

יום הטרשת הנפוצה הבינלאומי
يوم مرض التصلب المتعدد العالمي
Международный день Рассеянного Склероза
worldMSday



Survey of the Multiple Sclerosis Association 2018/2019

The study's objective is to examine multiple sclerosis patients' perceptions and positions towards the Israel Multiple Sclerosis Society and get it published for the International Multiple Sclerosis Day in May 2019

Geocartography directed by:

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Prof. Rina Dgany

The study was conducted for:

The Israeli Multiple Sclerosis Association
Information, Strategy & Solutions

האגודה הישראלית לטרשת נפוצה
מנהיגה שירותים לאלפי חולים ובני משפחות בישראל
The Israel Multiple Sclerosis Society
Израильская ассоциация рассеянного склероза
الجمعية الإسرائيلية للتصلب المتعدد



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Study Methodology

The study's objective is to examine multiple sclerosis patients' perceptions and positions towards the Israel Multiple Sclerosis Society and get it published for the International Multiple Sclerosis Day in May 2019

Study objective

Designated field survey

Methodology

Men and women diagnosed as afflicted with multiple sclerosis, members of the Israel Multiple Sclerosis Society

The responders

N=474.

Sample size

Maximal statistical error range is + 4.38% at a statistical significance level of 95%

Stat Error range

October 2018 – February 2019

Performance period

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Survey population and sample:

The Society has 4,900 registered members, of which 4,000 members have been sent questionnaires.

The questionnaires were completed between October 2018 and February 2019.

At the end of the completion phase, 474 questionnaires were received – 11.85% - a high rate of response.

305 printed questionnaires and 169 online questionnaires.

How the Questionnaires were completed:

- Independently by the Society members were sent back by email, fax, Israel Post;
- With the assistance of social work students from the Hebrew University, Mivchar College, Ashkelon College;
- By volunteers who assisted people who have writing difficulties;
- During conferences of the Society (Women Conference, General Assembly and conference, retreat, Ashkelon Conference, Haifa Conference)
- Online survey

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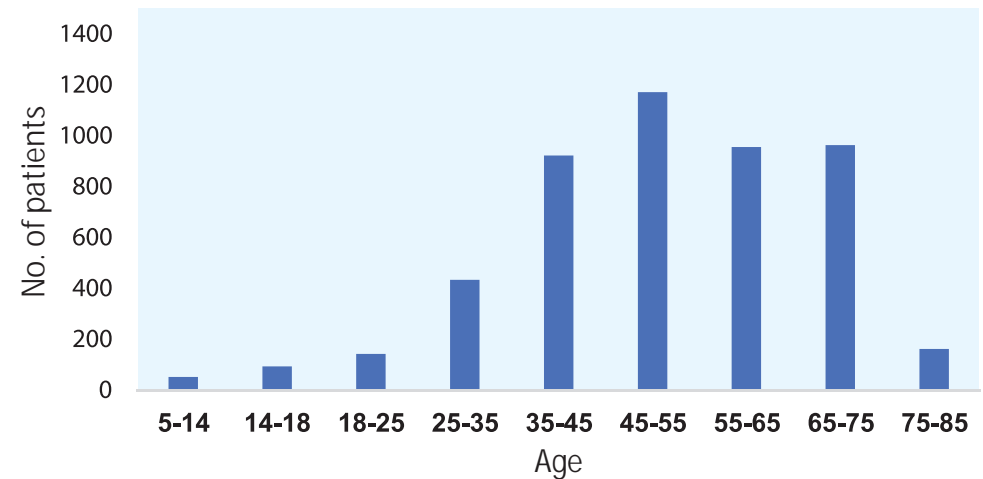
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Statistical data – the Israel Multiple Sclerosis Society

- a. Number of registered persons in the Society – 4,900 patients + 25,000 family members.
- b. 38% do not receive any treatment, mostly ages 55 – 85.
- c. Ages of multiple sclerosis patients registered in the Society:

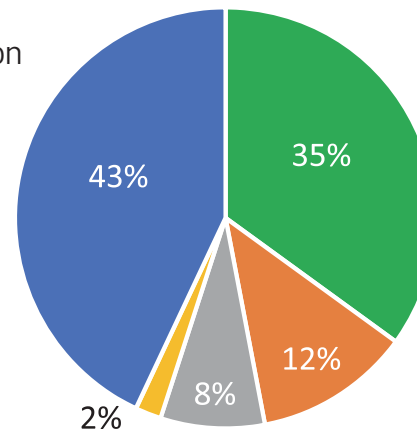
No. of patients	Age
52	5-14
94	14-18
143	18-25
434	25-35
923	35-45
1172	45-55
956	55-65
964	65-75
162	75-85

Ages of multiple sclerosis patients registered in the Society



- d. Segmentation by population

- From the former Soviet Union
- Israeli Arabs
- Ultraorthodox Jews
- Other minorities
- Israeli Jews



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Main findings (1/6)

MS characteristics and patients

MS period – 65% diagnosed for more than 10 years; 20% diagnosed for 6-10 years; 10% diagnosed for 3-5 years;
5% diagnosed for 1-2 years

Disability percentages – 17% has up to 19% disability percentages; 24% has 20%-34% disability percentages; 59% has 75% and more disability percentages

Mobility – 31% freely mobile; 30% on wheelchairs; 17% cane; 17% rollator; 13% walker; 5% crutches; 3% bedridden

By gender-

Females – 24% freely mobile; 11% use crutches; 12% use walkers; 12% use rollators; 19% use canes; 36% on wheelchairs; 3% bedridden

Males – 35% freely mobile; 2% use crutches; 13% use walkers; 20% use rollators; 16% use canes; 25% on wheelchairs; 3% bedridden

Drug therapy – 38% without any drug therapy

Additional comorbidities - almost half the members suffer from additional comorbidities – 43% hypertension; 35% sleep disorders; 31% chronic pain; 26% depression and anxiety; 21% diabetes

Use of catheter – 76% self-catheterization; 24% permanent catheter

Sharing the disease with their surrounding environment – 91% sharing with their families; 80% sharing with friends; 76% shared with their children; 69% shared with their spouses

Did not share due to concerns – 46% did not share at work – 48% were concerned about a change in the way they were viewed; 39% were concerned about lay offs; 34% wanted to keep their privacy.

