



How to get the help you need with “activities of daily living”

A woman's short guide to The Care Act (2014)

A WHEC Briefing

Women's Health and Equality Consortium (WHEC) is a partnership of women's charity organisations who share common goals of health and equality for girls and women. Its aims ensure that health policy reflects the real needs of girls and women. WHEC pools the expertise of member organisations to better inform and influence decision-makers and government. WHEC works to improve the sustainability of the women's and girls' health and social care sector, and to strengthen women's and girls' capacity to engage with the health and social care systems.

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Health and social care are areas of public policy, research and understanding which are continually evolving. WHEC develops its resources in response to change and welcomes feedback on this publication, and the topic of women's health in general.

WHEC members: FORWARD, Imkaan, Maternity Action, Positively UK, Rape Crisis (England & Wales), Women's Resource Centre.

www.whec.org.uk

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Who is this guide for?

Women over the age of 18

- who have a physical or mental impairment or an illness which means they need help with activities of daily living.

Or

- who are unpaid carers for friends or family members who need help with Activities of Daily-Living. This includes mothers and other carers of disabled children.

What is The Care Act?

The Care Act (2014) is a new law about the duty of councils (local authorities) in England to help people with “activities of daily living” if they can’t do things for themselves because of illness or disability. It came into force in April 2015.

Activities of Daily Living (ADLs) include things like washing, dressing, eating and going to the toilet. They also include getting out to work, study, pursue a hobby or volunteer; going to the shops or place of worship; or keeping in contact with friends and family and keeping safe from abuse. Help with activities of daily living is often called “adult social care”.

The Care Act tells councils what kind of help they should offer, when that help should be free of charge and when people have to contribute some or all of the cost themselves.

This is a short guide giving an overview. For more information, the government publishes fact sheets about The Care Act. <https://www.gov.uk/government/publications/care-act-2014-part-1-factsheets>.

The Care Act itself can be found at <http://www.legislation.gov.uk/ukpga/2014/23/contents> and the full guidance to Local Authorities at <https://www.gov.uk/guidance/care-and-support-statutory-guidance>

Other useful sources of information are given at the end of this guide.

Why is there a new law?

Before the Care Act there were lots of different laws and regulations about the help councils offered to disabled adults, older people and adults who were ill. The system was too complicated and often unfair. The law and the help offered was often organised around the reason for people needing help, for example “People with Learning Disabilities”. This meant that people who needed the same kind of help but for different reasons got different levels of help. There was also a lot of variation across the country about what help people received, who needed to pay for help and how much they had to pay for it. Also Councils trying to save money were only helping the people who had the most severe problems.

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The Care Act aims to make the system fairer and easier to understand.

The Care Act also tells councils that they have to help people and communities in ways that stop problems from getting worse. It also tells councils that they have to work with the local NHS and GP's, sharing money to fund services that help people whose ill-health stops them looking after themselves. Councils have to assist anyone who covered by the Care Act to find help even if they pay for the help themselves.

Is it working?

Most people agree that the Care Act was needed and that it sets out a good framework for adults to get care and support when they need it. However, the Care Act means Councils have had to make big changes to their systems and ways of working and in some cases to their culture and the attitudes of staff. The implementation of the Care Act came at the same time as "austerity" with the large cuts to the amount of money the Government gives Councils. This has meant that implementing the Care Act has been difficult for Councils and they vary in the changes they have made.

The Government has also delayed implementing a key part of the Care Act; a significant aspect that will put a top limit on the amount of money that anybody would have to pay towards their care.

This guide covers what the Care Act says should happen.

Who can get help?

You can get help if you need help for yourself or if you are an unpaid Carer for a friend or family member.

How do I find out what help is available in my area?

The Care Act says that your local council must make sure information is provided about the help that is available in your area. Most councils have information on their web-site and/or a telephone advice line. Some councils pay another organisation – like the local council for Voluntary Service (CVS) - to provide people with information and advice. Organisations that provide help to particular groups of people can also provide information. For example, Age UK provides information about help available to Older People, and Carer UK provides support and information to carers. Some have trained staff or volunteers who can help you work out what is available and what you need. Some organisations run groups or online forums where you can meet other people in a similar situation to yourself.

