



Member's Editorial

Self-help groups

Self-help groups provide very tangible benefits when it comes to handling the many stresses life can throw our way. Why, then, do so few seniors turn to them when they have an issue or a problem to deal with? That's the puzzle to be solved in this issue of *Expression*.

Seniors are great practitioners of mutual support – the senior-to-senior help with groceries, housework, and lifts to appointments that we celebrated in an earlier issue of *Expression* (volume 12, number 2). Yet seniors are under-users of self-help groups, with an estimated participation rate of only 2 to 4%.

Why? One reason could be generational. As seniors, we consider it a virtue to be able to look after ourselves *without* help from others. For many, this is embodied in such expressions as "The Lord helps those who



Photo : Health Canada

help themselves" and "Standing on your own two feet". Reluctance to join a self-help group may stem from a belief, instilled since childhood, that you should be self-reliant and keep your troubles to yourself. Many seniors have difficulty opening up with strangers or talking about subjects considered taboo. Or they may see joining a group as a sign of weakness or inability to cope on their own.

Members of self-help groups seek to reduce suffering and regain autonomy – to recoup a sense of control over their lives in the wake of illness or loss, to cope with stressful events

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Finally, different messages will need to become part of seniors' consciousness, such as "Shared grief is half the sorrow", and "Happiness when shared, is doubled."

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and experiences. Moreover, people who join self-help groups to find help for themselves end up helping others – which in turn helps them even more.

If seniors are to benefit from what self-help groups have to offer – and as we'll see, it offers many benefits – how can we build awareness and outreach? How do we attract seniors to self-help groups?

We need further research on what types of seniors and problems are most helped by groups. And we need to demonstrate how groups help people cope with common but traumatic events, such as bereavement and chronic disease.¹

If self-help is to serve seniors well, groups will also need to respond to seniors' diversity – taking into account differences in geographic location, ethnicity, gender, age, income, education, faith, social class, culture, language, and literacy.

Self-help – What's in it for seniors?

Each time seniors get together in a group to help one another, they're practicing self-help. The self-help movement dates back to the 1930s, when two recovering alcoholics discovered that they were uniquely qualified to offer each other the support and encouragement needed to keep the bottle at bay. The rest, as they say, is history. Along the way, self-helpers discovered the additional strength of having more than one person available for support, and self-help groups were born.

Defining our terms

Jean-Marie Romeder, a long-time advocate and student of self-help in Canada offers this definition of self-help:

Self-help groups are small, autonomous, open groups that meet regularly. As a result of a personal crisis or chronic problem, members share common experiences of suffering and meet each other

as equals. The primary activity of these groups is personal mutual aid, a form of social support that focuses on the sharing of experiences, information and ways of coping. In addition to personal change, members often engage in activities directed to social change. Group activities are voluntary and essentially free of charge.²

Why people seek self-help

- believe their concerns should not be addressed solely in medical or social services terms
- their needs do not fall exclusively under the domain of any one profession or organization
- dissatisfaction with traditional services
- believe that traditional services pay insufficient attention to psychosocial considerations or consider them irrelevant or unimportant

Bonnie Pape of the **Canadian Mental Health Association** (CMHA) explains that there are more than half a million self-help groups in North America. Some are chapters of larger organizations such as *Alcoholics Anonymous*, but many are groups developed to deal with specific problems, ranging from life transitions (loss of a partner, bereavement) to illnesses or

disabilities (cancer, low vision, heart surgery, hip replacement), to groups for family and friends of those with a particular problem (caregivers of people with Alzheimer and other chronic diseases). Groups can be very specialized indeed – there is one in Toronto called PW55+. It's a support group for older women of Portuguese origin.

Does self-help help?

