



Being a Carer and Having a Carer's Assessment

How to get help if you are doing a lot to look after another person

A Resource Pack for People with Learning Disabilities



Mae'r ddogfen hon ar gael yn Gymraeg, ac mewn ieithoedd a fformatau eraill ar gais.
This document is available in Welsh, and in other languages and formats on request.

Being a Carer and Having a Carer's Assessment

How to get help if you are doing a lot to look after another person

This pack is divided into different parts:

Introduction: What is this pack about?

Part 1: Am I a carer?

Part 2: What are my rights?

Part 3: Having a carers assessment

Part 4: What help can I get?

Part 5: Getting ready for my carers' assessment – a form for you to fill in

Part 6: The yellow section is a guide for people who may be helping you to work through the pack

Being a Carer and Having a Carer's Assessment

How to get help if you are doing a lot to look after another person

Introduction



What is this pack about?

This pack is to help people with learning disabilities that do a lot to look after someone else. These people are called '**carers**'.



This pack will help you think more about:

- If you are a carer
- How you might be able to get some help with caring.

A **carers' assessment** can help you get support for you and the person you care for. If you are a carer, you can fill in the form in this pack to help you get ready for a carers' assessment. There is a lot more information about carers' assessments in the pack.

This pack should also help others understand that you might be a carer and what will help you.



Help?

You might find it useful to read this with someone you trust to help you, like a worker, an advocate, a friend or someone from your family.

Sometimes thinking about what you do as a carer can make you feel upset. It might help you to talk about what you read with someone else. They can help you think about how you can use this information to get the help you need.

Important Points

- You can be a carer for someone else and still need help with some things yourself
- Speaking up about being a carer and what would help you is very important
- This pack will help you think about what will help you and how to get that help



Annette – how using carers' assessments helps me help carers

Annette Elliment from Bromley Mencap's Mutual Caring Project has spent a lot of time helping people with learning disabilities who are carers to fill in carers' assessments.

Annette says the carers assessment gave her a starting point for discussing a range of things with people with learning disabilities who are caring; *"it uncovers things you don't realise are happening even if you think you know what's going on at home"*.



Andrew's Story

Andrew (47) lives with his mum who is 78. Andrew says: *"I go shopping with my mum, and help her in and out of the bath, and I put the washing machine on and I do the cleaning. I help her with cooking. I put things in and out of the oven because mum can't see very well now and her knees are bad. When my brother died, I ended up doing everything for mum, because there was only me there. I work two days a week for Pizza Hut and someone from Mencap's Job Watch noticed that I was struggling. She asked me if she could tell Annette [Bromley Mencap's Mutual Caring Project] and I said she could, so Annette got in touch."*



Annette has helped me in lots of ways. She got me a freedom pass and money for caring called the Carer's Allowance. She helped my mum with her benefits and got an OT [Occupational Therapist] who helped us around bathing as I'm not comfy helping mum in the bath – she's so reliant on me. I'm now part of a carer's group and can talk about it with other people who are doing what I'm doing."

PART 1: Am I a carer?



Am I a carer?

Do you spend lots of time every week making sure another person is safe and well?

Yes ☐ No ☐ Sometimes ☐ Not sure ☐

Do you think the person you look after would be able to manage without your help?

Yes ☐ No ☐ Sometimes ☐ Not sure ☐

Do you find it difficult to do the things you want to do because of looking after someone else?

Yes ☐ No ☐ Sometimes ☐ Not sure ☐

If you ticked 'yes' to one or more of these questions, then you are probably a carer.



What is a carer?

A carer is someone who helps another person who would not be able to manage to live at home without help.

If you always spend quite a lot of your time each week helping someone else then you might be a carer.

Carers usually look after people from their family, like their mum or dad, brother or sister. Carers might also look after their husband, wife, partner or a friend.



Most of the time carers live with the person they look after, but not always. For example, some people live near their elderly parents and visit every day to make sure they are not lonely and to help with things like shopping and cleaning.



Carers are not paid for caring, but they might get an extra benefit called **Carers Allowance**. People whose paid job is to look after someone else are called care workers but sometimes people call them carers too. It can be very confusing!

People who are carers might do lots of different things to help. Some people may need lots of help with every day things like getting up, making a meal, taking their pills or using the toilet. Other people might need someone just to help make sure they stay safe or to stop them being lonely and upset.



Sometimes people don't think they are carers. They may feel they are just helping like anyone else would. It is important that people know they are carers because then they should be able to make more choices about:

- if they want to carry on caring
- getting help with caring
- how people support them as carers

Important Point:

Understanding your rights as a carer can help you get the support you need

PART 2: What Are My Rights?



