



This leaflet has been written
by independent health
writer/researcher
CATHY STILLMAN-LOWE



Social Care & Social Services - HOW TO GET HELP

INTRODUCTION

ME/CFS is a serious and sometimes devastating illness. It can affect every part of your life. Even the simplest tasks of living such as going to the toilet or climbing stairs can prove difficult.

Help to cope with everyday living may be available to you (and your carer if you have one) from your local

authority social services department. You can find the contact details of **your social services department** in the phone book, the local library, your GP's surgery or on the internet.

Arrangements for social care provision vary within the UK. Check the websites on page 5 for more detailed information about Scotland, Wales and Northern Ireland. There is also a glossary on page 5 to explain

the meaning of commonly used terms in social care. It is a good idea to keep a record of your contacts and communications with social services – build it up as you go along. You will find it very useful to refer to later.

Significant changes to social care provision were implemented in England in April 2015, by the **Care Act 2014**, and this leaflet explains how the new system operates.

FURTHER READING

Another good read from The MEA is our **Benefits Brief on the Carer's Allowance**.

To buy a copy online, visit www.meassociation.org.uk/shop/benefits-leaflets/carers-allowance/ fill in your card details and then download the leaflet. You can also phone our office on 01280 818 968, and we'll pop a copy of the leaflet in the post.

DISCLAIMER

We have made every effort to ensure that information in this leaflet is correct. We do not, however, accept liability for any errors or omissions.

The law and government regulations may change. Be sure to seek advice from your local council before embarking on a course of action.

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INFORMATION AND ADVICE

The Care Act requires each local authority to provide an information and advice service that is available to anyone who requests it and not just limited to those whose care and support needs have been assessed.

This service must include information on how the authority's system operates; the choice of types of care and support and the choice of care providers in the area; how to access the care and support that is available; how to access independent financial advice and how to raise concerns about the safety/well-being of an adult in need of care and support.

INDEPENDENT ADVOCACY SERVICES

If you need help and support through the process, and in understanding your options and making a decision about your care and support – and there is no other appropriate person to support and represent you – then the local authority must arrange for an independent advocacy service

to carry out this role and to facilitate your involvement.

There is an excellent guide to Care Act advocacy services on the NHS Choices website: www.nhs.uk/conditions/social-care-and-support/advocacy-services/

THE ASSESSMENT PROCESS

If you have ME and it affects your daily life, your local social services department has a **duty to assess your need for services**.

The assessment:

- must be provided to anyone who appears to need care and support – regardless of their finances or whether the local authority thinks their needs will be eligible;
- must be of the adult's needs and how they impact on their wellbeing, and the outcomes they want to achieve;
- must be carried out with involvement from the adult and, where appropriate, their carer

or someone else they nominate, including an **independent advocate** provided by the local authority.

Up until now, local authorities have been able to set their own eligibility criteria based on government guidelines to work out who qualifies for care and support services paid for by the council. The Care Act introduces a new **national minimum eligibility criteria threshold** that local authorities in England must comply with.

The threshold is based on identifying how a person's needs affect their ability to look after themselves and how this impacts on their wellbeing. A person will be eligible for support with their care needs if they are unable to carry out **two or more key tasks (outcomes)** in a list set out by the government.

If the person's needs do not meet the minimum criteria, the local authority must still provide a written record of advice on what could be done to reduce, prevent and meet their needs.

An adult's needs meet the eligibility criteria if:

- (a) the adult's needs arise from or are related to a physical or mental impairment or illness;
- (b) as a result of the adult's needs the adult is unable to achieve two or more of the outcomes list; and
- (c) as a consequence there is, or is likely to be, a significant impact on the adult's well-being.

Local authorities should **consider each outcome** as set out below:

- (a) managing and maintaining nutrition – whether the adult has access to food and drink to maintain nutrition, and is able to prepare and consume the food and drink.
- (b) maintaining personal hygiene – the adult's ability to wash themselves and launder their clothes should be considered.

(c) managing toilet needs – the adult's ability to access and use a toilet and manage their toilet needs.

(d) being appropriately clothed – the adult's ability to dress themselves and to be appropriately dressed, for instance in relation to the weather to maintain their health.

