Microscopic Colitis Foundation

Newsletter Archive

Wayne's Blog

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What If We Become Unable to Take Care of Ourselves?

by Wayne Persky

When we first develop microscopic colitis (MC), most of us tend to live a day-to-day existence while we're attempting to coax our disease into remission. We're afraid to plan ahead, because we never know what tomorrow will be like. And after we have the disease in remission, we tend to retain that apprehensive attitude, usually for years. If our remission is stable, we eventually learn to relax and resume a more normal lifestyle, but in the back of our mind, a little voice continues to remind us to be careful, anytime we're considering a vacation trip, a social event, shopping for food, planning a meal, or actually eating. For most of us, the severity of our initial encounter with this disease was more than enough to keep us ever vigilant, and always aware that our symptoms could flare, anytime we slip up.

> **MC keeps us ever-vigilant.**

> **As we age, we need to plan ahead.**

We're all getting older.

We're aware of most of the health risks associated with advancing age, but we rarely allow ourselves to think about them because most of us would be devastated if we had to rely on someone else to prepare our meals, or get us into the bathroom in time to prevent an "accident" if our MC happens to flare.

But maybe we need to plan ahead,

so that we won't be totally unprepared in case we happen to experience an adverse event that limits or ends our ability to take care of ourselves, and we have to rely on someone else for our daily needs. We came into this world wearing diapers, and many of us may leave the same way.

As we reach the "senior citizen" category, various problems begin to develop.

- Nutrient malabsorption and nutrient deficiencies
- Loss of appetite
- Weight loss and muscle wasting
- Social and emotional issues
- Neurological and cognitive issues
- Polypharmacy and comorbidities
- Impaired balance and gait

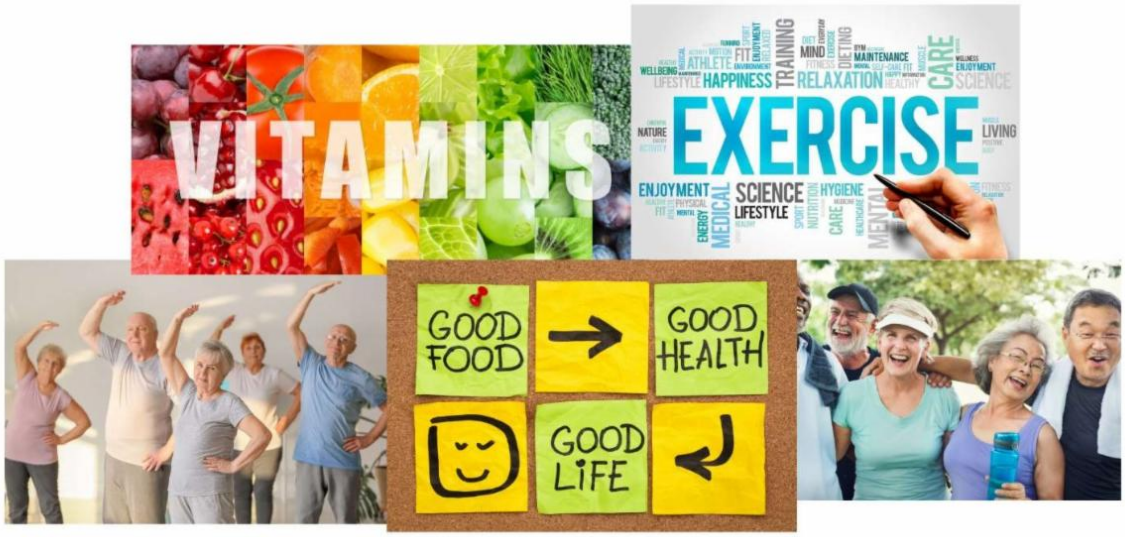
1. Nutritional deficiencies become a problem for many people as they age, particularly vitamin B12, vitamin D, magnesium, and calcium. But none of us are likely to be surprised that our risk of developing those deficiencies is significantly higher than the general population because of our restricted diets, and higher risk of malabsorption issues.
2. Older adults frequently experience diminished appetite, taste, and smell, which can make it harder to maintain adequate caloric and nutrient intake, especially on a limited diet.
3. Chronic diarrhea and malabsorption, combined with low food intake, can accelerate sarcopenia (age-related muscle loss), increasing frailty and fall risk.
4. Many older adults (especially those managing MC) avoid social gatherings that involve food (which is almost all of them), due to fear of symptom flare-ups. This can lead to feelings of exclusion and loneliness. The constant vigilance required to avoid symptom triggers can cause chronic stress and anxiety, reducing quality of life. Food is often tied to pleasure and memories. Limiting familiar or culturally important foods can create a sense of loss or grief.
5. And of course, the issues mentioned above can eventually lead to neurological problems. If mild