The Act also says that councils must make sure there is a range of good quality services available to provide the kind of help people in that district are likely to need. They can do

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this in different ways. For example; by providing services directly, providing services jointly (for example with local NHS organisations), buying services from the Voluntary sector, Social Enterprises (not-for-profit) companies or private (for profit) companies.

If you need assistance finding the right type of help then the council should help you. They should have a range of ways for you to contact them by telephone, e-mail, text, internet video link or sending a letter.

Do I have to go to the Council to get help?

No, you don't have to.

A lot of the assistance that is available to help with "Activities of Daily Living" can be bought directly by you. This might be buying a piece of equipment such as stair lifts or employing a person to help you such as a cleaner or a professional carer.

You can also go to any of the voluntary sector organisations directly and ask if they can help you, for example, to recommend a handy person, or to attend one of their social groups or a meals club.

However, the council should be a good source of advice and information for everyone who needs help with ADL's and you will probably find that some equipment or services are free.

If you can't afford the help you think you need, you can probably get the help more cheaply or for free through the council (See **Will I have to pay for the help I get?**)

I can afford to pay for help. Will the council help me organise the help I need?

Yes, even if you can afford to pay for help they will help you to decide what help you need and help to organise it. For example, you might not feel confident to organise things yourself or feel too exhausted to take on that job at the moment.

Do I have to be really struggling before I can get help?

No! Everyone can get information from the council before things get too bad. For example, if you think getting a stair lift will make a big difference, and that, once it is installed, you won't need any more help for the moment, then you can ask the council for information about how to get a stair lift.

If you are a carer you may feel that if you could have one regular evening free to meet with friends or take part in a hobby then you would feel better in yourself and more able to carry on being a Carer.

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It's worth looking at the council's information online or contacting the council to ask about the kind of help you want! They may make a suggestion you hadn't thought of. Also you may get some of the help you need free or at a subsidised rate.

If you need an aid or adaptation that costs less than £1,000 to buy and install then the council must pay for it (and arrange for it to be installed) – even if you could afford to pay for it yourself.

The council and the local NHS may also have free or subsidised services, for example, community transport, exercise classes, cheap gym membership or meals clubs.

If you are a Carer most councils provide free services so that you can look after yourself as well as help the person you support.

Can the council help everyone who needs it?

No. Councils can't afford to give help to everyone with everything so they have to decide if you are eligible for help from them. The Care Act means that the rules about this are the same in all parts of England.

You can get help from the council if all three things below are true:

- 1) You have a disability or illness

AND

- 2) Your illness or disability means that you can't do **two** (or more) of the things in the list below on your own without too much difficulty.

- Keep yourself well fed and hydrated
- Maintain personal hygiene
- Manage toilet needs
- Dress as you want to and keep your clothes clean
- Get about in your home safely
- Keep on top of housekeeping and home maintenance
- Be in touch with friends and family and make new friends (if you want to)
- Take part in work, training, education or volunteering (if you want to)

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- Get out and about in your community and use services such as public transport and social clubs/activities/exercise classes
- Carrying out any caring responsibilities you have for a child – your own or others you care for regularly (such as grandchildren).

AND

3) Not being able to do those things has a significant impact on your well-being

If all three things apply to you then you are eligible for help from the council.

What is well-being?

The Care Act says that our well-being is a combination of a number of parts of our lives – all of which are important. These are

- Personal dignity
- Physical and mental health and emotional wellbeing
- Protection from abuse and neglect
- Control over our day-to-day life
- Participation in work, education, training or recreation
- Social and economic wellbeing
- Domestic, family and personal relationships
- Having somewhere suitable to live
- Being able to make a contribution to our community/society.

Are the rules the same for people who need help and people who are Carers?

The rules are quite similar.

If you are a Carer you can get help (whether or not the person you are a Carer for gets help) if being a Carer is making your physical or mental health worse

or because being a carer means that you can't do at least **one** of the following things

- look after any children you have responsibilities for
- provide care to any other person
- maintain your home in a fit and proper state
- eat properly and maintain proper nutrition
- maintain and develop your relationships with family and friends
- take part in any education, training, work or volunteering you may wish to
- have time for social activities, hobbies etc.

