

# Myasthenia Gravis Association



## INFORMATION PACK

### Volume 4

## General Information about Support and Benefits for Myasthenic Patients

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1st Edition

### **Acknowledgements**

We are grateful to our authors who write impartially, give their services totally free and do not receive any funding from Valeant or other pharmaceutical companies.

We are also grateful to all the MGA members and friends who volunteered to proof-read this Volume.

### **Sponsors**

Whilst the MGA is unable to endorse any product or company, it is grateful to Valeant Pharmaceuticals Ltd for sponsorship of this Information Pack.



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**Note:** The information in this volume based upon the provisions which apply in England. Whilst much is common to the whole of the UK, there are variations in Scotland, Wales and Northern Ireland. For details of these, members should contact their local advice centres.

Members in Eire should contact their own Welfare Officers.

# THE INFORMATION PACK

The Board of Trustees of the Myasthenia Gravis Association has approved the following publications for supply, free of charge, to sufferers from Myasthenia Gravis and to the medical practitioners and professionals who look after them. Copies may be obtained from the MGA Headquarters at the address on the back cover. The pack comprises six volumes:

## **Volume 1 - A Medical Guide for Patients with MG**

Medical Information on Myasthenia Gravis for those people who have been diagnosed with the condition.

## **Volume 2 - A Medical Guide for Patients with LEMS or Congenital Myasthenia**

Medical Information on LEMS and Congenital Myasthenia for those people who have been diagnosed with these conditions.

## **Volume 3 - Additional Information for Myasthenic Patients**

Information on complementary treatments.

## **Volume 4 - General Information about Support and Benefits for Myasthenic Patients**

Information on Benefits and general assistance available to people with Myasthenia, including Driving and the DVLA, the DWP, prescription charges, insurance and other helpful organizations and charities.

## **Volume 5 - Medical Information (Medical Professionals)**

Information for people working in the medical profession. Details of Myasthenia Gravis, LEMS and Congenital Myasthenia with a greater emphasis on the neurological effects and drug information.

## **Volume 6 - Medical Articles**

Extracts from medical articles published in the MGA Newsletters.

The Association does its best to ensure that the information contained in these publications is complete and up to date at the time of printing, but cannot accept any legal liability whether for any inaccuracy or otherwise.

## **PRESIDENT'S FOREWORD**

Many of you will know that the MGA has been hoping for a long time to produce a booklet to cover this challenging field. We are very lucky to have eventually found such excellent, hard-working and experienced authors as Mrs R Palmer and Ms Jane Stein. We are doubly grateful to them for drafting Volume 4 so quickly, and also to Ms Jane Stein, Mrs T Robinson and Mrs B Rood for checking and updating it. I feel the MGA can be proud of the near-comprehensive coverage this volume now provides. It has certainly been worth the wait.

Ms Stein has very kindly agreed to keep monitoring the changes to the Rules. As those happen constantly, that is bound to be an open-ended task, so we expect to be up-dating this Volume continually (like the Forth bridge).

By the same token, Readers may well find examples where we have not quite covered their particular case, or have not mentioned some special Rule that affects them. If so, we would be very grateful if they would contact the MGA at Derby to help us in our updating – or, indeed, to suggest any other improvements. The Publications Committee is always grateful for constructive feedback.

In conclusion, I am sure Readers will realise how lucky we are in having access to such experts, so may I repeat my thanks to our kind authors and, of course, to Rodney Haverson, the editor.

John Newsom-Davis  
President

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# INFORMATION PACK

## Volume 4

### General Information for Myasthenic Patients

#### **About this Guide**

Welcome to Volume 4. This guide has been prepared to support myasthenic patients when applying for Benefits and to provide general information on practical matters. It is based upon the experience of volunteer advisers and professionals involved in the care and support of people with one of the Myasthenias. MGA can not accept any legal liability for any inaccuracy or otherwise, but we believe that information contained in this guide is accurate at the time of going to print.

## **BENEFITS**

### **1. Introduction**

Benefits are entitlements paid for through the National Insurance and Tax systems, **not handouts**. They provide extra money and services which enhance the lives of myasthenics. They are recognition that society takes the problems of the sick and disabled seriously. Do remember that:-

- In an effort to be fair, the system has become bogged down in so much bureaucracy that it sometimes has problems functioning. It also demands a lot of self-assessment. That's why, for most people, dealing with the benefit authorities is at best daunting, and at worst a traumatic experience. Please don't be put off by the pitfalls. Try to understand that the system exists to help you, and apply for all the benefits that you think you are eligible for. Go for it!
- Before you start it is essential to understand that MG is accepted by the Government as a chronic disabling condition, but this is no green light to entitlement to any Benefit. (Well, you will get free prescriptions without too much difficulty!)

- You will have to prove to the authorities that your condition and circumstances fit the Rules for every Benefit, so look at these with your Adviser (see section 4, page 6, Where to go for Specialist Independent Advice) to see if you have a chance of success before applying for each Benefit. A further hazard can be the departmental instructions (regularly updated) to Assessors on how to interpret those Rules. That's why it's so important to take expert advice at an early stage from those trained in Welfare Rights Law. If you get your application right in the first place, you are more likely to save the stress of having to appeal at a later date.
- Get all the emotional support you can from friends, family, carers, doctors and support groups.
- Have you been turned down for benefits in the past? Seek advice, and if you have a good case, don't be afraid to appeal or reapply. About 50% win their cases on appeal.
- No benefits are described in detail here. The aim is to give pointers on how to become more confident and better informed, and on where to go for support and advice.
- Although this guide addresses myasthenics directly, it is intended equally for use by family and carers. It also contains information on myasthenia and its effects which will be useful for advisers and the benefit authorities.
- At the back of this booklet you will find checklists which may help you to plan ahead. They will be helpful to those completing the self assessment applications for benefits such as DLA, AA & IB. More comprehensive lists are available on the websites we recommend.
- Sometimes the contact phone numbers we give do not apply to people in Wales, Scotland and Northern Ireland.

## **2. Communicating with the Department of Work and Pensions**

### ***Why do I need to make contact with the DWP?***

Benefits administered by the DWP include all the Disability Benefits, including Sickness and Incapacity Benefit, Disability Living Allowance, Attendance Allowance, and Carer's Allowance.

The Department also administers Low Income Benefits such as Income Support and Pension Credit.

## ***How to make a claim***

Wary of bureaucracy, scared of being patronized, or frightened of being accused of fraud? You are not alone!

The Department of Work & Pensions is a huge cumbersome organization, and its rules, like quicksand, are constantly shifting. There is no escape; you will need to deal with it.

DWP officials are there to explain the rules and to assist with the applications for benefits. Don't feel intimidated; take time to ask all the questions you need to, and to explain yourself clearly.

DWP officials know the basic rules and will help with form-filling, either at Job Centre Plus or on the Helpline, but they do not give specialist independent advice and they are not experts.

On your side you will need to complete applications fully and accurately, and to provide, to the best of your ability, the information needed for DWP to reach a fair decision about your entitlement. DWP officers have a duty to be sure that public money isn't being wasted.

Take control. Keep a box or file for each benefit application; in it keep all correspondence from DWP, copies of every letter, form or email you send, and a note of every phone conversation, **with the date** (it can be a vital foot-in-the-door).

Once DWP have your phone number, they may ring you and ask for more information. Unless the answer is very simple, it's reasonable to ask for time to think about it, or to consult an adviser. Ask to be rung back at a time convenient to you, e.g. when your carer can be with you.

