

# Beyond “His Sisters and His Cousins and His Aunts”: Discourses of Haemophilia and Women’s Experiences in New Zealand

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During an interview in 1995, a woman who experienced bleeding problems struggled to find words to explain to me her doubts about her own femininity. As the daughter of a man with haemophilia, she had been brought up to believe that only men had haemophilia. Yet she experienced haemophilia-related bleeding problems and therefore, she reasoned, she must be partly male or incompletely female. When I turned off the tape recorder she added that she felt “like a woman in a man’s body”.<sup>1</sup>

Medical discourses of haemophilia as a men’s disorder were so powerful that in 1994, when colleagues and I began a New Zealand-wide study of living with haemophilia, an X-chromosome-linked coagulation disorder, we were not prepared for the nine (out of 193) returned questionnaires completed by women with disabling bleeding problems.<sup>2</sup> We had understood that women were “only carriers”, although we had learned that a few might experience “mild bleeding problems”. As the mother of a little girl with serious bleeding problems complained in 1995, “It stipulated categorically on the first page of Jones’s<sup>3</sup> book that females couldn’t get it”. Subsequently, through our participant-observation at haemophilia events, especially the [then] annual camps, and in our travels around New Zealand to interview eighty individuals and families with haemophilia, we met and heard about many more women who experienced disabling bleeding problems. These women did not usually classify themselves as having haemophilia. They had been taught to use the terms “expressed” or “symptomatic carriers”. Yet, five years later, as described below, even elderly members of the haemophilia community had begun to question this positioning of women in haemophilia discourses.

As sisters, cousins and aunts, grandmothers, mothers and daughters, wives and girlfriends, women have provided a chorus of support to the male leads. This supportive work is crucial and highly valued in the haemophilia community. However, in this paper I concentrate on three other aspects of women’s experience of haemophilia: women as persons who bleed, as persons who may “carry” the genetic mutation that causes an interruption in the blood clotting process,<sup>4</sup> and as persons who are caught up in the new technologies of prenatal genetic testing. My purpose is to explore the interconnections between women’s experiences and the multiple and changing discourses of haemophilia, and especially to analyse discourses “to demonstrate the process by which biology and culture interact in the social construction of disease” (Lupton 1994:18-19).

Discourses of masculinity prevalent in New Zealand de-emphasise men’s reproductive responsibilities, as in the colloquial “She got herself pregnant”. They conspire with the biology of haemophilia to further de-emphasise men-as-carriers because of the characteristic leaping of a generation of this disorder if women as bleeders are discounted: it is men’s grandsons who have haemophilia (Park 2000). Although about one third of women carriers are estimated to have bleeding problems, these are usually less serious than men’s.<sup>5</sup>

## Bleeding

Until the mid-1990s, women with haemophilia-related bleeding problems often had difficulty in getting adequate treatment when they had to move outside their known circle of medical specialists because, as Ross (1997:5) described for Australia, “no-one believes they have a bleeding problem, especially not one called haemophilia”. Non-specialist doctors often dismissed women’s bleeding problems because of haemophilia’s exclusive association with males. Haemophilia is rare (1:5000 male births), many doctors and nurses never have to treat it, and little time is devoted to it in the crowded curricula of their degrees. Ironically, women most often experienced difficulties with minor things, like having a boil lanced, whereas more major surgery, which was usually carried out in large hospitals with familiar specialists and blood products available, did not usually present such problems.

Only a tiny minority of women had severe problems with bleeding, but this rarity caused even greater difficulty for them. The mother of a young girl whose “expression” of the haemophilia mutation lowered her clotting factor to less than one percent of normal (i.e., severe haemophilia)<sup>6</sup> had had a difficult time initially, both in getting information and in obtaining services for her daughter’s bleeding:

There are so few women and girls recognised as having haemophilia that everything is very male orientated... I find it a bit frustrating.... My daughter doesn’t realise that she’s the only girl [with severe haemophilia], and it’s going to be hard for her when she does realise that. (Questionnaire response 1995)

Invisibility, isolation and disconfirmation of their experiential knowledge of haemophilia were shared by most of the women with bleeding problems whom we

met. Because these women were few in number and scattered around the country, they did not even have the comfort of knowing that they shared this experience. This became very apparent during our interviews in 1995. One young woman in her late teens said, “I really don’t know how to describe the isolation. If you had other women to talk to and could say, ‘What’s it like for you, and how do you feel when this happens?’”. When we offered to put this person in touch with the woman whose remarks introduce the article we found that both leapt at the opportunity for mutual support and discussion.