Caring should be a choice.

Carers have the right:

- to ask for help
- to be recognised as a carer
- to work, study and live your own life

To get the right support as a carer, you can ask social services for a **carers' assessment**. This should show what help you need and the best way of getting that help. (There is more about this in [part 3](#) and [part 4](#))

Who can get help?

Even though you have rights as a carer, social services **don't** have to help you unless the carers' assessment shows things are very difficult for you.

Social services decide who they can spend money helping by using something called 'Fair Access to Care Services'. This means they look carefully at your needs (and usually the needs of the person you care for), and decide if the help you need is:



1. Very urgent
2. Urgent
3. Some help is needed but it's not urgent
4. Not much help is needed at the moment

Each area then decides who they have enough money to give a service to. For example, lots of areas don't have much money so they can only help people whose need for help is 'very urgent' or 'urgent'.

Remember

Not everything that can help carers needs to be paid for by social services. A carers' assessment will help you think about what else can help. (There is more about this in [part 3](#) and [part 4](#))



What if I don't want to be a carer any more?

Most people don't choose to become carers – it's something that just happens in their life. You should be able to choose to stop caring or do less caring if you want to.

If you choose to stop being a carer, it does not mean you stop caring about the other person. You still have the right to be part of the person's life for as long as you both want that to happen.

A carers' assessment can help you plan ways to spend less time or stop caring in a way that is best for everyone.



What if the person I care for doesn't want anyone else to help or to know what I do to help?

Even if the person doesn't want anyone to look at their own needs, you still have a right to ask for help. Carers are often in a difficult situation. They can feel trapped between what other people want.

It can also be difficult for workers to work out how best to help you both. They can see that both of you might need help but if one person doesn't want any help then it can be hard to go against their wishes. You can get trapped in the middle and not end up with the help you need.

It is important to talk to the person you care for about this. Try and make them understand you are finding things hard and want some help. Maybe an advocate, close friend or family member could help you talk with the person you care for about what would make things easier for you.



It is important to listen to why the person you care for might not want to talk to other people about the help they need or the help you are giving them. Sometimes people can be scared that if people know how much you are doing to help then you might be split up. This should not happen unless you both feel that this is what you want.



What all carers should expect

All people who are carers can find caring difficult. Carers should expect:

- other people to recognise if they are a carer
- good, useful information that is easy to understand and very clear
- time off or breaks from caring
- help to speak up and take part in things that affect them as a carer
- enough money so they are not poor because of caring
- time to do things they want and stay happy and healthy.

If you are a carer then you have rights. A good **carers' assessment** should help.

Important points

- **You have the right to ask for help as a carer**
- **Social services don't have to give you help but should listen**
- **All carers have the right to make choices about caring**



Richard's Story

Richard is 44 and lives with his partner, Tracey. They have lived together for a long time after they met at day services and went to parties together and realised they wanted to be together. Richard says that Tracey has quite severe learning disabilities and she has some difficulties getting around and needs lots of help with things in her life. Richard also has a learning disability and has difficulties hearing and diabetes. Although they have workers coming in to help at times during the day, Richard is Tracey's main carer, especially since her mum died.

When they started to live together, the services that were helping them both still treated them as if they were two separate people rather than making sure that some of their support was given to them as a couple. Social services didn't understand the help that Richard felt he needed as Tracey's carer. He was getting very tired in the afternoons because of the stress he was under as a carer. Richard got help to make a complaint so that social services would understand that he needed help. Now he has had a carers assessment which helped him explain what he was doing, how it made him feel and the sort of help he needed. After that he got some help to have a holiday. He also got some extra breaks because now a relief carer comes in for a few hours every week. Now Richard has a bit more time to do the things he wants to do and he says; *"at least I am now a bit more relaxed when I'm away from Tracey because I know she's got someone there and she's ok"*



Carol's Story

Carol is 60. She says: *"I look after my mum who's 76 and my dad who's 79. My mum's had a triple bypass and so I have to help with housework. It was difficult when mum was in hospital as I was looking after dad on my own. Dad doesn't do anything to help – he just sits on the chair. He's got dementia and he's diabetic too. I help mum out lots which is hard. Annette [support worker from Bromley Mencap's Mutual Caring Project] and I meet up and talk and she has helped me get pension credit. Things are a bit better for knowing Annette."*

PART 3: Having A Carers Assessment



What is a carers' assessment?

