

# Supporting you to support your family

A booklet for family and close friends of older families that include a person with learning disabilities



Part of the Mutual Caring Project

Foundation for People  
with Learning Disabilities

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# Introduction:

## Why should I read this booklet?

Today, people are living much longer than they used to, including people with learning disabilities. Indeed, many people whose families were told many years ago that they might not live to adulthood are now well into their 50s and over. And as families grow older together, they often need more help. They also need to think about the future.

If you are reading this booklet, you are probably part of an older family: a family in which both the family carer and the person with a learning disability are growing older. The person with a learning disability might be your sister, brother, cousin, niece or nephew – or you may be just a close friend whom everyone considers ‘part of the family’. Whatever your relationship, it’s likely that you have some worries. Even if everyone is managing very well at the moment, you’re probably concerned about what happens in the long term or indeed if there is an emergency now. It can feel really difficult to know what to do for the best.

Some families are able to talk very openly about difficulties they are facing now and their concerns for the future. Others find it much harder, especially if there are different opinions about what might be wanted or needed. Even if it is difficult, it really is important to start talking. You need to think about what is best for your relatives, both the person with a learning disability and the older family carer, and what is best for you too. In fact, it is quite likely that the amount of time and work you put into caring for one or both of these people means that you qualify for consideration as a carer yourself, either now or relatively soon in the future. Carers now have more rights than ever before, and there is a lot of information and support on offer.

It isn’t always easy to start these talks. Raising the issue, and talking about how things may change, can be a real challenge and there are often no easy solutions. However, the more you can do now to ensure that you, the older family carer and the person with a learning disability all get the support you need, the more smoothly the future should work out for all of you. Planning ahead really is the best way forward.

This booklet focuses on getting the right help now, preparing for emergencies and planning for the long term future. There are two other booklets in this ‘Mutual Caring’ series: one aimed at older family carers and the other aimed at people with learning disabilities living at home with older family carers.

# Part 1:


## Getting the right support now

As families age, everyone starts depending on each other a lot more. And broaching the sensitive topic of how well a family is managing can pose a huge challenge. Some people are hugely relieved to get the chance to talk, but others can be upset. It can also be very hard for you to raise the issue if you suspect that you may be asked to take on more responsibility than you can cope with. Altogether, it can feel like walking through a minefield.

But there may be support none of you have known about or thought of, which can help families stay together. Nobody can force your family to accept help – unless someone’s safety and wellbeing are considered to be at serious risk. But some of this support could make a big difference to you and your family and help bring you greater peace of mind about how they are coping.

### How well do you feel your family is managing now?

This checklist should help you think about help that could be useful to you and your family. 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.

		They manage well	I can or do help with this	Extra help may be useful
	Keeping the home clean and tidy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Doing the laundry	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Shopping	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Preparing meals	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Washing, bathing and seeing to personal care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Looking after the house and garden (changing light bulbs, cutting grass, etc)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Moving about indoors	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>



	They manage well	I can or do help with this	Extra help may be useful	<input checked="" type="checkbox"/>
Getting out and about (together and individually)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Medication and medical treatment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Arranging and attending health appointments	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Dealing with bills, forms, letters, etc	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Managing money, benefits, banking, etc	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Staying safe at home and when out and about	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Anything else?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

## Are your relatives looking after each other?

Many of the things in the checklist above may have become shared tasks.

It may well be that the older family carer and the person with a learning disability have developed routines and ways of coping over the years; during this time, the person with a learning disability may have taken on a lot more responsibility. In fact, that 'helping out' may have progressed into 'caring', if they have reached a stage where neither could manage without the other. This is known as 'mutual caring'.

There is nothing wrong with mutual caring and many people with learning disabilities are very proud of the support they provide. It also gives them an opportunity to develop and practise important daily living skills. However, like all carers, anyone who is doing this needs their caring role to be recognised, valued and supported.

Many families worry that, if other people find out how much mutual caring is going on, they will be split up or forced to accept help in a way they don't want. In reality, though, most services want to make sure that families can stay together as long as

they wish and will work with them to find good solutions. The problem is that often the people working in health or social services concentrate on one particular person's needs rather than the complicated way in which different family members help each other and rely on each other.

This is where you can play an extremely important role, because you are someone who can talk to your family members individually and get a real feel for what is happening. You can encourage them to get the help they may need – and can help explain to the people providing that support just how the family operates.

