

***EVALUATION OF THE ARTHRITIS SOCIETY'S
SUPPORT AND INFORMATION LINE***

PART 2

ANALYSIS OF CALL RECORDS MAY 26-AUGUST 22, 1994

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EXECUTIVE SUMMARY

An evaluation of the Arthritis Society's Support and Information Line (ASIL) was carried out between May 26 and August 22, 1994. Two ACREU staff members were trained as Arthritis Society (TAS) volunteers and answered a total of 198 calls. Most of these callers were between 35 and 64 years of age (71.6%), and the majority of callers were women (76.7%).

The most frequent reasons for calling the ASIL were for information on specific rheumatic conditions (most frequently fibromyalgia), support groups/meetings, medications, the name of a rheumatologist, arthritis in general and for information on the Arthritis Self-Management Program (ASMP).

As a result of the call, written information was mailed in over 70% of cases. Verbal information was also given to callers including telephone numbers of community and government agencies, support group contacts and pool programs. In 20% of cases, the volunteers did not know how to answer the question or had no information to send, in which case the caller's name and phone number were passed on to TAS staff.

As a result of this evaluation, changes have been made to the data collection forms for daily record-keeping. The evaluation underscored the importance of the ASIL in terms of its contribution to TAS, through mailing lists, dissemination of information, identification of needs and gaps in information and services and the potential for advertising TAS programs.

The ASIL plays an important role to people living with arthritis and enables people to gain valuable information to help them deal with this chronic condition.

INTRODUCTION

The Arthritis Society's Support and Information Line (ASIL) began in October, 1991 and its staff of trained volunteers have provided emotional support, information and referral to community resources in approximately 11,565 calls to date. The philosophy of the service is based on the belief that anyone affected by arthritis has the right to obtain information and support in order to: improve awareness and understanding, gain access to information and services available and receive emotional support as they learn to adapt to living with a chronic condition. The objectives of the ASIL are appended to this document (Appendix A). In addition to the ASIL, The Arthritis Society offers a number of programs and services, including the Consultation and Therapy Service (CTS), the Arthritis Self-Management Program (ASMP) and various support groups.

An earlier evaluation of the ASIL prepared by Elizabeth Badley (refer to *Evaluation of the Arthritis Society Support and Information Line*, January, 1994) concentrated on the frequency of calls coming into the line and the characteristics of callers. At the time of the study, it was not feasible to look at the reasons for calls.

The main objective of the current study was to examine the reasons why people called the ASIL during the period from May to August, 1994. Information was also collected on the action taken as a result of the call, as well as the demographic information which is routinely collected by all TAS volunteers.

METHOD

The evaluation was set up in two phases. During Phase I of this study (May 26-July 8, 1994) a detailed record of the reason for calls to the ASIL was kept by two ACREU staff members (D. Dalby and E. Harniman), who were trained as TAS volunteers and answered calls during this time period. Typically, calls to the ASIL would begin by callers stating the primary reason for their call, and with further probing from the volunteer, additional issues would often surface. In some cases, this was related to requests for additional information and/or emotional support. ACREU staff answered calls in much the same way as the other TAS volunteers, except for the fact that data collection may have been more thorough by ACREU staff, given their involvement in the evaluation.

As a result of Phase I, the data collection form was augmented to include other items identified as being important. Phase II took place between July 13 and August 22, 1994, and followed a similar protocol as in the first phase. Examples of The Arthritis Society's telephone log sheet (Appendix B) and the Phase I and II data collection forms (Appendix C and D) are appended. All data were coded and entered into the computer using the SPSS PC+ software package. Analysis was carried out using the SPSS for Windows software package.

RESULTS

During Phase I of the study, a total of 78 calls were taken by ACREU staff, and a further 120 during Phase II, of which 77.3% (92) were local, 17.6%

(21) came in on the toll-free line, 3.4% (4) were long distance and a further 1.7% (2) were in written form. This represents a small shift towards increased use of the 1-800 number from the previous evaluation by E. Badley (at 13%), perhaps indicating greater awareness in the population of this toll-free service.

