“Taking Care of Carers MS Plus Carers Strategy”

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Overview:

1. Definition of a Carer

2. Why do we care about carers

3. Background to the Carers Strategy Project
    - Methodology
    - Survey and Analysis
    - Results and Key Themes identified

4. Conclusion

Who is a “carer”

*Paid or
Unpaid
*2.65 million carers in Australia
*That’s 1 in 9 people
*235,000 young carers

*Integral part of Australia's Health care System

*Foundation of Aged/Community Palliative &
Disability Health Care Systems

*Disability
*Mental Health
*Chronic Conditions
*Terminal Illness
*Drug/Alcohol
*Aged

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**Not all people will identify as a “carer”, but in this project, have been referred to as “carers” to be inclusive of all contributors to this study

“Reference-”Carers Gateway”

Why consider carers

- Unexpected role/long term

- Caring responsibilities can take over, affecting carers’ health and wellbeing, limiting ability to participate in paid work, family life and social and community- leading to social isolation, loneliness, loss of social relationships and lack of support.

- Care giving can be a wonderful journey together, leaning into love you didn’t know possible, but we are all humans and the recognition of the importance of social connectedness and support in chronic health is well documented as contributing to overall improved outcomes for carer and recipient.

What happens to our pWMS if the carer burns out????

Burnout state of feeling emotionally and physically exhausted due to being exposed to excessive and prolonged periods of stress and may lead to the following symptoms:

- Fatigue and exhaustion
- Feeling unable to complete tasks to the same standard as before
- Changes in appetite
- Changes in sleeping patterns
- Loss of motivation
- Feeling helpless
- Increased cynicism and **negative** view of current situation
- Decreased satisfaction or sense of accomplishment
- Feeling a sense of **guilt** or shame, or doubting skills and ability to support others
- Social **withdrawal**
- Frequent headaches and tension
- Often getting sick (due to lowered immunity)
- Using alcohol or drugs to cope

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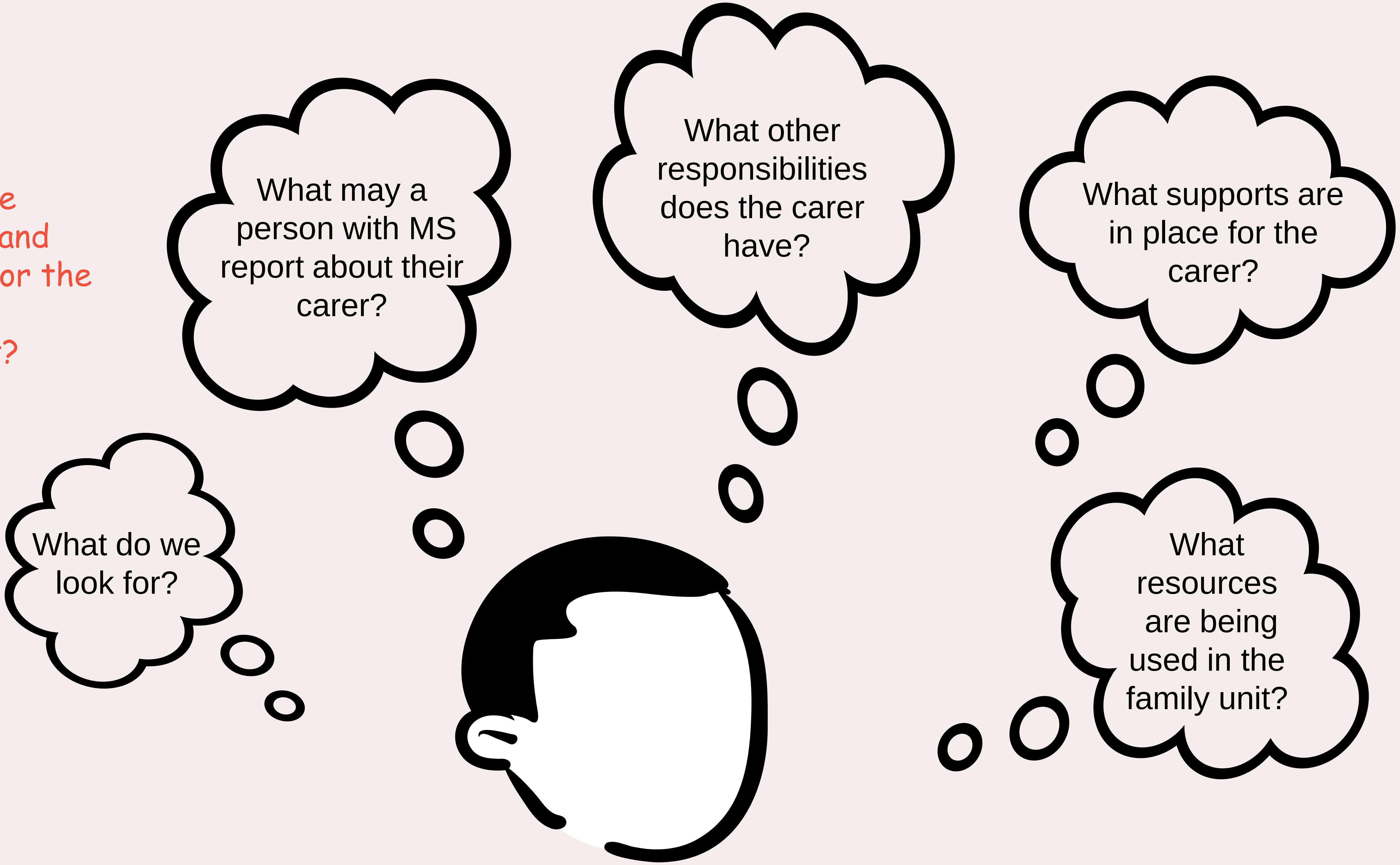
FOOD FOR THOUGHT:

How, as Nurses, do we make carers part of client care, and what is our responsibility for the recognition and advice on carers self-management?



What do we look for?

What may a person with MS report about their carer?

What other responsibilities does the carer have?

What supports are in place for the carer?

What resources are being used in the family unit?

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**To better understand and address carers unmet needs, MS Plus undertook a carer project **

MS Carers Project Background

Numbers

- 85% pWMS report they have a paid/unpaid carer/support person (half of these are partners/spouses)

Impact

- Impact of carers wellbeing poorly understood-further exploration needed to understand the unique barriers and supports needed for this group

Unique Population

- Higher numbers of men caring
- 69% reported need for daily emotional support >physical support
- Most diagnosed early adulthood=highly variable spectrum of carers (parents to older age)

COVID

- COVID pandemic = catalyst of revelation: deep impact of carer burden, isolation, lack of resources leading to decreased QOL for carer

5ustainability

- 2021 review of our available carers support service offerings were: unsustainable, developed in response to 'good ideas' rather than evidence-based, limited in scope and had a low return on investment (only benefited few rather than many). & were Not Co-designed

Methodology

Carers Reference Group

- *Guiding, designing, consulting and reporting on each step of the process*
- *6 participants*
- *Attended regular meetings*

Survey

- *249 survey responses from the carers were thematically analyzed: experiences, needs, demographics.*

Focus Groups

5 focus groups (2 proceeded, total of 8 people) used survey outcomes, and the identified themes as the focus of discussion.

One to one Interviews

- *to include diverse representation, including young carers and rural representation*

Reference: Carer Survey Report, Multiple Sclerosis Ltd, January 2022, Linda Rowley Consulting

Challenges and Limitations

Challenges

- The COVID pandemic restricted activities
- Limited to MS Plus patient cohort
- Survey participation low
- Engaging a diversity of carers recruitment

Solutions

- Converted to online solutions for holding groups and meetings
- Survey marketing and incentives
- One-to-one interviews to capture diverse representation

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Major Outcomes from the Survey:

- Male carers >Female Carers
- Over 50% carers were 55-74 years old
- 66% carers live metropolitan and 33% live rural
- 80% were a spouse or a partner
- Over 50% retired and close to 30% still working

