

A Guide to the Care Act

Top Tips for Family Carers of People
with Learning Disabilities

Introduction

As family carers it's essential we know what our relatives rights are – and what our rights are as their carers. We have put together this short document to act as a checklist for families when aiming to get the right support for their relative. We've tried to make this seemingly complicated process as simple as possible. It contains what we believe are the key things you need to know but, won't contain all the answers for everyone so we've added some contact details of people who may be able to help.

However, the best advice we were given regarding community care provision was that **if something you are told sounds wrong, then it often is**. If it's wrong then check it out – if it's wrong it can be challenged!

The Care Act 2014 replaced the NHS and Community Care Act 1990 but many of the principles in the old legislation remain...so what's new?

The Well-Being principle in the Care Act

New fundamental duty in the Care Act (Section 1): in everything a local authority does under the Act: they must promote the well-being of the individual, including:

- personal dignity and treating you with respect
- physical and mental health and emotional well-being
- protection from abuse and neglect
- control over day-to-day life including care and support and the way in which it is provided
- participation in work, education, training or recreation
- social and economic well-being
- domestic, family and personal relationships
- suitability of living accommodation
- contribution to society

Getting an assessment:

- **The council cannot refuse to assess a person's need for care/support.** The question should be whether it seems you or your relative are in need of services – not whether you will be eligible (they won't know this until the assessment has been undertaken)
- **You can request a reassessment for your relative** if you think their needs have changed or their needs are not being met by what is currently being provided – this can't be refused either!

- **The local authority cannot reduce support of services to your relative without a reassessment of their needs and a new support plan must be produced**

What should happen at the assessment (or reassessment)

- **Don't feel you need to do this on your own.** Your relative has a right to an advocate and so do you, as their carer (see below)

Independent Advocacy – for you and your relative

With the implementation of the Care Act, individuals who require support with the process of the care and support assessment and planning can get independent advocacy arranged for them by their local authority.

This applies to:

- **Adults who need care & support**
- **Carers of adults including young carers**
- **Carers of children in transition**
- **Children who are going through transition to adult services**

The Care Act emphasizes the importance of advocacy services by extending the range of people who are eligible for independent advocacy to enable them to be involved in every decision about their care and support.

Your local council has a legal duty to provide an independent advocate if you do not have an appropriate person to represent your wishes (such as a family member or friend) and you need assistance to understand information, express your concerns and goals, understand the issues related to assessment and review of your care, get the care and support you need and make decisions about your care. Local authorities must make sure that there is adequate provision of independent advocacy to meet their duties in line with the Care Act regulations.

The Care Act highlights four situations, any one of which may result in difficulty in being involved:

1. Understanding relevant information
2. Retaining information
3. Using or weighing up the information
4. Communicating views, wishes and feelings

- Assessments should normally be a **face-to-face** – not just a self-assessment questionnaire.
- **Ask for questions in advance from the social worker when assessment is due.** You can also ask if the Social Worker has training in specific conditions, such as autism.

- It's important to be aware that the person doing the assessment may not be a qualified social worker but, they must have proper training to understand the needs of the person they are assessing.
- **The person being assessed should be present** when the assessment takes place. *We know this sounds obvious but you'd be surprised how many times we hear that they weren't.*
- During the assessment – **you need to ensure all needs are clearly identified** – otherwise they won't be funded. Include the lesser needs as well as the more important ones because they all add up and need to be looked at as a whole.
- **Make sure your needs as a carer and your willingness to provide support are identified as well.** As family carers we want to provide support to our relatives because we love them but, we also need to consider our own health and wellbeing. We shouldn't feel guilty about wanting others to provide support.

“Authorities must not assume a carer is willing or able to provide any care – including additional care arising from a reduction in the care package. It will be maladministration for such a reduction to occur without assessing the carer and explicitly clarifying (and recording) whether she/he is ‘able and willing’ to provide the additional care” – Luke Clements –Professor of Law at Leeds University and solicitor

- **Remember the ‘what if’ question!** – make sure you emphasise the risks if the support needed is not there and your relatives needs are not met
- **It's vital that everything discussed in an assessment is recorded...** Get a copy of the assessment and check it. Ask for any missing details to be added. Don't sign the assessment until the changes have been made and you're satisfied that all your relatives needs have been included.
- **With personal budgets/direct payments it's even more important to get a clear record of everything that has been discussed and agreed**

Eligibility

- The assessment should identify **all needs**. These are the **assessed needs** but will not all necessarily lead to support being provided. The council will usually only provide for eligible needs. Although local authorities should consider meeting non eligible needs if it will help prevent them escalating and getting worse.

