

Getting the best from Neurological Services in Gloucestershire

A guide for people living
with a neurological
condition

This is the first edition of this booklet which was written by NCS Gloucestershire Reference Group in conjunction with GUIDe and PALS, in 2011. The booklet was a recommendation from an extensive consultation of people living with neurological conditions in Gloucestershire. The booklet has been launched as a collaboration of work between the Gloucestershire Neurological Alliance and the Neurological Commissioning Support, which encompasses the MND Association, MS Society, and Parkinson's UK.

Introduction

Who is this booklet for?

If you have recently been diagnosed with a neurological condition you may be experiencing all sorts of feelings. You may also be very concerned if it is one of your friends or family who has received a diagnosis. You may not be too sure where to find help. This book highlights what support is available locally. It has been produced in consultation with people who have neurological conditions. It provides answers to questions frequently asked by them. This booklet is designed for people living in Gloucestershire.

How to use this booklet

This booklet is for you to read when you wish. As you may not want to read all of it at one time, it is designed in a question and answer format. You can therefore look at the questions that concern you now.

What is a neurological condition?

Approximately 10 million people across the UK have a neurological condition; a result of damage to the brain, the spinal cord and other parts of the nervous system. Some conditions are present from birth (congenital), others are caused by illness or injury. These account for 20% of acute hospital admissions and are the third most common reason for seeing a GP. There are many hundreds of neurological conditions. Listed in the back of this book are many of the conditions and the charities associated with them.

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Health and Social Care

1 Where can I get information about my condition?

Your consultant and GP should be able to provide you with comprehensive information about your condition. In addition, most neurological conditions have a national organisation that represents the interests of people living with that condition. At the back of this booklet are comprehensive contact details for each of these groups. Their websites provide a range of information and the Helpdesk phone numbers for the various neurological charities, which will in turn give you the information for the local charities.

You can also call GUIDE & PALS on 0800 0151 548 for further details.

2 I want to learn more about my condition so I can manage it myself as much as possible. How could I do this?

If you are under the care of a consultant or specialist nursing team, please ask them for information in the first instance. If you would like more detailed information, GUIDE & PALS Information Service can research on your behalf. Tel: 0800 0151 548.

Gloucestershire Hospitals NHS Foundation Trust produce a comprehensive set of patient information leaflets which may be downloaded from www.gloshospitals.org.uk/ppi/leaflets/leaflets.asp, or telephone 08454 222 222 if you prefer a copy to be sent to you.

The various national support organisations provide helpful advice and information. At the back of the Neurological Alliance leaflet are comprehensive contact details for each of these groups. You may also search for contact details at www.guide-information.org.uk

In addition, Gloucestershire Care Services offers the **Expert Patient Programme** (EPP) in Gloucestershire. www.glospct.nhs.uk.

It is an NHS initiative to help those living with long-term conditions such as diabetes, Parkinson's, Lupus, epilepsy, ME, arthritis, fibromyalgia or heart disease to improve the quality of their life. EPP offers a free course (for those over the age of 18) which focuses on developing self management skills. Weekly sessions are two and a half hours long over a six week period. EPP is led by volunteer tutors, people who have long term conditions themselves. Participants learn ways to deal with stress, depression and low self image, how to manage pain and fatigue and new ways to relax and stay healthy. Participants are encouraged to manage their condition in partnership with health care professionals, learning how to improve communication with them in sharing responsibility for their own health.

Also in Gloucestershire there is a course called 'Looking After Me' which is a specific course for carers.

To register please contact the Expert Patient Programme Co-ordinator on 08454 221623, or contact Gloucestershire Care Services.

3 Are there any specialist nurses for my condition in Gloucestershire?

The specialist neurological nursing services in Gloucestershire can be contacted on the telephone numbers below:

Multiple sclerosis – 08454 226404

Epilepsy – 08454-226403

Parkinson's disease – 08456 598109

Motor neurone disease – 08456 598109

Progressive Supranuclear Palsy & Cortico Basal Degeneration – 01934 842366

4 How can I access a dietician?

The quickest way to access dietician services in Gloucestershire is to ask your GP, consultant or specialist nurse for a referral to the service.

5 How can I access a speech and language therapist?

In practice, the majority of referrals are received through GPs. However, Gloucestershire Speech and Language Therapy Service also operates an open referral process. This means that anyone, irrespective of age, language, gender, race, presenting communication difficulty or location, may refer themselves to the Speech and Language Therapy service.

If you are unsure how to get referred, please ring one of the following numbers and ask to speak to a Speech and Language Therapist who will be able to discuss your query with you:

Gloucestershire Royal Hospital	Cheltenham General Hospital
Great Western Road	Sandford Road
Gloucester, GL1 3NN	Cheltenham, GL53 7AN
Tel: 08454 228105	Tel: 08454 224120

6 How can I access a psychologist?

A range of support is available to people who have a long-term condition. As part of this, people may find it helpful to see a Clinical Psychologist who specialises in helping people and their families cope with the stresses and strains of such conditions.

Having a long-term condition can be difficult to cope with for anyone. Some of these difficulties can be dealt with by the person themselves, with the help of their families/friends, or possibly with the support of their health care team (nurses, doctors etc.). Some particular problems may also benefit from the help of the Neurology Psychology Service in Gloucestershire.

You can be referred by anyone in your health and social care team, or you can contact them directly (see number below).

- If you're not sure whether this is the right move for you, you could discuss it with another member of your care team, or ask to speak to the psychology team

- If you would like to go ahead, the Psychologist will either send you an appointment letter or telephone you to arrange a suitable time and place for the appointment
- You will usually be seen at Gloucestershire Royal Hospital or Cheltenham General Hospital. Home visits or appointments in other settings can be arranged if appropriate
- Appointments can last up to an hour

For more information call:

Gloucestershire Royal Hospital	Telephone 08454 225179
Cheltenham General Hospital	Telephone 08454 223447

7 How can I access an occupational therapist (health and social care)?

You can ask your GP to refer you to an Occupational Therapist or you can contact the Adult Helpdesk at the County Council by calling 01452 426868 or emailing socialcare.enq@gloucestershire.gov.uk

8 How can I access specialist palliative care services?

Palliative Care services aims to help patients with long-term conditions, and their families to achieve the best possible quality of life.

This might include:

- Helping you to live as actively as possible
- Taking account of your emotional, social and spiritual needs, alongside your physical ones
- Supporting you and your family in coping with your illness and the choices you wish to make
- Providing good relief from pain and other distressing symptoms

Your GP or Consultant can refer you to the specialist palliative care services. It is often useful to make this referral early in your condition so that you can meet members of the team and find out what they can offer.

The specialist Palliative Care Service in Gloucestershire Hospitals NHS Foundation Trust is made up of professionals with different specialities in the care of people with palliative needs. They act as a specialist resource to staff in the community as well as hospital care teams. They help with the management of complex problems when an existing plan does not seem to be working. A Multi-Disciplinary Team meeting takes place every week to discuss progress with patient care, treatment options and care plans. Patients are kept fully informed of any discussions that take place during this meeting.

Telephone numbers for the team can be found below

Community Palliative Care (Macmillan) Team

(self-referral or via health professional)	01452 371022
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Hospital Palliative Care Teams

Gloucestershire Royal Hospital	08454 225179
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Cheltenham General Hospital	08454 223447
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Hospices and Day Care

Sue Ryder Care Hospice, Leckhampton	01242 230199
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Cotswold Care Hospice, Minchinhampton	01453 886868
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Great Oaks Hospice, Forest of Dean	01594 811910
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9 How can I access a physiotherapist?

Referrals to physiotherapy can be made by GPs, consultants and other health care professionals. You can also self refer by completing a self-referral form at any physiotherapy department or by calling the numbers below.

Cheltenham General Hospital	08454 223040
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Moreton Bourton and Winchcombe	01608 812618
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Cirencester, Tetbury and Fairford	01285 884536
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Stroud	01453 562149
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Berkeley	01453 562010
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Tewkesbury	01684 853933
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Gloucester Royal Hospital	08454 228527 or 08454 228535
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Forest of Dean	01594 598129
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The information is also available on the following websites.