Self-helpers and advocates alike are quick to cite the benefits of active participation in a self-help group:

- developing a new capacity to alleviate the problem or adapt to a chronic situation
- gaining an expanded and enhanced support network
- greater feelings of control over one's life
- the satisfaction of helping others
- finding new ways of looking at one's problems and one's potential
- developing new knowledge and skills
- heightened feelings of hope
- reduced isolation and marginalization
- access to new resources
- opportunities to develop leadership, promote social change, and pursue political action.³

To judge the capacity of self-help groups to help members cope effectively with issues of aging, **Brian Hyndman** reviewed the research on support groups for widows and widowers, for

seniors caring for a spouse or family member with a chronic disease, and for seniors with disabilities. The studies showed such benefits as

- reduced levels of depression and anxiety in the bereaved;
- expanded social support networks and knowledge of community resources among family caregivers; and
- reduced rates of hospitalization in people with chronic diseases.⁴

What makes for success?

Equally interesting was a more general research finding that the more intensively self-helpers participate in a group, the higher their levels of satisfaction, the greater their coping skills, and the more positive their attitude toward the problem or issue. This suggests one of the elements of success for seniors' self-help groups: finding ways to support frequent attendance and ensuring that all members have the opportunity for meaningful participation.⁴

Another success factor is the use of seniors as facilitators and educators. This is very important to seniors, who tend to identify with their peers and value their opinions and advice. With appropriate training and their own experience, seniors can be effective leaders – benefiting themselves by helping others. There is a need, however, to provide support and back-up for senior group leaders, who may have concerns about the amount

of physical and emotional energy required – and who can be subject to burnout or “founder's syndrome”.⁵

Profile of a self-help group

Despite their great diversity, self-help groups share several characteristics:

- They are generally non-professional, run by members, for members. The structure is informal, leadership is shared, and decisions about the group are made by group members.
- Information and education available through a group come from members' experience, rather than professional expertise. Groups emphasize emotional support, practical coping skills, anticipatory guidance.
- They are not for profit – there is usually little or no cost to belong to a group.
- They are based on reciprocity (members both receive and give help) and equality (members treat each other as peers).
- They are open-ended and continue indefinitely, with membership open to anyone at any time.⁶

The “magic” of sharing

While not a replacement for professional assistance from medical and social services systems, support groups are an

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Ingredients for success

- shared leadership
- confidentiality
- readiness and continuity
- patience and persistence
- taking action together
- fun
- variety of self-help resources
- public attention
- stories
- peer support, one on one

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important complement to those services. Indeed, they offer something that just is not available through formal services systems.

This is what **Hector Balthazar**, of **Self-Help Canada**, called the “magic and the miracle” of self-help groups.² It’s still not clear just why they work the way they do, but the evidence is accumulating that self-help produces tangible benefits. The “magic” is that receiving emotional support and practical advice from someone who shares a problem – someone who has “been there” – helps both the recipient and the giver of help.

Recognizing the benefits of self-help and the fact that few seniors partake of its “magic”, a CMHA forum on self-help groups looked at ways to get the message out. Their strategies suggest an exciting, if challenging, agenda for seniors’ self-help – by promoting not only the help available to cope with difficult aspects of aging but also the more positive aspects, such as the possibilities suggested by “fun”, “intergenerational co-operation” and “stories” – three of the items on the Forum’s list of ingredients for success in self-help.⁷

Self-help and seniors

There are volunteer and self-help access centres in most regions of Canada. **The Self-Help Resource Centre of Greater Toronto** has documented self-help groups for seniors, put potential members in touch with them, and helped groups get started. **Randi Fine**, who was the Centre’s director for many years, notes that seniors’ self-help is often the same as what’s offered by other groups.

She says that age seems less important than the issue that brings self-helpers together; indeed, goal-specific groups appear more effective than age-specific groups covering a range of concerns.

The range of self-help groups seems limitless. The motto appears to be, “No issue too large or too small.” The Self-Help Resource Centre data base lists at least 100 senior-specific groups, including Alzheimer-related

support groups, the Older Women’s Network, GRAND (Grandparents Requesting Access and Dignity), and groups dealing with addictions, elder abuse, isolation, depression, chronic diseases and many more issues.⁸

And lest anyone think that it’s all doom and gloom, there are also groups like the Ulyssean Society, a cultural/social group, and SPRINT (Senior People in North Toronto). Even when groups are dealing with serious issues, they show that humour can be an effective antidote. Take “Totally Hip,” an online group for people preparing for hip replacement. Indeed, humour and shared laughter are an essential part of healing for many self-helpers.