Be persistent, but also be patient. If you communicate well with the individuals in your local office, or on the helplines, it will help to ease feelings of frustration.

Still feel out of your depth? Don't give up because you find application forms complex and the Rules for Benefits impossible to understand. Get independent advice.

## ***Contacting the DWP***

Contact your Local Benefits Agency or Jobcentre Plus to find out more information or to arrange an interview. Jobcentre Plus will probably have a display advertisement in your local telephone directory.

Contact DWP direct on the helpline for people with disabilities:  
**freephone: 0800 882200** You may have to hold the line for sometime,  
but information leaflets and forms can be requested.

There is a special line for those with sight & hearing difficulties:  
**freephone 0800 243355.**

Disability Living Allowance & Attendance Allowance advisory line:  
**0845 712 3456.**

0800 lines are free and 0845 lines are charged at local rates. Numbers  
may be different in Northern Ireland, Scotland and Wales.

Child Tax Credit and Working Tax Credit are not administered by  
DWP but by HM Revenue & Customs, helpline **0845 300 3900**.  
(Pension Credit is administered by DWP. Confused? We are.)

### **Official Web Sites**

*Note: Most public libraries provide internet access.*

**Department of Work & Pensions:** The official site for Department of  
Work & Pensions is: [www.dwp.gov.uk](http://www.dwp.gov.uk) - The site is easy to use.  
Application forms, together with explanatory notes, can be  
downloaded. If you don't have access to the internet yourself, a friend  
or carer may be able to find and download the information you need.

**Disability Rights Website:** Government sponsored disability rights  
website (separate sites for Scotland and Wales): [www.disability.gov.uk](http://www.disability.gov.uk)

**Disability Rights Commission:** [www.drc-gb.org](http://www.drc-gb.org) – official site &  
helpline for the Disability Discrimination Act 1995. For those who  
think they are experiencing discrimination because of their disability.

## **3. Applying for Benefits**

**Start by getting a copy of a small DWP booklet SD1: 'Sick or  
Disabled, a basic guide to entitlement'. Talk to the DWP, and to  
independent advisors. We also recommend the Disability Rights  
Handbook for the current year as a detailed reference book** (see  
section 4, 'Where to go for Specialist Independent advice' and Links).

***Tip:** It's always a good idea to consult the experts at the Citizens  
Advice Bureau or your local Welfare Rights Unit or Law Centre.  
Advice is essential if you are applying for Disability Living Allowance*

*(DLA) or Attendance Allowance (AA), or making a 'better off' calculation, or making an Appeal from any decision by Department of Work and Pensions (DWP) or other Government Department .*

- Remember that the officials who administer the Law and accompanying rules laid down by Parliament are not there to judge you, but they have to be sure that you are entitled to the benefit you have applied for.
- You, or your carer, need to understand the basic rules for each benefit, otherwise you may be disappointed. For instance Incapacity Benefit is for those unable to work, and Disability Living Allowance is for those who have problems caring for themselves day by day, and/or getting about. The rules for each of these Benefits are very different.
- In the first instance Disability Benefit claims are by self-assessment. Describe your situation clearly and accurately on the application form. It is important to provide supporting evidence from doctors and carers.
- The form is likely to be read by a computer, not a human, and success can often depend on how well you've completed the form. Don't let these hazards put you off. Get help!
- Another reason for getting help is because you will have to deal with a bewildering array of different government departments, local authorities, health authorities, doctors etc. A good adviser should be able to help you through this maze.
- DLA and AA are for those who have problems with caring for themselves and/or who have mobility problems; they are important benefits for myasthenics, they don't depend on **income, savings**, or National Insurance contributions, **there is no means-testing**, and they are **tax-free** and **paid in addition to other benefits** such as Incapacity Benefit and Income Support. Many myasthenics will be eligible because of the difficulties and disabilities they experience in caring for themselves, and/or getting about. But you will need to prove your entitlement.
- If you have little in the way of savings (don't include the value of your house as capital) and are finding it hard to make ends meet,

find out about Low Income Means-Tested Benefits and Tax Credits. Debts can build up if you are ill with MG and unable to work through no fault of your own.

- Some benefits are ‘passports’ or ‘gateways’ to other benefits. For example, getting Income Support automatically entitles you to receive other low income benefits such as Housing Benefit and Council Tax Benefit. Disability Living Allowance is a ‘passport’ to higher rates of Income Support. This gets complicated, but your DWP Benefits Agency or adviser will be able to explain how it works.
- If you are on Incapacity Benefit and hope to return to work part-time, or are working and off sick for irregular periods, there may be a ‘better-off’ calculation to be made, take independent specialist advice about this too.
- Once you receive a benefit, keep the DWP informed of any relevant change in personal or financial circumstances or you may find benefit stopped, or clawed back when you can least afford it. For example, DLA is not paid if you are in hospital for a long period, and Working Tax Credit and Child Tax Credit will be reduced or clawed back by the Tax authorities if your income increases.
- Look out for the time limits for each benefit application; if you don’t get the form in on time it may result in lost benefit.

**Keep a copy of every document and a note of every meeting and phone call. A dated phone call can be a vital foot-in-the-door.**

#### **4. Where to go for Specialist Independent Advice**

To find out who in your area is franchised by the government to provide expert welfare rights advice, check with your local librarian, Local Authority, or contact Community Legal Services  
tel:0845 345 4345 or [www.clsdirect.org.uk](http://www.clsdirect.org.uk)

- **Local Citizens Advice Bureau (CAB):** Some CABs have a dedicated Welfare Rights Unit (WRU), and most Bureaux have specialist trained disability welfare rights advisors who can help complete disability benefit forms, and give advice on preparing appeals. The CAB is also a good place to go for advice about money and debts.

- **Welfare Rights Units:** Some areas which do not have a CAB have a free Local Authority WRU.
- **Law Centres:** Some areas of the country have local centres which provide free specialist welfare rights advice. Check if your local centre will provide the service you need.
- **Publicly Assisted Legal Help:** This is means-tested. Be wary about going to a solicitor for welfare rights advice because it can cost a lot of money and not many solicitors are qualified to give it. Check first whether your solicitor is franchised to give advice on the topic you want help with, because even if you are eligible for free advice, the range of topics can be limited to help with appeals or formal complaints.

***TIP:** Those suffering from long-term health and disability problems are covered by the Disability Discrimination Act, and Agencies are required to make ‘reasonable adjustments’ to provide advice. If you are unable to get into a Bureau or Office it’s worth phoning or writing in to explain your difficulties; ask to be visited at home or helped over the telephone.*

**Phone, Internet Links and Guides:** There is a huge amount of information on the web. We suggest you start looking at reliable established sources such as those listed below, or contact one of the phone or internet links listed at the back of this brochure (Links Section).

- **The Disability Alliance website:** [www.disabilityalliance.org](http://www.disabilityalliance.org) – provides detailed information on benefits, and has links to other useful web sites. It has a regularly updated index of case law on DLA/AA which is helpful both for those wanting to understand how to apply for benefits, and for those preparing to appeal.
- **Benefitsandwork.co.uk:** A website which publishes detailed guides on disability and work-related benefits and a number of guides used by officials at DWP when they make decisions. The information has been obtained under the Freedom of Information Act. It costs £15 to join for one year.
- **Barton Hill Advice Service:** at [www.bhas.org.uk](http://www.bhas.org.uk) is a site with detailed guides on applying for disability benefits.