cognitive impairment or early dementia develops, it may become difficult to remember which foods are safe or how to plan appropriate meals. Physical limitations (such as arthritis, fatigue, or visual impairments, for example) can make grocery shopping, label reading, and preparing special meals difficult without help.

6. Older adults often take multiple medications (polypharmacy) for other chronic conditions, which can interact with nutrients or exacerbate GI symptoms (for example, NSAIDs, PPIs, or statins). Other digestive disorders such as diverticulosis, gastroparesis, or pancreatic insufficiency become more common with age and may conflict with or complicate dietary restrictions for MC.
7. Balance and gait issues are often a side effect of various medical conditions, but they can also be a result of certain medications, and can lead to dangerous falls.

> **Problems accumulate as we age.**

> **Balance issues and falls become more likely.**



What can we do to minimize these health risks?

Any of the issues mentioned above can lead to events that cause us to temporarily, or in some cases, permanently, lose our ability to care for ourselves. And if we wish to minimize our risks, then we may need to take certain preemptive measures, such as:

1. If we have normal kidney function, taking vitamins and minerals is normally safe, whether we need them or not, as long as they don't contain any of our sensitivities.
2. Obviously we need to try to keep the disease in remission, if at all possible, to maximize our nutrient absorption, and eliminate our symptoms.
3. We need to stay active, because increasing age normally leads to weight loss and muscle wasting, and once lost, muscles are not likely to be regained. As the saying goes "Use it or lose it".
4. Loneliness should be avoided by seeking companionship, joining a group with similar interests, or even joining a group to do volunteer work.
5. Neurological or cognitive issues should be supported by seeking help from qualified medical professionals, in addition to a qualified caregiver at home.
6. Ask your Doctor whether you actually need to be taking all of the medications that you have been

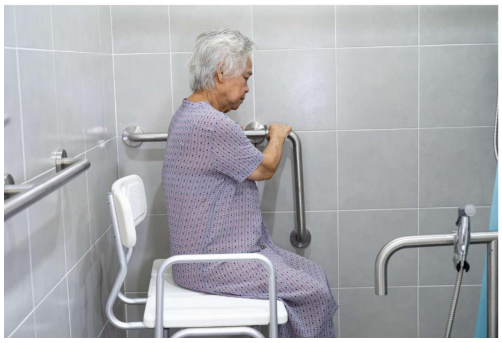
taking for years.

7. Falls due to balance and gait issues, whether associated with a disease, or a medication, are a major cause of loss of independence (and mortality risk).

> **Keep active.**

> **Maintain good nutrition.**

What's available if we do become unable to take care of our own needs?



If we're living at home, home modifications can help:

- Modifications such as raised toilet seats, grab bars, and motion sensing lighting can help.
- Installing a bidet reduces the need for twisting or bending when using the toilet.
- Commode chairs or bedside toilets, are especially useful if mobility is limited, making it difficult to reach the bathroom in time.
- Wipe clean flooring can help by making cleanup much easier in the event of an accident.

Special supplies can help if incontinence is a problem:

- Many brands of adult briefs or protective underwear are available, including low-profile, high absorbency options for discreet use.
- Perineal cleaning products such as gentle wipes or no rinse cleaning forms can help maintain hygiene without skin irritation.
- Skin barrier creams can help to prevent skin breakdown from frequent wiping or diarrhea.

