



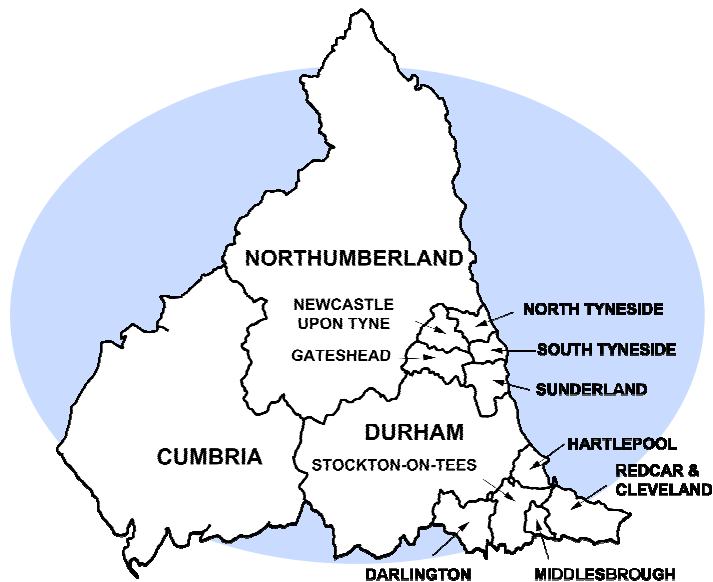
& North Cumbria

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ME NORTH EAST

WELFARE BENEFITS A GUIDE TO YOUR RIGHTS

INFORMATION ON BENEFIT ENTITLEMENTS FOR PEOPLE WITH
ME/CFS THEIR FAMILIES AND CARERS.



Compiled and Produced by Jennifer Elliott and Judy Blackett
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FOREWORD

I am delighted to introduce this booklet on benefits from the perspective of patients with CFS/ME. This is an area of great difficulty for patients and their carers and the current benefits system is not user-friendly.

It is clear that the likelihood of success is dependent on getting medical reports from specialists and even with these the outcome is not always positive.

The most important piece of advice is do not try and 'go it alone' - you will be more successful if you obtain professional help with the application and appeal processes.

This booklet is the first stage for ME North East in improving its support for patients in this area.

**Dr Gavin Spickett Consultant Immunologist
Clinical Champion for The Northern CFS/ME Clinical Network
Chair of ME North East Formal Medical Advisory Panel**

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WHAT THIS GUIDE IS FOR

This guide is to help you understand your rights and entitlements to a range of welfare benefits, and to enable you to get the best support available whilst living with or caring for someone with ME/CFS.

This guide covers only the main benefits that you may be entitled to, the system is complex and qualifying for one benefit may often lead to additional support.

It would be impossible to give details of all the benefits that may be available to you, but we hope this guide will help to explain those main entitlements, how to claim, what to claim, the process of applying and appealing against decisions as well as the amounts you are entitled to.

We also explain how to get help and support in going through the process of claiming. Completing the forms is difficult and can be extremely stressful. Filling in the forms is not simple, and we recommend you complete it over a period of time, in small bite size chunks, to avoid stress. Do not try to complete the forms on your own. We would urge all claimants to seek help and support. You may be offered the choice of completing an application over the telephone with an advisor asking questions. We do not recommend this approach, you need time and help to consider your answers.

ME North East wish to help in the best way we can, and whilst we are improving in our skills and capacity to do this, we recognise there are other organisations that specialise in this area of work, and we include contact details for additional help and support at the back of this guide.

***The figures in this guide are current up to April 2011.
Annual increases will be available on our website
www.menortheast.org***

Introduction to Benefits

Welfare benefits are paid to make sure that there is a minimum standard of living that no one should fall below.

This guide is for those who are sick or disabled or care for someone who is sick or disabled.

There are basically two sets of benefits

Means tested benefits – these are paid even if you have not paid enough national insurance contributions. But you will not get them if your income and/or savings are above a certain amount

Non means-tested benefits – these are paid even if you have not paid national insurance contributions, and is paid on top of any earnings or other income you may have.

You have a right to these benefits, both means tested and non-means tested. This guide will explain who has the right to claim which benefit and how to make a claim.

The benefits and social security system can be seen by many as being complex, time consuming, frustrating and generally not worth the hassle. Other views are that you are taking handouts from the state and people feel uncomfortable accepting them.

