

Do Midlife Women Receive Second-Rate Health Care?

By Janine O'Leary Cobb



A surprise telephone call. Someone from a congressional subcommittee in Washington asked if I would be willing to fly there for hearings — the date as yet unfixed, possibly the 16th — to investigate health care of mid-life women. I carefully wrote down the names: the House Select Committee on Aging (I'd read about it in American Association of Retired Persons literature) and the

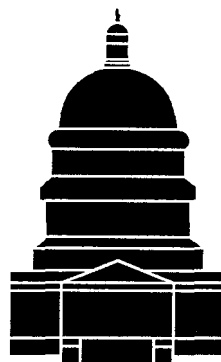
Subcommittee on Housing and Consumer Interests. I told the caller that I was due in New York City from the 14th–16th, that I was booked to go to Toronto and Hamilton from the 21st–23rd, and that I was flying to Vancouver and Seattle on June 2nd. Other than that, I was free!

How did a congressional subcommittee in Washington hear about me? And what did these hearings actually do? When I casually mentioned the invitation to Claire, my American research assistant, and to Karen, a friend from Philadelphia, they jumped on me. Testifying before a congressional subcommittee was a great honour and I should move heaven and earth to accept. Never mind that the airfare would cost \$500!

Two or three days later, I called Washington and said I would try to come, provided the final date could be worked into my schedule. They were now looking at May 30th but this depended on the availability of the chairperson, Marilyn Lloyd of Tennessee, and other subcommittee members. I was also told that it was the presentation I made at the inaugural meetings of the North American Menopause Society in New York City in September of 1989 which had led them to me. I had spoken about the education of the public and of health providers about menopause; the proceedings of these meetings had subsequently been published as *Multidisciplinary Perspectives on the Menopause* (New York: Academy of Sciences, Vol. 592).



A fax arrived at my hotel in New York confirming the date of May 30th, 9:30–11:30 a.m., and outlining the points I was to address. (I discovered that a package of background information had also been mailed to Montreal but, since it was franked for delivery in the U.S.A., had been turned back at the border). Part of the letter from Ms.



A Friend Indeed Goes to Washington

Lloyd read as follows:

The intent of the hearing is to examine the experience of midlife women health care consumers. Last year, my Subcommittee held a hearing which revealed the lack of attention paid to research into the health concerns of midlife and older women. Unfortunately for women, this lack of research has limited the understanding of women's unique medical needs. It has also affected the experience of the female health care consumer as she wades through the often contradictory information regarding menopause in order to try to make informed decisions about her medical care. The lack of adequate attention to women's health needs at midlife has also translated into a poor record of health screening and prevention techniques, despite older women's increased risk of disease.

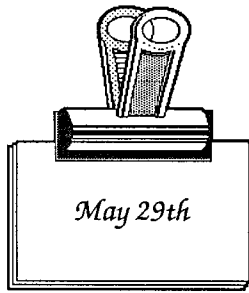
It is my hope that this hearing will be an important step in improving the way women are treated at midlife, both in society and in the health care system.

I had very little time to prepare. I was due to return to Montreal on the 17th, two sons and their "significant others" were invited to our cottage for the Victoria Day weekend, and I was due to leave early Tuesday morning. The written testimony (length at my discretion) was to be submitted by that Friday, the 24th! Oral testimony was limited to five minutes, to be followed by questions from the committee.



I had time to draft a few ideas and to pick up my laptop computer before I left for the cottage. I spent far too much time at the portable and far too little enjoying the good weather and my guests and family. On Monday I called Washington to say my written testimony could not possibly be ready for the 24th. May 27th was Memorial Day, a holiday in the United States, so I was asked to fax it then: the machines would be relatively quiet. On Tuesday morning I left for Toronto and, on Thursday was part of the opening panel of the CHEPA (Centre for Health Economics and Policy Analysis) meetings in Hamilton. On Friday I was surprised to see an article in *The Globe and Mail* covering the contributions of the other panel members, but omitting any mention of my contribution.

After a full weekend writing, the testimony was faxed to Washington, along with a brief biographical note. Then it was time to prepare oral testimony.