People who are carers might enjoy helping look after someone else, but some things can be very difficult. Sometimes carers don't have time to do things they want to do, like work, meet friends or spend time alone.

A **carers' assessment** could help with this.



The law says social services in your area are responsible for making sure people have carers' assessments. Different places do carers' assessments in different ways. But a carers' assessment should **always** help you to think about:

- what you do as a carer
- what parts of caring you find difficult
- what help and support you want
- what other people can do to help you enjoy your own life too.

A carers' assessment also helps other people know you are a carer. There are lots of people with learning disabilities who don't get help because workers don't know they are caring.

Remember:

A carers' assessment is not a test to see if you are doing a good job as a carer. It's about making sure that you have enough help and support to carry on caring if you want to and are able to.



Can every carer have a carers' assessment?

Every carer can **ask** for a carers' assessment. But your local social services can ask you questions to see how much time you spend caring each week and what sort of things you are doing.

If social services don't think you spend enough time caring then they might not help you get a carers' assessment. If they say 'no', then:

- they should still tell you where to go for more help or advice, like a Carers Centre or Advice Centre
- you could fill in the form in this pack to show them what you do and what you need help with. They might change their minds or find someone else to help you
- you could ask someone you know well to help you speak up about why you think their decision is wrong



Did you know...

Every area should have a leaflet about how to get a carers' assessment. Ask your local social services for a copy of their leaflet. If you don't understand the leaflet, ask for help.



Who do I ask for a carers' assessment

You will need to ask social services for a carers' assessment.

If social services already know you and the person you care for then they might ask you if you want a carers' assessment.



Other people can also help you ask for a carers' assessment. Some of the people who could help you are:

- a doctor or nurse
- your key worker or support worker
- an advocate or friend
- the person you care for
- your circle of support
- anyone else who notices that you are a carer and that you might need some help



Remember

People who ask social services if you can have a carers' assessment should ask you first.

If you say 'no', they might speak to social services anyway. This may be because they are very worried that if you don't have the right help then something bad might happen to you or the person you care for



How long will I have to wait for a carers' assessment?

You might have to wait a long time for a carers' assessment or it might happen very fast. It depends on:

- how urgently you need help
- how busy social services are

Remember

If things are getting more difficult and no one has told you when they can come, get back in touch with social services. Tell them you need help urgently and ask when they can come out.



Who can help me when I have my carers' assessment?

A social worker is usually the person who will help you with a carers' assessment.

Sometimes the person who helps you could be from a carers centre, your key worker or someone else. They should always tell you who they are before they visit.

Remember

You can ask for anyone you like to be with you when you have your carers' assessment. This could be a family member, friend or a worker you trust.



Where and when can I have my carers' assessment?

You should be able to choose where and when you have your carers' assessment.

You might want to have your carers' assessment at home or somewhere you feel safe and comfortable. You need to be able to talk without people listening in if you don't want them to hear you.

You might want to have the carers' assessment away from the person you care for so you can talk about how you really feel about being a carer. Sometimes it can be difficult to be honest in front of the person you care for. You might not want them to know what you find hard and you don't want them to feel guilty because you want some help.

Remember

Talking about the things you may find difficult does not mean you are complaining about the person you care for. It's important to feel safe to talk honestly about how you feel otherwise people can't help you think clearly about how they can help you.



How long will a carers' assessment take

How long a carers' assessment takes depends on each person. Sometimes it could only take an hour or two. Other times it might take a few meetings to get all the information needed.

Remember

The most important thing is to get all the right information in the carers' assessment. No one should rush you.



Can I do anything to get ready for my carers' assessment?

Yes! You can use the form that comes with this pack to think about what you do and the things that could help you.

Get someone you trust to help you fill in the form. Remember to think about your worst days when you fill in the form so that people can see the things you need help with.

Show the form to the person who comes to do the carers' assessment with you. They will find it very helpful.

What will happen during my carers' assessment?



1. You will meet with the person doing the carers assessment and anyone else you ask to be with you.



2. The person doing the carers' assessment will tell you what they will be doing. They will talk with you and ask you questions. They may show you the questions on their form. They will write the things that you tell them down on the form. They might ask you to check they have written things down right.



3. When you have finished talking, everyone should have a very clear idea of what your needs are as a carer. These should be written in a carers plan at the end of your carers' assessment.



The **carers plan** should say:

- what your needs are
- how you could get the help you need
- what needs to happen now
- who will do the things that need to happen



The worker should ask you to sign the form to say you agree with what has been written. Sometimes this is done later after the form has been typed up and given to you to check. You should be sent a copy of your carers' assessment. You might need to ask for a copy.

