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The information in this report shines a bright light on what is fast becoming a public health crisis in the United States. These survey results tell the story of a frequently overlooked and under served population. As a nation, we can, and must, do better. We must do better at proactively relieving the sense of isolation and stress that caregivers often feel by connecting them to resources that might help me succeed as Jeanne’s caregiver. And so I learned how to be good at providing care by first making every possible mistake.

The caregiver’s perspective

Foreword

When my wife, Jeanne, was diagnosed with secondary progressive MS, I stopped working for about a decade to serve as her caregiver. At the time of Jeanne’s diagnosis, her neurologist talked to us about symptom management and prescription medications that could be helpful in managing Jeanne’s MS. But there weren’t any discussions or referrals to resources that might help me succeed as Jeanne’s caregiver. And so I learned how to be good at providing care by first making every possible mistake.

As the population of the US grows and ages, caregivers will continue to play a critical role, leading to a substantial economic impact. Indeed, unpaid caregiving is one of the most important social and economic policy issues worldwide1. A report examining the global state of care, published by Embracing Carers™ in 2017, a collaboration between Merck KGaA, Darmstadt, Germany and leading global caregiver organizations around the world, highlighted the need to improve recognition and support for unpaid caregivers through increased discussions worldwide with stakeholders, healthcare systems, and policy makers about the role of caregivers. Recommendations included assessments of caregivers’ needs, sharing best practices across countries and identifying opportunities to increase support to unpaid caregivers.

Through a collaboration between IACO (International Alliance of Carer Organizations), and Merck KGaA, Darmstadt, Germany, this report explores the situation of those caring for people living with Multiple Sclerosis (MS) in the US, bringing their individual experiences into greater focus. A condition affecting almost one million people in the US2, MS is an unpredictable, often disabling disease of the central nervous system commonly diagnosed in people between the ages of 20 and 403.

Findings in this report are based on a survey of 150 MS caregivers in the US, which explored the challenges and impact of being a caregiver for someone living with MS. It aimed to better understand the impact on the individual caregiver, their own physical, emotional and financial health, and where they seek support and guidance.

The findings from this survey shed light on the needs of MS caregivers in the US and highlight practical steps that can be taken to improve support for them.

This can lead to little problems, left unattended, growing into bigger problems.

Former First Lady Rosalyn Carter said that there were only four types of people in the world. Those who have been caregivers, those who are currently caregivers, those who will be caregivers, and those who will need a caregiver. The story of being a caregiver is, in one way or another, everyone’s story. My hope is that this report ignites conversations about the vitally important role that caregivers play, and our collective responsibility in helping them succeed in that role without losing themselves in the process.

Jon is a caregiver to his wife, Jeanne, who was diagnosed with secondary progressive MS in 1997. With his caregiving experience, he volunteered to write the National MS Society’s first blog specifically for MS caregivers. He has previously facilitated a caregiver support group and one-to-one coaching for caregivers through his local National MS Society chapter.

Jon hosts and produces a weekly podcast, RealTalk MS, discussing the latest MS news and research. Every podcast episode also features an interview with world-class MS researchers, clinicians, advocates, and policy makers who are making a difference in the lives of people living with MS.

Join the conversation: #MSInsideOut

3 www.ninds.nih.gov/Disorders/Patient-Caregiver-Education/Hope-Through-Research/Multiple-Sclerosis-Hope-Through-Research#3215_1

US/NPR/0918/0409a Living with Multiple Sclerosis: The caregiver’s perspective 1
The International Alliance of Carer Organizations (IACO) is a global coalition of 15 member nations committed to building a global understanding and respect for the vital role of family caregivers. Recognized as an official NGO by the United Nations, each IACO member country is represented by a nationally-renowned caregiver organization. The coalition meets annually to share best practices, identify global issues, and advocate for family caregivers.

Embracing Carers is a global initiative led by Merck KGaA, Darmstadt, Germany, in collaboration with leading caregiver organizations around the world designed to increase awareness, discussion, and action about the often-overlooked needs of caregivers. Given that caregivers need support and often do not know where to turn for help, Embracing Carers was created to help fill that void.

We are pleased to have been involved in this study which documents the impact MS can have, not only on the MS patient but also his/her caregiver. MS is a devastating disease and the responsibilities assumed by caregivers intensify as the disease progresses. It impacts on the caregiver’s physical and emotional health, finances, and employment.

We encourage healthcare professionals and government officials to review the findings and identify ways in which they can better assist the MS caregiver.

Nadine Henningsen
Board Chair, Executive Advisor, IACO

EMD Serono, Inc.
EMD Serono – the biopharmaceutical business of Merck KGaA, Darmstadt, Germany, in the U.S. and Canada – is engaged in the discovery, research and development of medicines for patients with difficult to treat diseases. The business is committed to transforming lives by developing and delivering meaningful solutions that help address the therapeutic and support needs of individual patients. Building on a proven legacy and deep expertise in neurology, fertility and endocrinology, EMD Serono is developing potential new oncology and immuno-oncology medicines while continuing to explore potential therapeutic options for diseases such as psoriasis, lupus and multiple sclerosis. Today, the business has approximately 1,300 employees around the country with commercial, clinical and research operations based in the company’s home state of Massachusetts.