Please remember these benefits have been set up to acknowledge the difficulties and financial costs involved whilst coping with a disability, and the impact on yourself, your family and carers.

If you haven't already done so, we recommend that you at least review your current financial situation, sooner rather than later. Please note that claims cannot be backdated, so if you delay you could lose money you are entitled to.

Whilst the range of benefit entitlements are wide and complex, we focus here on the main benefits you may wish to look at:

- Disability Living Allowance
- Employment Support Allowance (since 2008 this replaces existing Income support and Incapacity Benefits)
- The Blue Badge parking scheme
- Attendance Allowance
- Carers Allowance

DISABILITY LIVING ALLOWANCE (DLA)

DLA is a benefit for adults and children with disabilities. It is for people who need help looking after themselves and those who find it difficult to walk or get around. You may qualify for DLA whether you are in work or claiming Employment Support Allowance. You don't need to have someone looking after you to qualify.

DLA is the main benefit for disabled children and adults up to age 65.

HOW TO CLAIM DLA

To claim a benefit you will usually have to fill in a form. Each benefit has its own form.

There are different departments that deal with different benefits, in some cases you can claim online or over the phone. However as some of the forms are quite lengthy and you will need some time to consider your responses to questions, it may be better to get a paper copy and take your time to fill it in. In many cases you will need help to fill them in, and it can be very difficult to work out if you qualify for certain benefits. To help you we list a number of contacts you can approach for help and support at the back of this booklet.

In most cases you will have to provide evidence to back up your claim, for instance you will have to give your national insurance number, and evidence of your residence as well as your income or savings. Always keep a copy of your claim and copies of any other forms or letters you may send in with your claim. If you have to send off original documents be sure to keep copies and send them recorded delivery to make sure they arrive safely.

You can claim online or get a claim pack by;

- Phoning the Benefit Enquiry Line 0800 88 22 00
- Contacting your local Jobcentre or social security office

The Benefit Enquiry Line 0800 88 22 00

This is a confidential freephone service for disabled people and carers; you can call the Benefit Enquiry Line and ask them to send you a claim pack. They can send you the claim pack in an alternative format if required – for example, Braille.

The Benefit Enquiry Line is open 8.30am to 6.30pm Monday to Friday and 9.00am to 1.00pm Saturday.

If you request a form from the Benefit Enquiry Line, the date of the request will be treated as your date of claim from which Disability Living Allowance can be paid, as long as the form you receive is returned within six weeks of that date. If you delay making a claim, you may lose out on benefit.

The person taking your call will not have your personal details but will be able to give you general advice. This advice must not be taken as a decision about your claim.

Contacting your local Jobcentre or social security office

If you request a form from your local Jobcentre or social security office, the date of request will be treated as your date of claim from which Disability Living Allowance can be paid, as long as the form you receive is returned within six weeks of that date. If you delay making a claim, you may lose out on benefit. You may be offered the chance to submit your claim over the phone. We strongly recommend against this.

INFORMATION TO SUPPORT YOUR CLAIM

Your GP may be asked to give a report on your medical condition. This information will inform the decision for your claim.

GPs are instructed by the DWP NOT to make any efforts to see you to make an up to date report, but to base their response from your patient notes.

If you have not attended your GP surgery for a time, the GP may not be aware of any change in circumstances, and this may affect your claim. Best advice is to regularly visit your GP to ensure he/she is aware of any change in circumstances, and also to determine whether any health problems are indeed as a result of your ME/CFS.

Letters of support, the claim will ask 'who knows you best'?

If you see a Consultant regularly then this would be the best person to name as a reference, many people go to see their Consultant simply because of this requirement. Other people may know of your condition better, this may be a therapist, nurse, or social worker. All could provide statements to support your claim if they agree to do so.

DLA is tax-free and non means-tested and you don't have to have paid any national insurance contributions. This means it is paid on top of any earnings or other income you may have.

DLA has two parts called components, the Care component and the Mobility component. Each is paid at different weekly rates, and you could get either components, or, either the care or mobility component by itself.

CARE COMPONENT

If you have care needs, it means that you need help with things like getting dressed, going to the toilet, or cooking a main meal for yourself. Or you must be looked after so you do not get hurt. It could include help outside the home. It does not matter if you do not actually get this help as long as you can show you need it.