<http://www.gloshospitals.org.uk/> <http://www.nhsglos.nhs.uk/>

10 How can I access orthotics?

The Orthotics Service (sometimes known as the Surgical Appliance Service) is responsible for the assessment and supply of equipment and appliances such as insoles, adapted shoes, leg splints and wrist supports. It can also be something more complicated such as a brace or caliper, depending on your individual needs.

A referral to the service can be made by a physiotherapist, Occupational Therapist or your GP.

11 How can I get help with care for my feet?

The Podiatry Service is an NHS service for anyone who has an identified medical and / or podiatry need for their feet. A GP referral is usually required. Your GP will contact the nearest clinic, which will issue an appointment for initial assessment on the basis of medical and / or podiatry need (age is not a criteria). A treatment plan will be arranged at this meeting. Clinics are held throughout Gloucestershire. A limited home visit service can be arranged where essential.

Where there is a social care need for foot care, rather than a clinical need, (e.g. you cannot reach your toenails), you can be referred to the **Best Foot Forward Project**. The four aspects of foot care provided are:

- toenail cutting;
- bathing of feet;
- filing of toenails;
- cream application to feet.

The service is provided in your own home by trained foot care workers. All service users have their own Foot Care kit, obtained from the foot care worker, to reduce the possibility of cross infection from other clients' feet. There is a fee, dependent on assessment.

All referrals must be through a health professional – please do not contact the Service directly

Advice on suitable footwear can be obtained from the Podiatry Department. This department provides a foot measuring service and offers all types of footwear for sale. They are often specially shaped to provide footwear for those who have difficulty finding comfortable footwear from high street shops. The price of footwear is similar to that which you would pay in a shoe shop. The footwear technician will advise you on how to choose shoes even if you do not order from them.

For further information contact the Podiatry Department at St. Paul's Medical Centre, 121 Swindon Road, Cheltenham. Tel: 01242 215470. Unfortunately, they are not able to make home visits.

12 Is there anyone who can co-ordinate my social care needs?

To discuss your care needs, please contact the Adult Helpdesk at the County Council by calling 01452 426868 or email socialcare.enq@gloucestershire.gov.uk

13 How can I access specialist continence services?

For professional advice on adults with continence problems call the Continence Helpline Number on 01452 891034, which is open from Monday to Friday 12.30-1.30pm.

14 How do I get a wheelchair? Will I have to pay for it?

If you need a wheelchair for long-term use, ask your GP to refer you to the NHS Wheelchair Assessment Service (tel: 01242 713900), which provides wheelchairs, pressure cushions and special seating to the residents of Gloucestershire with a permanent disability. Clients must meet eligibility criteria based on clinical need. Assessments can be undertaken in your home if preferred.

All wheelchairs issued are provided on long-term loan and are maintained free of charge. The service operates a Voucher Scheme which contributes to the cost of a wheelchair of higher specification, if needed. The service is only for long term or permanent wheelchair users who need their wheelchairs for mobility indoors. For shorter term needs, or where a wheelchair is needed for outdoor use only, please contact NHS Occasional Wheelchair Service on 01242 713906.

If, having undergone your assessment, you find that you are not eligible for a wheelchair from the above services, and have to buy one, please contact GUIDE & PALS on 0800 0151 548 for advice on suppliers and help with funding if needed.

For short-term loan of a wheelchair (voluntary donation invited) contact the Medical Equipment Loans Service run by British Red Cross at Unit 7, Wheatstone Court, Davy Way, Waterwells Business Park, Quedgeley, Gloucester GL2 2AQ. Tel: 01452 726666.

15 I am becoming increasingly disabled, and find it difficult to do simple things like answering the door, switching on the television and lights. I am told that NHS Environmental Controls may help. How do I arrange for these to be fitted?

You can request an assessment for getting environmental controls fitted within the home, by making contact with the Adult Helpdesk at Gloucestershire County Council on 01452 426868. They may be able

to refer you to the **Telecare** Service which provides equipment to help people stay independent in their own homes.

Telecare can provide you with further information on the range of equipment available. Tel: 01452 583743

16 Who should pay for tubing and other consumables needed to meet my health needs in my home within my home?

In general, many 'consumables' can be prescribed by your GP and obtained through your local pharmacy. More specialist consumables (eg. tubing for suction machines) are usually funded and provided by the community nursing service. Similarly, this is accessed through your GP.

17 Am I eligible for free prescriptions?

Current (2011) prescription costs are:

- £7.20 for a prescription,
- £104 for a 12-month prepayment certificate (PPC), and
- £28.25 for a three-month PPC.

You can get free NHS prescriptions if, at the time the prescription is dispensed, you:

- are 60 or over,
- are under 16,
- are 16-18 and in full-time education,
- are pregnant or have had a baby in the previous 12 months and have a valid maternity exemption certificate,
- have a specified medical condition and have a valid medical exemption certificate
- have a continuing physical disability which means you can't go out without help from another person and have a valid Medical Exemption Certificate

- hold a valid war pension exemption certificate and the prescription is for your accepted disability,
- or you are an NHS inpatient.

You are also entitled to free prescriptions if you or your partner (including civil partners) are named on or are entitled to an NHS tax credit exemption certificate or a valid HC2 certificate (full help with health costs), or you receive either:

- Income Support,
- Income-based Jobseeker's Allowance,
- Income-related Employment and Support Allowance, or
- Pension Credit Guarantee Credit.

18 I seem to be waiting a long time for assessments/appointments. Is there any way I can speed these up?

If you have been waiting a long time for an assessment you may like to contact the Adult Helpdesk on 01452 426868 or in the case of a child, the Children and Families Helpdesk on 01452 426565. The Helpdesk is the first point of contact for Social Care referrals and the Customer Service Advisors should be able to help with regard to waiting times for assessment.

If you are waiting for an outpatient appointment with a hospital consultant, and it is your first appointment, you should speak to your GP in the first instance. With the help of your GP you may be able to choose an alternative hospital with a shorter waiting time.

If you are awaiting a physiotherapy appointment and are concerned about when your appointment is likely to be please contact your local department. See section 9 for details.

If you have already been seen as an outpatient and are waiting for a follow-up appointment and think that this is taking too long you may like to contact the secretary of the relevant consultant in the first instance.

19 Who would help me record an Advance Decision to Refuse Treatment (ADRT)?

NHS Gloucestershire has developed a template on which can be recorded an Advance Directive (Living Will) which will cover all conditions. At present, however, it is best to seek advice from the health professional leading your care.

In addition, some of the neurological support organisations have information about ADRTs which can be sent to you or downloaded from the internet, eg MND produce a very good standard Living Will form. If you would like a copy, please phone 08457 626262.

There is also a website www.adrtnhs.co.uk with comprehensive information.

20 I have concerns about changes in my physical ability – who can I ask?

A re-assessment by your local physiotherapist with an interest in neurology would be helpful. You can self-refer yourself by contacting your local department. See section 9 for details.

21 I cannot access my dentist's surgery anymore. Where can I get NHS dental care in an accessible setting?

Details of local dental services and particularly those with accessible facilities and those dentists willing to provide domiciliary dental services can be found by contacting the Gloucestershire Dental Helpline on 08454 220 505.

Transport

22 Where do I obtain information and advice about driving

You must tell the DVLA if you have, or have ever had, a medical condition or an impairment that may affect your driving.

If you hold a current driving licence and have a 'notifiable' medical condition or disability, you must tell the DVLA right away. You should not wait until your licence is due for renewal.

You must also tell the DVLA if your medical condition or disability has become worse since your licence was issued or if you develop a new medical condition or disability.

'Notifiable' medical conditions and disabilities include epilepsy, strokes and other neurological conditions, mental health problems, physical disabilities and visual impairments.

The medical standards of fitness to drive are available to all medical practitioners. If your doctor, in accordance with these standards, has advised you that you should not drive you may wish to surrender your licence.

If you have multiple sclerosis, motor neurone disease or Huntington's disease you must complete a questionnaire form CN1. If you have Parkinson's disease you must complete form PK1. Both of these forms will allow the government medical adviser to contact your doctors and assess your capacity to drive. The forms are available from your doctor's surgery or online at

http://www.direct.gov.uk/en/Motoring/DriverLicensing/MedicalRulesForDrivers/DG_10010623

23 What happens when I contact the DVLA – will my licence be taken away?

Once the medical adviser has all the information he or she needs, they will make a decision about your licence. You may be able to keep your licence or get a new one.