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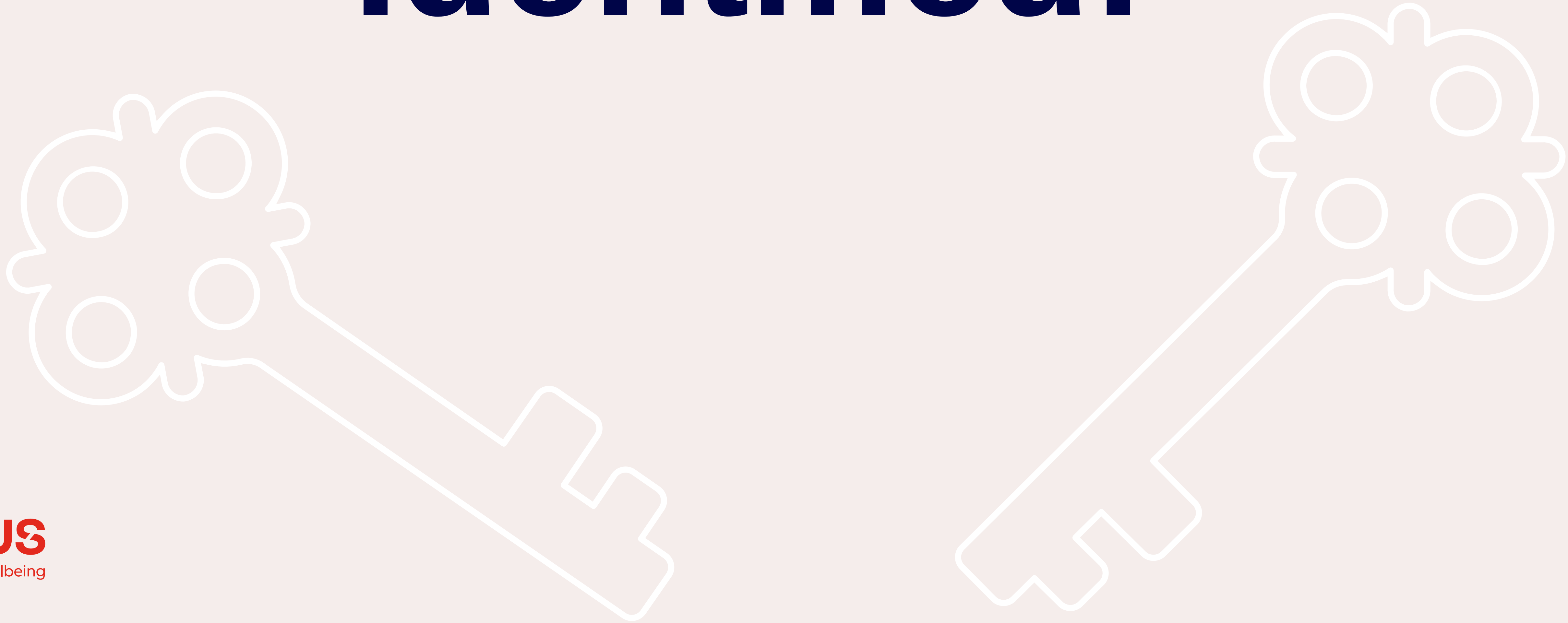
Reference: Carer Survey Report, Multiple Sclerosis Ltd, January 2022, Linda Rowley Consulting

Six Key Themes Identified:



Focus area one

Information on support services and MS-specific education

46% support services for the pWMS,
36% carers role information, needing accessible information”

Opportunities

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

Carer Resources

- ✓ Navigate Series for families and friends (Nurse led session for newly diagnosed)
- ✓ Carers website toolkit

Partnerships

- ✓ Partner with the Menzies Institute for Medical Research at the University of Tasmania to create MOOC for Carers

Key Worker Carer Champions

- Develop individual Key Worker portfolios to understand the needs and resources available for carers

Centralised Records

- ✓ Review how we resister and record information so carers and client needs and stories can be recorded together

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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

- Design opportunities for carers to connect with each other and the wider MS community, through innovative activities created by the MS Plus events team
- 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

✓ The Key Worker each client is partnered with formerly checks in with the carers as part of their routine support

On-demand Support

- We’ll be developing online tools to use on demand, including access to monitored forums and online communities.

