

# Supporting you as an older family carer

A booklet to support older family carers of people with learning disabilities to get the right support now and to plan for emergencies and the long term



**Part of the Mutual Caring Project**

**Foundation for People  
with Learning Disabilities**

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# Introduction: Why should I read this booklet?

Whether you are a mum, dad, brother, sister, aunt, uncle, grandparent or close family friend, you have probably spent a large part of your life supporting your relative with a learning disability. You have a unique relationship that has grown over many decades together.

This booklet is not going to tell you to change anything before you are ready. It is intended to help you think about things that may help you and the person you care for:

- as you grow older together
- to prepare for any unexpected emergencies
- to prepare for the future.

Many say that the two things they worry about all the time are:

1. What will happen to the person I care for in an emergency?
2. What will happen to the person I care for when I can no longer manage?

This booklet tells you more about options and opportunities, but it cannot tell you exactly what will happen in your situation. However, it should give you a good starting point for finding your own solutions.

And remember, you should not have to do this on your own. Other family members, social workers, support workers and a

host of people can all help with different things. They can look through this book with you, taking note of where you've ticked boxes and made notes, and can help you take things forward from here.

Planning ahead is always the best way forward. The more things you do now to make sure you and the person you care for have the right support now, the more smoothly the future should work out for both of you.

# Part 1: Getting the right support now

You may be managing fine at the moment. But there may be help you haven't thought of, which will help keep you together as a family for as long as you wish. This is up to you, though – nobody can force you to accept help unless they are very concerned that someone is at serious risk.

## How well are you managing now?

This checklist should help you work out if help might be useful. The rest of this section will tell you more about the types of help that may be available in your local area – either now or in the future.

## Checklist

It may feel difficult to admit that some things are no longer easy to manage. Please don't let this stop you filling in the checklist. It might be helpful to talk through your answers with someone you trust, especially since they might be worrying about you already.

	We manage well	Some help may be useful	
Keeping our home clean and tidy	<input type="checkbox"/>	<input type="checkbox"/>	
Doing the laundry	<input type="checkbox"/>	<input type="checkbox"/>	
Shopping	<input type="checkbox"/>	<input type="checkbox"/>	

	We manage well	Some help may be useful
Preparing meals	<input type="checkbox"/>	<input type="checkbox"/>
Washing, bathing and seeing to our personal care	<input type="checkbox"/>	<input type="checkbox"/>
Looking after our home and garden (changing light bulbs, cutting grass, etc)	<input type="checkbox"/>	<input type="checkbox"/>
Moving about indoors	<input type="checkbox"/>	<input type="checkbox"/>
Getting out and about (together and individually)	<input type="checkbox"/>	<input type="checkbox"/>
Medication and medical treatment	<input type="checkbox"/>	<input type="checkbox"/>
Arranging and attending health appointments	<input type="checkbox"/>	<input type="checkbox"/>
Dealing with bills, forms, letters etc	<input type="checkbox"/>	<input type="checkbox"/>
Managing finances, benefits, banking, etc	<input type="checkbox"/>	<input type="checkbox"/>
Staying safe at home and when out	<input type="checkbox"/>	<input type="checkbox"/>
Anything else?	<input type="checkbox"/>	<input type="checkbox"/>

### Help you are entitled to as an older family

A lot of different organisations, from your council and health services to charities like Age Concern/Help the Aged (now Age



UK), Mencap, Crossroads Care and carers' centres can help older families to stay independent for as long as possible.

Your local council, libraries, GP practices, carers' centres and advice centres are all places where you may find leaflets about what is available locally. A lot of organisations have websites and helplines too.

Do you have up to date information about how your council and other local organisations can support older people, people with learning disabilities and carers?  
Yes  No

Would you like someone to help you find out more about what help may be available and how to get it?  
Yes  No

How would you like to receive this information?  
Leaflets  Telephone   
Films  Face to face



## Getting support from your local social services

If you feel you need help now, you can get in touch with your local social services department and ask for help. If you don't feel able to do this yourself, ask someone you trust to do this.

The person who takes your call will usually ask lots of questions. They do this to find out how urgently you need help, and also to check whether another organisation may be able to help you better.

Please make it clear to the person you speak to that you are a carer.



Use the answers from the checklist to help explain what you're finding difficult at the moment.

Would you like someone to help you get in touch with your local social services?    Yes     Not at the moment

After the first call, a social worker will usually get in touch to arrange to come and see you and find out more about what you need. They may call this an assessment. Don't let the word 'assessment' put you off – they are just trying to understand more about what will help you and your family.

They should also offer to do a carer's assessment with you. It is very important that they look at:

- your own needs
- the support you currently provide
- support you may need to carry on caring.

Some families find that they keep being passed between services for older people and services for people with learning disabilities. A local advocacy service, such as a carers' centre or Mencap, can help you through this.