- **Books: The Disability Rights Handbook**, your local library should have a copy. It is published annually in April by DA, and is often described as the ‘Benefits Bible’. (See the Links Section).

**Child Poverty Action Group:** Another excellent, but more detailed guide used by experts and lawyers is the Welfare Rights and Tax Credits Guide published by CPAG.

Both guides are updated each year in April, they should be available in your local library, but are also for sale at a reasonable cost to disability benefit claimants (£8.00 for the CPAG Guide, and £13.50 for the DRH in 2006/7). (See Links section for the addresses.)

- **Your neurologist:** You will need to muster evidence to support your claim for DLA or AA, and also for long-term Incapacity Benefit. It’s very helpful to have a letter from your neurologist explaining your MG symptoms and how they affect your care and mobility needs; they are well used to doing that. Some specialist myasthenia clinics will have an occupational health nurse or even a benefits adviser. Check what is written about you is accurate. We suggest that you copy the ‘Information for Benefit Assessors’ (Checklist section at the back of this booklet) from this guide and show it to your advisor. It has been prepared by neurologists specialising in myasthenia.
- **Information on aids and concessions for the disabled:** Make contact with your local Occupational Health Service through your GP, Primary Care Trust or local hospital. Patient Advice and Liaison Support Groups which are part of some Hospital Trusts can provide advice and contact details. Your local Social Service Department can also help.
- For more general, non-specialist support, try the **MGA**, its publications and website, or your **local MGA Branch**. They may be able to point you in the right direction, or have access to a local Benefits Advisor.
- Many people entitled to benefits find it difficult to make successful applications because the system is so complicated, so the number of voluntary or local authority confidential information and advisory services is increasing. Even those not licensed to provide legal advice can be helpful in giving assistance with form-filling, visiting at home and providing information about local services.

- Those who belong to a Trade Union can often get help and support, particularly on employment matters.
- It can be hard to get expert advice because of the shortage of trained advisors, and you may need to be persistent. Don't give up.

## **5. Statutory Sick Pay (SSP) & Incapacity Benefit (ICB)**

**Ring BEL (Benefits Enquiry Line) freephone 0800 88 22 00 for more information**

**SSP:** If you've been off work for 4 days or more, don't delay in claiming SSP from your employer. If you leave it longer than 7 days, you may lose your entitlement. You don't need a doctor's certificate until you've been off work for 7 days, but check your contract of employment for how you should report sickness to your employer. SSP is paid for up to 28 weeks of sickness, and spells off work can be linked as part of one claim provided they are not more than 8 weeks apart.

If you are unable to get SSP because you are self-employed, unemployed or not employed, or your SSP has ended, claim ICB.

**ICB:** This is for working age people who have paid a certain number of National Insurance contributions and have become incapable of work through illness and/or disability (except for those aged between 16 and 20, for whom it is non-contributory).

If you're not eligible for either SSP or ICB, then claim Income Support or Pension Credit. Even if you get SSP or ICB, you may still be eligible for a top-up from Income Support or Pension Credit.

The Government has announced that ICB will be replaced by another Benefit in 2008. This has caused much concern among myasthenics, particularly those who are unfit for work and receive the long-term rate of ICB.

MGA is lobbying to ensure that myasthenia is well understood as a chronic condition, and that benefits for those with MG are enhanced rather than downgraded.

Be alert to developments, and keep MGA informed of your experiences and problems.

At present, ICB long-term benefit is subject to tests such as the ‘capacity to work test’ which is part of a ‘personal capability assessment’ which takes place after 28 weeks off work to assess if you can get back into work. Find out more about these assessments before you undergo one. Decisions are made by ‘Decision Makers’ who are not doctors, but base their decisions on objective criteria and documentary evidence, so it’s very important that your neurologist supports your claim.

At present there is a limited opportunity to do ‘permitted work’ whilst receiving ICB, with a maximum earnings allowance of £81 per week in 2006. Take advice.

ICB is paid at three different rates according to the time you have been off sick; it is not paid if you were over state pension age when you became sick.

To top up your income and for help with housing costs, see ‘Low Income Means-Tested Benefits and Tax Credits’ (section 8, page 13).

## **6. Claiming Disability Living Allowance (DLA) or Attendance Allowance (AA)**

DLA is for those aged 0 - 64, AA is for the over 65s. These benefits are for those who have problems looking after themselves or getting about. The mobility component is never paid to those under 3.

They definitely make a difference. Even the lowest rates provide useful extra income to enable you to have more independence or the odd luxury.

DLA and AA are not means-tested, they are tax-free, and you are unlikely to need to undergo a medical examination to qualify. They are paid to working people as well as those at home; they are paid on top of other benefits, and regardless of savings or income. Depending on the extent of the disability, different rates apply.

To qualify it’s necessary to show that you need or would benefit from regular, not constant, attention/supervision during the day and/or night. Attention is when someone is doing something active with you like helping you get dressed, or verbally encouraging you to get dressed.

This type of care needs to be ‘reasonably required’ not medically required. The need for a reasonable social life is taken into account (DLA applicants only). You will need expert advice on what this means in law.

The test for children is that they need much more help or looking after than other children. The ‘Barton Hill Advise Service’, **bhas** website (see Links has a useful paper on claiming DLA for a child.

Take advice at an early stage because you need to understand how the law relates to your personal situation, and to explain this on your application form. There are Commissioners and High Court decisions on how the law will be interpreted. Online sources of help include: **www.benefitsandwork.org** which has a detailed guide about filling in application forms, and a two minute ‘Am I eligible for DLA?’ test. At **www.bhas.org.uk** you will find specialist guides, including one on claiming DLA for a child, and ‘Five Minute Tests’ which give pointers as to whether you are likely to qualify. The Disability Alliance website **www.disabilityalliance.org** has up to date information on the law, and their handbook, although detailed, is invaluable.

You don’t need a carer to qualify.

Look for emotional support from friends, family, support group or your carer because it is a tough task to prepare your claim.

The rules do make allowance for fluctuating conditions such as MG. Don’t delay. You cannot submit a claim before you’ve had problems for 3 months, but you can start to prepare that claim. If you are approaching 65, get your claim in before your birthday as the rates for AA are substantially lower than those for DLA. There is no mobility component in AA, and the tests for care needs are more rigorous.

Checklists on Daily Care and Mobility Needs are included as **checklist E** (page 30) at the back of this book to get you thinking about what your needs really are. It may be helpful to discuss these with a carer who knows you well.

Remember that when describing care and mobility needs you should be realistic and include information about your needs when you feel at your worst. If your needs vary you should explain this.

If you can face it, keeping a diary is useful. It's easier to describe how difficult it is to manage when you feel at your worst so jot it down, or get someone else to jot it down for you (see Checklists).

It's important to gather written evidence and letters of support from your neurologist, health service professionals and from the carers who know you. Make a specific appointment to discuss your claim with your neurologist. Check what the medical professionals say about you is accurate and ask for any statements which aren't correct to be revised.

Decisions on DLA and AA are made by non-medical staff who may consult doctors and healthcare specialists. They are called 'decision makers'.

Once you've been awarded DLA or AA you may be eligible for other benefits which you weren't eligible for in the past. Check with DWP or a welfare rights adviser.

If you receive DLA or AA you may be entitled to VAT relief on certain items.

