Home Care Delivery

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

People with M.E. may be some of the sickest people that you and your staff will have contact with, particularly if their case is severe.

Providing Home Care to people with severe M.E. requires great awareness and sensitivity.

However it can be very rewarding to the care giver, and greatly valued by the person with M.E.

Whether you are an agency manager with responsibility for arranging to deliver suitable home care, or a social worker charged with ensuring that an effective care plan is in place, or a manager commissioning care services, we hope that you will find this briefing helpful. ***Feedback is welcome.***

This guidance may also be useful for the care of clients who are said to have 'chronic fatigue syndrome' (CFS) as this diagnostic label is often given to people with M.E.

Key Messages

Basic issues for planning and organising care delivery for this client group include:

- **Ensure staff are aware that clients with M.E. should *not* be encouraged to do more for themselves – this is counter productive.**
- **Ensure staff are aware of any special dietary and food preparation requirements and able to meet these.**
- **Take effective action to ensure maximum stability of care worker allocation; but …**
- **Do not hesitate to pull a regular care worker from the call if they may be carrying an infection.**
- **Do not require staff to take or make mobile phone calls during care calls.**

1. Approach to Care - *Less is More*

In contrast to the general vogue, Home Care Workers should be advised not to encourage clients with M.E. to do more for themselves.

Strategies that are normally seen as 'enabling' or 're-enabling' are complete misnomers where M.E. is concerned. Attempting to do more will actually leave the person able to do less. Clearly this is counter productive.

People with M.E. are only too well aware of how their illness affects them, and immensely frustrated by the high price they pay for any effort. 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. The client can do nothing to over ride this.

Post-exertional malaise is the key defining feature of this illness. There is a characteristic 'push ⇨ crash' pattern.

This means that experiencing pressure to impose an obligation to be more active is enormously stressful and alarming. Our advocacy service is acutely aware of the fear and apprehension at the prospect of being 'obliged' to undergo 're-enablement' – which would only make them more ill - as a condition of receiving care causes. As well as being unpleasant, stress is a risk factor in further deterioration.

For people with M.E., energy is scarce and very precious. The less an M.E. sufferer has to do, the better the possibility they have to heal. There is no evidence that people with M.E. are debilitated because they have become physiologically deconditioned.

Avoid 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. Adverse after effects can continue for many days, even weeks.

So it is important that all staff attending care calls are made aware of the client's particular needs and limitations in terms of sensitivity to noise, lights, vibrations, and chemicals and are equipped to deliver care in a way that respects these.

GUIDANCE FOR HANDS ON CARERS ….

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

Let the client dictate the pace. The client knows best. Please do not try to impose <u>your</u> views, <u>your</u> priorities or <u>your</u> values on clients.

When receiving instructions listen carefully, and take your own notes to assist memory if required.

Keep Communication to a Minimum

The more the client is required to say and do during a care call, the less they will be able to say and do for the rest of the day.

There may be very little reserve of energy. A client with M.E. may quickly become confused, or struggle to say what they want to say, or become unable to talk at all.

GUIDANCE FOR HANDS ON CARERS …

Some clients with M.E. are too debilitated to ask you to be quiet when needed, or to ask you to talk in a quieter voice.

Clients with M.E. may seem rude or disengaged at times. They may ask you to 'go away' or to 'be quiet'. This is not meant badly.

If the person isn't chatty it's because they feel too ill. It is not reflective on you. Observe the silence. Don't make the person feel they must talk, to be polite.

If you are doubling up with a colleague, please don't chat to each other over the person you are caring for. This is never good practice. And it makes it even harder for a client with M.E. to speak and be heard.

A client's relative or informal carer might appear to 'talk for the person' e.g. giving you the tasks. They are not being domineering or trying to rule the life of the person with ME, but trying to conserve their energy. They know them best.

Alternatively the family / or the agency could make a very detailed care plan with times and tasks with the need for minimum questions.

Chemical Sensitivity

Not all clients with M.E. will suffer from sensitivity to chemicals. However this is common in people with M.E. and in some cases the trigger threshold is extremely low, and the consequences if breached are severe.

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."*

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, including scented beauty products
- Plastic wrappings, plastic bags
- Printed materials
- Acrylic nails (also unhygienic)
- Nicotine

A care worker smelling of nicotine can trigger off unpleasant reactions in a chemically sensitive client. If a client stipulates that they require a non smoker it means just that – a carer who does not smoke – not just someone who does not smoke while in the client's home.

'... A full functional assessment of the personal and domestic needs of the patient within the home should be completed (for example, people with severe CFS/ME are often sensitive to light, noise and chemicals, so may require quiet, dark surroundings with no or limited use of household products such as cleaning products or air fresheners) ...'

extract from 'NICE' clinical guideline 53

The Use & Misuse of Mobile Phones

Please organise communication with Home Care Workers outside of care sessions and neither encourage nor require staff to use mobile phones during care calls.

