MS PLUS
Neuro Wellbeing

Carers Strategy

Taking Care of Carers

Supporting a partner, family member or friend living with MS can be incredibly meaningful and rewarding. We also understand it can be challenging at times and impact your ability to achieve your own goals and live well.

MS Plus has undertaken research with more than 250 people who support someone living with MS, thanks to funding from the Victorian Department of Families, Fairness and Housing. The learnings provided by the generous carers who participated allowed us to identify a set of common needs and develop strategies to meet these.

We're committed to providing you with the ongoing support you need at every stage of your journey as you support your loved one living with MS.

Who is a carer?

While not all people identify as 'carers', we have used the term broadly to describe a partner, family member, neighbour, friend, or any other significant person who provides support to a person living with MS. We have also used 'loved one' to refer to the person you support who lives with MS throughout this strategy. Examples of support can include physical, emotional, administrative, and social support. This support can vary in frequency, intensity and duration.

Summary of research

MS Plus engaged Linda Rowley Consulting to undertake research.

These activities were designed to gain an insight into who cares for our clients. It sought to determine the key priorities for these carers and identify the actions MS Plus can take to meet their needs.

Carer reference group

A carer reference group was recruited with five key members who represented diversity in age, location, cultural background, and employment status. The group met five times to guide the design and implementation of the research for the carers strategy.

Survey

An online survey was distributed to all MS Plus registered carers, with 249 responses received. The survey included questions about their experience supporting a loved one living with MS. Through the survey, respondents identified supports that would be helpful in overcoming barriers encountered.

Focus groups

Across two focus groups, carers discussed the key themes arising from the survey in detail. They examined additional issues they were facing and talked about potential supports that could be helpful.

One-on-one interviews

A challenge identified in the process of the focus groups was the lower representation of younger carers. To address this need, seven one-on-one phone interviews were conducted to capture the needs of younger carers.

Findings

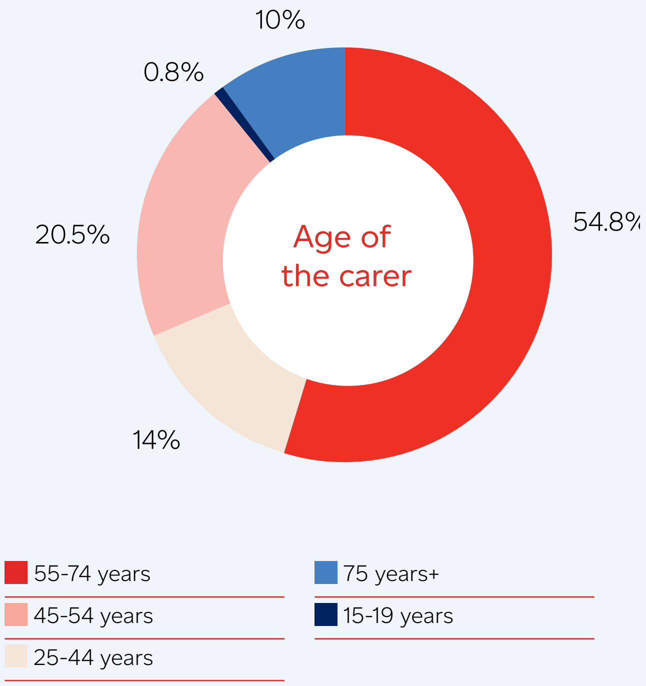
The research sought to understand the primary barriers, strategies and supports needed for living well while caring for someone with MS. Six key focus area emerged that have informed this plan.