What happens next?



The worker will take your carers' assessment back to their manager and show them the **carers plan**. They will decide what happens next.

If social services do need to pay for things to help you then they need to go to a panel and ask for the money to pay. They may not always be able to get money to pay for things you need - it depends how urgently you need help.

If there are things that other people can help you with then they will let them know what they can do to help you and the person you care for.

Someone should keep in touch to find out how things are going for you and the person you care for. This is called a **review**.



What if I'm still not happy?

If you are not happy with the way your carers' assessment was done or what happened next, tell the worker who did it or their manager. If this doesn't work then ask how to make a complaint.

You may want to ask someone you trust well to help you talk to social services or help you make a complaint.



Eve's story

Eve is 41 and lives with her husband, Pete. They have been happily married for 3 years. Both Eve and Pete have learning disabilities. Not long before they got married, Eve realised that Pete needed more help than he was getting and although Eve is happy to help him as she loves him, as Eve says; *"I agreed to be his wife but not his carer"*. Over the years it has become harder for Eve to be Pete's carer as she has health difficulties of her own.

At first Eve really struggled to get social services to believe she was a carer with a learning disability and to accept she needed help. Eventually Eve managed to get a carers assessment which showed that she needed to have breaks from Pete so she now gets vouchers for breaks – but only for 2 hours a week. The carers assessment also led to their home being changed so Pete could manage more easily. For example, they now have a walk-in shower – although Eve misses being able to soak in a bubble bath!

Eve has recently had her carers assessment reviewed. She says *"it's really important that people with learning disabilities who are carers do ask for a carers assessment and that other people support them with the right advice and information. It unlocks the gates to the right help!"*



Janet's story

Janet is 60 and lives with her mum. Her father died a year ago. Janet says: *"I do the shopping and housework for my mum. Mum's ok for a little while on her own but she coughs a lot so I need to get her water. Years ago we used to make dresses together and she still does. We get on well. She wouldn't manage without me. We had a carer once for a couple of weeks but we got rid of her because she wasn't doing her job properly. I like feeling like I've done a good job."*

Annette from Bromley Mencap's Mutual Caring Project has been supporting Janet and her mum. Janet felt she needed some breaks from caring to do some things for herself. Annette organised for Janet to start going swimming once a week and to go to Age Concern to help out in one of their shops. Janet loves these activities.



Tony's story

Tony is 69 and he lives with his mum who is 91. Tony says: *"I try to help with hoovering, cleaning and washing. Mum won't let me do the cooking, she's very independent. If she's ill or anything, she doesn't mind but she always tells me how she wants things done. Annette's [Bromley Mencap Mutual Caring Project] done a lot for me. She helped me sort out all my pension credit for being a carer, she got my mum some money from Attendance Allowance. I said to my mum 'if Annette hadn't sorted that out I don't know what we'd have done.' I worry about how my mum is when she is out on her own. I'd rather go with and know she's ok. She's my mum and she looked after me and now I look after her. 50:50 I call it."*

PART 4: What help can I get?



What sort of help could I get?

A carers' assessment can help you work out what you find difficult and what you need help with.

The person who helps you fill in the assessment and other people you trust should be able to help you think of things that would help you as a carer.



Some of the things that might help you are:

- help for the person you care for so you can have some time to do things you want
- help to see if you are getting all the money you should be
- information about what is wrong with the person you care for
- someone to talk to
- pills in a box so you can give them at the right time
- equipment that can help, like a stair lift
- someone to come in to your house and help you with things you find difficult, like cooking or helping someone have a bath
- help with things like gardening and changing light bulbs
- an alarm that gets you help when you press a button





Social services may need to pay for some things that will help you, like someone to help the person you care for get washed or dressed. Even though you may need help, social services may decide that there are other people need help more than you. Some areas can only afford to pay for people who need help the most so you might be disappointed.



Other organisations might be able to help with some things you need. For example, Age Concern might be able to help you look after your garden or you could join a group and meet other people who are carers. Whoever helps you with your carers' assessment should help you find other services that can help with things you need.



You or the person you care for may have to pay for some of the help you get.

Remember

Sometimes things won't change even if you have a carers' assessment. It is still important to have one because at least then people will know you are a carer.



Mo's story

Mo is 56 and lives with her mother who is 84. They live in a very small town in the middle of the country and it's often difficult to get around easily on the buses and there are no trains. Four days a week Mo goes to a day centre which she really enjoys as she's been going there for 25 years and knows everyone very well and enjoys the activities she does.