You may also find it difficult to cope with knowing how much mutual caring is happening. Some people have said that it makes them feel guilty to know that their relative with a learning disability has become a carer now. Yet they know that the options for the older person may be far more limited without this support. Others struggle with the dilemma of knowing that their relative may not be in a position to make choices over how much caring they are doing, whilst knowing that they are not able to take on additional responsibility themselves. It can be a real challenge and it's important that you also have support to talk about the situation.

There are two resources that may help you talk to both your older relative and your relative with a learning disability about the care and support they are each giving and what might help them. *Being a carer and having a carer's assessment* is a pack written specifically for people with learning disabilities who are carers. *Carers' Assessments: What's in it for me?* is for any carer of a person with a learning disability. You may also find this useful to read through yourself to help you think about the amount of caring you are involved in and what would help you.



Details of how to get *Being a carer and having a carer's assessment* and *Carers' Assessments: What's in it for me?* can be found in the Useful information section at the end of this booklet.

## Help you and your family could be entitled to

A lot of different organisations, from your council and health services to charities like Age Concern/Help the Aged, Mencap, Crossroads Care and other local services can help older families to stay independent, safe and well supported.

Your local council, libraries, GP practices, carers' centres, advice centres and the internet are all places where you may find information about what is available in the area where your family lives.





## Asking for help

Once you've got the information about what is available, you may well want to ask directly for help. Before you do this, do if at all possible try and discuss this with your family, and get their agreement. If they don't agree but you do feel it's quite urgent, you're obviously in a very difficult position. Don't keep your worries to yourself. Talk it over with the people you trust – and you can also get advice from a local organisation like a carers' centre, or one of the national help lines such as Carers Direct, Learning Disability Helpline or Seniorline. They will definitely understand your dilemma and may have some new suggestions for ways round it.

See the Useful information section at the end of this booklet for information about Carers Direct, Seniorline and the Learning Disability Helpline. All of these national help lines can signpost you to help available in your local area or the area where your family lives.



## Support from social services

If and when you do ask for support, your local social services department is usually the best place to start. 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. If, for any reason, you are making the referral without the knowledge or consent of your family, make sure the person who is taking your referral understands the reasons for this and can help you move forward sensitively.

It is very important to make sure the person taking the referral understands that your referral may be about both the older person and the person with a learning disability - and the fact that either, both or all of you may have needs as carers.

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.



After the initial referral, a social worker or care manager will usually get in touch to arrange to come and see your family (which may include you as well), to find out

## Part 1: Getting the right support now

more about what is needed. They may have to complete assessments of everyone's different needs in order to get a thorough understanding of what will help.

They should also offer carers' assessments at this stage to the family members who are clearly caring: probably the older person and the person with a learning disability, and quite possibly you as well. This will cover:

- the care you provide
- your right to work, learn, train and have opportunities for social and leisure time
- your willingness and ability to continue caring in the same way
- plans for emergencies.

A thorough carer's assessment can be enormously helpful in moving things forward for you and your family. It will also help determine your family's eligibility for funded support from your local council.

Even if your particular council cannot offer your family and 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 family members 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 a tenancy, money, and so on
- 'direct payments' or a 'personal budget' to pay for support. This can often be a very good option, because it can be used flexibly and creatively to suit your particular family. (See Useful information at the end of this booklet for more information about this.)



## Practical support that could be useful to you and your family

Here are some suggestions about what may be available locally. Think about whether your family might find them useful.

Put a tick in the boxes to remind yourself about things you feel it would be helpful to follow up on.		<input checked="" type="checkbox"/>
<p><b>Advice and information services</b> Information, advice and guidance with benefits, housing and similar issues. These services can often provide home visits and/or outreach sessions in different languages.</p>	<input type="checkbox"/>	
<p><b>Emergency call buttons</b> Alarm schemes linked to the telephone through a pendant or wristband. Alarms are linked through to a central base staffed 24 hours a day. Someone answers the alarm call, and can either call the emergency services or send someone to help.</p>	<input type="checkbox"/>	
<p><b>Assistive technology</b> Other types of alarm can be linked in through your telephone: for example, gas sensors to detect leaks, or pressure mats that will alert an alarm if they are not stepped on regularly.</p>	<input type="checkbox"/>	
<p><b>Benefits</b> Many older people are missing out on benefits they should be receiving. You may also be entitled to carer's allowance yourself. Advice centres, your local council or other specialist services could help.</p>	<input type="checkbox"/>	
<p><b>Equipment</b> Equipment ranging from jar openers and kettle tippers to bath chairs and stair lifts can make a huge difference. Specialist shops and catalogues stock a wide range, or an occupational therapist (ask your GP or social services for a referral) could recommend the equipment you would find most useful.</p>	<input type="checkbox"/>	
<p><b>Adaptations</b> Your local council or a specialist organisation like Age Concern may be able to advise you about adaptations to your property that can help your family manage.</p>	<input type="checkbox"/>	
<p><b>Handyperson, decorating and gardening schemes</b> Many local areas have handyperson, decorating and/or gardening schemes.</p>	<input type="checkbox"/>	