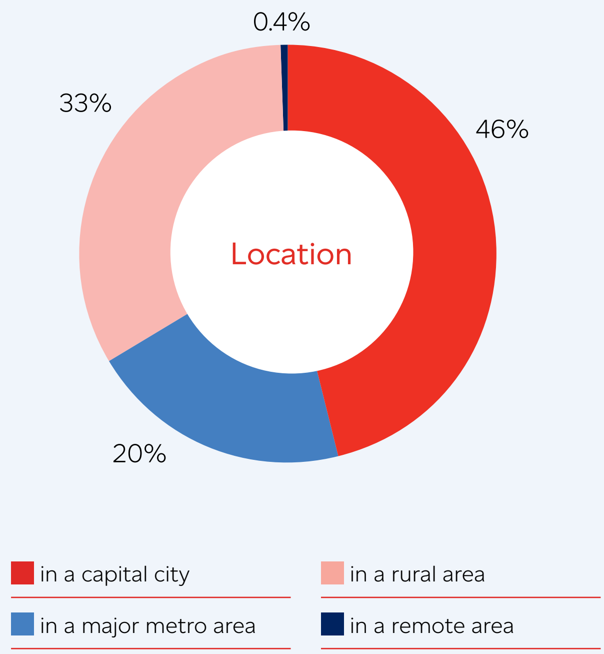
Development of strategy

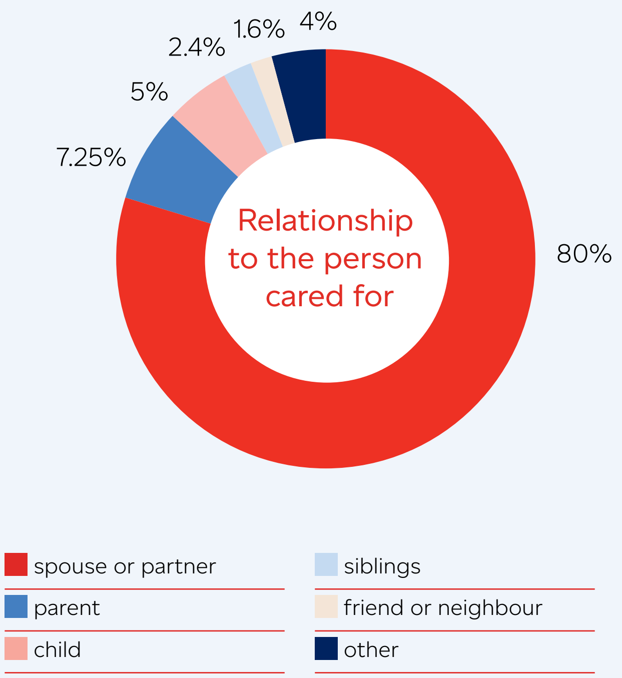
Opportunities and priority actions have been identified for each focus area. These actions have been developed from recommendations provided by carers through the survey, focus groups and one-on-one interviews.

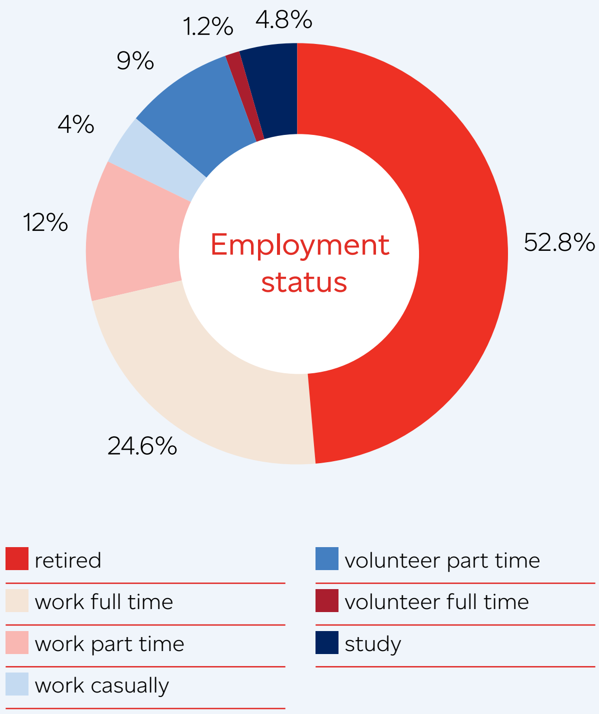
Summary of research

> “(I have) a feeling of guilt if I take time out for myself.”









