

# “I Don't Want To Be a Burden”:

## *Needing Assistance in a Context of Disentitlement*

*By Jane Aronson*

“I don't want to be a burden” is a statement commonly made by old people. It rings with familiarity as I think of women I have watched growing old in my family: my grandmother, aunts, godmother, my mother. I have heard it spoken, too, among older women taking part in an ongoing research project on their experiences of emerging needs and challenges as they age. If we delve behind this terse statement, we can identify some realities about the current social context facing old women. Being ‘burdensome’ would, logically, mean imposing or depending on others whose assistance or willingness to help cannot be assumed or counted on. The words suggest a lack of confidence, a lack of entitlement to a supportive response. They are also other-centered rather than self-centered; the focus is on curbing demands or claims on others, rather than on the needs of the speaker.

That elderly people may need help or support of various degrees is well-known. While aging is certainly not an inevitable downward progress and the necessary association of old age with ill health has been properly dispelled, it is probable that for many health and ability will lessen with increased age. Health concerns and lessening capacities may translate into needs for a range of assistance and support — from help with everyday household tasks to negotiating the physical environment outside the home, to aspects of personal care — that will depend on people's particular activities, environments and resources. These emerging and changing needs are especially characteristic of the very elderly, among whom women predominate now and will do so for the foreseeable future.<sup>1</sup>

How is it then that, on the one hand, a slowing down and lessening of capacities

is expectable and normal while, on the other, many older women share an expectation that receiving needed support may be an imposition rather than a taken-for-granted entitlement?

This article explores this uncomfortable and unfair tension. In interviews with older women in a variety of circumstances (health, age, living situations, family contexts, income, experiences with health and social services, engagement in social and political activities), I have gathered their accounts of the prospect of old age and possible frailty. Depending on their circumstances, women talked about the prospect or experience of turning to health and social services for needed help or, much more commonly, to family members, usually daughters or daughters-in-law. The views and concerns that they voiced about these processes often revolved around the notion of being burdensome or disentitled. Many took for granted this troubling sense of weighing on others, feeling that it was up to them to cope well, that it was a particular feature of their family situation or that it was simply an inevitable part of growing older to be endured. Others resisted this sense of inevitability, looking beyond their own immediate personal worlds and reflecting on ways in which the experience of old age could be one of security and confidence, instead of precariousness and disenfranchisement. Their comments and the insights of older women writing about their own aging challenge us to look beyond the status quo and envision other possibilities that can enhance women's autonomy in later life.

### **The Prospect of Needing Assistance**

Faced with the prospect of needing assistance of some kind, families emerged

in women's accounts as the first line of resort and the most enduring source of assistance: “I don't know what I'd do without my daughter — she'll keep me going here;” “I'm very lucky to have my niece. She comes in regularly and does all the things I can't do;” “I feel so sorry for [friend]. She has no children to turn to now.” The reality that most of the care of old people is provided by families and, within families, by women is reflected clearly in these observations. Publicly-provided services (supportive services at home, various forms of institutional care) remain very much in the background and, with cuts in spending on health and social service programmes, are likely to remain so.<sup>2</sup>

A number of the women I spoke with had been recipients of home care services (homemakers, meals on wheels, visiting nurses). They all welcomed them, but recognized that they were in short supply: “When I came out of hospital, I had a homemaker for a bit. She was good... it got me over the worst.” Another woman explained that, after such short-term help at home, she and her daughter negotiated with the homemaker to continue coming after medicare coverage of her services ended. The ability to afford such private solutions to emerging needs is generally not an option for elderly women, a large proportion of whom continue to live near the poverty line.<sup>3</sup> For this woman, the privately-paid homemaker meant that she could just manage to live in her own apartment and not face the prospect of “a home.”