You may be given a driving licence for a period of one, two or three years if the medical adviser decides that your 'medical fitness to drive' needs to be reviewed in the future.

You may get a driving licence which states that special controls need to be fitted to the vehicles you drive so you can overcome the effects of a physical disability.

If the medical adviser's enquiries confirm that, as a result of your medical condition, you are not fit to drive, your licence may be withdrawn.

If they have to take this course of action they will explain why they made this decision and, if possible, tell you when you can reapply for your licence; and send you a notice which will explain your right to appeal.

You are also required to inform your insurance company of your condition.

24 Am I eligible for the Motability Scheme?

The Motability Scheme can help you with leasing or buying a car if you are getting the higher rate of the mobility component of Disability Living Allowance (DLA). Even if you do not drive yourself, you can apply for a car as a passenger and propose two other people as your drivers.

If money is a problem when financing the car or adaptations, Motability may be able to provide a grant through their own charitable fund or the Specialised Vehicle Funds, which they administer for the government.

Motability: Tel 0845 4564566 www.motabilitycarscheme.co.uk

25 Where is my nearest Regional Driving Assessment Centre?

Regional Driving Assessment Centres give practical and independent advice and assessment to disabled drivers and passengers. The staff there will assess your ability to drive, advise you about vehicles that might suit you and about any adaptations you may need. They are well informed on motoring and disability issues generally. Talk to them about any mobility problems you have.

An assessment for a driver will cost from £50 to £130

The nearest centres to Gloucester are at Eynsham in Oxford (telephone 0845 3371450 or Fishponds, Bristol (telephone 0117 9659353).

26 How do I buy an adapted vehicle?

Firstly, it is best to get advice from your nearest Regional Driving Assessment Centre (see question above). You may also find the Ricability website helpful – www.ricability.org.uk

If you are buying your vehicle under the Motability Scheme (question 24), you may find the dealer nearest to you on their website <http://motability.directenquiries.com/Motability/finddealer.aspx> and simply enter your postcode. Alternatively you can telephone them on 0845 456 4566.

Motability also produces a very useful booklet 'Choosing Your Car' available for download from www.motabilitycarscheme.co.uk. Even if you are not buying your car through their scheme this booklet is full of very useful facts, tips and suggestions.

27 Is there any financial help towards buying an adapted vehicle?

The Motability Scheme can help you with leasing or buying a car if you are getting the higher rate of the mobility component of Disability Living Allowance (DLA). Motability offers a wide selection of vehicles for no

more than the cost of your weekly mobility allowance, currently around £46 a week. They have around 250 cars available with no advance payment.

Other financial help may be available from local branches of national charitable organisations. Information can be found on their websites or you can contact their helpdesks (see Question 1). GUIDE & PALS may be able to do a search of charities and trusts that issue grants.

28 How can I choose the best type of mobility scooter? Where do I get one from?

Scooters and buggies are not available through the Wheelchair Service, which means that potential users will need to purchase them privately and there are a huge range of suppliers. It is therefore very important to get as much independent advice as possible about the range of scooters and buggies available. A comprehensive advice factsheet entitled 'Choosing a Buggy or Scooter' is available free from the Disabled Living Foundation.

Disabled Living Foundation

380-384 Harrow Road, London W9 2HU

Tel: (020) 7289 6111 Fax: (020) 7266 2922

Helpline: 0845 130 9177 10am-4pm

Textphone: 020 7432 8009 Email: advice@dlf.org

Website: www.dlf.org.uk

Assistance with funding may be possible from various charitable bodies. They can also be purchased through the Motability by offsetting some or all of your Disability Living Allowance.

29 Do local buses take wheelchairs and/or mobility scooters?

Wheelchairs can be accommodated on most modern local buses however this is not the case for mobility scooters. To check whether the buses on your local route are suitable for wheelchairs, telephone the Gloucestershire County Council transport line: 01452 425543.

None of the regulations for buses or coaches deal with the carriage of scooters. This is because scooters are outdoor vehicles intended for use as an alternative to public transport for short trips. They are generally less manoeuvrable than wheelchairs and cannot be used as a seat on a vehicle because of their instability and difficulty in providing appropriate restraint systems for the both the scooter and the user.

You can hire a Shopmobility scooter at the following locations:

Gloucester: 1, Hampden Way (next to car park), Gloucester GL1 1SX.
Tel: 01452-302871

Gloucester Quays: Designer Outlet, (1st Floor, next to disabled parking), St. Ann Way, Gloucester GL1 5SH.
Tel: 01452-501839

Cheltenham: Level 1, Beechwood Shopping Centre, High Street, Cheltenham GL50 1DQ.
Tel: 01242-255333

30 How do I get a powered wheelchair?

Please see question 14. Powered wheelchairs are not usually provided by the NHS Wheelchair Service but you may be eligible for help with buying one through their Voucher Scheme.

If you would like advice on choosing a powered wheelchair and where to buy one, please contact GUIDE & PALS on 0800 0151 548 for information on local suppliers and help with funding if needed. Some of the local providers are listed below, but we cannot make recommendations:

- GIS – reconditioned wheelchairs for sale – Tel: 01452 874971
- Keep Able, Cheltenham – Tel: 0800 2981902
- Optimum Mobility, Malmesbury – Tel: 01666 840060
- Assured Mobility, Gloucester – Tel: 0800 4961495

31 Where can I get a hoist to put my wheelchair in the boot of the car?

If you are unable to lift your wheelchair into a car or if you have a heavy scooter or wheelchair, there are various types of equipment to help get it into the car.

- hoists which lift a manual or powered wheelchair into the boot of a vehicle
- rooftop hoists which winch a manual wheelchair up and onto the roof of a car
- racks which carry a wheelchair on the back of a car
- trailers and ramps.

Whatever type of equipment you want, it is worth talking to a Regional Driving Assessment Centre about how the various alternatives available may suit you.

Hoists are usually installed by vehicle adaptation firms or by their local dealers. The suppliers listed here (web version only) should be able to tell you about fitting agents and provide details of local dealers.

32 Which taxi firms provide a service for wheelchair-dependent passengers?

GUIDE & PALS Information Service can help you locate local wheelchair-friendly taxi firms on 0800 0151 548.

In addition, as taxi firms are regulated by local councils, you should be able to get information about which ones accept wheelchairs by calling the licensing departments below:

Cheltenham Borough Council

Tel: 01242 775004

Email: licensing@cheltenham.gov.uk

Cotswold District Council

Tel: 01285 623000

Email: licensing@cotswold.gov.uk

Forest Of Dean District Council

Tel: 01594 812445

Email: licensing@fdean.gov.uk

Gloucester City Council

Tel: 01452 396396

Email: heretohelp@gloucester.gov.uk

Stroud District Council

Tel: 01453 754440

Email: licensing@stroud.gov.uk

Tewkesbury Borough Council

Tel: 01684 272167

Email: licensing@tewkesbury.gov.uk

33 Am I eligible for a disabled person's railcard? How do I get one?

You are eligible for a disabled railcard if you receive:

- Attendance Allowance
- Disability Living Allowance (low or high rate mobility or middle/high rate personal care)
- Severe Disablement Allowance
- War Pensioner's mobility supplement
- War or Service Disablement Pension (80% or higher)
- Are buying or leasing a vehicle through Motability

To apply for your rail card call 0845 605 0525.

If you have difficulty with walking and need assistance at the railway station, it is possible to pre-book assistance with the relevant railway company (eg. First Great Western).

34 Am I eligible for free or subsidised bus travel?

Since April 2008 anyone in England who is 'eligible disabled' is entitled to free off-peak bus travel.

You are 'eligible disabled' if you:

- are blind or partially sighted
- are profoundly or severely deaf
- are without speech
- **have a disability, or have suffered an injury, which has a substantial and long-term effect on your ability to walk**
- do not have arms or have long-term loss of the use of both arms
- have a learning disability

You will need to apply to your Borough, District or City Council for your free pass depending on where you live within Gloucestershire. You will need to prove that you are eligible, permanently live in the area and provide them with a passport sized photo.