Five years ago, workers at the day centre noticed that Mo had not been coming as often. Her key worker, Cherrill, spent time talking with Mo and found out that Mo's mum was not well and Mo was missing her day service because she was spending more and more time looking after her. Mo said she wanted to look after mum but that she was missing her friends and finding some parts of caring very difficult.

Mo and Cherrill worked together to fill in a carers assessment form that had pictures and symbols to help Mo understand the questions better. One of the things Mo said was difficult was getting the shopping up the steps because they were very high. She was worried about being safe at home because now she was the person who opened the door and they'd been burgled twice in the past. She also said she wanted to be able to see her friends at the centre and go to church on a Sunday.

After her carers assessment, a plan was agreed with Mo about what would happen next. A handrail was put up by the steep steps which made a big difference for Mo and her mum. People came to help Mo make the house safer. She had a peep hole fitted and window locks and a chain on the door. She went back to the centre as mum started to get a little better, and once a week she goes shopping with her key worker to get the heavy things so she has help to take them home. Another family member comes and sits with mum so that Mo can go back to church.

Mo says *"Not enough people listen. I felt I was struggling until people started to listen to me"*



Pat's story

Pat is nearly 62 and her partner, Roy, is 65. Although they don't live together, Pat and Roy have been a couple for over 30 years. They live close by each other and see each other most days. Pat has a learning disability. Pat does voluntary work on a regular basis, often helping other people understand what it's like to have a learning disability.

Last year, Roy had a stroke and he is now paralysed down his left side. Since then, Roy has paid care workers who come in and help him four times a day for 30 to 45 minutes each time. The rest of the time he is by himself. Pat comes round nearly every evening to help by cooking meals and washing up and generally keeping him company. She also goes round during the day if she's not busy doing her voluntary work.

Once Pat got over the shock and busy time when Roy first had his stroke, she realised that she would be doing a lot of caring for Roy, even though she doesn't live with him all the time. Roy had a package of care sorted out and his social worker recognised Pat as a carer and offered her a carers assessment. At first Pat said 'no' because she was worried Roy may lose some of his services. She talked things through with the social worker and people who she knows and trusts and then changed her mind and agreed to have a carers assessment.

Pat got ready for her carers assessment by going through a form first with someone who knew her well. The form helped Pat understand the amount of caring she was doing. She then went through it with the social worker and her friend stayed with her to help make sure that Pat said everything she wanted to. Some of the things Pat said she struggled with was cooking and cleaning. Hopefully, Roy will get some extra help with that now and they waiting to find out about it.

Pat says: *"it is very important that everyone who is caring for someone has a carers assessment and find out what you're entitled to. Don't be nervous about it – people need to know what you are doing and what you need help with"*

PART 5: Getting Ready for your Carers Assessment



You can fill in this form to help you get ready for your carers' assessment. Fill it in with someone you trust and who will help you if the questions make you feel sad.

Next, show this form to the person who comes to do your carers' assessment with you. It will help them to understand what you do and what would help you.

Make sure you always keep a copy of the form.

It's important to think about how things are on really bad days when you fill this form in so people understand the sort of help you need.



1. About Me

My name is



I live at:

..... Postcode:



My telephone number is: My date of birth is:

I have a learning disability



I look after more than one person





I need help with some things in my life too

Please put a circle round the things that **you** need some help with



Keeping myself clean

Feeling safe

Looking nice

Being healthy

Speaking up

Feeling happy



Cooking meals

Shopping

Doing laundry

Cleaning my home

Looking after the garden

Taking medicines



Filling in forms

Paying bills

Using money

Reading letters

Using the telephone



Using transport

Going to appointments

Other things?

Finding things to do with my time

Meeting up with people



Who helps **you** with the things you need help with?

.....

.....

.....

Is the person who helps you most the same person you care for? Yes ☐ No ☐



Who do **you** talk to about things that are worrying you?

.....

.....

.....

If you don't get the right help you need, someone should look at what will help you. This may be different from the help you may need as a carer.

If the person who helps you most is also the person you care for, they might also need to have a carers' assessment so they get some more help.

The most important thing is that both you and the person you care for have the right help and support that you need.



2. About the person I care for

The name of the person(s) I look after is:

They live with me: Yes ☐ No ☐ Sometimes ☐

If no, where do they live?