Seniors’ groups also vary in their structure and method of operation. A survey of one Canadian city found six types of groups operating:

- traditional self-help groups (as defined earlier)
- groups run with the support of professionals or formal service organizations

- groups making the transition from “supported” to traditional self-help groups
- telephone networks
- groups offering peer leadership and counselling by seniors specially trained to provide them
- mutual aid networks.

There are also Internet groups enabling people to converse, gather information and provide mutual aid through electronic conversation. These may be especially helpful for people who feel uncomfortable or pressured in groups, who live far away from where a group meets, or who find it difficult to get out of the house.⁹ Many seniors could benefit if they have the necessary computer access and skills.

Peers or professionals?

Many seniors’ support groups include professional involvement. This seems to be for several reasons:

- The issues being dealt with may be medically and socially complex, requiring a variety of resources to be brought to bear.
- Professionals may be in a better position to form a group because they are more likely to encounter the requisite number of patients or clients with similar needs.
- Professionals can help overcome barriers to a group getting started – lack of awareness, the isolation of potential members, some of whom may have mobility

difficulties, the need for meeting space and other facilities.

But can a support group organized and/or led by a professional (a doctor or nurse, a social worker) meet the test of being a “true” self-help group? Many self-helpers argue that disillusionment with traditional health and social services is what led them to a group in the first place. Some groups actually make change or reform in these systems part of their *raison d’être*.

Self-helpers are also concerned that “professionalization” of a group reduces the opportunities for “real” self-help by shifting the emphasis away from emotional support, experience-based advice, and consideration of alternatives to “traditional” types of treatment or care. Some professionally led groups charge a fee and are offered over a limited period of weeks or months. This, too, critics say, is contrary to the “self-help way”.

These concerns are no doubt behind a growing literature of advice for professionals on how to work with groups. The Self-Help Resource Centre, for instance, has a pamphlet outlining 10 steps for professionals thinking about developing a group.

If the general tenor of the advice can be summed up in a single phrase, it is “Professionals – on tap, not on top”. The phrase was coined by

Andrew Farquhason, a professional who has worked with the self-help community for many years and who believes peers and professionals have distinct kinds of knowledge and expertise to contribute.

The bottom line? There is room for both “traditional” self-help groups and those with professional involvement – and many variations in between. Their benefits for health alone – improved health status, healthier behaviour, less use of health services – are enough to support the idea of partnership between self-helpers and professionals. These groups could be important ingredients of reform and renewal in Canada’s health system.³

Promoting participation

Experts in self-help and gerontology have identified barriers to greater participation by seniors in self-help:

- mobility restrictions
- sedentary lifestyle
- reluctance to disclose personal problems to strangers
- lack of information on availability of groups
- availability of support from family and friends
- lack of information on how to form a group
- geographic distance.¹⁰

Efforts to remove these barriers will contribute to an increased participation of seniors in self-help groups.

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The diversity of seniors' interests, needs and capacities emphasize the importance of matching individual seniors with an appropriate group. For some seniors and caregivers, for example, a telephone support network could be effective in reducing isolation and loneliness and providing social and emotional support, while for others the need to meet face to face would be paramount. In rural areas, factors such as distance to health facilities and the length of time between visits create a natural situation for self-care through self-help. Indeed, self-help is often thought to be an urban phenomenon, but in rural areas, it is often just an extension of existing mutual support networks among community members.¹¹

Randi Fine points to the need for sensitivity to issues and concerns that may emerge as individuals age and for attention

to the special needs (if any) of older participants, such as proper lighting to accommodate low vision, sound enhancement for the hard of hearing, transportation, and accessibility of the meeting space.