## What sort of support might you get from social services?

Even if your particular council cannot offer you direct support itself, it may well be able to put you in touch with other organisations that can help. Support you may be offered includes:

- a service such as someone to come in regularly to help with tasks like personal care, cooking, cleaning or shopping
- opportunities for you and/or the person you care for to get out of the house more, separately or together
- details of other organisations that can support you
- help with equipment and adaptations
- help with managing your tenancy, finances, and so on.
- a 'direct payment' or your own 'personal budget' to pay for the support you decide will suit you best.

Social services have the right to charge you a contribution towards services they fund. Every area has a different policy, but you should always be offered a financial assessment, to work out whether you will be charged and how much. The financial assessment should also show if there are other benefits you should be receiving.

If the charge is for a service for your relative with a learning disability, the council will be looking at their income and not yours.

## Family teamwork

Many families work together to manage everyday tasks, such as shopping, cooking and housework. And – just as in all families – it's very natural for younger relatives to take on more responsibility over time.

It is very important to many people with learning disabilities that they are able to give back some of the help you've given them unconditionally for all of their lives. Some family carers are amazed at how well the person they care for is able to take on some tasks; they have usually had the opportunity to learn from the best role models and teachers – YOU!

However, sometimes the person you care for may be struggling to do something, or you may feel uncomfortable about them doing it. They may also find it hard to understand why you are not doing things the way you always used to.

If you would find it very difficult to manage on your own without the regular help or presence of the person you care for, then they too may be a carer. There is nothing wrong with this – and you may both be entitled to support that will help you carry on as a family.



The checklist below may help you work out how much the person you care for does to help you, and explain to others about the support you both need.

	Tick here if they help	Tick if you feel they need help coping with this
Shopping	<input type="checkbox"/>	<input type="checkbox"/>
Cooking	<input type="checkbox"/>	<input type="checkbox"/>
Cleaning	<input type="checkbox"/>	<input type="checkbox"/>
Personal care like bathing me	<input type="checkbox"/>	<input type="checkbox"/>
Getting out and about	<input type="checkbox"/>	<input type="checkbox"/>
Being safe on my own in the day	<input type="checkbox"/>	<input type="checkbox"/>
Being safe on my own at night	<input type="checkbox"/>	<input type="checkbox"/>
My medication and treatments	<input type="checkbox"/>	<input type="checkbox"/>
Coping with loneliness and isolation	<input type="checkbox"/>	<input type="checkbox"/>
Other?	<input type="checkbox"/>	<input type="checkbox"/>



## Part 2: Practical support you may find useful

It can be difficult to know what might help you if you don't know what is on offer. Here are some suggestions about what may be available in your area.

Put a tick in the boxes to remind yourself about things you feel would be helpful to you now, and things you'd like more information about.

### Advice and information services

Advice services can usually offer you information, advice and guidance with benefits, housing and similar issues. They often have home visiting services and offer outreach sessions in different languages. They can also write letters and make phone calls on your behalf.



I need help from an advice service now

I would like information about advice services in my local area

### Emergency call buttons and assistive technology

Alarm schemes linked to your telephone are really useful. A pendant or wristband alarm will work in your home or garden. If the alarm button is pressed, alarm service workers either talk to you through a speaker system, or call the emergency services and your contacts if they are unable to get a response from you.

These are also very easy for people with learning disabilities to use.

Other types of alarms can be linked in through your telephone. For example, gas sensors can be fitted that shut off the gas supply if it's accidentally left on or there's a leak, or pressure mats can be put in places that people always use, so that the alarm is raised if no one has used the toilet for a long time.

An alarm like this would be useful now	<input type="checkbox"/>	<input checked="" type="checkbox"/>
I would like information about alarm schemes in my local area	<input type="checkbox"/>	
Assistive technology could be very useful to me now	<input type="checkbox"/>	
I would like information about assistive technology available in my local area	<input type="checkbox"/>	

## Benefits

Many older people are missing out on benefits they should be receiving. Advice centres, your local council or other specialist services in your area could help you do a full benefits check to make sure neither you nor the person you care for is missing out.

A full benefits check would be useful now	<input type="checkbox"/>	<input checked="" type="checkbox"/>
I would like information about who can help me get my benefits checked	<input type="checkbox"/>	

## Equipment and adaptations

Equipment ranging from jar openers and kettle tippers to bath chairs and stair lifts can make a huge difference to how you cope in your home. Specialist shops and catalogues have a wide range to choose from. You might want to talk to an occupational therapist. Their role is to help you work out ways of managing daily tasks with the right equipment. They may even provide some equipment directly.

Similarly, your local council may be able to advise you about adaptations to your property that can help you and your relative manage. Most local councils also work closely with organisations that help people who are older and/or disabled and own their own property to plan and carry out adaptations.