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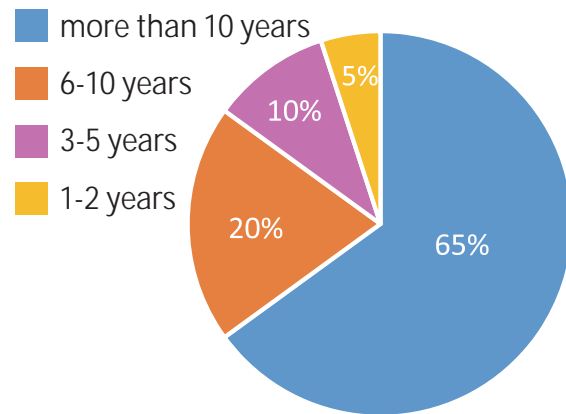
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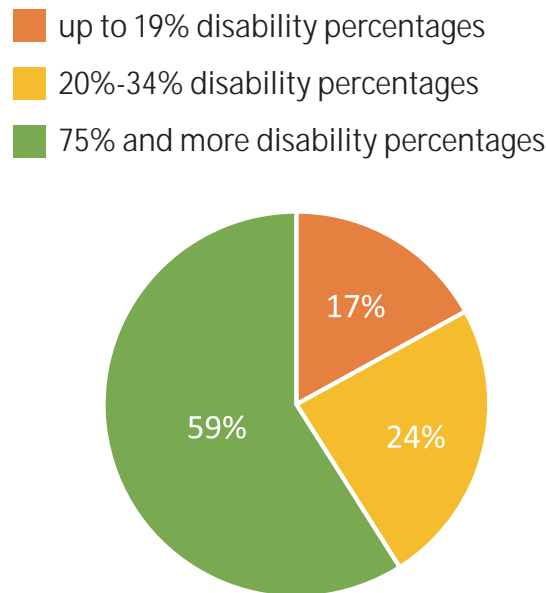
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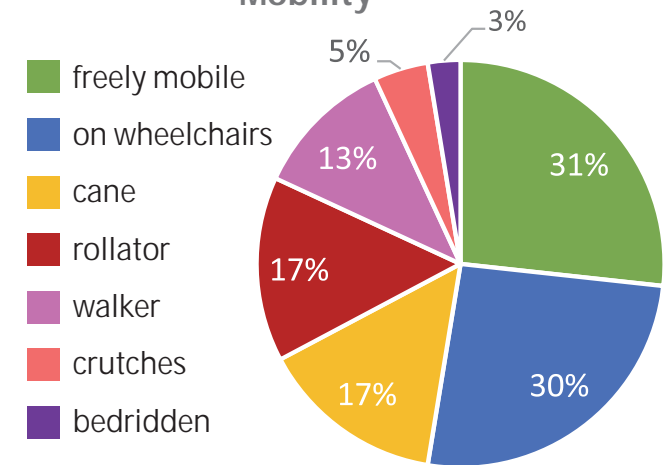
MS period



Disability percentages



Mobility



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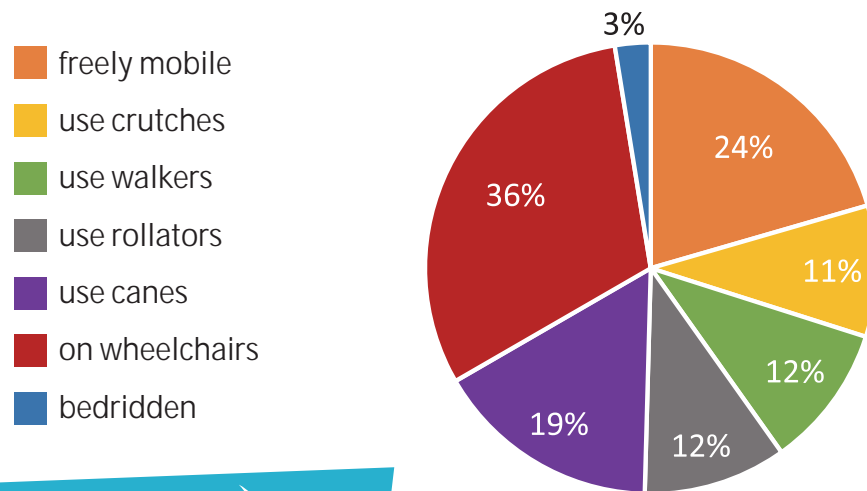
MS characteristics and patients

Mobility by gender -

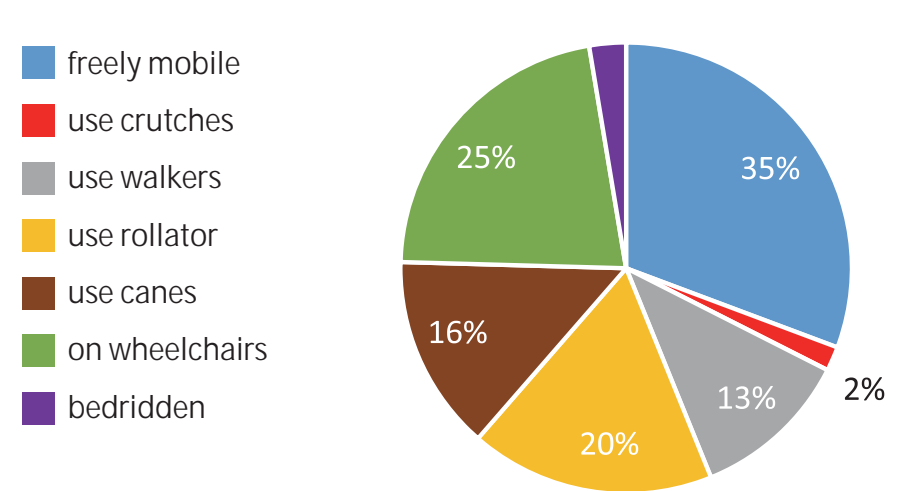
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Mobility by gender - females



