



“No-one can take away from me the word ‘Mother’.
I have a child I can be proud of and memories of
a beautiful baby that grew inside me.”



Summer 2002

SANDS

Stillbirth and Neonatal Death Society



Support Offered

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SANDS AIMS: offering support and pressing for improvements in care

SANDS offers support to bereaved parents whose baby is stillborn or dies soon after birth. Our support and information services are available at any time from before to long after bereavement.

- We have a helpline for anyone affected by the death of a baby, whether you are a parent, family member or health professional. You can speak in confidence to an experienced support worker.
- SANDS local support groups are run by and for bereaved parents. They can offer one-to-one befriender support from someone who knows first hand how it feels to lose a baby. They may also offer group meetings where you can share your experience with other parents.
- We have a range of resources for bereaved parents and families, including leaflets, books, information sheets, a CD and SANDS' own newsletter. We also help with a broad

Welcome to SANDS summer newsletter

Above everything else SANDS offers a place where you can remember your baby and share your experience with others who know how bereavement feels. We know that each baby who has died is precious, and how much they are loved and missed. If you are recently bereaved, or you have only lately heard about SANDS, we hope you find some support from this newsletter and through the other services SANDS offers.

We are always trying to find new ways to let parents know that SANDS is here. With more people turning to the Internet for help we are developing our website and expanding the information available to parents, SANDS groups and health professionals. You can read more about our plans on page 8.

On page 6 you can find out about the joint study day held in May, which SANDS hosted with CESDI. With the shared aim of seeing a reduction in the

numbers of babies who die, both organisations are committed to promoting CESDI's recommendations for improving care. The day was a very positive step towards this goal.

I am sure you will be impressed by the energy and stamina of the runners who took part in the London Marathon this year, raising money for SANDS. The four (pictured on page 4) who carried a sedan chair around the course have left me, for one, full of admiration. Many thanks to them and to everyone else who has given their time and energy around the country to fundraise and promote SANDS' work.

SANDS has many ways of offering support, comfort and hope throughout the UK. Please do not hesitate to keep in touch with us.

Janet Scott, Editor

range of enquiries relating to stillbirth and neonatal death.

We aim to improve the care parents receive by working in partnership with health care professionals. We are working to raise awareness of the fact that babies die, and of the grief and distress that follow a baby's death.

- We have publications aimed at those caring for bereaved parents – our 'Guidelines for Professionals' are essential reading for anyone interested in improving care.
- Many SANDS groups work with their local hospitals; many raise money for better facilities for bereaved parents. SANDS is also involved in providing training for health professionals.
- We are working with CESDI to promote research into the causes of stillbirths and neonatal deaths, and to press for changes in practice that could save more babies' lives.

Membership

SANDS is a small UK wide charity. We rely on donations to enable us to continue to offer these services. Membership is an important source of funding. By becoming a member you are directly helping to support our work.

SANDS members receive three newsletters per year, regular mailings on SANDS activities and can claim 10% discount on our publications and resources. You can participate in Befriender Training free of charge. You will be invited to our Annual Members Conference and can vote at the AGM.

To find out more about our services, or to join SANDS, please contact the office on 020 7436 7940, or look at our website at www.uk-sands.org

**The Helpline number is 020 7436 5881
Mon-Fri, 10:00-16:00.**



Hurtful mailings of baby products

Sarah Rowe has developed a solution to unwanted direct mail.

We were so excited – twins. After years and years of ‘trying’, we were finally going to be someone’s parents. We were hungry for information – I filled in questionnaires, clipped coupons, and in return, received lots of useful information and samples.

And then my body went into labour. Jack and Rebecca were born too early for their tiny bodies to have stood a chance. Words can’t describe the emptiness and loss we feel.

We coped. Each day became a little less painful. But, the baby post kept on coming, and each mailing hurt. What had been relevant a few weeks beforehand was now painful ‘Junk’. Just before ‘due date’, a pack of sample nappies arrived. I sat on the stairs and howled.

So, I decided to do something about it. I work in the Direct Marketing industry, and worked out how a scheme could be put in place to stop maternity and nursery mailings to bereaved parents.

I talked the idea through with SANDS, who were fully supportive. I then handed the scheme over to the Direct Marketing Association, who are the trade body for companies that promote their products by post. The service is confidential – information will never be used for any other purposes, and stops hurtful post with the minimum of fuss.

I’m delighted that the Baby Mailing Preference Service is now up and running and that it will remove some additional hurt from suffering parents; but most of all, I see it as a memorial to our children.

Sarah Rowe

How the MPS Scheme works

It can be very painful to receive mailings about baby products when your baby has died. But if the companies who have your details don’t know what has happened, they will continue to market their products to you unaware of the hurt this causes.

How can these mailings be stopped? No one wants to have to contact and explain their new situation to each company. Sarah’s scheme, sponsored by the Direct Marketing Association, provides a simple solution.

By registering once with the Baby Mailing Preference Service (Baby MPS), most unwanted mailings will be stopped for you.



To use the scheme parents (or someone acting on their behalf) need to give a few basic details about themselves, via a postcard or on the web. The MPS then advises all companies in the system that you no longer wish to receive baby related mailings. The information about you is kept strictly confidential and can be used only for this purpose.

The industry has welcomed this scheme; companies have no wish to send mailings that might cause distress. The service will be launched in July 2002. The leaflets containing the registration postcard should start appearing in GP surgeries, shops etc. around the country.

We at SANDS are delighted this service will soon be available, and congratulate Sarah for her excellent idea and for getting it off the ground. Particular thanks are due to Tessa Kelly of the DMA, who was very quick to support the scheme. She has been responsible for turning the idea into reality and pushing it through the industry.

To register with the Baby Mailing Preference Service you can pick up a leaflet or register online at www.mpsonline.org.uk. You can request a leaflet directly from the MPS by ringing 0202 7291 3310 or e-mailing babymps@dma.org.uk. SANDS groups are welcome to ask for a stock of leaflets to distribute.

Janet Scott





SANDS fields its largest ever London Marathon team

SANDS was magnificently supported in this year's London Marathon with eighteen runners all completing the course. Not only did they bring SANDS to the notice of the many spectators, but they are also on target to raise a fantastic £26,000.

Besides the physical challenge of taking part, the SANDS runners were all running in memory of a baby who had died: there were fathers, mothers, a grandfather, and friends of bereaved parents.