Fine also notes the importance of outreach and marketing. Just 20% of the information and referral calls to Toronto's Self-Help Resource Centre come from seniors, so the Centre reaches out to seniors – in shopping malls, beauty salons, drug and grocery stores, and by promoting self-help to health and social services professionals.¹² Although seniors as a group are under-users of self-help, particular groups within the senior population are especially unlikely to turn to self-help. They include men, members of ethnocultural communities, and seniors with lower incomes.¹³

One obvious barrier to self-help for seniors may be the absence of a group on a particular issue. One survey, for

example, reported a lack of groups on elder abuse, ethnoculturally specific groups, groups on macular degeneration and related visual impairments, depression and the older adult, and senior couples.¹⁴

The CMHA forum on self-help identified several structural supports that are missing: strategies for building awareness, public education, models that can be replicated, a national infrastructure, a research agenda, and increased funding. It emphasized that failing to capitalize on what self-help can offer seniors brings costs. Without recourse to self-help resources, the demand for professional services increases and the senior's support infrastructure is weakened. As a result, issues escalate, resulting in increased stress for the individual. When information and emotional support dwindle, the ultimate result is that conditions worsen to the point where care must become medicalized and more costly.⁷

Arguments based on cost containment do, however, raise concerns in the minds of many about whether authorities are looking to the self-help and volunteer sectors to shoulder responsibilities that more properly belong to governments.

The ripple effect

Many seniors are reluctant to share intimate feelings in a group setting, believing that you should



Photo: Club de l'âge d'or Saint-Paul d'Aylmer

“keep your own counsel” when it comes to personal problems. And how many more seniors miss out on what self-help has to offer through lack of information and awareness? Fortunately, it is in the nature of self-help to grow by the ripple effect.

With increased promotion of self-help, more and more seniors will experience its benefits and word of mouth will help to close the gap between what self-help for seniors is today and the wonders it will accomplish in the twenty-first century.

What a self-help group can do for family caregivers

- reduce isolation, give caregivers support and hope
- improve their problem-solving skills through meetings and telephone support
- give members an opportunity to ventilate their feelings and frustrations
- education and mutual support for members
- public education and advocacy for public support and services



Canada, a society for all ages

Tips List

Where can I find out about self-help groups in my area?

- the United Way or similar agency
- a self-help clearinghouse or resource centre
- seniors' centre or association
- provincial office on aging or ministry responsible for seniors
- local volunteer bureau
- church or other religious institution
- family physician or other health professional
- hospital or specialized clinic
- “disease” associations (Canadian Cancer Society, Heart and Stroke Foundation, Arthritis Society)
- counsellor, therapist, or other mental health professional

Organizations

The Support Network

11456-Jasper Ave.
Edmonton, AB T5K 0M1
Phone: (403) 482-0198, ext. 231
Fax: (403) 496-1495
E-mail: supnet@compasmart.ab.ca

Family Support & Self-Help Program CMHA

P.O. Box 785
Charlottetown, PEI C1A 7L9
Phone: (902) 566-3034
Fax: (902) 566-4643

The Self-Help Resource Association of B.C.

303 -1212 West Broadway
Vancouver, BC V6H 3V1
Phone: (604) 733-6186
Fax: (604) 730-1015
website: <http://www.vcn.bc.ca/shra/welcome.html>

Information and Referral Centre of Greater Montréal

801 Sherbrooke Street, Suite 401
Montréal, QC H2L 1K7
Phone: (514) 527-1375
Fax: (514) 527-9712
(publish a Directory of Self-Help Groups in the Greater Montreal Area)

Manitoba Self-Help Clearinghouse Inc.