The care component is paid at three rates (low, middle and high) depending on how much extra care is needed for you or your child. It is available from three months of age.

The highest rate (£71.40) is paid if;

- You or your child needs looking after during the day and night

The middle rate (£47.80) is paid if;

- You or your child needs frequent help or continual supervision throughout the day time OR
- During the night time, you or your child needs repeated or prolonged attention, or someone needs to be awake so that they can keep an eye on you to avoid danger

The lowest rate (£18.95) is paid if;

- You or your child needs some help in the day with things like bathing or going to the toilet or changing clothes or getting into or out of a chair.

MOBILITY COMPONENT

If you have mobility needs, it means you cannot walk, or you walk with difficulty, and you cannot walk outdoors or on an unfamiliar route without the help of someone else most of the time. It does not matter if you do not actually get this help, as long as you can show you need it.

This component has two rates, low and high, depending on your disability needs and condition.

Higher Rate: (£49.85) is paid if;

- If you or your child cannot walk at all. For example you use a wheelchair to get around OR
- Walking outside is very limited – for example, because of pain or breathlessness OR
- It is dangerous for you to walk (even if you are able to) – for example because of a heart condition OR
- You are both deaf and blind and cannot get around without help OR
- You are severely mentally impaired and have severe behavioural problems and also qualifies for the higher rate care component

Note: receiving high rate mobility allows you to apply for a Blue Badge and for road tax exemption

The Lower rate (£18.95) is paid if;

- You are able to walk, but cannot walk outside without guidance or supervision on routes you do not know well. This could be because of things like poor eyesight or a learning disability

The decision-maker who will assess your application will determine the level of financial support you receive. Although if you dispute the decision (if it is at a lower rate than you expected), you can request a revision or lodge an appeal against this decision. It must be remembered that if you do ask for a revision you should clearly identify the reasons for doing so. Insufficient information could result in losing **all** mobility rate.

Disability Living Allowance – Medical Examination

The decision-maker can approve your claim without a medical examination if they are happy with the information they have got. If they need more information, or are unsure about any details they may ask for a medical examination.

What happens at the medical examination?

- The medical examination will involve an interview (asking you to respond to a list of questions)
- A physical examination, including requests to do what may appear to be simple tasks, this examination is unlike an examination you would expect from your GP
- This examination is not to diagnose or discuss treatments of your illness or disability; it is to assess how it affects you and your ability to manage

Before the medical examination

To prepare for your medical examination, you might want to think about:

- What everyday tasks you have difficulty with, or are unable to do
- If you can do more on some days than others, explain what a typical day is for you
- Those tasks that you can do on one day but cause problems as a result later

DLA – your rights to a medical examination

The medical examination will usually take place in your own home at a time that suits you. It may also take place at a Medical Examination Centre near where you live. You should be given 7 days notice of your examination, but you can make an earlier appointment if it suits you better. If you miss your first examination appointment, the doctor must make a second attempt to visit you. If you miss two appointments, or refuse to attend, your benefit claim may be turned down. You have the right to have a friend, relative or support worker with you at the medical examination. (We would urge you to have someone present). You have the right to see the report the medical examiner writes and asks you to sign.

DLA – medical examination – what happens next?

Your medical report will be sent to the department responsible for making a decision on your claim (The Disability and Carers Service). This will be considered along with all the other information provided. They will decide whether to approve your claim and what level of DLA you may receive.

If you are unhappy with the medical examination

If you are unhappy about the way the medical examination was carried out, you can complain to Medical Services. The complaints procedure is explained in the letter you receive about your medical examination. You can also complain to the doctor at the time of the examination. If they cannot resolve the problem, they will give you a brochure explaining the formal complaints procedure.

The Doctors Report

You can ask to have a copy of the doctor's report sent to you at any time. If you appeal against the benefits decision, you will be able to see the doctor's report as part of the appeal process.

What to do if your claim is refused or you are unhappy with a benefit decision?