Mobility by gender - males



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Main findings (1/6)

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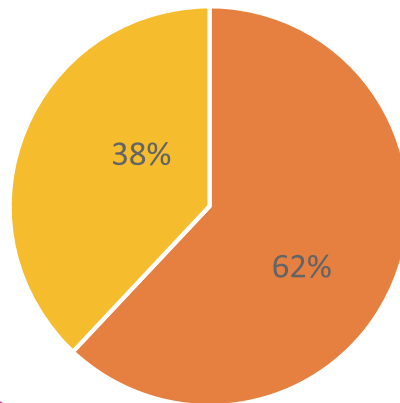
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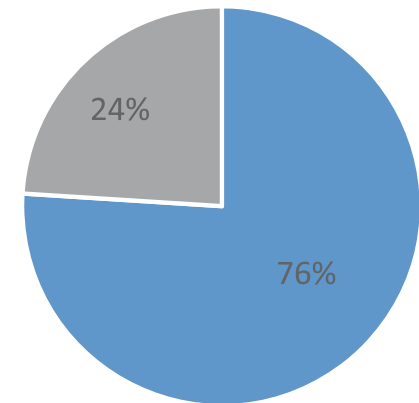
Drug therapy

- Use drug therapy
- Don't use drug therapy



Use of catheter

- self-catheterization
- permanent catheter



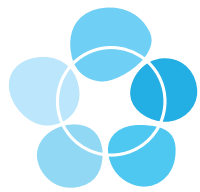
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Main findings (2/6)

Treatment of MS and its impact on one's life style

Important parameters in treatment of MS - similarly to the previous survey, the most important parameters in multiple sclerosis treatment are long term effect and impact on the disease progression EDSS. In the current survey the effect of the drugs taken on the number of attacks as well as the adverse effects of the drug have gained additional importance.

It seems that the percentages of patients involved in selecting the treatment has grown, same as their stated set of important considerations (the treatment not only should work, but also be convenient);

64% of the respondents said, "That the drug will have long term effect"; 59% That the drug will not affect the progression of the disease EDSS; 38% affect the number of attacks; 37% adverse effects

Selection of treatment – 46% received or were assisted by the neurologist's recommendation in selecting their desired treatment. We may note that patients with higher education – tend to be assisted more by the neurologist and fewer of them choose not to receive any treatment.

Adherence to the treatment – 81% adhere to the treatment, **manners of improving adherence**: request of reminders from the accompanying nurse from the pharma company and reminders and alerts on the cell phone.

Switch of treatment in the last two years – reason for switch – 55% did not switch in the last two years, the most common reason for switching is due to undesirable adverse effects of the drug. The treatment effectiveness continues to be high. Percentage of responders without attacks has dropped from 63% to 20% under the effect of the treatment. Even in the group that still suffer from attacks under the treatment a decrease in the attacks reported frequency was registered

Medical marijuana – 83% do not use medical marijuana and similarly to the previous survey the main reason is not wanting to. Other reasons for non – use demonstrate less fear from the effects of marijuana. 48% don't want to smoke; 43% - their neurologist did not discuss this topic with them.