Apprehension and “dread” at the prospect of institutional forms of care was voiced by many of the women I interviewed. Associated with being “herded together,” it was seen as surrendering control and a last resort: “What else was I

going to do? I couldn't cope any longer. I had to give up." Having a daughter was recognized by many as the only way to fend off the possibility of institutional care. A woman in her late seventies who spoke at length about not wanting to impose on her daughters expressed this recognition with great reluctance:

*I think they (children) should be sympathetic ... but I certainly don't think they should give up their youth and be domi-*

sible for their own mothers in the past, the importance of concealing their needs and measuring their requests for help was heightened. A "sandwich generation" before the term was coined, they remembered how they felt their primary responsibilities were to their husbands and children. They felt guilty at diluting attention to their families, thus defined, guilty about their mothers, and torn and stretched by the competing claims on their time and energy. These women did not want to visit

mands. A woman in her late 60s captured this dilemma acutely. She likened herself to her mother who, years before, had asked for little help despite considerable disability and distress. At the time, she had found her mother's behaviour irritating; now she recognized her mother's silence as "a matter of pride," and found herself keeping quiet and containing her needs too.

In these patterns, we see the working out in old age of the selflessness, low

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*nated by a parent ... I certainly don't. That becomes a worry when you're over 70. If anything should happen ... I almost made my daughter promise, I said: "Please don't put me in a home" ... I'm in that position where I just worry about the end of life. Who is going to ...*

Thus, institutional care serves as a deterrent; its negative associations make alternative solutions — in the shape of unwanted dependence on adult children — acceptable. Most subjects found this absence of alternatives unremarkable, noting, for example, that "we can't expect much" and "there are so many of us now."

Living with this lack of alternatives and, thus, having to turn to younger relatives was not an easy process. A commonly-expressed sentiment about accepting the help of younger family members was a wish not to feel indebted or diminished in any way. For example, in explaining how her daughter helped her out in numerous ways for which she was less and less able to reciprocate, one woman was quick to assert that her acceptance of help did not render her a "poor granny." She and others noted that they paced their requests for help from their children, so as not to seem "demanding," sometimes deciding that it was simpler to just go without whatever it was they needed, rather than risk appearing burdensome. For women who remembered feeling respon-

the same tensions on their daughters.

Recognizing their marginal status in their daughters' lives and the dearth of publicly-provided solutions to their needs, many of the women I spoke with acknowledged that it was imperative for them to be as independent and self-sufficient as possible: "I must manage ... it's a struggle. I pray my health won't let me down." "Managing" and self-sufficiency were experienced by many not just as necessities, but as valued images to which they felt old women should adhere. For them, contemporaries who did not live up to this independent paradigm were viewed negatively. For example, speaking of her son-in-law's mother, one subject observed: "And I don't want to be one of those possessive mothers that just ... will act the martyr or ... play dependent, you know, at all." Frail herself and quite anxious about her future, this woman and others like her had taken on a cultural image of older womanhood to which they could only conform with considerable struggle and self-denial. She noted that she would feel "ashamed" if her daughter knew how vulnerable she sometimes felt.

The prospect of shame at appearing needy or demanding meant that few women spoke of their feelings with either their contemporaries or with their daughters or younger family members. Besides revealing their weakness, they were concerned that expressing their needs straightforwardly would be seen as making de-

expectations and capacity for self-blame that characterize women's psychological structuring over the life course and that silence complaint or anger.<sup>4</sup>

#### **Beyond the Silence: Future Responsibilities**

In an outspoken account of her experiences of ageism and, specifically, of feeling stifled in the women's movement, Barbara MacDonald underscores the unfairness and implications of the silence generally expected of older women:

*If an old woman talks about arthritis or cataracts, don't think old women are constantly complaining. We are just trying to get a word in edgewise while you talk and write about abortions, contraception, pre-menstrual syndromes, toxic shock, or turkey basters.*

*Don't feel guilty. You will then avoid us because you are afraid we might become dependent and you know you can't meet our needs. Don't burden us with your idea of dependency and your idea of obligation.<sup>5</sup>*

MacDonald demands that we listen to and appreciate her needs and complaints, not filter them through our own guilt and apprehensions of what we may be required to do in response. She challenges us, too, to think beyond individual ties

between women of different generations for solutions to older women's needs. Pressed into such ties by the absence of alternatives, it is no surprise that women often experience them as tense and unwelcome; we have seen how, for older women they generate feelings of burdensomeness and shame and, for younger women, feelings of obligation and guilt. Just because the present pattern of care presses women into these ties of dependence and responsibility does not mean that alternatives are not possible: men could share equally in caring for others; public services could be provided in ways that afford old people choices and the right to exercise them.