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How does the council decide if I am eligible for help from them?

The council has to carry out an assessment called a 'needs assessment'.

Everyone has the right to have a 'needs assessment'. You can ask for one yourself or you might be referred by someone else – for example, your GP (they will normally ask for your consent before they make a referral on your behalf). If you don't want a 'needs assessment' you can refuse to have one. That will mean that you can't get help from the council. You can change your mind if you find out later that you do want help from the council.

A 'needs assessment' can take place over the telephone, or in some areas you can fill in a form (a self-assessment) online. If you fill in a form the council will talk with you about what you have said on the form to check if you have explained what help you need and why you need it.

Unless you know exactly what you need, most people recommend that you ask for a face-to-face assessment. This might be with a social worker or a worker from a specialist organisation. If you need help because you are ill then you may have a joint assessment with a social worker and a nurse or an occupational therapist (OT). In some areas social workers, nurses and OT's are all part of the same team.

A face-to-face assessment works best if you need help to manage several parts of your life. It means that you can make sure you fully explain the help you need and why. It also means that you can ask questions!

If you want, you can have someone of your choosing with you during the assessment. If you have difficulty understanding the assessment or in expressing your views you can ask someone (e.g. your partner or Carer) to help. If you haven't got anyone suitable to help you the council must pay for an Independent Advocate to help make sure that the assessor(s) understand what you need help with and why.

What happens next?

If you are eligible for help the council will work with you to make a "care and support plan". This will include all the help you need including help that you are already getting – for example, from a Carer or help that you have organised yourself.

If you are not eligible for help at the moment the council must give you information about local services that might be able to help you get the support you need.

If you disagree with the assessment you can make a complaint through the council's complaint process.

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This is another situation where you might want to ask for help from an Independent Advocate or a specialist organisation that helps people with similar needs to yourself. The organisation who gave you this guide could be a good place to start.

What is a Care and Support plan?

A Care and Support plan lists all the parts of your life where you need help. It states the things you want to achieve by having help. These are called outcomes. For example: 'I want to be able to eat well every day'.

The plan then says how the outcomes are going to be achieved. For example; 'I will go to the local community centre luncheon club on Mondays and Thursdays; a volunteer from the Parkinson's Society will come and take me to the shops on Tuesday and I will buy enough food to cook for two days a week. The council will buy me a microwave and I will have frozen meals delivered and prepare them myself for two other days. On Sundays I will go to my sister's house'.

As you can see, the plan can be quite long (especially if you need help with most parts of your daily life) and the type of help and who provides it can be quite varied. It is important to have an agreement as to how you can get help if part of the plan goes wrong for any reason.

If you are a Carer your plan should specifically cover what happens if an emergency stops you being able to provide help to the person you support.

Will I have to pay for the help I get?

Only if you can afford it.

The Care Act makes rules about who has to pay for help. The money to help people pay for help comes from the Government which comes from taxes paid by companies and individuals.

Most women can't afford to pay for all the help they need. This may be because illness or disability has stopped women from working; or because they worked in the home looking after a young family; or because wages for women have been low compared to those for men. All of these things can mean that, through no fault of their own, many women have not had a chance to build up a pension or other savings.

If you can't afford to pay for help and paying would mean you couldn't afford basics like food or rent, you won't have to pay. This might be because you are on benefits or because you only receive a small pension.

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Paying for help must not take your income below the Minimum Income Guaranteed (MIG).

In 2016 this is £189.00 a week for a single person over pension credit age and £144.30 each for people in a couple. If you are also a carer, your income can be £43.25 higher before you have to make any payments. There are also “premiums” if you are disabled or have a dependent child living with you.

If you are working (for an employer or self-employed) **the income you earn through work** does not count, so if you don't have any other income or savings then **you don't have to pay** for help. This is because going to work is generally good for people's well-being and the Care Act says it is important that people don't stop work so that they can get free help!