Because the existing discourse excluded women as bleeders, a few women had doubts about their own femininity, as in the opening quotation: “I am different, I can’t describe it, different to other women”. The younger women were unsure about what it really meant for them, especially in regard to having children. A woman in her thirties who had a partner, but who had decided not to have children, explained her decision:

“I didn’t want to go through what I imagined would be fearful childbirth. So I decided way back that a family wasn’t for me... [but] perhaps way back, had I the right contacts and reassurance, my life may have gone in a different direction.” (Interview 1995)

Even in the 1980s, women had been offered hysterectomies when they were in their teens or early twenties: A mother told us in 1995, “Doctors wanted to give her a hysterectomy when she was fifteen and she told them she was not even sexually active yet and it was too big a decision to make at her age.” A few women eventually did have hysterectomies, often after one or two children, because the almost constant (up to three weeks long) heavy periods led to anaemia and other problems.

Over the latter part of the 1990s and into the 21st century, the value of contact between women with bleeding problems, the seriousness of bleeding problems for women, and other women’s issues, gained much more attention (e.g., Huszti and Cooksey 1996, Paper 1993, Ross 1997). This was true in the international haemophilia community, as reflected in the programmes at successive World Congresses,<sup>7</sup> and in New Zealand. At national haemophilia camps and in the HFNZ<sup>8</sup> Newsletter, *Bloodline*, women’s issues were on the programme. Women expressed great satisfaction at what they learned from sharing their knowledge and experience with others. Through these sessions many more women realised that they too had bleeding problems. By the end of the decade they had learned that their bleeding could be treated and that they had a variety of options. In 1999, during a family interview, a woman reflected:

“Knowledge is empowering, isn’t it. And just the sharing. There was one woman there [at the camp a year before] and we talked about it afterwards,

this woman and I, and she said that when she has her periods—I didn’t realise the other woman had it too—she’d actually have to call out for her husband to pass her a towel.... And you realise that there are other women out there who have that predicament.”

I suggest that the general silence about menstruation among generations of New Zealand women (Smith 1991:91) contributed to the silencing of women with haemophilia in their monthly struggles with prolonged and heavy bleeding, and that the silence was exacerbated by the focus of attention on men’s pressing needs, especially in relation to the trauma of the blood-borne disorders. Women had accepted the bleeding and bruising that was a result of their having reduced clotting factor levels as normal, something they had to put up with. This can be seen as a further example of the discourse of stoicism: “you just get on with it” (Beasley 2003:172), expected of and espoused by Kiwi women. These values influenced the “local biology” (Lock 2001) of women’s experience of haemophilia.

A woman who had read our initial report told us after a meeting in 2003 how much she had enjoyed reading about “carrier women”, as “that issue had been swept under the carpet.” Growing up she had always been “the sister” to her brothers with their bleeding crises and now she was “the mother” of a boy with haemophilia. Despite low clotting factor levels she was not a person/patient in her own right, no one paid her any attention, nor did she think of herself as someone who might need looking after. In hindsight she was horrified about what might have happened during her home births: haemorrhages and intracranial bleeds.

Occasional problems of access to treatment for girls still persisted at the end of the century, as a mother of a haemophilic boy discovered when she took her concussed daughter to hospital. In the emergency department they were asked about family history (from an interview in 1999):

“Yes, my son’s a haemophiliac.”  
 “She’s a girl. It only happens with boys, you know.”  
 “Yes, I know, I’ve got a haemophilia boy.”  
 “Well, what are you worried about?”  
 “Because she has undiagnosed possible carrier status and carriers also have lowered levels of Factor Eight.”  
 “Oh no, but it only happens to boys.”