Merck KGaA, Darmstadt, Germany in Multiple Sclerosis
Merck KGaA, Darmstadt, Germany has a long-standing legacy in neurology and immunology, with significant R&D and commercial experience in multiple sclerosis (MS). Merck KGaA, Darmstadt, Germany aims to improve the lives of those living with MS, by addressing areas of unmet medical needs.
ABOUT THE REPORT

PRIMARY RESEARCH FORMS THE FOUNDATION OF THIS REPORT.

It was important that the findings were an accurate reflection of the day to day experiences of caregivers. To do so, an online survey was conducted through Vitreous World, a full-service research consultancy with specific expertise in healthcare. The survey data was collected during June and July 2018, and was part of a wider survey of 1,050 MS caregivers aged 18 and over across 7 countries – the UK, US, Canada, France, Spain, Italy and Germany, with 150 respondents per country. The survey was conducted on behalf of Merck KGaA, Darmstadt, Germany, from a database of caregivers with 150 respondents per country.

A total of 32 questions was asked during the survey, focusing on three main areas:

- details on the caregiver themselves and the person for whom they were caring
- the impact of caregiving
- potential solutions to the challenges of caring

In addition, the report also features testimonies from caregivers who share their unique and very personal experiences of taking care of a loved one with MS.

The sample size of this survey means that while the results are not exhaustive, they are illustrative of the MS caregiver population across the world. This report focuses on the experiences of caregivers in the US and may be used to generate discussion and policy ideas. Any categorization of the severity of MS of the person they care for is based on the caregiver’s own assessment.

AREAS FOR FURTHER STUDY

This report draws attention to the situation of MS caregivers in the US but also highlights the following for further investigation. These include, but are not restricted to, questions around:

- how frequently they care for someone with MS
- the percentage of those that are divorced from the person they are caring for due to the strain of MS
- impact on issues of intimacy
- how often they speak with a healthcare professional about MS
- what type of organizations they look to for support

Due to the impact of caring on employment, further research is also needed to understand how MS caregivers are obliged to adapt their work to meet the demands of caring, which raises questions about the economic impact of MS on the workforce, alongside the economic impact on the family.

GLOSSARY

**MS caregiver** – there is no uniform term for caregiver across the world and terms such as carer, caregiver and care partner are amongst those which may be used. For the purposes of this report we have used the term MS caregiver to cover any person providing care for someone living with MS. This individual is usually unpaid and could be a partner, family member, neighbor, friend or other significant individual who takes on a caring role to support somebody with diminished physical ability, a debilitating cognitive condition or a chronic-limiting illness.

**Younger caregiver** – throughout the report, those that are described as “younger caregivers” were aged 18 to 34 years of age when surveyed. The minimum age of respondents to our survey was 18 years old, therefore we did not survey those that would be considered child caregivers.

**Third-party organization** – this term refers to organizations such as non-profit organization, charity, government or other organization providing support.

**Multiple Sclerosis (MS)** – a chronic, inflammatory condition of the central nervous system and is the most common, non-traumatic, disabling neurological disease in young adults. It is estimated that approximately 2.3 million people have MS worldwide, with around one million in the US. While they can vary, the most common symptoms of MS include blurred vision, numbness or tingling in the limbs and problems with strength and coordination. The relapsing forms of MS are the most common.

**The course of MS is different for everyone, which makes it difficult to predict.**

**Relapsing remitting MS (RRMS)** is the most common form of MS – around 85% of people with MS are initially diagnosed with this type. For most people this starts with a first attack, usually but not always followed by a full to almost full recovery. Weeks, months or even years may pass before another attack occurs, followed by a period of relief from symptoms.

**Primary-progressive MS** is characterized by a gradual physical decline with no noticeable remissions, although there may be temporary or minor relief from symptoms.

**Secondary progressive MS** is a stage of MS which comes after relapsing remitting MS for many people. In SPMS, people may or may not continue to experience relapses caused by inflammation; the disease gradually changes from the inflammatory process seen in RRMS to a more steadily progressive phase characterized by nerve damage or loss.

1 www.nationalmssociety.org/nationalmssociety/media/msnationalfiles/brochures/brochure-just-the-facts.pdf
2 www.nationalmssociety.org/What-is-MS/Types-of-MS/Relapsing-remitting-MS
3 www.nationalmssociety.org/What-is-MS/Types-of-MS/Secondary-progressive-MS
**EXECUTIVE SUMMARY**

**HIGHLIGHTS**

**MS CAREGIVERS PLAY A CRUCIAL ROLE IN THE LIVES OF PEOPLE LIVING WITH MS. A PROGRESSIVE DISEASE OF THE CENTRAL NERVOUS SYSTEM, MS IS TYPICALLY DIAGNOSED BETWEEN 20 AND 40 YEARS OF AGE**¹ **AND IS THOUGHT TO AFFECT AROUND ONE MILLION PEOPLE IN THE US**².