Claimants need to be aware that over 80% of first applications are turned down. The reasons for such a large number failing is not clear, but it does show how important it is to make your claim with as much evidence and clarity as possible. If you are turned down, don't give up, we encourage you to appeal. With help and support over 65% of appeals are successful. There are several steps you can take; Try to get more information. You will receive a letter advising you of your benefit decision. The letter will tell you what you need to do if you want someone to explain the contents to you, and you should contact the person who sent it either by

- telephone, or visiting the benefit office in person.
- Ask for the decision to be looked at again (a benefit review). You have one month from the date you receive the decision to ask the benefit office look at it again. This course is only recommended if you feel they have missed something very obvious or not enough information was made available to them.
- You can appeal against the decision, either straight away or after the revision. An appeal means that your benefit decision will be taken to an independent tribunal – the members of this independent tribunal are completely separate from the officers that make the benefit decision. If you have the right to appeal, you will be told this in your decision letter.
- You have one month from the date of the decision letter in which to appeal. It is advised to lodge the appeal quickly, and then prepare the case for appeal. You may need expert help to make an appeal.

Once you have been awarded DLA

Your DLA award will be either for a fixed or an indefinite period. The decision-maker will set the length of time of your award depending on whether your disability or illness is permanent or your needs may change. If your award is for a fixed period, you will be invited to make a new claim before the award runs out. This is called a 'renewal claim'. Renewal claims are processed exactly the same way as new claims, so you may be asked to attend a medical examination again.

Effect on other benefit entitlements

If your claim for DLA is successful, it might increase the amount of other benefits or credits you are entitled to, such as;

- Income Based Jobseekers Allowance
- Income Support
- Pension Credit
- Housing Benefit or Council Tax Benefit
- Working Tax Credit
- Child Tax Credit

If someone is paid Carer's Allowance for providing care for you, you may not be able to receive an extra amount for severe disability in any of these benefits or credits.

For more information, you should contact the office dealing with your claim for the benefit or credit concerned or contact the Disability Living Allowance helpline.

EMPLOYMENT SUPPORT ALLOWANCE

Employment Support Allowance (ESA) replaces Incapacity Benefit and Income Support for new claimants (from October 2008). If you are already receiving Incapacity Benefit, you will continue to get it as long as you are eligible. You may also qualify for Disability Living Allowance (DLA) whilst claiming ESA.

We all agree that people are better off in work – not only financially, but also in terms of their health and well being, their self-esteem and the future prospects for themselves and their family. However there are times when remaining in employment or finding work becomes impossible because of illness and disability.

Employment Support Allowance (ESA) offers you personalised support and financial help, so that you can do appropriate work, if you are able to. It also gives you access to a specially trained personal adviser and a wide range of further services including employment, training and condition management support, to help you manage and cope with your illness or disability at work.

ESA involves a new medical assessment called the Work Capability Assessment. This assesses what you can do, rather than what you cannot, and identifies the health-related support you might need. Most people claiming ESA will be expected to take steps to prepare for work, including attending work focussed interviews with their personal advisor.

Under ESA, if you have an illness or disability that severely affects your ability to work, you will get increased financial support and will not be expected to prepare for a return to work.

HOW TO CLAIM Employment and Support Allowance

There are several ways you can claim;

By telephone 0800 055 6688 or textphone 0800 023 4888

Lines are open Monday to Friday 8.00am to 6.00pm

Calls from BT landlines are free

Textphones are for people who find it hard to speak or hear clearly.

Textphone numbers can only receive calls made from another textphone.

If you do not have a textphone of your own but need to use one, try your local library or an advice centre like the CAB who may have one.

You can claim online

You can claim online via the Department of Work and Pensions' Benefit online service.

If you would like to fill in the claim form by yourself, you can download it. You can fill it in online and use the save facility to complete the form in your own time. You will have to print this form and post it to the Jobcentre Plus. You can also download and print the form and fill it in by hand. There are guidance notes, which you need to read before filling in the claim form.

INFORMATION TO SUPPORT YOUR CLAIM

Your GP may be asked to give a report on your medical condition. This information will inform the decision for your claim.

GPs are instructed by the DWP NOT to make any efforts to see you to make an up to date report, but to base their response from your patient notes.

If you have not attended your GP surgery for a time, the GP may not be aware of any change in circumstances, and this may affect your claim. Best advice is to regularly visit your GP to ensure he/she is aware of any change in circumstances, and also to determine whether any health problems are indeed as a result of your ME/CFS.

Letters of support, the claim will ask 'who knows you best'?

If you see a consultant regularly then this would be the best person to name as a reference, many people go to see their consultant simply because of this requirement. Other people may know of your condition better, this may be a therapist, nurse, or social worker. All could provide statements to support your claim if they agree to do so.

