AIMS Ireland

Association for Improvements in the Maternity Services - Ireland

AIMS IRELAND SURVEY REPORT

CARE AT A TIME OF LOSS: AIMSI PREGNANCY LOSS SURVEY

APRIL 2009

Association for Improvement in the Maternity Services Ireland (AIMS Ireland)

Supporting Women, Promoting Change

www.aimsireland.com

AIMSI REPORT ON PREGNANCY LOSS AND MATERNITY SERVICES IN IRELAND

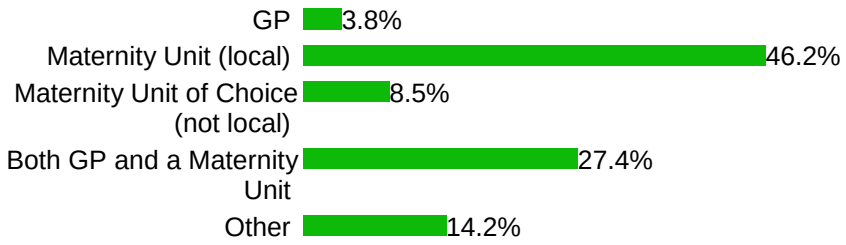
In 2008, AIMSI ran an electronic survey asking women to detail their experience of care around the time of a pregnancy loss: 106 women responded all of whom were self-selecting and anonymous. Access to the survey was via the AIMS Ireland website (www.aimsireland.com) and also via links on a number of parenting websites and forum boards.

CARE AT A TIME OF LOSS: AIMSI PREGNANCY LOSS SURVEY

The ***Association for Improvements in the Maternity Services, Ireland (AIMSI)*** is a consumer advocacy group seeking to improve women's experiences in the Irish maternity system. AIMSI has been contacted by many women regarding services and care around the time of a pregnancy loss. We appreciate that this is a sensitive and emotive topic. AIMS Ireland would like to extend our most sincere condolences on your loss. AIMSI has created this survey to further investigate services received around pregnancy loss. AIMSI believes that the nature and quality of services offered to women at this time is very important. If you wish to share your experiences of the health and maternity services you received around the time of your loss, we would ask you to complete this survey. If you would like to discuss your experiences in more detail, or if you need any further support relating to your loss, please contact AIMSI Support and Information at support@aimsireland.com. Thank You.

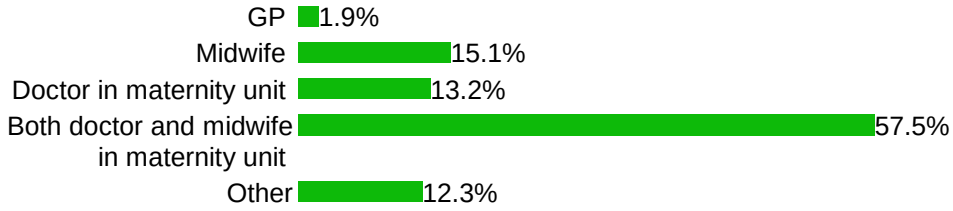
Date Activated	**1/2/2008 – 31/12/2008**
Total Participants:	**106**

Question 1:	**When you suspected you were miscarrying, which care option did you access?**
Number of responses:	106



Question 2:	Who looked after you?

Number of responses: 106



Among those who did not seek services in their local maternity unit, many explained that they were attending another hospital for fertility treatment and therefore attended that hospital. Others learned they were miscarrying at routine scans, which they described as very traumatic. In some cases, several services were contacted over a few days, often with poor communication between services.