<input checked="" type="checkbox"/>	Advice and information about equipment would be useful now	<input type="checkbox"/>
	Advice about adaptations to our home would be useful now	<input type="checkbox"/>
	I would like information about equipment and adaptation schemes in my local area	<input type="checkbox"/>

## Handyperson, decorating and gardening schemes

Sometimes it can be a struggle to keep up with the simple tasks like changing a light bulb or cutting the grass. Many local areas offer a variety of handyperson, decorating or gardening schemes or can provide tenancy support services to help you.



Help to maintain my house and garden would be useful now



I would like information about handyman, decorating and gardening schemes in my local area

## Home safety checks

Many areas offer home safety and crime prevention schemes to assist older people and disabled people. For instance, they can install smoke alarms, window locks and door chains and deal with potential dangers in your home – such as taping down a fraying carpet that someone might trip over.

I would like someone to carry out a home safety check



I would like more information about home safety and crime prevention schemes in my area

## Lunch clubs, support groups and activities

Most local areas support a network of lunch clubs for older and/or disabled people. They usually provide door to door transport and a fresh hot meal. These and other sorts of support groups are also invaluable for getting out and meeting other people who are in the same position as you.

I would like to be put in touch with relevant groups in my local area now





I would like information about lunch clubs, support groups and social activities that are available in my local area

## Shopping services

Almost all the big supermarket chains now deliver to people who can use the internet to order their goods. Most councils also offer deliveries or other shopping support to people who need it.



I would like to be put in touch with a shopping scheme now

I would like information about shopping schemes available in my local area

## Transport

All older people and disabled people are entitled to concessionary travel, but in many places there are other community transport schemes too. They can include community cars driven by volunteers, dial-a-ride buses and buses that take you to and from hospital appointments. You may have to pay a charge, but these schemes are often invaluable, especially if your local transport is poor.



Help with transport to certain places would be useful now

I would like information about community transport schemes in my local area



The information in this booklet may have started you thinking about the practical support you would find useful – and there are other forms of support out there too. Make a note of anything else with which you and/or the person you care for might need some practical support. Show the list to someone you trust or who helps you now, and they can help you find out more and move things forward.

You may have said that you need help with one or more things in this section. If you have, then you should get in touch with your local council. You could phone the main council number and explain what help you are looking for. They should put you in touch with either a social work team or a service for carers. If you would find this difficult, you could ask a relative, friend or someone who provides support to you or your relative to make a phone call for you.

Notes: 

# Part 3: Preparing for emergencies

“What’s going to happen to the person I care for if something unexpected happens to me?”

One of the biggest worries that most family carers of people with learning disabilities face is what will happen to the person they care for if something unexpected happens to them – whatever age they are.

You have the right to ask for help to make a plan for emergencies.

Carers know that an emergency can be anything from getting home late to sudden illness or worse. When you are making plans to cope with emergencies, there are three time frames:

1. what needs to happen straight away
2. coping for the first two or three days
3. working out what needs to happen if the emergency looks likely to cause longer term difficulty.

You and your relative with a learning disability need a plan that looks at help for one or both of you in case of an emergency. There are lots of things that you, the people close to you and any services you use can do to help you both prepare. This is often compared to putting ‘cushions’ in place: because if you were to fall, the more cushions you have in place, the softer your landing is likely to be!

## A. Cushions that you, your family and friends can put in place to prepare for emergencies

### 1. Phone numbers

- Do you have a clear, up-to-date list of phone numbers: including details of your emergency contacts, next of kin, GP (yours and your relative's), workers in services that know you, and the daytime and out-of-hours numbers for social services?
- Do your emergency contacts know where you keep this list?
- Do your emergency contacts and relevant services have their own copy?

Done it <input type="checkbox"/>	Need to do it <input type="checkbox"/>	I need help with this <input type="checkbox"/>	<input checked="" type="checkbox"/>
Notes:			

## 2. Emergency call button

- Are you and the person you care for registered with an alarm scheme that can offer help 24 hours a day at the press of a button?
- Does the person you care for know how to press the button in an emergency?
- Does the alarm company have up to date information about your emergency contacts and know that you are a carer?

Done it  Need to do it  I need help with this

Notes:



## 3. Emergency key holders

- Does someone have a key to your home?
- Do your emergency contacts know who has a spare key?
- Does the person you care for know where to get a key from if you are not in (if it is safe for them)?

- If you have no-one that you trust to leave a key with, do you have a key safe fitted, which the emergency services and your emergency contacts can use? A key safe is a box you can store a spare key in outside your home.

Done it     Need to do it     I need help with this

Notes:



#### 4. Mobile phone

- Do you carry a mobile phone for use in an emergency?
- Does the person you care for carry a mobile phone and understand how to use it in an emergency?
- Have you put in an ICE (In Case of Emergency) number in your phone contact list so emergency services know who to contact first in an emergency?