The most common symptoms of MS are fatigue, visual disturbances, altered sensations and difficulties with mobility, meaning that most people living with MS need support at some stage following their diagnosis.

As a result, a substantial number of partners, parents, young adults, members of extended family and friends throughout the country care for a loved one with MS, helping with everything from basic chores to administering medication.

While the vital role that caregivers play, and the societal and economic value of their role, are being more widely acknowledged, these survey findings highlight that there is much to be done to ensure that caregivers are adequately recognized and equipped with the financial and emotional support they deserve.

**Caregivers: an unacknowledged and unsupported workforce**

This survey highlights the work that is carried out by MS caregivers, a role that is frequently invisible and unsupported. While over half (55%) of caregivers were looking after a partner with MS, almost a third were caring for either a child or a parent with the condition. As a consequence of these relationships and due to the long-term nature of MS, some caregivers take on a responsibility which can last decades. In fact, nearly a quarter of those surveyed had been caring for somebody for 11 years or more, and 14% had been caring for over 16 years. Of those surveyed, 41% started caring for somebody when they were 34 years old or younger.

**The result: many people are spending their early adult years and a significant part of their own life, being responsible for someone with a progressive and unpredictable condition.**

**The challenge of a life of uncertainty**

Nearly all of those surveyed (95%) agreed that there were many positive aspects to caring, and 58% acknowledged that the role had made them stronger as a person. This is particularly the case when caring for a person with MS, partly attributable to the unpredictable and episodic nature of the condition, which includes bouts of worsening symptoms. Other positive experiences included improved relationships with their family member (45%) and meeting great people (17%). Despite the positive impact, 49% of the caregivers surveyed reported that their caring responsibilities had negatively impacted on their life goals and plans, while a similar proportion admitted to experiencing either severe or high stress levels all the time or often.

Many caregivers feel pressure to remain in employment due to the financial strain of healthcare costs or the necessity of maintaining their income or health insurance cover.

**The right support, at the right time**

Most of those surveyed (93%) agreed there is a need for support, particularly due to the unique way MS affects each individual patient. When asked about the different times support was needed, 33% selected at the point of diagnosis, increasing to 38% of caregivers aged 18-34. As is the case with any disease, with information comes empowerment, so it is critical that caregivers are equipped with sufficient knowledge relating to both the disease and the support systems that are available to them.

**51%** of those questioned said that the healthcare professional did not explain the disease, its progression, and potential care needs very well, identifying an area to improve upon.

1 IN 10 of those surveyed lost a job due to caring, leaving many in a vulnerable position, being less able to plan or save for the future.

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² www.nationalmssociety.org/About-the-Society/MS-Prevalence

4 Living with Multiple Sclerosis: The caregiver’s perspective US/NPR/0918/0409a
The need for support
The long-term, unpredictable nature of MS means support is critical from the initial point of diagnosis. Caregivers need support as they juggle the challenges of caring for their loved one, with the realities of life – education or employment obligations, life aspirations, and overall health and wellness.

The long-term nature of MS means there is a need for a broad range of professionals and professional organizations to understand the responsibilities and challenges MS caregivers face and a need to provide information, support, policies and practices.

INFORMATION AND SUPPORT NEEDED THROUGHOUT THEIR MS CAREGIVER JOURNEY:

- Information for MS caregivers at the point of diagnosis about disease progression and what to expect.
- Broader awareness of, and access to, information and support currently available to caregivers.
- Awareness of the emotional and mental support MS caregivers need, so friends and those closest to the caregivers are equipped to spot the signs of severe strain and provide suitable support.
- Schools and universities, to provide support to MS caregivers to manage their caring responsibilities alongside their educational development.
- Information and financial guidance for caregivers wanting to plan their future.
- Employers to recognize and understand MS caregivers’ needs and develop policies which support them during times of greater caring responsibility.
- Greater awareness of access to respite care to alleviate the strain of caring.
I’ve been a carer for my mother since she was diagnosed with MS seventeen years ago when I was a teenager. Mom had been unwell for about ten years before that. We didn’t know that it was MS until she had a relapse and underwent a spinal tap. Having a name for what was wrong gave us treatment options and a new perspective.

At the time of her diagnosis, mom experienced periods of paralysis and limited speech. It was challenging. My dad and I shared the caring responsibility. It was essential that someone was always by her side.

Looking back, I realize that while I was given practical support in terms of supporting my mother physically, there was little available in terms of emotional or mental help, either for me or my parents. We were so focused on filling the gaps – cooking dinner, keeping the house clean and supporting mom – that there was little time to consider the emotional toll of caring.

In terms of information, there was nothing to be found that was appropriate for me. So I read the patient handouts, told a few friends, and talked to friends and family about things when necessary.

I’ve been living out of state from my mom for the past five years. I still see myself as a carer, it’s just a different type of care that I now provide. We talk every day and stay connected. You can still offer valuable care from afar. It’s not vital to live in the same home and be there every day. It’s more about staying engaged and involved, wherever you are.