In-home assistance is available

- Certified nursing assistants (CNAs) are trained to help with toileting, bathing, and hygiene, in a respectful, supportive way.
- These services can be covered by Medicaid waivers, long-term care insurance, or out-of-pocket, depending on your state and plan.

In-home meal support:

- Personal care attendants (PCAs) or homemakers can assist with shopping, label reading, and preparing meals exactly to your needs.
- You can train your aide or caregiver to follow your safe food list and cross-contamination protocols (such as using separate utensils, pans, and surfaces for your food preparation)
- A registered dietitian (ideally one who specializes in food sensitivities and IBD) can help to create meal plans and training your caregivers.

Specialized meal services are available

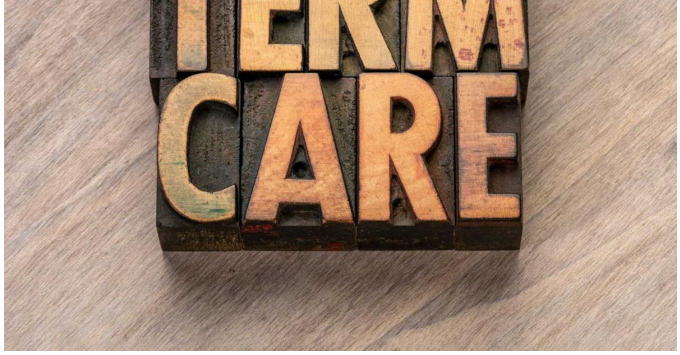
- Some meal delivery companies offer customized plans for medical diets) for example, low-FODMAP, gluten-free, dairy free). Calling to verify ingredient safety is advisable.
- "Modify Health" and "Epicured" are examples of such food delivery services.
- Local dietitian run services may be available in some locations.

Aging in-place options for MC specific challenges are available.

In-home care agencies offer customizable services like help with cooking, cleaning, toileting, and even transportation to doctor's appointments.

Consumer directed personal assistance programs (CDPAP) are available.

In some states, Medicaid allows you to hire and train a family member or friend as your paid caregiver.



Assisted living with dietary accommodations is available in some areas. Some assisted living facilities and memory care units have custom dietary support. They offer:

- Gluten-free kitchens
- Staff trained to handle food allergies and sensitivities
- Personalized menu planning

You'll need to interview the facility to make sure they understand the medical seriousness of your restrictions (for example no cross-contamination).

Consider long-term care facilities as a last resort.

Nursing homes often accept patients with complex G.I. conditions, but the quality of dietary accommodations varies widely. If this should become necessary, choose a facility with:

- An on-site registered dietitian
- Staff willing to collaborate with your G.I. team
- A history of safely managing residents with severe food sensitivities
- Arranging to have a custom meal delivery service bring your meals to the nursing home (at extra cost, of course) might be an option, if the nursing home agrees to that.

Financial and logistical support may be available.

- Medicaid Home and community-based services (HCBS) waivers may cover personal aides, home modifications, transportation, and meal support.
- Area agencies on aging (AAA) offer help locating in-home services, transportation, and sometimes meal assistance for older adults with medical needs.
- If you have a long-term care insurance policy, it may cover daily assistance, nursing services, or even customized meal delivery.
- Supplemental nutrition assistance program (SNAP) can be used for medically safe groceries if you're on a tight budget.

> **Explore options for aging in place.**

> **Advance planning eases the transitions as we age.**

The Bottom Line

While the loss of our ability to take care of ourselves may seem like a worrisome prospect, a little planning can go a long way toward easing and simplifying such a transition, if (or when) it becomes necessary. Eventually, unless we experience a fatal misfortune before then, most of us will presumably need to deal with this issue at some point.

As a first step, before our cognizance declines, we need to document our dietary needs in writing, and make sure that our instructions are easy for aides or facilities to follow. And that document should be stored in a safe place where it can be found, if (or when) it's needed. Preferably, multiple copies should be stored in multiple places, to improve the chances that it can be found, when it is needed.

In the current political climate, attempting to predict the availability of financial support in the future is fraught with peril. That suggests that our best bet may be to take extra pains to keep our disease in remission, and make an extra effort to try to safeguard our health for as far as possible into the future as possible.

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