

Your independence and identity

Loss of independence is a common concern for people with MS as they get older. Losing some independence can also affect your sense of identity (how you feel that others perceive you) and sense of self (the person you feel you are).

In this booklet, we look at:

The help you might need as you get older

Who might provide that help

Protecting your identity and boosting your self-esteem



Living well with MS as you grow older

www.msif.org/resource/living-well-with-ms-as-you-grow-older/

What help might you need?

Compared with younger people, those with MS who are over 65 years old say they have more difficulty with:

- bathing, dressing and going to the toilet
- getting out of bed or around a room
- taking medication
- shopping and getting around the community.

The services they find most important to staying healthy are shown in the graphic below.

Services that help older people with MS to stay healthy

Based on a survey of people over 65 years old



In a 2021 survey by the Danish MS Society, about two-thirds of people with MS over the age of 65 said they need some help from others.

Many people with MS do not progress to the point of serious disability. However, the effects of MS and getting older may mean you need to consider some **adjustments to your lifestyle** and level of independence.

You might need help due to physical limitations or changes in your cognitive function (thinking, learning and memory).

Who will provide your care?

Help and support from a partner, family member or friend is invaluable to many older people with MS. Often, this is unpaid.

Many older people with MS have help from professional carers too, which might be funded personally, publicly, through insurance, or a mix of these. People living alone are more likely to use professional help.

'I think it is important to be open to those little things that can really give us happiness: a grandchild's kiss, a shared lunch, listening to music, reading a good book, a smile from our caregivers or the hug of a loved one. These things can help us protect our identities.'

LUIS FROM SPAIN, DIAGNOSED IN 1997

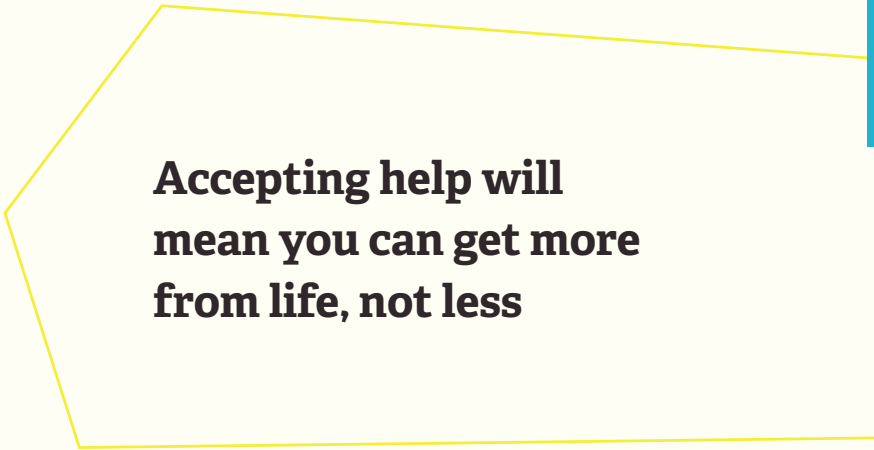
Concerns about needing more help

It's natural to want to keep your independence. Becoming more dependent on others can feel a threat to your freedom to do what you'd like at the times you'd choose. It can also make you feel vulnerable. **However, accepting help will mean you can get more from life, not less.**

People living alone or away from friends and family may worry about getting sufficient support. Conversely, it's common for those living with a partner, friends or family to worry about being a burden.

If you currently provide care to others – for example, older relatives or grandchildren – needing to take a step back can have practical and emotional impacts. Changing your roles in the family might alter your sense of identity or self, which we discuss below.

Receiving care from a partner, friend or family member can alter both of your lives in many ways. It can also alter the dynamics of your relationship. To keep your relationship healthy, **talk openly** about how you're both feeling and your needs.



**Accepting help will
mean you can get more
from life, not less**

Protecting your identity and boosting self-esteem

Changes you make to your life as you adapt to growing older can alter how you view yourself, including:

- how you feel others perceive you (your sense of identity)
- the person you feel you are (your sense of self)
- how valuable you feel (your self-esteem).

This could have a knock-on effect on your mood and mental health. Find activities, roles and friendships that support you in knowing who you are.

It can help to **connect with others** through groups or family. Charities supporting people of older ages can also be a great source of practical and emotional support. Many provide advice and tips on dealing with big changes in later life such as retirement, becoming a grandparent, losing a loved one, or changes to independence.

To **work through your feelings**, you might find a counsellor's help useful. If loss of identity or low self-esteem is affecting your mental health, speak to your doctor or a mental health professional.

TIPS

protecting your independence and identity

- **Plan ahead.** Think about what help you might need in the future. Make realistic plans with others about how you'll get this support. Planning will help you to feel more in control and less threatened by what the future may bring.
- **Research professional care services.** Look into the local options for professional help. Even if your partner, friends or family usually provide your help, it is good to know which professional services you could call on in an emergency or if they would like a break.
- **Adapt your home.** Simple changes to your home could make it easier to do some daily tasks independently. Examples are installing handrails on stairs and in bathrooms, using electric devices (such as an electric toothbrush or can opener), and chairs or stools for the shower or gardening.
- **Use assistive devices.** A wide range of devices are available that could help you to stay mobile. These include leg braces, canes, walkers, wheelchairs and scooters, and shoe inserts. Ask your doctor what is suitable for you.
- **Connect with others.** Conversations with others can help you to identify your feelings, needs and what's important to you. Being part of groups – including MS groups – can also strengthen your sense of identity and self.
- **Do things that bring you joy.** Identify the things you find most rewarding, enjoyable and that maintain your sense of identity.
- **Work on relationships with caregivers.** If your partner, family member or friend is caring for you, this could affect your relationship. Talk openly about each of your feelings. Doing activities you enjoy together can help you to protect your relationship.



Image Source: Ageing Better

Resources

Online information and tools

Finding MS support near you

<https://www.msif.org/living-with-ms/find-ms-support-near-you/>

Adapting your lifestyle: A guide for people with MS

<https://www.msif.org/resource/adapting-your-lifestyle-a-guide-for-people-with-ms/>

Optimising mobility (National MS Society)

<https://www.msif.org/resource/optimising-mobility-free-from-falls-program-3/>

Seven principles to improve quality of life

<https://www.msif.org/living-with-ms/what-influences-quality-of-life/seven-principles-to-improve-quality-of-life/>

Moving well with MS: For people with MS and their caregivers (MS Society UK)

<https://www.msif.org/resource/posture-and-movement-for-people-with-ms-and-the-people-around-them/>



This is a section from the guide 'Living well with MS as you grow older'. Download the full guide here:

www.msif.org/resource/living-well-with-ms-as-you-grow-older/



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