WORK CAPABILITY ASSESSMENT

Work capability assessment is the main assessment for Employment Support Allowance claims.

When you make your claim, you will be required to complete a questionnaire about how your illness or disability affects your ability to complete everyday tasks. Your own doctor may be asked to provide a medical report.

An approved healthcare professional will consider the questionnaire and any medical reports, along with any other information you may have provided.

If they feel more information may be needed to make a decision on your claim, they will recommend that you attend a face-to-face medical assessment.

The medical examination will usually take place in your own home at a time that suits you. It may also take place at a Medical Examination Centre near where you live. You should be given 7 days notice of your examination, but you can make an earlier appointment if it suits you better. If you miss your first examination appointment, the doctor must make a second attempt to visit you. If you miss two appointments, or refuse to attend, your benefit claim may be turned down. You have the right to have a friend, relative or support worker with you at the medical examination. You have the right to see the report the medical examiner writes and asks you to sign. Please make sure this report is accurate before signing.

The Medical Assessment

The medical assessment consists of up to 3 parts. Afterwards a report will be sent to the DWP

Before the medical assessment

To prepare for the medical assessment, you might want to think about:

- What everyday tasks you have difficulty with, or are unable to do
- If you can do more on some days than others, what a typical day is like for you
- How your illness or disability affects your ability to work
- What you need to bring on the day of the assessment
- Identification; a passport is adequate on its own, otherwise you will need three documents which can include birth certificate, a full driving licence, bank statement, policy documents
- You should also bring a note of pills or medication you are currently taking and have a note of any aids or appliances you find helpful
- What support you think you need to improve your ability to work

What happens at the medical assessment?

- This will involve an interview and sometimes a physical examination, if the approved healthcare professional feels one is needed.
- The assessment is likely to be different from what you would expect from your own doctor. The assessment is not to diagnose or discuss treatment of your illness or disability; it is to assess how it affects you and your ability to work.
- The last part is usually a Work Focussed Health Related Assessment.

After the medical examination –what happens next?

The approved healthcare professional will complete the report after the medical assessment. They will submit the report to the Department of Work and Pensions. You will not normally see it before it is submitted.

You can request a copy of the approved healthcare professional's report from the DWP. You will get it through the post.

If a work-focussed health related assessment is completed, the approved healthcare professional will send this report to your personal adviser. They will also send a copy of this report to you.

The person responsible for making a decision on your claim

The decision maker will consider the report along with all other information provided for your claim and decide whether you are entitled to ESA. If you are entitled, they will also decide whether you should be placed on the Work Related Activity Group or The Support Group. You will receive a letter stating their decision.

If you are unhappy with the medical examination

If you are unhappy about the way the medical examination was carried out, you can complain to Medical Services. The complaints procedure is explained in the letter you receive about your medical examination. You can also complain to the approved healthcare professional at the time of the assessment. If they cannot resolve the problem, they will give you a brochure explaining the formal complaints procedure.

The Doctors Report

You can ask to have a copy of the doctor's report sent to you at any time. If you appeal against the benefits decision, you will be able to see the doctor's report as part of the appeal process.

If you disagree with the benefits decision

If you think the decision about your benefit claim is wrong, or you disagree with the level of benefit you have been awarded, you can;

- Ask the office who made the decision to explain it
- Ask to have the decision reconsidered by another decision-maker
- Appeal against the decision to an independent tribunal

Amount of Employment Support Allowance

The amount you get paid depends on your circumstances; several things may be taken into consideration. It also depends on what effect your disability has on your ability to do any work. In most cases you will not get any money for the first three days of your claim, these are called "waiting days".

Employment and Support Allowance consists of two phases;

- 1) The assessment phase is paid for the first 13 weeks of your claim, when your ability to work and illness/disability will be assessed. This may involve attending a medical called The Work Capability Assessment.

During this first phase (up to 13 weeks) basic rates of benefit will be;
£51.85 per week for a single person aged under 25
£65.45 per week for a single person aged 25 and over.

- 2) The main phase starts from week 14 of your claim, if the Work Capability Assessment shows that your illness or disability does limit your ability to work

There are two groups within the main phase

Claimants whose assessment phase has shown their illness/disability limits their ability to work will go into the main phase from week 14.