45% less time/energy=barrier for social life-need to talk to accessible understanding support person

Focus area three

Respite, outings and retreats

Opportunities

Creating opportunities for carers to take time out

Refuel time-out program

- We are scoping for opportunities for carers to take time out and connect with others on a similar journey to them.

✓ Family camps now include opportunity for carer time out and support

MS Plus Respite Service

- Promote vacancies in our Plus Respite service.

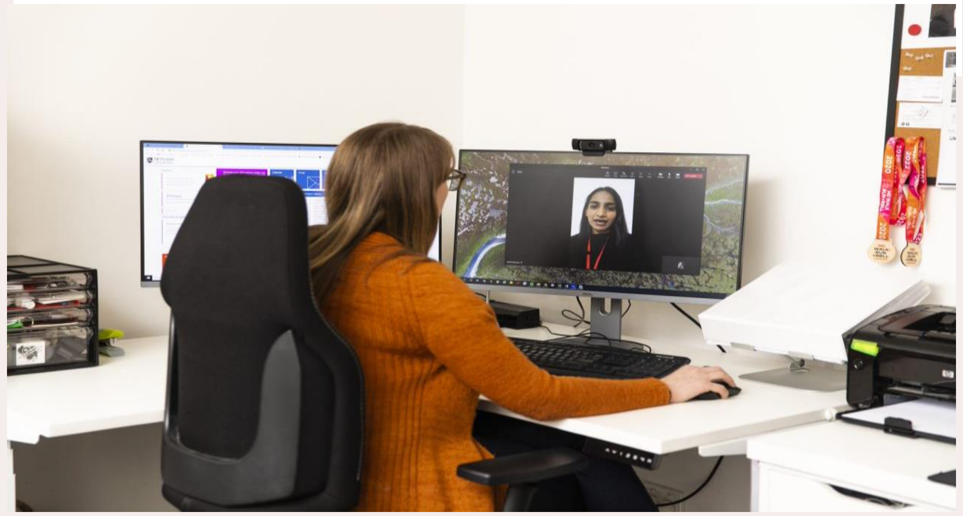
49% of carers identified this focus area

Focus Area four

Financial assistance and employment support

Opportunities

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



Employment and workforce support

- ESS team will work with the education team to develop workplace-related resources

Financial Wellbeing Support

- Financial Wellbeing Program (in the design phase) to support people living with MS to meet financial challenges associated with the caring role.

✓ Social workers currently support clients and carers.

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

Focus area five

Advocacy and support for navigating the service system

Opportunities

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

Key Worker Resource

✓ Key workers provide education and information on NDIS for people with MS and their carers

Navigate Series: Family and Friends

✓ Includes session on navigating health care resources

NDIS information for carers;

- Online resources (Toolkit)

Focus area six

Access to programs that support mental health and wellbeing

Opportunities

Mental health and wellbeing support for carers including time out

Mental Health and wellbeing support programs

- ✓ At MS Plus we practice 'radical empathy' — moving beyond putting ourselves in someone's shoes, to taking action and creating lasting change. Mental health support is currently embedded in everything we do and offer
- ✓ Continue to explore ways to support mental health

"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. & 80% of Victorian carers reported a decline in mental health since the pandemic."

Conclusion:

- MS Nurses can play a vital role in the care of a carer…
- Carers are at risk.
- Reality –no doubt supporting someone in need is a beautiful privilege, but it is well documented that long term responsibility can cause health issues for the carer.
- Deliverables are being mapped to be delivered over the next 3 years. These are very difficult to achieve. Solutions are not easy with financial constraints and resources poor

"When you take good care of yourself, you feel better, you function better, and you take better care of others…for longer!! " ….Carer quote

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Thank you for listening…
Questions or Comments?

