

Practical ways that Nursing Staff & Others can Support a Person with Severe M.E.

(1) Please see the patient's Care Plan & 'My Needs' documents if they have those informative pieces; these will provide detailed information re the patient's illness & needs & will come in especially useful if the patient cannot talk at any time due to illness severity.

Alternatively, please talk to the family or carer or advocate if there is one with the patient.

(2) The most important thing you can do while caring for a person with Severe or Very Severe M.E. is to help them conserve their energy as much as possible.

Chat with the person you are caring for, if possible, or with their carer/ advocate, to see what works best for them when it comes to:

- Bathing, Toileting & Brushing Teeth
- Getting Dressed
- Mobility, better positioning & transfers
- Setting Up a Room/ Bed area in a Ward

Tips for Bathing

Give patients a sponge bath at their bedside or while in bed to conserve energy.

Wash various parts of their body at separate times e.g., face on one day, hair on another day.

Ensure use of hypoallergenic soaps & shampoos without, being careful if the person you care for is sensitive.

Check their skin & look for any red areas or sores.

Make sure they rest immediately after washing & before dressing if needed.

Wrap in towel or robe & return them to bed.

Consider bathing them every few days or once a week instead of daily.

For showering, provide a shower chair & a shower with grab bars.

If using a bath, a transfer board can help when moving the person between the chair & bathtub. Provide a pillow for neck support. Elevate feet & start with lukewarm water.

Tips for Toileting

Provide a raised toilet seat preferably with handrails.

Or provide a bedside commode to avoid a post exertion response (relapse) & conserve energy for other activities.

The patient may need support to transfer from bed to the toilet.

If the person is unable to transfer or be upright, they may need to use adult diapers, a bedpan, or a catheter.

Try planned toileting on a regular basis to help reduce urgent visits & accidents.

Tips for Brushing Teeth

Conserve energy by having the patient brush their teeth in bed if needed. Provide a soft bristle brush & mild-flavour toothpaste or just water, though the patient will likely have their own brush & toothpaste.

Tips for Moving & Positioning

Use foam wedges, bolsters & pillows for support & positioning. Make sure the person's neck & lumbar are well supported for proper alignment. Look at the importance of regular repositioning if tolerated.

Tips for Dressing

Help the patient to dress in bed to conserve energy, if required.

Provide hospital gowns that are fragrance-free & have been washed in chemical-free laundry detergents.

Keep an eye out for any sensitivity to clothes such as contact dermatitis.

Make sure the patient is wearing loose-fitting clothing made of soft, lightweight, breathable material in plain colours.

Consider adaptive clothing—e.g., slip on, no closures or buttons as these are easier to put on/take off. The patient will know best what suits them.

If one side is more weak or painful for the person, put the garment on that side first, & take it off on that side last.

Help them to dress in stages if they are not able to complete it all at once.

Help to change clothes for comfort & cleanliness, rather than daily only if the patient is able.

Tips for Setting Up a Room/Bed Area

A person with Severe M.E. will likely need shade at all times & plain curtains with no patterns.

Keep the room temperature & humidity controlled as much as possible.

Limit sounds from inside & outside the room when & where you can.

Provide protection such as ear plugs to minimise sound, though the patient may have their own headphones.

Do not provide hospital items/ products that have a strong smell, such as cleaning supplies or perfumes.

Arrange for assistive technology such as call buttons, remote controls for lights, aircon fan & TV & make sure the person knows how to use them if possible.

Set up a bedside table with adjustable height, tilt & a swivel top so the person can reach things on it easily.

Keep an eye on the person's balance, fall risk & hazards such as stairs & bathroom mats.

Tips for Eating & Drinking

Provide foods that are highly nutritional such as shakes, bars, soft or liquid foods.

Referral to a nutritionist may be needed for the right dietary advice.

Make sure the person can easily access a variety of snacks.

Help them to eat or drink in bed, if needed, to conserve energy.

Provide lightweight bowls, plates & cutlery such as plastic or bamboo.

Provide a non-spill water bottle or small, lightweight cup for drinking.

Provide a short straw as it requires less effort to suck.

Paper disposable straws may be more appropriate.

Be aware of the possibility that the person's oral nutrition & hydration has not been adequate because of difficulties chewing and swallowing.

There may be a profound issue that requires regular reassessment & different foods will need to be tried out with care & caution.

The above is based on an original piece 'Practical Recommendations for Energy Conservation and Management: Summary of ADLs to be evaluated in the bed bound patient and examples of corresponding activity modifications and adaptations that can be employed' from Table 2 of the 2021 paper entitled 'Caring for the Patient with Severe or Very Severe

Myalgic Encephalomyelitis/Chronic Fatigue Syndrome' by Jose Montoya and others:
<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8544443/>