During the main phase you will be placed in one of two groups;

- The work-related activity group where you will prepare for returning to work OR
- the support group, for those who are not expected to take part in any work.

1) Work Related Activity Group

If you are placed in the Work related Activity Group, you will be expected to take part in work-focussed interviews with your personal adviser. You will get support to help you prepare for suitable work.

You will receive a work related activity component in addition to your basic rate. If you refuse to go to the work focused interviews, or refuse to take part fully, it may affect your entitlement to ESA.

2) Support Group

If you are placed in the support group because your illness or disability has a severe effect on your ability to work, you will not be expected to take part in any work. You can do so on a voluntary basis if you want to. You will receive a support component in addition to your basic rate.

If you are in the support group you do not have to go to interviews, but you can ask to talk to a personal adviser if you want to.

During this main phase (from week 14) basic rate benefits will be; £91.40 for a single person in the Work Related Activity Group
£96.85 for a single person in the Support Group

For those who receive a pension income, this will affect your level of payment.

ESA in Youth - ESA(Y)

ESA(Y) is a set of rules that allow certain young people from age 16 to qualify for contribution based ESA even though they may not have paid enough or any national insurance contributions.

There is a qualifying period for ESA(Y). However this qualifying period can be before age 16. You would need to get a backdated sick note from your GP.

“Permitted Work”

Working whilst claiming ESA

You can do some limited work while claiming ESA. There are rules about what work you can do and how many hours you can work. You may have to pay income tax on your earnings.

About Permitted Work

Generally, you are not allowed to work while you are getting ESA because of an illness or disability.

You may be able to do some types of work and within certain limits. This is called “Permitted Work” and it allows you to test your own capacity for doing some work and perhaps gain new skills.

Supported Permitted Work means work that is supervised by someone who is employed by a public or local authority or a voluntary organisation, and whose job it is to arrange work for disabled people. This could be work done in the community or in sheltered workshop. It also includes work as part of a hospital treatment programme.

Although you do not need permission to do Permitted Work, you must check that the work you want to do is allowed under the Permitted Work rules. You should discuss this with your personal adviser.

You do not need approval from your doctor or have a medical assessment just because you are doing Permitted Work. If a medical assessment is due as part of your ongoing benefits-related review, it will go ahead as planned.

Permitted Work is a benefit arrangement – employers do not offer, “permitted work”

Under the permitted work rules you can:

- Work for less than 16 hours a week on average. With earnings up to £93.00 a week for 52 weeks
- Work for less than 16 hours a week, on average, with earnings up to £93.00 a week if you are in the Support Group in the main phase of Employment and Support Allowance
- Work and earn up to £20 a week, at any time, for as long as you are receiving Employment and Support Allowance
- Do Supported Permitted Work and earn up to £93.00 a week as long as you are receiving Employment and Support Allowance, provided you continue to satisfy the Supported Permitted Work criteria

How to appeal

If you are refused Employment and Support Allowance or if you have questions about your payment, you can ask the office that dealt with your claim to look again at their decision. If you are still unhappy with the outcome, you can appeal.

THE BLUE BADGE PARKING SCHEME

What is a Blue Badge?

This scheme is to give people with disabilities the ability to park close to the facilities and services they need to use, so as to improve lifestyle, independence and freedom of choice. The scheme is designed to help severely disabled people to travel independently, as either a driver or passenger.

Holders of a Blue Badge are allowed to park in places where other drivers cannot. For example, you may be able to park on single or double yellow lines for up to 3 hours, and in some cases may park free of charge (although please do check first!).

Do I qualify for a Blue Badge?

Automatic qualification applies if you receive the higher rate of the mobility component of the Disability Living Allowance.

You may still qualify if you have a permanent and sustainable disability which means you cannot walk, or which makes walking very difficult. In this instance you may be asked to answer a series of questions to determine your eligibility.

It is very important that your GP supports your application as he/she may be asked to confirm your condition. A supporting letter from your GP or your Consultant will help your application.

A problem faced by people with ME/CFS is the need for the disability to be described as 'permanent' in order to meet the criteria. The dictionary definition of 'permanent' is "lasting or intended to last or function indefinitely" which under some circumstances could apply to ME/CFS.

It is recognised that it is becoming more difficult for people with ME/CFS to qualify. There is no right of appeal if you are unsuccessful, however you can re-apply if you are turned down.