- **The Care Act introduced a new single, national eligibility framework for all local authorities.** To be eligible for support your relative must meet three requirements...
 1. Their needs must result from a physical or mental impairment or illness
 2. They must be unable to achieve two or more of the **outcomes** set out in the eligibility criteria, and
 3. As a consequence there is likely to be a significant impact on their well-being

The eligible outcomes are:

- Managing and maintaining nutrition
- Maintaining personal hygiene
- Managing toilet needs
- Being appropriately clothed
- Being able to make use of your home safely
- Maintaining a habitable home environment
- Developing and maintaining family or other personal relationship
- Accessing and engaging in work, training, education or volunteering Using necessary facilities or services in the community including transport and recreation

The decision about your eligible needs must be ‘carer-blind’. This means any help you are getting or could get from carers, whether paid or unpaid, must be ignored when determining whether your needs are eligible. The assessment should record if there is unpaid help that family or other carers are willing to give, and you agree with this. This can be taken into account when the authority decide what support they will provide, but not when deciding what your relatives eligible needs are!” : Kate Whittaker – Community Care Solicitor

Care and Support planning

After the assessment has taken place a care and support plan must be produced. The care and support plan must be in writing and all the how, who, what and when should be clear. Having a Direct Payment makes no difference – the care and support plan and record of assessment must still cover everything. If your relatives support or services change, check that a reassessment of their needs has been completed. As family carers you should be involved and consulted in this. **If a reassessment has not been completed then you should challenge any cuts as it is unlawful to reduce support or services without this**

A Care and support plan must include:

- A note of all your relatives needs identified during assessment
- Details of which ones are eligible needs
- The needs that the authority is going to meet, and how it will do this – may be partly or all by a direct payment
- Agreed outcomes you and your relative want to achieve and how support will be organised to meet them
- Support which you as a carer and others are willing and able to provide – or make clear if you or they are not willing
- Your desired outcomes as a carer, about providing care, work, education and recreation and how support will be organised to help meet them – may be by direct payments or other support to you or your relative
- The personal budget, including details of any financial contributions your relative will need to pay
- Details of what can be done to reduce or prevent your relatives needs getting worse
- The amount and frequency of any Direct Payments your relative will get

❖ Remember...

If you are opting for a Direct Payment. The amount of a Direct Payment must be enough to cover all the associated costs, for example...

- Recruitment costs, payroll services, DBS checks on employees
 - National Insurance, VAT, statutory holiday pay, sick pay, maternity pay,
 - Employers' liability insurance, public liability insurance
 - Start-up costs, training
 - Brokerage/advocacy
 - Hourly rate – enough to get (and keep) suitably skilled staff
- **Make sure you get clear information about what is involved in managing a personal budget and what support you can get, both at the start and if there are difficulties**

Beware of “We don't do that here” statements - always question!

Local authorities can't have 'blanket policies' such as:

- 'We don't provide help with bathing without a doctor's note'
- 'We don't provide help with shopping and cleaning'
- 'We don't provide travel help anymore'
- 'We don't provide evening/weekend services'
- They can't impose an upper limit on help, e.g. 'If you need 24-hour care then it will have to be funded by Health' or 'The weekly personal budget can't be more than the cost of a care home'

❖ **Local authorities must**

- Adjust provision to meet your needs – not the other way round.
- Disabled people should be able to choose where they live on an equal basis with other people

❖ **Local authorities cannot say:**

- “We don't have anything suitable, so you will either have to use a service outside our area” or ...
- “You will have to arrange this yourself using a personal budget”
- ‘We have funded you in an out of area care home and you are settled and happy there but now you must come back’
- “Although there is an ideal service for you (such as a respite care home) we are not going to fund it because it is out of area”

If nothing suitable is available locally for your relative, ask for evidence that the local authority is taking steps to arrange or commission a new service, such as from a charity or other independent provider

Ask how they will adjust provision to meet your relative's needs.

If your relative lacks capacity to decide where they live ask for a ‘best interests’ meeting. Family carers must be included in this meeting and the planning for what is best.

There may be many different ways of meeting a particular need, but remember, it all needs to tie in with the process of the council deciding what they are eligible for

- You or your relative may have a preferred way of meeting a need, but if the local authority has a cheaper way that it says can meet the needs of your relative adequately, it can limit the personal budget it provides to the cost of the cheaper way.

❖ **It's important to question and check how they say the needs can be met for the money – don't just accept it if you disagree that it would work.**

❖ **Think again about the consequences/risks if needs are not met properly – tell them.**

On occasions a local authority may suggest that although a person's eligible needs have not changed, the funding can be cut as the need can be met by a less expensive method. The explanation may be that a different care agency is available that can provide the necessary care at a lower cost.

Where this argument is raised, various things should be understood, including:

- 1. The cheaper arrangements must actually exist, as opposed to being a hypothetical alternative. It is not acceptable for the authority to reduce support on the basis of a supposed care package (that does not at present exist)**
- 2. The alternative support arrangement must meet the person's eligible needs. Care plans need to be detailed statements spelling out how the eligible needs will be met by the provision of the necessary support – including the fine detail – the “how, who, what and when”.**

By way of example, not infrequently a key component of a care and support plan is to maintain continuity and to ensure that the paid carers have specific training and / or skills. Where continuity is crucial – for example because the disabled person becomes distressed by changed routines or has had bad experiences of previous changes – then this could be a significant factor weighing heavily against any change. – *Luke Clements*

Carers needs and eligibility for support

As well as the needs of your relative, your needs as a carer/s and your ability to continue to provide support should be taken into account and included in assessments. There are separate criteria to decide whether carers needs are eligible.