My flight for Washington left at 1 p.m., a "business express" flight stopping in Albany. I didn't sleep much the night before and was surprised to find that the plane held only nineteen passengers, and had four-foot headroom. And to think I'd had the temerity to ask if lunch would be served on this flight. In Albany a delegation of large and very loud Russian businessmen got on. It was impossible to read because the plane bounced so much, so I spent my time speculating about their particular mission in America. It was 32° C in Washington and very sticky. I stayed overnight with a friend — a comforting and supportive presence — but again I slept badly. Next morning, she showed me the daily notice of hearings in the *Washington Post*. On that one day alone, there were over a dozen hearings for various branches of government. I knew now that some were investigative (as mine was) and some were legislative, but that the recorded transcripts of each hearing were prologue to the formulation of laws and/or policy and that they would be part of an official congressional record. It was a daunting thought.



Grabbed a cab and arrived at Rayburn House Office Building, a vast granite edifice flanking Capitol Hill, with security guards hovering and X-ray machines for visitors' belongings. A fountain and a statue of Sam Rayburn grace an inner court. Surrounding that court are miles of marble corridors, probably ten feet wide, with panelled double doors at regular intervals. The walls ring with the sound of footsteps on marble, reverberations. Each double door marks the office of a congressman/woman, often with a state and national flag outside the door.

I entered Room 2226 at the back. It was considerably smaller than the ones I'd seen on television (such as for the Oliver North hearings), but the principle was the same. It was sparse and utilitarian and, with a bank of big windows down one side, had the feel of a Quaker meeting-room. The witnesses had been assigned to panels of from three to five and I had been scheduled for the first panel. I found this frightening but consoled myself that it would be over with that much faster. I just hoped my voice wouldn't shake.

Each congress representative (of eighteen subcommittee members, six were present) was given time to make an introductory statement: some were prepared and some were extemporaneous. Each stressed the reasons why she or he was particularly interested in improving health care for midlife women. Then the first panel was asked to move into place.

There were three of us — Maurice Butler, a gynaecologist at Columbia Hospital for Women in Washington; Bobbie Sue Foster, a nurse who had been transformed into a dedicated educator on the topic of breast cancer as a result of her own unhappy experience; and me. As it turned out, being on the first panel was a definite bonus: it was the only one to be heard without interruption and more congress representatives were present.

Dr. Butler spoke first. In my own testimony (summarized in the September 1991 issue of *A Friend Indeed*), I planned to present the problem of finding adequate information about menopause, and the tendency of physicians to dismiss or trivialize midlife women's complaints. Dr. Butler personified the kind of physician I meant. His testimony was in "medicalese" ("signs and symptoms of this hypoestrogenic state are due to atrophic changes in all estrogen target tissues and a peripheral hormone milieu that is now more androgenic"), with complete disregard for the comprehension level of his audience, and he read it without looking up. He unwittingly gave me a welcome boost of confidence and determination.

I spoke about the kinds of health problems faced by midlife women, how they learn about menopause (if at all), the attitudes they might encounter on the part of physicians and, finally, how the large pharmaceutical companies take advantage of generalized ignorance (on the part of doctors as well as women themselves) and a society-wide fear of aging in order to create a need for hormones. Some women *do* benefit from hormones; there is no doubt about that. But when we see what happens in other societies where hot flashes are virtually unknown, where osteoporosis is more of a problem for men than for women, where heart disease is less of a problem, then we have to acknowledge that the understanding and treatment of menopause in North America is in its infancy.

After giving our testimony, but before question period, the bells rang and the congress representatives had to leave. Only three returned and their numbers dwindled even more as the hearings went on. The chairman was alone by the time the final panel spoke.

I was also lucky during the question period. Most of the questions were addressed jointly to Dr. Butler and me. He jumped in to answer each question first, which gave me time to figure out exactly what I wanted to say. For instance, when asked why women might not want to take estrogen every day, Dr. Butler explained that patients generally have a problem with any medication which must be taken daily. It was easy for me to follow up with the idea that there is often a serious lack of communication between doctors and their patients.