My experience as a carer has taught me to be more patient and to focus on the positives in life. I am a firm believer in the importance of self-care and I take time to do the things that I want to do and spend time with loved ones. This didn’t come naturally! When I got to college, it became clear that I had grown so entrenched in the role of carer that I simply didn’t know how to put myself first. Friends would come to me with questions or seeking help and my instinct was to drop everything to be there for them. Learning that it was ok to say no was a gradual process but an important life skill.

I believe that the work of carers is not adequately recognized. In fact, I don’t think that carers themselves recognize the contribution they make. I know I don’t. My mom tells me how much of a difference I make to her and her life and my response is simple: “this is life, this is how I grew up, and the only way this could have been.” I don’t think I missed out on anything as a result of being her carer.

In terms of support from the caring community, what is helpful is the validation that it’s ok to feel frustrated, it’s ok not to have all the answers, and it’s ok to have relationships you’re still working on. Sometimes, knowing I’m not alone is enough.
Across the US, many of the estimated 1 million people living with MS lean on family and friends for day to day support. Whether preparing meals, cleaning the home, dressing them or providing medical care, these tasks and more are carried out by people who are unpaid and largely unrecognized. The survey sheds further light on these vital but unsung heroes.

Caregivers in close-up

The caring pathway can commence at any age. 41% of caregivers surveyed were 34 years old or younger when they took on their caring role, with 10% under 18 years of age.

Of those aged under 18 years when they began caring, over two thirds were the child of a parent with MS, while more than one in ten were looking after another family member. The older the person was when they took on the role of caregiver, the more likely they were to be the partner of somebody with MS. This was the case for nearly two thirds of those aged 18-34 or 35-54.

Just over half (55%) of those surveyed were partners looking after a loved one with MS, which may put an additional strain on their relationship. This compares to 51% being partners of someone with MS across all countries surveyed.

Those who were parents were most likely to be mothers looking after a female with MS, unsurprising given that MS is at least two to three times more common in women than in men. Similarly, young people looking after a parent with MS were also most likely to be female and were exclusively caring for their mother with MS.

10% of respondents were caring for a relative with MS that could be their sibling, grandparent, grandchild etc., and a third of those they were looking after were aged 34 or younger.

What is your relationship to the person with MS?

- I am the partner of a person with MS (55%)
- I am the parent of a person with MS (17%)
- I am the child of a person with MS (13%)
- I am a family member of a person with MS (but not their partner/parent/child) (10%)
- I am the friend of a person with MS (4%)
- Other (1%)

Caring is not a role from which one can easily resign, it may well be a responsibility for the majority of somebody’s life. In fact, the majority of caregivers surveyed had held the role for between one and five years, and potentially have many more years of caring ahead.

The average time spent caring for someone with MS was eight years. Over three quarters (77%) of those surveyed had been caring for somebody for 10 years or less, the majority of whom were partners or the parent of somebody with MS.

| How old were you when you began caring for the person living with MS? |
|-----------------|---|---|---|---|
| Under 18 | 18-34 | 35-54 | 55+ |
| USA | 13 | 47 | 34 | 35 |
| Canada | 17 | 47 | 31 | 27 |
| France | 3 | 43 | 47 | 47 |
| Germany | 3 | 43 | 47 | 47 |
| Italy | 12 | 27 | 8 | 11 |
| Spain | 8 | 27 | 6 | 5 |
| UK | 6 | 22 | 15 | 15 |
At the other end of the scale, 14% of those surveyed had been caring for somebody for 16 years or more. Most of these caregivers were aged 55+ but more than one in ten were aged between 18-34, suggesting that they have spent around half of their lives caring for somebody else and balancing responsibilities such as education and/or employment.

Nearly three quarters (71%) of those surveyed were supporting a female with MS. Although consistent with the fact that MS is at least two to three times more common in women than in men.

Nearly two thirds (63%) of those caring for someone with MS were also female. This is due to relationships such as a friend caring for somebody with MS, a child caring for someone with MS or a distant family member caring for those with MS almost exclusively being undertaken by female caregivers.

How would you describe the person’s disease status?

- 20% Mild
- 59% Moderate
- 19% Severe
- 1% Not sure

In most cases, the individual being cared for had moderately advanced MS, as assessed by the caregiver themselves. 59% of those surveyed were looking after somebody that they had assessed as having moderate MS, nearly three quarters of whom were female MS patients. One fifth were described as having mild MS by the person that cared for them, just under a fifth were described as having severe MS. The most frequent caregivers for people with severe MS were their partners, however the second most frequent answer was that they were the child of somebody with MS.

Overall, 27% had been caring for someone prior to their diagnosis with MS, or since their loved one started showing signs of MS (23%). When someone took on the responsibility of caring varied depending on their relationship with the person with MS. For example, the partner of someone with MS was much more likely to start looking after somebody prior to diagnosis or as soon as they were diagnosed with the condition, possibly due to the proximity of living with that person. In contrast, most children caring for a parent with MS took on the role at a much later stage, either when they began showing symptoms or when they could no longer care for themselves. This is also reflective of the results seen for all the countries surveyed, where a fifth of younger caregivers surveyed began looking after a parent when they could no longer look after themselves.