If you have savings or capital invested in shares, or get income from shares or savings or a pension fund, or if you own a house (or part of a house) **you will probably have to pay part or all of the cost** of the help you get. The council isn't allowed to charge you more than the help costs but, if you can afford to pay for all of the costs of the help you need, they can also charge you an administrative fee for carrying out the needs assessment or organising the help.

If you only have a small income but have capital invested in a house then you can make an agreement with the council to make a “deferred payment”. This means that the council keeps account of how much you owe them for the help you get and the money is paid to them when your house, or share of a house, is sold. This might be if you choose to go and live somewhere else, perhaps with a relative or supported accommodation, or when you die.

If you are a **carer you may not have to pay** for the help you get directly for yourself. For example, transport to your exercise class. This will vary from council to council. If they can afford it, the person you are helping may have to pay for the help that they get so that you can have a break. For example, the cost of someone who comes to be with the person you care for whilst you are at your exercise class. This will be part of their financial assessment (see **How does the council work out how much money I need to pay?**)

I have worked hard to get some savings. Will I have to spend them all before the council give me any help to pay for the help I get?

A few services that councils provide are **free to everyone**, for example, aids and adaptations that cost under £1,000.

Some types of help are funded by the NHS – like “continuing health care” (CHC) and they are **free** to the people who need them, however much money they have. If you, or someone you care for, needs a lot of help because of ill-health, then the council should help you get a “continuing health Care Assessment”. If you are eligible you will not have to pay for the help you need as it will be paid for by the NHS.

If you have been in hospital and need help to get back to managing your daily life (“**Reablement**”) a minimum of the first 6 weeks of the help you get is also **free**. Some

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people who have been a mental health patient also get free help and support.

You do have to pay anything for help to meet your care and support plan if you have less than £14,250 in savings or capital (and no income from capital).

If you have more than £23,250 in savings or capital, then you have to pay the whole cost of the help you get. Your house does not count as capital if you are still living there.

If you have **between £14,250 and £23,250** then you will be asked to pay **£1 per week for every £250 in capital** you have between the two amounts. For example, if you have £18,250 in savings - £4,000 above the lower capital limit - **you will be charged a maximum of £16 per week** towards the help you need (because £4,000 divided by £250 is 16).

If a person moves to live in a care home on a permanent basis then the value of their house is counted as capital. If they co-own a property then the value will be assessed as being their share of the potential sale of the property. However, if you live in a house you own, and decide to move into a Care Home, the house does not count as capital in your financial assessment if your partner or a child or another dependent adult lives there.

The Care Act says that there should be a limit on what any individual pays towards the costs of their Care and Support plan over their life time. The introduction of the limit has been delayed until 2020. The limit was set at £72,000 in 2016. Some people are worried that the delay means that the limit will never be introduced. The main people that this limit would affect are single/widowed people who own a house that is worth more than £72,000 and who might decide to live in a care home as well as those that might inherit that house.

All of the amounts above are set by regulations. They are correct in June 2016. These can and probably will be changed in the future.

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Will I have to pay for services I need as part of my support plan?

(please note this is a short guide, you will need to ask how the rules apply to your specific situation)

My support plan includes	How much will I have to pay?		I have moved into a care home, does the value of my old house count towards my capital?
Aids and adaptations that cost less than £1,000		Free	No
And/or			
Care and support because of a serious health problem		Continuing health care assessment	Free (paid by NHS/"CHC Funding") No
And/or			
Care and support following discharge from hospital "Reablement"		First six weeks	Free No
And/or			
Other care and support/activities		Have less than £14,250 in savings or capital	Free N/A
		Have between £14,250 and £23,250	£1 per week for every £250 you have more than £14,250 Yes - unless it is also someone else's home and they still live there. If it does count you can make a deferred agreement to pay.

How does the Council work out how much money I need to pay?

Once your care and support plan has been agreed, the council will add up how much it will cost. This is called your "Personal Budget". The person who made the plan with you will probably have to take it to their manager or a panel to get it agreed. You can change how the money is spent later, so long as it still means you achieve the outcomes set in your care and support plan.

The council will carry out a financial assessment.