Rhys Randall's son Jacob was born still in January last year. Rhys said "His death devastated me and my family and SANDS have been amazing in helping us. Running the London Marathon was always on my list of things I wanted to accomplish.... When the opportunity presented itself I jumped at the chance. My most vivid memory of the day was crossing the finish and crying tears of sadness and joy; sadness because I had run for my dead son, happiness because of what I had achieved. It was truly a memorable day."

Runners Kevin Hannah and Kate Duckett also thought it was an amazing day. They ran the marathon for baby Nicholas who died a year ago, son of their close friends Vicky and Martin Davenport. They said their fundraising, which was also in aid of the St John's Ambulance, had been "beyond our wildest expectations and has made all the hard work and self-denial worth it many times over!" Karen said "People were amazingly generous. It seemed so many had been touched by a similar tragedy."

All the runners wanted to acknowledge the tremendous support they had had from family and friends. Jackie Wren, running in memory of her son Ian who was stillborn fourteen years ago, spoke for many when she said "I may have been the one who did the miles on the day, but it was definitely a 'team' event."



The Sedan Chair Team

Making history in the London Marathon was a team of four SANDS runners carrying a sedan chair with a human passenger. Team member Matthew Ridgwell wanted to raise sponsorship for SANDS following the support he and his wife received after their first son, Carl-Oscar, was stillborn in August 2001.

The chair, made from a carbon fibre helicopter seat and racing yacht poles, was carried at waist height by the four runners. Matthew described the challenge as amounting to "running the marathon in step and with an 18 kg lop-sided rucksack." The 'cargo' was Acer Nethercott who coxes for Isis, the Oxford rowing team. The ride is far from comfortable but, as Acer said, "I can't

complain as I suspect I'm getting the easiest deal out of the five of us."

The team completed the course in 6 hours and 4 minutes. Matthew said of the experience, "Despite appearances I thoroughly enjoyed myself", to the extent that he would like to enter two teams next year and race to the finish!

Thanks

It was an extraordinary day and everyone involved would agree with Jackie Wren who said "The atmosphere was brilliant; it surpassed all that I had imagined." We are hugely grateful to all the runners and their supporters for the hard work that made it happen.

Right: Kate Duckett and Kevin Hannah
Top: The Sedan Chair Team
Far right: Jackie Wren





Statistics for 2000

The runners:

Liz Davies
 Dave Driver
 Kevin Hannah
 Kate Duckett
 Ryan Higgins
 Roger Howard
 Tess Hurley
 Martin Jacobs
 Robin Leith
 James Parkinson
 Rhys Randall
 Andy Searle
 Rachel Taylor
 Jackie Wren
 Sedan chair team:
 Simon James
 Tim Philips
 Matthew Ridgwell
 Charlie Thompson
 Acer Nethercott (seated)

	Stillbirths	Perinatal deaths	Neonatal deaths	Total stillbirths & neonatal deaths	Live births
Scotland	298	448	212	510	53,076
Northern Ireland	93	157	82	175	21,512
England & Wales	3203	4963	2335	5538	604,441
UK totals	3594	5568	2629	6223	679,029
Rates per 1000 for the UK *	5.3	8.2	3.9		

* Stillbirth and perinatal death rates are based on total live and still births; neonatal death rates are based on live births only.

Sources:

- 2000 Annual Report of the Registrar General for Scotland: Stillbirths and Infant Deaths
- Annual Report of the Registrar General for Northern Ireland 2000: Stillbirths and Infant Deaths
- Office for National Statistics for England and Wales, DVSS.1 2000 Infant and Perinatal Mortality Statistics

Up-date on the SANDS CD

SANDS 2 track CD is selling well. I am continuing to develop ideas for a full SANDS album, and suggestions are coming in for songs and poems that could be used. Just some of the ideas are shown in the adjacent box. Please do contact me with any others you think would be suitable.

We are still seeking donations towards this project. Please contact Neal Long if you can help with fundraising.

Colin Spencer, Executive Producer

Colin's contact number has recently changed to: 07811 387220, or colinfwspencer@hotmail.com

Grateful thanks to Bromley SANDS and Southampton SANDS who funded all the costs of producing the 2 track CD.

SANDS CD is available from the UK office.

Songs written or performed by parents, family or friends

- [Naked](#) by Tino Troy
- [The birth song](#) by Mark Archer
- [When pain is searing](#) by Sheena Helyer
- [Almost a mother](#) by Reg Nelson
- [Fleetingly known](#) – to the tune of Morning Has Broken

Recorded Songs

- [Rose](#) by Bette Midler
- [I can see clearly now](#) by Hothouse Flowers
- [Angels](#) by Robbie Williams
- [A prayer for the Unborn](#) by Gary Numan
- [Cradle song](#) by Brahms
- [My heart will go on](#) by Celine Dion
- [Tears in heaven](#) by Eric Clapton

Poems

- [Had I the Heaven's embroidered cloths](#) by W B Yeats
- [Two of me](#) by Marilyn Shaw
- [Absent one](#) by Anne Alexander

Hymns

- [Be still for the presence of the Lord](#) by David L Evans
- [Father I place into your hands](#) by Jenney Hewer

Thanks to Groups

More and more SANDS Groups are contributing important development and core funding to SANDS.

We would like to thank Steve Fisher and Basingstoke SANDS for arranging the funding for a new computer, which has enabled us to use e-mail and the Internet from the UK office. Additional contributions have come from Cheltenham, Coventry, Solihull, Southampton and Wirral.

Thank you also to Bristol and Birmingham who together consistently contribute over £5,000 p.a to core funds.



Bridging the communication gap - SANDS/CESDI study day

Communication is the key

SANDS and CESDI (The Confidential Enquiry into Stillbirths and Deaths in Infancy) teamed up on the 8th May to run their first collaborative Study Day. The focus of the day was communication between parents and health professionals, something that has been highlighted in virtually every CESDI report since the organisation was set up in 1992.

CESDI was founded by the Department of Health with the aim of understanding how the risk of death for babies (between twenty weeks gestation to one year) might be reduced. Anonymised details of almost all stillbirths and infant deaths are reported to CESDI by health authorities around the UK (excluding Scotland). CESDI compiles the information and each year, focusing on a particular area of practice, identifies and reports in detail on patterns of sub-optimal clinical care. The reports are compiled by a panel of experts who examine individual cases in detail and then make specific recommendations aimed at improving practice.

In the early days of CESDI parents had little or no voice in the process but since the mid nineties, following the concerted efforts of former SANDS Chair Gill Mallinson, that has changed. As Lucy Lelliott, another former SANDS Chair, said: "Mutual respect (between health professionals and parents) is growing all the time and we are hoping to build on that mutual respect and to understand each other's work and each other's viewpoint."