Despite the mother being confident in her own knowledge, she and her daughter were “dismissed” by the doctor who knew that only boys bled. Thus while women’s increased confidence in their knowledge was empowering in most contexts, it was not always enough to get them (precautionary) treatment: testament to the power of medical discourse. However, dismissal

was perceived as becoming less of a problem by some women, because “young doctors are trained to listen”.

An elderly gentleman member of the haemophilia community said in 1999:

“I hadn’t thought about it before but both men and women did *carry* haemophilia and maybe we should be thinking about both men and women *with* haemophilia, although it affects them both in different ways.”

Later that year in an interview, a woman who was a mother of children with and without haemophilia said, “...it’s not just the boys that are bleeders, they are also carriers.... For years... it has been known that the man with haemophilia will carry it to his daughter, and yet that’s not discussed. And the automatic blame that the woman has to carry.”<sup>9</sup>

At the beginning of the 21st century “men are bleeders; women are carriers” was no longer the only discourse of haemophilia. A more nuanced view of women as potential bleeders and men as carriers was being promulgated in the haemophilia community in New Zealand and internationally. While the focus remained on the men’s bleeding, many more of whom are affected with severe and moderate haemophilia, women’s voices and issues were more often heard, in the time and space created by the waning of the devastating epidemics of blood-product related HIV and then Hepatitis C.

### Being a “Carrier”

Rather than a girl or woman being “just a carrier”, I suggest that “carrying”, irrespective of personal bleeding problems, is an important aspect of women’s personhood with its own challenges and dilemmas. Questions concerning carrier status and its implications for motherhood were very much to the fore for women. Most families were inclined to tell their obligate carrier daughters early, so that they grew up “always knowing”, although as the girls grew older their understanding of the implications would deepen. Discussing the imparting of knowledge, many parents compared their enlightened approach with the lack of information and confusion in earlier generations.<sup>10</sup> As long as the parents understood genetic inheritance well enough and passed the information on, girls and young women in the families of men with haemophilia did not experience uncertainty about their status.

“But we’ve explained it all to her and she’s actually done a study, a disability thing [for a school project]. We’ve sort of said to her that you don’t need to say you’re just not going to have kids ‘cos they might be bleeders. She understands that there is a chance that they might not be. But I think they’ve accepted it, they’ve grown up with it.” (Interview 1995)

Not all families agreed with this approach. For example a man with haemophilia, interviewed in 1999, explained that his wife was opposed to talking to their ten year old daughter about her obligate carrier status and its implications and had felt under pressure during a women’s session at the haemophilia camp. His view was that over time his daughter would understand what it was all about through helping her father with his treatment and attending haemophilia functions. At her age, he said, she was more interested in getting a black and white fluffy cat than in what might happen if she had a male child!

The daughters of mothers who inherited a haemophilia mutation are in a different, uncertain, situation. Statistically, half of the daughters of carrier mothers will also be carriers. Although there was some difference of opinion between families, and strongly held beliefs about the best time to have the girls of female carriers tested and the best time to explain the results to them, the majority favoured a relatively early age so that the girl slowly became aware of her status. Some felt very strongly that it was irresponsible for parents to allow their daughters to reach the age where they could have children without having their carrier status tested.<sup>11</sup> However, by 2004, several parents explained that regulations concerning informed consent were often interpreted to mean that parents could not have their daughters tested for carrier status until the girls were old enough to give informed consent.

Carrier testing of children is recognised as a complex issue in bioethics discourse. On the basis of his review of international and United Kingdom guidelines, Shenfield (2002:271) concluded that there “should be a presumption against testing young children for carrier status”. However, if a young person understands the implications and clearly consents, their informed choice to test or not should be respected. This may occur before the legal age of consent, if the test of Gillick competence is met.<sup>12</sup> A British Medical Association report (2001, cited in Shenfield 2002:271) on these issues found that genetic testing of symptomatic children or of children who may benefit from preventive treatment is generally supported. It therefore seems that where there is reason to suspect the baby or young girl has bleeding issues, carrier testing could be authorised by parents.

