

***For Severe M.E. Awareness 2015 - A Day for Understanding and Remembrance....***

***... and, we hope, a time to be 'heard'.***

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***service user 'Susan' shares her experience .....***

***Thanks to all government departments for looking after me .... can I talk with you? .....***

I became ill suddenly. I had no experience of community social care. I had worked in the NHS but none of this prepared me for the complex road I had to travel.

I am writing this from the depths of my heart to appeal to everyone in a position of providing services to people with severe ME.

I want you to really listen to severe ME sufferers to find out how best to work with us to avoid aggravating symptoms and to make the best use of your time and money when trying to come to decisions about what is needed and then how to deliver the provision for that need.

What I have written here is based on my own experiences and perceptions. I have been diagnosed with very severe ME. I have been this way now for over a decade.

Many of my friends have lived with severe ME for over 20 years now, some friends have died from it, or from the complications it causes, sometimes from misdiagnosis, or from new symptoms of ME being overlooked, or attributed incorrectly to be mental health problems. Some sadly but understandably chose suicide to stop the unbearable pain and suffering or when they feel they can no longer keep fighting all that's involved in having their needs met, when totally dependent on others and government departments.

I discovered the range of emotions from trying to come to terms with and manage a very difficult, complex and severe disease, which seemed determined to destroy every aspect of my life, were compounded by having to learn how to deal with the complicated repetitive maze of the very departments the government established to be there to help and support me.

Add to this so much misunderstanding, about the nature of Severe ME.

I have experienced some fantastic care managers and times when social services have been extremely helpful. These good times have shown me how well it can work and I have felt proud as a country we have a system there to enable this.

However, I have also repeatedly experienced very many more difficulties resulting in my need of legal advocacy on many occasions to assist me in communications with my local authority. That is not a good situation for me or for the local authority to be in.

If government departments design the wrong support or come to incorrect decisions, they can do so much more damage that is often permanent to the sufferer - which I'm sure is not what anyone wants.

I now have a package of care that is meeting my needs. The journey to get there has often felt like a series of vicious 'tornadoes' constantly coming at me from every direction, with me desperately fighting to survive and keep my basic physical needs met.

Each battle causing major relapses from all the cognitive activity used to deal with each twisting whirlwind demanding attention! If each 'blast' is not dealt with and fought for correctly, care might get lost causing a certain overwhelming avalanche of increased symptoms and further deterioration.

I'd lost enough function already, I needed to desperately cling on to and preserve what I had left.

When you need homecare, healthcare or finances for the basics to survive, the fear of not getting what you need to keep your condition stable is terrifying.

***So, the stakes are high - how to 'get it right'? Susan continues ....***

**We need to find best ways to work on the assessment of need, and provision to meet needs, for people with severe ME with social services and other departments across the country. Everything in the life of a severe ME sufferer depends on those needs being met in a suitable way, or deterioration is inevitable.**

**To help 'get it right' in planning and providing care, please think about....**

### **Cost effective long term planning**

Severe ME is a long term chronic multisystem illness. Recognising this from the start and planning for that scenario, rather than taking a short-term view in the hope that that person will improve, gives a realistic optimum standard of care. This will help to prevent further deterioration - and the person requiring even more care for so much longer and costing even more to provide for.

Please be aware that, unfortunately, some people become progressively worse despite everyone's best efforts.

### **Getting the type of care delivery correct 25% M.E. Group Survey Feedback**

This is vital to give the best chance to avoid excessive deterioration, which can be quite rapid and drastic.

Giving somebody 'enablement' who is not well enough to be able to do what is being asked is only going to be detrimental.

Most severe sufferers would struggle to maintain an activity or a conversation within a half-hour care visit. At times I am not well enough to talk to anyone, or even tolerate somebody being in the room.

This has a major impact on the type of care provision for sufferers as every task has to be broken down with rest times for the client, and be done quietly gently and without instruction.

*"Delay from social services - in providing an assessment and care - meant that care was not available, my condition deteriorated drastically as we struggled to cope.*

*I feel that things might well never have become so awful if we had been given appropriate help at the outset. The delay cost us, and social services, dearly."*

So people with severe ME generally need longer visit times than you would normally allocate for the care tasks to be done.

To deepen understanding of *why* this is important, and improve adherence, we need to look at ways of improving knowledge of patterns of symptoms in severe ME, and how these relate to activity, and to exposure to stimulus, along with the resulting effects and consequences on functioning and well-being.