## **7. Help for Carers**

An informal carer who looks after someone on DLA at the middle or higher rate, or on Attendance Allowance for 35 hours or more a week, can apply for carer's allowance. It is not affected by any savings they may have but there is an earnings limit. It is taxable. They will be credited with Class 1 National Insurance contributions towards their pension if they are under State Pension age.

There is an overlapping benefit rule which means that patients can be paid only one of certain Benefits they may be entitled to. A carer will be paid the Benefit with the higher rate. The fact that you have claimed and are entitled to Carer's Allowance will give you extra money if you claim any of the Means-Tested Benefits such as Income Support, Housing Benefit, Pension Credit or Council Tax Benefit. This is a very complicated area and you must seek advice, especially if the person you are caring for lives alone.

The role of the full time carer can be very stressful, and it is still poorly recognized by society. You may have to fight for enough support services and respite care to be provided by your Health Authority or Social Services Department. Get all the emotional support you can from friends and family and ask Social Services to put you in touch with a support network. Social Services has the responsibility for conducting a needs assessment on disabled people and carers, and for arranging respite care.

### ***Home Responsibilities Protection***

HRP protects your pension by reducing the number of years you have to pay contributions in order to get a Pension. Qualifying Carers need to apply on a special form each Tax year. Get advice.

## **8. Means-Tested Low Income Benefits**

Most benefits are paid at a higher rate for those with disabilities.

Once you receive a disability benefit, or reach pension age, the ‘threshold’ (the maximum amount of income and savings you can have before you are eligible) goes up. If you’ve been turned down before for these benefits, check from time to time to see if your circumstances have changed and you are now eligible.

The amount of savings you can keep before you lose the right to Income Support (IS) and other low income benefits varies. For example, as of 2006, everyone can keep up to £6,000, but some benefits are available for those with up to £16,000 or more. Check out the figures for each benefit according to your personal situation.

### ***a. Benefits administered by the DWP***

***Income Support (IS):*** if you find yourself short of income, and you don’t have a large amount of savings (excluding the value of your home) you are probably eligible for Income Support which provides regular weekly income, and entry or ‘passport’ to a whole range of other benefits, including help with housing costs. If you receive IS and do not need to register for work because you are caring for someone, you should automatically receive Home Responsibilities Protection for your Pension. IS also ‘passports’ to lump sum payments such as maternity expenses through the Social Fund.

Although rental is paid via Housing Benefit, you are unlikely to get help with mortgage payments straight away and should take advice about this.

***The Social Fund, for those on IS or receiving Pension Credit:*** gives help with expenses which are hard to pay out of regular income. Crisis Loans and Budgeting Loans have to be paid back: Community Care Grants don't have to be paid back.

It is best to discuss with your CAB or other welfare rights adviser which grants you can qualify for because this is a complicated area. Those receiving sickness and disability benefits will be 'passported' to a wider range of help.

Contact your local Benefits Agency or Job Center Plus.

***Pension Credit:*** provides extra income for those over pension age in the form of a tax credit. Check your eligibility. Over 2 million pensioners who could claim Pension Credit are not doing so. Ask if you need someone to visit to help you with your claim.

Claimline: freephone 0800 99 1234 (08081006165 in Northern Ireland).

### ***b. Benefits administered by the Local Authority***

**You don't need to be receiving Income Support to claim these**

***Housing Benefit:*** help for those who pay rent and service charges. Although this is a national scheme conducted under rules set by Parliament, it is administered locally.

***Council Tax Benefit:*** money to help pay the Council Tax bill. There are discounts for sole occupancy of a property, and a Disability Reduction Scheme. The amount you pay depends on your income.

Contact the Benefits Section at your local council directly. (If you do receive Income Support or Pension Credit, you will be 'passported' to these benefits and don't need to make a separate claim.)

### ***c. Benefits administered by the Tax Authority***

***Child Tax Credit - Working Tax Credit:*** is for those aged 16 or over who are working at least 16 hours a week, are disabled or are responsible for a child or young person. (Check for other situations which can apply.)

Contact Inland Revenue on 0845 300 3900 or textphone 0845 300 3909.  
Or visit [www.inlandrevenue.gov.uk](http://www.inlandrevenue.gov.uk) for an application pack.

There is a lot of publicity about the pitfalls of these schemes, but the truth is that they can provide substantial extra income for applicants who come to grips with the system. They are usually well worth the effort of claiming. **Be careful;** if your income goes up, you will have to tell the authorities, and they will claw back any money overpaid. The CPAG Benefits and Tax Credits Handbook has detailed information.

## 9. Making an Appeal

You'll feel at best disappointed and at worst angry that you've been turned down. Don't give up! About half of all appeals succeed.

Get a copy of booklet GL24: 'If you think our decision is wrong' and study it or take it to an adviser. It is important to understand the procedure.

You must send your Notice of Appeal, in writing, within the strict time limits set by DWP. You're likely to have no more than 4 weeks to do this after the first decision has been made, unless you have special reasons for a delay.

If you are turned down for a benefit, before you make an appeal, you should ask for a written or verbal explanation immediately. You will also be offered the opportunity to have the decision reviewed by DWP before making a full appeal. It's normally better to ask to have your case heard by a Tribunal which is independent of DWP. Don't be deterred: if you believe you are entitled to the benefit, make the appeal and DWP will probably review it anyway.

If you are researching for yourself, start with the CPAG Welfare Rights Handbook, the Disability Rights Handbook, or the DLA and other recommended websites (see section 4, 'Where to go for Specialist advice', page 6) which provide good up to date information on all aspects of benefits and appeals.

If you have received an award, but you think it should be at a higher rate or for a longer period, there's always the danger that the award may be reduced or taken away altogether on appeal.

Appeals are based on the law, and on the evidence given on your application. If your circumstances have changed, or you failed to provide all the evidence on the original application, then put in a new application.

Although Tribunal members are normally patient and courteous and understand the law, we strongly recommend that you are supported at any hearing by an experienced Welfare Rights Adviser. The law is complex, and case-law decisions may help or hinder your case.

Commissioners' Decisions or Case Law made in respect of disabilities other than myasthenia gravis can be relevant because it is always the PRINCIPLE which is important and not the condition itself. Important relevant decisions for myasthenics on DLA include Mallinson (House of Lords) in which the appellant was blind, and Halliday, which establishes the need for disabled people to get out and about and have a reasonable social life.

## **10. Independent Living Fund**

This provides allowances for those between 16 and 66 years who already receive the highest care component of the Disability Living Allowance to pay for care to help them to continue to live independently in the community.

It is means-tested for those not already on Income Support, and certain other benefits can be deducted from the total you receive.

## **11. Access to Work**

A practical scheme for those myasthenics who want to work, but find it difficult because of their disability.

Employment can be full-time, part-time or temporary. You can also be self-employed.

Help includes:

- Special aids and equipment.
- Adaptations to premises or existing equipment.
- Help with travel if public transport can't be used.
- A support worker.

Contact your local Job Centre or Jobcentre Plus and ask for the Access to Work Adviser or Disability Employment Adviser.

## **12. Disability and Discrimination**

An employer has a duty to make 'reasonable adjustments' to your working arrangements if you are at a substantial disadvantage due to disability. The Disability Rights Commission (tel: 08457 622 633 – [www.drc-gb.org](http://www.drc-gb.org)) is the statutory body responsible for implementing legislation under the Disability Discrimination Act 1995. If you aren't communicating well with your employer and feel that you are being discriminated against because you suffer the effects of myasthenia, take expert advice from a CAB or law centre. If you belong to a Trade Union, seek advice from them.