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If you can easily show that you can't afford to pay for any of the help you get – for example because you already receive means tested benefits OR because you can easily show that you will have to pay for all of the help you get – for example, because you have a shares worth more than £23,250, then the council can carry out a “light touch” assessment. This means they don't have to know the details of your financial arrangements.

If you have some capital – but less than £23,250 the council will carry out a full financial assessment to work out how much you need to pay. This means they will want to know all the details of your income (from all sources), your savings and your capital. You can refuse to be assessed but if you do you will be charged as if you have more than £23,250.

How is the help that I need organised?

The Council can organise the help you need. To start with, a social worker will make sure everything is in place. After that your care and support plan should be reviewed regularly to make sure you are getting the help that you need. It should also be reviewed if you need more or less help than you are getting. You can ask for a review at any time and this should be agreed if your request is “reasonable”.

You can also choose to organise **all OR part** of your help using “Direct Payments”. This is when the cost of your care and support plan is worked out and you are given the money it costs to buy the help you need yourself. You don't have to spend it in the same way the council would, but you do have to spend it on meeting the outcomes set in your care and support plan. Lots of people find that direct payments allow them to be more creative in the type of help they buy and also that they can make changes to their day-to-day plans more easily, for example, arranging for help to go on a day out .

You can use Direct Payments to buy services that the council usually organises such as help getting up in the morning and to bed at night, but you can also buy other things that help you live your life. You can, for example, employ your friend's daughter to support you to attend a web-site design course at the local college or employ a gardener who helps you to do some of the gardening yourself. However, organising lots of help and employing other people can be quite demanding especially if you have not done it before. For example you will need to comply with the law in relation to employment and know what to do about national insurance, income tax and pensions. The council can also offer to provide help with this. You can also ask someone else to manage your direct payment for you, or pay a specialist organisation to do it.

If someone can't understand how to manage a direct payment, another person can do this for them. You might be nominated to do this if you hold Lasting Power of Attorney for finance and property; or the (older) Enduring Power of Attorney; or if you are the person's carer; or if you agree to help a relative or friend by managing their direct payment. The council has to agree that you are a suitable person to do this and will make sure the money is spent on providing help that the person needs.

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I've heard the phrase "person centred". What does it mean?

The Care Act tells councils that they must remember that people have better lives (and accordingly use less assistance services) when they are in control of their day-to-day lives. The Care Act tells councils that the person needing help must be at the centre of, and totally involved in, decisions made about their life. This means that no decisions about what help you need or what kind of help you will or won't get should be made without you being fully involved. This means you should be able to attend any meetings that are about you and the help you need. It means that meetings should be arranged so that you can attend and take part. For example, this may mean that you agree to meetings taking place in your home if it is difficult for you to get out (or if it feels more comfortable) or that there is an interpreter provided if you need one to take part at meetings.

Where someone has difficulty understanding what help they need, what help is available and what they need to do to get it, the council should make sure the person has help to understand and decide what they want to happen. They should also have someone to speak on their behalf if needed. This could be a relative or a friend, or if there is no one supportive to do this, then the council must arrange for an Independent Advocate to help the person decide what help they want and to make their views known.

If the person-in-need has very little understanding, for example, because they are experiencing advanced stages of dementia, then the person who has the registered "lasting power of attorney (LPA) for health and welfare" will be involved in making decisions on the person-in-need's behalf. If the person who needs help has not made an LPA for health and well being then the council must organise for a "best interests decision" to be made. "Best interests decisions" are made by the council, but they must consult with the person-in-need's friends and family about what the person-in-need's views, preferences and interests are/have been.

The law about making decisions for people who can't make their own decisions is covered by The Mental Capacity Act (2005).

What happens if I move?

The Care Act says that if you have a care and support plan set up in one part of England and you are planning to move to a different council area then

- 1) The council where you live should support you to arrange an assessment of need by the council whose area you are moving to
- 2) The council where you are planning to move to must carry out a needs assessment and a financial assessment and tell you in writing if your care and support plan or the amount you will have to pay will change when you move.

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Young Women

If you are under 18 and have a disability or illness that means you need help with activities of daily living the Care Act says that plans should start to be made around the time you are 14 as to what your care and support plan might be when you are 18. You or your parent can ask Adult Services to carry out a needs assessment as you approach your 18th birthday. You should be fully involved in making your care and support plan. Your plan should cover the help you need to plan your next steps. For example the help you need to go to college, get a job, run a business; with having fun and relationships and with choosing where to live and with whom.

