

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



Part of the Mutual Caring Project

**Foundation for People
with Learning Disabilities**

Acknowledgements

The Mutual Caring project helped to promote the recognition of good practice and provide the guidance in supporting older families where a person with learning disabilities is providing regular and substantial care to their elderly relative who is also their carer.

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Contents

Why should I read this booklet?_____	1
Part 1: Getting the right help now_____	4
Part 2: Getting ready for emergencies_____	15
Part 3: Getting ready for the future_____	22
Useful information and contacts_____	28
The Mutual Caring project_____	29

Why should I read this booklet?



If you live at home with an older person who looks after you, then this booklet is for you. Perhaps you look after them too.

The person you live with may be your mum, dad, brother, sister, aunty, grandma or someone else. You have probably lived with them for most of your life. These people are called 'family carers'.

Lots of people are very happy living with their family. But as you and your family get older, things might get more difficult for you both.



Lots of people worry about telling other people that they are finding it hard to do some things. They worry that someone will interfere and maybe even stop them living together.

But this should not happen, so please don't worry about telling other people that you need some help. If they understand about what you are both doing and things you find hard, they should be able to get you the help you need. And that will mean it is much easier for you all to stay together.

Why should I read this booklet?



This booklet is not about making you move or stopping you from being with your family.

It is about the things that can help you all live together now. It also talks about some of the things that you can do to prepare for an emergency, and about other changes that you may want to think about.



- People should help you and your family carer if things are difficult at home.

How to use this booklet

This booklet tells you more about:

- Good questions to ask
- Things that can help you now and in the future
- Some of the people who can help you.



There are boxes for you to tick and write in to show what will help you.

Ask someone you trust to go through the booklet with you. They can talk with you about it and help you get support you might need.



- This booklet is for people who live with older families.
- It's about getting the right help now and in future.
- Ask someone you trust to help you go through it.

Part 1:

Getting the right help now



Some older people can keep doing the things they have always done, like cooking, cleaning, driving a car and filling in forms. But other older people find these things difficult.

Sometimes it gets harder for them to do things for themselves, like get in and out of the bath. Or they may start forgetting things and asking lots of questions over and over again.

It's often difficult to notice when a person starts finding something more difficult. Many families change the way they do things, so that everyone can manage. For instance, you might do more of the shopping now, or you might help your mum or dad have a bath.



Even though you and your family are getting older, you may still be managing together very well at the moment.

You may feel nothing needs to change.

But you may feel that you need some extra help now, if you are doing lots more to help your family.



Or you may feel that you are OK now, but you might need some help soon.

It's important to think about what might help you and your family as you get older. Getting the right help now can help you stay together for longer. It can also help you all cope better if something unexpected happens.



- It can get harder for people to do everything they used to do as they get older.
- The right help can help older families stay together longer.

Are you looking after each other?


Older families make great teams. They have found ways of doing things together. But some of those things may be getting hard to manage.

Do you do lots to help the person you live with?

Yes ☐ No ☐ Sometimes ☐

Do you think your relative would be OK if you didn't help?

Yes ☐ No ☐ Some of the time ☐



Perhaps you do a lot to help out at home, and to help the person who is your family carer. If they need your help with lots

of things, you may be a carer too. This is called mutual caring. 'Mutual' means shared, because you are both caring for each other.

There is nothing wrong with this. Lots of older families are very proud of the help they give each other. But lots of carers do need a bit of help. They may need help with doing things, or they may need someone to talk to. They may want to find out more about what help they could get, or they may just need a break from caring.

There is another pack called *Being a carer and having a carer's assessment* that can help you think more about your role as a carer. The back of this booklet tells you how to get a copy.



- You and your older family carer might be looking after each other. This is called mutual caring.
- You can have help as a carer too.

What do we need help with?



Do you need help with the things you do every day?

Tick the boxes on the next page to show how well you feel you are managing.