## **GENERAL INFORMATION**

### **1. Help with Health Costs**

Get leaflet HC11 'Are you entitled to help with health costs', available at your local surgery, hospital or main post office. It provides a quick guide.

#### **Free Services**

Prescriptions are free for all myasthenics.

If you are still paying, apply for a NHS Medical Exemption Certificate. The form should be available at your local surgery, and you can get help there with completing it. Your GP will send it off to the Prescription Pricing Authority on your behalf.

Keep your receipts from the chemist, and claim a refund on items already paid for (ask for claim form HC5).

Flu vaccines are also free for myasthenic patients and you are normally recommended to have one annually by your GP.

There is no entitlement to free eye tests or dental work

### **More Help With Health Costs**

There is no automatic entitlement based on the diagnosis of myasthenia gravis, but help is available for certain groups. It may be in the form of free tests or treatments, it may be help with the costs of getting to and from medical appointments, it may be the provision of vouchers towards the cost of items such as spectacles and dentures.

If you belong to one of the following groups, check what is available:

- Children and young people under 19 in full time education.
- The over 60s.
- Pregnant women and new mothers.
- People already receiving low income benefits (who are ‘passported’ to receive help with health costs).
- People on a low income.

If you have a low income, but do not get any of the Low Income Benefits listed above, it’s still worth applying to the DWP (using form HC1).

Health benefits are administered by the Department of Health.

The NHS Customer Enquiry helpline is tel: 0845 850 1166.

## **2. Equipment and Adaptations**

### **An overview:**

Under the Chronically Sick and Disabled Persons Act 1970, one of the responsibilities of Social Services is to make arrangements for the provision of practical assistance in the home such as necessary equipment, and to assist in arranging for the carrying out of any works of adaptation in the home, or the provision of any additional facilities designed to secure the greater safety, comfort and convenience of disabled people. They assist only those who are ordinarily resident in their area and who are assessed as meeting their eligibility criteria. Eligibility criteria may vary in different areas.

A disabled person and/or their carer may request an assessment of need at any time.

Following assessment a clearly recorded assessment of need and objectives should be provided. Unmet needs should also be recorded.

Once an eligible need has been assessed, the Local Authority has an absolute duty to meet that need within a reasonable time frame.

### **Equipment:**

Depending upon the requirements of the disabled person, equipment to meet the needs may be provided by Social Services, the NHS or another agency.

### **Equipment - NHS provision (nursing needs)**

Equipment required for a health or nursing need is generally provided free of charge by the NHS.

Equipment required for home nursing is usually provided via the District Nursing Service. This may include commodes, urinals, pressure relieving mattresses and height-adjustable profiling beds.

Continence equipment may be supplied following assessment by the Continence Adviser. Initial contact should be made to the GP or District Nurse.

Ventilators and related equipment are also provided by the NHS. The respiratory consultant and/or GP can offer further advice.

### **Equipment - NHS provision (mobility needs)**

Walking aids such as a walking stick or rollator are provided after assessment by a doctor or physiotherapist. The equipment belongs to the NHS and is provided on loan for as long as is required.

Specialised buggies (for small children), and wheelchairs (manual and powered) are supplied by local Wheelchair Services - these are part of the NHS. Eligibility criteria may vary in different areas. You may request a copy of the eligibility criteria for your area.

Provision should not be denied on grounds of age.

In some areas, provision of Electrically Powered Indoor/Outdoor Chairs, known as EPIOC's, is limited to people who are unable to walk at all. Users are required to take a competency test before a powered

wheelchair is provided and a home assessment is usually carried out to ensure that the property is suitable for the use and storage of a powered wheelchair.

A voucher scheme may be available either to enable users to contribute towards the cost of a more expensive wheelchair of their choice which they own (and which they will be responsible for repairing and maintaining), or to enable users to contribute towards the cost of a more expensive wheelchair of their choice from a range selected by Wheelchair Services (who will still own, maintain and repair it).

In some areas this scheme is limited to manual wheelchairs only.

The Muscular Dystrophy Campaign will shortly be publishing “Best Practice Guidelines for Wheelchair Provision for Adults and Children with Muscular Dystrophy and other Neuromuscular Conditions.” A copy of these guidelines can be obtained by contacting the Muscular Dystrophy Campaign on 020 7720 8055 or e mail [info@muscular-dystrophy.org](mailto:info@muscular-dystrophy.org)

### **Equipment - NHS provision (environmental controls)**

Environmental controls enable people with severe disabilities to operate appliances independently in their home from a single control. An environmental control can be used to open a door, answer the telephone, turn on a TV, close the curtains etc.

Simple systems are often provided by Social Services but if an individual has more complex needs an approved local Medical Consultant will make an assessment and arrange installation of the recommended equipment.

Your Occupational Therapist, hospital specialist or GP can arrange this assessment for you.

### **Equipment for use at home (Social Services provision)**

Essential equipment that enables a disabled person to be as independent as possible in their own home, or which assists their carer to care for them, is usually provided by Social Services following assessment by an Occupational Therapist. This may include equipment to assist with moving and handling, toileting, bathing/showering, feeding etc.

In some areas there may be a small charge.

A disabled person or their carer can refer themselves directly to Social Services.

### **Equipment from other sources**

On occasions you may need, or want, to obtain equipment from an alternative source.

For holidays or for very temporary difficulties, basic nursing equipment and manual wheelchairs can be borrowed from the medical loans department of your local Red Cross. You can refer yourself. There is a small charge for the loan of equipment.

Equipment can be purchased privately from specialist stores or via mail order. This is often useful for small, relatively cheap items such as little gadgets for the kitchen. You should never purchase expensive, specialist equipment without taking the advice of an independent expert. Do not rely on the sales reps of a commercial firm for this assessment. Your Occupational Therapist may be able to offer advice.

Consider visiting an Independent Living Centre/Disabled Living Centre to assess equipment without feeling under pressure.

Telephone 020 7820 0567 for advice on your nearest centre or see the Assist UK website: [www.dlcc.org.uk](http://www.dlcc.org.uk)

Contact the Disabled Living Foundation on 0845 130 9177 for information on equipment.

Some equipment that is used by a disabled person may be VAT exempt.

Wheelchairs may be purchased and vehicles may be leased or purchased through the Motability Scheme but only for those getting the high rate mobility component of Disability Living Allowance. Contact Motability on 0845 456 4566 for more information or see their website: [www.motability.co.uk](http://www.motability.co.uk)

### **Housing Adaptations**

*Note: Different arrangements apply in Scotland.*

For advice on housing adaptations, request an assessment of need by an Occupational Therapist at Social Services. A disabled person or their carer can make the referral.

Minor adaptations such as the installation of grab rails or the fitting of a banister rail are usually arranged free of charge following an assessment.

For major adaptations, much will depend upon who the property is owned by and what work needs to be done. Major adaptations include, for example; building a ground-floor bedroom with en suite bathroom; adapting a kitchen for a wheelchair user; the provision of wheelchair access into and around a property; sometimes even installing a stairlift or an automatic door-opener

Disabled Facilities Grants (known as DFG's) are available help owner-occupiers with the cost of essential adaptations. The maximum grant in England is £25,000. There are differences in Northern Ireland, Scotland and Wales. (Wales is a more generous £30,000). The DFG is means-tested except in respect of adaptations for a child under 18. For adults over 18 it is the person requiring the adaptation who is means-tested, not the owner of the property. The DFG means-test takes into account actual income and savings but makes standard allowances for certain outgoings, for example, mortgage costs.