(e) being able to make use of the home safely – the adult's ability to move around the home safely, which could for example include getting up steps, using kitchen facilities or accessing the bathroom.

(f) maintaining a habitable home environment – whether the condition of the adult's home is sufficiently clean and maintained to be safe. A habitable home is safe and has essential amenities.

(g) developing and maintaining family or other personal relationships – whether the adult is lonely or isolated, either because their needs prevent them from maintaining the personal relationships they have or because their needs prevent them from developing new relationships.

(h) accessing and engaging in work, training, education or volunteering – whether the adult has an opportunity to apply themselves and contribute to society through work, training, education or volunteering, subject to their own wishes in this regard. This includes the physical access to any facility and support with the participation in the relevant activity.

(i) making use of necessary facilities or services in the local community including public transport and recreational facilities or services – the adult's ability to get around in the community safely and their ability to use facilities like public transport, shops or recreational centres

should be considered. Local authorities should consider what support is required when an adult keeps healthcare appointments.

(j) carrying out any caring responsibilities the adult has for a child – the authority should consider any parenting or other caring duties being undertaken.

An adult is to be regarded as being **unable to achieve an outcome** if he or she is:

- (a) unable to achieve it without assistance;
- (b) able to achieve it without assistance but doing so causes the adult significant pain, distress or anxiety;
- (c) able to achieve it without assistance but doing so endangers or is likely to endanger the health or safety of the adult, or of others; or
- (d) is able to achieve it without assistance but takes significantly longer than would normally be expected.

Local authorities must consider the potential **fluctuation** of a person's needs. So, where the local authority is aware that an adult's needs fluctuate over time, the assessment should not be just a snapshot of a particular moment but should take into account the adult's history to get a complete picture of the person's needs.

There may be a wait for your assessment. There isn't a set time in which you can insist on having one but, if you feel that the waiting time is unreasonable, you can make a complaint. Any informal carer (partner, family member or friend who provides you with care and practical support) is also entitled to a carer's assessment. This is described later. Once the assessment has been completed, there may be a referral to **NHS Continuing Healthcare** (see *Glossary on page 5*).

PREPARING FOR THE ASSESSMENT

Social care assessments should not be things done to you but things done with you.

Be ready to play an active part as far as you can. It's your assessment, and you may be able to carry out a self-assessment as part of the process. Check with your local authority to see if this will happen.

To make the best contribution to your assessment, you will need to prepare for it. Think about the day-to-day impact of ME in your life and the ways it affects you.

Write down the names and contact details of the health care staff that social services should consult with as part of the assessment.

The list of outcomes above should cover most of the aspects of everyday life that may be affected by your disability. Social workers – even those specialising in adult disability – may not know much about ME. You can suggest that they view the ME Association website for information.

Remember that fatigue will be invisible to the assessing social worker unless you tell them about it. Ask your carer or someone who understands the impact of your illness to be present if you wish. You can ask a carer, relative, professional or advice agency to provide written information on your behalf with details of your needs.

Your needs assessment will usually be carried out by a qualified social worker who may be called a 'care manager'. It will usually take place at your home. Be sure to get the person's name and contact details. The assessor will consider a number of factors, such as:

- your needs and how they impact on your wellbeing – for instance, a need for help with getting dressed or support to get to work;
- the outcomes that matter to you – for example, whether you are lonely and want to make new friends; and

- your other circumstances – for example, whether you live alone or whether someone supports you.

The aim is to get a full picture of your needs and goals.

If you think you might benefit from special equipment, eg you have great difficulty climbing stairs, or you find it difficult to get into and out of the bath or shower, you can request an OT assessment. **The OT (occupational therapist)** is qualified to assess your needs relating to your disability. The OT can help find ways to enable you to live independently or to support your carers.

This may result in:

- providing equipment
- advising where you can buy equipment
- advising on alterations to your home
- finding alternative ways to carry out day-to-day activities.