You must apply to your local council for an application form. To find their contact details and for more on the Blue Badge Scheme visit www.direct.gov.uk

ATTENDANCE ALLOWANCE

This replaces Disability Living Allowance for those over 65 years. It is non means-tested (it does not usually matter what your income or savings are).

It is provided for those who need help and support with personal care.

Who can get Attendance Allowance?

You may get Attendance Allowance if;

- You have a physical or mental disability, or both
- Your disability is severe enough for you to need help caring for yourself
- You are aged 65 or over when you claim

Medical Examination

You will not usually need a medical examination when you claim for Attendance Allowance, but sometimes it is necessary in order to assess how your condition affects you.

The amount you get depends on how much your disability affects you. There are two rates of Attendance Allowance
Higher rate is £71.40 a week
Lower rate is £47.80 a week

CARERS ALLOWANCE

Carer's Allowance is money for a person who cares for someone who has a disability.

This is a contribution towards the income of carers who are unable to work full-time. It is not a wage for caring.

If you or your child is getting the middle or high rate care component of DLA, you may be able to receive Carer's Allowance.

You must be over 16 years old and care for the person for more than 35 hours per week.

You are allowed to earn up to £95 per week net (meaning after any tax deductions), but must not be in full-time education (for 21 hours per week or more).

You do not have to have paid national insurance contributions to get Carer's Allowance.

The amount of savings you have does not affect Carer's Allowance

For Carer's Allowance a 'week' is seven days Sunday to Saturday, so you can still get Carer's Allowance even if you only provide care at week-ends.

The weekly rate is £53.90 although this may be reduced depending on certain other benefits you may be getting, but is not affected by any savings you may have.

FILLING IN THE FORMS

Explaining ME/CFS and how it affects you on a day-to-day basis is very difficult. Those who understand the condition recognise it is a fluctuating illness and can change from week to week, day to day, even hour by hour. The forms do not allow for this, in them you are asked to describe an "average day", when clearly this does not allow for irregularity, varying severity or the after effects of daily tasks that can cause deterioration in your condition.

ME/CFS is recognised within the Disability Discrimination Act 1995, and it is the duty of the decision maker to consider each application based upon the outcomes of living with a disability, regardless of the diagnosis.

Each task you are asked to comment on carries a "score". The score is higher for the greatest difficulty in completing a task, down to a nil score if the task can be completed with relative ease.

Some tasks are scored at a higher rate than others.

A minimum total score of 15 is required to qualify for your application to be considered, (with the other evidence that may have been included as part of your claim).

When completing the form you should use your "average day" as a poor day and comment also on how this affects you as a consequence, perhaps the next day or even after that. You must clearly show how disabling the result of an activity affects you.

WHERE TO GO FOR HELP

ME North East can offer help and support to all our members, we have guidance on helping to complete the forms, and how to appeal against a decision if you feel it is unfair.

Home visits and one-to-one support presently only covers those with severe ME/CFS, who would not be able to access other advisors and means of support on their own.

All social service departments have welfare rights advisers who are there to help you with your claim.

Citizens Advice Bureau also offers help to complete the forms and can also advocate on your behalf at the appeal stage.

Disability North, a regional charity based in north Tyneside also offer this help.

If you need help to find your nearest welfare benefits advisors please call ME North East and we will signpost you accordingly. (0191 3892222)

Useful websites for more detailed information

Government Department for Work and Pensions

www.dwp.gov.uk

Online guide to benefits and work

www.benefitsandwork.co.uk

Citizens Advice Bureau

www.citizensadvice.org.uk

AGE UK

(The new name for Age Concern and Help the Aged)

www.ageuk.org.uk

Equality and Human Rights Commission

www.equalityhumanrights.com

Disability North

www.disabilitynorth.org.uk

A 5 minute free benefit check up

www.entitledto.co.uk

Free and confidential telephone helpline

National Welfare Benefits Helpline

0800 88 22 00

This booklet is available in pdf format on our website www.menortheast.org and may be reproduced without modification for use in the ME/CFS community with full acknowledgement of the source.



Bullion Hall
South Approach
Chester-le-Street
Co. Durham
DH2 2ES

Tel: 0191 3892222

Fax: 0191 3891841

email: info@menortheast.org

website: www.menortheast.org

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