The other "expert witnesses" were Cynthia Pearson, Program Director of the National Women's Health Network (the organization which published *Taking Hormones and Women's Health: Choices, Risks, Benefits*); Phyllis Mansfield, a psychologist and professor at Penn State University who has done research on the ways in which women learn about menopause; Marilyn Rother, a professor in the College of Nursing at Michigan State University, and principal investigator in a study of women's judgments of estrogen replacement therapy; Bemadine Healy, a cardiologist and the newly-appointed director of the National Institutes of Health; Nancy Dickey, a family physician representing the American Medical Association; Catherine Garner, president-elect of a large nursing association and also president of a firm which counsels hospitals on the best way to attract and treat women; Lila Wallis, past president of the American Medical Women's Association and founder of the National Council on Women in Medicine; and Wulf Utian, co-author of *Managing Your Menopause* and president of the North American Menopause Society. Dr. Healy arrived after the first panel had answered questions; with her came an entourage of aides and media types. She was thanked profusely for attending and the schedule

was hurriedly changed to allow her to testify and leave. By this time, I was feeling very grateful that I'd already had my turn.

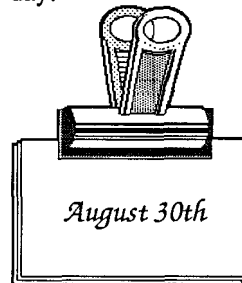
Most witnesses spoke about what should or could be done to improve health care for midlife women, but Drs. Hickey and Healy both presented new policies of their respective organizations. Dr. Hickey was fresh from a large press conference in New York City, at which the AMA had pledged money and effort towards a new Women's Health Campaign. And Dr. Healy was there to admit to the failures of the NIH in the past (particularly the absence of women as subjects in research projects sponsored by the various Institutes) and to pledge a new interest in and research support for various aspects of women's health.

By the time Dr. Healy had answered the questions put to her (flashbulbs popping all the time), the hearings were way behind schedule. The last panel was forced to rush their testimony in order to relinquish the hearing room to another group at 1:00 p.m.

During the breaks, I met Cindy Pearson and Catherine Garner (with whom I had corresponded), shook hands with Dr. Utian (who had chaired the meetings in September 1989), and visited with Dr. Mansfield, who is a fellow member of the Society for Menstrual Cycle Research. I left with Dr. Wallis, a charming woman in her sixties. I wanted to ask her more about one part of her presentation — the notion of a core curriculum for training primary physicians for Women's Health, developed by the American Medical Women's Association, and proposed as a board-certified medical speciality. The AMWA argue that gynaecologists do not receive the proper training to be adequate medical caregivers for women because their education focuses too narrowly on the reproductive system and ignores other medical and psychosocial skills necessary to be a true specialist in women's health.

We lugged our suitcases down the mall to the National Gallery cafeteria and ate together. After lunch, befuddled by the heat, I had a few hours to kill before my 6:00 p.m. flight. I found my way to the new Erickson-designed Canadian Embassy, hoping to find someone to show me around. The receptionist regretted that tours were for groups and by appointment only. I was too hot and tired

to stumble around with an overnight bag and a briefcase, so I just sat in the cool foyer and quietly read my book. When 4:00 o'clock came and went, she took pity on me and invited me on a private tour of the Embassy — a most impressive building. In the library, I found that day's *The Globe and Mail* and, on the front page, an article about my part of the presentation in Hamilton and about my trip to Washington. I could hardly believe my eyes. What a day!



Two months after the hearings. I'm awaiting my bound copy of the transcript which should arrive any day now. *The Globe and Mail* article stimulated a lot of enquiries, as did an article in *USA Today* which appeared on June 6th. I am more and more optimistic about the potential clout of our growing network of midlife women, and about the possibility of ultimately effecting real change in the delivery of health care. Certainly there seems to be a big push on in the U.S.A. and, whether we like it or not, we almost always follow American trends. This is one trend that I welcome.

I know that many aging women find it very hard to meet their doctors head on — to press for more information, to insist on the right to make their own decisions, to turn down prescribed drugs, to stall until they get a second or even third opinion, to elect not to have elective surgery. These are the tactics of younger, more assertive women, tactics which are difficult for women who were brought up (as I was) to respect and defer to physicians.

Now there is some promise that pressure for change, for a better quality of care for midlife and older women, will also be coming from doctors' associations and government agencies which control or strongly influence allocation of research funds. This is the kind of support that women desperately need if we are to learn to manage our own health care — not only through menopause, but through all the years that follow.

The battle is not yet won, but the visit to Washington was a step forward.

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