You will be eligible if...

- The needs arise as a consequence of providing **necessary** care to an adult
- The effect of your needs is that:
 - Your physical or mental health is deteriorating or at risk of deteriorating
 - You are unable to achieve one or more of the outcomes including carrying out caring responsibilities for others, maintaining a habitable home environment, maintaining nutrition, family or personal relationships, work, training or volunteering, recreation or using local facilities or services.
 - **As a consequence there is likely to be a significant impact on your well-being**

If you need support as a carer, it may be provided as support given to you, e.g. direct payments to get a cleaner or support to have a break, e.g. respite.

- ❖ **Remember that many of us have other caring responsibilities as well as supporting our learning disabled son or daughter – make sure you include any other responsibilities in the assessment.**
- ❖ **As parent carers we will often have been providing support for many years...its becomes the 'norm' for us, to the point we don't always mention, or think to mention some of the things we do on a daily basis. Try keeping a diary for a week or two and log everything you have to do to support your relative. Make sure you write everything down to demonstrate the extent of what you do.**

Once an assessment has taken place it will go to a panel of people in the local authority. Senior people, who make the decisions about funding.

- **The panel should not simply refuse to approve proposals put forward by the social worker who has done a detailed assessment of your needs, because of the cost**

Action:

- Request a written response from the panel which details how the council will fulfil its duty to meet the assessed need.
- If the panel's decision feels unjustified, complain

If you believe the local authority have made a mistake and acted unlawfully then you should make a formal complaint

- Ask for a copy of their complaints procedure and make sure you follow it.
- Contact OXFSN and we will advise further

A concern that many family carers have and an argument often used for not providing what is needed is...



The Council have to make savings. There's not enough money to pay for this!"

The fact remains that whether the local authority have the money or not, they have a duty under the law to meet eligible needs. **As families we have a duty to get the right support for our relatives.**

This is what the law says:

Councils must meet the eligible social care needs of disabled and older people as well as those of carers. The duty to meet eligible needs is one that exists regardless of the resource problems a local authority may have.

Although local authorities should review care packages at least once a year, the revised Statutory Guidance stresses that the 'review must not be used as a mechanism to arbitrarily reduce the level of a person's personal budget' (para 13.4).

If, as a result of a reassessment, the support package is reduced or changed in a significant way, then the law requires that the council provides a detailed and convincing explanation as to why this is happening (for example, because the person's condition has improved substantially)

The fact that a local authority has financial problems or is using a Resource Allocation System 2 ('RAS') is not a lawful reason. Eligible needs must be met and the support cannot be cut unless there is convincing evidence as to why the previous support is no longer required.

Because local authorities must meet the eligible needs of disabled and older people (and carers) it is unlawful for authorities to impose arbitrary limits on what they are prepared to pay for care packages. Eligible needs must be met regardless of cost: as the revised Statutory Guidance to the English Care Act explains, a local authority's finances are relevant when it decides how to meet the eligible needs of an individual 'but not whether those needs are met' (para 10.27). The revised Statutory Guidance goes on to stress that authorities 'should not set arbitrary upper limits on the costs [they are] willing to pay to meet needs through certain routes'. (*Luke Clements*)

- ❖ **It's important to understand that the courts have always been sympathetic to the financial pressures facing local authorities and that the Guidance does make clear that the local authorities will have regard to the most cost effective ways of meeting needs - provided of course that needs are still appropriately met.**

More information and individual advice

Organisations:

Disability Law Service – provides telephone or email advice on Community Care law. Free to disabled people and their family carers.

www.dls.org.uk Tel: 020 7791 9800 Email: advice@dls.org.uk

Getting Heard (*formally Oxfordshire Advocacy*): Getting Heard exists to support disadvantaged adults, ensuring their needs are expressed and their voices heard, empowering them to have their rights, views and wishes taken into account in important decisions that affect their lives.

Website: <https://www.gettingheard.org/> E-Mail: office@gettingheard.org

Telephone: 0300 343 5718

Oxfordshire Family Support Network – we are always happy to provide individual advice and support. We can also signpost to other individuals/agencies better placed to support you with specific issues.

Tel: 07891 734987 or email: info@oxfsn.org.uk

Department of Health: Care Act Statutory Guidance: <http://gettingheard.org/wp-content/uploads/2016/04/Care-Support-Statutory-Guidance-Department-of-Health.pdf>

Disclaimer: This guide was written by Gail Hanrahan for Oxfordshire Family Support Network (March 2017) - This information is offered in good faith as an overview and while we have made every effort to ensure the information is correct we advise that you follow up the relevant resources before acting on anything referred to. Neither OXFSN or Gail Hanrahan can accept any liability regarding this information.

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