AVERAGE AGE THAT THE CAREGIVER TOOK ON THE ROLE: 38

AVERAGE TIME SPENT CARING FOR SOMEONE WITH MS: 8 YEARS
CHAPTER 2: A LIFE OF UNCERTAINTY

Many caregivers reported experiencing positive developments and outcomes of looking after a person with MS. Despite this, it is evident that the responsibility of being a caregiver takes its toll on caregivers’ own health and wellbeing, with many acknowledging that their role had impacted both their financial stability and their ability to progress in their career.

The physical strain of caring
22% of those surveyed felt their physical health, including weight and ability to exercise, had been significantly affected since becoming a caregiver (compared to 43% recorded by UK respondents).

The health and emotional wellbeing of the caregiver is important. If a caregiver does not look after their own health, they may be more susceptible to conditions which leave them unable to continue caregiving. In the absence of a solid support network, the caregiver may be the only person available to take on the caring role. Unsurprisingly, 41% of those looking after somebody they assessed as having severe MS felt their physical health had seen a big impact, compared with 20% of those caring for someone deemed to have mild MS.

When asked how much free time the caregivers had each week to spend on any activities that did not involve caring, work or other responsibilities, 31% of respondents selected that they had less than five hours a week, equivalent to less than an hour a day. This was similar to the overall result, globally, which saw 34% of respondents across countries have less than five hours a week of free time.

The responsibility of caregiving can lead to harmful habits and lifestyle choices (smoking, inadequate food or sleep habits) and an inclination to avoid taking preventative health measures, (such as medical appointments) with the potential for a decline in the health of the MS caregiver. Despite the negative coping approaches, many caregivers opted for positive steps to cope with the challenges of being an MS caregiver, including nearly a quarter choosing physical exercise, and over half taking time out for themselves, including reading a book or getting some fresh air.

The emotional impact of caring
A third of caregivers surveyed testified that the emotional and mental strain of their role was the most challenging aspect, exceeding making plans for the future by 19 percentage points. Almost half (45%) of all respondents stated that their responsibilities as a caregiver had had a notable impact on their mental or emotional health (e.g. feelings of depression or anxiety, difficulty sleeping).

Thinking about the following areas, how much of an impact has being an MS caregiver had on your health? (Those selecting “big impact”)

- Physical health (e.g. weight, ability to exercise, etc.)
- Mental or emotional health (e.g. feelings of depression or anxiety, difficulty sleeping)
- Financial situation (e.g. caring has impacted on my earning potential and/or ability to save money)

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<td>47%</td>
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<td>48%</td>
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45% of all respondents stated that their responsibilities as a caregiver had had a notable impact on their mental or emotional health.

The emotional/mental strain of the role was relatively evenly spread across all respondents, regardless of age group. There were, however, differences seen in the level of emotional/mental strain seen depending on the relationship the caregiver had with those with MS, and the severity of the condition as defined by the caregiver. For example, around two fifths of parents or children of somebody with MS selected the emotional/mental strain as the most challenging aspect, a result 13 percentage points higher than those caring for a more distant family member. Over two fifths of those looking after somebody they perceive to have severe MS also selected this as the...
62% of respondents felt as though the people around them did not really understand what it means to be an MS caregiver.

The emotional/mental strain is probably compounded by 40% of caregivers being affected by severe or high stress all the time or often. This figure is reflective of the overall result, as 41% of all those surveyed felt they were affected by severe or high stress all the time or often. The biggest worries of respondents included the person that they care for having a relapse (53%), or something happening that would prevent them from continuing their caregiving role (19%).

Reflected a role that can often leave caregivers feeling isolated and unappreciated, 62% of respondents felt as though the people around them did not really understand what it means to be an MS caregiver. This was the highest percentage of caregivers of any country included in the study.

The financial implications
42% of respondents stated that their role as a caregiver had had a big impact on their financial situation, whether that be their earning potential or their ability to save money.

Financial instability or concern was a key theme for US caregivers, and perhaps a reflection of the difference in healthcare systems in the US. For example, the most widely selected reason chosen by those stating that being an MS caregiver had negatively impacted their future plans was the negative impact on their ability to save for their future.

When asked about their biggest worries as caregivers, 17% of respondents said financial insecurity. This, perhaps, is reflected by 54% of respondents in the US selecting additional financial support when asked what, if any, support would be helpful to them. Taken in context, this proportion is higher than that of support from friends (31%) or a healthcare professional (29%).

Balancing caring with work
41% of those surveyed had a full-time job, which they balance alongside their role as a caregiver. Nearly half (47%) of US caregivers surveyed stated that their caring responsibilities had led to them having to take time off work over the past year. This was 11% higher than the overall result. When questioned about what, if any, support they would find helpful as a caregiver, 54% selected financial support and 14% chose support from their employer, including flexible working, reduced hours or condensed days.