That essentially was what the 8th May was all about. It brought together eighty five parents and health professionals from all over Great Britain to exchange experiences in an attempt to "bridge the gap", as CESDI Director, Mary Macintosh, put it.

Top: Lucy Lelliott, former SANDS Chair and current link with CESDI; Mary Mackintosh, CESDI Director; and Hélène Currie, SANDS current Chair.
Below, Nancy Kohner, author, trainer and SANDS Advisor; and Prof. Jem Berry, Consultant Paediatric Pathologist.

CESDI has compiled eight annual reports so far, covering a range of issues including: a study of babies who die during labour; paediatric post-mortem issues; and the antenatal and postnatal care of women who have a stillbirth.

In its latest and eighth report, results from a 1997/8 study of 422 stillbirths show that in around 50% of those cases, "it was felt that different care might have made a difference to the outcome." In other words, the lives of around two hundred babies might have been saved if better care had been given.

Jacob's story

Take the story of Jacob, bravely told by his mother Fiona Randall. Fiona described events that led up to the death of her son at forty one weeks gestation on 12th January 2001. Fiona had an intuition that all was not well with Jacob the week he was stillborn, and to this day she regrets not having emphasised her concerns more, even when she had been reassured that everything was okay. There were other symptoms during the last ten weeks of her pregnancy that had been a worry: itching, high blood pressure and pain in her side. Had these symptoms been taken as a whole, her consultant later told her, Jacob's death might have been avoided.





Fetal movements

So why is a story like Fiona's still familiar? Mary Sidebotham, a CESDI research midwife, said "midwife-led holistic care is what we're aiming for and not achieving." Failure to detect subnormal growth and reduced fetal movement was a recurring theme in many case studies, as was failure to respond to a mother's concerns.

"In our technological age, health professionals are losing basic clinical skills," she warned. Listening, using ones hands and even making use of an old-fashioned tape measure, if necessary, can all make a difference. "If a woman says 'I don't feel right', it's a reason to look even if it's not evidence-based," said Mary. Likewise busy expectant mothers should be supported and encouraged to spend time focussing on their unborn babies, so they can become familiar with their individual patterns of movement, and feel more confident in recognising changes in those patterns which might indicate a problem.

Later in the day a workshop on fetal movement highlighted some of the gaps in communication. Continuity of care was cited throughout the day as a problem. Parents said they preferred honesty to over-assurance from health professionals. Equally, ante-natal classes need to make parents aware early in pregnancy that problems can arise. There was also a call for more support for midwives. As one parent put it: "I simply don't know how you do your job."

Post-mortem

Another key issue of the day was informed parental choice with regards to post-mortem. Professor Jem Berry, a leading paediatric pathologist, said that events of the last few years at Bristol and Alder Hay Hospitals had resulted in "a loss of trust." CESDI studies show "post-mortem is the most frequently criticised area of post-delivery care."

CESDI identified cases where the issues of post mortem were not discussed

appropriately with parents: where information was inadequate or inaccurate, or where parents' feelings were not given sufficient attention. Post-mortem information needs to be comprehensive (the Department of Health are in fact drawing up standardised forms), said Professor Berry, and delivered by the appropriate, well-informed person who can explain definitions of 'tissue' and the possibility of having a limited post-mortem. There needs to be better communication and better systems in place to collect all the important elements of information.

In workshops that afternoon parents and midwives added their own voices to this sensitive issue. They called for better training for health professionals, and said that when the hospital failed to provide the right information it was left to community midwives to pick up the pieces.

Partnership

Author of 'When a Baby Dies', trainer and SANDS Advisor, Nancy Kohner gave the final talk on what had been an extremely thought-provoking day. Why, she asked, did it take events like those at Bristol and Alder Hey to get things changed for the better? Why were there still such huge gaps in mutual understanding? "How do we change the approach to making change?" Honest and open communication is essential but ultimately, said Nancy Kohner, "talking isn't enough". She urged the audience to abandon our culture of blame and take joint responsibility for change, by involving parents in the actual work in hand and not just as voices heard and acted upon.

Ending on a positive note she said "Partnership is a tender plant struggling in a difficult environment but because both sides are so eager to help this is one area in the health sector where partnership really can succeed."

Lucy Lelliot, who chaired the day, has been the link between SANDS and CESDI

since January 2000. The study day was, Lucy admitted, "an experiment" but judging by the comments made by delegates as they left at the end, it had been an extremely worthwhile one. However as Nancy had said, talking isn't enough. What is important now is to move from discussion to action, to ensure improved communication and awareness in the future.

Fiona Randall and Charlotte Bevan

We are extremely grateful to both the Royal Institute of Public Health and to Irwin Mitchell, Solicitors, whose sponsorship of this event meant that the day was free of charge to delegates.

- Notes on the speeches and workshops from the study day are available. If you would like to read more please contact the UK office for a copy.
- CESDI's annual reports are available on their website at www.cesdi.org.uk



Above: Fiona Randall, mother of Jacob.
Below: Mary Sidebotham, Research Midwife.





Information

Website news

Many SANDS groups are now thinking about having their own websites, and are wondering how their site and the UK SANDS site can link together.

I am now in the process of redeveloping SANDS' website, with a new look to match the style of the newsletter, new layout for navigating around the site, and many new sections and pages. We have received generous funding from several SANDS groups to go towards the costs of the programming and design work.

We would like to have the network of all SANDS websites linked together. On the new UK SANDS site I will have linking buttons to all the individual local group sites. You can also put a button on your site, linking it to us at www.uk-sands.org. In this way visitors to any SANDS site will easily be able to find local information or access the general information on the UK site.

If you would like more information about SANDS website, please ring Janet Scott on 01327 861212.

- Ayrshire SANDS have recently launched their new website at www.ayrshiresands.co.uk.



Tracing a baby's grave

Many parents whose baby died some years ago do not know where he or she is buried. Tracing a baby's grave can be a difficult task. It takes courage to start the search and it ought to be stressed that the results can often be frustrated by lack of records or insufficient details. However there are successes.

The Hospital records

If you decide you want to trace your baby's grave the first place to try is the hospital where the baby was delivered.

You should contact the Hospital Administrator who will need to know:

- the full name and address of the mother,
- the date of delivery,
- any other details about the birth or funeral you might have.

They may have a record of where the baby is buried and details of the Funeral Directors involved, who would be able to tell you the cemetery or crematorium used. You can then ask to see the relevant register of burials or cremations.