	<p><b>Home safety checks</b>                  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 deal with potential dangers in your home</p>	<input type="checkbox"/>
	<p><b>Lunch clubs, support groups and activities</b>                  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 group are also invaluable for getting out and reducing isolation.</p>	<input type="checkbox"/>
	<p><b>Nomad system and prescription delivery</b>                  Most chemists now offer a free prescription delivery service. GP practices can arrange to make sure that repeat prescriptions are picked up automatically, and/or that the medication is organised into the 'Nomad' blister packs, where each dose of medication is in a separate blister and the time to take it is clearly marked.</p>	<input type="checkbox"/>
	<p><b>Shopping services</b>                  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.</p>	<input type="checkbox"/>
	<p><b>Transport</b>                  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.</p>	<input type="checkbox"/>

The list above may have helped you begin to think of practical things that may help your family. Make a note of anything else you might wish to follow up on.



# Part 2:

## Preparing for emergencies

One of the biggest worries for most families is what they will do in an emergency. Often, it's the relatives and friends in your position who find themselves having to keep things going as best they can – and also find themselves torn between the needs of different family members. In fact, you can be the person who is most neglected.

Do make sure that any emergency plans you make do take your own needs into account; you shouldn't be expected to carry it all, with no support. Make it very clear what is and isn't possible for you – particularly to services. For example, if you are able to stay with a relative or have them to stay with you, you can ask for extra support for that person while you are at work.


When you are making plans to cope with emergencies that could happen with the older family you support, there are three main time frames to consider:

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 difficulty looks likely to be more long-term.

### Who can help you prepare for emergencies?


Most carers' support services and organisations like Age Concern/Help the Aged can help you to find out more about what is available locally. So could a social worker or another worker who is already linked in with your family.

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

	<p>Use the information on the following pages to think about the plans you and your family could put in place for emergencies. Put a tick against things you feel could be helpful.</p>
<p>Make sure there is a clear, up to date list of relevant <b>telephone numbers</b>, including the out of hours number for social services and the numbers of any services used. Make sure that everyone who needs a copy of these has one. Don't forget to check that any workers or services have the right numbers for your family's emergency contacts too.</p>	<input type="checkbox"/>
<p>Encourage your family to register with an <b>alarm scheme</b> that can offer help 24 hours a day at the press of a button.</p>	<input type="checkbox"/>
<p>Make sure someone nearby has a <b>spare key</b> for emergencies. If there is no one nearby that your family trusts, a discreet key safe can be fitted for use by emergency services and emergency contacts.</p>	<input type="checkbox"/>
<p>Encourage your family to use a <b>mobile phone</b>. There are some special big button mobiles available with pre-programmed numbers. Don't forget to set an ICE number (In Case of Emergency) in your contacts so that emergency services know whom to contact if necessary.</p>	<input type="checkbox"/>
<p>Find out about <b>emergency carer cards</b> in your area. These fit in a wallet or purse to show a person is a carer and who to contact in an emergency. (Your local carers' centre or council may run a scheme).</p>	<input type="checkbox"/>
<p>The '<b>Message in a bottle</b>'/<b>fridge scheme</b> operates in most areas. If you have a green cross sticker displayed on the inside of your front door, workers from emergency services look in your fridge for a container with important information about the people living in the house. Most councils and older people's organisations can give you bottles.</p>	<input type="checkbox"/>
<p>Encourage your family to put together all the important <b>information</b> about each person, such as details of health conditions, support plans, person centred plans and health action plans. This information needs to be put in one place, which you and other emergency contacts know about. <i>This is a priority. There may be local workers and services who can help your family collect this information together if it is not easily available. Information must also be kept up to date.</i></p>	<input type="checkbox"/>

