



Home Care & 'Re-ablement'

'...just plain cruel'

Recently we have been working to raise the profile of home care, and way care needs must be responded to if a person with M.E. is to be protected from deterioration.

Most recently, to mark *Severe M.E. - A Day for Understanding & Remembrance* on August 8th 2015, we published a feature on 'Home care - getting it right', and circulated our Home Care Delivery Briefing, with a pro forma letter for members to use to send this on to social services departments. We've also highlighted the excellent care guidance developed by Greg Crowhurst of Stonebird 'The Lived Experience of Severe M.E.' www.stonebird.co.uk

Sadly, going by the feedback we are receiving from members, and our awareness of the 'big picture' in terms of current ideology, nothing could be further from the approach that social services tend to adopt.

'Re-ablement'

It's become mainstream to imagine that, rather than accessing ongoing care, people seeking support can be 'enabled' to do things for themselves. This is known as 're-ablement'.

This has its roots in NHS efforts to avoid unnecessary hospital admissions among elderly patients, and always had potential to be a slippery slope given the cost cutting motivation. It has now mutated into a pervasive response to adults seeking care from social services.

The 'thinking' goes something like this:

Ongoing care support = 'dependence' = bad

'Re-ablement' = regaining 'independence' = good

The idea is that care workers from 're-ablement' teams will attend care call for a few weeks, leaving the client able to do things that they couldn't previously. How, exactly, they have obtained these quasi-magical powers is not at all clear. The term 'brainwashing' would not be entirely out of place. And this is becoming ever more entrenched.

The National Institute for Clinical Excellence – commonly abbreviated to 'NICE' – is now the '*National Institute for Health and Social Care Excellence*'. This means that methods beloved of 'NICE' in considering what healthcare people in England should have access to are now being applied to social care.

Back in spring we learned that 'NICE' had development of a guideline on 'short term interventions for regaining independence' on their agenda.

The consultation on scope stated the client group as: "*All adults identified as having lost, or being at risk of losing their independence.*" We responded, highlighting the enormous breadth of this catchment and specifically warning against the application to people with M.E. Reply? - "*We agree that re-ablement may not be appropriate for all people and anticipate that this will be an important issue for the Guideline Committee to discuss*"

Consultation on a draft guideline is scheduled to begin in January 2017. This is just over a year away, and it would be good to be ready to go at this stage. It would be better still to have made input to try to influence the content of the draft.

As things stand, there is no guarantee that there will be a 'call for evidence' to underpin the January 2017 draft.

How to ensure that 'evidence' from people with M.E. is in the frame We'd like to hear from you, so that the 'NIHCE' folks have the opportunity to consider the import of your experience.

Have you have been pushed towards a 'reablement' team?

Have you had 'reablement' involved?

What were the consequences?

Alternatively - individuals can follow this channel noted:

"In addition, the NCCs will accept relevant confidential information."

"For some, it's just plain cruel" was the contribution from a rep at a recent meeting attended by one of our members. This person was not representing people with M.E. So there *are* links to be made.

You can find out more about the 'guideline in development at: <http://www.nice.org.uk/guidance/indevelopment/gid-scwave0709>

NOTE: Clinical Guideline 53 on 'CFS/ME' advises further reading when seeking to care for severely affected patients, citing : ***Supporting people with severe myalgic encephalomyelitis*** Crowhurst, G; Nursing Standard 19, 21; 38-43, 2005

Copies are available from the 25% ME Group and via the group's website.

Although much of CG53 is unfit for purpose for a person with M.E. there is some guidance in Chapter 7 – '*People with Severe CFS/ME*', which could be helpful with a view to accessing suitable, and suitably delivered, home care provision.

We have highlighted this in our Home Care Delivery Briefing.

We can also supply a sheet with the relevant extracts.