GETTING THE RESULT OF YOUR ASSESSMENT

You are entitled to a copy of the final assessment along with formal notice of whether your needs qualify you for a service. Where you are found to have no eligible needs, the authority must inform and advise you on what can be done to meet or reduce your needs (for example what support might be available in the community to help you or your carer) and what can be done to prevent or delay your needs increasing in the future.

One of the most important new initiatives in social care in the UK is 'personalisation' or **self-directed support**. This is the process by which people who are eligible for social care are allocated a specific amount of money (called a '**personal budget**') and can control how that money is spent to get the support they need in the way they want.

The important change is that control is with service users rather than professionals. You can take all or part of your personal budget as a **Direct Payment** (see page 4). In Scotland, personal budgets are referred to as individual budgets.

You may wish to employ a **broker** to help you (a broker is someone who helps people plan and organise the support they require to meet their social care needs).

Your local council is obliged to offer you the option of receiving Direct Payments in place of services you currently receive or are assessed as needing. This means that the council will give you the money they would have spent for you to arrange and pay for your own care, instead of arranging the care for you.

Direct Payments are not a replace-

ment of income so they will not affect your eligibility for other benefits.

SUPPORT PLANNING

The care and support planning process is in place to help you decide the best way to meet your needs.

It considers a number of different things – such as what needs you have, what you want to achieve, what you can do by yourself or with the support you already have, and what types of care and support might be available to help you locally.

Please note that the local authority is not obliged to meet any of your eligible needs if they are already being met by a carer – for so long as the carer continues to do so.

You must be involved in developing your care and support plan. The local authority will have to do everything it

reasonably can to agree the plan with you.

The authority must also provide an **independent advocate** to help you take part in the planning and review process, if you would otherwise have substantial difficulty in doing so.

The local authority has a legal responsibility to review the plan to make sure that your needs and outcomes continue to be met over time. If anything has changed, the authority must carry out a new assessment. You also have the right to request a review of your care and support plan, if you wish.

FUNDING YOUR CARE

Depending on your financial circumstances, you may have to make a financial contribution to the cost of your care.

In England and Wales, councils will have local charging policies. Ask your council for details. Not all types of care and support involve a cost for the person. Local authorities may not charge for services which the regulations say must **always be free**, for example reablement services (see *Glossary*) or equipment and minor adaptations to the home.

DIRECT PAYMENTS

Since April 1997, it has been possible for the local authority social services department to offer cash, rather than services. This system is called 'Direct Payments' and people who receive this money must use it to arrange services for themselves to meet their care needs.

These payments are not taken into account when benefits are assessed, neither are they liable to income tax.

A disabled parent can also receive Direct Payments to meet the cost of services needed by their children as a result of the parent's disability. Of course, if the local authority offers you Direct Payments and you do not feel confident about dealing with the limited paperwork, then you can

decline this option. Your council will have more information about what is involved.

Many authorities have arrangements with local organisations to support people who receive direct payments, so ask your council about this.

HELP FOR YOUR CARER

The government recognises that many unpaid carers – family members, friends, partners – may also need help. Social services are required to offer to assess the needs of any person providing care for you.

The authority will assess whether the carer has needs and what those needs may be. This assessment will consider the impact of caring on the carer. It will also consider the things that a carer wants to achieve in their own day-to-day life; whether the carer is able or willing to carry on caring, whether they work or want to work, and whether they want to study or do more socially.

If both the carer, and the person they care for, agree, a combined assessment of both their needs can be undertaken.

Following a **carer's assessment**, the council will decide whether services should be offered to meet your carer's needs, and what those services might be.

Carers Trust Website:

www.carers.org

Email: support@carers.org

Head office:

Carers Trust

32-36 Loman Street

London SE1 0EH.

Tel: 0844 800 4361.

WHAT SHOULD I DO IF I AM NOT SATISFIED?

If you are not satisfied with the assessment, discuss it with the person who is working with you, and ask them to provide you with more information about how the decision was reached. If you still disagree

with the decision, **you can appeal**.

There is a three stage process – with the emphasis on early resolution, wherever possible.