In general, the characteristics of callers were similar to those in the previous evaluation. Most callers, during Phase II, were between 35 and 64 years of age (71.6%) and over 75% were female (Table 1). The most prevalent condition among callers was fibromyalgia (29.5%) followed by osteoarthritis (OA) and rheumatoid arthritis (RA), at 21.6% for each of these conditions. Over 60% of callers were seeing a rheumatologist at the time of the call or had seen one in the past. There was a significant relationship between having RA and seeing a rheumatologist ($p < 0.01$), but this was not significant for the other conditions.

Most people calling the ASIL found out about the service through the phone book or library (38.9%) or through a friend or relative (24.1%) (see Figure 1). Smaller proportions were told about the ASIL through their caregiver, The Arthritis Society or read about it in a newspaper or magazine.

Table 2 outlines the top 5 reasons for calls to the ASIL. The most common reason for calling the Support Line was for information on a specific rheumatic disease (43.9%), with the highest proportion of these calls inquiring about fibromyalgia (19.2%), followed by lupus (8.6%), RA (7.6%) and OA (6.6%). Other important reasons included information

on support groups and meetings (8.6%), medications (7.6%), the name of a rheumatologist (6.1%), general arthritis information and information on the ASMP, at 5.6% each. We also collected information on whether or not the caller was using the Consultation and Therapy Service (CTS), and none of the callers indicated that they were. In fact, 38.3% of callers in the second phase did not know of the existence of the CTS.

During Phase II, data were collected on the action taken as a result of each call received. In most cases, (72%) information was mailed to the caller. There were also a number of other pieces of information that were given verbally by the volunteers. For example, in the case of 9 callers (7.5%) who had not been to see a rheumatologist, it was suggested that they consult their family physician about a referral. As well, the volunteers gave out the 1-800 number (3.3%) to callers phoning long distance. In addition, phone numbers were often given to callers for various government and community agencies, pool programs and support group contacts. In a few cases, callers were told how to order books or videos and suggestions were sometimes made about seeking professional advice regarding topics such as exercise and medications.

Information on the ASMP was sent to 35 (29.2%) callers, information on the CTS to 53 (44.2%) individuals, and information on support groups was sent to 32 (26.7%). The high proportion of callers to which this information was sent reflects the extent to which other issues were raised that were not the primary motivation for contacting the

ASIL. Information on books was another topic that generated relatively few calls (5 or 2.5%) and yet was included in 20% of the mailed packages.

There were also a large number of calls for which the volunteer did not have any information to send to the caller or was unable to answer the question at hand. This occurred in 24 (20.0%) cases. These questions included very specific disease-related issues, information on publications such as *Arthritis News*, journal articles and specific books, information on alternative therapies such as chiropractors, acupuncture and massage therapy and specific information on support groups. In most cases, the volunteer asked for help from TAS staff and/or passed on the caller's name and number to a staff member, usually the ASIL co-ordinator.

DISCUSSION AND RECOMMENDATIONS

The ASIL was created to fill a gap in the support services of The Arthritis Society, Ontario Division by providing an easily accessible support and information service. The goal of the service is to encourage and support positive health behaviours by providing information and emotional support to those affected by arthritis. It also provides referrals to needed community and health services.

In most cases, volunteers were asked for information on specific diseases and were able to answer the caller's question with the resources available. However, of the calls taken during Phase II, 20% involved questions for which the volunteer had

no answer or was unable to locate appropriate written information. It may therefore be worthwhile to have a permanent binder where volunteers can record questions for which they could find no answer. These can then be reviewed and if possible information gathered on those subjects. During this evaluation some of the topics lacking information included new drugs and drugs not specifically for treating arthritis, such as Prozac, and alternative therapies such as chiropractors, acupuncture, herbal remedies and massage therapy, which could point to a need for The Arthritis Society to prepare appropriate informational materials on these topics.

During this evaluation only a quarter of the callers had called the ASIL previously. Volunteers should be encouraging callers to call again if they have any further questions, need more information, or just need someone to talk to. This indicates the importance of giving first time callers basic information on all TAS programs such as the CTS, ASMP, pool programs, support groups and the Arthritis Support & Advocacy Network. This could be done verbally or in the form of a pamphlet on TAS programs which could be included in the general package.

Emotional support is a very important function of the ASIL and should not be underestimated. Other studies of callers to information services have found many callers just wish to talk about their problems (1). During this evaluation about 10% of calls involved emotional support. This may be an area where volunteer training

should be given, possibly through another organization providing emotional support, such as a distress centre.