Done it     Need to do it     I need help with this

Notes:



### 5. Emergency carer card

- Do you carry an emergency card that shows you are a carer and who to contact in an emergency? (These are available through most councils or carers' centres)
- Does the person you care for carry information about who to contact in an emergency?
- Do your named emergency contacts know you've named them and who the other contacts are?
- Many areas have schemes linked to such cards so that workers can come to your home in an emergency and provide care for up to 72 hours.

Done it  Need to do it  I need help with this

Notes:



### 6. 'Message in a bottle'/fridge scheme

This scheme operates in most areas. If you have a green cross sticker displayed on the inside of your front door, workers from emergency services look for important information in your

fridge! Most councils and older people's organisations can give you bottles.

- Do you have a 'message in a bottle' in your fridge?
- Does your bottle contain important information about you and the person you care for?
- Do you have an extra bottle for the glove box of your car in case you get into an accident?

Done it <input type="checkbox"/>	Need to do it <input type="checkbox"/>	I need help with this <input type="checkbox"/>	<input checked="" type="checkbox"/>
Notes:			

## 7. Information

- Do your emergency contacts know where you keep important information that you or your relative with a learning disability may need in an emergency?

Useful information to keep includes:

- person centred plan

- life story book for the person you care for
- Age Concern LifeBook (see back page for details)
- support plans or care plans
- any regular health care your relative needs (like checking blood sugar levels)
- health action plans
- copy of assessments and carer's assessments.

It is a good idea to keep any information you already have in one place. If your relative isn't able to easily tell other people what they need, it would help them to make sure there is a person centred support and health plan. Your local team for people with learning disabilities should be able to help you with this.

<input checked="" type="checkbox"/>	Done it <input type="checkbox"/>	Need to do it <input type="checkbox"/>	I need help with this <input type="checkbox"/>
Notes:			
			

## 8. Agreeing emergency support

You may have family members or close friends who would be

happy to offer to stay with the person you care for – either in your home or in theirs. If so, you may want to:

- agree clearly between you the length of time for which they are offering support
- sort out what help they may need (for instance, extra hours of support so a person can carry on with their job)
- make sure they know about all necessary medication
- make sure they know how your relative gets access to money in an emergency
- make sure that social services and any other services that your relative uses know about plans.

Done it <input type="checkbox"/>	Need to do it <input type="checkbox"/>	I need help with this <input type="checkbox"/>	<input checked="" type="checkbox"/>
Notes:			

## **B. Cushions that workers and services could help you put into place to prepare for emergencies**

Go through the sections below and tick the boxes to show the things that workers and services have already done, that need doing or that you need help with.

### 1. Everything in section A!

If you are struggling to put the steps in section A into action, workers from social services, health or other organisations such as Age Concern, Mencap and carers' centres may be able to help you, or refer you to someone who can help you further.

<input checked="" type="checkbox"/>	Done it <input type="checkbox"/>	Need to do it <input type="checkbox"/>	I need help with this <input type="checkbox"/>
Notes:			
			

### 2. Making use of overnight short breaks/respice services

If the person you care for already uses an overnight short breaks/respice service, that service may be able to offer short term support in an emergency. Even so, you will probably need to check or make further contingency plans.

<input checked="" type="checkbox"/>	Done it <input type="checkbox"/>	Need to do it <input type="checkbox"/>	I need help with this <input type="checkbox"/>
Notes:			
			

### 3. Support in your home

- If other people already come into your home to support the person you care for, you may be able to get an agreement that they will continue this or extend it – perhaps even to cover 24 hour support in your home for an agreed time.
- If you don't already have this and it seems the best option, it may be possible to make links with agencies and workers now.
- For example, a district nurse might need to come in to help with insulin injections.

A social worker will usually need to get agreement for this to happen. They will usually need to complete a needs assessment and carer's assessment for this to happen and review them regularly.

Done it <input type="checkbox"/>	Need to do it <input type="checkbox"/>	I need help with this <input type="checkbox"/>	<input checked="" type="checkbox"/>
Notes:			

#### 4. Registering your emergency plans

It is very important that services know you, your relative's and other workers' plans and how to get access to these.

- Ask how your family's emergency plans are recorded centrally on whatever systems your council uses.
- Ask for your emergency plans to be covered in annual reviews and during updates of any other assessments.

<input checked="" type="checkbox"/>	Done it <input type="checkbox"/>	Need to do it <input type="checkbox"/>	I need help with this <input type="checkbox"/>
Notes:			
			

You may have other ideas or questions about what might happen in an emergency. Use the space below to write them down so you can discuss them with whoever seems most appropriate for you.

Notes:



# Part 4: Preparing for the future

“I just want some peace of mind that he’ll be all right in the future, when I’m not here to look out for him.”

No-one will ever replace you and no-one will ever look after your relative like you have. That is why you’re the most important person to work with your relative, other family and friends, workers and services to prepare for whatever the future holds. And there are far, far more options these days than there used to be. We are past the days when families were offered institutional care or nothing. All situations are different and you and your family will need to take the approach that suits you all best.