More on this in our:

**25% M.E. Group  
Home Care Delivery  
Briefing**

We also have a  
companion paper :

**Key Messages for  
Home Care Workers.**

### **The assessment and review process**

The uncertainty of future care provision is a stressful time.

It's a breakthrough moment - helpful to both assessor and service user - when it's recognised and fully understood that quite serious difficulties with cognitive skills and physical functioning ability can be masked by adrenaline, and it will only be afterwards that sufferer is left extremely ill, in pain, in turmoil, and not really have taken in 75% of what's been discussed.

How the person can best be helped through an assessment process may vary from client to client -what is consistent is that each person will know how they can best deal with such things. Failure to acknowledge and adjust for difficulties can make the process of having an assessment quite a damaging experience.

It worked best for me when my care manager was given the time she really needed to do my assessment, making follow up reviews so much easier for both me and the local authority - so time well invested.

We agreed a plan as to how we needed to do that, over several short visits. We set time limits with rest

breaks, agreeing to finish earlier if needed, rather than risk me becoming unwell for weeks or longer having pushed myself beyond my limits.

**Preparation & Support** Severe ME sufferers will normally need support to prepare for an assessment or review.

Such support, with the option of advocacy, should always be offered. This can be *vital* to ensure appropriate flow of information to social services in the course of the assessment. This is due to the complex cognitive difficulties sufferers experience, along with the deterioration in health and ability to function going through those processes causes.

Support is also required to assist a severe ME sufferer to be involved in assessment and review meetings /visits. However, some will find it very hard - even impossible - to communicate and exchange detailed information even with a supporter or advocate.

### **Continuing Health Care (CHC) funding applications**

The Continuing HealthCare process, ostensibly involving health and care professionals working together, can cause disastrous delays via extended or repeat assessments before decisions are reached - which I'm sure is frustrating for all.

These assessments are the worst I've been through.

Something really does need to be worked out with health and social care to make this process easier, quicker, and less dangerous to the sufferer.

After all, you have to be in a bad way for the decision to be made to consider NHS CHC funding in the first place.

***Susan concludes ....***

***It is only from the point of needs being met correctly that an ME sufferer has any hope to gain improvement - and then only if the disease allows that to happen.***

***Thank you for 'listening'***

#### **25% M.E. Group Survey Feedback**

*"When I requested appropriate levels of funding I was told I must have a complete reassessment by a 'multidisciplinary team' of seven including a psychiatrist and a psychologist.*

*This large number would cause a MAJOR relapse .*

*My original diagnosis of ME was questioned & Social Services & Health Authority wanted a complete reassessment after 22 years of illness. I made a formal complaint, which was upheld."*

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### ***We hand over to 'Marion' - and her insight as a carer...***

I have been a Carer in different ways for most of my life, but I'd not come across M.E. until I met Mary. She was struggling to discover why her health had taken a hard blow and she could no longer live life as she chose, or achieve what she had planned.

Eventually I began to support her a little and heard that she had been diagnosed with M.E. This was a new learning experience for me and I found it very difficult to understand.

Mary lived about 45 miles from me so I didn't see her often, but we were in almost daily contact by text and email. It was very confusing that she was describing problems that I couldn't really understand.

I began to support her one day a week and eventually went to her home 3 times a week as a volunteer. At that point we applied for Direct Payments. I didn't really want to be paid for helping her but the cost of petrol for more than 270 miles a week was beginning to add up.

Mary came to stay with us over Christmas and then returned home. Twice she asked to come back to stay

and eventually told me she could no longer cope alone without help. We made arrangements for her to stay with us .

***What a difference emerged when I was with Mary all the time rather than seeing her part time in her own home. It was only then that I realised the full impact that M.E. has on a person and began, little by little, to understand it.***

I experienced her condition fully all the time and saw how difficult life was for her.

For example Mary couldn't plan anything as she either could not sleep, or slept excessively but was still too weak to get up or to complete anything useful. She made long lists now and then, planning what she wanted or needed to do.

My husband had previously asked why I spent so much time at her home. When staying with us he'd come home and ask if she was still there, as he hadn't see her for weeks. Mary couldn't cope with loud noises so my husband could not play the piano as the sound reverberated throughout the house. The smell of the shower gel he used wafted upstairs and made her choke. He couldn't answer the front door and stand there chatting loudly with friends.

When I took Mary to a medical appointment she was immediately back in bed as soon she arrived back. Fully clothed, she'd collapse on the bed with pain and exhaustion.

Life was so different for all of us.

