

# Are you aware of M.E.?

M.E. is a much more common condition than many people think. This booklet aims to educate and inform, to build an understanding of how M.E. can affect sufferers, and how friends, families and carers can ensure they are supportive in the right ways

*produced by*

**Richmond & Kingston**



**M.E. Group**

**Serving Richmond & Kingston Boroughs & the surrounding areas**  
**[www.richmondandkingstonmegroup.org.uk](http://www.richmondandkingstonmegroup.org.uk) Tel: 07984 860 309**

# Think of what a severe hangover feels like...



- headache
- nausea
- intolerance to bright lights and loud noises
- lethargy
- diarrhoea
- dry mouth/thirsty

even when you haven't had a drink!

# Think of what a fever or flu feels like...

- muscle and joint pains
- raised temperature and sweating



- sore throat
- severe headaches
- weakness/fatigue and general discomfort
- coughing and runny nose
- chills/shivering

# Think of how debilitating a broken leg would be. You wouldn't be able to:

- walk without pain
- sit or stand comfortably
- get up/down stairs without difficulty
- wash easily
- do your normal job
- do your normal exercise
- do your normal hobbies



# What effect would these conditions have on your ability to...

- look after other people?
- go grocery shopping?
- do the washing up?
- do the laundry?
- do the cooking?
- eat and drink what you want?



# What effect would a chronic illness have on keeping...



- good relationships with colleagues?
- sick leave?
- your job?
- a continuous employment record?
- healthy finances?
- your usual standard of living?

# What effect would it have on enjoying your...

- hobbies?
- free time?
- exercise?
- social life?
- relationships?
- love life?
- family?
- holidays?



**Now imagine having a combination of all these things. This is what M.E. feels like. But there's more:**

- it gets worse if you try to do any physical or mental activity
- you don't know how long the illness will last, if it will improve or get worse
- it is virtually invisible, particularly when you are well enough to be out and about, which may be as little as two hours a day or less
- it makes even the basic day-to-day activities much more difficult, let alone working or having fun
- you may be faced with disbelief from family, friends and the medical profession



# My frustration about M.E.

*A person with moderate M.E. writes...*



- I am forced to try to manage my life very carefully. Even moderate sufferers will experience virtually all the symptoms described. It is very restrictive
- M.E. is a variable illness, and if I ever exceed my very strict personal limits, I exacerbate all my typical symptoms and get extra ones too, quickly sliding towards severe M.E. symptoms, at least temporarily
- Luckily, as long as I rest totally for several days, I can usually get back on track if I am especially careful for the next few weeks or months

# The balancing act of trying to control symptoms and relapses

- It is impossible to reduce my activities down to a base level below which I wouldn't have these symptoms. Dressing, washing, eating, drinking and going to the toilet can all push me past this limit
- Even keeping them to a minimum, food shopping, washing up, laundry and cleaning can push me well over the limit
- This really leaves absolutely nothing in reserve for working, filing for benefits, paying bills, etc., so all these activities make my symptoms worse

# Managing to live with M.E.: Pacing

- I have to work out in advance, wherever possible, what I am going to do during the week
- I get help with things if possible, then divide up the remaining tasks across the week to reduce the negative impact of doing them
- I also break down jobs into smaller chunks and have rests between these parts
- I have to prioritise carefully, because I never have enough energy for all the things I *have* to do, let alone for the things I *want* to do
- All the symptoms affect me every day, to a lesser or greater extent, depending on by how much I have exceeded my limits

# It's like being constantly overdrawn

- You could compare your personal energy to a bank balance, only with M.E. you are always overdrawn and being charged penalties whenever you do anything at all
- To enable you to try to get better, or at least stop being heavily penalised, you have to try to keep within a very tight overdraft limit
- Any unexpected events nearly always mess up the very fine balance you are trying to keep
- This results in your account being frozen – or, in M.E., a relapse, until you rest for a long time to get back on track