The DFG will only cover work which has been approved by your Occupational Therapist and the Grants Officer. Help is never given retrospectively.

People living in privately rented property are often in a difficult position as the owner of the property must agree to the adaptations being made and the tenant will need guaranteed rights to remain in the property.

Tenants of council or housing association property should liaise with their landlords and their Occupational Therapist in respect of their housing adaptation needs. It is unusual for tenants to be asked to contribute towards the cost of adaptations.

With major adaptations it is vital to consider both current and future needs. Specialist equipment that forms part of the adaptation (for example, a 'clos-o-mat' toilet, a height-adjustable wash basin or a specially designed bath) must be properly assessed at an early stage with the occupational therapist present. If a ceiling track hoist might be required this too needs to be considered when plans are being designed.

The Muscular Dystrophy Campaign publishes an *Adaptations Manual* that explains the whole process in great detail. It is an invaluable aid to anyone planning an adaptation to their home. The manual may be obtained through the Muscular Dystrophy Campaign on 020 7720 8055 or email [info@muscular-dystrophy.org](mailto:info@muscular-dystrophy.org)

### **3. Charities and Benevolent Organisations**

A number of Charities – though not the MGA, alas – will give grants or make periodic payments, mainly to help pay for things the Government doesn't fund. The problem is to make a compelling case to a charity which has many demands on it, so it's best to have someone authoritative who can act as your advocate and put your name forward. Discuss how to organize this with a CAB adviser.

Your local library and CAB will have copies of books which list these organizations such as 'A Guide for Grants to Individuals in Need'. Social Services departments will also be able to advise, and to give a list of local charities which may help.

### **4. Keeping Warm**

Under the Social Action Plan all energy suppliers have an obligation to provide services for the disadvantaged customer. Discuss payment options and any debts you may have with your supplier.

### **5. Using Your Phone**

#### **Social Services**

In some cases social services will help with phone charges.

#### **British Telecom**

If your eyesight is affected you can register for free directory enquiries.

Registration as a disabled person at risk gives priority for breakdown repairs.

### **6. VAT**

People registered as disabled, may obtain goods and services for their personal use in connection with living with the disability, free of VAT. Full details may be found on the HM Revenue and Customs website. (See Links Section)

## 7. Information for Drivers

### Ability to Drive

Myasthenics should plan their journeys for times of peak strength and not attempt to drive when tired.

Myasthenic drivers need to explore ways of making driving safer and more comfortable for themselves. Often simple adaptations can make a difference, so don't lose confidence.

There is a legal obligation to inform the Drivers' Medical Group at the Driver and Vehicle Licensing Authority (DVLA) at Swansea about MG even if at present you have no symptoms. Phone 0870 600 0301 (Monday – Friday 8.00 am to 5.30pm), and they'll send a copy of form B1 for you to complete. Form B1 is also available for download, together with further information, from the DVLA website at [www.dvla.gov.uk](http://www.dvla.gov.uk)

Discuss any worries you have about your ability to drive with your GP, and preferably your consultant as well, because both of them will probably be contacted by the DVLA as part of a medical assessment.

A network of Mobility Assessment Centres throughout the UK provide free independent general advice on all aspects of disability and driving. If needed, experts will work with you to overcome physical problems, suggest adaptations, and give a view on your safety to drive. Some centres can provide overnight accommodation. The cost varies according to the type of assessment you need. Funding may be available. Contact them for advice on freephone 0800 559 3636, or visit their web site at [www.mobility-centres.org.uk](http://www.mobility-centres.org.uk)

Another helpful organization is the Disabled Drivers Association, freephone 0870 770 3333 or visit [www.dda.org.uk](http://www.dda.org.uk) for more information. In 2005 it cost £14 pa to join. It offers a confidential correspondence and telephone service on a range of driving matters and publishes a newsletter.

*Note: The Disabled Drivers' Association has merged with the Disabled Drivers' Motor Club to form 'Mobilise Organisation'; full details of the new organisation have not yet been made available, (contact can still be made at the above freephone number and website March 2006).*

## **Car Insurance**

Under the terms of your policy you are required to notify your car insurers in writing that you have been diagnosed with MG (keep a copy of your letter). This shouldn't affect your ability to obtain insurance in the normal way and at the same cost as before, because insurance companies rely on the DVLA to assess your ability to drive.

The MGA has secured the services of brokers Heath Lambert who specialise in providing insurance to groups such as those with myasthenia.

## **Motability**

This is a registered UK charity which enables disabled people to use the higher rate mobility component of their DLA to lease or buy a vehicle; you can also use DLA to buy a scooter or wheelchair. Children over 3 and non-drivers who receive the allowance can apply. Phone 01279 635999 or visit [www.motability.co.uk](http://www.motability.co.uk)

## **How to obtain a Disabled Person's Parking Badge**

The Blue Badge Scheme is a European Union and nation-wide scheme of parking concessions and exemptions, mostly for street parking. To qualify you must receive the higher mobility rate of DLA or be unable to walk without severe discomfort. The Scheme is administered by your local authority. Contact your local Social Services Department.

The scheme doesn't apply in certain Inner London Boroughs where a local Purple Badge is needed. Nor does it apply in some town centres with limited access.

Inner London Boroughs provide a very limited number of parking bays for Blue Badge holders.

## **Transport for those who don't drive**

Your local authority Social Services or Primary Care Trust Occupational Therapy Service will be able to advise you of what is available in your area. Sometimes volunteers provide a car service, or cheap taxi fares are on offer. Escorted shopping schemes are increasingly common. The Patient Transport Service provides free accessible transport to non-urgent hospital appointments; contact your GP or local hospital

Those on a low income or a means-tested benefit may be eligible for the Hospital Costs Travel Scheme. The amount is based on the estimated cost of fuel, or cost of public transport. You can claim for an escort too. Contact HTCS on 0113 254 6106, or enquire locally.

## CHECK LISTS

### **A. MG: Bullet points for Benefit Assessors**

We suggest that you hand a copy of these notes to your assessor or welfare rights adviser and that you attach a copy to your benefit applications. Remember that the fact that you have myasthenia will not in itself help your application for DLA or AA – that will depend specifically on your care problems.

*Neurologists specializing in the treatment of MG have contributed to this note.*

#### **Facts about Myasthenia Gravis**

- Myasthenia Gravis (MG) means severe muscle weakness, and is caused by problems with nerve to muscle transmission. It is potentially life-threatening.
- MG is a rare chronic condition.
- It affects movement of the voluntary muscles, commonly of the eyes, throat, upper body and limbs.
- MG is fatiguable; the harder patients try, the weaker they get. So carrying out the standard tests does not always give a true picture of the patient's average weakness. Rest is essential.
- The severity and extent of disability vary widely between patients.
- The effects of MG can vary from hour to hour or week to week in one individual.
- Drugs used in treatment often have side-effects, for instance high doses of steroids commonly cause diabetes or osteoporosis.
- It is hard for doctors to give a global view of the severity of the condition in any one patient because MG is unpredictable.
- Although MG can usually be controlled, unlucky patients have substantial residual disability.
- Relapses occur (often after catching an infection), but then so do remissions.

