

**Rights for ME is a pioneering benefits casework project which aims to improve the lives of people suffering from ME in the Morecambe Bay area and to push for longer term changes which will benefit far more.**

**The project is funded by the Big Lottery Fund for a three-year period. It is the result of a partnership between Morecambe Bay ME Group and Lancaster Citizens Advice Bureau. The service is available to those with ME/CFS, their carers and families, living in Barrow, Lancaster and South Lakes districts.**

ME stands for Myalgic Encephalomyelitis / Encephalopathy. ME is also known as CFS, Chronic Fatigue Syndrome.

The illness has a complex range of symptoms, varying from one person to another. The illness can take a mild form, or it can be so severe that people are bed-bound and need help all the time with basic tasks such as feeding and washing.

## WHY HAVE A DEDICATED SERVICE?

ME is an illness that is not always understood by others, including those in government, the medical profession, one's family and friends and neighbours. It was realised by the partners of the project that employing a specialist caseworker could help people with the illness to represent the condition to others on their behalf.

People with ME have regularly missed out because the sickness and disability benefit rules do not seem to fit the symptom pattern of the illness, and the process of claiming benefits can be very challenging and frustrating. People with ME have said they have been unable to complete the process of claiming benefits, because the resulting stress has led to a worsening of their symptoms.

The process of claiming is time-consuming: the benefit system is complex and subject to frequent change, and can take considerable energy to understand.

The same factors can affect requesting help from others, such as Social Services, managing money matters, and more.

## CITIZENS ADVICE INFORMATION, ADVICE AND REPRESENTATION

Most of the project work will be assisting people with ME in claiming sickness and disability benefits, that is *Incapacity Benefit* (IB), *Income Support* (IS) on the basis of being too ill to work, and *Disability Living Allowance* (DLA) / *Attendance Allowance* (AA).

The project caseworker will explain the **eligibility criteria** for the different benefits, and the **application procedures**. Advice will be available about how to **improve these applications**, and how to **challenge benefit decisions** where possible.

The project also provides support for two other areas of enquiry : other benefits, to do with overall income, housing costs, benefits for carers; and claiming occupational pensions/sickness insurance when stopping work because of sickness.

General information is available via referrals to specialists where possible for enquiries about: the application of the Disability Discrimination Act in the context of employment; requests for Community Care assessments and other assistance from Social Services; dealing with debt; and housing suitability.

### **SOCIAL POLICY**

The project has also another function: to campaign with others to challenge discriminatory and unfair policies, procedures, services and legislation. This social policy work is carried out by collecting statistical information from client cases, as well as presenting arguments to policy makers, and influential figures in the area such as MPs.

The Rights for ME project has been launched at a time of change for people with ME: there has been official recognition of the illness followed by NHS funding for a nationwide CFS/ME service, after the publication of the Chief Medical Officer's Report in 2002 into the disease; parts of the benefits system are under review; considerable changes are proposed for sickness benefits; and there seems to be slowly increasing recognition of the illness by statutory bodies.

### **WHO BENEFITS?**

The project is for people with ME, their families and carers living in the Barrow, South Lakeland and Lancaster districts. The boundaries of the project are: to the south, Galgate in Lancashire; to the north Grasmere in Cumbria; Sedbergh in the east, and Barrow-in-Furness in the west.

### **HOW THE PROJECT IS DELIVERED**

Clients are referred to the project caseworker by the referral line of Morecambe Bay ME Group (01524 65842), through Lancaster Citizens Advice Bureau, or through the NHS CFS Local Multidisciplinary Team.

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## One person's ME Story

*Falling ill with ME is a disaster at any age, but being hit by this devastating condition in your teens is especially cruel. This should be a time of dreaming, ambition, finding your own voice, and a busy social life.*

*Jo, from Kendal, suffered her first bout of ME in 1997 when she was just 17.*

*"I was studying for A-levels at Queen Katherine School, Kendal, and kept getting tonsillitis and became rundown. Then I got a flu-like virus and literally collapsed," Jo recalls.*

*The array of physical problems she went on to suffer comprised the classic core of ME symptoms: unrelenting exhaustion, unlike anything the sufferer has experienced before, little relieved by sleep; severe muscle pain, especially after minor exertion; loss of concentration; dramatic sleep problems, and a fluctuation from day to day, in the severity of these symptoms.*

*"I was diagnosed by a locum GP. I was shocked at the term ME; I knew that a girl at school who was in a wheelchair had had it. This doctor said I wasn't exercising enough, yet in truth I had increased my amount of exercise because I thought to feel so ill must mean I was unfit."*

*This was the worst advice Jo could have received and it began to dawn on her that the more she pushed herself the worse her symptoms became. The ME diagnosis was confirmed by a consultant at Westmorland General Hospital, but he could offer no cure or specific treatment.*

*By this time Jo had become bed-bound and remained that way for the first year with her parents caring for her.*

*"During the second year I built up my strength to the point where I could potter around the house. Eventually I was able to go back to school part-time. The school's attitude was fantastic. They understood the constraints of the illness and let me come and go as necessary. By balancing rest and activity I was able to*

pass some A-levels and I got into university.”