35 Is there any financial help available for me to get to work?

Access to Work might pay towards the cost of getting to work if you cannot use public transport. You may be eligible for help if you are:

- in a paid job
- unemployed and about to start a job
- unemployed and about to start a Work Trial
- self-employed
- and your disability or health condition stops you from being able to do parts of your job.

Your disability or health condition may not have a big effect on what you do each day, but may have a long-term effect on how well you can do your job.

In Gloucestershire your regional Access to Work centre is:

Access to Work Operational Support Unit

Alexandra House, 377 Cowbridge Road East, Cardiff CF5 1WU

Telephone: 02920 423 291 Textphone: 02920 644 886

Fax: 02920 423 342

Email: atwosu.cardiff@jobcentreplus.gsi.gov.uk

Alternatively, ask the Disability Employment Adviser (DEA) at your local Job Centre about Access to Work.

36 How do I apply for a Blue Badge in Gloucestershire?

The Blue Badge scheme is designed to give eligible people the ability to park close to the facilities and services they need to use, so as to

improve their lifestyle, independence and freedom of choice. All new badges issued are blue and are usable in all European Community countries.

Under current regulations governing the scheme, badges may be automatically issued to disabled people if they:

- receive the higher rate of the mobility component of Disability Living Allowance (DLA) (help with getting about)
- are registered severely sight impaired;
- use cars supplied by a government department or receive a government grant towards their own vehicles;
- receive a War Pensioners Mobility Supplement.

Other people may be issued a badge if their disability is:

- permanent and substantial and makes them unable or virtually unable to walk,

For example, applicants should generally be physically incapable of visiting shops, public buildings and other places unless allowed to park close to their destination. The applicant's inability to walk or severe difficulty in walking must be permanent and not just intermittent or temporary. Things such as difficulty in carrying parcels are not taken into account. A badge will not be issued under this rule to a person who will be travelling purely as a passenger.

If they have a severe disability in both upper limbs, regularly drive a motor vehicle but cannot operate, or have considerable difficulty operating, all or some types of parking meters or pay and display equipment.

If you feel that you qualify for a badge please contact the Adult Helpdesk. You will be sent an application form requesting details of your disability, your doctor's name and address etc. The completed form should be returned to the Blue Badge Team in Cheltenham Locality Office together with two passport-sized photographs of you, signed on the back. Please ring the Blue Badge Team on Cheltenham

01242 532302 if you find it hard to provide the photos. You will also need to sign the sticky label that, with your photo, will be put onto your badge and laminated. (Your photo should be placed face down on the dashboard, not on public display.) There is a small registration fee of £2.

37 Are there any other transport schemes in the county which may be able to help me?

Community transport is a friendly, safe and affordable transport service, provided by local groups to help a range of people with transport problems.

There are a number of schemes that operate in the county of Gloucestershire. Some provide wheelchair accessible minibuses which provide door to door transport on request. Passengers must be registered members and will incur charges for registration and fares. Others provide volunteer drivers who use their own cars to transport those who are unable to access public transport. There will also be a charge for using this service.

In some parts of Gloucestershire, there are community buses. A community bus operates to a scheduled timetable and with volunteer drivers. They provide services where commercial operators do not want to, but where people would otherwise have no service. The telephone numbers for each area are listed below.

Gloucester Community Transport	01452 627851
Cheltenham Community Transport	01242 515388
Tewkesbury Community Transport	01684 297209
Forest of Dean Community Transport	01594 844558 / 843809
Newent Dial A Ride and Volunteer Car Service	01531 821227
Bream Voluntary Car Service	01594 560257
Stroud Volunteer and Community Action – Volunteer Car Scheme and Ring and Ride	01453 759005

Cotswold Community Transport (Cirencester Dial A Ride and Voluntary Car Service)	01285 658802
Cotswold Community Transport (Fairford Dial A Ride and Voluntary Car Service)	01285 712852
Cotswold Community Transport (Tetbury Voluntary Car Service)	01285 659374
Cotswold Community Transport (Tetbury Dial A Ride)	01666 502514
North Cotswolds Voluntary Care Scheme	01608 651115
Hedgehog North Cotswold Community Bus Association	01386 430075
Villager Community Bus Service	01608 658579

38 It is difficult for me to get to hospital appointments, and the public transport is inaccessible/unavailable in my area. Am I eligible for transport to appointments? If so, how do I arrange this?

Please see Question 37 for community transport options.

Patient Transport is a service provided for patients whose medical or mobility condition requires skilled staff to support them to and from treatment. Patient transport is available for outpatient appointments, inpatient treatment, discharge from hospital and hospital transfers. However an individual will require an eligibility assessment before patient transport can be authorised. If this is a first referral to a hospital appointment, the individual will need to speak to their GP about whether they are eligible to receive this service. Subsequent referrals for patient transport should be made by the health professional providing your treatment.

Leisure / Education

39 Do I get any concessions for (e.g.) swimming, evening classes?

Concessions are widely available throughout Gloucestershire for a wide variety of local authority-run leisure and education activities for people with disabilities. Each Borough, District or City Council within Gloucestershire applies different charges and operates different concessionary rates. In each case it's worth contacting your local authority leisure and education departments for current details (see Question 48 for contact details)

40 Are there any pools particularly suitable for people with disabilities?

All pools in Gloucestershire are fully accessible for disabled people, with hoists to assist entry into and out of the water, however not all run disabled-only swim sessions. Cascades in Tewkesbury (tel: 01684 293740) is particularly accessible for disabled people and has weekday disabled-only sessions. Dursley pool (tel: 01453 546441) also has a disabled-only session.

41 What facilities are in place to allow disabled people to pursue higher education opportunities?

nextstep Gloucestershire is the local office of the nextstep national network which provides advice to adults seeking to retrain or take up further or higher education. They can be called on 0845 850 5070, during business hours. This a free advice service on all aspects of training and adult education.

Connexions Gloucestershire can provide advice on adult education and retraining to anyone under the age of 25 yrs with any kind of additional needs.

There are three main Connexions Centres in Gloucestershire:

- 301-305 High Street, Cheltenham Telephone 01242 250317
- 92-96 Westgate Street, Gloucester Telephone 01452 426900
- 44 High Street, Stroud Telephone 01453 757133

Young people living in the area of Tewkesbury Borough can contact Connexions on 01684 854940.

The **National Star College** is a specialist residential further education college for students, aged sixteen to twenty five, with a physical disability and/or an acquired brain injury. Funding is generally provided through the local Learning and Skills Council, with occasional support from Social Services or the Health Authority.

The College has a strong team of therapists, trained support workers facilitating care and educational needs, and twenty-four hour nursing care. All students are involved in developing an individual time-table to suit their highly specific needs.

There are also non-residential courses for adults (sixteen plus) with a disability living in Gloucestershire.

For further information contact the National Star College, Ullenwood Manor, Cheltenham GL53 9QU Tel: 01242 527631

A full range of undergraduate, post-graduate and diploma standard courses are available at **The University of Gloucestershire**.

Many courses can be studied on a full or part time basis.

For further information please telephone 01242 532825, or see website at www.glos.ac.uk

There is good disabled access and parking at all campuses.

42 I am finding it difficult to use my computer and it is my lifeline. Is there any practical or financial support available to help me?

AbilityNet is a national charity helping disabled adults use computers and the internet by adapting and adjusting their technology.

Their special expertise is ensuring that whatever your age, health condition, disability or situation you find exactly the right way to adapt or adjust your ICT to make it easier to use. They will send you a questionnaire to access your needs and they hold a bank of equipment which they can give out on long-term loan. The service is free to individuals and they have a tremendous success rate.

To contact AbilityNet telephone their general enquiry line on 0800 269545.

GUIDE & PALS maybe able to do a search on your behalf of the database, which lists charities and trusts that issue grants. Contact 0800 0151 548.

43 I want to go on holiday, but I require carers to help me with my personal care whilst I am away. Where can I find out places which would be suitable?

The national charitable organisations which represent the interests of people with neurological conditions such as the MS Society, Parkinson's UK and the MND Association all have helpline numbers. Each organisation has a wealth of experience and knowledge, and can advise people regarding practical issues with their own specific conditions. All keep details of places which are offering suitable holiday accommodation and personal care support.

Telephone numbers for all the organisations can be found in the back section of the Neurological Conditions booklet.