## Why start planning now?

Preparing for the future takes real courage for many of us, whatever our situation. But remember, this is just preparation: nothing has to happen before you are ready. And starting to plan now gives everyone a far greater chance of getting the right solution later. If there is a sudden crisis that means you cannot care for your relative, they will not be left without any support – but it may not be possible to offer the option that suits them best.

It’s really important to involve the person you care for in any planning about their future wherever possible. Indeed, they may also be worrying about it, even if they haven’t raised the issue with you. Other people may find it simply too difficult to cope with thinking of a time when you may no longer be together.



You shouldn't have to do this on your own. The more people who know your relative and whom you can involve in the planning process, the better: including other family members, key workers, social workers, advocates and carer support staff. In fact, it's often particularly useful to learn from other people involved in your relative's life, because they may tell you that away from home your relative acts in a slightly different way, or enjoys things you might not expect.

### **Where to start?**

Don't feel you have to do everything at once or all on your own – it's important to go at the pace that suits you and your family.

Start by reading through the stages below to begin focusing on the steps that you can take now or in the future. Again, it may be a good idea to read this through with someone you feel happy to talk to.

Supporting older families that include a person with a learning disability to plan for the future is a priority for most learning disability services. You may find that your area has some specialist support projects or workers who can help you plan. Often this will be called person centred planning.

## The seven stages of preparing for the future

### Stage 1: Get the support you need now to continue, and make plans for emergencies

It is really hard to be able to think about the future with any confidence if your current situation is difficult, or if you are terrified of what may happen in an emergency.

Use the earlier sections of this booklet to help you and your family get the support you need now and in an emergency. Remember, if you don't feel able to move things forward and have no-one close to help you, why not ask social services, your GP or organisations like Age Concern (now Age UK), Mencap, a carers' centre or advice centre to support you?

### Stage 2: Start talking about the future

This may sound simple, but it often isn't. Some people have no problems discussing their concerns, but others find it very difficult even if they have privately been very worried. It can be particularly hard to talk openly if you suspect someone else will tell you something you don't want to hear – or indeed if you know you will have to say something unwelcome. But getting those conversations going now is the only way you will sort out the future. And indeed, it may be a lot easier than you think, especially talking to your relative with a learning disability. Often people with a learning disability are much more aware of the ups and downs of life than others realise.

There may be other relatives who might be worrying about whether or not they can offer a home to your relative in the future. Make sure they understand that, even if they can't do this, they can play a crucial role in supporting and speaking up for them. In fact, taking on this role is probably the most important thing anyone can do.

Some things that may help you feel comfortable to open up about your hopes and concerns for the future include:

- Showing this book to other members of your family, close friends or someone else you feel comfortable talking to.
- Talking to someone else in a similar situation. Carers' centres, Mencap groups and other organisations are all good places to find support groups.
- If the person you care for, and/or other family members, doesn't feel comfortable talking about this with you, they may still be happy to talk to someone else like a key worker, support worker or an advocate.
- You might also find it useful to bring in someone to talk to the whole group of family and friends involved. It's often a great relief to have someone who can answer your questions and discuss the options available.
- If it's appropriate, ask for copies of the other booklets in this series (one for the person with a learning disability you care for and one aimed at other close family and friends).

Once you've started talking about your overall concerns, you can start working out the important things your relative will

need in the future. They may already have a person centred plan and health action plan. If not, you may want to think about:

- Who is most important in your relative's life and how do they see their involvement in the future?
- What are the things that are most important to your relative?
- How does your relative need to be supported to ensure they are safe, well, happy and able to live a full life?
- What is working really well at the moment? Why?
- What could be improved?
- What sort of support is absolutely essential – for instance, with health needs, or travelling, or money matters?
- What would you all ideally prefer? For instance, would your relative prefer to stay in this house or move?
- What worries you most (for instance, are you worried that your relative will get bored, or lonely, or lose contact with other relatives)?

It's useful to start writing things down at this stage of planning. One way to approach it is by writing each question on a separate piece of paper, and going through each one at different times with different people. However you do it, do keep this information with any other papers you've put together for an emergency!

Once you have talked about these different topics, you are in a much better position to start working out which of the options on offer might suit your relative best.

Done it <input type="checkbox"/>	Need to do it <input type="checkbox"/>	I need help with this <input type="checkbox"/>	<input checked="" type="checkbox"/>
Actions/notes:			

### Stage 3: Sort out some of your own affairs

Many people find it really important to organise their affairs as they grow older, but it can be difficult to know where to start. The good thing is that there is a lot of practical help available. Most organisations for older people, like Age Concern/Help the Aged (Age UK), can offer you face to face advice and support.