The person I look after is my:

Mum ☐ Dad ☐ Brother ☐ Sister ☐ Husband ☐ Wife ☐ Friend ☐ Housemate ☐ Girlfriend ☐

Boyfriend ☐ Grandma ☐ Grandad ☐ Auntie ☐ Uncle ☐ Neighbour ☐

Someone else ☐ Who?

I look after them because: (you can ✓ more than one box if you need to)

☐ they have a learning disability

☐ they are frail

☐ they are ill

☐ they have a physical disability

☐ they can't see or hear very well

☐ they can't manage as well as they used to

☐ they find it difficult to be alone

☐ they have problems with their mental health

☐ something else?

.....

3. Things I do a lot as a carer



I help the person I care for with the shopping

Yes ☐ No ☐ Sometimes ☐ We do this together ☐

What I do

.....

I need help with



I help get meals ready and cooking for the person I care for

Yes ☐ No ☐ Sometimes ☐ We do this together ☐

What I do

.....

I need help with



I do lots of cleaning for the person I care for

Yes ☐ No ☐ Sometimes ☐ We do this together ☐

What I do

.....

I need help with



I do the washing and drying for the person I care for

Yes ☐ No ☐ Sometimes ☐ We do this together ☐

What I do.....

.....

I need help with.....



I help the person I care for get washed, showered or have a bath

Yes ☐ No ☐ Sometimes ☐ We do this together ☐

What I do.....

.....

I need help with.....



I help the person I care for put their clothes on and take them off

Yes ☐ No ☐ Sometimes ☐ We do this together ☐

What I do.....

.....

I need help with.....



I help the person I care for get in and out of bed Yes ☐ No ☐ Sometimes ☐

I wake up to help the person I care for in the night Yes ☐ No ☐ Sometimes ☐

What I do

.....

I need help with



I help the person I care for to take their pills and medicine at the right time

Yes ☐ No ☐ Sometimes ☐ We do this together ☐

What I do

.....

I need help with



I help the person I care for to carry things around Yes ☐ No ☐ Sometimes ☐

What I do

.....

I need help with



I help the person I care for by looking after the house and garden

Yes ☐ No ☐ Sometimes ☐ We do this together ☐

What I do

.....

I need help with



I help the person I care for to keep safe at home

Yes ☐ No ☐ Sometimes ☐ We do this together ☐

What I do

.....

I need help with



I help the person I care for manage their money

Yes ☐ No ☐ Sometimes ☐ We do this together ☐

I help the person I care for pay bills and collect money

Yes ☐ No ☐ Sometimes ☐ We do this together ☐

What I do

.....

I need help with



I help the person I care for to get around outside

Yes ☐ No ☐ Sometimes ☐ We do this together ☐

What I do

.....

I need help with



I help the person I care for to make appointments Yes ☐ No ☐ Sometimes ☐

I help the person I care for talk to people like doctors Yes ☐ No ☐ Sometimes ☐

What I do

.....

I need help with



I help the person I care for when they fall down or are ill

Yes ☐ No ☐ Sometimes ☐

What I do

.....

I need help with



Calling for help

Yes ☐ No ☐ Sometimes ☐

What I do

.....

I need help with



Meeting up with friends and family

Yes ☐ No ☐ Sometimes ☐ We do this together ☐

What I do

.....

I need help with



Helping when the person I care for is feeling upset

Yes ☐ No ☐ Sometimes ☐

What I do

.....

I need help with



Use this page to tell us about anything else you do to help the person you care for.
(For example, collecting benefits, changing the bed, ironing)

4. How I feel about being a carer

People have lots of different feelings about being a carer. People can feel very proud of what they do to help out and knowing that the person they care for is happy, safe and well looked after. But at times carers can also feel very tired and fed up. It is ok to feel like that. This bit of the form helps you think about how you feel about caring and what sort of things would help you.



Things I like about being a carer (Please ✓ the box if you agree with what is written)



I like knowing the person I care for is being looked after properly ☐

I like being able to stay together ☐

I like knowing the person I care for is safe and well ☐

I like other people not taking over ☐

I like learning to do more things myself ☐

I like being able to be a carer ☐

Other things I like about being a carer are:

.....

.....

.....

