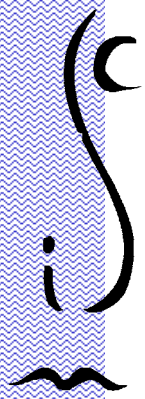
Scottish **C**are and **I**nformation on **M**iscarriage
Providing Therapeutic Counselling for Miscarriage, Stillbirth & Neonatal loss

17th January 2014

Scottish Care & Information Response to Letters in relation to petition PE1443
(Full Response Pages 2-5)

Executive Summary



SCIM agrees with the Scottish Government that guidelines for the medical management of miscarriage are essential. However, we would like a change in current testing guidelines to make care better by offering women a choice about testing. Presently, women are being denied the choice to make an informed decision about their future based on current policy. No one is happy with the current management of miscarriage.

Background

- Current policy means that women have to suffer three consecutive losses before testing is offered (RCOG, 2011)
- There is no moral reason for asking women to have more than one miscarriage before they are tested, should they wish to be tested. (SCIM, 2013)
- Miscarriage affects 5,708 women in Scotland each year (ISD Statistics, 2010)
- There is significant variation on the level of care provided (NICE Guidelines, p27, 2012)
- Women are offered choice around the medical management of miscarriage (green-top guideline No 25). However, women are denied patient choice around testing for the cause of miscarriage (SCIM,2013)

Responses to the committee

- Professor Quenby, a leading authority, agrees that there are insufficient evidence based trials conducted (Quenby, 24th Dec 2012) SCRCOG, and Scottish Care & Information on Miscarriage (2013)
- No respondent has supported the policy of three miscarriages before testing.
- No respondent has offered a medical reason for supporting three consecutive miscarriages in the first trimester before testing.
- Women should be offered patient choice in receiving testing following one miscarriage; Scottish Care & Information on Miscarriage (2013)
- Only 50% of hospitals have specialised Early Pregnancy Units (AEPU, 2009), and this is still true.

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- There is no uniformity in the way miscarriage is responded to which varies according to location or negotiation. There is no support for this situation to continue.
- The women might be treated in accordance with guidelines however this is not always the case.
- Scientific study would assist in offering preventative measures and early intervention for future generations in line with the current Scottish Parliament Policy.

I said in my opening statement to the Petitions Committee on the 27th of November; "this petition is about the people who can be helped by testing, it is not about the ones who cannot". The focus is on offering all women a choice about testing as miscarriage effects 5,708 women in Scotland a typical year (ISD Scotland 2010) and has a distressing effect on women's emotional wellbeing.

"A third of women attending specialist clinics are clinically depressed, and one in five have levels of anxiety that are similar to those in psychiatric outpatient populations" (Rai, 2006)

Our main aim in bringing the petition to the committee's attention is to highlight the devastating emotional effect that the current guidelines have on women. The pre-counselling evaluations that women complete before they begin therapy with us show the traumatic effects of miscarriage. This is also backed by research into Women's Perceptions of Counselling Following Miscarriage (2007) and we also regularly hear about the effects that this policy has during our counselling sessions with clients who are referred to us by the NHS through their GP, health visitor, Early Pregnancy Unit or Mental Health Units. These referrals come from all over Scotland.

Since SCIM was set up in 1994 we have had the best all round care for women in Scotland. This includes links with and regular referral to Early Pregnancy Units (EPU), GP practices, Women's health centres and other appropriate services through the web and try to maintain regular contact with. We offer links to The Association of Early Pregnancy Units and NHS Maternity Services. Most recently we have spoken with Rosslyn Crocket (Director of Nursing), mental health clinic staff and medical/midwifery staff from various hospitals in Scotland.

With reference to the replies the committee has received, it is reassuring for us to read that all of the groups, who were consulted, acknowledge the need for proper professional counselling support. Also that this is carried out by specialised qualified counsellors and that this type of emotional support is recognised as being essential in offering support to families who have suffered miscarriage. This is backed by Dr John Duncan (RCGP) who agrees that psychological support improves pregnancy outcome. His letter recommends that GPs offer counselling to women following one loss. It is encouraging to hear, in Dr Duncan's 2nd letter to the committee, that GPs receive comprehensive training which is

ongoing in its development and that their overall intention is to offer patients the best care following miscarriage. However, I stand by my original comment that according to our client group, the recommendation to offer counselling and provide information about support groups is seldom practiced. This is backed up in Dr Mack's response, on the 4th of October on behalf of the RCGP, when he refers to GP training on miscarriage. He states that there are no records of the number of GPs taking the course and that it does not function as a measure of preparedness in dealing with miscarriage anyway. Dr Miles also states that GPs have an individual choice as to whether they engage in learning about miscarriage or not. Most worryingly there is no specific learning course about miscarriage. Perhaps with the RCGP's reminder about the importance of supplying such information to patients the practice will become more of a reality than an expectation. As an award winning training centre we would invite GPs to take up our training on miscarriage which is based on qualitative research, 19 years of face-to-face client work, and evaluations with women and families who have suffered loss.

One of the doctors refers to TLC (Tender Loving Care) that is a critique of organisations that offer tea and sympathy. This has never been our position. We want the very best possible guidelines. It is more than TLC that is necessary.

Our experience in working therapeutically with women and couples who have suffered miscarriage, stillbirth and neonatal loss is that they make a good emotional recovery when given access to professional services. This assists them in preparation for their future and good emotional health in the longer term. However this requires regular engagement, not just a quick fix. The idea that information leaflets and direction to website information is the solution matches more with a DIY approach to the management of miscarriage than proper professional care.