Do you need help with the things you do every day?	 We manage well	 We need help	
 Keeping our home tidy and clean	<input type="checkbox"/>	<input type="checkbox"/>	
 Washing our clothes	<input type="checkbox"/>	<input type="checkbox"/>	
 Cooking meals	<input type="checkbox"/>	<input type="checkbox"/>	
 Getting washed and dressed	<input type="checkbox"/>	<input type="checkbox"/>	
 Getting medicines	<input type="checkbox"/>	<input type="checkbox"/>	
 Taking medicines	<input type="checkbox"/>	<input type="checkbox"/>	
 Reading letters and filling in forms	<input type="checkbox"/>	<input type="checkbox"/>	
 Getting money	<input type="checkbox"/>	<input type="checkbox"/>	
 Paying bills	<input type="checkbox"/>	<input type="checkbox"/>	
 Getting out to see family and friends	<input type="checkbox"/>	<input type="checkbox"/>	
 Going to appointments	<input type="checkbox"/>	<input type="checkbox"/>	
 Feeling safe at home	<input type="checkbox"/>	<input type="checkbox"/>	
 Keeping busy and active	<input type="checkbox"/>	<input type="checkbox"/>	



Anything else:



Your answers will help show other people how they might be able to help you and the person you live with.

What if I think we need help but the the person I live with does not agree?



Lots of families disagree about how much help they need. The person you live with may not have realised that you have been finding it hard to do things or that you are worried. Or you might be surprised at what they say.

But you do need to talk to each other about this, because if you need help your problems will not go away. And if you get help, it will help you all a lot.

If you are worried about talking about this, you could get someone else that you both trust to come and be with both of you when you discuss it. That could be someone else from your family, or it could be someone like a support worker.



- You and the person you live with might not agree straight away about what would help you both.



- Someone you both trust could help you agree about help that is needed.

What sort of help could we have?

There are lots of ways you and your family could get a bit more help now.



Tick the boxes below if you would like to find out more



Advice service: someone to help you sort out your money, write letters and get hold of the right people when you have problems.

☐


Alarms linked to your telephone: if you or your family carer falls, is ill or scared, you can get help by pressing a button.


















☐






Money: you may not be getting all the money you should. There are lots of people who can help you find out what money you should be getting and how to get it.

☐


Equipment: things like special chairs in the bath, or rails along the stairs. These could make it easier for you and your relative to cope at home.

☐

	 <p>Handyperson: someone to help with little jobs around the house like changing light bulbs and decorating.</p>	
	 <p>Help at home: someone to come to your home to help with things like cleaning, cooking and personal care.</p>	
	 <p>Help to keep healthy: your doctor or nurse could talk to you about healthy eating and exercise. They could tell you about looking after your nails and feet. They can give you a regular health check.</p>	
	 <p>Gardening: someone to help cut the grass and make sure your garden is kept tidy.</p>	
	 <p>Safety checks: someone to come to your home and make sure you have smoke alarms, a chain on your door and other things so that you feel safe at home.</p>	
	 <p>Lunch clubs: these are a good way of getting out, meeting other people locally and enjoying a fresh hot meal.</p>	
	 <p>Hospital appointment support: help taking you to hospital appointments.</p>	
	 <p>Social, sports and leisure activities: things you can do either on your own or together.</p>	

	Transport: help to get out and about to different places near where you live.	<input type="checkbox"/>	
	Shopping: help with going shopping. Or you can get your shopping delivered to you at home.	<input type="checkbox"/>	
	Pills and medicine deliveries: your doctor or chemist can help get any medicine you need delivered to you at home.	<input type="checkbox"/>	

Are there other things you need to find out too? For instance, do you need to know more about a health problem? Or do you want to find out how to get more help from a social worker?

The person helping you with this booklet could help you find out more about how to get the help you need.



- There are lots of ways you and your family could get the help you need.

Who can help us?

There are lots of people who could help you and the person you live with to get help, including:

- other people in your family
- close friends

- neighbours
- your doctor or nurse
- a social worker
- a support worker or key worker
- someone you talk to at activities you attend.



Some people can help you themselves. Other people can help you get in touch with the right person or service.

You might want a circle of support. Circles of support are groups of family, friends and supportive people you know. You could get them together to give you support and friendship. For more information see the back of this guide.

Some of the help you need may come from social services. Or it might come from organisations like Age Concern or Crossroads Care.



Someone may need to talk to you and the person you live with to get more information so that they can find the right sort of help for you both.

That means that people may come and meet you and the person you live with to ask you more about the help you need. They will probably ask you lots of

questions, and fill in forms with your answers. They need to ask these questions so they can help you in the right way.