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Main findings (2/6)

Satisfaction of the Attending neurologist functionality is high – 81% are satisfied, particularly from referrals to various treatments and testing and less satisfied from the ability to talk to the neurologist on the phone when needed.

MS impact on the symptoms of the responders' daily life –

The situation has changed for the worst as a result of: 87% fatigue; 73% activity of the urine bladder; 71% sleep interference; 71% pain; 71% mood; 71% sensitivity to heat; 70% interference in sensation; 67% sexual reaction; 65% status of employment; 60% depression; 60% self confidence; 58% continence control; 55% anxiety; 54% interference in vision; 51% control of bowel movement; 51% social life; 35% interference in speech; 35% uncontrollable cry and laughter bouts; 34% interference in swallowing.

MS impact on the symptoms of the responders' daily life –

The situation has changed for the worst as a result of 64% mobility at home; 56% ability to dress oneself; 55% washing; 37% eating.

The situation has changed for the best: 63% relationships between parents and children

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Main findings (4/6)

Satisfaction from the Israel MS Society's activity

The majority (82%) believe the Society provides most of the professional services they require as patients.

Awareness and perception of the Israel MS Society

The Society (staff and website) are used as almost the sole updating source on the activities and services the Society provides. The awareness of the Society and its importance and necessity continue to be high among the Society members.

74% are aware of all the activities of the Society.

Source of information about treatments

62% receive information from the Society; 42% from the Society's website.

The Society continues to be the most common source of information on possible treatments for MS.

Updates on activities, services and legal rights

79% from the Society's staff

21% from the Society's website.

Importance of the Israel MS Society in Israel

93% believe that the activities of the Society are professional, important, necessary and create an impact in Israel

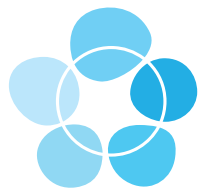
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Main findings (5/6)

Satisfaction from the Israel MS Society services

81% are satisfied with the Society's activities in general;

80% are satisfied with the annual newsletter; 79% are satisfied with the information and explanations they receive from the Society; 62% are satisfied with the conferences; 62% are satisfied with the website; 56% are satisfied with the support groups; 50% are satisfied with the annual retreat; 46% are satisfied with the summer camp.

The necessity of additional Multiple Sclerosis societies –

81% - most of the responders did not think its necessary to have additional Multiple Sclerosis societies in Israel

The effect of additional Multiple Sclerosis societies on donations to the Israel MS Society –

78% believe that operation in parallel of MS Societies may harm the fund raising of the Israel MS Society, same as the previous survey.

Connection to the Israel MS Society and sources of information

Connection frequency with the Society – 51% are in contact with the Society between 1 - 6 times per year (Discussions, consulting, meetings)

Communication routes with the Society – 84% receive materials from the Society; 40% enter the Society's website; 40% take part in conferences; 34% take part in support groups; 26% take part in the retreat and the summer camp.

The Society's Facebook page – only 38% are members

Barriers to the Society's Facebook membership – 42% don't have Facebook; 32% are not interested in becoming involved with a social network; 26% are not interested in being identified as multiple sclerosis patients

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Main findings (6/6)

Satisfaction from the authorities handling services in Israel

In comparison with the previous survey a general increase is noticed in the number of persons requiring the services of the institutions in question, and many turn to the Israel MS Society in applications of assistance with the authorities. In reference to most of them, a decrease in satisfaction was noted compared to the previous survey.

The following authorities stood out in their negative reviews: Amidar (housing), Ministry of Aliyah and Integration (immigration to Israel), mortgage insurance service providers and the Ministry of Construction and Housing, Leumit HMO.

The low satisfaction rate from the service providing authorities is standing out in its negativity perhaps in contrast with the difficult symptoms of the disease. The members hardship in operating with the authorities provide a vast opportunity for action and change, and that's where the Israel MS Society steps in and assists its members in forwarding their requirements and needs, by bringing to light and help make a change in the public arena.

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