You may well find it a good idea to:

- Make sure that the people who are closest to you understand your wishes about how you want to be supported as you grow older
- Make a Will. (Remember: If you wish to leave any money or property to the person with a learning disability you care for, it is particularly important to seek legal advice. Make sure your solicitor has a clear understanding of your relative's needs, and knows about options like discretionary trusts)

- Separate out your finances from the finances of the person you care for so that they can have access to their money in an emergency. If necessary, establish who will take over helping them manage their money and act as appointee
- Arrange who will take over your own decisions about your finances, healthcare and personal welfare if you reach a point where you can't do this for yourself. You will need to seek legal advice about this.
- Arrange and pay for your funeral in advance.

The Age Concern LifeBook is a particularly useful tool, because it brings all the key information together. You can either ask for a copy to be sent to you free of charge, or complete it online and then print it off (details at the back of this booklet). Remember to let your emergency contacts know where it is!

Done it  Need to do it  I need help with this

Actions/notes:





## **Stage 4: Find out about housing and support options for your relative**

When you are thinking about the future, it's important to understand that the term 'independent living' does not mean 'living on your own with no support'. In fact, lots of people with extremely complex support needs who are described as 'living independently' have a 24-hour support package.

Today, most people use the term 'supported living' instead because it's more accurate; but what is important is that the person with a learning disability should get a lot more choice about their housing whatever their support needs are. Housing and support are separate things. The next section looks at options for support.

Housing options for people with learning disabilities include:

- Staying on in the same home
- Buying and owning their own property or a share of their property through a shared ownership scheme
- Their own tenancy
- A joint tenancy with one or more other people
- Supported accommodation (for instance a small group home)
- Private renting
- A registered care home, with or without nursing

- Living with another family in an adult family placement scheme (similar to fostering)
- Extra care housing
- Sheltered living schemes
- Living with other family members or close friends.

Housing Options is a national housing advisory service for people with learning disabilities, their families and supporters: see contact details at the back of this booklet.

<input checked="" type="checkbox"/>	Done it <input type="checkbox"/>	Need to do it <input type="checkbox"/>	I need help with this <input type="checkbox"/>
Actions/notes:			
			

The options for supporting your relative's housing choice include:

- Outreach, floating or domiciliary support: this means people who come in at agreed times such as meal times, night time or to help with personal care. This can include someone who is there all night if necessary



- Live-in support: someone who lives in the same house as your relative, who provides some or all of the necessary support
- Support workers provided by the organisation (such as a housing association) that also provides the housing
- Assistive technology, like alarms if you fall and gas sensors
- Relatives and friends. There are different ways of doing this. If one person takes on full responsibility for providing all the support necessary, they should ask for a carer's assessment to make sure their contribution is formally recognised and they are offered any support they are entitled to.

Often people use a combination. It's good to have enough support in place to cover emergencies.

Support staff might be employed by the council, a housing association or a support service provider. Some people choose to have a direct payment and employ staff themselves. Your relative may have health needs that mean regular help is required from a district nurse, or a nurse may need to give some extra training to support workers.

Your local council, housing associations in your area and local organisations like Mencap should all have information about what is available in your area. One of those organisations may employ a specialist worker who focuses on housing options for people with a learning disability. The services your relative uses at the moment may also be able to go on supporting them in some way later on. And it's also important to talk to other

family carers who have gone through this already – they may have other information and/or ideas, and will be able to tell you about what worked and did not work for them.

Most councils are moving towards personalisation: people who have money allocated to cover their support needs get much more choice over what this money buys. There are different ways of doing this – you or your relative need not manage this money directly. Contact your council to ask for more information about direct payments and personal budgets.

<input checked="" type="checkbox"/>	Done it <input type="checkbox"/>	Need to do it <input type="checkbox"/>	I need help with this <input type="checkbox"/>
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Actions/notes:



### Stage 5: Wait for the time being or carry on?

At this stage, you and your family may decide that you've done a lot already and this is enough for now.

If so, make sure that you've covered everything so far, and dealt with any 'gaps' you spotted.

Even if you don't want to go any further at the moment, it's worth following up on some of the actions this booklet has already recommended: for instance, making sure you've made a Will and that you and your relative have separate finances. You could make sure your relative is registered in their own right with a GP. You could also register on the council and housing association waiting lists if you think your relative may need that kind of accommodation later. You won't have to move anywhere at the moment, but you will start moving up the list.

In terms of day to day living, this is also a good time to offer your relative as many opportunities as possible to learn and practise some of the skills they may need in future, and to get used to people other than you helping them.

You should not have to do things on your own. Ask social services or other organisations that you're in touch with for any help you need.

Actions/notes:



On the other hand, you may decide that the time is right to continue planning towards a move or change.

## **Stage 6: Putting plans into action**

You've already done a lot of the work by this stage, and you and your relative will be pretty clear on what you both want and need in the future.

