

MS ACROSS YOUR LIFESPAN

More About MS – Workshop Handout

Most people are diagnosed between the ages of 20–50, although 10 percent are below age 18, which means that many people will be living MS for decades. What does that mean for daily life, career and family decisions, and aging, which, of course, brings challenges of its own?

Let's take a look at three major periods in an adult's life – and how MS may impact them.



YOUNG ADULthood

MID LIFE

AGING

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YOUNG ADULTHOOD

DISEASE ACTIVITY

- 85% of people are diagnosed with RRMS, a more inflammatory phase characterized by relapses followed by periods of remission
- Starting treatment early
- Assembling your healthcare team

FAMILY

- Independence vs. Dependence
- Support: Emotional? Financial? Advice?

SOCIAL LIFE

- Dating
- Disclosure: How, When, Why
- Managing symptoms (fatigue, sexual changes)

WORK AND SCHOOL

- Disclosure: How, When, Why
- Accommodations: What, How

FAMILY PLANNING

- Discuss plans w/ healthcare team well ahead of time so your medication can be planned
- Fertility, conception, childbirth, nursing are A-OK
- Women & men with MS can be great parents!

PLANNING FOR UNPREDICTABILITY

- Financial and vocational planning early on will help you feel more secure and less vulnerable

THE ROLES OF WELLNESS

- Wellness strategies help manage and prevent co-morbid health conditions and that speed MS progression
- Wellness for care partners is essential too

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MID LIFE

DISEASE ACTIVITY

- Within 10–20 years of diagnosis, many people will transition to SPMS – characterized by less inflammation and more progression

CAREER TRANSITIONS

- Some people will need to change careers or transition out of the workforce

PLANNING FOR UNPREDICTABILITY

- Think about your finances, housing, neighborhood, support system

RELATIONSHIPS

- Roles may need to shift within a partnership
- Socializing with others may become more challenging
- Adolescents are hard to parent with or without MS

WELLNESS STILL MATTERS

- Continue with a healthy diet, exercise geared to your abilities, restful sleep, attention to your mood....
- Care partners too!

BUILD YOUR TOOLBOX

- Tools, gadgets, mobility aids benefit the whole family, save energy, keep your world large, safe, interesting

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AGING

DISEASE ACTIVITY

- Disease activity may slow, but a discussion with your provider is essential before stopping your DMT

SYMPTOMS: IS THIS MY MS? MY AGE? MENOPAUSE?

- Cognitive changes
- Sexual changes
- Mobility challenges
- Mood changes
- Bladder/bowel changes
- Temperature sensitivity

REDEFINING YOUR SELF

- Who am I now that I'm retired? Less independent? Less active? Less cognitively sharp?
- What do I want for myself? What matters to me?
- It's never too late to set goals for yourself
- Find new ways to do favorite activities and/or try new activities you've never done before.
- Adventures are still possible

LONG-TERM CARE IS A CONTINUUM

- Help in your home can be invaluable for you and your care partner

WELLNESS STILL MATTERS

- Keep active and engaged in whatever ways are possible for you – a PT or OT can help you
- Nurture your emotional, social, and spiritual self
- Keep your stimulated and challenged

KEEP GROWING YOUR TOOLBOX

- Learn from your rehabilitation providers and get ideas from others living with MS