There is also a national charitable organisation which provides holiday information to anyone with extra needs:

Tourism for All

c/o Vitalise, Shap Road Industrial Estate
Shap Road, Kendal, Cumbria LA9 6NZ
Tel: 0845 124 9971 info@tourismforall.org.uk

Work

44 Who can advise me about being able to continue working?

Your GP and consultant can give you specific advice about your condition and your ability to continue full or part time employment. 'Access to Work' a government scheme established to help those affected by a disability or health condition will also be able to advise you. An Access to Work adviser can speak to you and your employer to reach a decision about the best support for you. In most cases, this can be done over the telephone, but a visit can be arranged if necessary.

Sometimes specialist advice may be needed, which the Access to Work adviser will help to arrange. For example, your adviser may arrange for a specialist organisation to complete an assessment and recommend appropriate support.

See question 35 for details on how to contact your local Access to Work adviser or visit http://www.direct.gov.uk/en/disabledpeople/employmentsupport/workschemesandprogrammes/dg_4000347

45 Is there any financial help for my employer to adapt the workplace?

The amount of help which you may receive from Access to Work will vary depending on how long you have been employed, what support you need and whether you are self-employed.

Access to Work can pay up to 100 per cent of the approved costs of adaptations if you are:

- unemployed and starting a new job
- self-employed
- working for an employer and have been in the job for less than six weeks

Whatever your employment status, Access to Work will also pay up to 100 per cent of the approved costs of help with:

- support workers
- fares to work
- communicator support at interview

Access to Work pays a proportion of the costs of support if all of the following apply to you:

- you're working for an employer
- you've been in the job for six weeks or more
- you need special equipment or adaptations to premises

After between one and three years, Access to Work will review your circumstances and the support you're receiving.

46 Where do I go if I think I am being discriminated against in the workplace because of my disability?

If you think you are being discriminated against in the workplace you should seek expert advice. Your local **Citizens Advice Bureau** can help you and provides specialist employment rights advice. Their service is free, impartial and independent and you can contact them at: 75-81 Eastgate Street, Gloucester GL1 1PN
Tel: 01452 527202, email: bureau@gloucestercab.cabnet.org.uk

The Disability Law Service (DLS) is a registered national charity providing free and confidential legal advice for disabled people. Address: Ground Floor, 39-45 Cavell Street, London E1 2BP. Tel: 020 7791 9800, email: advice@dls.org.uk. Web page: www.dls.org.uk

ACAS – The Advisory, Conciliation and Arbitration Service provides advice to both employees and employers regarding any employment issues.

Their helpline is 08457 47 47 47 www.acas.org.uk

If you are a member of a Trade Union, contact your local union representative as they can provide free advice and representation.

47 I am now not able to continue to work in the same role, due to my disability – who can I speak to to find out about my legal rights, and to find another job?

In terms of your legal rights please see Question 46 above.

To find another job your first point of contact should be Access to Work (Questions 35 and 44)

48 I am now off sick from work due to my disability and cannot afford my rent. What can I do?

Housing and Council Tax Benefit is available to help people who can no longer afford their rent and council tax. Eligibility criteria are complex, however anyone with a limited income (even if you or your partner are working full time) and savings of less than £16,000 (at 2010) can apply for help.

The scheme is administered by the Borough, District and City Councils within Gloucestershire and you should contact them for an information pack and an application form:

Cheltenham Borough Council

Municipal Offices, Gloucestershire GL50 9SA
Telephone: 01242 264341

Cotswold District Council

Benefits Section, Promenade, Cheltenham, Trinity Road, Cirencester, Gloucestershire GL7 1PX

If your surname begins with the letter:

A to K call 01285 623035 for all enquiries.

L to Z call 01285 623036

To request a home visit: 01285 6233784

Forest of Dean District Council

Council Offices, High Street, Coleford, Gloucestershire GL16 8HG
Tel: 01594 810000 council@fdean.gov.uk

Gloucester City Council

North Warehouse, The Docks, Gloucester GL1 2EP.

Tel: 01452 396396

Stroud District Council

Ebley Mill, Westward Road, Stroud, Gloucestershire GL5 4UB

Tel: 01453 766321

Tewkesbury Borough Council

Council Offices, Gloucester Road, Tewkesbury, Gloucestershire GL20 5TT

Tel: 01684 295010

49 What benefits may I be entitled to?

There are a whole array of benefits which you may be entitled to and this depends on individual circumstances. Those people with a disability will usually claim one or more of the following:

- Disability Living Allowance
- Severe Disablement Allowance
- Attendance Allowance
- Carers Allowance

Rules are complex and some benefits are paid at different rates depending on the extent of your disability. Your entitlement to one benefit can also be affected by other benefits you may be claiming. It is always worth seeking independent advice and we would suggest you contact your local Citizens Advice Bureau (see Question 46 for contact details) in the first instance for comprehensive advice and assistance, or call the **Benefits Advice Line** free on **0800 055 66 88**.

In addition to the above benefits there are a whole range of others designed to support people on low incomes including:

- Income Support
- Employment and Support allowance
- Income related
Job Seekers Allowance
- Working Tax Credit
- Housing Benefit
- Pension Credit
- Council Tax Benefit
- Child Tax Credit

50 What parts of my care will be free?

NHS Continuing Healthcare is the name given to a package of care which is arranged and funded solely by the NHS for individuals outside of hospital who have ongoing healthcare needs. You can receive Continuing Healthcare in any setting, including your own home or a care home. **NHS Continuing Healthcare is free**, unlike help from social services for which a financial charge may be made depending on your income and savings.

In your own home, this means that the NHS will pay for healthcare (e.g. services from a community nurse or specialist therapist) and personal care (e.g. help with bathing, dressing and laundry). In a care home, the NHS also pays for your care home fees, including board and accommodation.

Anyone assessed as having a certain level of care needs may receive NHS Continuing Healthcare. It is not dependent on a particular disease, diagnosis or condition, nor on who provides the care or where that care is provided. If your overall care needs show that your primary need is a health need, you should be eligible for NHS Continuing Healthcare. Once eligible for NHS Continuing Healthcare, **your care will be funded by the NHS** but this is subject to review, and should your care needs change the funding arrangements may also change.

If you are not eligible for NHS Continuing Healthcare, the local authority will discuss with you whether you may be eligible for support from them. If you are not eligible for NHS Continuing Healthcare but still have health needs, then the NHS may still pay for part of the package of support. This is sometimes known as a 'joint package' of care. One way in which this is provided is through NHS-funded nursing care.

Another way of receiving a 'joint package of care' is where the NHS provide other funding or services towards meeting your needs. Where the local authority is also part funding your care package then, depending upon your income and savings, you may have to pay a contribution towards the costs of their part of the care. There is no charge for the NHS part of a joint package of care.

Whether or not you are eligible for NHS continuing healthcare, you are still able to make use of all of the other services from the NHS in your area in the same way as any other NHS patient.

You should receive NHS-funded nursing care if:

- you are resident within a care home that is registered to provide nursing care, and
- you do not qualify for NHS continuing healthcare but have been assessed as requiring the services of a registered nurse.

Most individuals will not need to have a separate assessment for NHS-funded nursing care if they have already been considered for NHS continuing healthcare as this process will give sufficient information to judge the need for NHS-funded nursing care.

51 What elements of the care I need will be means-tested? Who do I contact to be means-tested and how long will it take?

Social care such as help with washing, dressing, feeding and leisure activities is available from Gloucestershire County Council and in a variety of settings including your home. However your needs will have to be assessed and part of this assessment process includes means-testing. Some people will be entitled to all their costs paid whilst others with savings may have to pay the full cost of the care they receive. Most will fall between these two points and will have to pay a contribution towards the costs of their care.

Social Care commonly means:

- Residential and nursing care
- Temporary or respite care
- Services you receive in your own home (Home Care) or at a Day Centre

Social Care Departments have a duty to assess people who appear as though they may benefit from a community care service. When you

enquire about receiving services you will be asked about your circumstances so that you get a proper assessment of your needs. Waiting times for assessments vary greatly according to demand; for an assessment and further information on current waiting times you will need to contact the Adult Social Care Team Helpdesk:

Some Social Care services such as Occupational Therapy services are not means tested. Further information is available from the Adult Helpdesk.

