

Home Care Worker Briefing

Looking After People with Myalgic Encephalomyelitis (M.E.)

Care Topics

- 1. Approach to Care
- 2. Sensory Overload
- 3. Protecting from Infection
- 4. Shopping & Cooking

1. Approach to Care

People with M.E. may be some of the sickest people you will have contact with.

You may have been trained to try to help clients achieve independence, and that this means doing more for themselves. To encourage people with M.E. to do more for themselves is not appropriate, and can actually lead to us becoming even less able and even more dependent on care.

Post-exertional malaise is the key defining feature of this illness. There is a characteristic 'push ⇌ crash' pattern. Many people with M.E. are operating at or beyond their safe limits, even though they may be doing very little. Even a slight increase in exertion or a higher level of concentration than usual can bring about a lasting deterioration.

So please do not impose your views, your priorities or your values on clients.

The client knows best. Let the person with M.E. dictate the pace. For the most part, we need care to be delivered calmly, quietly, and gently. When receiving instructions listen carefully, and try to remember for the future or take notes.

For people with M.E. energy is scarce and very precious. Our physical energy and mental activity are limited. This means that the more we have to say or do during a care visit the less we will be able to say and do for the rest of the day.

Communication and cognitive abilities

For people with M.E. scope for concentrating is limited and can quickly run out. A client may come across as quite focussed and 'on the ball' when you arrive, but quickly become confused or struggle to say what they want to say, or become unable to talk at all. (*Comparison:* This is very different to a dementia patient, who may be demanding and repetitive but has plenty of energy to speak)

At times clients with M.E. may seem rude or disengaged. For example we may ask you to 'go away' or 'be quiet'. This is not meant badly. (*Comparison:* Think of patients who are breathless - they say and do the minimum).

Are you one of many carers?

It does make life more difficult for both the care giver and cared for person when there is little or no opportunity for the care worker to learn from experience. For a person with M.E. it is very frustrating to be repeatedly expending scarce energy explaining things. Please be aware that this presents a significant challenge, and bear with us.

2. Sensory Overload

People with M.E. commonly have a low tolerance of sensory input of all kinds. Noise, light, physical sensation, and vibration can become extremely unpleasant, causing ongoing discomfort and pain.

This may be due to changes affecting sensitivity in the central nervous system (as inflammatory changes have been found at autopsy in severely affected patients). The impact on the patient is like turning the volume dial right up, and after effects can continue for some time.

How to respond to Noise Sensitivity (Hyperacusis)

Do not be boisterous: Adopt a quiet, gentle, delicate demeanour. Speak quietly. Do not bang and crash around.

Washing up: do it quietly, gently, close any doors to reduce noise.

Hoovering: close doors or omit altogether.

Mobiles: there is no necessity for mobile phones to be switched on or used during a call; also, its just plain rude!

Light Sensitivity (Photophobia)

You may find clients with M.E. wearing dark glasses, living with their curtains shut, and using only low inten-

sity lighting. Please respect our need for shielding from light. This may necessitate meeting personal care needs in very dim conditions.

Multiple Chemical Sensitivities (MCS)

Not all of us suffer from sensitivity to chemicals, however MCS is common in people with M.E. There is evidence to suggest this is due to malfunctions in the immune system. Whatever the reason, quite serious adverse effects can follow exposure to many items that are commonly used. For example:

- Perfume and alcohol - found in many common household products
- People wearing products containing perfume and/or alcohol
- Plastic wrappings, plastic bags
- Printed materials
- Acrylic nails (also unhygienic)

Personal example from a patient *“For several days after exposure to a carer who had used products containing chemicals I was unable to talk, unable to think clearly or make decisions, and I had problems concentrating.”*

3. Protecting from Infection

Protect your client - Don't carry an infection in

Clearly all clients should be protected from exposure to infection. However people with M.E. may be particularly vulnerable. Catching infections tends to make people with M.E. much worse, also they find it difficult to get over infections. There is quite a bit of evidence of abnormal immune function, which may help explain this.

What infections are you in contact with?