Cemeteries and Crematoria

Hospital records are rarely kept for more than ten years, so this avenue may not produce the information you want. The next place to try is the local council Cemetery and Crematoria Department, which keeps a register of stillbirths and deaths for the area. The Superintendent Registrar usually heads the department.

The public are legally permitted to inspect burial registers, but are not automatically allowed to see the cremation register. However a search can be done on your behalf. You will need to know:

- the baby's surname and
- the date of death or stillbirth.

You may not know that in many cases babies were, and sometimes still are, buried in shared graves with other babies or sometimes with another adult. Graves are often unmarked, though they do have a plot number.

Babies born before the legal age of viability

The term 'stillbirth' refers to babies born dead after 24 weeks completed gestation. Before 1992 the age was 28 weeks. There is no legal requirement to certify or register a baby born dead before this 'legal age of viability'. Despite this, it is still possible that records may exist about the disposal of the body in these circumstances. Over the years it has been left to hospitals to formulate their own policy on what to do. This has obviously varied widely, with some hospitals keeping records and others not. Therefore it is true that it may be more difficult to find records for pre 24 (or pre 28 week) old babies.

Practice on the disposal of fetal remains has been closely scrutinised in recent years, as we all know, and hospitals now should consult fully with parents about the disposal of the body. Not only should remains be disposed of with dignity, whether or not the parents are involved, but hospitals should also keep clear records of what is done, regardless of the baby's gestational age.

These issues are covered in the SANDS 'Guidelines for Professionals' – available from SANDS office. The Institute for Burials and Cremations has recently issued a new policy for the disposal of fetal remains, which you can see at www.ibca.uk.co.

If you want to talk to someone about tracing a grave then please do ring the SANDS helpline, which offers support to all parents however long ago bereaved.

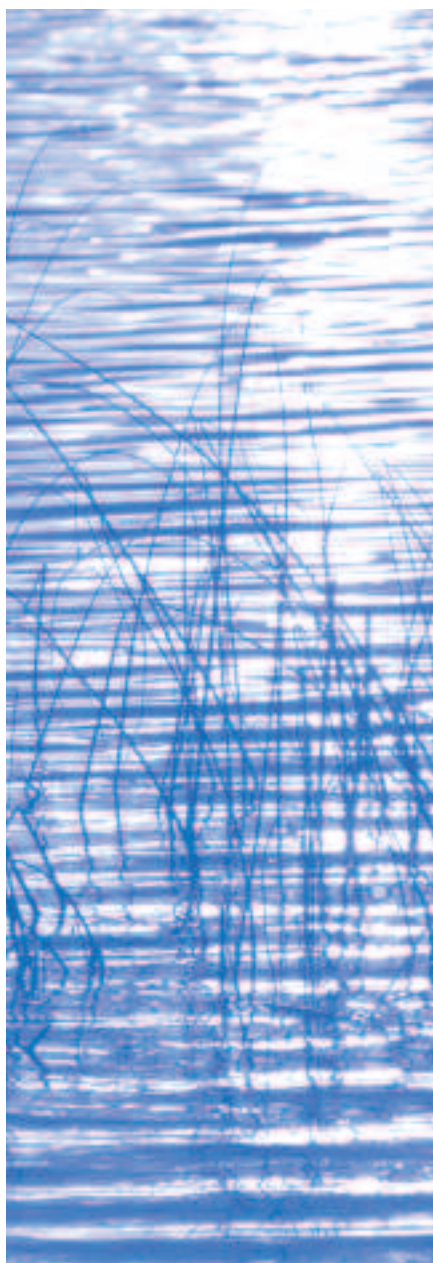
- In the next newsletter we will have information about obtaining a certificate of a baby's death, so if you have any questions about this or about tracing graves, which we



A parent's experience of tracing her baby's grave

could answer in the newsletter, please send them to Janet Scott.

- We are putting together information for a leaflet and for the website for parents who were bereaved long ago. We would very much like to hear from anyone about their own personal experience of this.



On 12th May 1976 I gave birth to my first child. She was stillborn.

I had a perfectly normal healthy pregnancy. I knew something was wrong from my examination at thirty four weeks. I was sent for a scan. No-one would talk to me. I later learnt that a decision was made to tell me nothing. At thirty six weeks they said my baby was small and it would be better if she was born now.

After thirty six hours of labour I was finally told my baby was dead and that I needed an emergency Caesarean Section. I remember everything, every detail, every word spoken, every action, every feeling. I thought I was going to die and I wanted to.

Then nothing. A blank space, a void where there should have been a new life starting.

I asked questions which were mostly avoided or went unanswered. I was not allowed to see or to hold her. I was told to forget, get on with my life, to get pregnant again. I was told my daughter had Hydrocephalus and Spina Bifida. When I asked about the funeral I was told that she had been 'slipped' in with someone else. When I tried to give her a name I was told there was no provision to name a stillborn child.

I named her Angela and wrote the name on her certificate myself.

Then in January 2001 came Organ Retention and the knowledge that the hospital I was in was one of the ones being investigated. Now everything I hadn't been told was menacing. After several months, and only after I had been advised who to write to by a solicitor, I started to get answers.

My daughter was not involved in any organ retention but suddenly I had more information than I ever dreamed possible. My daughter had a funeral. She was in a public grave with four adults and six babies. I have all their names. I remember the moment I spoke to the cemetery because that was the

moment she became real to me and I felt her, close to me, within me. We were together at last.

I have never forgotten her or grieved for her or come to terms with her loss. I have missed having her and knowing her. I have been aware over the years of times that I was crying for her but the emotion had to be suppressed. No-one would understand the tears after all the years.

I have visited, with my son, the patch of grass that is her unmarked grave. I wrote a letter to her telling her of my feelings. I wanted to bring her home and hold her close. A shrub that will flower in May, around the time of her birthday, has been planted in our garden. A tree to grow and flourish, as she did not, has been planted in the land of her ancestors, Scotland. I took a page in the book of remembrance at the hospital.

There must be so many women like myself who were trying so hard to forget but not succeeding. I used to say that I had lost a baby and I truly had in every sense of the word. No one had the right to make decisions for me or keep information that was my right as a mother, from me. At last I have been able to grieve, to feel anger and the hurt and pain and to cry the tears that needed so badly to be shed, to begin a healing process. Andrew, my son, understood and grieved with me for the sister he had never known. He was a great support and comfort to me.

I am smiling in my heart and holding you close, we are together at last.