<p>Discuss and agree any <b>emergency support</b> you or others are able to give. For example, there may be neighbours happy to help out initially for a few hours, or you may be happy to stay with your relative or have them to stay with you for a certain amount of time. Be realistic, though – see the points above.</p>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
<p>If the person you care for already uses an <b>overnight short breaks/ respite service</b>, 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.</p>	<input type="checkbox"/>	
<p>If paid staff already provide <b>support in the home</b>, they may agree to extend this in an emergency - perhaps even 24 hour support for an agreed time. If you all feel this could be the best option, a social worker will usually need to complete needs assessments and carers' assessments.</p>	<input type="checkbox"/>	
<p>Keep <b>everyone informed</b>, and if possible register your emergency plans with social services too – each area has different systems for recording emergency plans.</p>	<input type="checkbox"/>	
<p>Keep your <b>plans up to date</b>. Review them regularly – there is no point in having a plan if some of the arrangements have changed, and you won't have time to do this in an emergency!</p>	<input type="checkbox"/>	

You may have other ideas or questions about what might happen in an emergency. Use the box below to make a note of these so you can discuss them with whoever seems most appropriate for you.



# Part 3:

## Planning for the future

You have almost certainly had concerns about the future for a very long time: especially about what will happen to your relative who has a learning disability. You are probably also worried about the older family carer. It can often feel like a bit of a balancing act – particularly because if one person has a crisis it will immediately affect the others.

You may have discussed the situation openly, or it may just be too hard to talk about. Even if you have made plans, everyone's circumstances may have changed. You may have committed yourself to things that you're not sure about now. The older family carer who asked you to take on caring responsibilities may be worried that you've got too much on your plate already, but that you're also the only person who will look after your relative properly.

There are no easy answers to what will happen in the future. Yet there are options – very probably more options than you've realised. Many older families aren't up to date about what is available in terms of housing and support, and have only seen the scare stories about what can go wrong. They may also be misled by the term 'independent living', which suggests that their relative will be left alone without any help if they don't stay with someone in the family. In reality, 'independent living' means living outside the family home but with support. This includes people who need 24 hour support with every aspect of their personal, health and social care needs. Things can still go wrong, obviously, but there is a lot to celebrate too. Today, people with learning disabilities can have far more control and choice over their lives than they ever did before. And whether or not your relative with a learning disability lives with you in the future, you can still easily play a key role in their lives.

### Why start planning now?

Most of us, whatever our situation, don't like confronting the prospect of what's going to happen in the future. But remember, this is just preparation: nothing has to happen before people are ready. Starting to plan now gives everyone a far greater chance of getting the right solution later. In a sudden emergency, your family should not be left without any support – but it may not be possible to offer the option that suits them best.





## 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 information below about the steps that can be taken now or in the future.

Please remember that you don't have to do this alone. If it is too sensitive a topic to raise with your family now and you don't have anyone you feel you can talk to openly, why not approach a local organisation like a carers' centre or local Mencap, or contact one of the national help lines and websites detailed at the back of this booklet? You may find that your area has some specialist support projects or workers who can help you plan. Often this will be referred to as person centred planning.



## Talking openly about the future

It's often as hard – or harder – to talk about the future as it is to talk about how everyone is managing at the moment. It can be particularly difficult 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 it may also be a lot easier than you think, especially talking to your relative with a learning disability. Often people with learning disabilities are much more aware of the ups and downs of life than others realise.

## Supporting your older relative in planning for the future

There are lots of practical things which are useful to sort out. Most organisations for older people, like Age Concern/Help the Aged, can offer lots of face to face advice and support.

- Talk to your relative about how they want to be supported as they grow older.
- Encourage them to make a Will. This is particularly important if they intend to

leave any money or property to the person with a learning disability, because they need to make sure that this doesn't affect their benefits and/or isn't all used on care costs. Make sure that they use a solicitor who understands options such as discretionary trusts.

