

# Caring for people with severe or very severe M.E.

## Key Messages for Home Care Workers

Providing Home Care to a person with severe or very severe myalgic encephalomyelitis (M.E.) requires knowledge and skill. However it can be very rewarding to the care giver, and, greatly valued by the client.

### Approach to Care

Home Care Workers should not encourage clients with M.E. to do more for themselves.

This is counter-productive. The person will feel even more ill and be even less able to function afterwards if they do too much. Even trivial activity can provoke a worsening.

For people with M.E. energy is scarce and very precious.

Let the client dictate the pace.

#### NOISE

Don't be boisterous: Adopt a quiet and gentle demeanour. Speak quietly. Don't bang and crash around.

Washing up: Wash dishes quietly and close any doors to reduce noise.

Hoovering: Close doors or postpone.

Mobiles: There is no necessity for mobile phones to be used or switched on during a home care visit.

#### LIGHT

You may find clients with M.E. wearing dark glasses, living with their curtains shut and using only low intensity lighting. Please respect their need for shielding from the light. This may mean meeting care needs in very dim conditions.

#### MANNER

People with M.E. need care to be delivered calmly, quietly and gently.

They may ask you to talk in a quieter voice or to be left undisturbed.

This applies when doubling up. Please do not chat to each other over the person you are caring for.

#### PERFUME & CHEMICAL SENSITIVITIES

Some people with M.E. experience very severe reactions to fragrance. It may be necessary to completely avoid wearing perfume or any perfumed products.

Some have acute chemical sensitivity and will need to be protected from exposure to many items that are commonly used - for example in cleaning products.

### Protecting from Infection

People with M.E. are particularly vulnerable to infection and tend to take longer to recover. Catching an infection could make a client with M.E. much worse.

#### HANDWASHING

Frequent hand washing is vital to avoid passing on any infection:

On arrival wash your hands

If you touch your face wash your hands again

After shopping wash your hands

If you go to the toilet wash your hands again

#### HANDLING

When handling items that have been in contact with bodily fluids - tissues, sheets, clothes, continence pads - use gloves and an apron. Change gloves as often as required.

### Shopping & Mealtimes

Extra support around nutrition & mealtimes may be needed. Stomach problems are common and, for some people with ME, are very severe.

#### SHOPPING

Details can be very important. If a certain brand or a particular shop is requested there may be a medical reason for this. So please follow shopping instructions carefully.

#### PREPARATION AND COOKING

People with M.E. may have food intolerances and dietary sensitivities. So they may require food to be cooked from scratch. Wash all meat, fish and vegetables before cooking to remove bacteria or chemicals.

Clients with M.E. may struggle to maintain stable blood sugar. So your client:

may need to eat more frequently.

may need a diet rich in whole foods / complex carbohydrates and protein.

#### SUPPORT TO EAT

Clients with M.E. may need help to eat and drink. Swallowing may be difficult. Pain and overwhelming debility may make the physical activity of eating difficult.

Remember: the client knows best how their illness affects them. Please try not to impose your views, your priorities or your values on them.

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The 25% M.E. Group ♦ Advocacy and Support for Severe M.E.

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