52 How do I apply for a Disabled Facilities Grant?

A Disabled Facilities Grant is a local council grant to help towards the cost of adapting your home to enable you to continue to live there. A grant is paid when the council considers that changes are necessary to meet your needs, and that the work is reasonable and practical.

- You can claim if you, or someone living in your property, is disabled and:
- you, or the person on whose behalf you are applying, are either the owner or tenant (including licensees) of the property
- you can certify that you, or the person on whose behalf you are applying, intend to occupy the property as your/their only or main residence throughout the grant period - currently five years

A grant can be used for adaptations to give you better freedom of movement into and around your home and/or to provide essential facilities within it.

If you are disabled, acceptable types of work include:

- widening doors and installing ramps
- providing or improving access to rooms and facilities – for example, by installing a stair lift or providing a downstairs bathroom
- improving or providing a heating system which is suitable for your needs
- adapting heating or lighting controls to make them easier to use
- improving access to and movement around the home to enable you to care for another person who lives in the property, such as a child

An occupational therapist will look at your circumstances and can recommend the type of adaptation(s) needed.

The amount paid is usually based on a financial assessment – a ‘means test’ – of your average weekly income in relation to your outgoings.

Means-testing will take into account savings above a certain limit. Certain benefits including Disability Living Allowance and Income Support are generally ignored.

If you have a partner, your combined income will be assessed jointly. Capital is included in the means test. The first £6,000 of savings is disregarded.

A range of premiums and allowances is used for all essential outgoings, for example, rent/mortgage and personal expenditure. Actual outgoings are not taken into consideration.

Depending on the outcome of this assessment the amount of financial assistance offered can vary from 0 to 100 per cent of the cost.

To apply, contact the housing or environmental health department of your local council (see Question 48 above) and ask them to send you an application form.

You must apply for a grant before you start any work – you will not normally get any grant if you start work before the council approves the application.

The local council must notify you of the result of your application, in writing, within six months of the date of application.

53 Is there any other financial help available?

If you are on a low income and faced with costs that are difficult to pay for out of your normal income, the Discretionary Social Fund maybe able to help. The Discretionary Social Fund can provide grants and interest free loans for a variety of needs that are difficult to meet from weekly benefits. There are three types of payment.

Community Care Grants – These are intended to promote community care by helping people on qualifying benefits to live independently in the community.

Budgeting Loans – These are interest free loans to help people who have been on a qualifying benefit for at least 26 weeks to help with intermittent expenses for particular items to which it may be difficult to budget, allowing the cost to be spread over time.

Crisis Loans – These are interest free loans for people on benefits or not, who are unable to meet their short term needs in an emergency or as a result of a disaster, or in certain circumstances, such as for rent in advance.

Qualifying Benefits are:- Income related employment and support allowance, income support, income-based jobseekers’ allowance and pension credit.

To apply for a Community Care Grant, request form SF300 and for a Budgeting Loan, form SF500, which are available from your local Jobcentre Plus Office or can be downloaded from the DWP website www.dwp.gov.uk

GUIDE & PALS is Gloucestershire’s Health Disability and Social Care Information Service. Staff maybe able to do a search of local charities and trusts that issue grants. For further details, please contact GUIDE & PALS on 0800 0151 548 or 08456 583888. You can also email the office at enquires@guide-information.org.uk.

Some other financial help may be available from charitable sources. Access to these funds can depend on a number of criteria and there are a variety of different charities offering financial support. In the first instance we would recommend contacting the help desk or information line for your neurological condition.

54 How do I apply for Continuing Health Care funding in Gloucestershire?

To apply for Continuing Health Care funding in Gloucestershire you'll require an assessment. The assessment of an individual's health needs is central to providing appropriate NHS health care including continuing health care services.

In many cases people with continuing health care needs will require additional specialist assessment. Specialist assessment is undertaken by appropriately qualified or experienced clinical staff and ensures that the individual receives the most appropriate health care. The decision as to whether an individual meets the eligibility criteria will be reached through the process of clinical assessment. An assessment comprises many elements including:

- assessing the individual patient's condition and health needs
- establishing the health objectives for the patient
- assessing the requirements for health services
- identifying different health care treatment options
- discussing the health care treatment options with the patient and, if appropriate, with their carer/relative
- deciding the appropriate mode of delivery of services
- agreeing the outline treatment plans including when it will be reviewed
- agreeing a detailed treatment plan up to the first assessment
- identifying the health professional's responsibility for reassessment

Specialist assessment means: that which is undertaken by clinicians who have additional recognised specific training and/or qualification, or expertise equivalent to a qualification, within that area of medical or nursing treatment.

In the first instance you will normally be medically assessed by your GP or your consultant who may then refer you to the specialist service, usually for a multi-disciplinary assessment to determine what further help or treatment may be appropriate for you.

For further information, please ring the Continuing Health Care team at NHS Gloucestershire on 08456 598106.

55 What do I do if I am turned down, and wish to appeal?

The duty on NHS Gloucestershire (previously known as the Primary Care Trust, or PCT) is to carry out an assessment in accordance with the criteria set by the Strategic Health Authority (SHA). NHS Glos informs the person assessed of the outcome of the assessment and, if that person is not satisfied they can request a review of the decision not to provide NHS Continuing Health Care, which should take place within 14 days.

NHS Glos will attempt to ensure that the dispute is resolved through local discussions with you and if this cannot be done a full review panel will be organised to look at your case afresh. Anyone who is dissatisfied about the procedure followed by NHS Glos, or the application of the criteria, whose case has not been able to be resolved informally, may apply for review of the case to the panel appointed by the SHA.

If you are unhappy with the response to your complaint, you should be told that you can request an independent review from the Healthcare Commission. If you remain dissatisfied following a review or if a review is refused you can then approach the Health Service Ombudsman.

The Ombudsman will normally expect complainants to have tried to resolve their concerns through the NHS complaints procedure before he or she considers taking a case on.

If you would like support, you may wish to contact the Independent Complaints and Advocacy Service (ICAS) on tel: 01225 762723 (Gloucestershire).

56 Where would I go to make a Will?

Most high street solicitors will provide a Will writing service and, just as you would if you were looking for a plumber, it's well worth shopping around for the best price. Many can also arrange a home visit in order to take your instructions in respect of your estate. Some people can get this free or at a reduced cost, however you must be aged over 75 and satisfy a means test requirement. Any solicitor offering advice under the Legal Advice and Assistance Scheme can give you more information about this.

In addition to solicitors there are certain commercial Will writing companies who advertise locally (see your Yellow pages). Costs will vary.

You may also like to see the following useful website:
www.makingawill.org.uk

It is also possible to write your own Will and you should seek professional advice on how to do this and how to obtain the necessary forms. The Citizens Advice Bureau (see Question 46 for details) can give you more information about this. Information on this subject is also available from the various neurological charities.

57 How do I establish an Enduring Power of Attorney?

The Public Guardian's Office gives full information on their helpful website:
<http://www.publicguardian.gov.uk/arrangements/arrangements.htm>

A Power of Attorney is generally made to ensure that a loved one and/or relative can look after your affairs and best interests once you lack the mental capacity to do this yourself. They are made in advance and therefore can give you tremendous peace of mind that, should the worse happen, your chosen attorney will always be able to look after your best interests. If a person already lacks the necessary mental capacity then they will be unable to create a valid Power of Attorney.

However, concerned relatives can ask the Court of Protection to make decisions on behalf of someone who is having difficulties in making decisions themselves.

Some people will have an Enduring Power of Attorney and if this is the case it is still a valid and useful document. However, from April 2008 Enduring Powers of Attorney were replaced by a new system of Lasting Powers of Attorney (LPAs) which are designed to increase the level of security and introduce certain checks and balances into the Power of Attorney system.

There are two basic types of LPA, one which is designed to help if you want to make arrangements for your financial affairs and another if you want to make arrangements for your wellbeing and health. Different forms are applicable for each LPA and you can download these from the above webpage.

There is a fee for lodging an LPA with the Public Guardian's Office. The forms are fairly straight forward to complete, however if you feel you need some help then contact your local Citizens Advice Bureau (see Question 46).

Personal care/daily living

58 Is there anywhere I can go to try out equipment (e.g. bath lifts, shower etc) before I buy it?

The right equipment can make a big difference to your ability to live independently in your home. It's a good idea to get specialist advice and to always try out equipment before you buy it.