### ***Common Care and Mobility Problems for the patient.***

- MG often first affects the eye muscles, causing double vision, risk of falls and problems in daily care. Double vision/ droopy eyelids may not sound serious but can be a major handicap, e.g. for office workers or drivers.
- The weakness can spread to the throat and chest muscles, causing choking whilst eating or drinking, or even breathlessness.
- Weakness in leg muscles can affect walking, or cause falls.
- Weakness in arm and upper body muscles makes dressing and cooking difficult.
- MG frustrates the management of daily life because it fluctuates from hour to hour or day to day in one individual; also, many simple tasks take longer.
- Its unpredictability is a major factor in making daily care difficult because there is a danger of suddenly falling or losing your grip and dropping things.

### **B. Hints on preparing a claim for DWP**

- Get a copy of the correct form, study the explanatory rules and look at the questions.
- Open a box file or ring binder for each application and keep all your records in it.
- Don't delay making an application because you don't have the full information you need.
- Forms are now read in the first instance by a computer, not by humans. It is vital that every small box is completed accurately or your claim will be rejected.
- You may prefer to start by filling in forms in pencil. When you're sure about everything use black ink.
- Get help putting together the information you need as evidence to back up your claim. See checklists D - F before go to interview.
- Good advice at an early stage can save the stress of being turned down and having to appeal.

- Get support and written evidence from the health service professionals and other carers who know you. Get your neurologist to back up your claim for health and disability benefits.
- Keep a diary. It's easier to describe how difficult you find it to manage when you feel at your worst if you jot it down, or get someone else to jot it down for you (see 'Keeping a Diary' below).
- Keep copies of all documents.
- Try to keep a note of every phone conversation you have and the name of the person you spoke to and the date.
- Don't be rushed into giving information you're not sure about on the phone.
- Take a friend with you to interviews.

### **C. Keeping a Diary**

When you apply for disability benefit, you will describe your situation at its worst.

It is easier to remember the difficulties you experience in caring for yourself and getting about if you can jot it down, or get someone else to jot it down for you. Don't be depressed; note your achievements as well.

Ask your carer to keep notes as well.

Try to keep notes for a couple of weeks before completing the application form for a Disability Benefit.

Record what you can do, and what you can't do. Keep a realistic note about the things you can no longer do as easily as you used to. In our experience many claimants give too optimistic a picture of their condition. The reasons for this vary from too much personal optimism to fear of fraud.

Note down what is important to you in your own way. Any information you can jot down will be helpful. If you are too sick or depressed to keep any records ask your adviser or carer to note that fact down too.

It will help your doctor if you can show him an accurate record of what medication you are taking each day, when you take it, and the side-effects, if any. It will also help you to feel more in control of your own drug taking.

Use the Checklist for Care Needs and the Checklist for Mobility Needs for guidance on what to note down. Checklists on websites such as [www.bhas.org.uk](http://www.bhas.org.uk) can also be helpful.

## **D. What to take to a Benefits appointment**

***Keep this information in a file, either a box or ring binder will do.***

1. Your National Insurance number.
2. Any letters that you have received telling you about your benefits. Include those that that you've been awarded, the rates they are paid at and any that have been refused.
3. Contact address for your GP.
4. Contact address, and any letters from your neurologist or other doctor.
5. A copy of MGA Checklist: Notes for Benefit Advisors.
6. List of medications.
7. Any forms you'd like help in completing.
8. Any diary you've kept on care and mobility needs.
9. Any notes kept by your carer.
10. If you work: details of hours (if variable) and pay slips.
11. If you've lost your job: final pay details and slips, a letter saying why the job has been lost.
12. If you are applying for any means-tested benefit include:
  - a. Letters giving details of any tax credits
  - b. Details of savings and investments
  - c. Details of mortgage payments or rent payments
  - d. Details of Council Tax payments
  - e. Details of any pensions or maintenance payments
  - f. Information about the people you share a house with

## **E. Care needs: Checklist for DLA/AA**

### ***Disability Living Allowance/Attendance Allowance:***

- Application forms for Disability Benefits ask questions about care needs. It is no good just answering ‘yes’ or ‘no’. The adjudicators don’t want to know about myasthenia, but about the degree of your disability. Describe when and how your needs occur, and what happens as you go about the daily tasks of caring for yourself. You will have to describe your needs in such a way that the DWP Assessor and the computer understand your problems. For this reason **WE SUGGEST THAT YOU TAKE EXPERT ADVICE** before you send in the form, or have an assessor’s interview.
- You may find it helpful to use the checklist below to ask yourself about your daily care needs, because there may be things you haven’t thought about. You will probably find it helpful to go through this checklist with someone who cares for you or knows you well.
- Remember to think about what happens on days when your disability is at its worst. Reflect your worst case and do not tick a box because you can manage occasionally.
- Remember that you don’t have to have a carer in your home to qualify.
- If the answer to some of the questions is YES, think about examples, and write them down at the appropriate place on the DLA application form.

### ***Washing and dressing***

1. Do you need prompting to get washed or dressed?
2. Do you have problems keeping your clothes clean?
3. Do you have to wear ‘easy’ clothes because you find it difficult to get them on and off?
4. Do you need help with:
  - a. Washing hands or face?
  - b. Cleaning your teeth?

- c. Getting in and out of the bath or shower?
- d. Drying yourself?
- e. Washing all over?
- f. Brushing and combing your hair?
- g. Shaving?
- h. Putting on make-up?
- i. Putting on and taking off clothes?
- j. Doing up buttons?

### ***Eating and drinking***

- 1. Do you find it difficult to swallow?
- 2. Can you eat solid foods without danger of choking?
- 3. How often do you eat when alone? What do you eat when alone?
- 4. Do you need help:
  - a. With cooking?
  - b. Peeling vegetables?
  - c. Cutting bread?
  - d. Opening tins?
  - e. Cutting up food?
  - f. Boiling a kettle?
  - g. Drinking?
  - h. Preparing or taking your medication?
  - i. Remembering to take your medication regularly? What happens if you don't take it regularly?
  - i. Getting about the house?

### ***Mobility***

- 9. Do you sit in a chair all day unable to move?
- 1. Are you afraid of being shut in, e.g. if left indoors all day?
- 11. Do you need help with:
  - a. Sitting down and getting up from a chair?

- b. Manoeuvring your wheelchair?
- c. Adjusting your position in a chair?
- d. Climbing stairs?
- e. Walking around the house?
- f. Going to the toilet?

### ***Personal Hygiene***

- 12. Can you control bladder and bowels at all times?
- 13. Have you had any mishaps? If so, what happened?
- 14. Do you need help:
  - a. Getting out of bed to use the toilet, or with using a bedpan?
  - b. With your clothing when going to the toilet?
  - c. Going to the toilet at night?

### ***Sleeping***

- 15. Do you:
  - a. Stay in bed all day?
  - b. Sleep very little?
  - c. Feel nervous if left alone in bed?
  - d. Wander indoors or outdoors at night?
  - e. Need someone to bring food, drink or medication at night?
- 16. Can you reach out to the bedside table for pills or drink, and put your glass back on the table after drinking?
- 17. Do you need help with:
  - a. Getting in and out of bed?
  - b. Being soothed to sleep?
  - c. Turning and moving in bed?
  - d. Sitting up in bed?
  - e. Rearranging bedding?
  - f. Going downstairs at night?
  - g. Avoiding danger?