As a result of the evaluation, the call record log has undergone many changes. It was decided that daily record keeping be minimized while ensuring adequate information was collected regarding the action taken, the caller's age, the type of arthritis experienced by the caller, the origin of calls on the toll-free line and how the caller heard about the service. For most questions, tick boxes are used to aid in efficient data collection. A detailed statistics sheet was also developed to aid in collection of monthly data related to these topics. It was decided by TAS staff that detailed data collection and evaluation could presumably be done one or twice per year, and could include more specific details about the reason for the call, caller knowledge and use of TAS services and details about the emotional support provided by volunteers.

One suggestion for future evaluation of the ASIL is a mailed or telephone "user survey". This survey could tap into caller satisfaction with the information received, whether or not the caller did something as a result of the call, would the caller use the service again and whether or not the information was useful in decision-making.

The ASIL has an important role to play with respect to its contribution to The Arthritis Society. For example, caller names and addresses are forwarded to direct mailing lists for future use by TAS, the volunteers play a

major role in all TAS activities, the ASIL helps TAS monitor gaps in information and needs for services and also plays an important role in advertising TAS services such as the CTS and ASMP.

The ASIL is a vital part of The Arthritis Society's contribution to people in the community living with arthritis. By providing information and support to this group, the ASIL enables individuals to take positive steps towards better health and provides them with resources to help them cope more effectively with one of Canada's leading chronic conditions.

1. Haynes J, Dieppe P. Increasing awareness of arthritis - the public's response. *British Journal of Rheumatology* 1993;32:623-624

Table 1: Characteristics of callers (Phase II)

<i>Characteristic</i>		<i>n (%)</i> †
Age	under 35	8 (10.8)
	35-44	16 (21.6)
	45-54	22 (29.7)
	55-64	15 (20.3)
	65-74	10 (13.5)
	75+	2 (2.7)
Sex	Male	20 (23.3)
	Female	66 (76.7)
Type of arthritis	fibromyalgia	26 (29.5)
	OA	19 (21.6)
	RA	19 (21.6)
	lupus	7 (8.0)
	psoriatic	3 (3.4)
	ankylosing spondylitis	1 (1.1)
	gout	1 (1.1)
	scleroderma	1 (1.1)
	juvenile arthritis	2 (2.3)
	not known	6 (6.8)
other	5 (5.7)	
Seeing a rheumatologist	yes	50 (62.5)
	no	30 (37.5)