Ann Room

Written on Mothers day, March 2002



Personal Experiences

Thank you to all the authors of these personal experiences. It is not always easy to write down what happened and how it felt, and we are grateful to those who have done so for this newsletter. It is clear from several of the pieces how much comfort reading about someone else's experience can give. Please think about writing about your own experience for the newsletter. It can be prose or poetry, long or short; you can be a parent, family or perhaps a health professional who has cared for a baby that has died. If you write more than can be fitted in, I can help with editing. All pieces really are welcome. **Janet Scott, Editor**

Harriet Amber

Andrew wrote to SANDS at the end of April, soon after the death of his daughter Harriet. He and his partner had been very moved by reading the personal experiences section of the last newsletter. Andrew kindly offered to let me print his letter.

Our daughter, Harriet Amber Thompson, died on 12th April 2002.

She died 'just' one or two minutes before she was born, in the final stages of labour. None of the investigations have provided us with any cause for her death. We are left, perhaps like other parents of stillborn babies, repeatedly asking why, how and what if. We cannot believe she has died.

Other people we saw on the day we went to hospital and on the occasions we went to parent-craft now have their babies. Instead we have photos, locks of hair, post-mortem results and copies of the medical notes.

Family friends and employers have been supportive and caring, yet nothing and nobody can give you what you want, your child, our child Harriet back.

“Nothing and nobody can give you what you want, your child, our child.”

We have been told 'it is early days yet'; but we cannot believe that the pain of these days will dissipate with weeks, months or years. How can your lost, longed for future with your child ever be reconciled?

Of course we know our futures will now take on a new course, a sad course that has been trodden by many of your members.

Thank you to the authors of the articles in your newsletter. They stimulated our tears and memories.

Andrew Thompson

Andrew included these words, which he and Harriet's mother wrote to her.

A planned life conceived in love and anticipated with joy.

Your earliest moments brought us more happiness than you could imagine.

So how can we ever be reconciled to your departure?

We spoke to you and felt your movement when you were safe within mummy, but we never saw your eyes or heard your cry.

For this we are eternally sad.

Constantly we shout out why, how and what if?

Answers could help, yet what can fill the void?

Perhaps we shall never know, but we want to say that you will live forever with in both our hearts and minds, a first beautiful daughter.

For James

Surrounded by love in a meadow of green,

Our baby is with us, though no longer seen.

You'll never face turmoil; you'll never face strife

As your special soul has eternal life.

We may not have answers, we may not know why?

Apart from a plan which is meant from on high.

We'll see you again, of that we are sure

As we join you in heaven when we exit life's door.

Martin Blessett,

Martin and Vicki's son, James John Martin Blessett, was stillborn on 26th July 2001.





Our story about Jack

Melanie's son Jack was stillborn on the 26th December 2000. She wrote to us in April saying:

"After reading the Spring 2002 newsletter I have decided to write and share our experience of stillbirth. I have personally found it comforting to know that I am not suffering alone. Your newsletter has taught me that!"

We discovered our son Jack had died on the 20th December 2000. My uterus had ruptured suddenly. I wasn't even in labour.

After days of failed induction Jack was delivered by Caesarean Section. He was born on the 26th December 2000 weighing 7lbs 3ozs. I was just three weeks from my due date.

Nothing can correctly explain the feelings of utter disbelief, failure, helplessness and great sorrow.

That feeling of leaving hospital with no baby in your empty arms. Part of me wanted to stay in hospital to keep the connection there. The other part of me wanted to get as far away as possible.

The pain never leaves you. Even now fifteen months on the pain is as great. The large gaping hole inside. The aching of our hearts.

The worst the is when people say, "Never mind, at least you've got your daughter."

"That feeling of leaving hospital with no baby in your empty arms."

Yes, we know we have, but we have also got a son. He doesn't live with us, he lives with the angels, but he's still our son.

Melanie Copley

Zak and Rhianna

In May 2000 I became pregnant after our second try at (ICS)IVF. At seven weeks I found out I was expecting twins. All seemed to be going well, but at a routine eighteen week scan I discovered that there was a problem with one of the babies. We didn't know the sex of the twins, as it would spoil the surprise.

The consultant told us that one of the babies was anacaphic spina bifida at the brain end. To say it was a shock was an understatement. After much discussion among the doctors with knowledge of this it was decided for us that we would carry on with the pregnancy as to do anything else would have put the other twin at risk.

My husband and I decided that it would be easier not to tell anyone as they would ask lots of questions that we couldn't answer.

At twenty seven weeks my waters broke and I was admitted to hospital for bed rest and monitoring. Then in the early hours of the 1st December I went into labour and my waters broke completely. All seemed to be well with the twins apart from the obvious problems. After transferring to another hospital and having a scan, we were informed that the bay with anacaphic had died in the womb. We were both devastated and relieved, as we couldn't have watched him die.

Our son Zak was stillborn at 13:06pm. Then our daughter Rhianna was born at 13:12pm.

I didn't see Zak as soon as he was born but I did see him after Rhianna was born. He was absolutely perfect in every way apart from the back of his head. We kept Zak overnight, which I am so pleased about. It is only now that I wish I had him more. Zak was buried on the 15th December and this is now his special day.

Rhianna has always known she was a twin as we talk about Zak quite often and she comes along to the cemetery

whenever we go. I often feel that she misses him and thinks that something is missing in her life.

I have read in a magazine about lone twins and would like to find out more information about studies that have been done.

"He was absolutely perfect.."

Rhianna is coming along in leaps and bounds. I'm sure that Zak is up there in the clouds watching over her. We made a promise whilst I was pregnant that the surviving twin would always know they were a twin and we have photos of Zak to show her, and as she gets older we can tell her more and explain things to her.

Unfortunately since then my husband and I have split up. However the care and upbringing of Rhianna is still the same and she will grow up knowing that she is loved by both of us no matter what happens.

Lisa Dickinson

If any parents have information or experiences they would like to share with Lisa, please write via the SANDS office. TAMBA (Twins and Multiple Births Foundation) have a bereavement support group for parents who have lost one baby or more from a multiple pregnancy. Their phone number is 0870 770 3304.





Personal Experiences

Katie

I found out I was pregnant four days after Andrew had asked me to marry him! We were both thrilled although it seemed to be doing everything at once! We got married some four months later on and then moved into our new home.