### **Planning for your relative to stay on in your home**

If the plan is for your relative to stay on in the family home when you are no longer living there, you may need to do one or more of the following:

- If you rent – contact your landlord to ensure your relative has a right to take over the tenancy
- If you own your property - leave your property in trust for your relative to live in
- Approach a housing association that could manage the property for your relative in the future
- Help your relative to get used to accepting other people coming into the home to support them with tasks like cooking and shopping
- Gradually build up the amount of time your relative is happy to spend alone, safely and confidently, if this is appropriate.

If you don't already have social services involved, it's very important to ask for input at this stage. They need to assess your relative's support needs and get agreement for funding that may be needed to support them in the future. This funding

may only be agreed in principle at this stage; this is because it will need to be reconsidered in detail at the point when it is definitely needed.

I want help to start setting this up now



Sometimes social services decide that they cannot afford to pay the full amount of money that's necessary to support a person to live on their own. If this is the case, then at least you will know where you stand, and workers will help you look for alternative options.

## Planning for a move elsewhere

If the plan is for your relative to move to another home in due course, then you have probably already identified the most suitable housing and support options. There are a few things you could do now:

- If you don't have a social worker, now is the time to contact social services for help in putting plans into action. It's also very likely that social services (and possibly health services) will need to assess the cost of the support your relative will need in the future. When you contact social services, make sure they know you are an older family carer, as this can help to speed up your referral
- Contact the housing department of the local council, and/or housing associations, for information about their waiting list and how your relative can get a place to live

- If your relative wants to share with other people, ask social services, specialist housing workers or local organisations like Mencap if they know of anyone suitable. Some areas keep databases that match people up with a view to living together
- If your relative already gets on with specific people who are also looking to move on, you could approach your local housing department and social services together for help to find the group a home and the right support.



I want help to start setting this up now 

Even though you may be ready now, getting a move right can take a long time: sometimes over a year. This can be frustrating, but the most important thing is getting the result – and the support – that will work best for everyone, now and in the future.

### **Stage 7: Making sure things are working out for everyone**

Just because a person has left the family home, it doesn't mean they have left the family. If your relative moves elsewhere, you can still be involved in his or her life.

Make sure you, your relative and their support workers discuss how you'll be involved, and any support either of you need to make this happen. For instance, your relative could visit you at home regularly, and/or phone or email you. They may also want to invite you to tea regularly or continue holidaying with you.

You probably know your relative best, and will be able to tell if they are not happy or if they don't seem to be getting the support they need. However, do bear in mind that some things are bound to be different from the way you did them.

It can be very hard to cope with the new move, especially in the first year. Even though things should be going well, it takes time to get used to the new arrangements. One of the most important steps you can take at this stage is to work hard at building up a good relationship with the people supporting your relative – and they should definitely be doing the same, as you're the expert here. Good communication between you all is essential in order to get the best result for the person with a learning disability.

### **Don't forget about you!**

After a lifetime of caring, it can be very hard to get used to the fact that your relative is no longer at home with you. Probably the only people who will understand the whole mix of emotions are families who have gone through the same thing themselves.

Why not contact your local carers' centre, Mencap or other groups and see if there are any opportunities for you to meet people in similar situations?

I would like help to do this



On a practical level, there may have been lots of things that your relative did to help you out every day (and they may be worrying themselves about how you're going to manage). Now

may be the time to re-visit the first sections of this booklet to think about the help you may find useful yourself as an older person.



I would like help to think about things that may help me now



Notes:



# Useful contacts and resources

The following information gives you national sources of information and support. Some of the organisations below may have local branches in your area. If you do not have access to the internet, ask someone who does to have a look for things for you and print off relevant information.

## Contacts:

### Age Concern and Help the Aged (Age UK)

These two organisations have joined together to form a single charity aimed at improving the lives of older people. At the time of writing they still have separate phone lines. They offer a range of information guides, fact sheets and services.

Age Concern helpline: 0800 00 99 66

Website: [www.ageconcern.org.uk](http://www.ageconcern.org.uk)

Help the Aged telephone: 020 7278 1114

Website: [www.helptheaged.org.uk](http://www.helptheaged.org.uk)

SeniorLine (part of Help the Aged) is able to offer free, impartial and confidential advice on a range of welfare rights issues. It can also signpost people to relevant local or national organisations.

Telephone: 0808 800 6565

## Carers Direct

Carers Direct provides information on a wide range of carers' issues. The confidential Carers Direct information and advice helpline is available if you need help with your caring role and want to talk to someone about what options are available to you. The helpline is open from 8am to 9pm Monday to Friday and from 11am to 4pm at weekends. Calls from UK landlines and some mobile phone networks are free. Helpline advisers have access to Language Line, a telephone translation and interpreting service that has access to more than 100 languages. Helpline advisers can put you in touch with specialist organisations or local sources of help.