Question 3:	How would you describe your care in your own words:

Concerning their care, some women described their experiences as positive and felt they were treated with compassion. For example, one woman explained,

> *"The care I was offered was faultless. I could tell every nurse, midwife and doctor had been carefully trained in how to deal with my situation. Not one person said anything I found offensive or hurtful. I received brochures from the hospital itself and ISANDS. The support service provided afterwards was excellent…"* (p 36)

Conversely, some women had very negative experiences: *"horrific, treated appallingly, wouldn't treat an animal in the same way"*. Some women distinguished between care providers; medical and midwifery care were both described alternately as compassionate and abrupt. The lack of facilities in some services made their experience even worse—especially when this meant being told news with other people around or having to be admitted to wards with antenatal and/or postnatal women. For example, hearing other women's babies' heartbeats was *"truly, truly heartbreaking and I will never forget it"* (p 56). Women describe poor care very vividly—hurried, abrupt, cold, like an interrogation:

"busy loud and impersonal" (p 2*), "I was completely devastated by my stay in hospital"* (p 10)*, "efficient but non-caring"* (p 16). Women described interactions they had with professionals; for example, one woman describes being "told off" by a midwife, while she was miscarrying, for taking home her file. Several women described feeling just like a number, as staff told them that miscarriage often happens, that miscarriage is *"a daily occurrence for them"* (p 96). Women remembered particular healthcare staff responses; for example, one woman recalled *"one nasty doctor who told me to get dressed and then said 'your womb is empty' just like that!! Everyone else was so nice"* (p 99).

Question 4:	**Did you understand the decisions made about your care?**

Number of responses: 106

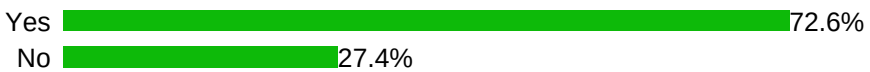
Question 5:	**If you have any additional comments regarding the decisions made about your care please write them here in your own words:**

Regarding the **decisions about their care**, many women were unhappy about the way they were informed about what was happening; for example, one woman said she *"was just having orders barked at me"* (p 2). Again this varied across care providers: *"I understood the decisions made about my care from my own private doctor but the doctors in A&E did not explain anything"* (p 29). Another woman said that she *"went to the EPU [Early Pregnancy Unit] for two visits and found the care and support there excellent"* (p 25). Women understandably were upset and shocked which made it very difficult to take in what was happening:

> *"I should have asked questions but was too upset."* (p 2)
>
> *"I was so upset that everything that happened went over my head." (*p 32)
>
> *"I had to ask repeatedly for information."* (p 49)

Question 6:	**Were you involved in the decisions?**

Number of responses: 106



Question 7:	If you have any additional comments regarding your involvement in the decision process, please write them here in your own words:

Some women were happy about their **involvement in decision-making**

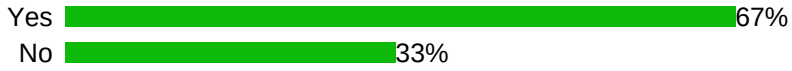
> *"All options were explained clearly and my decision was accepted without question."* (p 32*)*

> *"I felt that all staff—midwives, registrars, anaesthetist, theatre nurses and consultants couldn't have been more communicative and compassionate in their dealing with me. They fully involved me in their decisions."* (p 15)

Others felt they had no or little choice and went along with the doctors' decisions: *"I had no involvement in the decision process. It was simply 'we will admit you tomorrow for a D&C"* (p 38)*.*

Question 8:	Were you given sufficient verbal information?

Number of responses: 106



Question 9:	If you have any additional comments regarding verbal information, please write them here:

Regarding **verbal information,** most women who responded felt that they got little verbal information and mostly only when they asked questions: *"I was given NO information in the maternity hospital, not even the miscarriage book the Department of Health produce"* (p 35). Women wanted to know more about what was happening*: "I'd like to know what's going on instead of being scared of what's happening and not getting any explanations"* (p 33); *"I had to search the Internet to see what was happening and what to do"* (p 18).

Question 10:	Were you given sufficient written information?

Number of responses: 106

Question 11:	If you have any additional comments regarding written information, please write them here:

Regarding **written information**, some women received a booklet or other written information while most who responded to this question did not: *"I was never given any sort of written information or any leaflet on having a miscarriage"* (p 19); "*The one booklet is very clinical and not very caring"* (p 46).

Question 12:	Were you given sufficient time with professionals?

