

YOUNG PERSONS' SURVEY REPORT



INTRODUCTION

In early 2023, MS Ireland conducted a comprehensive survey aimed at understanding the experiences and needs of young people living with Multiple Sclerosis (MS), aged 18 to 35. The primary objectives of this survey were to assess how young people engage with MS Ireland, their awareness of the organisation, and to identify the barriers they face. A total of 126 participants took part in the survey, and the data collected included both qualitative and quantitative responses. We would like to thank all who took part in this survey. Your input will enable MS Ireland to be more informed, responsive and supportive of young people in the MS community.

RESULTS

AWARENESS OF MS IRELAND

The survey found that awareness of MS Ireland amongst young people with MS varies:

- 28.07% of respondents reported knowing a lot about MS Ireland and the organisation's work
- 65.79% had limited knowledge
- 6.14% admitted to knowing nothing about MS Ireland

This data highlights the importance of improving awareness amongst this demographic of the work MS Ireland is engaged in and how they can contribute to the direction and delivery of the services we provide.

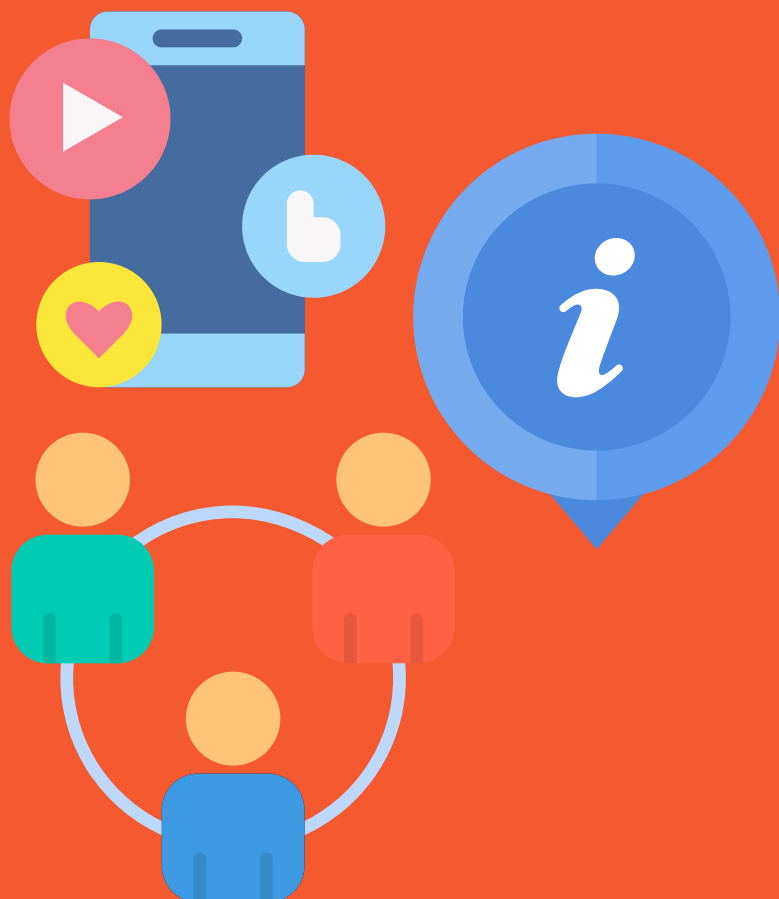


SIGNPOSTING TO MS IRELAND

Signposting to MS Ireland at the time of diagnosis was addressed in the survey:

- 50% of respondents reported being signposted to MS Ireland at the time of their diagnosis
- Among those who were not signposted, 84.2% expressed a desire for such guidance

These results emphasise the significance of enhancing collaboration with healthcare professionals to ensure that individuals with MS are informed about the services offered by MS Ireland from the outset.



84.2%

OF THOSE WHO WERE NOT
SIGNPOSTED TO MS IRELAND
FELT IT WOULD HAVE BEEN BENEFICIAL
TO RECEIVE THIS SIGNPOSTING
AT THE TIME OF DIAGNOSIS

ENGAGEMENT WITH MS IRELAND

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The time between diagnosis and engagement with MS Ireland was analysed:

- 58.7% of respondents engaged within one year of diagnosis
- Within two years, 74.3% had engaged with MS Ireland
- Within five years, 85.3% had engaged in some manner with MS Ireland

These statistics suggest that a majority of young people living with MS reach out to MS Ireland relatively soon after diagnosis.

REASONS FOR NOT ENGAGING WITH MS IRELAND

Some of the reasons cited for not engaging with MS Ireland included:

- Not perceiving MS as a priority
- Feeling unprepared or not 'sick' enough to use MS Ireland's services
- Lack of awareness of MS Ireland and the services provided
- Belief that the services available were not suitable for their needs

Understanding these barriers is vital for improving engagement with this demographic. Readiness to engage may be a factor for those who choose not to engage with MS Ireland.