Telephone: 0808 802 0202

Email: [carersdirect@nhschoices.nhs.uk](mailto:carersdirect@nhschoices.nhs.uk)

Website: [www.nhs.uk/carersdirect](http://www.nhs.uk/carersdirect)

## Directgov

This government website offers practical and clear information and advice about a range of public services. There are specific sections around caring, disabled people, health, finances and growing older.

Website: [www.direct.gov.uk](http://www.direct.gov.uk)

## Learning Disability Helpline

The Learning Disability Helpline is an advice and information service for people with a learning disability, their families and workers. It is made up of a telephone helpline, community based advisers and the Mencap website. Advice and information is offered about a range of topics and a translation service is offered through Language Line. The helpline is open from 10am to 6pm Monday to Friday and from 10am to 4pm on weekends and bank holidays.

Telephone: 0808 808 1111

## Housing Options

Housing Options is a housing advisory service for people with learning disabilities, their families and their supporters. The Housing Options website is a comprehensive source of information about housing and related issues for people with learning disabilities. There is a range of fact sheets, briefings and other resources on a range of housing options. They also have an Easy Read section of their website with pictures and sound to make them easier for people with a learning disability to understand.

Housing Options helpline: 0845 456 1497

Email: [enquiries@housingoptions.org.uk](mailto:enquiries@housingoptions.org.uk)

Website: [www.housingoptions.org.uk](http://www.housingoptions.org.uk)

## **Respond**

Respond provides emotional support for people with learning disabilities and their support networks. It has a dedicated telephone support line for older families and their supporters.

Telephone: 0207 380 825

## **Resources:**

### **Age Concern LifeBook**

This free booklet helps you organise your affairs to make it easier for you, and anyone who may support you in an emergency. The LifeBook can be ordered from Age Concern by calling 0845 685 1060 and quoting reference ALL 721

### **Carer's Assessments – What's in it for you?**

A guide to help carers of people with learning disabilities understand their right to a carer's assessment, and how it can benefit them and the person they care for. The booklet includes a detailed checklist to use as preparation that will help family carers get the most from their carer's assessment.

You can download it at: [www.learningdisabilities.org.uk/our-work/family-support/mutual-caring](http://www.learningdisabilities.org.uk/our-work/family-support/mutual-caring)

# The Mutual Caring project

The Mutual Caring project was set up to help promote recognition of good practice and develop improved service provision for older families where the balance of the caring relationship between the long-term family carer (often a parent) and the person with learning disabilities (normally an adult son or daughter) has changed. This project aimed to highlight this neglected area and provide evidence of practical approaches that can be used in different settings.

Publications in this series include:



*Mutual Caring* – a DVD containing 4 films: Being a Carer, Carer’s Assessment, Person Centred Planning, and Peer and Group Support. All of these films feature older families where mutual caring is happening.



*Supporting You as an Older Family Carer: A booklet to support older family carers of people with learning disabilities to get the right support now and to plan for emergencies and the long term*



*Supporting You and Your Family as You Grow Older Together: A booklet for people with learning disabilities who live at home with an older family carer*

## The Mutual Caring project



*Supporting You to Support Your Family:* A booklet for family and close friends of older families that include a person with learning disabilities



*Supporting Mutual Caring:* A booklet for workers in services who are supporting older families that include a person with learning disabilities



*Circles of Support and Mutual Caring:* A booklet outlining the use of circles of support with older families that include a person with learning disabilities



*Need 2 Know Mutual Caring:* A briefing note for policy makers, commissioners and services from the Foundation for People with Learning Disabilities



*Being a Carer and Having a Carer's Assessment:* A pack to help people with learning disabilities work out if they are a carer and some of the ways to get help.

This pack was produced by the Valuing People Support Team and written as part of the Mutual Caring Project.

For more information on all these or to receive any of them please visit the Mutual Caring website:

[www.learningdisabilities.org.uk/mutual-caring](http://www.learningdisabilities.org.uk/mutual-caring)

This project has been supported by Lloyds TSB Foundation for England and Wales. We would also like to thank Valuing People and the Calouste Gulbenkian Foundation for the funding for various phases of the Mutual Caring Project.



## About the Foundation for People with Learning Disabilities

We promote the rights, quality of life and opportunities of people with learning disabilities and their families. We do this by working with people with learning disabilities, their families and those who support them to:

- do research and develop projects that promote social inclusion and citizenship
- support local communities and services to include people with learning disabilities
- make practical improvements in services for people with learning disabilities
- spread knowledge and information.

**If you would like to find out more about our work, please contact us:**

Foundation for People with Learning Disabilities  
Sea Containers House  
20 Upper Ground  
London SE1 9QB

Tel      020 7803 1100  
Email    [fpld@fpld.org.uk](mailto:fpld@fpld.org.uk)  
Web      [www.learningdisabilities.org.uk](http://www.learningdisabilities.org.uk)

The Foundation for People with Learning Disabilities is a part of the Mental Health Foundation, registered charity number 801130 (England) & SC 039714 (Scotland).