It is also a relief to hear that over the last two months the Scottish Government's statement of good practice on the management of Early Pregnancy loss (1996) which places considerable emphasis on the human element in medicine, be reiterated to hospital staff by Dr MacLean. This is a document in which The Scottish Government acknowledge the contribution made by SCIM. I feel confident that Dr MacLean also restates the Scottish Government's recommendation that SCIM's contact details be given to couples seeking counselling support.

Through, the Scottish Qualifications Authority (SQA), we have also provided regular counselling skills training to midwives in units such as Ayrshire Central and Wishaw General. As an award winning training centre we currently offer specialised counselling skills training to university counselling students.

From a medical point of view the responses from four different organisations SAEPN, AEPU Executive Committee, Tommy's and the BMA demonstrate with our point that there is no uniformity in the way miscarriage is responded to medically. I can only reiterate some of the examples given by the medical profession: only 50% of the hospitals have specialised EPU units in place while others do not, some hospitals offer testing after 2 miscarriages while others do not. Surely it should not be left for women to negotiate for themselves especially when they are in such a vulnerable state.

Our experience, from a professional therapeutic counselling point of view, shows that this random approach is unhelpful in clearly identifying the cause of miscarriage and it is unsupportive in terms of emotional recovery. The arguments put forward are circular. Scientific study which can be shared and built on is what would be the most helpful for women in the longer term and of course would assist in offering preventative measures and early intervention for future generations in line with the current Scottish Parliament Policy.

We would like to see standardised testing for women who have suffered miscarriage with a view to creating the facts on which proper study can be based, in an effort to relieve some of the anxiety that the existing policy causes. The idea that the cause of miscarriage is random or chance, argues the need for testing. As does Dr Duncan's point that current testing only identifies a cause in a minority of cases, and that somehow a minority of cases are not enough to merit proper care. The lack of proof is a point that is clearly recognised by Professor Quenby, Professor of Obstetrics, who agrees that there are insufficient evidence based trials conducted. This statement is also backed by the SCRCOG who state that, the incidence and relevance of investigations following one miscarriage is not well established and that a proper evaluation of miscarriage management after one loss is essential. A statement of reassurance that is contradictory does nothing but confuse and upset women further, the idea that you ***have to suffer consecutive loss before*** you are offered testing as unkind as it is unscientific. Dr Duncan's idea that offering investigation to examine the cause of miscarriage would somehow cause women greater anxiety is paternal to the point of insulting.

According to the Green-Top Guideline No 25, women are offered choice around the medical management of miscarriage. It states that; ***"women with miscarriage who choose their own treatment, had the best health-related quality of life"*** How can choice be therapeutic at the most traumatic time for the patient, but choice over testing not be therapeutic? We would like to see this more personalised approach to patient choice extended to testing.

Dr Mack refers to Dr Duncan's response and states that it would be wrong to test patients unless there is evidence of benefit but without saying how that evidence is to be obtained. The tests exist and are desired by some women. The final consideration that needs to be taken into account is that the findings of those tests will convey information on the benefits of testing and offer potential guidance from the results gained, for the future.

In response to the Scottish Government's reply in support of the RCOG Guidelines for investigations and treatments following miscarriage, the scientific evidence referred to currently excludes woman who have less than three consecutive miscarriages. Therefore, the guidelines are only based on very limited evidence, we would ask again that this is recognised.

We would agree with Dr Mack that from the patient point of view it is important that their needs are met and responded to; but current guidelines do not allow individual women to be responded to in the way that they would prefer. We also agree that an individual patient's response to miscarriage can vary, this means that not every woman would want

to have testing carried out. With reference to Dr Mack's letter of the 18th of December, we are not asking the Health Service to refer patients for testing; we are asking that women are able to access testing. We are requesting that the patient has a right to ask for testing following a single miscarriage. Mr Froggatt refers to patient-centred health care as being "mutually beneficial partnerships between the patients and those providing healthcare." If this is true then why, when women ask to be tested is their request being ignored? This is not beneficial in terms of developing an effective doctor-patient relationship, as the patient is not being treated holistically. The patient's preferences and expectations are left unsupported, which has a devastating effect on women's healthcare, especially in future pregnancies. From the doctor's point of view, this approach is not empirically supported nor does it establish a commitment to quality within the area of miscarriage treatment.

It has never been SCIM's position that the tests are compulsory. It is unusual in any case for testing to take place without the consent of the person taking part. As I said earlier my argument is not for women who do not want to have testing; it is for the women who specifically are asking to be tested. It is the effects of the lack of response to their needs that leaves woman emotionally exhausted and excluded.

SCIM would also agree with the Scottish Government that guidelines for the medical management of miscarriage are essential in providing good post-miscarriage care across Scotland however we would like a change in the current testing guidelines to make that care better.

The 1,184 people who signed our petition agree that there should be a change in policy. The current policy is unacceptable as it only delays finding medical reasons for miscarriage. This policy condemns some women to the trauma of miscarriage over and over again. Change would mean that fewer women would have to go through that.

There is no question that it would greatly assist women in Scotland if in reviewing this policy the committee were to exercise its remit and urge the Scottish Government to change this policy in favour of the women in Scotland in 2013 who may suffer miscarriage like the 5,708 women in Scotland who suffered miscarriage in 2010.

Yours sincerely,

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