As a care worker, it is critical that you don't attend a call to a client with M.E. when you have an infection yourself or when you have been in contact with anyone with an infection – including your children and your previous clients. This would include stomach bugs; coughs / colds; chest infections – however minimal; or if you are on antibiotics.

Personal example from a patient: *“I caught a chest infection from a home care worker in 2007 – I still have it in 2012”*

Hand Washing is Vital to Avoid Passing on Infection

On arrival wash your hands

If you touch your face wash your hands again

After shopping you need to wash your hands again

If you go to the toilet you need to wash your hands again

Protect yourself and your other clients

We don't know exactly how M.E. is caused, but persistent infectious agents have been implicated. So:

Use gloves when handling anything that has been in contact with bodily fluid *i.e.* tissues, sheets, clothes, continence pads

Use the protection of aprons and sprays as required

4. Shopping & Cooking

Gastro intestinal problems and reactions to certain food-stuffs are common. These are very severe in some patients.

This means that specific details of the shopping requested can be very important. If a certain brand or shop is stated there may well be a health related reason for this.

Personal example from a patient: *“I ate a ‘Maggi’ brand tamarind sauce, not realising it contained MSG (monosodium glutamate) - I was awake all night and became very ill.”*

Many of us cannot eat basic staple foods, such as wheat, gluten and dairy products. And we can react very badly to certain food additives & preservatives - like nitrates/sulphates, which are commonly found in sausages, ham, and packaged cold meats. In this case your client's meals will need to be cooked from scratch from carefully selected ingredients.

For some clients it will be essential to wash all meat and vegetables before cooking, to remove bacteria and chemicals.

Clients with M.E. may struggle to maintain stable blood sugar, if so we need to eat frequently and fare better on complex carbohydrates *e.g.* brown rice rather than white. Again, this means that cooking can take longer.

Management Considerations

- **5. Preparing Staff**
- **6. Continuity of Care**
- **7. Use & Misuse of Mobile Phones**
- **8. Managing Infection Risk**

As a home care manager, it is vital that you are aware of the above issues around hands on care. Additionally there are management considerations around planning and organising care delivery.

5. Preparing Staff

In contrast to what may be the norm for staff training, home care workers should be advised *not* to encourage clients with M.E. to do more for themselves.

Home care workers should be aware of the food intake and food preparation needs of their clients, and crucially must be aware of any food that the client cannot safely digest.

Have your home care workers had food hygiene training? Do they have the skills to prepare food and cook from scratch as required? Are their skills and training culturally appropriate to the client?

Modelling – new carers learn by example

To conserve the client's precious energy, and avoid unnecessary exposure to noise and interaction, it is appropriate for new care workers to learn by example, quietly *observing* a more experienced person as they work with the client.

6. Continuity of Care

Having visits from many different home care workers is unlikely to be any client's preference. For clients with M.E., having to deal with many different home care workers can be particularly damaging.

M.E. affects a person's ability to concentrate and communicate. Energy is scarce and precious, as we have very limited resources for mental and physical effort. Post exertional deterioration is a feature of this illness, that the client can do nothing to over ride.

Assigning a variety of different home care workers may also be downright dangerous. There is too much for each fresh care worker to become aware of, and to remember. Without experience it is less likely that changes that give cause for concern will be picked up – for example noticing if the person is more ill than usual, or has forgotten to take their medication.

Personal example from a patient *“I have had 50+ carers that I can name over the last 10 years; that is 50 times I have had to explain where the dustbins go out and where the recycling goes etc; and 50 people who have my personal details”*

Avoid High Turnover of Staff

Having to cope with many new home carer workers can:

- make a person with M.E. avoid having the call and doing without care
- lead to the breakdown of the care package

Does your service have sufficient depth of personnel to

cope with annual leave and sickness absence? Do you invest in staff, and provide conditions of service that encourage prolonged commitment ?