The impact of hearing a mobile phone 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.

If you need to update staff then messages can be left on mobiles, for checking *in between* care calls.

GUIDANCE FOR HANDS ON CARERS …

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

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

Hoovering: close doors; if still too noisy try using an old fashioned Ewbank carpet sweeper or omit altogether

Mobiles: there is no necessity for mobile phones to be switched on or used during a call

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

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2. Protecting from Infection

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.

Personal example from a patient: *"I caught a chest infection from a Home Care Worker in 2007 – I still have it seven years later."*

Does your agency have sufficient staff to avoid exposing vulnerable clients to risk of infection at all times?

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 – including their children, or a previous client. It is critical that Home Care Workers know not to attend a call to a client with M.E. In any of these circumstances. It is all too easy to fall into the trap of imagining that because you are starting to feel better the client is no longer at risk of catching your infection.

In addition, the usual health and care protocols should be followed.

GUIDANCE FOR HANDS ON CARERS …

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 again

If you go to the toilet wash your hands again

When handling anything that has been in contact with bodily fluids - used tissues, sheets, clothes, continence pads - use gloves and also the protection of an apron, dependent on the task. Please ensure that you have sufficient supply of gloves to change them as required.

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3. Shopping, Cooking, Support to Eat

There are many reasons why additional support around mealtimes may be required.

Gastro intestinal problems and reactions to certain foodstuffs are common. These are very severe in some patients. Many M.E. patients cannot eat basic staple foods such as wheat, gluten and dairy products, and react very badly to certain food additives & preservatives - like nitrates/sulphates, which are commonly found in sausages, ham, and packaged cold meats: this mean the client's meals will need to be cooked from scratch from carefully selected ingredients.

'Dietary interventions and supplements

People with severe CFS/ME may face many difficulties in achieving adequate and balanced dietary intake including:

- **pain and fatigue making the physical process of eating difficult and possibly requiring help with feeding**
- **sensitivity to the smell or taste of food**
- **difficult or painful swallowing**
- **sore throat making eating difficult**
- **nausea affecting the ability to eat**
- **bowel symptoms affecting food choices**
- **food intolerances leading to a restricted diet**
- **disturbed sleep patterns causing meal patterns to be disrupted**
- **the need for carers to help with all aspects of food purchase and preparation.'**

extract from 'NICE' clinical guideline 53

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

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

Home care workers must be fully 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 eat.

GUIDANCE FOR HANDS ON CARERS …

Details of shopping can be very important. If a certain brand or a particular shop is requested there may well be a health related reason for this. So please observe the instruction carefully.

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

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4. Allocating Staff to Home Care Calls

Having calls from many different Care Workers is unlikely to be any client's preference. However, for people with M.E., having to deal with many different Home Care Workers can be particularly damaging. Continuity of care is vital.

M.E. affects a person's ability to concentrate and communicate. Energy is scarce and precious, with very limited reserves for mental and physical effort. The stress and effort involved in engaging with a changing stream of home care workers can make the person even more unwell.

This can make a person with M.E. avoid having call and doing without care. Having to cope with many new Home Care Workers can lead to the breakdown of the care package.

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

Assigning a variety of new Home Care Workers can also place the client in danger. There is too much for the fresh care worker to become aware of, and to remember. It is less likely that changes giving 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.

For clients who are entirely bedbound, it is essential that staff providing care are trained in specialist techniques such as changing bed linen with the person remaining in bed, and/or moving the patient using slide sheets in such a way as to causing the minimum of pain.

'Modelling' – new carers learn by example

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

GUIDANCE FOR HANDS ON CARERS …

If giving a bedbath, check the temperature of the water as the person may not be able to feel it. This applies to the temperature of food & beverages also.

Avoid putting weight – e.g. of pillows – on feet as this will push the feet down, causing pain and possibly long term damage.

If your client is unable to move ensure you support the limbs properly – speak to your moving & handling person if in doubt.

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5. *Very* Severely Affected Client Care

For severely affected M.E. patients there is often a tension between their requirement and wish for support, and their need to keep what can be an intolerable level of suffering down. This presents an excruciating dilemma for those who are most severely affected.

A very low threshold of symptom exacerbation can lead a client to decide to do without, rather than risk being made worse by carers. Often care providers simply do not comprehend what is driving the person to decide to do without care that they clearly require and cannot provide for themselves.

In this difficult situation enormous sensitivity, awareness and mutual respect is required in order to find the best way through.

You can help minimise adverse impact by ensuring maximum continuity of care, taking effective steps to ensure that all carers are well briefed regarding the client's needs around delivery of care, and ensuring there is ample opportunity to quietly 'shadow' and observe a more experienced carer, before leaving any carer to deliver a care session alone.

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