

## What our members are telling us:

A recent survey to assess the needs of severe ME highlights that although there are clear similarities between severe ME sufferers, individual assessment and tailoring of care packages is essential, as one size does not fit all. Some services/treatments are not transferable and may cause more harm than good.

### 3 Priority areas highlighted:

- \* The importance of understanding ME and believing it is a "real illness"
- \* Managing daily living and needs
- \* Accessing Welfare Benefit entitlements

### What we can offer:

- \* Someone to visit at home
- \* Help to access to medical services
- \* Help with welfare benefits
- \* Help with activities for daily living
- \* Help to access other voluntary sector agencies
- \* Telephone helpline
- \* Regular newsletters



- \* The Voice for ME/CFS in the North East and North Cumbria
- \* The Regional Patient Representative for dedicated ME/CFS services
- \* Empowering people to make informed choices
- \* Educating and informing service providers in health, education, social services and the workplace to recognise the reality of this disabling disease
- \* We operate an open referral service to all with a diagnosis of ME/CFS

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Improving the lives of the severely neglected with ME/CFS

Advocacy & Support  
for  
People with  
Severe ME/CFS  
and their  
Families  
across the  
Northern Region

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## What is ME/CFS?

ME/CFS affects 12,000 people in our region. 25% are severely affected, housebound/bedbound for long periods, (figures based on Department of Health prevalence rates).

**The varying symptoms and disabilities which many severe ME sufferers experience include:**

- \* visual problems
- \* vocal/muscular problems
- \* general chronic weakness of limbs
- \* cognitive problems such as memory loss and concentration difficulties
- \* problems with balance and fine motor muscle pain
- \* malaise
- \* hypersensitivity
- \* sleep and temperature disturbance
- \* cardiovascular symptoms
- \* digestive disturbances
- \* neurological disturbance

## What is the correct name?

We prefer to call it ME (Myalgic Encephalopathy) and the Department of Health and doctors prefer CFS (Chronic Fatigue Syndrome). To satisfy both we call it ME/CFS.

## Why Advocacy and how will it help?

There are five CFS/ME teams across the region offering diagnosis, assessment and therapeutic treatments for the mild to moderate ME patient who can access outpatient clinics.

Insufficient funding within the teams mean domiciliary services are very limited and in some areas non-existent.

It is such an isolating illness that the majority of people are "invisible", hidden from society and neglected by service providers.

ME North East have been awarded a second 5 year grant by The Big Lottery Fund to continue our domiciliary advocacy and support project, helping this patient group access a range of services that may help to improve their quality of life.

## What we do

We provide a service for adults with severe ME covering local authority areas in Northumberland, Tyne & Wear, County Durham & Darlington, Tees Valley and North Cumbria.

We bring together a range of services to enable each person to better manage their illness, improve their well-being and reduce the often significant stress caused by ME.

To achieve this we offer a person centred approach for predominantly house bound service users which will provide them with access to a range of services and benefits that they are presently unable to access due to the isolating and debilitating nature of their illness.

Specifically the project provides individual advocacy and support for approx. 60 new service users per year. A person centred package of care is developed, tailored to suit the needs of the individual and link with a range of statutory and voluntary agencies to improve quality of life.

We employ a multi-disciplinary approach involving health care, social service support, access to welfare benefits, as well as access to a range of other voluntary sector agencies that can offer additional help to the care package.