Those who had to take time off work were asked a follow up question on how they felt taking time off had affected their work. Over a third stated that they could not dedicate as much time as they’d like to their job, while almost a third answered that they had to miss a lot of days because of caring.

Nearly one in ten caregivers had been obliged to take time off from schooling/education in the last year because of their caregiving responsibilities. Although a relatively small proportion of the total, it still provides an indicator of the pressures faced by MS caregivers. This is because when asked, every single respondent that had missed time at school or in education cited a negative impact. This included 57% who said that their responsibilities left them unable to focus, 50% who couldn’t dedicate enough time to studying as they’d like to, and 36% who felt it had left them struggling to catch up. In fact, 43% of these respondents may identify themselves as full time students, but a third seem to be taking schooling/education part-time, possibly while also working a job.

Of those surveyed, 15% of respondents identified themselves as part-time workers, 2% as freelancers and 5% self-employed. While these working roles may provide the benefit of flexibility, they could also add to the
stress and strain due to limited hours contracts or leaving the caregiver in the position of having to shoulder the financial role of the household with an unpredictable income.

The responsibility of caring could eventually lead to a point where a person feels as though they cannot hold down a job or their education because of caregiving responsibilities. One in ten US respondents that had to take time off work because of caregiving responsibilities felt that they couldn't hold down a job because of caring and 7% had actually lost a job because of caring. In fact, one in ten of those questioned described their current working status as unemployed, with nearly two thirds of them aged between 35-54. This could put a huge amount of financial pressure on a household where a caregiver is unemployed.

An uncertain future
Almost half (49%) of MS caregivers surveyed in the US said that caring for a person with MS had had a negative impact on their plans for the future or life goals.

Of these respondents, 53% were aged 35-54, the highest proportion of the age groups, followed by 30% of those aged 55+. Partners of someone with MS were also above average in their response, with around 60% agreeing that their role had negatively impacted their future plans or goals, when they represented 55% of the respondent pool.

Of those who answered that being an MS caregiver had negatively impacted their future plans or life goals, the most frequently cited aspect was their ability to save for their future (45%). Over half (58%) of the younger age group selected this, compared to 44% of those aged 35-54.

35% answered that being an MS caregiver had had no impact on their future plans or life goals.

The positive impact of caring
Almost all (95%) respondents selected at least one positive aspect they had experienced whilst caring for somebody with MS. Nearly three quarters (73%) of those surveyed said that they had learned a lot about MS in general, whereas 58% said that their caring experience had made them a stronger person, and 45% stated that their relationship with the person with MS had improved.

A higher proportion of the 18-34 year group selected each one of the positive traits when compared to the other age groups. This was striking when two thirds of those aged 18-34 years old stated that helping others made them feel good, compared to just 27% of those 55+, a difference of 39 percentage points. Taking this a step further, a higher proportion of the 18-34 year old age group stated that being an MS caregiver had either had a positive impact on their future plans or life goals, or had not had an impact at all (whether positive or negative).

An uncertain future
Almost half (49%) of MS caregivers surveyed in the US said that caring for a person with MS had had a negative impact on their plans for the future or life goals.

Of these respondents, 53% were aged 35-54, the highest proportion of the age groups, followed by 30% of those aged 55+. Partners of someone with MS were also above average in their response, with around 60% agreeing that their role had negatively impacted their future plans or goals, when they represented 55% of the respondent pool.

Of those who answered that being an MS caregiver had negatively impacted their future plans or life goals, the most frequently cited aspect was their ability to save for their future (45%). Over half (58%) of the younger age group selected this, compared to 44% of those aged 35-54.

35% answered that being an MS caregiver had had no impact on their future plans or life goals.

The positive impact of caring
Almost all (95%) respondents selected at least one positive aspect they had experienced whilst caring for somebody with MS. Nearly three quarters (73%) of those surveyed said that they had learned a lot about MS in general, whereas 58% said that their caring experience had made them a stronger person, and 45% stated that their relationship with the person with MS had improved.

A higher proportion of the 18-34 year group selected each one of the positive traits when compared to the other age groups. This was striking when two thirds of those aged 18-34 years old stated that helping others made them feel good, compared to just 27% of those 55+, a difference of 39 percentage points. Taking this a step further, a higher proportion of the 18-34 year old age group stated that being an MS caregiver had either had a positive impact on their future plans or life goals, or had not had an impact at all (whether positive or negative).
I’ve been a carer for my husband since his diagnosis with MS twenty-four years ago. The news came as a huge shock to us and, at the time, little information was forthcoming. What I clung on to was the assurance that, in his case, it wasn’t a fatal diagnosis. That was very important to us. We felt very strongly that as long as we were together we could handle it.

What was particularly tough was the way the diagnosis was given to us. A more compassionate delivery would have made a lot of difference. Having a care team there to talk through what is available and what to expect would have also helped. As it was, all we could do was leave the doctor’s office and go straight to church to talk to our priest. We have since switched neurologist and, fortunately, now have a team that listens which is vital.

