

Thinking ahead: a planning guide for families

Updated 2015 to reflect the Care Act



foundation for
people with
learning disabilities



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Barchester Healthcare is one of the largest national providers of care and support services in the UK and is committed to delivering national quality with local flexibility. We do this through working in partnership with local communities and the people the organisation supports, whilst always respecting the individual and the way they want to live their life. Barchester work with and support a wide range of people including older people, people with dementia, people with a learning disability, people with mental health needs and people with long and short-term neurological needs. For more information visit: www.barchester.com



**Why think
ahead?**

This guide has been produced in response to what people with learning disabilities, their parents and siblings have been asking for years: what is going to happen in the future, and how can we shape it?

The project work that has led to the guide was originally called 'When I'm Gone' – words that were frequently said by parents expressing their very real fears about what should happen if their son or daughter with learning disabilities outlived them. We changed the title to 'Thinking Ahead' because planning for the future is the best solution to this problem – talking about it as much as possible and putting as much in place as you can whilst you have the energy and time.

This guide offers ideas for how different people can help parents, and contribute to thinking and planning for the future. Parents usually need support to think ahead. Siblings and other close relatives as well as friends and neighbours bring a helpful perspective. People with learning disabilities need support to shape their future and be central to any planning. People working in local authorities and voluntary organisations have a role to play in supporting families through discussions, providing information and supporting change. In summary, planning for the future is the responsibility of all of us.

Parents have often said their hope for the future is that they will outlive their adult son or daughter, but as people with learning disabilities are living longer, this is frequently not the case. But in any event, living with fear and worry for the future shouldn't be the way for a family to live. Planning will help put things in place to ensure that the person with learning disabilities has the best adulthood possible, even after the death of a parent.

As Caroline Tomlinson, parent of Jo, said:

'The time has come for a very different conversation, a conversation which frightens us to death, which works out how the people we love and care about have a good life which is sustainable when we are no longer here, because as we all know love simply won't be enough.'

(*'Love is simply not enough'*, Tizard Learning Disability Review, Vol. 17: 1, pp.26–31)

Families who have looked at the different options and have made some decisions about the future usually say they feel a huge sense of relief. Jean Willson, mother of Victoria, said during a conversation about the importance of putting things in place:

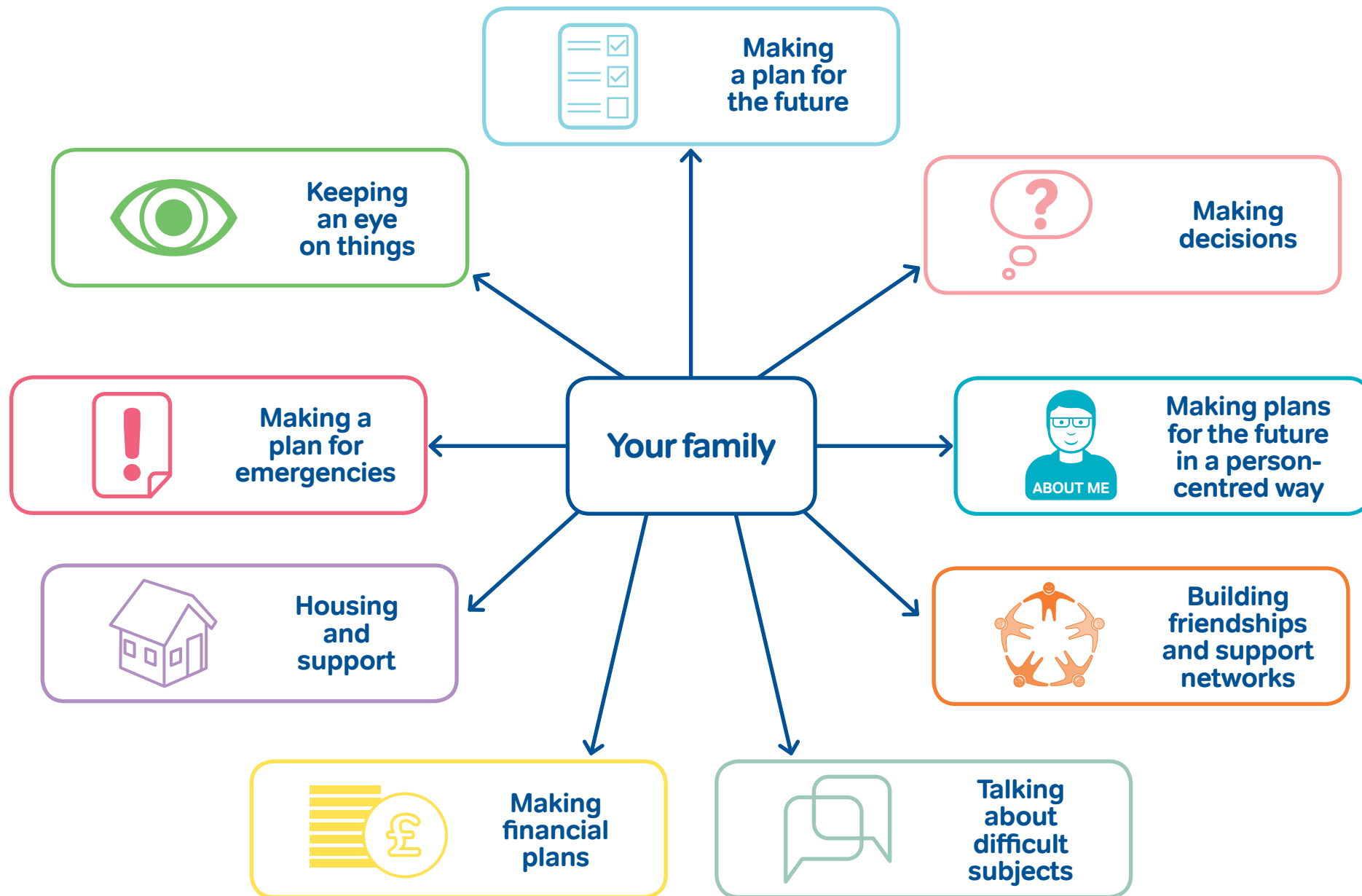
'Making plans is my gift to Victoria.'