One father whose wife was a carrier put forward a less usual viewpoint in 2004 during a discussion with other HFNZ members. He wished to have his young daughter tested because if she were a carrier he would think very carefully about bringing other children into the world who might have haemophilia. Until that date I had heard only men with haemophilia, whose daughters always are carriers, expressing similar perspectives about bringing carrier daughters into the world, and even then that was very rare. More usually this perspective was voiced by mothers about boys with haemophilia. The validity of the father’s reason for having a daughter tested was hotly

disputed by some in the group, but others agreed that it was at least worth thinking about. Bioethicists and physicians do, of course, consider family responsibilities and family dynamics in these complex decisions about testing of young potential carriers but the individual child's best interest is the main criterion. Shenfield (2002:270) summarises the bioethical consensus that: "children should not generally be used as a means for others to attain their goals".

Most parents made a point of bringing up their daughters with a matter-of-fact understanding of haemophilia, whether or not they were carriers; often in contrast to their own upbringing. As a result, many quite young girls were well informed. At a haemophilia camp in 1999 two little girls of about seven were playing on the playground slide and chatting: "Well, I'm a carrier of haemophilia and that means if I have boys they might have haemophilia." Her friend said, "Is that mild or moderate?" The implications of this knowledge will grow as they grow, but it seems likely that those two young women will take their carrier status in their stride.

Despite this trend, throughout the decade there were still young women well into their twenties who either did not know their carrier status or who had it confirmed only by giving birth to a son with haemophilia. When one such young woman learned she was a carrier, her whole family were tested. As she said, "Everyone started learning". At an education session in 1999, a haematologist advised women to have their factor levels and genetic studies completed before becoming pregnant, preferably well before, because the process could take several months. Some participants in our research found that it had taken years.

These women whose carrier status could not be confirmed in the usual period of a few days to a few months had particular difficulties. They were usually women whose inherited mutation was not one of the readily identifiable ones or women with no family history for whom the mutation had yet to be isolated. Occasionally, the delay was because the samples provided were not satisfactory. As one woman in this waiting situation said, of all the issues she faced with haemophilia "the uncertainty is the main problem". For this woman, who had difficulty in conceiving, the information about her carrier status was crucial to her plans for another pregnancy. In another instance, although the mutation had not been identified, both the woman we interviewed and her sister had children with haemophilia, so their carrier status was indirectly confirmed. A few women (estimated as around ten percent of carriers) may never know their status, although they can have a "bleeding time" test for their own bleeding issues. They are advised to proceed as if they were carriers, so that, for example, if they are in labour a boy baby will be treated as if he may have haemophilia, thus avoiding intracranial bleeds. However, this advice does not help women and their partners trying to plan families.

Women who were confirmed carriers had a number of specific needs: for information; for emotional support as they struggled with the implications of their status; and for medical support, including the possibility of prenatal tests if they became pregnant. The need for support could surface again, if a carrier became the grandmother of a boy with haemophilia. Some grandmothers felt guilty to see their daughter, son-in-law and grandson coping with haemophilia that they believed they had inflicted on them. One daughter explained, during an interview in 1995:

"My mother blames herself. She really blames herself, thinking if she didn't have me and if she had known she was a carrier, she wouldn't have had me and she wouldn't have had kids, and I wouldn't be putting [my son] though this. But she blames herself completely."

Although the focus of attention about having children remains on women carriers, partners are of course involved in the decision. But, as one of the carrier women explained, husbands tend to see it as the wife's choice because "it would be you that would be having ultimate responsibility [for the child]".

### Testing Times

Deciding whether or not to have a child, whether to carry a pregnancy to term and accepting that a particular child is likely to have haemophilia is a complex matter for women and their partners (Park 1998). Prenatal testing plays a role in this. The most frequently used test is chorionic villus sampling (CVS), which has been used in New Zealand since 1989 (Van de Water *et al.* 1991).<sup>13</sup> Most women were aware of prenatal testing and had a range of deeply felt experiences and views on the subject. By mid-1999, 18 pregnant women in New Zealand had undergone CVS for haemophilia. The rate had fluctuated between zero and three tests per year. As a result of these tests, three pregnancies with male foetuses with haemophilia had been terminated, but all three carrier females had been carried to term (Berry 1999).