Number of responses: 106

Question 13:	If you have any comments on your time with professionals, please write them here:

Regarding **time with professionals**, many women commented that they felt rushed *"in and out"* (p 1); one woman said she *"was given less than 5 minutes with the doctor in A&E and then sent home"* (p 13). On the other hand, many women described positive experiences: *"The midwives at all times gave us plenty of time to talk through everything"* (p 14); *"I was given so much time and attention in the time I was in the hospital"* (p 17). Some people specifically mentioned that they were in private care when they had positive experiences and good communication with professionals.

Question 14:	Did you have enough privacy during your care?

Number of responses: 106

Question 15:	If you have any comments regarding your privacy, please write them here:

Regarding **privacy**, most women who commented felt that they lacked privacy and had to wait in inappropriate places where people were visiting newborn babies or were pregnant:

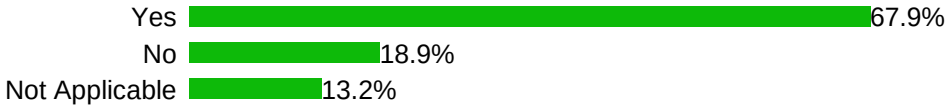
"Although we were in a private examining room, it was on the maternity ward so I had to walk past pregnant ladies and newborns when I knew I was losing the baby I had been trying for, for 3 years" (p 11).

"I was in a public ward with 6 women in labour. This has devastated me and has scarred me for life".

Women were critical of the emergency room provision, while EPUs seemed to offer more privacy. Some women stated that having private care gave them more privacy. Basic toilet facilities were lacking for many women. One woman was on a men's ward due to overcrowding (p 33).

Question 16:	**If applicable, was your support person(husband/partner, mother, friend, etc) able to stay with you during your assessment/treatment?**

Number of responses: 106

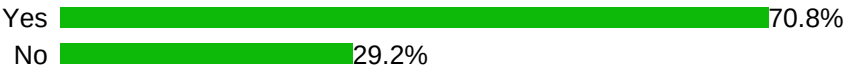


Question 17:	**If you have any comments regarding your support person, please write them here:**

Most women felt that it was very important to have a **support person** with them*: "Yes, my husband was able to stay with me the whole time, which is great"* (p 7); *"He was not allowed in—I was terrified. It was the most unkind thing I have ever had happen to me"* (p 1); *"He was shoved out of the way and into the hall, wasn't told anything either"* (p 32). Many times, not being able to have a support person was related to the lack of facilities*: "emergency room, no partners allowed"* (p29).

Question 18:	**Were you treated with compassion?**

Number of responses: 106



Question 19:	If you have any comments regarding your treatment (compassion), please write them here:

Regarding whether they received compassionate treatment, again there was a wide variety of experiences described by women. Some comments were very positive*: "couldn't have been better"* (p 22); *"my doctor held my hand and hugged me and she was great"* (p 57); *"the admitting midwife offered me her condolences which was appreciated"* (p 56). Some were very negative: *"don't think they know the meaning of the word [compassion]—miscarry in public and on your own???"* (p 2). Some made distinctions between various professionals—in some cases doctors were compassionate and not midwives, and vice versa: *"I was treated with great compassion by my doctor and nurse at my fertility unit; the nurse at the maternity unit was rude, aggressive and unprofessional"* (p 10). One woman commented that female staff were compassionate and male staff were not. Again, moving between services caused some women difficulties:

> *"Doctor on call actually complained that I should have waited until I could get appointment in EPU and that she was very busy, that it was ridiculous my GP sending me in after hours. (My GP had told me to go straight to [hospital] for treatment.)"* (p 21)

Question 20:	Was your pregnancy loss acknowledged appropriately in your view?

Number of responses: 106

Question 21:	If you have any comments regarding the acknowledgment of your loss, please write them here:

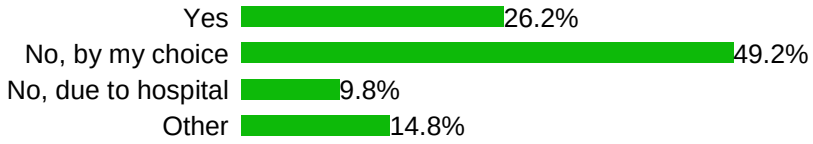
Regarding **acknowledgement of loss**, again comments were mixed. Particular staff were remembered: *"They have a wonderful bereavement nurse who was very good to me"* (p 11). Other women described negative experiences: *"No one came to talk to me about my miscarriage, I was just another woman who had a miscarriage"* (p 23); *"Because it is so common I think the medical profession are blasé about it"* (p 34).

Question 22:	Were you offered any follow up services after your loss? (Counselling, Support Services, etc)

Number of responses: 106

Question 23:	If you were offered follow up services after your loss (Counselling, Support Services, etc), did you use them?

Number of responses: 61



Question 24:	If you have any additional comments regarding accessing follow up services, please add them here:

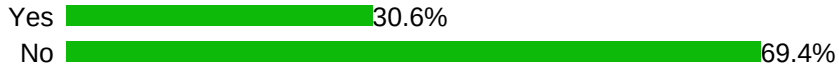
Regarding **access to follow-up services**, women mentioned a range of services they accessed—private counselling, hospital counselling staff, family, friends and Internet-based peer groups. Many people expressed the need for better and more services. Some women who used these services found them helpful, others did not use them as they did not feel able to contact someone: *"More active information giving and follow up procedures for women in this position would be beneficial"* (p 31). Several women mentioned the Miscarriage Association as being helpful.

Question 25:	If applicable, after your experience with pregnancy loss, did you receive reassurance and extra support on subsequent pregnancies? (early scans, tests, counselling, etc)

Number of responses: 106

Question 26:	If you have had more than one pregnancy loss, have you been offered investigation for your losses?

Number of responses: 62



Question 27:	If you have any additional comments regarding investigation for more than one pregnancy loss, please add them here:

Regarding **investigations for more than one pregnancy loss**, women again gave mixed descriptions of their experiences: *"I was told they wouldn't waste resources on me because I had three healthy babies previously"* (p 2); *"They told me to lose some weight and not to bother worrying because I'm only 21, that was after my third miscarriage"* (p 27). Some women were offered investigations but did not take them up. Some had full investigations while other women felt that they would like investigations but were not offered them because they had to wait until they had 3 miscarriages. Some people found this prerequisite very upsetting and not appropriate for them; in this case, some women sought out private investigations.

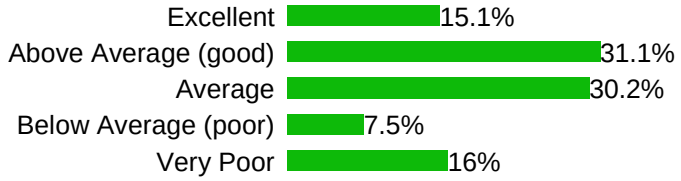
Question 28:	In your view, how could the service you received be improved?

Asked how the **services could be improved**, several points were made—more time for women, better listening, better facilities not shared with pregnant women or babies, the need for a dedicated unit where they did not exist, the need for compassion, for privacy, to have equal treatment for public and private patients, for better written and verbal information, better training for doctors and all staff, better reception staff, better communication between GPs and hospitals. Many of these aspects are captured in the following quote:

> *"The one thing I would like to say to any professionals in the field is that one sympathetic word will go a long way towards making a sad experience bearable, whereas one callous word will devastate an already upset and vulnerable woman/couple. It doesn't take much to say 'sorry for your loss', or to take a few minutes to explain things, and that will go a long way to making a woman/couple feel like a they are a patient being treated with respect and dignity, rather than making them feel like they are an annoyance and part of a long conveyor belt of inconveniences to the professional. I realise of course that I am just one of many, many women they see each week who are losing their pregnancies, and they are*

probably desensitised to a certain extent, but to each of us who are going through pregnancy loss, it is traumatic and a huge deal to us, and it would be good to at least acknowledge that. Perhaps also it could become routine to just book a patient in for a follow-up appointment." (p 90).