## Personal Safety

18. Are you unsteady on your feet?
19. Are you clumsy and accident-prone?
20. Have you had previous accidents? If so describe them. Do you:
  - a. Drop things?
  - b. Bump into things?
  - c. Fall over?
  - d. Have spasms or collapses?
21. Is it safe for you to:
  - a. Make a cup of tea?
  - b. Stand in front of the fire?
  - c. Be in the bath?
  - d. Go to the toilet?
  - e. Go up and down stairs?
  - f. Stand on the landing?
  - g. Deal with hot liquids?
  - h. Walk a short distance?
  - i. Be left alone?

## ***Other things***

1. Are you able to concentrate on reading?
2. Do you have any side-effects from your medication? If so, what are they?
3. Do you get upset or confused by everyday events?
4. Do you avoid changes to the daily routine?
5. Do you need encouragement and support to pursue hobbies?
6. Do you get easily upset, scared, panicky or confused?

## **F. Mobility Needs: Checklist for DLA/AA**

1. How long does it take to get to the shops/upstairs/ down the garden?
2. How often do you rest en route?
3. Do you need to hold things (e.g. a frame or pushchair) in order to walk?
4. Do you have difficulty using a walking aid?
5. Do you experience pain in walking?
6. How long does it take to recover from walking?
7. Do you trip on pavements/uneven ground?
8. Has the doctor told you to be careful when taking exercise?
9. Do you take pain killers?
  1. Do you avoid going out?
  11. Can you cope with traffic?
  12. Do you get into any trouble when going out?
  13. Does medication or your condition affect your ability to walk or to cope?
  14. Can you turn round?
  15. Do you feel safe in a crowd?

*Copies of these Check lists in larger print, size A4, may be obtained from the MGA.*

# LINKS

## Useful National Organisations:

For a first 'Port of Call' we recommend:

### **The Disability Alliance**

The Disability Alliance  
Universal House  
88-94 Wentworth Street  
London E1 7SA  
Tel: 020 7247 8776/8763  
[www.disabilityalliance.org](http://www.disabilityalliance.org)

Disability Alliance (DA) publishes an excellent, comprehensive guide to benefits, The Disability Rights Handbook, which is updated each year in April. It is detailed, and may be too complicated for some claimants. It should be available in your local Reference Library, so if it isn't there, ask the librarian to buy it. It is available for the reduced price of £13.50 in 2006, to disability benefit claimants. At the back is a useful directory of other helpful organizations.

DA has a good website containing lots of useful information on all aspects of disability, including up to date information on appeals. It is well set out and should be reliable. DA has online links to other relevant organisations on its website. DA has a helpline for professional advisers only, funded by the Big Lottery Fund.

### **Age Concern**

Branches can often arrange for an adviser to come to your home to help with filling in benefit application forms

Tel: 020 8765 7200

[www.ageconcern.org.uk](http://www.ageconcern.org.uk)

### **Association of Charity Officers**

Unicorn House  
Station Close  
Potters Bar  
Hertfordshire EN6 3JW  
Tel: 01707 651777  
[www.aco.uk](http://www.aco.uk)

Provides information about charities that make grants to individuals in need.

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

This is the website of the Advice Services Alliance. It provides online information on everything from benefits to dealing with debt, and more.

### **Barton Hill Advice Service**

A Bristol-based advice service with practical advice on claiming benefits, disability benefits, and making an appeal. Has a useful internet site – [www.bhas.org.uk](http://www.bhas.org.uk)

### **[www.benefitsandwork.com](http://www.benefitsandwork.com)**

Provides detailed online advice and information on all aspects of work and disability, including guides to applying for the sickness and disability benefits. It costs £15 to join for one year but the information it provides is extensive and practical.

Benefits and Work,  
PO Box 2479,  
Foxham,  
Chippenham, Wilts SN15 4XN.

### **Counsel and Care**

Counsel and Care provide advice and help for older people.

Counsel and Care  
Twyman House  
16 Bonny Street  
London NW1 9PG

telephone helpline 0845 300 7585 (Monday to Friday 10.00am - 12.00 noon and 2.00pm - 4.00pm, Closed on Wednesday afternoon).

### **Community Legal Service Direct**

[www.clsdirect.org.uk](http://www.clsdirect.org.uk) - tel: 0845 345 4345 A useful internet site which lists providers of legal advice who achieve the government 'quality mark' standard for welfare rights advice. Check that the provider you select is qualified to give the type of advice you need. Leaflets on welfare benefits, including DLA and leaflets on how to appeal.

## **Charity Search**

25 Portview Road  
Avonmouth  
Bristol BS11 9LD

Tel: 0117 9824060 (Monday - Thursday 9.00am - 3.00pm).

Applications in writing preferred.

Helps link older people with charities that may provide grants to individuals.

## **Child Poverty Action Group (CPAG)**

Publishes annually the authoritative Welfare Benefits and Tax Credits Guide

94 White Lion Street, London N1 9PF  
Tel: 020 7837 7979 and 0141 552 3303 (Scotland)  
[www.cpag.org.uk](http://www.cpag.org.uk)

## **Diabetes UK**

A helpful organization supporting those who suffer from Diabetes, also of interest to patients with Myasthenia.

10 Parkway  
London  
NW1 7AA  
Tel: 020 7424 1000  
[www.diabetes.org.uk](http://www.diabetes.org.uk)

## **DIAL UK**

Provides information on a national network of benefits advisers

Tel: 013302 310123  
[www.dialuk.info/index.asp](http://www.dialuk.info/index.asp)

## **RADAR**

The Royal Association for Disability and Rehabilitation is a National UK organisation run by and for disabled people. RADAR campaigns for better lifestyles for disabled people and their families. They supply keys giving access to public disabled toilets.

12 City Forum  
250 City Road  
London EC1V 8AF

Tel: 020 7250 3222  
Fax: 020 7250 0212  
Minicom: 020 7250 4119  
[www.radar.org.uk](http://www.radar.org.uk)

### **Medic Alert Foundation**

1 Bridge Wharf  
156 Caledonian Road  
London  
freephone 0800 581420

Medic Alert Foundation is a charity depending on donations and a 'voluntary' annual subscription of £17.50. The member supplies Medic Alert with a list of their medical conditions, the drugs they take and details of their Consultant and GP. They then wear a bracelet or medallion purchased from Medic Alert which has a contact phone number and brief details of their condition engraved on it. Medic Alert also issues each subscribing member with an information card, to be carried in the wallet or purse. If you fall ill in the street, or suffer a medical emergency, Medic Alert will provide a 24 hour service to authorized hospitals, doctors or paramedics, giving details of your medical condition, including possible drug interactions and potential anaesthetic complications.

### **Medi-Tag**

Medi-Tag, a department of Hooper's Health care products working in partnership with West Midlands Ambulance Service NHS Trust, provides a similar service to Medic Alert.

Medi-Tag Department  
Hoopers,  
37 Northampton Street  
Hockley  
Birmingham B18 6DU  
Tel: 0121 200 1616  
[www.medi-tag.co.uk](http://www.medi-tag.co.uk)

### **HM Revenue & Customs and Excise.**

[www.hmrc.gov.uk](http://www.hmrc.gov.uk)

Search for 'VAT disabled'. Gives full details of VAT exempt purchases for disabled persons.



Myasthenia Gravis Association  
First Floor, Southgate Business Centre  
Normanton Road, Derby  
DE23 6UQ

Tel: 01332 290219, Fax: 01332 293641,

Freephone: 0800 919922 (UK)

1800 409672 (EIRE)

Web Site: [www.mga-charity.org.uk](http://www.mga-charity.org.uk)

Email: [mg@mga-charity.org.uk](mailto:mg@mga-charity.org.uk)

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July 2007