You or the person you live with might have to pay some money towards some of the help that you get.



- Lots of people can support you to get help.
- Different people may come to see you to arrange for your family to get the right help.
- You may have to pay towards some help.

What next?

This part of the booklet has helped you think about things that might help you and the person you live with now.



It's important to talk to the person you live with before arranging new things. They may have ideas about how to get help too. The person who has helped you with this booklet could talk to you both together if that helps.

Ask the person supporting you with this to help you plan how to get help with the things you have ticked.



I need support to get the right help now.



You may have decided that you don't need any help at the moment. That's good news. Why not keep this booklet somewhere safe and look at it again when things change and more help could be useful?



I'm OK now but please remind me to look at this booklet again.



When?



- Ask for help to follow up ideas from this booklet to help you and the person you live with.
- Read this booklet again if you need more help in the future.

Part 2:

Getting ready for emergencies



An emergency is something unexpected and difficult that happens. That can be anything from no-one being there to meet you when you get in, to you or your carer becoming ill very suddenly.

Emergencies can feel very frightening. But there are lots of ways that you, your family and the people who support you both can get ready, so that if there is an emergency you will all know what to do.

It's important to talk with your family about getting ready for emergencies. It can be difficult to talk about, so someone else could help you with this.

I would like someone to help me talk to my family about getting ready for emergencies



The best thing to do is to start working on emergency plans when everything is going well. That way you can practise doing some of the things you might need to do, like making phone calls.

Lots of people can help you and the person you live with get ready for emergencies. You, your family, close

friends, workers and services you use all need to work together to make plans.



- It can be hard to cope with things that change suddenly.
- There are lots of things you and your family can do to get ready if things go wrong.

Things you and your family can do to get ready

Emergency Contacts



One of the most important things to arrange is 'emergency contacts'. These are the people who have said that they can help you straightaway if you have an emergency. They need to be quite close by, so that they can come to you quickly, and easy to get hold of. You can arrange more than one person – in fact this is a very good idea.



I know who has said they will be the emergency contacts for me and the person I live with.





Information



Another very good thing is to write down the important information about you and the person you live with. This information tells people about the help you need to stay safe and healthy, and about what support you need. Once all the information is written down, you need to know where it is kept.


I know where information about me is kept ☐

My emergency contacts know where to find information they may need in an emergency ☐

We need support to collect information together ☐



Then there are lots of other things you can do. Read through the list below and put a tick next to the things you already do. Tick the other box if you would like some help with them.




	I can do this	I could learn to do this with support
Telephone  I can use the phone at home by myself	<input type="checkbox"/>	<input type="checkbox"/>






Part 2: Getting ready for emergencies



	I can do this	I could learn to do this with support
Mobile phone  I have a mobile phone that I can use safely. It has the numbers programmed in for my emergency contacts	<input type="checkbox"/>	<input type="checkbox"/>
Phone numbers  I have a list of people to ring in an emergency, and I keep this list with me	<input type="checkbox"/>	<input type="checkbox"/>
Phone alarm button  I can press the red button on a phone to make sure people know I need help	<input type="checkbox"/>	<input type="checkbox"/>



	I can do this	I could learn to do this with support
Alarm necklace  <p>I have a special alarm necklace and I can press the red button to make sure people know I need help</p>	<input type="checkbox"/>	<input type="checkbox"/>
Key  <p>I have a key to my home and can get in and out safely</p>	<input type="checkbox"/>	<input type="checkbox"/>
Spare key  <p>I know who has a spare key to get in to my house</p>	<input type="checkbox"/>	<input type="checkbox"/>
If nobody else is home  <p>I know what to do if no-one is in when I get home</p>	<input type="checkbox"/>	<input type="checkbox"/>



Use this space to think about and write down other things that you might need help with in an emergency.

Other plans

What are the things you want to happen, and the things you don't want to happen?

You might want to think about:

- Whether you can stay at home on your own if you have to
- How long you can stay at home for and be safe
- Who will come and help you if you stay at home
- Where you will go if you don't stay at home
- The things you will need to take with you if you go somewhere else
- The friends and family you will want to talk to if you have an emergency.

You don't need to have an answer to everything. But it is a good idea to think about things like where you would like to be, if the person who cares for you is ill for a few days.