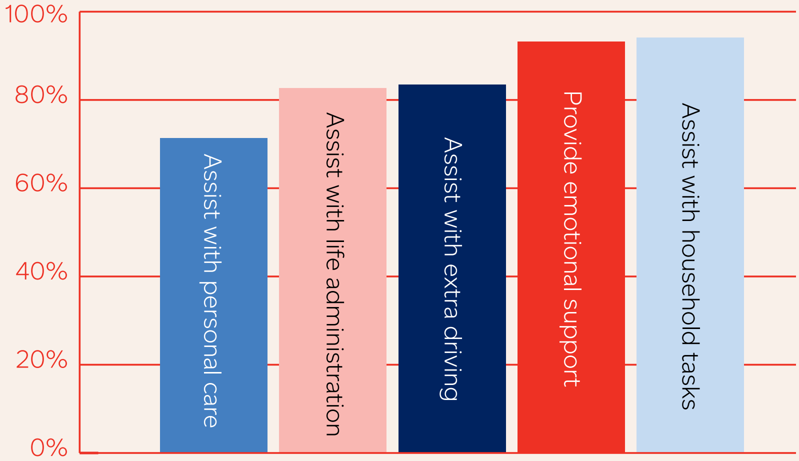
The most common barriers to living well for carers included (in order of prevalence):

- Lack of time for themself
- Less time and energy to maintain a social life
- The impact on their mental wellbeing (e.g., feeling isolated or burnt out)
- Viewing caring as their duty/role
- The physical nature of the caring role and their own physical wellbeing
- The changed relationship with the person they care for
- Lack of support to allow them to maintain their own career and interests
- Lack of finances.

The focus areas that emerged from the survey and were then explored in further detail in the focus groups and interviews included:

1. **Information on support services and MS specific education**: 43% of respondents identified information about services and support for the person they care for as a helpful strategy to overcome barriers to achieve their goals. 36% indicated information for themselves in their caring role would be beneficial. More than one in two carers identified lack of time as a barrier to living well.
2. **An understanding person to talk to:** 45% of carers reported less time and energy to maintain a social life as a barrier to living well. They need access to support people who understand and are available to listen and talk to them.
3. **Respite, outings and retreats**: 49% of respondents indicated respite would support them to overcome barriers to living well. They need in home and out of home respite, social outings and retreats.
4. **Financial assistance and employment support:** 31% of carers identified financial help as being useful to living well. They need help to overcome their financial and employment barriers.
5. **Advocacy and support for navigating the service system:** carers need strong advocacy and practical help for accessing the services available to them.
6. **Access to programs that support mental health and wellbeing:** 43% of respondents indicated the impact of caring on their mental wellbeing was a barrier to living well. They need information and support programs that help them maintain and enhance their mental health and wellbeing.

Types of support provided each week



Focus area one: Information on support services and MS specific education.

> "It's daunting at the beginning. You don't want to look at a full range of possible things that could happen, so you take what information you need and leave the rest."

Opportunities

- Improve understanding of MS (particularly at the time of diagnosis)
- Improve understanding of the services available for people living with MS
- Improve understanding of services available for carers.

Key actions:

Key worker carer champions

We're introducing dedicated key workers, who will partner with our clients from day one. It's a new approach to supporting those who have just been diagnosed, and we want to extend this approach to the carers of people living MS.

- We will have two key worker carer champions – they'll support our team of key workers to understand the resources available to carers so they can support both you and your loved one living MS.
- We'll provide our champions with ongoing learning opportunities.
- We'll continue to develop our catalogue of resources to support carers.

Carer resources

If your loved one has recently received an MS diagnosis, it's normal to feel scared and confused. You want to support the person, but it can be difficult to know what to do or say and you may be wondering what the implications will be! In addition to the introduction of key workers, we're developing a package for those who are newly diagnosed with dedicated support for carers. As part of this package, we will:

1. **Provide one-on-one sessions** with a member of our team for the family and friends of the newly diagnosed person.
2. **Develop a suite of resources** including podcasts, webinars and written resources specifically for family and friends of people who are newly-diagnosed.