- Firstly, there's the early resolution stage, where the local authority facilitates open and constructive dialogue with the person making the appeal with the aim of achieving a prompt resolution.
- If early resolution is not reached, the appeal progresses to the second stage. This is the independent review stage; where the local authority appoints an Independent Reviewer to review their original decision and make a recommendation as to whether they view the local authority's decision was correct.
- The third and final stage of the process is the authority decision; this is where the local authority itself makes a decision while considering the Independent Reviewer's recommendation.

While your appeal is being considered, you may ask for your current care package (if you have one) to continue until the matter is resolved.

Do not feel uncomfortable about using the appeal process – make it clear that your complaint is about a process or decision and not about personalities. It should be possible to maintain cordial and professional links with individual staff and it is always worth making the effort to do that.

If you want to appeal you could ask an experienced adviser from Citizens Advice to help. To find your nearest Citizens Advice Bureau, visit their website: www.citizensadvice.org.uk or check the local telephone directory. Remember, if your needs change, you can request a reassessment.

GLOSSARY

Advocacy

An advocate can help you express your needs and wishes, and weigh up and take decisions about the options available to you. They can help you find services, make sure correct procedures are followed and challenge decisions made by councils or other organisations.

Assessment

Process by which a person's need for support and the outcomes they wish to achieve are identified.

Increasingly this process is carried out by people themselves and this is known as self-assessment. Alternatively, a co-produced assessment can be produced in partnership with a social care practitioner.

Broker or Support Broker

Someone who will help people plan and organise the support they need to meet their social care needs. Sometimes the term support broker is used. The process of working out what should be in a support plan can be described as support planning or brokerage and is not necessarily something that is done by a professional. Support planning can be done by yourself or with the help of friends and family.

Care and support

The mixture of practical, financial and emotional support for adults who need extra help to manage their lives and be independent – including older people, people with a disability or long-term illness, people with mental health problems, and carers. Care and support includes assessment of people's needs, provision of services and the allocation of funds to enable a person to purchase their own care and support.

Council-Managed Account

This is where the personal budget is held and managed by the council. The council makes payments from

the personal budget to providers for services.

The service user has no additional responsibilities around managing the money. Sometimes this is called a nominal or virtual account.

Direct Payment

Direct Payments are cash payments made to individuals with eligible needs instead of the council arranging social care services on their behalf. If the option of Direct Payments suits, it is possible to take part or all of a personal budget as a Direct Payment.

Eligible needs

Eligible needs are needs which have been identified in the course of a social care assessment as meeting criteria described by the Care Act 2014.

NHS Continuing Healthcare

Where it appears that a person may be eligible for NHS Continuing Healthcare (NHS CHC), local authorities must notify the relevant Clinical Commissioning Group (CCG). NHS CHC is a package of on-going care that is arranged and funded solely by the NHS where the individual has been found to have a 'primary health need'.

Occupational Therapist

An Occupational Therapist (OT) works with people of all ages to help them overcome the effects of disability caused by physical or psychological illness, ageing or accident.

Personal Budget

This is the amount of money that a local authority will allocate to a person with eligible social care needs so that the person can make decisions and choices about the care and support they want.

When the assessment is complete, a provisional planning amount is given to the person to start working out what to put into a support plan.

When the support plan is agreed by the council, the personal budget amount is confirmed.

Some people may prefer not to look after their personal budget or make their own arrangements, but the council should always tell people what the personal budget would be.

Reablement

Reablement is designed to help people accommodate illness or disability by learning or re-learning the skills necessary for daily living. Reablement workers must encourage people to regain or re-learn the ability to do things for themselves.

Self-Directed Support

This is the process by which everybody who is eligible for social care is allocated a specific amount of money and can control how that money is spent to get the support they need in the way that they want. The important change is that control is with service-users rather than professionals.

Support Plan

A support plan describes how the budget will be used to achieve the changes or outcomes a person wants to see, in the way they choose.

LINKS for further information

Care and Support Guide:

www.nhs.uk/Conditions/social-care-and-support-guide/Pages/what-is-social-care.aspx

England:

<https://www.gov.uk/careandsupport>

Scotland:

www.selfdirectedsupportscotland.org.uk

Wales:

<http://gov.wales/topics/health/socialcare/>

Northern Ireland:

www.dhsspsni.gov.uk/index/hss.htm