Taking on the role of carer meant that I had to leave my job as an accountant. That was very tough. It felt like I was giving up who I was. My potential income growth has decreased significantly because I have had to become self-employed and build my client base around my household situation. Thankfully, I have been fortunate with my clients who are very understanding about my need for flexibility, depending on my husband’s needs.

I would describe caring as an emotional rollercoaster as you never know quite what to expect. Just as you get used to something, it changes again. It’s important to be flexible and that’s one of the key things I’ve learned as a carer, along with resilience, patience, and, most of all, faith.

So far, I haven’t connected with other carers but I think it would be helpful. I went to a state advocacy meeting recently and found it interesting that I was the only carer there – everyone else was a patient. I think there needs to be more resources for carers to get together in a safe environment to share their concerns and gain support from each other.

The whole experience has changed me. I have become a huge advocate for my husband, as well as for the whole family. That is a role that had to evolve. We were previously very traditional in our roles but the progression of the disease meant that the household roles had to evolve to adjust to the family’s needs. In the case of our sons, it has made them very caring and compassionate. They are always looking for ways to improve their dad’s quality of life.

I think it’s fair to say that there is little official recognition or understanding of the work that carers do. I feel greatly appreciated by my family, but not by the wider community or the government. That said, I wouldn’t change my journey for anyone or anything. It has been rewarding and fulfilling, and allowed me to evolve tremendously as a human being.
CHAPTER 3:
The Right Support, at the Right Time

CONSIDERING THE EMOTIONAL AND PHYSICAL STRAIN THAT CAREGIVERS ARE UNDER, A SOLID SUPPORT SYSTEM AND ACCESS TO INFORMATION IS ESSENTIAL AND YET CONTINUES TO BE LACKING IN KEY AREAS.

The survey highlights that the guidance, information and awareness of support networks that caregivers receive at diagnosis can make a notable difference in the level and quality of support caregivers see or request later in their role.

HCP communication of the diagnosis
With just over half (51%) saying that the healthcare professional did not explain the disease, its progression and potential care needs very well, there is clearly an opportunity to improve this dialogue between caregiver and healthcare professional.

This figure increased to 65% of those looking after someone they described as having severe MS, and those that care for a friend with MS. The latter may be due to the more distant relationship they have with the person with MS, that they were not as included in visits to HCPs than say a partner or member of the immediate family may have been.

Overall, 36% felt that it was not explained very well, and 15% thought it was not explained at all. This includes a higher proportion of caregivers currently aged 18-34, but who were probably younger when they met with the HCP. The initial diagnosis is a critical time for both the person with MS and the caregiver. This is reflected by a third of those surveyed stating that they would have liked extra support at the point of diagnosis, with this preference more evident among younger caregivers (38% compared to only 25% for older caregivers).
CHAPTER 3:
THE RIGHT SUPPORT, AT THE RIGHT TIME
CONTINUED

Sources of information
Unsurprisingly, there were generational differences in some of the answers to where caregivers seek out information to support them in their caring role. For example, those aged 55 and over were more likely than younger caregivers to use books or publications to source information. Conversely, younger MS caregivers were more inclined to use patient or caregiver blogs than older caregivers.

29% selected websites as the source they use most for information to support them whilst being an MS caregiver

However, there were also key differences depending on the source and audience. For example, HCPs were a source of further information for 27% of respondents, the second most popular option overall. Likewise, nearly one third (29%) selected websites as their preferred source for information. However, this was largely driven by caregivers aged 35-54 years old, with both the younger and older age groups seeing much lower results.

23% Yes, I have accessed support through third-party organizations

The availability and use of third-party organizations
Just under a quarter (23%) of US caregivers surveyed had accessed support through patient or caregiver organizations, increasing to nearly one third (31%) of 18-34 year old caregivers and 34% of those looking after somebody they deem to have severe MS.

Of those who did connect with other MS caregivers or patient organizations, they were more likely to be aged 55+, with younger caregivers missing out on this type of support structure. When asked what additional support structures would be helpful to them as young caregivers, 17% selected peer support groups, either online or face to face, suggesting a demand for these groups amongst caregivers, particularly those who are the child of somebody with MS.

27% I am not aware of programs that I would be eligible to access for support

Overall, 70% of respondents said they had never connected with other MS caregivers to share experiences and get support, whether online or face to face. Worryingly perhaps, more than half of respondents were either unaware they were eligible, unaware of any third-party organizations they could access for support, or unable to access support. Improved communication or education on the support programs that are available could result in caregivers feeling more supported by the communities around them.

Support reflecting the fluctuating experience of MS
Of those surveyed, 83% felt that, in their experience as an MS caregiver, there are varied times when you need different support. 88% of those caregivers surveyed aged 18-34 answered in a similar way, stating that there are different times when extra support is required. This compared to those aged 55 or over who were less likely to respond this way, with only three quarters agreeing. This may be because the caregivers older in age have more experience of caring and therefore feel more equipped to deal with all eventualities of caring than those who are younger.