825 Sherbrooke Street
Winnipeg, MB R3A 1M5
Phone: (204) 772-6979
Fax: (204) 786-0860

Self-Help Community Service

Box 6125 Station “A”
St. John, NB E2L 4R6
Info line: (506) 633-4636
Phone: (506) 634-1673
Fax: (506) 636-8543

Self-Help Connection

63 King Street
Dartmouth, NS B2Y 2R7
Phone: (902) 466-2011
Fax: (902) 466-3300

Connecting Seniors of Canada Institute for Human Development

University of Toronto
222 College Street, Suite 106
Toronto, ON M5T 3J1

Self-Help Resource Centre of Greater Toronto & Ontario Self-Help Network

40 Orchard View Blvd., Suite 219
Toronto, ON M4R 1B9
Phone: (416) 487-4355
Fax: (416) 487-0344
E-mail: shrc@sympatico.ca
website: <http://www3.sympatico.ca/shrc/>

On line

- <http://www.opc.on.ca/healthinfo/> – Information on health and self-help groups.
- <http://www.gov.mb.ca/sd/guide/chronic.html> – Manitoba Seniors Guide to resources for dealing with chronic diseases, including self-help.
- http://www1.bc.sympatico.ca/healthyway/HEALTHYWAY/feature_sel2.html – General site on self-help, with links.
- <http://publish.uwo.ca/~cmcwili/NCP> – Discussion of issues related to self-help, self-care and mutual aid among seniors.
- <http://www.totallyhip.org> – Online self-help for people anticipating hip surgery.
- <http://interact.withus.com/interact/mbc> – For men with breast cancer.

For further information...

Self-Help Resource Centre of Greater Toronto. *Seniors and self help* (leaflet, n.d.); *Getting started and making it work*. Toronto: 1997 (booklet and video – \$30).

Weick, Beth. *A Support Group for Caregivers: A Guide for Starting a Group in Your Community*. Penticton (B.C.): The Caregivers Support Group of the Penticton & District Retirement Complex, 1990.

Pape, Bonnie. *An introduction to self-help/mutual aid*. Toronto: Canadian Mental Health Association and Self-Help Canada, 1990.

Notes

- 1 Greg Meissen, "Types of self-help groups research with seniors", in *Self-help/mutual aid for seniors: research challenges*, Report of the discussion session at the Canadian Association of Gerontology, Montréal, 30 October 1993, p. 13.
- 2 Jean-Marie Romeder et al., *The self-help way: Mutual aid and health*. Ottawa: Canadian Council on Social Development, 1990.
- 3 Francine Lavoie and Miriam Stewart, "Mutual aid groups and support groups: the Canadian context", *Canadian Journal of Community Mental Health* 14/2 (Fall 1995).
- 4 Brian Hyndman, *Does self-help help? A review of the literature on the effectiveness of self-help programs*. Toronto: Centre for Health Promotion, University of Toronto, 1996.
- 5 See Kate R. Lorig et al., "Evidence suggesting that a chronic disease self-management program can improve health status while reducing hospitalization", *Medical Care* 37/1 (1999); and Randi Fine, *Taking charge: seniors helping seniors*, final report. Toronto: 1992, p. 7.
- 6 See Karen Hill, *Helping You Helps Me*, revised edition (Ottawa: Canadian Council on Social Development, 1987); *Self-help/mutual aid for seniors*, especially articles by Fine, p. 25, and Romeder, p. 8; Bonnie Pape, *An introduction to self-help/mutual aid* (Canadian Mental Health Association/Self-Help Canada, 1990); and Joy M. Rogers, *Mutual aid as a mechanism for health promotion and disease prevention* (Toronto: Clarke Institute of Psychiatry, 1987.)
- 7 Canadian Mental Health Association, *Bringing the self-help message to seniors*, National Forum Report (Toronto: 1998).
- 8 *Toronto's Self-Help News*, newsletter of the SHRCGT, winter 1999.
- 9 Health Canada, *Supporting self-care: the contribution of nurses and physicians, an exploratory study; programs and tools*. Ottawa: 1997, p. 62.
- 10 Benjamin Gottlieb and Miriam Stewart, in a Fact sheet on Self-help and Mutual aid, n.d.
- 11 Meissen in *Self-help/mutual aid for seniors*, pp. 19, 20.
- 12 Fine in *Self-help/mutual aid for seniors*, pp. 25, 28.
- 13 Rogers, *Mutual aid...*, p. 5.
- 14 Fine, *Taking charge*, p. 7

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