- If your older relative intends to make you and others trustees for any property or money in the future, try to clarify how they want the trust to be used to benefit the person with a learning disability. It's also a good idea to find out what being a trustee involves, and any help you can get with this.
- Encourage them to separate their finances from that of the person with a learning disability. Separate bank accounts mean that your relative with a learning disability can get hold of their money independently in an emergency and there aren't problems in the long term. It's also useful to discuss who may take over helping with money management and appointeeship for the person with a learning disability: your local social services should be able to tell you about appointeeship services in your area.
- Talk about who may take over making decisions about your older relative's money, healthcare and personal welfare if they reach a point where they can't do this for themselves. You will need to seek legal advice about this.
- Talk about any wishes and plans they have got for their funeral. It may be upsetting, but many older people appreciate knowing that the people who care most about them will give them the send-off they want. There are also schemes where people can arrange and pay for their funeral in advance so they can get things exactly how they want.



The *Age Concern LifeBook* is a particularly useful tool, because it helps guide people through the process of putting their affairs in order and making sure people in your position know all the key information that may be needed in the future. The booklets are sent out free or can be completed securely on-line. Details of how to get hold of a copy are at the back of this booklet.

### Supporting your relative with a learning disability in planning for the future

These are some of the most important questions to think about when planning for the future with your relative with a learning disability:



- Which people are most important in your relative's life, and how do those special people see their role 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, healthy, happy and able to live a full life?
- What is working really well at the moment? Why? Is there anything that must not be changed?
- What could be improved?
- What sort of support is absolutely essential – for instance, with health needs, 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 all most? (For instance, are you worried that your relative will become isolated or bored, or lose contact with other family?)

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 all in a much better position to start looking into different options that might suit a person best.

### Circles of support

One of the things that friends and family worry about most is the question of who will support your relative with a learning disability in speaking up and getting heard, when their main carer is no longer able to do so. Who's going to notice if they aren't happy or if they need new clothes or more things to do? The most reassuring thing you can do is let your family know that there will always be someone filling this advocacy role. That person may well be you. Whoever it is, however, they don't have to do it on their own.

Circles of support are groups of family, friends and supportive workers who come together to give a person support and friendship. They are a way of providing person centred support, because they help the person do the things they would like to do and achieve new things in their life. Circle members usually become a great source of support for each other too.

It's a good idea to get a circle going sooner rather than later, and most people find it a huge relief knowing that this circle is already in place for difficult times that may follow. (See the back of this booklet for more information about circles of support).



It may help you to involve other people your family members have a good relationship with in discussions about the future. People like key workers from services often have a different perspective they can bring that is really useful. There may also be projects and workers in your local area whose job is to support individuals and their families to make and implement plans around how they want their life to be.

### Finding out about housing and support options

Housing options for people with learning disabilities can include a person staying in their own homes, buying their own home, sharing a tenancy with others, privately renting their own home, living in registered care, living in sheltered schemes or living with family. When you're working out what would suit your relative best, it's important to keep a distinction in your mind between where they live and the support they need. Even if they need 24 hour support, they may well have more choices than you initially expected.

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, and they may well not need to manage this money directly. Ask your council for more information and see details of In Control at the back of this booklet.

Your local council, housing associations and local organisations like Mencap should all have information about what is available in your area. If you're lucky, one of those organisations may employ a specialist worker who focuses on housing options for people with learning disabilities. The services your relative uses at the moment may also be able to go on supporting them in some way later on and can also start helping them to develop their daily living skills.

The support options 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.

These are not the only possibilities, and many people use a combination. It's good to have enough support in place to cover emergencies.

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.



### Pausing... or putting plans into action

Some families start finding out more about long term options and feel the time is right to move forward on changes. Others may feel differently.

Even if you and your family don't feel the time is right for major changes, following some of the tips from this booklet should prepare you all better for the time when it does feel right to plan further. In terms of day to day living, this is also a good time to encourage the person with a learning disability you support to start taking small steps towards learning and practising some of the skills they may need in future, and to get used to other people helping them.

In the same way, if you know that eventually your relative with a learning disability will be living in another place, it may be a good idea to contact the housing department of the local council, and/or housing associations, for information about their waiting lists. Putting a name on the list doesn't commit anyone to anything, but it may cut the waiting time down if and when your relative does want to move.

When you do start moving on, it's important to cover some basic points.

### a. If your relative is planning to stay on in the family home

- If the property is rented, contact the landlord to ensure your relative has a right to take over the tenancy.
- If the property is owned, make sure it is left in trust for your relative to live in.
- If the property is to be left in trust, approach potential trustees or an existing housing association who could manage the property for them.
- 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.