70% had never connected with other MS caregivers to share experiences and get support

Have you accessed support from any third-party organization for people with MS, or for those caring for them?
In terms of when caregivers felt they needed extra support, most (64%) cited when new symptoms emerge and during times of relapse (63%) as when caregivers felt they would like extra support.

In relation to the types of additional support that would be helpful, 63% selected better treatments, 54% selected financial support, and 31% opted for support from friends. There were some anomalies in the results, perhaps reflecting the varying experience of MS caregivers. For example, those looking after someone they deemed to have severe MS were more likely to opt for face to face peer support than other groups. Also, a higher proportion of those who were the child of somebody with MS selected every option of additional support compared to the overall result. This suggests that these groups require and would like more support but may not know where to find them.

What, if any, kind of additional support would be helpful to you as an MS caregiver?

- Availing of respite care/break from caring
- Better treatments for MS
- Financial support
- Support from friends
- Support from healthcare professional, e.g. increased contact, calls, visits, appointments
- Support with my studies, e.g. longer deadlines
- Support from employer, e.g. flexible working, reduced hours, condensed days
- Better/more information, e.g. online or in person
- Peer support (from other MS caregivers) – face to face or online

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US/NPR/0918/0409a  Living with Multiple Sclerosis: The caregiver’s perspective  15
As a caregiver, it is vital to take care of yourself and recognize the signs of burnout.

My wife was diagnosed with MS in 1995 at age 25. When we met five years later, her condition was not as it is now; she was still working and travelling the world. We got married in 2002 and, as her condition worsened, she began to use a cane to assist her walking. Today, my wife is living with secondary progressive MS.

When our daughter was born, my wife progressed from a cane to a walker. I would set up the bedroom with everything she and the baby needed; they spent their time on our king-size bed together while I worked.

My wife had a major exacerbation in 2013. When she came home from rehab, we both slept in the living room. My wife in a hospital bed, me on the couch, taking care of her 24/7. With no long-term care insurance, we were eligible for just four hours a day of support from an aide through Medicare.

As a carer to someone with MS, you do what you must do to make them comfortable. In our case, my role was a fine balance between work and caring. The process was a steep learning curve: I was never trained, never given guidance. I learned about wheelchairs, hoist lifts, medical equipment and home health care. I learned about insurance, finances, Medicare and Medicaid (there are big differences in what they cover). All on my own, often late into the night. I would get up at 4.30am, do what I had to do for work and our daughter, now in 3rd grade, and get ready for the external caregiver who arrived 9:00am. It was tough.

After another exacerbation in late 2013, it was clear we needed to get my wife onto community Medicaid to ensure she had all the resources she needed. There were two stark options open to us: get a divorce, or sign a spousal refusal. By signing the refusal and eventually liquidating her assets she became eligible. Medicaid provided a home health aide 24/7 along with transportation to PT/OT/medical appointments. Funds from liquidated assets went towards additional equipment not covered by Medicaid, such as a wheelchair accessible van.

People ask what caring has taught me. A husband’s mindset and a caregiver’s mindset don’t always fit together seamlessly; there are times you have to be the husband and times you have to be the caregiver. Caring has taught me that it can be difficult to simply flip the switch on and off at a moment’s notice and how to deal with that. There are times you want to be out with your family as a husband and father and then, suddenly, you need to be a carer. You have to be prepared to jump into that role right away.

The most important advice I would give carers starting out is: don’t be afraid to ask questions or ask for help. Burnout does and will happen. It happens to everyone. It is vital to take care of yourself first and recognize the signs of burnout. For “me” time, I run on the treadmill. Exercise has been a great relief, even during some of the most stressful times. All of this, alongside sharing a sense of humour, is what has kept our family going through it all.

I often receive compliments for what I do for my family. I don’t think that, as a caregiver, I’m looking for that recognition. For me that’s not what it’s about – it’s about my family.
WHERE TO FIND SUPPORT

CAN DO MULTIPLE SCLEROSIS
Delivers health and wellness education programs to help families living with MS thrive.
To learn more, visit www.CanDo-MS.org

CAREGIVER ACTION NETWORK
A non-profit organization providing education, peer support, and resources to family caregivers across the US free of charge.
To learn more, visit www.caregiveraction.org

MSAA
Multiple Sclerosis Association of America (MSAA) – a leading resource for the entire MS community, improving lives today through vital services and support.
To learn more, visit www.mymsaa.org

MS FOUNDATION
The Multiple Sclerosis Foundation, known in the MS community as MS Focus, is a non-profit organization focused on providing free services that address the critical needs of people with MS and their families.
To learn more, visit www.msfocus.org

NATIONAL ALLIANCE FOR CAREGIVING
A non-profit coalition of national organizations focusing on advancing family caregiving through research, innovation, and advocacy in the US.
To learn more, visit www.caregiving.org

NATIONAL MS SOCIETY
Resources & Support – Connecting all those affected by MS to the information, resources and support needed to navigate the challenges of MS.
To learn more, visit www.nationalmssociety.org/Resources-Support