Keeping everyone informed and up to date



Other people need to know your plans!

It's important to tell the people who support you about what you want them to do if there is an emergency and who your emergency contacts are. Tell them the things that you want to happen and the things you don't want to happen.

I know what plans have been made for an emergency ☐

Other people know about plans for an emergency ☐



And last of all, ask someone to help check regularly that you don't need to do anything new. For instance, are all the phone numbers still correct? Has anyone moved? Do you need help with anything extra now?



- Work out emergency plans with your family and other people who know you well.
- Don't forget to keep checking your plan still works.

Part 3:

Getting ready for the future



Sometimes things can happen that make it difficult for everything to stay the same. You might have watched TV programmes like Eastenders and Coronation Street when people have moved house, been ill or even died.

Sometimes change can be good. Sometimes it can make you very sad, especially if the person you live with can't go on helping you. But it is better

to think about change before it happens, so that you can make some plans.

Think about the things you want to happen later on. Then you have a much better chance of making sure that they happen.

Where should I start?



It's important to talk with your family and other people who know you well. Talk about what you want to happen in the future and what you don't want to happen.

Some people find it easy to think about the future and talk about it. Other people find it really difficult and can get

very upset – and that's OK. Ask someone you trust to help you talk about it if it will help you. Maybe they could talk to you on your own first, and then to the people you live with. Then you can all talk together.



Perhaps you want one thing in the future, and the people you live with want something else. Talk to each other about what you want, and about the things that worry you. It's important to understand the things that other people worry about too. That way, you can make plans together that stop everyone worrying so much.



- Starting to make plans for the future early can help you.
- It's important to talk to other people about plans.

Who can help me and how?

You and your family can ask someone to come and help you plan. You can ask someone you know and trust. Or you can ask for someone who does a job helping people with learning disabilities plan for the future.

That person might be a:

- social worker

- person centred planner
- housing worker.



The plan will include things that need to happen to get ready for changes. This is often called 'person centred' planning, because you are the person who is at the centre of all the plans.



I would like someone to talk to me more about making a plan about my future



- Other people can help you and your family plan.
- You can get information about your choices.

Starting to plan

The two main things that you need to think about for the future are:

1. Where do I want to live?

- What sort of place do I want to live in?
- Where do I want to live?



- Do I want to stay in this home, or do I want to go and live somewhere else?
- Do I want to live on my own or with other people?
- What do I need near the place where I live?

2. How do I want to be supported?

- What will I need help with?
- What can I manage alone?
- Do I need someone around all the time to help me stay safe?
- Do I need help to stay healthy and well?
- What sort of people do I want to help me?



It can be really difficult to think about the answers to the questions on your own. Perhaps you have one idea, and the people who know you have another idea. That's OK. This is not a quiz – you can have different answers!

The important thing is that you all take your time, and listen to each other.



- You will need to think about where you want to live and how you want people to support you in the future.

Taking your plans further



When you know what is important to you, you can think about the places where you might live, and the help you may need.

There may be booklets, photos or films about housing and support. There may also be people who can help you meet and talk to other people who have moved.



I would like some more information about housing and support in my area ☐

The best way of me having information is:

Booklet with words and pictures ☐

Pictures and photos ☐

Films ☐

Visiting places and people ☐

What next?

Once you and the people closest to you are clear about the plans you want for the future, you can all decide what you want to do next.



You have two choices:

1. You decide that you've done enough for now.
2. You decide that you have a plan and you want to do something about it. A social worker or your planner can help you and your family take the next steps.



- When you have made your plan, you can all decide if you want to stop now or make the plan happen now.



It can take a long time to make plans happen, so it is worth taking your time and getting things right. The more you plan, the more choices you may have.

Useful information and contacts

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. 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

Website: www.mencap.org.uk/page.asp?id=2236

Housing Options

Housing Options is a housing advisory service for people with learning disabilities, their families and their supporters. They have an Easy Read section of their website with pictures and sound to make them easier for people with learning disabilities to understand.

Housing Options Helpline: 0845 456 1497

Email: enquiries@housingoptions.org.uk

Website: 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

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



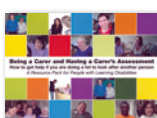
Supporting Mutual Caring: A booklet for workers in services who are supporting older families that include a person with learning disabilities



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 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

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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.

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