Sometimes social services decide that they cannot afford to pay the full amount of money that is needed 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.

### b. If your relative is planning to move elsewhere

- If your relative doesn't have a social worker, contact social services for help in putting the plans into action. It is also very likely that social services will need to assess the cost of the support your relative will need in the future.
- If you haven't done so already, contact the housing department of the local council, and/or housing associations, for information about their waiting lists and how your relative can get a property.
- 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.



- You can also use private landlords and estate agents to help you.

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.

### **After a move**

Just because a person has left the family home, it doesn't mean they have left the family. If your relative moves elsewhere, you and your family should still be involved in his or her life (if you and they want this). This time of transition and everyone getting used to change is a particularly important time for your family members to be supported to speak up about how things are going. A circle of support can be useful as members can help ensure good communication between everyone and help all your family adjust to change.

Whilst there are bound to be some teething problems, people can often surprise you with how well they settle into new routines and ways of doing things. This can feel like a mixed blessing to many older family carers: they are happy a person is settling, but they can feel they themselves are being left behind now or even that they have hampered their relative's progress in some way. These feelings can cause great distress and depression in some people and it's important to recognise and address them. Sometimes other family carers who have been through the same process can be the best people to talk to and there may be local carers' support groups you can encourage them to join, or counselling offered by local services to carers and people coping with a loss.

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

However much you are supporting your family members, you need to remember to look after yourself too. It's really important to make sure you have people you can talk to openly and people who can support you with your own responsibilities in a family emergency. Above all, you should feel you can make choices in your own life. You are not alone. There are a lot of people in your position who understand both the complexities of your life and the great joy of being part of a family that includes a person with a learning disability.

# Useful information

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.

## Organisations and contacts

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

These two organisations have joined together to form a single charity aimed at improving the lives of older people. Both organisations offer a range of information guides, fact sheets and services.

Age Concern Free helpline: 0800 00 99 66 Website: [www.ageconcern.org.uk](http://www.ageconcern.org.uk)  
Help the Aged Telephone: 020 7278 1114 1 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. It is open from Monday to Friday from 9am to 4pm

Telephone: 0808 800 6565

### Carers Direct

Carers Direct provides information on a wide range of carers' issues. The confidential 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)



## Directgov

This government website offers practical and clear information and advice about a range of public services. There are specific sections about 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 learning disabilities, 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. The website also has an Easy Read section with pictures and sound.

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.

Helpline: 020 7380 825

## Sibs

Sibs is the UK charity for people who grow up with a disabled brother or sister, providing siblings with information and support, and influencing service provision for siblings throughout the UK.

Telephone: 01535 645453

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

## In Control

The In Control website can help you understand more about self-directed support, the system where people are more in control of the support they need to live their lives as they choose. This system of 'personalisation' is being brought into local authorities across the country and offers greater opportunities to older people, people with learning disabilities and carers to get their support needs met in a more joined up, flexible way. The website can signpost you to clear, easy to use, information.

Website: [www.in-control.org.uk](http://www.in-control.org.uk)

## Family Carer Support Service (FCSS)

Hft's Family Carer Support Service provides free telephone and email support, workshop courses and written information to family carers who have a relative with a learning disability. FCSS, run by a team of family carers and experienced family support staff, has been supporting family carers living anywhere in England since 1993.

Telephone: 0117 9061751

Email: [familycarersupport@hft.org.uk](mailto:familycarersupport@hft.org.uk)

## Circles of support

Circles of support are groups of family, friends and supportive workers who come together to give support and friendship to a person and to promote their empowerment and inclusion. Get more information about circles from either of the following websites:

Foundation for People with Learning Disabilities: [www.learningdisabilities.org.uk](http://www.learningdisabilities.org.uk)

Circles Network: [www.circlesnetwork.org.uk](http://www.circlesnetwork.org.uk)

## Publications

### 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.

Download a copy from: [www.learningdisabilities.org.uk](http://www.learningdisabilities.org.uk)

# 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



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



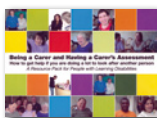
*Supporting Mutual Caring*: A booklet for workers in services who are supporting older families that include a person with learning disabilities



*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 a learning disability 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 or to receive any of the above please visit the Mutual Caring website [www.learningdisabilities.org.uk/mutual-caring](http://www.learningdisabilities.org.uk/mutual-caring)

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## 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:**

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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)

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