If you are a young carer, for example, you do a lot to look after a parent or a sibling then you are entitled to help to make sure you can get to school/college and have time to see friends, pursue hobbies etc. Ask your council for a carers assessment.

What help can I get to stay safe?

The Care Act says that councils have a duty to help people stay safe from abuse or neglect if they can't do this for themselves because of their illness or disability. If you are experiencing any kind of violence or abuse the safeguarding procedures apply. This includes situations where you are being mistreated or neglected by professional carers, situations where you are being harassed (e.g. Hate Crime such as racist or sexist harassment or because you are disabled) and all forms of gender based violence such as female genital mutilation (FGM), forced marriage, sexual assault and domestic abuse.

The "safeguarding" procedures bring the organisations that can help people stop abuse or neglect together to make a "safeguarding plan". The plan is made after "enquiries" which finds out what abuse is happening and what harm it is causing. The plan will be made at a "safeguarding meeting/conference".

If you are experiencing gender based violence you can make direct contact with or ask to be referred to specialist women's organisations that can help. They may offer a telephone help-line for advice and information, individual or group support. Where they are able to, they can come to any meetings about your safeguarding plan to support you and use their expertise to get you the help you need. There may be specialist advocates who can support you. For example, an Independent Domestic Violence Advocate (IDVA) or an Independent Sexual Violence Advocates (ISVA). They will also support you if you choose to go to court to give evidence against the person who abused you. As well as safeguarding meetings there are also special committees that help plan the safety plan for people who are at high risk of Domestic Abuse – Multi-agency Risk assessment conferences (MARAC).

A safeguarding plan is a specific type of care and support plan focusing on safety. The plan will depend on the type of help that is needed. If someone is committing a crime, for example, harassing someone on the grounds of their disability (hate crime), or there is

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domestic abuse from a person's partner or another member of the household, then the police can be involved to use the law to stop the abusive person causing more harm.

If someone is not getting the care that they need because no one in their household or family knows how to look after them (neglect) then the family can get training so they can provide the help needed or extra help can be brought in from outside. If someone might need to be able to get help quickly but can't use a telephone then they might be given a pendant that can be used to call for help.

If a professional carer has been neglectful or abusive or stolen money or possessions there will be an investigation by their employers as to whether they are fit to do the work they do. The police will be involved if there has been a crime. If a care home, or hospital, or other service, is run so badly that people are hurt or neglected, then the Care Quality Commission will be involved to decide if they are fit to run a health and social care organisation.

Help provided by agencies to stop abuse or neglect – such as the police, housing, social services and specialist women's organisations is usually free. This doesn't stop you paying for other help if you want to/can afford to, for example, from a solicitor or for CCTV.

Other information about the Care Act

The Care Act – easy read version Department of Health

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/365345/Making_Sure_the_Care_Act_Works_EASY_READ.pdf

Your guide to care and support – NHS Options <http://www.nhs.uk/Conditions/social-care-and-support-guide/Pages/Care-Act-2014-overview.aspx>

What does the Care Act mean for me? Getting social care support under the new law in England – Factsheet. Independent Age <http://www.independentage.org/factsheets/the-care-act/>

Introduction to the Care Act 2014 Factsheet Age UK http://www.ageuk.org.uk/Documents/EN-GB/Factsheets/FS90_Introduction_to_the_Care_Act_2014_fcs.pdf?dtrk=true

Social care for adults in England. Sense. <https://www.sense.org.uk/content/social-care-adults-england>

Carers Assessment – Carers UK <https://www.carersuk.org/help-and-advice/practical-support/getting-care-and-support/carers-assessment>

Fact sheet: Overview of the Care Act. Skills for Care <http://www.skillsforcare.org.uk/Document-library/Standards/Care-Act/learning-and-development/introduction-and-overview/care-act-overview-fact-sheet.pdf>

Please note this guide is not intended to cover all situations and you should ask your local council about the help they can give you