Things I find difficult about being a carer (Please ✓ the box if you agree with what is written)



- | | |
|--|--------------------------|
| I find it difficult to do everything myself | <input type="checkbox"/> |
| I don't know who to ask for help | <input type="checkbox"/> |
| I often feel lonely | <input type="checkbox"/> |
| I am scared about what might happen in an emergency | <input type="checkbox"/> |
| I don't like helping with personal care | <input type="checkbox"/> |
| I don't like doing things like pills, medicine and injections | <input type="checkbox"/> |
| I don't sleep well at night | <input type="checkbox"/> |
| I don't feel people listen to me or understand I'm a carer | <input type="checkbox"/> |
| My back hurts from helping out | <input type="checkbox"/> |
| I get very stressed and worried | <input type="checkbox"/> |
| Sometimes I feel I can't carry on much longer | <input type="checkbox"/> |
| I worry about what will happen to me when something happens to the person I care for | <input type="checkbox"/> |

Other things I find difficult about being a carer are:

.....

.....

.....

5. Things that would help me and should be part of my **Carers Plan**

In this form you have already said what would help you when you are caring. Here are some more ideas of things that many carers find useful. Tick the box of things that might help you



Please ✓ the box if you agree with what is written



Time off from caring

I want to have regular daytime breaks from caring

☐

I want to be able to go to work or somewhere else

☐

I want to have a social life

☐

I want to have overnight breaks from caring

☐

I want to go on holiday alone or with friends & family

☐

I want to go on holiday with the person I care for

☐

Information – clear and easy to read

I need information about who can help me and how

☐

I need information about what's wrong with the person I care for

☐



Other help

I need help with housing

☐

I need help with money and benefits

☐

I need the right equipment to help me care, like a bath seat

☐

I need help with practical things, like reading the post

☐

I need help getting around with the person I care for

☐

I need someone I can talk to when I am tired or upset

☐

Anything else that could help you as a carer?



My Carer's Plan

Hopefully, this form should have helped you think of some things that might help you as a carer. Fill in this chart to show what help you need now or might need soon.

What needs to happen	I need this now ✓	I might need this soon ✓

The date when we will check what has happened and if things have changed is

What next?

Show this form to the person who is doing your carers assessment.

Tell them they can make a copy.

Ask them to use this form to help make a plan with you about trying to get you the help you need

PART 6: Guidance for people supporting carers with learning disabilities to use this pack

This section is for you if you are a worker, advocate, friend or family member supporting someone to use this pack. The pack has been designed as a resource you can work through to help a person with learning disabilities think about if they are a carer, what they are doing and if there is any support they'd find helpful. This section gives you more information about carers with learning disabilities and using the pack.

People with learning disabilities can be carers too

The number of people with learning disabilities who are becoming carers is growing. People may be caring for elderly parents, husbands, wives, partners, friends or housemates. Like other carers, many people with learning disabilities are happy to care for others and proud of what they are doing as it seems a natural role to take on. However, again like other carers, this does not mean that they do not need some help in the role and that they have been supported to make decisions about the type and amount of caring they are doing.

Some of the key issues for people with learning disabilities who are carers include:

- Generally not being recognised for their role as carers
- Not always being offered many choices about continuing to care or the way that other support is being provided
- Fear from both the person with learning disabilities and the person they care for of being judged and separated if others discover the extent of the care being provided
- Lack of information that is accessible and easy to understand about peoples rights as a carer, support that might be available and the different health conditions that the person they care for may be suffering with
- Lack of practical support with some tasks that might make a big difference, such as with shopping, changing light bulbs, getting to appointments, getting the right benefits, planning and cooking meals
- Feeling very isolated and having reduced opportunities for friendship and breaks.

All of the points above are issues that all carers often struggle with anyway. However, the struggle is even more difficult if a carer has a learning disability.

The difference between 'helping out' and 'caring'

Many people with learning disabilities do a lot to help out at home or with family and friends. However there is a distinction between 'helping out' and 'caring'.

Most people are encouraged to do as much for themselves as possible and we all do things to help with the running of our homes, friends and families. However, when a person becomes a carer, it is likely that the person they care for would not be able to manage to live or cope as independently in the community without their support. Sometimes the support given is clear to see, such as preparing meals, pushing a wheelchair or helping a person with their personal care. At other times caring can be less obvious but no less essential, such as providing emotional support, companionship, making sure someone is safe in their own home and taking their medication.