After graduation Jo worked, travelled extensively and completed intensive teacher training at St Martin’s College, Lancaster. “I was lucky enough to get a job at my old school as an English teacher.”

But by February half-term, 2005, her old ME symptoms began to threaten. At Easter she suffered the relapse from hell. The condition was back with a vengeance and she had to leave work.

“My muscle problems are particularly severe. I’ve had times when I can’t even brush my hair. I can’t read a book nor can I drive because of the exhaustion and concentration problems.”

From holding down a demanding and well-paid job, Jo, at 26, is now dependent on benefits.

“I don’t have enough NI credits to qualify for Incapacity Benefit but I receive Income Support, Housing Benefit and Disability Living Allowance. I live in a shared house with friends, who are extremely supportive, as are my parents.”

The benefits people were understanding but Jo found filling in all the claim forms a nightmare.

“They’re confusing, ambiguous and draining. You can’t say what you are like on average as it varies such a lot within the spectrum of the illness. You have to focus so much on what you can’t do and this is a very disheartening exercise. I turned to Kendal Citizens Advice Bureau whose help was invaluable.

“I couldn’t survive without Disability Living Allowance and I will use Morecambe Bay ME Group’s new benefits worker because my current housing situation isn’t really suitable. I need a ground floor flat but don’t know how leaving here would affect my benefits.”

She adds: “When the benefits system does work it’s great because you can shed that worry and put all your efforts into getting well. I hope by next year I’ll be able to take up voluntary or part-time work. I’m not going to agonise over returning to full-time work because this last relapse has taught me that I must

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It is planned for referrals to the project to also be made through other Citizens Advice Bureaux in the area, from doctors' surgeries, and from Social Services.

After an initial contact by telephone with the caseworker, a **home visit** will be arranged if support from the caseworker is necessary. Home visits are key to the project, because they enable clients to make the most use of their available energy in contact with the caseworker, and avoid them having to travel to a venue for an appointment.

Contact details for the project are on the back page.

*Other information available from the Rights for ME project:*

**Rights for ME booklets**

Benefit Applications and Appeals  
Attending the Doctor's Examination  
Voices of ME

**Rights for ME Leaflets**

Disability Living Allowance checklist  
Incapacity Benefit checklist  
Summary of activities and functions for DLA and IB  
Writing a diary as evidence  
Disability and Sickness Benefit Map  
Social Services Care Assessments – rules and principles

## Links to useful other organisations

### **Action for ME (AfME)**

Third Floor, Canningford House, 38 Victoria Street,  
Bristol, BS1 6BY

**Telephone support service , tel.: 0845 123 2314**

Tues-Fri 11am-1pm, Mon 6.30am-8.30pm

AfME offers telephone welfare rights advice for their members

**[www.afme.org.uk](http://www.afme.org.uk)**

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### **The ME Association (MEA)**

4 Top Angel, Buckingham Industrial Park,  
Buckingham, MK18 1TH

**tel. 08704 441 836**

daily, at these times:10am-12noon, 2-4pm, 7-9pm

**[www.meassociation.org.uk](http://www.meassociation.org.uk)**

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### **25% ME Group**

for people with severe and very severe ME (house/bed bound)

21 Church Street, Troon, Ayrshire, KA10 6HT

**tel. 01292 318 611**

25% ME Group employ an Advocacy Worker

**[www.25megroup.org](http://www.25megroup.org)**

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### **MEActionUK (website only)**

very active analytical group, watching parliament and research

**[www.meactionuk.org.uk](http://www.meactionuk.org.uk)**

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### **Carers UK**

20-25 Glasshouse Yard, London, EC1 4JT

tel 02074908818

***Carers Line* tel. 0808 808 7777**

Weds and Thurs, 10am-12noon, 2pm-4pm

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### **Association of Young People with ME—AYME**

PO Box 5766, Milton Keynes, MK10 1AQ

AYME's local rate helpline: 08451 23 23 89

Mon– Fri 10am-2pm, Weds 6pm-9pm

**[www.ayme.org.uk](http://www.ayme.org.uk)**


To contact the Rights for ME (**RfME**) project:  
referrals line:  
tel. **01524 65842**  
or by email to:  
**enquiries@lancastercab.org**  
or  
**info@bayme.org**

**Aims and Principles of Citizens Advice Service**

*to ensure that individuals do not suffer through lack of knowledge of their rights and responsibilities or of the services available to them, or through an inability to express their needs effectively and equally*

*to exercise a responsible influence on the development of social policies and services, both locally and nationally*

The service is free, confidential, impartial, and independent

<p>The Rights for ME project is a partnership between Lancaster CAB &amp; Morecambe Bay ME Group.</p>	<p>Supported by</p>
	
<p>Morecambe Bay ME Group</p>	
	