Eventually after a year, a meeting with Social Services took place and they decided that she must live at her flat full time and they would provide Home Care Workers for her.

Her GP spoke at the meeting and said that she *knew* that Mary would get well again. That left me speechless!

On one occasion the same GP had 'explained' to Mary that when she was a child her mother had taken her to the doctor frequently, so that was why she kept returning to see her with new symptoms as an adult.

***That was the end of carefully crafted care and the beginning of care chaos, with hundreds of different carers, with various levels of understanding or lack of it.***

The nightmare for so many people with M.E.

'Rehabilitation care' and the 'well you could do that the other day, so you can do it yourself ' attitude is so disturbing for someone struggling to cope but being taunted by the idea that they are choosing to remain ill.

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### **Coping with Assessment**

#### ***25% M.E. Group Member Survey Findings***

This process had adversely impacted on all who had participated in their Community Care Assessment:

- fewer than 1 in 5 of those who had been assessed felt that they had been well enough to cope during the assessment [12/66; 18%];
- all of those who had participated in the assessment visit(s) had been exhausted afterwards; and
- the vast majority had taken 3 days or longer to recover from the adverse impact of the assessment process, with some taking over a month.

Some had been too ill to be involved in any way, and had been represented for CCA purposes by family or an advocate. (And a family member had responded to our survey on their loved one's behalf.)

### ***Messages for Home Care Management...***

- Do make staff aware that encouraging a client with M.E. to do more for themselves is *not* advisable.
- Do take effective action to maximise stability of care worker allocation; however —
- Do not hesitate to pull a regular worker 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.

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### ***Messages for Home Care Workers***

#### ***Approach to Care:***

- People with M.E. may be among the sickest people you will ever have contact with
- Do not 'push' - let the client dictate the pace
- Be aware that your client may not be able to concentrate for long
- 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 - do not expose them to chemicals or perfumes

#### ***Infection:***

- Protect your client - don't carry an infection in
- Wash your hands repeatedly: vital for infection control

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### ***Resources from the 25% M.E. Group include ...***

1. Home Care Delivery: *Looking after people with M.E.* Briefing for Providers, Managers, and

Commissioners

2. **Key Messages for Home Care Workers**
3. **Social Services Survey Findings & Feedback, Report**
4. **Information Leaflet for Professionals Caring for People with Severe M.E.: *A Patient's Perspective***
5. **Resources for Understanding & Remembrance**  
[www.25megroup.org/campaigning\\_Severe\\_ME\\_Day.html](http://www.25megroup.org/campaigning_Severe_ME_Day.html)
6. **Exercise & Ensuring Patient Safety: *Why exercise is contra indicated***  
*these can be downloaded from the 25% ME Group website - [www.25megroup.org](http://www.25megroup.org)*

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### ***Some Further Materials for Education & Awareness....***

#### **Supporting people with severe myalgic encephalomyelitis**

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

#### **A practical guide to supporting someone with Severe ME**

by Linda & Greg Crowhurst

[www.stonebird.co.uk/A%20Practical%20Guide.pdf](http://www.stonebird.co.uk/A%20Practical%20Guide.pdf)

#### **Supporting someone with Severe ME : Care Sheets**

by Linda & Greg Crowhurst

[www.stonebird.co.uk/Care%20Sheets.pdf](http://www.stonebird.co.uk/Care%20Sheets.pdf)

#### **ME/CFS: A Clinical Case Definition & Guidelines for Medical practitioners - *Overview of the Canadian Consensus Document***

Bruce M Carruthers and Marjorie I van de Sande 2005

£1.75 each plus p&p from [www.investinme.org](http://www.investinme.org)

#### **BOOKS**

##### **Severe ME/CFS - A Guide to Living**

By Emily Collingridge

[www.severeme.info/about-emily.html](http://www.severeme.info/about-emily.html)

##### **One Last Goodbye**

By Kay Gilderdale Ebury Press 2011

[www.whsmith.co.uk/products/one-last-goodbye-sometimes-only-a-mothers-love-can-help-end-the-pain/product/9781409034728](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**

Invest in M.E.

[www.investinme.org/LostVoicesBook/liME%20Lost%20Voices%20home.html](http://www.investinme.org/LostVoicesBook/liME%20Lost%20Voices%20home.html)

#### **DVD**

##### **Voices from the Shadows**

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

***If you wish to access any of these and are experiencing difficulty, please contact the 25% ME Group***

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**The 25% ME Group**  
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