

Media briefing for reporting on multiple sclerosis (MS)



Reporting on MS These tips might assist you to report on an MS event, interview a person living with MS or report on, or write about, MS more broadly. They should be read in conjunction with this [Key Facts and Figures about multiple sclerosis](#) document.

What is MS?

Multiple sclerosis (MS) is a chronic disease that attacks the central nervous system (the brain, spinal cord and optic nerves). The progress, severity and specific symptoms of MS cannot be predicted. MS is a lifelong disease for which a cause and a single cure are yet to be found; however, doctors and scientists are making discoveries about the treatment and management of MS every day.

Common characteristics of MS

- Its course is unpredictable and unique to individuals; MS differs from person to person.
- It is episodic, often with gradual onset, acute stages or progressive decline of function.
- Symptoms may vary and be unpredictable on any given day.
- Symptoms also interact with other co-morbidities (compounding effect).
- Invisible symptoms can be debilitating and result in a range of functional impairments.
- Carers of people living with MS may experience significant carer burden; potentially leading to relationship difficulties and breakdown.

Symptoms of MS

MS symptoms are varied and unpredictable, depending on which part of the central nervous system is affected and to what degree. No two cases of MS are the same and symptoms, depending on where MS lesions develop on the brain and spinal cord, can manifest in many different ways.

Symptoms may include motor control issues such as muscular spasms and problems with weakness, coordination, balance and functioning of the arms and legs. Many MS symptoms are invisible, such as incontinence, fatigue, pain, cognitive dysfunction, memory loss and depression, heat sensitivity, vertigo, pins and needles, and visual disturbances. How someone looks is not an indication of the symptoms they may be experiencing or how they are coping with these symptoms.

Myths and misunderstandings about MS

- **Everyone's MS follows the same path?** No, because of the epidemiology of MS, each person's disease course and the resulting functional impairments are unique to them.
- **Only old people get MS?** No, MS can be diagnosed at any age – even in children. The majority of people diagnosed are in their early 30's.
- **MS is curable?** No. MS is a lifelong disease for which a single cure is yet to be found, however doctors and scientists are making discoveries about the treatment and management of MS every day.

A guide to talking about disability: [\(from Arts Access Victoria\)](#)

The language of disability is always evolving and different terms are used within and outside of Australia. It can be political, it can be personal, and it can be quite confusing.

- Avoid stereotypical or stigmatising depiction of people with disability
- Avoid phrases and words that demean individuals with disability
- Promote the 'people first' concept
- People with disability are not 'suffering from', 'victims of' or 'afflicted by' their disability
- People with disability are not overcoming their disability, but the barriers that the rest of society puts in front of them
- People with disability should not be portrayed as courageous or tortured, but rather as individuals who find alternative means to accomplish everyday activities

Living with disability

A person living with MS may or may not have a disability. Many people live well with MS and many do not consider themselves to be disabled.

Remember to:

- Talk directly to the person with MS, not their family member, carer or support worker.
- Don't focus on their impairment (if they have one). Get to know the social model of disability - where physical and attitudinal barriers created by society are more disabling than a person's body. More information on the social model can be found at People With Disability Australia <https://pwd.org.au/resources/social-model-of-disability/>
- Don't make assumptions through language. Terms like 'wheelchair bound' and 'suffers from' assume the person with disability is doing it tough. But wheelchairs create freedom, and people are generally able to live with their condition and/or disability.
- Avoid using euphemisms like 'special needs' and 'differently abled'. This perpetuates stigma. The words 'disability' and 'disabled' are fine.
- Avoid inspiration objectification, also known as 'inspiration porn'. If you are new to the concept, inspiration porn is the objectification of disabled people for the benefit of non-disabled people. Think of the videos of disabled people that make you cry - videos of disabled people just existing. It wouldn't be a story if it was not about a disabled person. And it shouldn't be that way. People living with multiple sclerosis and/or a disability don't exist to inspire or make other people feel better about their lives. The late Stella Young - comedian and writer - coined the term inspiration porn. It is prevalent in mainstream media and social media, and another reason why ableism is so prevalent. Because of inspiration porn, many people see people living with disability and/or MS as heroes or tragic victims. Please familiarise yourself with [Stella's Ted talk](#) and [Stella's Ramp Up article](#).

Disability, not disabled

Arts Access Victoria uses and recommends as best practice the use of the term 'people with disability.' Other terms commonly used in Australia include: 'people living with disability' and 'people with lived experience of disability.' This is because the word 'disability' is being used in its social model context, which means that someone has been disabled by social barriers and/or discrimination, not by their disability.

Recommendations on language:

WORDING WE RECOMMEND	WORDING WE DON'T RECOMMEND
Person with MS	Patient
Person living with MS	Victim
Person affected by MS	Sufferer
Person challenged by MS	
Person died from complications related to MS	Person died from MS
People/person with disability (preferred)	Differently abled / diffability
Person with a disability	Handicapped
People with disabilities	Physically challenged
	Someone who can't [speak, walk, etc]
People/person without disability /nondisabled person	Able-bodied
	Normal
Wheelchair user	Wheelchair bound
	Bound/confined to a wheelchair
Intellectual disability	Retard/ed
Learning disability	Slow learner
Cognitive impairment	
Mental health issues	Person with mental illness
Person with lived experience of mental illness	Mental health problems
	Mental
	Mentally-ill
Accessible toilet	Disabled toilet
Adapted toilet	
Accessible parking	Disabled parking
Has	Suffers from
Experiences	Afflicted with
Lives with	
Do you have any access requirements?	Do you have a disability?

References

1. A guide to talking about disability, Arts Access Victoria
2. Carly Findlay, Access to Fashion, Media Briefing for reporting on people with disability, September 2018
3. Baker D, Anandhakrishnan A, Tuite-Dalton KA, et al. How to refer to people with disease in research outputs: The disconnection between academic practise and that preferred by people with multiple sclerosis. Mult Scler Relat Disord. 2016; 10: 127-133.

For information about Multiple Sclerosis and MS Australia:
www.msaustralia.org.au