I gave up work eight weeks before she was due (we were always sure she was a girl and Andrew gave her the name Katie quite early on) and spent the time resting in between getting the nursery ready etc. The pregnancy was uncomplicated and we just waited for her to come. The due date came but no sign of labour. Two mornings later I was concerned that I had not felt any movement for a while - during the previous night I had felt a single sharp pain in my side and found myself thinking the seemingly ridiculous thought that she could be dead. All through that day and the next night that feeling kept returning even though I thought I had felt movements. In the end I rang the midwives number at 4.00am to ask someone to come and see me in the morning, then I sat and read the chapter on stillbirth in my pregnancy book.

What actually happened was that I went to them in the morning - neither of the two midwives who tried could find the baby's heartbeat so they sent me up to the hospital. Andrew met me there and the worst was confirmed with a scan - Katie's heart had stopped beating.

"I found myself thinking the seemingly ridiculous thought that she could be dead."

We stayed at the hospital and chose for me to be induced that evening. I think we both hoped that maybe they were wrong and she would still live. Katie was born that night after a very quick and relatively straightforward labour and for a while I felt exhilarated (the morphine might have had something to do with it). I held her then and all was well. The midwife brought her back to us after they had taken photos and footprints for us and we had her with us all night. She looked pretty bad and it was difficult to imagine how she might have been if alive. I think we could both see that she

had been very poorly although we did not discuss it at the time.

The funeral followed the post mortem and friends and family gathered round to say goodbye to Katie. She is buried in our village churchyard, ten minutes walk away, which has been a great blessing.

We were told six weeks later that Katie had Down's Syndrome and that was why she had died. It took a while for this to sink in - I don't know what horrors we had imagined, that somehow we might have done something 'wrong'. We both would rather she had lived and we know we would have coped but I am glad for her that she died in peace and safety. I know she is with God now, sometimes I wish I was with her but there is much to live for here on earth. For the short time she was with us we gave her all our love and she in turn brought us much joy. She has been a huge influence on us and our family and friends and I know she is working hard praying for us now!

Since then I have miscarried another baby. I was very angry about this and seemed to find it much harder to cope with. I found a Christian counsellor and with her help, and that of Andrew and my mum, I was able to talk through the violent feelings I had. I am now expecting our third child in May 2002. We are feeling very positive about this little one!

Ann Churchill -Stone

Katie was stillborn on 5th February 2001

For John

Born into heaven,
Our darling baby John.
Our many months of waiting
Our dreams now shattered and gone.

If we had just one wish John,
It would be that you could stay,
But always in our hearts you'll be,
Loved more and more each passing day.
And when we see the stars at night,
All glowing and shining bright,
We send a prayer to our Lord,
To hug and hold you tight.

Little man, watch us from above,
And remember we send to you
All our everlasting love,
And hugs and kisses too.

Loved forever by your Auntie Kerry.

by Kerry Plunkett

John Trevor Pye was stillborn on 19th February 2000





Joseph

Wednesday and only two days to go before our first born was due to arrive into the world, but a little voice in my head started nagging away at me that something was wrong. At first I tried to ignore it as right up until the night before I had always had good movements but today felt different. So reluctantly I called our friends and asked if they would drive me to the hospital, as I didn't want to drag Dave home from work.

As I lay on the couch I thought about how soon I would be on my way back home mocking myself for being so silly. But the midwife was taking too long; she kept moving her "ear trumpet" to a different part of my belly. She then reached for the sonograph - but nothing, just silence.

Another midwife joined us and suggested a scanner be brought in...by this time Debbie had left her seat at the end of the room and joined me by the bed...I said nothing, I just stared at the ceiling, my heart racing.

"I felt numb and full of disbelief, this wasn't happening."

The scanner arrived and I could see the screen. I was convinced at the time that I could see for myself that the heart had stopped, but looking back I don't think so...I already knew before then that our baby was dead.

They moved us into a private room. I just stared at the wall. I felt numb and full of disbelief, this wasn't happening? Deb's left me briefly to ring Dave - she told him they were having trouble locating a heartbeat, she couldn't tell him the whole truth, after all she wanted him to arrive in one piece.

Richard, Debbie's husband, joined us, but still I couldn't look at anyone.

When Dave walked in the room that's when I cried. He didn't need to be told, he knew straight away. He just held me and told me how much he loved me.

A second doctor arrived and then a third - it was she that dropped our second bombshell - FULL LABOUR! - I was mortified. How could they possibly expect me to go through all that pain and pushing for nothing? Dave stressed how dreadful it would be for me, but they were adamant, a Caesarean was not an option. The doctor explained the risks involved and said they would ease the pain with a full epidural. He was very nice and advised us to go home and try to get some sleep first.

We went back to Richard and Debbie's but later returned home around 10.30pm. In the nursery the freshly washed blankets, baby grows and stuffed toys were all at the ready. At 5.30am my waters broke. We went back to the hospital and they gave me a pessary to help speed labour. At 9.20pm Joseph was born. 8lb 6oz.

Whilst Dell, my doctor, sutured me I closed my eyes. The next thing I remember was Andy, my anaesthetist, squeezing bags of fluid in through my drip. He kept telling me to focus on him. More and more people rushed in but all I wanted to do was sleep. Dave was slowly pushed away and I'll never forget the look on his face as they rushed me into theatre.

When I awoke I felt very peaceful. Dave was there as were Richard, Debbie, Dell, Andy and others that I didn't know. I didn't give a thought as to where I was or what had happened. After the ventilator was removed a Consultant came to see me. I was told that I was in Intensive Care; I'd been a very sick and had suffered a catastrophic haemorrhage. I'd had 25 units of blood, 22 units of blood products and until I woke up they didn't even know if I was going to pull through.

I murmured "you've done a hysterectomy haven't you?" which understandably took her by surprise. She immediately asked how did I know but in truth I didn't, I'd just had this feeling. Dave squeezed my hand but I told him I was OK. I suppose I was too tired to react any more than that.

Seeing Joseph was delayed for us. By the time I was strong enough it was Monday, and as the door opened we immediately burst into tears. For the first time I could hear joy in Dave's voice as he said with pride how beautiful and perfect his son was. He looked more like three months than new born, a real whopper!

I stroked his head through the hat he was wearing and peeked at his ears. Dave touched his face but I didn't want to touch his skin, I knew he would feel cold and I didn't want to remember him like that - I told myself instead that he was just sleeping.

We stared at him feeling only joy and wonder. When the time came to say goodbye we both kissed him and told him how much we loved him.

Two weeks later a special service was held at his graveside. Both our parents and brothers attended, as did Richard and Debbie (we had originally chosen them as Godparents but never got the chance to ask). Dave and I placed a small display of white roses his casket.