ENGAGEMENT CHANNELS

The survey revealed the various channels through which people engaged with MS Ireland, including

- Website
- Community Worker Service
- Social Media
- Physiotherapy
- Local Voluntary Branches
- Fundraising
- Information Line
- Webinars, podcasts, and other events such as wellness days, eNews, emails, and young persons' events

These channels should be optimised and expanded to better cater to the needs of young people with MS.

REPRESENTATION OF THE AGE COHORT

Regarding whether MS Ireland represents the 18-35 age cohort well, the results were mixed:

- 46.73% of respondents felt well represented
- 53.27% believed they were not well represented

Factors contributing to a lack of representation included the perception that MS is an older person's condition, a lack of visibility of young people at events, and timing issues with events held during typical work hours.

CATERING FOR THE AGE COHORT

When asked if MS Ireland caters well to the 18-35 age group, the results again displayed a divide:

- 54% felt well catered for
- 46% did not feel well catered for

Reasons cited for feeling under-catered for included a perceived focus on an older age cohort, a lack of young people at events, and a shortage of information tailored to the newly diagnosed.

CHALLENGES FOR YOUNG PEOPLE LIVING WITH MS

The survey identified numerous challenges faced by young people living with MS, including:

- Symptoms (cognition, fatigue, pain)
- Access to services
- Struggles to achieve life milestones
- Public misunderstanding
- Barriers to work and education
- Relationship impacts
- Financial concerns
- Fear of the unknown
- Discrimination
- Isolation

Understanding these challenges is crucial for tailoring support and services.

At a time in life where decisions regarding relationships, education, housing, careers and family planning are common, supports and information are essential to best support people to make meaningful choices that enable them to live the lives of their choice.

Young people with MS often grapple with feelings of isolation, as their daily challenges and medical needs can set them apart from their peers. The invisible nature of the condition can leave them feeling isolated, as their struggles may not be readily apparent to others. Coping with uncertainty and adapting to a unique life path can intensify their sense of being different than their peers. Building a support network and raising awareness can help combat these feelings and foster a sense of belonging.



KEY ACTIVITIES

Respondents suggested several key activities for MS Ireland to engage in, including:

- Social events for young people
- Employment support
- Information tailored for young people.
- Groups, peer support, and buddy systems
- Public awareness campaigns
- Research and advocacy
- Support for communicating needs
- More relatable content
- Online forums and themed Zoom meetings
- Physical activity opportunities
- Informative videos on platforms like TikTok and Instagram
- Counselling services
- Greater balance of times for activities and engagements



JUST ONE THING..

When asked what one thing MS Ireland could do, young people responded with a range of suggestions, such as:

- Sharing stories on Instagram
- Offering support groups
- Counselling services
- Creating opportunities for connections
- Providing information on lifestyle modifications
- Financial awareness/support
- Annual check-ins
- Ensuring young people know they are not alone

DISCUSSION

The survey highlights the diverse needs and perspectives of young people living with MS. It is evident that many respondents perceive MS Ireland positively, but there is a significant portion that feels underserved and underrepresented. The survey's findings indicate a need for increased public awareness and information campaigns, improved representation of young people in MS Ireland materials, and tailored resources to address specific questions and concerns of this age cohort. Collaborations with healthcare professionals and employers, peer support, and improved outreach through digital platforms are essential strategies to better engage and serve young people with MS.

RECOMMENDATIONS

Based on the survey findings, the following recommendations are proposed:

1. Conduct a public awareness and information campaign to increase awareness of MS Ireland's services among young people and healthcare professionals
2. Increase representation of young people in MS Ireland's materials, publications, and digital platforms
3. Develop tailored resources to address the specific questions and concerns of the 18-35 age cohort
4. Enhance collaboration with healthcare professionals to ensure that individuals with MS are informed about the services offered by MS Ireland
5. Work with employers and workplaces to provide support for young people with MS
6. Implement peer support programs to facilitate connections among young people with MS
7. Expand digital outreach efforts, including TikTok and Instagram, to reach a younger demographic
8. Making counselling services available across a variety of platforms
9. Greater involvement of young people in MS Ireland service planning to ensure that our offering is representative of this age cohort (e.g. flexible times including evenings for activities and engagements)
10. Assisting this age-cohort in promoting positive mental health (e.g. access to peer support and counselling)



MS Ireland has a significant opportunity to better engage and serve young people living with MS by addressing the issues and recommendations raised in this survey. These efforts will help create a more supportive and inclusive environment for this demographic.



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