Sometimes what starts as 'helping out' evolves into caring. It's important to be aware of this and to watch for signs that a situation is changing. For example:

A woman with learning disabilities was known to be living at home with her elderly mum and they were considered a great team – both seen regularly together shopping at the local centre and having a great laugh together. One Monday, a key worker at the daughter's day service noticed that she had brought in sandwiches made with mouldy bread. When she asked about it, the daughter became very distressed and said her mum wouldn't listen to her when she said the bread was mouldy and that she didn't understand why her mum had kept asking her the same questions all the time. The key worker contacted social services and helped the daughter explain what was happening at home in more detail. She was clear that she didn't want to be split up from mum but she did want help to understand what was going on and with practical support at home. A social worker for mum and a separate one for daughter then worked together to put in more support at home for things like cleaning, shopping and taking mum out whilst the daughter was at her day service. The situation was monitored very closely and eventually the daughter became unable to carry on caring at home and helped to choose somewhere for her mum to live that was nearby so she could visit a few times a week.

Making the most of this pack

There is a lot of information in this pack but it has been divided into different parts to try to make it less daunting to people with learning disabilities. Whilst it is not essential to go through every section with them in detail, the information is there if a person wants it and it should help them work out if he or she is a carer and the sort of help they might need. **It is important that you try to read through the pack before using it with a person so you are familiar with what's in it and can pick out the right sections that might help a person with any questions or concerns they might have about being a carer.**

If you aim to complete the form with a person to find out how much care they are providing and what support they need, then try to plan to do it in a place the person feels comfortable and relaxed and able to talk openly.

Although the person being cared for does not have to know what is happening, it may be appropriate to help them understand the importance of looking at the person with learning disabilities' needs as a carer and the process involved. This may need to be handled very sensitively as some people will be worried that they may be separated or forced into making decisions they are not happy with. **It should be stressed that the overall purpose of the process is to provide the help and support needed to both the person being cared for and the carer to enable them to stay as independent as possible for as long as possible.** It is not unusual for there to be *mutual caring* happening, particularly in older families, where both the person with learning disabilities and the older person are looking after each other. In these situations it may be important that both people are encouraged to have both a carers' assessment and an assessment of their individual needs also.

If you are not sure if the person with learning disabilities is a carer then you should start with Part 1 of this pack: '*Am I a carer?*' The three questions posed in the first box may help them understand that they are a carer, that the pack is for them and that completing the form together should be useful.

10 Main Steps for using this pack:

1. Familiarise yourself with the information in the pack. You may need to find out from a social worker whether there are already systems or forms used to support people with learning disabilities who are carers specifically. E.g. Shropshire has a Carers Assessment form specifically designed for carers with learning disabilities
2. Talk to the person with learning disabilities, and where appropriate, the person they are caring for about the pack. Discuss any concerns they may have about the process and any possible repercussions.
3. Check if the person wants anyone else to be with them – like a family member, key worker or advocate
4. Make sure you go through the pack somewhere they feel safe and can talk openly
5. Plan enough time or meetings to go through this information and complete the form without it feeling rushed
6. Go through the 3 key questions in part 1 with the person you are supporting to check if they are a carer
7. Talk with the person and use the pack to answer any questions they may have and to explain the purpose of completing the form together
8. Complete the form. Remember, the first part is to help a person understand their own needs, the second part is about the help they provide as a carer and the third part is about help they need. It is very easy to fall into the trap of thinking about the person's needs as someone with learning disabilities all the time rather than thinking of their needs as a carer
9. Make sure you fill in the Carer's Plan at the end of the form. Help the person think about what needs to happen now and what might need to happen in the future. There will probably be a range of outcomes, from practical support to emotional support from someone remembering to ask if they are ok and how things are at home to pick up on whether their needs are changing
10. Make sure the form is used and followed up on regularly. If you cannot put the actions into place yourself, make sure a copy of the form is passed on to someone who can help, such as a social worker or key worker.

This pack has been produced by:

Valuing People
Support Team

and was written by Dalia Magrill
on behalf of the Mutual Caring Project

**Foundation for People
with Learning Disabilities**

The Mutual Caring Project is supported by



CALOUSTE
GULBENKIAN
FOUNDATION



Lloyds TSB | Foundation for England and Wales

The Valuing People Support Team supports a Network for people with learning disabilities who are carers. We would like to thank members of the Network for all their hard work in putting this pack together.

A big thank you to all the people who have shared their stories and who have tried out the pack to see if it is helpful. In particular thanks go to Andrew Rossey, Annette Elliment and other members of Bromley Mencap's Mutual Caring Project, Eve Rank and Richard West from the 'Who cares for us?' campaign supported by Inspired Services, Maureen Hobley, Cherrill Knott and Flick Pennal from Shropshire and the Older Families Planning Project in Sheffield.

This pack is also available to download from the Valuing People website at **www.valuingpeople.gov.uk** and the Foundation for People with Learning Disabilities website at **www.learningdisabilities.org.uk**