Some suppliers offer home demonstrations of equipment. For further information you may like to contact GUIDE & PALS on 08000 151 548.

Disabled Living Centres offer the chance to try out a wide range of equipment. They offer free, independent advice about what products are available, how much they cost and where to get them.

Local Disabled Living Centres:

Living (dlc), The Vassall Centre, Gill Avenue, Fishponds, Bristol BS16.
Tel: 0117 965 3651

Ease

Independent Living Centre, The Independent Living Centre,
Stratton Road, Swindon, Wiltshire SN1 2PN. Tel: 01793 643 966

Assist Birmingham Centre (ABC) for Independent Living,
St Marks Street, Springhill, Birmingham B1 2HU. Tel: 0121 464 4942

The **Disabled Living Foundation** helps older and disabled people find equipment to enable them to live independently in their own homes. Their services include:

- a helpline service, which answers queries about equipment
- an equipment demonstration centre, where you can try out equipment and get advice from occupational therapists and physiotherapists
- a range of online factsheets to help you choose equipment, including stairlifts, hoists, scooters and household equipment

The foundation has also launched an online service to help choosing products around the bathroom, bedroom, stairs and telecare. The 'Living made easy' <http://www.livingmadeeasy.org.uk> website provides free, impartial information on all products available in the UK.

59 Will equipment be provided by health and social care services?

Some equipment may be provided after an assessment of your needs by an Occupational Therapist. This may include bathing aids and grab rails or other personal care aids. To make a request for assessment please contact the Adult Helpdesk on 01452 426868 or talk to your GP or District Nurse.

60 Where can I get a stair lift?

Stair lifts can be obtained from a number of local suppliers. It is important to be correctly assessed for your individual needs.

For further information you may like to contact GUIDE & PALS health, social care and disability information and advice service on 08000 151 548.

61 How do I get help with: housework, gardening, simple DIY – eg. putting up shelves, changing lightbulbs, larger home adaptations?

Within the county of Gloucestershire, there are a number of home improvements agencies. They offer advice and practical assistance with household repairs and adaptations for older and/or disabled homeowners. They can help with minor repairs and odd jobs. They can also supply and fit a range of minor adaptations to independent living approved by the Community and Adult Care Directorate. Some offer a gardening assistance scheme.

Care and Repair (Gloucester)	Tel: 01452 544938
Care and Repair (Cheltenham)	Tel: 01242 515280
Care and Repair (Forest of Dean)	Tel: 01594 812420
Care and Repair (Stroud)	Tel: 01453 753471
Care and Repair (Stroud – Dursley Outreach Office)	Tel: 01453 547100
Care and Repair (Stroud – Gardening Assistance Scheme)	Tel: 01453 767154
Anchor Staying Put – Tewkesbury	Tel: 01684 291962
Anchor Staying Put – Cotswolds	Tel: 01285 641766

For help with housework, GUIDE & PALS have details of private domiciliary care agencies that operate in the county. These agencies provide a range of services within people's homes.

This can range from light domestic work such as cleaning, laundry and shopping, to providing personal care such as bathing and toileting. If you would like a list of the domiciliary care agencies operating in your area, please contact GUIDE & PALS on 0800 0151 548 or 08456 583888.

62 Do I have any choice in home carers who come to the home?

You may have a home carer provided directly by your local Community and Adult Care Directorate of Gloucestershire County Council. Whilst they cannot guarantee you a choice of provider, if you have particular preferences they will try to accommodate them. They will also do their best to provide services that fit in with your way of life and your cultural needs.

Alternatively, you may have paid for a home carer that is provided through an agency. Again, if you have any preferences or concerns, you should discuss this with the agency in the first instance.

There may also be the option depending on your circumstances of Direct Payments. Direct payments are local council payments for people who have been assessed as needing help from social services, and who would like to arrange and pay for their own care and support services instead of receiving them directly from the local council. You can contact the Adult Social Care Team Helpdesk (01452 426868), to find out more.

63 What call systems are available for people in their own homes?

Gloucestershire County Council offer **Telecare**, which provides 24-hour direct communication with a monitoring centre by using sensors located around the home to detect potential dangers. The use of Telecare equipment allows the user to be able to live more safely and independently within their own home, and also provides support for

people with dementia, learning disabilities, physical disabilities and mental health problems. There are many different sensors that can be used and each person will have a home visit to assess the equipment that would suit them best individually. The equipment used includes fall detectors, smoke detectors, flood detectors, panic buttons and much more. Call the Adult Helpdesk for further information: 01452 426868
Other systems available include:

Severn Vale Community Alarm Service (Tewkesbury Borough and North Cotswolds) provides 24 hour peace of mind. It consists of a small personal radio transmitter (pendant) that can be worn around the neck, clipped to clothing, or worn on a wrist strap. The pendant will trigger a base unit that will sit alongside your telephone. It is both easy to use and keep clean. Simply press the red button on the alarm unit or the pendant and you will be connected to the service's control centre through your telephone line. Upon receipt of the call, the control room staff will talk to you over a loud speaker and identify the problem. They will decide what course of action can be taken, either by contacting your family, friend, or an emergency service. The service is available to anyone within the Tewkesbury Borough Area and covers the North Cotswold Area (GL54 north of the A40 and the whole of the GL56 area). Tel: 01684 272745.

Forest Careline in the Cotswolds is a 24 hour monitoring service, covering the whole of Cotswold District and beyond. In the event of an emergency, or situation that causes concern, a personal alarm or wireless detector calls the control centre, where trained personnel will contact a nominated relative, neighbour or friend, or the emergency services if appropriate, and request that they respond to the call. Tel: 01453 825473 or 01594 812505

Forest Linkline: as above, for Forest of Dean residents. Tel 01594 812505

Cheltenham Lifeline: as above, for Cheltenham Borough residents. Tel: 01242 774963

Stroud Careline: as above, for Stroud District residents.
Tel: 01453 754149

Gloucester City Lifelink: provided by Gloucester City Homes.
Tel: 01452 396505

Age Concern Aid-Call: Tel: 0800 772 266

64 Is there any way my spouse/family carer can have training in moving and handling and first aid?

Carers Gloucestershire (www.carersgloucestershire.org.uk) is an independent, carer-led charitable organisation that supports carers across the county. Part of their service is to offer training to carers in partnership with Gloucestershire County Council. Ring 01452 386283 for details of training available.

65 How can my partner get a break from caring for me?

You should contact the Adult Social Care Team Helpdesk (01452 426868) as there is a variety of help available:

- Organised Respite Care
- Carers' Emergency Scheme – when a carer has an emergency the Adult Social Care team can put in up to 48 hours of care without charge
- Carers flexible services scheme – £250 available which can be used by the carer for various purposes including domestic support
- Direct Payments to arrange your own support and breaks
- 2gether Trust – for the carers of people with mental health issues.

All these statutory services require a carer's assessment first; some will need to be classed as 'substantial' or 'critical' need. However, voluntary agencies and charities can often respond more quickly to a particular need, for example:

Carers Gloucestershire:	01452 386283 www.carersgloucestershire.org.uk
Crossroads Care (Cheltenham & Tewkesbury):	01242 584844
Crossroads Care (Forest of Dean):	01594 823414
Crossroads Care (Stroud & Gloucester):	01453 755999

66 Can I receive free continence aids/pads?

Free continence products (pads) are available (if appropriate) following individual continence assessment. Assessments are carried out by a specialist nurse in the Continence Clinic or, if leaving the house is becoming increasingly difficult for you, your district nurse or practice nurse can do a home visit.

A "Paediatric" Continence Nurse Specialist is available to deal with problems encountered by children and young people.

Gloucestershire Continence Service can be contacted as follows:

Gloucestershire Royal Hospital

Great Western Road, Gloucester GL1 3NN
Tel: 08454 225305

All information in the book was correct at time of collation. Should you be aware of any information having changed please contact the Gloucestershire Neurological Alliance www.glosna.org as they will be updating the information.