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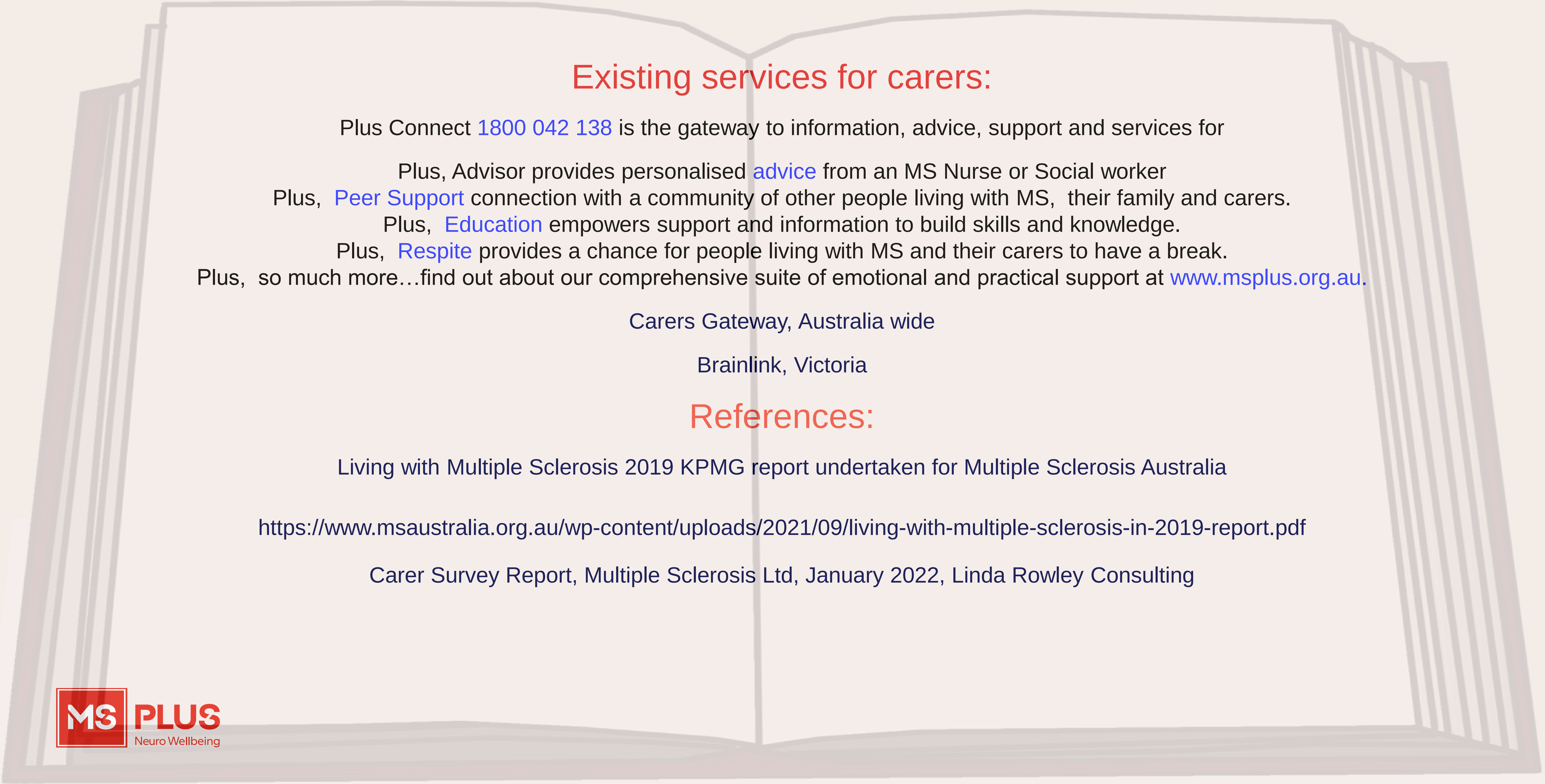

Existing services for carers:

Plus Connect 1800 042 138 is the gateway to information, advice, support and services for

Plus, Advisor provides personalised advice from an MS Nurse or Social worker
Plus, Peer Support connection with a community of other people living with MS, their family and carers.
Plus, Education empowers support and information to build 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.

Carers Gateway, Australia wide

Brainlink, Victoria

References:

Living with Multiple Sclerosis 2019 KPMG report undertaken for Multiple Sclerosis Australia

https://www.msaustralia.org.au/wp-content/uploads/2021/09/living-with-multiple-sclerosis-in-2019-report.pdf

Carer Survey Report, Multiple Sclerosis Ltd, January 2022, Linda Rowley Consulting