Joseph was buried dressed in an outfit my Mum had bought when I was thirty four weeks. He was wrapped in a hand crocheted shawl, a gift from a friend, and with him was placed the small blue bunny rabbit I'd bought when I'd last visited Mothercare. I remember being unable to decide between pink or blue or both, but instead relied on my instincts.

With him also are two red roses from his dad and me. These we threw after he had been lowered into the ground and are a symbol of our love that will stay with him always.

Caroline Youde.

[Caroline and David are parents to Joesph, stillborn in October 2001.](#)



Personal Experiences

In the last newsletter we had an article about returning to work after the death of a baby. The experiences here were sent in response to that article.

Returning to work

Ben

My son Ben died at nine hours on 19th December 2001, and I have not yet been able to return to work.

For the first few months I was not able to see or speak to anyone who was not a close friend. I felt dread towards my place of work. I think I had so many memories of being pregnant and looking forward to this baby that I dreaded returning. Also a colleague was due around the same time as me and although I was obviously glad her outcome was good, I was frightened of hearing about how well she was getting on and how the baby was growing, when my son never would.

My manager was very good. Nobody has pressured me and they have been very understanding. Nobody knew what to do or say; what might be OK one minute is not the next.

As I am not sleeping well I still feel very tired; my concentration is not very good and especially in the early months I would not have been able to get any enthusiasm for anything.

I will go back to work but will definitely wait for the first year to pass.

The trouble is so many small things trigger a memory – hearing about other babies, children's birthdays, Ben's name. I will let you know how things go when I do return.

Ben's mum



Molly

After I had my miscarriage, I left work to be at home with my eighteen month old daughter. I couldn't face going back and wanted to concentrate on trying for another baby without added pressures. At that point colleagues had said, "oh well, never mind, try again" or "it was for the best". So when I lost my daughter Molly a year later, a day after she was born, I endured more silly comments, "look to the future", "there will be others". I was glad that I was not working there anymore or I would have probably shouted at some of them!

"Little did I realise that 2 years later I would be totally unprepared for how I would feel..."

When I had the chance to start a part-time job at my daughter's school, I thought that it would be good for me, mixing with adults again; gaining confidence, not too much pressure. Little did I realise that two and a half years after I would be totally unprepared for how I would feel knowing that Molly should be amongst all the other reception children running around the playground outside with me and eating her lunch in the dinner hall.

The head teacher will be unaware of my situation and only one colleague knows about Molly and how I feel. It is not a subject that crops up in conversation very often, so I'm left alone to cope with my feelings and have to learn to live with them, although it's not easy! But I have a wonderful husband to share it all with, good or bad.

Samantha Speakman

mother of Molly, March 2002

Micky

Karen's story about returning to work after the death of her son, Micky, is a wonderful example of what an employer can do to make the transition back into the workplace as positive as possible.

I work as a long haul Air Stewardess for Virgin Atlantic Airways, so as soon as I was pregnant I was grounded immediately and was given an office job. It was a wonderful place to work with sympathetic colleagues and no problem about time off to attend appointments or suddenly rushing to hospital because we had not felt the baby move.

Our son Micky was stillborn at thirty five weeks in July 2001. The response from work was amazing. So many cards, letter, bouquets and phone calls. It was a bit overwhelming at first but it helped to know that they regarded my son as important. The funeral was the same. Lots of people from work came, I don't remember who exactly but I was told there were about twenty colleagues there.

Two weeks after the funeral Steve, my line manager called me at home. He was so nervous as he felt he was intruding. He stressed that grieving and coming to terms with Micky's death came before any thought of coming back to work and that I should do things at my own pace.

Steve continued to call every two weeks or so just to see how I was. I never felt pressured to return to work. I finally met up with him in early November. He offered to come to my home (over an hours drive), but I decided to go to the office. I had to get over the first hurdle of walking through those doors again. Last time I had been pregnant and so happy. The meeting was really to determine if I should go onto long-term disability payment (which I did not). This was handled with tact and gentleness. We sat in a private room for over two hours. I cried and cried. We talked about Micky, my fears about coming back to work, my health. Steve was crying with me and



we hugged. I left his office feeling braver and calmer.

In December I saw a nurse/counsellor from the Occupational Health Department. Louise was wonderful. I told her I was ready to go back to work. She asked lots of questions about my sleep, diet, panic attacks etc. She felt I was not ready to come back so armed with lots of leaflets I went home again. I told Louise and Steve that I felt like I was burdening them and that I should pull myself together. They were horrified and said how strong they thought I was.

After two more weeks Louise and I agreed I was OK to start back at work, but not flying. I was to work three days a week – Louise explained that grief carries extreme tiredness and that if I did too much too early I would be back to square one.

“It helped to know they regarded my son as important.”

She was absolutely right! I was grateful for my days off. I worked for Customer Relations in a small private office. Christmas was here and I was having mini breakdowns every five minutes. Nobody knew what had happened, except Natalie who I shared the office with (which is what I wanted), so there were no awkward moments.

I began my Return to Flying Course in February, with Steve checking up on me throughout to make sure I was coping. I told the group all about Micky and they were wonderful. Lots cried and some were just in shock. I certainly raised awareness! At the end of the course the girls bought Micky some white tulips to place on his grave.

I then returned to flying. I was offered a buddy roster and so I flew with someone I had chosen, who looked after

me. I was also on a reduced number of flights per month to ease me in gently. They were concerned that being away from my husband and Micky’s grave would be hard. They did not want me to feel torn between work and being at home.

Virgin decided to give me full pay from the moment Micky died. This extra money helped so much, especially where the funeral was concerned. I was assured it was discretionary, compassionate pay and not sick leave.

I was extremely lucky – I’m sure Virgin is a role model to follow. They have taken the time to read up on infant death and its consequences. They understand that a happy, healthy staff equals the secure running of a great company.

Karen Docherty

April 2002



Beautiful One

You came to us to dry our tears,
To ease the pain of the last five years.
Beautiful One we did not know
Our time would be so short,
You would have to go.
All we can do is ask ourselves why
Our beautiful son had to die?
There’s no limit to love, no limit to pain.
Beautiful One we will see you again,
And when that time comes
We know you’ll be there,
To open those gates and say Mummy
and Daddy are here.
This time the tears will be of joy and
not pain.
The three of us can be a family again.
We can hold you, kiss you,
Surround you with love,
And finally forget that sad day
You were taken from us.
Beautiful One we want you to know
You are our firstborn child and we love
you so.

Simone Ives and Andrew Skyers

whose son Kaden was stillborn on
12th November 2001.