Charities – All Neurological Conditions

**Gloucestershire
Neurological Alliance**
www.glosna.org.uk

Brain and Spine Foundation
*Information and support about
all neurological conditions*
Helpline 0808 808 1000
helpline@brainandspine.org.uk
www.brainandspine.org.uk

**Brain and Spinal
Injury Charity (BASIC)**
Helpline 0870 750 0000
enquiries@basiccharity.org.uk
www.basiccharity.org.uk

Charities – Specific Neurological Conditions

If your neurological condition is not listed, please contact one of the charities on the previous page which deal with all neurological conditions. They will be able to suggest the charity most suited to your needs.

Contact a Family
*The charity holds an index of
specific conditions and rare
disorders.*
Helpline 0808 808 3555
info@cafamily.org.uk
www.cafamily.org.uk

NeuroSupport (formerly
Mersey Neurological Trust)
*Provide non-medical information
and support to people with
neurological conditions.*
0151 298 2999
info@neurosupport.org.uk
www.neurosupport.org.uk

Sue Ryder Care
*Provides neurological care
centres.*
General enquiries: 0845 050 1953
info@suerydercare.org
www.suerydercare.org

**Acoustic neuroma
British Acoustic
Neuroma Association**
Freephone 0800 652 3143
admin@bana-uk.com
www.bana-uk.com

**Ataxia
Ataxia UK**
Helpline 0845 644 0606
helpline@ataxia.org.uk
www.ataxia.org.uk

**Ataxia-telangiectasia
Ataxia-Telangiectasia Society**
01582 760733
info@atsociety.org.uk
www.atsociety.org.uk

**Brain tumour
Brain Tumour UK**
0845 4500 386
enquiries@braintumouruk.org.uk
www.braintumouruk.org.uk

**Samantha Dickson Brain
Tumour Trust**
0845 130 9733
patientinfo@sdbtt.co.uk
www.sdrct.co.uk

**BSE
Human BSE Foundation**
0191 389 4157
info@hbsef.org

**Cerebral Palsy
Scope**
Helpline 0808 800 3333
response@scope.org.uk
www.scope.org.uk

**Charcot-Marie-Tooth
disease
CMT**
0800 6526316
info@cmtuk.org.uk
www.cmt.org.uk

**Dementia
Alzheimer's Society**
Helpline 0856 300 0336
enquiries@alzheimers.org.uk
www.alzheimers.org.uk

Dementia UK
020 7874 7200
info@dementiauk.org
www.dementiauk.org.uk

**Dyspraxia
DANDA (Developmental Adult
Neuro Diversity Association)**
info@danda.org.uk
www.danda.org.uk

**Dystonia
The Dystonia Society**
Helpline 0845 458 6322
info@dystonia.org.uk
www.dystonia.org.uk

**ADDER (Action for Dystonia
Diagnosis, Education and
Research)**
0191 477 7700
info@actionfordystonia.co.uk
www.actionfordystonia.co.uk

**Encephalitis
Encephalitis Society**
01653 692583
support@encephalitis.info
www.encephalitis.info

Epilepsy

Epilepsy Action

Helpline 0808 800 5050
helpline@epilepsy.org.uk
www.epilepsy.org.uk

The National Society for Epilepsy

Helpline 01494 601400
www.epilepsynse.org.uk

Gullain Barre Syndrome

Gullain Barre Syndrome Support Group

Helpline 0800 374803
admin@gbs.org.uk
www.gbs.org.uk

Head and Brain Injury

Headway

Helpline 0808 800 2244
helpline@headway.org.uk
www.headway.org.uk

Child Brain Injury Trust

Helpline 0845 601 4939
helpline@cbituk.org
www.cbituk.org

Rehab UK

020 8579 9671
ninahillier@rehabuk.org

Headache and Migraine

Migraine Trust

020 7631 6970
info@migrainetrust.org
www.migrainetrust.org

Migraine Action Association

Helpline: 0116 275 8317
www.migraine.org.uk

Hemiplegia

Hemihelp

0845 123 2372
support@hemihelp.org.uk
www.hemihelp.org.uk

Huntingtons disease

Huntington's Disease Association

0151 298 3298
info@hda.org.uk
www.hda.org.uk

Hydrocephalus

Association for Spina Bifida and Hydrocephalus (ASBAH)

0845 450 7755
mailto:helpline@asbah.org
www.asbah.org

Meningitis

Meningitis Trust

0800 028 1828
helpline@meningitis-trust.org
www.meningitis-trust.org

Myalgic encephalomyelitis (ME)

ME Association

Helpline 0844 576 5326
meconnect@meassociation.org.uk
www.meassociation.org.uk

Motor Neurone Disease

Motor Neurone Disease (MND) Association

Helpline 08457 626262
helpline@mndassociation.org
www.mndassociation.org

Multiple Sclerosis

Multiple Sclerosis Society

Helpline 0808 800 8000
helpline@mssociety.org.uk
www.mssociety.org.uk

Multiple Sclerosis Trust

01462 476700
info@mstrust.org.uk
www.mstrust.org.uk

Multiple system atrophy

The Sarah Matheson Trust for Multiple System Atrophy

020 7940 4666
www.msaweb.co.uk

Muscular dystrophy

Muscular Dystrophy Campaign

020 7803 4800
info@muscular-dystrophy.org
www.muscular-dystrophy.org

Myasthenia gravis

Myasthenia Gravis association

Helpline 0800 919922
mg@mga-charity.org
www.mgauk.org

Narcolepsy

Narcolepsy Association UK (UKAM)

0845 450 0394
info@narcolepsy.org.uk
www.narcolepsy.org.uk

Neurofibromatosis

Neurofibromatosis association

020 8439 1234
info@nfauk.org
www.nfauk.org

Parkinson's disease

Parkinson's UK

Helpline 0808 800 0303
hello@parkinsons.org.uk
www.parkinsons.org.uk

Polio**British Polio Fellowship**

Freephone 0800 018 0586
 info@britishpolio.org.uk
 www.britishpolio.org.uk

Lincolnshire Post-Polio Network

01522 888601
 info@lincolnshirepostpolio.org.uk
 www.lincolnshirepostpolio.org.uk

Progressive supranuclear palsy**The Progressive Supranuclear Palsy (PSP Europe) Association**

01327 322410
 psp@pspeur.org
 www.pspeur.org

Rett syndrome**Rett UK**

01582 798910
 info@rettuk.org
 www.rettuk.org

Spina bifida**Association for Spina Bifida and Hydrocephalus (ASBAH)**

0845 450 7755
 mailto:helpline@asbah.org
 www.asbah.org

Spinal injuries**Spinal Injuries Association**

Helpline 0800 980 0501
 sia@spinal.co.uk
 www.spinal.co.uk

Syringomyelia**The Ann Conroy Trust**

01788 537676
 enquiries@theannconroytrust.org.uk
 www.theannconroytrust.org.uk

Stroke**The Stroke Association**

Helpline 0303 303 3100
 info@stroke.org.uk
 www.stroke.org.uk

Different Strokes (for younger stroke survivors)

Helpline 0845 130 7172
 webcontact@differentstrokes.co.uk
 www.differentstrokes.co.uk

Tourette syndrome**Tourettes Action**

Helpline 0845 458 1252
 help@tourettes-action.org.uk
 www.tourettes-action.org.uk

Transverse Myelitis**Transverse Myelitis Society**

020 8568 0350
 lewgray@blueyonder.co.uk
 www.myelitis.org.uk

Tremor**National Tremor Foundation**

Freephone 01708 386399
 enquiries@tremor.org.uk
 www.tremor.org.uk

Tuberous sclerosis**Tuberous Sclerosis Association**

0121 445 6970
 www.tuberous-sclerosis.org

Disability Issues**DIAL UK**

01302 310123
 informationenquiries@dialuk.org.uk
 Website: www.dialuk.info

Equality and Human Rights Commission

Helpline 0845 604 6610
 englandhelpline@equalityhumanrights.com
 www.equalityhumanrights.com

Disabled Living Foundation

Helpline 0845 130 9177
 helpline@dlf.org.uk
 www.dlf.org.uk

RADAR (Royal association for Disability and Rehabilitation)

020 7250 3222
 radar@radar.org.uk
 www.radar.org.uk

Carers**Carers Gloucestershire**

01452 386 283
 www.gloscarers.org.uk

Carers UK

Carersline 0808 808 7777
 info@carersuk.org
 www.carersuk.org

Crossroads Association

0856 450 0350
 www.crossroads.org.uk

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