7. Use & Misuse of Mobile Phones

Please organise communication outside of care sessions and neither encourage nor require staff to use mobile phones during home care calls. The impact of hearing mobile phones ringing could be distressing and damaging to a very sick and noise sensitive client. It is also rude and unprofessional for home care workers to use mobile phones during care delivery sessions, for anything other than matters relating to the care needs of the person they are with. If you need to update staff then messages can be left on mobiles, for checking between care calls *i.e. once no longer in the client's home.*

8. Managing Infection Risk

Protecting a client with M.E. from potentially lasting and damaging infections means replacing a member of your staff when they have an infection, or if they have recently had contact with another person with an infection.

Does your agency have sufficient staff and to avoid exposing vulnerable clients to risk of infection at all times? How will this be funded?

In order to protect clients and staff during calls, guidance on infection control should be adhered to. Current guidance for England can be found in:

The Health and Social Care Act 2008 *Code of Practice on the prevention and control of infections and related guidance;*

Clinical Guideline 139 March 2012 *Infection: Prevention and control of healthcare-associated infections in primary and community care*

Providing Home Care to people with M.E. requires awareness and sensitivity. However it can be very rewarding to the care giver, and greatly valued by the cared for person.

This article is based on a talk given to home care workers at a London agency in April 2012. C Ross, who delivered the talk on behalf of Richmond & Kingston M.E. Group, has had M.E. for some time and has 10 years experience of having care workers providing care at home. It is written from her own experience. She is moderately affected but hopes this briefing will be of use to those more severely affected than herself.

Recap of Key Messages

Approach to Care:

- Do not 'push'. Let the client dictate the pace.
- The client knows best - don't try to impose your views, your priorities or your values.

Sensory overload:

- Keep noise to a minimum. A quiet manner is best.
- Do not use mobile phones during care calls.
- Protect clients with chemical sensitivities by **not** exposing them to chemicals / perfumes.

Infection:

- Wash your hands. Repeatedly.
- Protect your client - don't carry an infection in.

Shopping & Cooking:

- Your client may have very specific dietary requirements and food sensitivities - details matter.
- Your client may require to eat little and often.

Management Considerations:

- Make staff aware that encouraging a client with M.E. to do more for themselves is *not* advisable.
- Ensure staff are aware of any special dietary and food preparation requirements.
- Take effective action to ensure maximum stability of care worker allocation: however —
- Do not hesitate to pull the regular member of staff from the care call if they may be carrying an infection.
- Do not require staff to take or make mobile phone calls during care calls.

Further Materials for Education & Awareness

A practical guide to supporting someone with Severe ME by Linda & Greg Crowhurst

<http://www.stonebird.co.uk/A%20Practical%20Guide.pdf>

Supporting someone with Severe ME : Care Sheets

by Linda & Greg Crowhurst

<http://www.stonebird.co.uk/Care%20Sheets.pdf>

A Patient's Perspective – Information Leaflet for Professionals Caring for People with Severe M.E.

Supporting people with severe myalgic encephalomyelitis.

Crowhurst, G; Nursing Standard 19, 21; 38-43, 2005

Both of the above items can be downloaded from the 'Publications' section of the 25% ME Group website

Resources for Understanding & Remembrance

http://www.25megroup.org/campaigning_Severe_ME_Day.html

If you would like to have any of these and do not have access to the web, please contact the 25% ME Group - details are below

BOOKS (all cost under £10)

One Last Goodbye

By Kay Gilderdale Ebury Press 2011

<http://www.whsmith.co.uk/products/one-last-goodbye-sometimes-only-a-mothers-love-can-help-end-the-pain/product/9781409034728>

Lost Voices from a Hidden Illness

<http://www.investinme.org/LostVoicesBook/IiME%20Lost%20Voices%20home.htm>

Severe ME/CFS - A Guide to Living

By Emily Collingridge

<http://www.severeme.info/about-emily.html>

DVD (costs under £10)

Voices from the Shadows

<http://voicesfromtheshadowsfilm.co.uk/shop-dvds/>

NB: This article is about looking after people with myalgic encephalomyelitis (M.E.). You may not be aware that nowadays people with M.E. are often given a different 'label'. They are said to have 'chronic fatigue syndrome' (CFS) or even 'chronic fatigue'.

Whether you are a care service manager or a care worker, we hope you find this briefing helpful.

Additional copies are available from the 25% ME Group

The 25% ME Group,

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