Question 29:	How would you rate the care and services you received over-all during the time of your loss?
Number of responses:	106



Question 30:	Final Additional comments:

Further **additional comments** were added by some women. In general women re-emphasised their earlier comments about their experiences, both positive and negative. Their comments reflected the large impact their experiences had on them, with descriptions of the *"deepest hour of grief"* (p 1) experienced by someone miscarrying, the *"sad memories"* (p 24), the *"detrimental effect"* of not adequately being helped psychologically (p 22). On the other hand, women who received good care described how important this was: *"My experience of this pregnancy loss was devastating but I know that the support I received was exceptional and helped me to cope"* (p 33); however, the same woman went on to say that she *"went on to lose a further 2 pregnancies and my experiences were very different"*, showing that quality of care is markedly inconsistent.

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Discussion

Most women accessed their care in their local maternity unit where they were attended to by doctors and midwives. Women had both positive and negative experiences in their interactions with staff. Clearly, hospitals are attending large numbers of women suffering from miscarriage* and the resultant 'desensitisation'

of certain staff to the trauma of the sufferer/s is a cause of considerable upset to the women who responded to this survey.

The majority of women understood and were involved in decisions in their care but with satisfaction rates averaging at around 70%, there is room for improving inconsistencies in this area. Verbal information appears to be good across care-givers but clearly written information is lacking with just over half of women not receiving any material. A sizeable 43% of women who responded also felt they were not given enough time with professionals at their examinations.

The issue of privacy is also a source of concern: 42% of women felt this was lacking both on initial examination and afterwards when, for example, being inappropriately accommodated in wards with pregnant and postnatal women. Surprisingly, 19% of respondents were not allowed to be accompanied by their support partner at this time, adding to the psychological and physical distress experienced by women.

Compassion and acknowledgement of loss by staff are extremely important to women at such a traumatic time and again there is room for improvement here in interactions with women.

Worryingly, follow-up services for women who have suffered pregnancy loss appear grossly inadequate with a massive 60% of respondents not being offered or told about any further support services available to them. Regarding subsequent pregnancies, only 41% of women felt they received extra care and reassurance and for those who experienced further pregnancy loss, only 30% were offered investigations.

Respondents highlighted areas for improvement of which three in particular stand out: facilities, aftercare and communication. Regarding the latter, whilst practical support (e.g. written information) is considered important by respondents, time and again the psychological impact of their experience and how carers interact with them has a huge bearing on how women cope with their loss.

Overall, 30% of respondents rated services around pregnancy loss as average with a further 30% rating them above average. However, with almost 1 in 4 women in this survey experiencing poor or very poor care, service providers in Ireland would do well to re-evaluate their service and inconsistencies therein and work collaboratively toward improving the experiences of women and their families at this difficult time.

*1 in 5 women experience miscarriage in Ireland, approximately 50 miscarriages a day
Source: Miscarriage Association of Ireland. Accessed www.miscarriageireland.ie 16/4/09

Recommendations

Based on the feedback of women in this survey, AIMSI recommends the following:

- Information booklets available/given to women and their families at GP surgeries, public health clinics and maternity units.

- Private examining rooms and separate ward areas for women experiencing miscarriage, i.e. away from antenatal and postnatal women and their babies.

- Further training for healthcare professionals and staff in attending and supporting women suffering miscarriages.

- The publication of a standard procedure and guideline policy document on miscarriage which will outline all steps from initial care procedures through to aftercare and follow-up. This document should also be made available on hospital websites for the benefit of service users and healthcare professionals alike.

- Review of hospital policy for support partners.

- Review of aftercare and support services available to women.

For questions or more information, please contact AIMS Ireland at info@aimsireland.com or visit our website www.aimsireland.com

AIMS Ireland would like to sincerely thank all women who took part in completing this survey. We appreciate the sensitive nature of this topic and greatly appreciate you sharing your experiences for the benefit of improving services in this area.