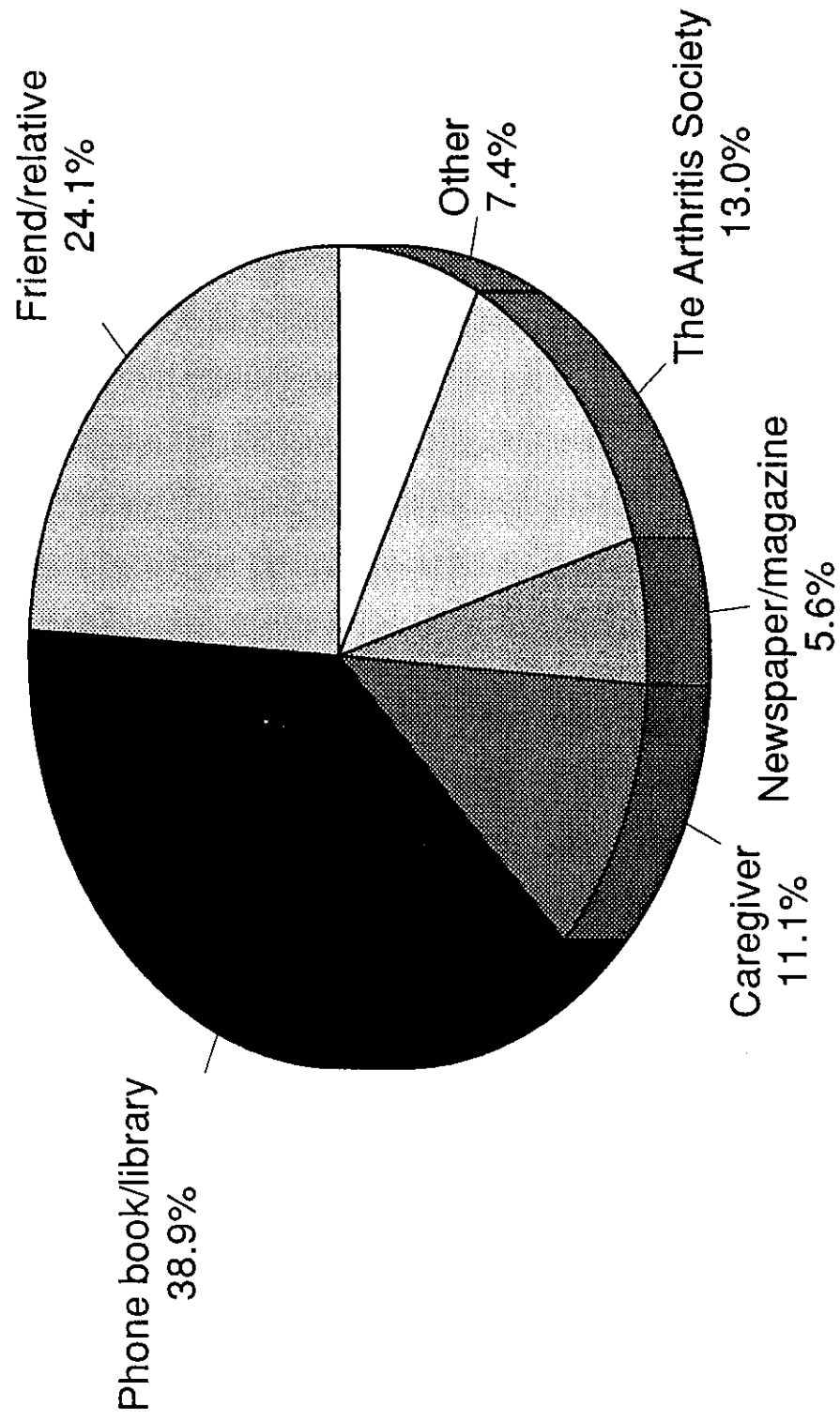
† missing values removed

Table 2: Top 5 Reasons for Calls to the ASIL (Phase I and II)

<i>Reason for Call</i>	<i>Percent of Total† Calls (n=198)</i>
1. Information on specific rheumatic diseases	43.9%
Fibromyalgia	19.2%
Lupus	8.6%
Rheumatoid Arthritis	7.6%
Osteoarthritis	6.6%
Other	4.0%
2. Information on support groups/meeting	8.6%
3. Information on medications	7.6%
4. Name of a rheumatologist	6.1%
5. General arthritis information	5.6%
Information on the ASMP	5.6%

† callers can have >1 reason for an individual call

Figure 1: How did you hear of our service?



OBJECTIVES:

THE ARTHRITIS SUPPORT AND INFORMATION LINE

1. To offer information, suggestions, encouragement and emotional support to assist callers in learning how to manage arthritis.
2. To listen to callers in a calm and supportive way and help reduce their anxiety.
3. To help callers with initial concerns and fears when they first learn they have arthritis.
4. To encourage callers to take steps toward positive health management by making them aware of the health team involved in treating arthritis.
5. To discuss various coping mechanisms for dealing with arthritis.
6. To assist callers in locating appropriate community, health and government resources, providing current addresses and phone numbers.
7. To answer basic questions about arthritis, send appropriate pamphlets and/or information and encourage caller to seek appropriate services.
8. To encourage callers to be cautious about new and unproven cures and remedies that they may have heard or read about.
9. To be understanding and empathetic to callers if they are concerned about taking recommended medications due to side-effects.
10. To remain neutral if callers should express dissatisfaction with their doctor and encourage callers to become active partners in their health care.
11. To determine what services and support groups will best meet the callers' needs and make appropriate referrals and/or recommendations.

APPENDIX B

CALL RECORD LOG - ARTHRITIS SUPPORT & INFORMATION LINE

Date: _____

Volunteer: _____

Length of Call: (minutes) _____

1-800 ___ Local ___ LD ___ Written Req. ___ Walk-in ___

Reason for call: _____

Action Taken: _____

Support Provided: _____

Referral to Arthritis Society &/or Community Services:

- Consultation & Therapy Services: _____
- Arthritis Bluebird Club (Support Groups throughout Ontario): _____
- Arthritis Support & Advocacy Network (Toronto Support Group): _____
- Pool Program: _____
- Arthritis Self-Management Program: _____
- Specific Disease Assoc. (specify): _____

- Professional Services: _____
- Community Resources: _____

Personal Information

Caller's Name: _____

Address: _____

Postal Code: _____

Tel: () _____

Have you called us before?
 Yes ___ No ___

Is this a professional call?
 Yes ___ No ___

(i.e. doctor's office, pharmacy, student, etc.)
 If **no** please complete questionnaire.