In the 1994-95 research, most women saw the link between taking the test, getting a positive result, and terminating the pregnancy as so strong, that they did not want to have the test at all (Park and Strookappe 1996). And indeed, all three decisions to terminate occurred before 1994. Between then and 1999 all the male foetuses were normal (Berry 1999). Opposition to abortion was seldom on religious grounds. More frequently the idea was that with children "you took what you got". An additional consideration for parents who already had children was "What message are you giving to a child with haemophilia if you abort the next?"<sup>14</sup> "Doing something with the results" was experienced as a great burden by some women. To avoid it, an apparent solution was to avoid the test, but

because the test is available not having a test is also making a choice. This inescapable incitement to choose is an artefact of the technology of genetic testing and neo-liberal discourses of choice and responsibility. In this context, "taking what you get", rather being construed as an ethical and stoic acceptance, can be criticised as a refusal to exercise consumer choice, as Strathern (1992:34) indicated. The minority of women or couples who had had a prenatal test did so mainly for two reasons: to prepare themselves for having a child with haemophilia (or not), or to help them decide whether or not to terminate the pregnancy.

By 1999 prenatal testing appeared to have won somewhat greater acceptance, but the dilemmas and pressures and individual differences were still the same. A woman with one boy with haemophilia accepted the offer of testing when she unexpectedly became pregnant. Although counselling advice suggests that one should be well along the decision-making path before getting the test results, she said that she had found it impossible to make a decision without the results in front of her. Women in similar positions in other countries concur (Gates 1994:191). While some women believed that costs of life-long haemophilia treatment motivated tests, and therefore women were under pressure to abort, other women's experience had been of complete acceptance and support by their specialist when they had the test to prepare themselves for their new baby, even when they had declined abortion from the outset. There were also some women who refused, or would refuse, the test because they did not want to be in the position of making a choice about termination. However, this decision, too, was not taken lightly, as the internal dialogue shared by a mother of a child with haemophilia indicates:

"[Prenatal testing] is a really difficult one, because I find that quite a conflicting question. Part of me says, 'Yes, I should know whether I was having another haemophiliac child'. I would NOT abort, either way. I don't believe in choosing the perfect baby – 'Oh, this one is not good enough, I'm going to get rid of it'. I'm sorry, that really does not sit with me at all. I think if you're given the baby then you live with what you've got." (Interview 1999)

This woman went on to say that she had debated the issue with her sister and her father. Her father is "one of those very straight and strict [men], he said 'people who have defects, genetical defects, should not breed', basically is what he said".

To terminate a foetus with a costly disorder in order to spare resources is described by Harper as "particularly unsavoury". Harper advises that while attempting to prevent pain and suffering and to allow reproductive choice should be the aim of testing programmes, the consequences for children born with the disorder should also be considered, especially the evaluation of testing

programmes on the basis of numbers of affected babies born (Harper 1997 in Shenfield 2002:271).

In making their decisions, women assumed that adequate treatment in New Zealand for people with haemophilia would be available into the future at little financial cost to them, and, especially by the time of our 1999 update study, people were more confident that many of the risks of blood-borne viruses would be overcome through the use of recombinant clotting products, which are not derived from blood, and eventually through gene therapy. As a result, most women we spoke with did not regard even severe haemophilia as a life-threatening disease, e.g., a woman talking about accepting a baby with haemophilia said, "Maybe it's easy for me to say because haemophilia isn't an incredibly severe condition". However, this view was not universal. Two Dunedin carrier sisters lobbying the Government to implement preimplantation genetic diagnosis were reported in a newspaper article as saying they would never knowingly bring a child with severe haemophilia into the world, even with current and new treatment options, because of witnessing their father's suffering (Wane 2004).

Prenatal tests shape the experience of pregnancy and maternity for women (Lippman 1994:21). Some research suggests that women delay their commitment to the pregnancy until after the procedure, creating what Rothman (1994) has called a "tentative pregnancy". The opportunity to test may be experienced as burden as much as choice, and that choice is always partial and contextual, as the lives that the affected mother and child will lead are shaped by the culture and political-economy of their society. Medium term anxiety and discomfort and a higher rate of spontaneous miscarriage are well recognised, but research in Sweden has identified prolonged depressive reactions following testing for some women with pre-disposing factors (Tedgård *et al.* 1997). In addition, women carriers and their spouses experienced terminations as very emotionally painful, and many women experienced depressive moods even years afterwards (Tedgård 1998). Whatever the outcome, detailed research indicates that prenatal genetic testing is a "major psychological and social event for women" (Black 1994:286).

Hall *et al.* (1998) point out that assessing the benefits and costs of genetic testing and selective termination is particularly difficult, as these go well beyond the individual being tested. Indeed, for the testing to be possible, "family members" outside the nuclear family of the patient will be asked for blood samples. These "family members" are strictly biological kin. Genetic testing works against some contemporary understandings of family and relationships as being fluid and flexible, and may even be an instrument for connecting up erstwhile separated parts of extended families as "real" genetic relatives are sought for blood samples, or branches of families reconnected based on a shared,

rare mutation (Finkler *et al.* 2003:408-9). Such testing reimposes kinship as a natural fact, while simultaneously showing up reproduction as a technical procedure.

Whereas in our initial study members of the haemophilia community seldom mentioned the effects of increasing numbers of people with haemophilia on treatment services and on health expenditure, there was mention of these issues by the time of the update study. HFNZ has counselled its members to think carefully about having more children and to consider the broader issues involved. Individuals also raised these issues in interviews and discussions.<sup>15</sup>

These are painful subjects, made more so by the assumption that decisions to use genetic testing and other new reproductive technologies are really only the business of those couples or women using it. Genetic counselling, in which relationships with the wider family and community are explicitly excluded, is a good case in point. One of the roles of the genetic counsellor is to present the information about choices and consequences in a neutral manner and to try and ensure that the couple do not come under undue pressure from any quarter, so that they can make up their own minds (Rapp 1991:385). What constitutes the relevant information to be presented by the genetic counsellor to the couple does not necessarily or ever include extended family or community concerns. Yet, as Finkler *et al.* (2003) describe, in genetic testing, the family, not the individual, becomes the patient. In addition, genetic counselling at pregnancy is far from the best time for this kind of information to be shared. The increase in discussion of these issues within the haemophilia community is therefore very helpful in creating a context for decision-making that is more informed than the individual consumer choice model that constructs prenatal tests for inherited disorders in atomistic terms of “what parents want”. Absent from this model, and from much bioethics discourse, is a concept of parents as citizens with rights and responsibilities and moral claims on one another based on the mutual interdependencies of a citizenry (Sharp 1994:247).

Scholars have analysed several overlapping discourses of genetic testing (Rapp 1993). Rothman (1994) points out that women’s dilemmas about testing tend to be medicalised and trivialised in counselling and academic discourses by being couched in the psychological language of personal “anxiety”. Yet when these same issues are debated by ethicists or lawyers they are hailed as major moral issues of our time (Rothman 1994:268). While recognising that prenatal testing can cause suffering for the women involved, I suggest that mental health discourses should not obscure women’s work as decision-makers who address major moral issues and shape future contexts, alongside bioethicists and law-makers.

## Conclusion

In this paper, I have acknowledged women’s highly valued work as carers, but have concentrated on other aspects of their personhood. I have described increasing recognition within the haemophilia community that some women have bleeding problems requiring treatment and precautionary measures. Their ability to voice and share their experiences as bleeders has, in turn, affected those experiences in a positive way, and at the same time, has created a new space for “women with haemophilia”. During the same period, several dimensions of women’s experience as carriers of haemophilia, in addition to their bleeding problems, have attracted attention. Rather than carrier status being imagined only as a breathing space between the generations, women as carriers are now more recognised as having their own specific needs and, more tentatively, as actively engaged at the forefront of decisions about genetic testing. Testing, whether for carrier status or for prenatal diagnosis, has implications for the individuals involved, for families and for wider society in the ways we think about kinship, reproduction, ethics and human worth.

Despite these considerable burdens, the women I have written of would not appreciate being overly dramatised as moral pioneers, so I conclude with a light-hearted tribute, drawn from Gilbert and Sullivan, which perhaps endorses the value of stoicism but not silence. There is no doubt that these “ladies who can smile so brightly” would be welcome anywhere.

## Notes

1. My paper is offered as a tribute to Ann’s contributions to understanding the lives of women in the communities in which she worked. In addition to this academic focus, we share a love of Gilbert and Sullivan, and of cats.
2. The 1994-95 research group was Julie Park, Kathryn Scott, John Benseman and Elizabeth Berry, see Park *et al.* (1995). There are estimated to be 400-500 men with haemophilia in New Zealand, and about three times that number of carrier women. The initial postal questionnaires were completed by 193 people and these were followed up with eighty interviews. The 1999 update research was done by Park and Scott and consisted of (mainly) telephone interviews with thirty people. From 1994, we have participated in meetings, camps, conferences and social events with members of the haemophilia community.

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3. Peter Jones is a UK haematologist who has written well-received guides for lay people as well as many academic articles. This particular book is Jones (1995). On p.5, Jones says that women will have haemophilia only if a man with haemophilia mates with a woman carrier. He uses male pronouns and referents throughout, but he does not explicitly say "females can't get it".
4. Men too carry the gene—to *all* of their daughters who are thus known as "obligate carriers". As they contribute their Y chromosome to their sons, none of their sons are carriers.
5. Because women have two X-chromosomes, their other X usually modifies or suppresses the expression of the X-chromosome with the haemophilia mutation that they inherit from their father with haemophilia or their carrier mother, protecting most of them from severe bleeding problems. However, often this protection is partial, as part of the non-affected X shuts down.
6. Haemophilia is classified into "severe", "moderate" and "mild", based on the amount of clotting protein produced, and into two types: Factor VIII for Haemophilia A or Factor IX for Haemophilia B, depending on which particular protein is low or missing. "Severe" is less than one percent of normal, "moderate" between one and five percent and "mild" from five to twenty-five percent. Because the type and degree of severity is controlled by the specific genetic mutation, the type and degree is inherited in families. Women who have less than about fifty percent of normal clotting factor may experience bleeding problems (Kelley 1999:397).
7. For example, at the 2004 World Congress in Bangkok, several presentations related to attempts to ascertain the prevalence and exact causation of women's bleeding problems (Lee and Kessler 2004:3).
8. When we began our research the haemophilia community organisation was the NZ Haemophilia Society (NZHS). It was reconstituted as the Haemophilia Foundation of New Zealand (HFNZ) in 1998. For example, *Bloodline* 32(1) 2005, out just as this goes to press, contains a preview of a "Young Woman's Workshop Weekend" and a report from London on "Women's Bleeding Disorders and Haemostasis".
9. Women carry the gene, carry the baby, carry the blame and carry the responsibility for caring.
10. In some families, parents did not know that all daughters of men with haemophilia would inherit their fathers' X chromosomes, and one older man swore he had been told by a doctor that he "could not pass it on".
11. Carrier testing is done on blood samples: either by an assay of the level of the women's Factor VIII or IX (a much less accurate method) or by DNA analysis, either of markers associated with the haemophilia gene or directly by comparing the factor gene of the woman with that of a man with established haemophilia (Kelley 1999:243-44). A clotting time or bleeding time test will not definitively establish a woman's carrier status, but will indicate if bleeding is a problem. Approximately thirty percent of haemophilia in any generation is due to a new (non-inherited) mutation.

12. Gillick competence is based on a UK legal precedent. The child must be "of sufficient intellect and maturity to understand fully the nature of what is being proposed" (Shenfield 2002:270).
13. CVS samples hair-like tissue from the placenta. DNA tests are undertaken to show the presence or absence of genetic markers for haemophilia. CVS is relatively low risk and comparatively accurate, with results potentially obtainable in a few days. It is carried out in the first trimester of pregnancy, which is desirable if a termination is contemplated.
14. See also Rapp's (1994) work with amniocentesis, and the discourses of parents and disability organisations (Kaplan 1994) for similar views.
15. Public discussion on limits to treatment by haematologists and the president of the HFNZ in the *New Zealand Medical Journal* did not mention prenatal genetic testing or family planning (Carnahan 2003, Faed 2003, Harper *et al.* 2003).

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