Contacts

SANDS local support groups and contacts throughout the UK

Where a group has a dedicated phone line, it is printed below.
To contact any other group, or to find out which group is closest to you, please ring or write to the UK office.

ENGLAND

Avon	Bristol SANDS 0797 0930 513
Bedfordshire	Bedford SANDS
Berkshire	East Berkshire SANDS
Buckinghamshire	Milton Keynes SANDS
Cambridgeshire	Huntingdon SANDS, Peterborough SANDS, Wisbech Contact, Ely Contact, Cambridge SANDS
Cheshire	Crewe Contact, Halton & Widnes SANDS
Cleveland	Cleveland Contact
Co Durham	Shildon Contact
Cornwall	Falmouth Contact, Torpoint Contact, Truro contact
Cumbria	Carlisle SANDS, South Cumbria Contact
Derbyshire	Derby SANDS
Devon	Collompton Contact, Plymouth contact
Essex	Chelmsford SANDS, Colchester SANDS, Ilford Contact, Havering SANDS
Gloucestershire	Gloucester SANDS, Cheltenham SANDS 07901 562 325
Greater Manchester	Manchester SANDS, Oldham SANDS, Oldham Contact, Rochdale/Bury SANDS, Salford SANDS, Stockport SANDS
Hampshire	Southampton/New Forest/Winchester SANDS 07970 981 550, Portsmouth Area SANDS 023 9236 1689, Farnborough SANDS Baby & Infant Bereavement Group, Basingstoke SANDS 01256 323339
Hertfordshire	St Albans SANDS, East Herts SANDS, North Herts SANDS (Formerly Hitchin SANDS), N.W Middx & S.W. Herts SANDS
Hull	Hull SANDS
Isle Of Man	Isle Of Man Contact
Isle Of Wight	Isle Of Wight SANDS
Kent	Tunbridge Wells SANDS, Thanet Bereavement Support Group SANDS
Lancashire	Burnley & Pendle SANDS, Lancaster & Morecambe SANDS, Preston SANDS - Empty Cradle Support Group, Blackburn & Hindburn Contact, Blackpool SANDS
Lincolnshire	Lincoln SANDS, Scunthorpe SANDS, Grimsby SANDS
London-North	Jewish Baby Bereavement - SANDS
London-South	South West London SANDS
London-South East	Lewisham/Greenwich SANDS
London-West	West London Group SANDS
Merseyside	Bootle SANDS, Formby & Southport SANDS, Chester & South Wirral SANDS 07736 669194
Norfolk	Kings Lynn SANDS, Norwich SANDS
Northamptonshire	East Northants Contact, Wellingborough Contact, Northampton Contact
Northumberland	Ashington Teardrop Multi-Bereavement Group SANDS 01670 852264
Nottinghamshire	Nottingham SANDS
Oxfordshire	Oxfordshire SANDS, Didcot Contact
Shropshire	Shropshire SANDS
Somerset	Taunton SANDS, Yeovil Multi-Bereavement Group SANDS
Staffordshire	Burton & District SANDS, Stafford & District SANDS
Suffolk	Lowestoft & Great Yarmouth SANDS
Surrey	Surrey SANDS
Sussex-East	Battle Contact, Brighton & Hove SANDS
Sussex-West	Chichester Area SANDS 01243 673535
Tyne & Wear	Newcastle Upon Tyne SANDS, Washington SANDS
Warwickshire	Coventry And District SANDS Support Group 0247 626 9160

Contacting UK SANDS

28 Portland Place, London W1B 1LY

UK Office: 020 7436 7940 Opening hours 10.00am - 5.00pm Mon - Fri

Helpline: 020 7436 5881 Opening hours 10.00am - 3.00pm Mon - Fri

Fax: 020 7436 3715

Email: support@uk-sands.org Website: www.uk-sands.org

West Midlands	Solihull SANDS 07890 780433, Birmingham SANDS 01214 345 815
Wiltshire	Salisbury SANDS, Trowbridge & West Wiltshire contact
Worcestershire & Herefordshire	Wyre Forest SANDS 0775 284 5115
Worcestershire	Worcester SANDS
Yorkshire-North	York SANDS, Harrogate & District SANDS 07950 509975
Yorkshire-South	Barnsley SANDS, Sheffield SANDS, Doncaster Womens Hospital 07866 843481
Yorkshire-West	Calderdale & Kirklees Contact, Hebden Bridge Contact, Bradford SANDS, Leeds SANDS, Keighley SANDS
CHANNEL ISLANDS	
Guernsey	Guernsey SANDS
Jersey	Jersey SANDS
NORTHERN IRELAND	
Belfast	Belfast SANDS
Co Antrim	Ballymena & Ballymoney contact, Coleraine SANDS
Co Armagh	Portadown SANDS
Co Down	Banbridge Contact, Newry SANDS
Co Tyrone, Co Londonderry & Co Fermanagh	North West SANDS (NI)
REPUBLIC OF IRELAND	Republic of Ireland Contact
SCOTLAND	
Aberdeenshire	Aberdeen SANDS 01358 701 707, Banff SANDS Fraserburgh & Peterhead SANDS
Argyll	Campbeltown SANDS, Tighnabruaich Contact
Ayrshire	Ayrshire SANDS 01294 323530
Borders	Borders SANDS
Caithness	Caithness Misc, S/B & Neonatal Support Group
Dumfries & Galloway	Dumfries & Galloway Contact
Fife	Fife SANDS 01592 206924, Anstruther Contact
Highlands	Inverness Contact
Lothian	Lothian SANDS 0131 622 6263/4/5
Morayshire	Moray SANDS
Orkney	Orkney Contact
Shetland	Shetland SANDS
Strathclyde	Lomond SANDS, Glasgow SANDS
Sutherland	Sutherland SANDS & Miscarriage Support Group
Tayside	Perth SANDS
WALES	
Clwyd-North	Clwyd North Contact
Glamorgan	Vale Of Glamorgan
Gwynedd	Gwynedd SANDS
Powys	Powys Multi Bereavement Group SANDS
OVERSEAS	
Germany	Germany - BFPO 16, British Forces Germany SANDS
Gibraltar	Gibraltar Contact
Sweden	Sma Anglar (Little Angels)
United Arab Emirates	Dubai SANDS
Malta	Malta SANDS



Editor: Janet Scott

Proof reading: Kate Volker

Design: Ellipsis - 020 7691 2400

Print: Ripping Image - 020 7357 7774

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Charity Registration: 299679

Company limited by guarantee:

No.2212082