Centralised records

We understand it's frustrating having to repeat your story to someone new every time you pick up the phone for support. In addition to introducing our key workers who will partner with you and your loved one from diagnosis onwards – we'll be reviewing the way we record information so your needs and stories can be recorded together. This means we can provide relevant information and advice personalised to your situation.

Partnerships

We'll once again partner with the Menzies Institute for Medical Research at the University of Tasmania to create the MOOC. This means you and anyone else in your network can get access to high-quality information about multiple sclerosis for free.

Planned delivery:
September 2023

Focus area two: An understanding person to talk to.

Opportunities

- Reducing isolation through connection
- Ensuring carer 'check ins'
- 'Right time' carer support

Connecting carers with formal and informal support opportunities

Peer support is the act of connecting with others who are in a similar situation. MS Plus provides a free peer support program for people living with MS or caring for someone with the condition. We will promote our formal support opportunities, along with more informal opportunities to connect with the MS community. We will also:

1. **Design opportunities** for carers to connect with each other and the wider MS community, through innovative activities created by the MS Plus events team.
2. **Promote opportunities** for younger carers to connect with online global support and collaborate to develop targeted support groups – e.g., young Australian carers.

Carer check-in program

Our new key worker initiative means it's not just your loved one living with MS who has a dedicated partner from day one – but you do too! The key worker we match each client with is there to support their carer too and will be checking in regularly to provide tailored advice and recommended services for your individual circumstances.

On-demand support

No matter where you live and no matter what time it is – we want you to connect with the support you need, when you need it. We'll be developing online tools you can use on-demand, including access to monitored forums and online communities.

31 MAR **Planned delivery:**
March 2023

> "It would help to have ways to communicate with other young carers, a meet up or online blog. It's hard as a young carer, your friends don't understand or get it."

Focus area three: Respite, outings and retreats.

Opportunities

- Creating opportunities for carers to take time out.

Plus Respite service

Our Plus Respite service gives you the restorative break you need to recharge – while ensuring your loved one stays in a friendly and safe environment with a caring and experienced team on hand. We'll widely promote vacancies in our Plus Respite service so you know about them. We're also building 19 two-bedroom units that will be a mix of short and long-term accommodation at our new MS Plus Wellbeing Centre at Lidcombe. This will increase our respite capacity for our NSW clients, with the new centre expected to open in 2024.

Refuel time out program

We'll scope further opportunities for carers to take time out and connect with others on a similar journey to them. This could be a school holiday program or creating opportunity as part of our free family camps to provide some respite to carers.

Planned delivery:
December 2023

> "I wish I could talk to someone. I don't want to talk to family members or friends, and I don't have one person who understands. I feel like I need to be strong and positive."

> Knowing you are not alone gives us the opportunity to go: It's not just me!"

Focus area four: financial assistance and employment support.

Opportunities

- Bespoke employment and workforce re-entry support for carers
- Financial wellbeing support for carers including financial future readiness.

Employment and workforce support

Plus Employment Support is here to help our clients until they feel secure in their current job or have found new work. And now we want to extend that support to you! Our education team will collaborate with our employment support team to develop a program for carers, which could be a webinar or podcast series to explore the specific challenges facing the carers of people living with MS in the workforce and the opportunities available.

Financial wellbeing support

We know that MS doesn't just impact the physical health of our clients – it can often impact the financial health of their families as well. That's why we're developing a Financial Wellbeing Program to support people living with MS to get the most out of their money. We'll extend this program – developing resources and tools to support your financial wellbeing too.

We'll also investigate how we can sustainably provide opportunities to carers as part of our existing Financial Assistance Program – with the potential to fund opportunities to take time out from caring responsibilities.

31% of carers of people with MS identified financial help as being a support to help them overcome barriers to living well.