# What happens when I relapse?

- I have even more pain in my muscles and joints, as well as total exhaustion
- I have a severe migraine-type headache
- I can hardly turn over in bed
- I cannot get comfortable in any position
- I struggle to get to sleep and often wake up at the slightest thing, still in pain, and unrefreshed, even after many hours of trying to rest or sleep
- I cannot have a shower. Sometimes I have to resort to a strip-wash, or not wash at all, until I improve enough
- I cannot do anything but try to rest until it passes
- Even getting to the toilet is a major difficulty

# What I need to do when I relapse

- I need to lie still in a very quiet, very dark room

---

- I must try to lie down flat, with my arms straight, by my sides, and my legs straight

---

- I cannot tolerate noise, light, changes in my body temperature, touch, or speaking

---

- Regardless of ambient temperature, I often get too hot and sweaty, or I get too cold and shivery

---

- I cannot eat or drink as normal

**I am extremely sensitive to light  
and noise so I need to sleep or  
rest in a quiet, blacked out room**

# I am extremely sensitive to noise and need to try to rest in total silence

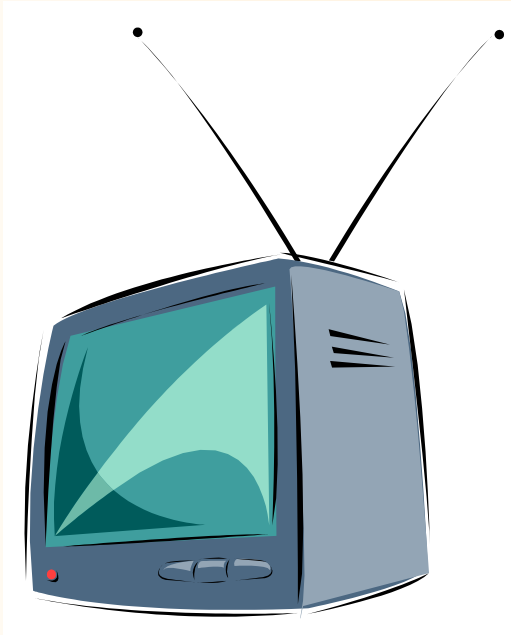


No

- talking
- laughing
- shouting
- crying babies
- children playing
- dogs barking



- I cannot tolerate computers



- I cannot tolerate television

- I cannot tolerate music



- I cannot tolerate road works



- **I cannot tolerate building work or DIY**

*So many of the everyday things you take for granted make my life harder. Whispers turn into shouts. Phone calls and face to face conversations can be deafening and debilitating. Having the radio on, hearing traffic outside, being in a crowd... all can prove too much for someone with M.E.*



# Other people's reaction to someone with M.E.

- It is invisible to other people most of the time, because we can only see people or go out when we are having a good day
- Some people, including friends, family, colleagues, benefit decision makers, medical staff and even carers do not understand or believe in our illness, even when we describe all the symptoms we are suffering
- For many years M.E. was considered a form of depression, but the evidence to the contrary is overwhelming

# Some of the emotions I feel because of M.E.

- Frustration – at my inability to do all the things I used to take for granted, and at other people still taking these things for granted
- Anger – at the lack of a cure and the disproportionately little amount of time and money being put in to search for a cure
- Hope – that I will get better in time
- I strive to be thankful for the free time I have now, and try to find positive, very low energy ways of enjoying it

# Hopefully now you understand more about M.E. and how it affects people

- M.E. affects us physically
- M.E. affects us emotionally
- M.E. affects our finances
- M.E. affects our relationships with other people
- Possibly most importantly, other people's reactions about M.E. and their actions in their dealings with us can have an enormous impact on how we feel

Thank you for taking the time to read this booklet.

To find out more about Richmond and Kingston M.E. Group, use our website:

<http://richmondandkingstonmegroup.org.uk>

Or please contact us using:

Telephone 07984 860 309

(this is an answer phone, so please leave a message and we will get back to you)

E-mail: [randkmegroup@yahoo.co.uk](mailto:randkmegroup@yahoo.co.uk)

We also have a **facebook** page. Please pay us a visit at:

<http://www.facebook.com/RichmondandKingstonMEGroup>

Finally, you can donate to help our work at:



<http://localgiving.com/richmondandkingstonmegroup>

**After reading  
this, if you  
meet someone  
with M.E., how  
will you act?**