Age of person with arthritis: Under 35 ___; 35-44 ___;
 45-54 ___; 55-64 ___; 65-74 ___; over 75 ___

Sex: M ___ F ___

Physician: Family Doctor ___
 Rheumatology ___
 Other ___

Form of arthritis:

Osteoarthritis	___	Scleroderma	___
Rheumatoid Arthritis	___	Fibromyalgia	___
Psoriatic Arthritis	___	Lupus	___
Ankylosing Spondylitis	___	Gout	___
Juvenile Arthritis	___	Other	___
Not Known	___		

Are you using our Consultation & Therapy Service?
 Yes ___ No ___
 P.T. ___ O.T. ___ S.W. ___

How did you hear of our service? _____

Volunteer's Comments: _____

APPENDIX C

CALL RECORD LOG - ARTHRITIS SUPPORT & INFORMATION LINE

Phase I

Volunteer's name: _____ Identification Number: _____

Today's Date: _____

Reason for call (please check all that apply):1. Education/Information

- general information on arthritis
- disease-specific information
- | | |
|---|---|
| <input type="checkbox"/> fibromyalgia | <input type="checkbox"/> lupus |
| <input type="checkbox"/> rheumatoid arthritis | <input type="checkbox"/> ankylosing spondylitis |
| <input type="checkbox"/> osteoarthritis | <input type="checkbox"/> gout/pseudo gout |
| <input type="checkbox"/> juvenile arthritis | <input type="checkbox"/> other (please specify) _____ |
- diet
- exercise
- medications (please state which one) _____
- books
- videos
- coping with stress/pain management
- foot care
- Arthritis Self-Management Program (ASMP)

2. Community Services

- home care
- pool programs
- transportation
- health insurance/disability pension information
- support groups/meetings
- housing information

3. Medical and Related Services

- name of a rheumatologist
- CTS physiotherapy
- hydrotherapy (pool programs)
- occupational therapy
- social work
- other rehabilitation service (please specify) _____
- surgery
- alternative therapies (ie. acupuncture, herbs, homeopathy)
- name of a chiropractor
- assistive devices

4. Arthritis Society Information

- how to become a member of TAS
- memorial donations

5. Miscellaneous

- newspaper articles

6. Other (please specify) _____

APPENDIX D

CALL RECORD LOG - ARTHRITIS SUPPORT & INFORMATION LINE
Phase II

Volunteer's name: _____ Identification Number: _____
 Today's Date: _____

Reason for call (please check all that apply):

1. Education/Information

- general information on arthritis
- disease-specific information
 - fibromyalgia
 - rheumatoid arthritis
 - osteoarthritis
 - juvenile arthritis
 - lupus
 - ankylosing spondylitis
 - gout/pseudo gout
 - other (please specify) _____
- diet
- exercise
- medications (please state which one) _____
- books
- videos
- coping with stress/pain management
- foot care
- Arthritis Self-Management Program (ASMP)

2. Community Services

- home care
- pool programs
- transportation
- health insurance/disability pension information
- support groups/meetings
- housing information

3. Medical and Related Services

- name of a rheumatologist
- CTS
 - physiotherapy
 - hydrotherapy (pool programs)
 - occupational therapy
 - social work
- other rehabilitation service (please specify) _____
- surgery
- alternative therapies (ie. acupuncture, herbs, homeopathy)
- name of a chiropractor
- assistive devices

4. Arthritis Society Information

- how to become a member of TAS
- memorial donations

5. Miscellaneous

- newspaper articles

6. Other (please specify) _____

7. Issues raised during the call (please check all that apply)

- caller did not know about the existence of rheumatologists
- caller did not know about the existence of the CTS
- caller was upset and volunteer provided emotional support (please describe)

- caller cited a negative experience with their physician or other caregiver (please describe)

- volunteer faced with a question for which they had no answer and/or no information to send out (please describe)

Other comments:
