as a late period' – and every one of them came from health professionals. I saw 14 people in three different hospitals before anybody said 'Sorry'. My much wanted and much loved baby was referred to as 'fetal tissue'. When I asked what would happen to him if I had surgical management, I was told he would be incinerated by the hospital. I chose to go home.

I returned to a different hospital where the consultant asked me to tell her about what had happened. She held my hand as I wept, gave me tissues and a leaflet from the M.A.. She said she was sorry and asked if I needed to see a chaplain. She made me feel like my sadness was justified, my baby had existed and my pain was real. She asked my wife how she was coping and acknowledged that she too was profoundly affected by the loss of her baby. In short she treated us like human beings who had experienced loss.

The Miscarriage Association

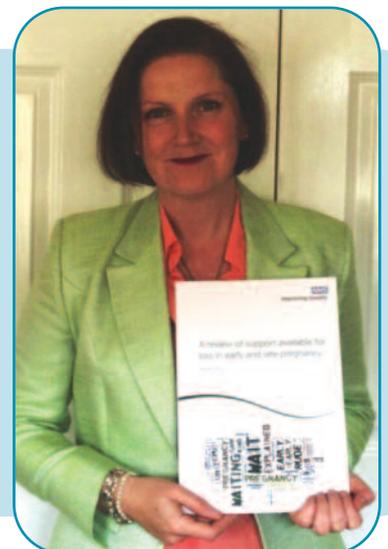
works with health professionals and key organisations to promote and support the best possible care for people affected by pregnancy loss.

In 2013/14 we achieved this through:

- in-house training and presentations for hospital staff, GPs and delegates at the annual RCOG Early Pregnancy and Emergency Gynaecology course
- working with the Association of Early Pregnancy Units (AEPU) to develop an e-learning module on communications and breaking bad news
- working with NHS England's Improving Quality team to inform and publicise their report on support after pregnancy loss
- supporting implementation of the NICE guideline *Ectopic Pregnancy and Miscarriage*. This emphasises the need to 'provide all women with information and support in a sensitive manner, taking into account their individual circumstances and emotional response
- guidance and consultancy, especially in relation to the disposal of pregnancy remains
- help for providers in making positive use of patient experiences, thoughts and feedback.

“For staff in these areas miscarriage is a routine part of their daily work, but for the women it is an individual journey that should be proactively supported by sensitive care, good information, effective communication and choice.”

A review of support available for loss in early and late pregnancy.
NHS Improving Quality, February 2014



Kath Evans, Head of Patient Experience, NHS England.

Abridged financial statements | April 2013 - 31 March 2014

	General funds £	Designated funds £	Restricted funds £	Total £
Income:				
Donations & similar income:				
Membership fees	5,040	-	-	5,040
Government grant	-	-	26,560	26,560
Donations & grants	98,261	-	-	98,261
Branch income	-	-	4,452	4,452
Activities to further the Charity's objects:				
Sales	27,152	-	-	27,152
Training & consultancy fees	1,200	-	-	1,200
Activities to generate funds:				
Fundraising activities	92,307	-	-	92,307
Sales	1,287	-	-	1,287
Interest received	3,644	-	-	3,644
Total income	228,891	-	31,012	259,903

Expenditure:				
Cost of generating funds:				
Fundraising	31,075	-	-	31,075
Charitable expenditure:				
Service provision	84,525	4,404	39,316	128,245
Governance	30,865	-	1,873	32,738
Total expenditure	146,465	4,404	41,189	192,058
Net surplus/(deficit)	82,426	(4,404)	(10,177)	67,845

BALANCE SHEET

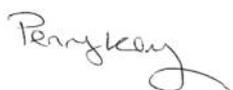
Fixed assets				2,204
Current assets				308,798
Total liabilities				(7,952)

Net assets				303,050
Represented by:				
Brought forward from 2012/13	160,775	55,000	19,430	235,205
Net surplus/(deficit) 2013/14	82,426	(4,404)	(10,177)	67,845
Transfer between funds	(2,653)	2,653	-	-
Balance carried forward	240,548	53,249	9,253	303,050

This financial statement has been agreed by Mazars LLP as being consistent with the full financial statements for the year ending 31 March 2014. These were prepared in accordance with the Statement of Recommended Practice Accounting by Charities (revised 2005) and receive an independent examination report.

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 financial statements, the independent examiner's report on those financial statements and the Trustees' annual report should be consulted. Copies of these can be obtained from the Miscarriage Association, 17 Wentworth Terrace, Wakefield WF1 3QW.

The full financial statements were approved on 13 September 2014 and have been submitted to the Charity Commission, the Office of the Scottish Charity Regulator and Companies House.



Signed: Penny Kerry (Chair)

Independent Examiner

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

Reviewing our finances 2013/4

The Miscarriage Association continued its policy of managing its resources wisely in the year ended 31 March 2014, prioritising the need both to maintain and to further develop high-quality services.

During the year we invested in developing our online services and reach by appointing a digital marketing and social media manager. Even after just six months this resulted in an 87% increase in website visits, a mobile-friendly website, an additional linked website, www.daysthatmatter.org.uk and a 48% increase in people seeking online peer support.

The Trustees also invested in two new projects: developing resources for partners of women who miscarry and for young people. These will be launched in 2014/2015.

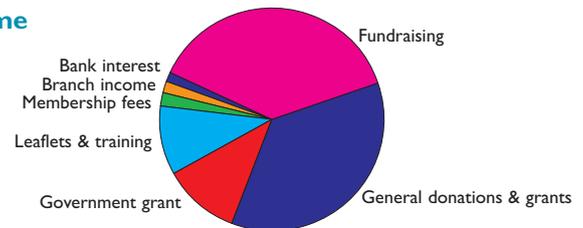
Overall expenditure decreased by 5% compared with last year. While expenditure on service provision reduced slightly, this includes both a significant reduction in staffing costs and an increase in spending on new projects and on developing the charity's online presence. Overall, two-thirds of our expenditure was on service provision with the remaining third split between governance and fundraising.

Total income for the year, at £259,903, showed an 8% increase on the previous year's results. This is a really positive achievement in the current economic climate. Much of this improvement was due to a 29% increase in donations from individuals and groups, especially reflecting the growing number of people doing a variety of fundraising events for the M.A.. Despite pressures on NHS budgets, demand for information remained strong with leaflet sales slightly higher than in the previous year.

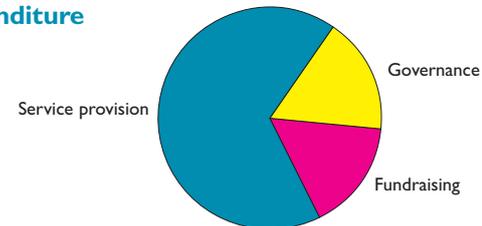
It is important to note the costs which were saved. The generously donated services of volunteers enable us to keep the costs of providing direct charitable support relatively low. Gifts in kind, from payroll processing to web hosting, also help to save funds. All these gifts are greatly appreciated, along with the financial and moral support provided by donors, members, supporters and friends. We are fortunate too in the dedication of staff and Trustees who manage the M.A.'s limited resources with great care. It is this sound financial management that enables us to hold down costs without compromising our services.

The Miscarriage Association ended the year with a healthy cash balance. This enables us to maintain a reserves fund of six months' operational costs while still allowing us to develop additional plans for the future. These will always be in line with the M.A.'s overall aims: to make a positive difference for people affected by pregnancy loss, now and in the years to come.

Income



Expenditure



...and thanking our supporters

The Miscarriage Association would like to express our thanks to all those who have contributed to our funds this year. Grants, individual donations or the proceeds of fundraising events – every contribution, large or small, is greatly appreciated. While we don't have space to list all our fundraisers and donors here, we would like to express special thanks to the following supporters who helped us maintain and develop our services in 2013-14:

Individuals and groups

Kerrie Bennett
Andrew Chalmers
Andrew Foster
Lesley Lewis
Joni & Bob McGlade
Sarah-Jane Molier
Donna Walker
Lucy Williams
Faye Wilson
Our Marathon runners
Our Nightrider and Ride London teams

Government

Department of Health

Charitable trusts & companies

Barclays Bank plc
Duncan Norman Charitable Trust
Gynaecology Ultrasound Centre
Hogan Lovell
Lloyds TSB
Morgan Stanley
Norton Rose Charitable Trust
Santander

Gifts in kind

Activ Computer Services
i2i, via Stuart Thomas
Landau Morley LLP
Rap Spiderweb
University College London
(Beacon Bursary)

Making a difference: 2013-2014

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

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

Our thanks also go to the people who help to select and support volunteers; those who help administer and moderate our online support platforms; our media volunteers; all our fundraisers; and all those who have informed and contributed to our printed and online information.

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

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

- Nicky Bullard, Executive Creative Director of digital and direct marketing agency LIDA
- Sarah Owen, Partner/Owner of PR, media and marketing company Pumpkin
- Dr Petra Boynton, Social Psychologist
- the members of our Professional Advisory Board
- Peta Harrison, editor of our members' newsletter
- Nigel Wood, our webmaster



Dr Petra Boynton

Patrons:

at 31 March 2014

Nigel Martyn

Professional advisors:

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

Trustees:

at 31 March 2014

Penny Kerry
Nicola Caplan
Lisa Dixon
Kerry Addison
Jan Birrell
Sarah Dunnett
Barbara Hepworth-Jones
Karen House
Matt Jarrett
Karolina Ker

Chair & Hon Treasurer
Vice-chair
Acting Vice-chair

Staff:

at 31 March 2014

Ruth Bender Atik
Lisa Bruce
Ann Collier
Elizabeth Stelmach

National Director
Senior Support Worker
Support Worker
Support Worker

Freelance staff:

Clare Foster
Natasha Judd

Raising funds and awareness



Donna Walker celebrating her birthday



Artist and runner Andrew Foster



Filming for 'Partners Too'

Planning for the future: 2013-2014

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

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

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

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

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

Our plans...

- maintain our staffed helpline five days a week, backed by a network of support volunteers
- launch new resources for the partners of women who experience miscarriage, ectopic or molar pregnancy
- develop new resources for teenagers and young adults affected by pregnancy loss
- continue our active involvement in high-quality research into miscarriage causes, management and treatment
- further improve our website and online presence so we reach and serve a wider audience;
- collaborate with key stakeholders to develop online training for health professionals working in the field of pregnancy loss;
- continue our active involvement with the Association of Early Pregnancy Units; and maintain positive links with all the relevant professional organisations, government departments, hospitals and health centres to improve care for couples who experience pregnancy loss;
- work to raise public awareness of the facts and feelings of miscarriage, ectopic pregnancy and molar pregnancy
- maintain and promote our reputation as an expert source of information on pregnancy loss.

...and how you can help

- become a member of the Miscarriage Association and help shape and drive our work
- join our online forums and help to support others
- talk to family, friends and colleagues about pregnancy loss and the work of the Miscarriage Association
- 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

“ It was good for me to post on the forum at the weekend.
It was the first time I had told anyone outside my family about my miscarriage, and I think it's helped the healing process.

I also wanted to thank the M.A. for the sterling work you all do. I was given your leaflet in hospital, and after my miscarriage I also visited your website. I found the information there invaluable in understanding the emotions I was going through, and it helped me start to come to terms with my miscarriage.

I also directed other family members to the website, so they could have some guidance on how best to support me and my husband, and they found it beneficial as well.

Without your efforts to compile and distribute this information, I would be left feeling confused and isolated at a time when I didn't feel ready to talk about it. Even though I didn't contact you directly at the time, it was comforting to know that there was support available if I needed it.

Thanks again and keep up the good work! ”