On the latter point, we hear a great deal from federal and provincial governments about long term care reform and policies and plans for health and social services for an aging population. Central to such reforms is the effort to keep old people out of institutions and in their own homes. Community services and home care programmes are heralded as the solution to old people's needs — albeit with meagre commitments of resources. Community-based and institutional types of care for old people are depicted as opposites: community care is portrayed as good, cheap, humane and preferred by old people, while institutional care is seen as bad, expensive, inhumane and disliked by old people.

In light of the comments of some of the women I spoke with, the range of possibilities that these policy developments provide for (and the assumptions underlying them) seem very narrow and simplistic. While many women certainly spoke of their "dread" of institutions, others pointed out that what they feared was the loss of control and impersonality that is characteristic of institution and would feel more secure:

*But it'd have to be permissive in the sense that I could draw in bed — even if I have trouble getting out of bed — or I could sit up at the window to read. Uh, if that wasn't built into it — if I was just supposed to lie there until they came and moved me or did something to me — I wouldn't want to be there.*

Others envisioned different forms of congregate care that they felt would not jeopardize their autonomy or sense of self-direction:

*I think a home in which there are half a dozen people and one person or two to look after them...that person is their employee, not the manageress, because then that little bit of bossiness comes in.*

In these comments, we see the possibility that institutional care could be reframed — that it could enhance rather than jeopardize autonomy. The disempowerment associated with institutions and their negative images has, however, prompted ready acceptance of non-institutional alternatives whenever possible. Earlier, we saw how one elderly woman reluctantly reconciled herself to accepting her daughter's help, if that would fend off the spectre of "a home." Fending off that unwelcome prospect perhaps has led us to be very indiscriminating about community-based care, too, accepting it as preferable without real scrutiny. Several of the women I spoke with challenged this unquestioning acceptance. For example, one woman speculated that staying at home with a few services coming in would be very isolating:

*I know that's the trend (community care) but I wouldn't like it. I imagine it'd be lonely. For example, there's a woman down the hall whom I take for a walk sometimes. A homemaker and someone from VON go into her. The other twenty-three hours she's quite alone.*

Another questioned whether receiving services at home would necessarily foster a sense of control or independence, as is commonly claimed:

*When you're an old lady, frail, maybe a little bit helpless, you haven't got the gumption to stand up against a person who's coming in to do a service and say: "That wasn't good enough." You just let it happen.*

These women's questions are driven by needs for security, control, autonomy, choice and a balance between privacy and companionship. Their articulation of these needs blurs and complicates the formulaic notions of 'community' and 'institution' that dominate current debate and planning for the care of old people.

In her "critical reflections on growing old," Doris Marshall notes that services and responses to the elderly are: "...the result too often of planning for old people,

without input from them." <sup>6</sup> Ensuring input and participation in the future will be no simple task: we have seen how commonly older women feel silenced and jeopardized, and how little, when able to speak, older women's concerns correspond with the directions and assumptions of health and social programmes. Calling women of all ages to begin the task and to work on our ageism, MacDonald urges:

*Don't think that an old woman has always been old. She is in the process of discovering what 70, 80 and 90 mean. As more and more old women talk and write about the reality of this process, in a world that negates us, we will all discover how revolutionary that is.*

<sup>1</sup> Gee, E. and Kimball, M. (1987). *Women and Aging*. Toronto: Butterworth.

<sup>2</sup> Aronson, J. (1986). "Care of the Frail Elderly: Whose Crisis, Whose Responsibility?" *Canadian Social Work Review*.

<sup>3</sup> National Council of Welfare. (1990). *Women and Poverty Revisited*. Ottawa: Ministry of Supply and Services.

<sup>4</sup> Baker Miller, J. (1976). *Towards a New Psychology of Women*. Boston: Beacon Press.

<sup>5</sup> MacDonald, B. with Rich, C. (1983). *Look Me In The Eye: Old Women, Aging and Ageism*. San Francisco: Spinsters' Ink, pp.74-75.

<sup>6</sup> Marshall, D. (1987). *Silver Threads: Critical Reflections on Growing Old*. Toronto: Between the Lines, p.27.

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