31 JAN **Planned delivery:**
January 2023

> "Work doesn't look like it used to look years ago when you would find a job ad in the paper and circle it. Now there are many ways to create your own business – home and internet-based things that didn't exist in the past. MS Plus could help us look at non-traditional work and encourage a creative approach for people with MS and their carers."

Focus area five: Advocacy and support for navigating the service system.

> “We have found this a minefield to navigate and (find) access to the right support and benefits.”

Opportunities

- Resources to support health care service navigation
- Resources to support NDIS navigation and advocacy.

NDIS engagement resources

Navigating the NDIS can be confusing and challenging, but we want you and your loved one to know that you’re not alone. We have existing services to help people living with MS to access the NDIS and manage their plan once approved, including Plus Engagement, Plus Support Coordination and Plus Plan Management. In addition to this, we’ll be:

- upskilling all our key workers to give them specialist knowledge of the NDIS application process so they can guide you to our Plus Engagement team and support you on your application journey with the NDIS.
- tapping into the extensive knowledge of our Plus Support Coordination team to develop resources to assist carers to navigate the NDIS and the healthcare system on behalf of their loved one.

Right information at the right time

MS treatment requires a whole team of people to provide care and support. Our findings demonstrate a need for MS Plus to play a role as the gateway for carers to help them navigate and access services and support for their loved one.

We’ll be taking a right information at the right time approach by:

- developing an ‘In my shoes’ podcast advice series on accessing support from fellow carers who have successfully advocated for their loved one and navigated the system. This will also include in-depth tip sheets from our team.
- continuing to upskill our key workers, so they can provide you with the right information about services for both you and your loved one at the right time.

30 NOV **Planned delivery:** November 2022

> “Advocate to support us. Tell us about support services and guide us to them.”

Focus area six: Access to programs that support mental health and wellbeing.

> "Mental health support would be great, to accept and prepare for the future."

Opportunities

- Mental health and wellbeing support for carers including time out.

Mental health and wellbeing support programs

We know the mental health and wellbeing of carers has been significantly impacted over the past two years. A recent survey by Carers Victoria indicated around 80% of respondents' mental health had worsened since the start of the pandemic. While a third of MS carers from our research identified access to programs to support their mental health and wellbeing as a key strategy to living well.

At MS Plus we practice 'radical empathy' — moving beyond putting ourselves in someone's shoes, to taking action and creating lasting change. That's why we'll be investigating how we can resource a dedicated program to support the mental health of carers.

2024 -25 **Planned delivery:**
2024-25

43% of MS carers indicated the impact of caring on their mental wellbeing (e.g. feeling isolated or burnt out) was a barrier to living well.

About MS Plus

At MS Plus, we want to see the MS community thrive and we want to help more people living with other neurological conditions to do the same.

We believe people can be more than their condition. That's why we're offering more services, more expertise, more awareness, more research.

From NDIS and allied health services to employment programs, accommodation, expert advice, wellbeing and peer support.

We're passionate about providing emotional and practical support for every stage of the journey.

We also understand that MS impacts not only the person living with the condition but their loved ones as well. MS Plus provides ongoing support for all the most important people in our clients' lives, including their friends, family, colleagues, carers and more!

Whether you are in the CBD, the suburbs or a regional area – you can access our services virtually or face-to-face through one of our wellbeing centres.

Existing services for carers

We offer a range of support for the carers of people living with MS that you can access right now, including:

Plus Connect is the gateway to information, advice, support and services for you and your loved one.

Plus Advisor provides personalised advice from an MS Nurse.

Plus Peer Support connects you with a community of other people living with MS, their family and carers.

Plus Education empowers you with support and information to build your skills and knowledge.

Plus Respite provides a chance for people living with MS and their carers to have a break.

Plus so much more...find out about our comprehensive suite of emotional and practical support at **www.msplus.org.au.** Alternatively you can give our Plus Connect team a call on **1800 042 138** for personalised support.

Contact MS Plus

Phone: **1800 042 138**
Website and online chat: **www.msplus.org.au**
Email: **connect@msplus.org.au**

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