Information in this guide

There are nine sections that look at different aspects of thinking about and preparing for the future:

The sections are:

1. **Making decisions:** information to help you understand the legislation and practice that relates to decision-making.
2. **Making plans for the future in a person-centred way:** an introduction to how person-centred planning can help you to think about what options might work well for your relative.
3. **Building friendships and support networks:** describes the benefits of having more people involved in your relative's life and ideas for achieving this.
4. **Talking about difficult subjects:** ideas about how to talk about subjects that can be difficult to raise, such as growing older and death and dying, with your relative.
5. **Making financial plans:** an introduction to making a will, setting up a discretionary trust and power of attorney.
6. **Housing and support:** information about the different housing options for your relative and how to get the support they need.
7. **Making a plan for emergencies:** how to put together a plan that can support your relative to get the right support should you suddenly have an emergency.
8. **Keeping an eye on things:** how to ensure your relative has a good life and is well supported when they leave the family home.
9. **Making a plan for the future:** drawing together your ideas to make a plan for the future.



How to use the guide

The nine sections in the guide can be used in any order that makes sense for you and your relative: start with the section that is most useful to you at this point in time. There may be some sections that are not relevant either now or in the future.

Most of the sections have:

- an explanation about why the section might be helpful;
- information you may need to know;
- ideas about how to put suggestions into practice;
- questions you might want to ask your local authority or support organisations;
- places to find further information on the subject;
- ideas about how the section links to other sections in the guide.

Some of the sections refer to templates: blank copies of these are available at the end of the guide. They can be used to record information and ideas. You may want to make a copy of the blank templates before you fill them in so that you can reuse them. Alternatively, you could adapt them to make your own versions.

We have designed this information to be stored in an A4 ring-binder so that you can add information you collect and notes you make. You can also move sections around to put them in an order that suits you.

How this guide can help

The aim of this guide is to:

- encourage conversations within families about what the future might be like;
- give families the information they need to look at the options that can be considered;
- give families the confidence to make plans and put things in place to improve the future, including planning where to live and how to be supported;
- prevent people with learning disabilities from worrying about their future and perhaps experiencing trauma when something happens to their parents or their main family carer;
- reduce the worry and anxiety that family carers feel when they think about the future;
- give siblings the tools to encourage their parents to plan for the future (if they are reluctant) and to contribute to future thinking and planning.

Who is this guide for?

This guide is for families with an adult relative with learning disabilities who would like ideas to help them think about and plan for the future. By families we mean parents, their son or daughter with a learning disability and also siblings and other close relatives and friends. It could also be used by people outside the family who want to offer support.

We have made the information as flexible as possible so that it can be adapted to each family's individual circumstances. Families may be at different stages of planning for the future:

- Some may be in an emergency situation and urgently need to look at options.
- Others may be needing or wanting to make changes in the near future and actively looking at places to live and how best to sort out good support.
- Others may be 'dipping a toe in the water' to gather initial bits of information but not at the point of making changes to their current situation.

Planning for the future is often seen as planning to leave home, but it doesn't always have to mean that. This guide offers families ideas for taking small steps in planning with their relative for times ahead even if leaving home is probably a number of years away.

This guide will also be useful to families if their relative has already left home but they still want to put other plans in place to make sure their future life is as good as possible.

Planning for the future is often focused on older families, but younger families have told us they want support to think ahead so that they don't have to make rushed decisions later on.

We hope this guide will give families in all these different situations the confidence to be able to influence and shape the future.

Involving other people in planning for the future

You will probably get more out of this guide if you can involve other people in thinking through some of the issues with you.

Some family carers may feel that their relative would get distressed by talking about change or thinking about a future when their parents, or other relatives, are no longer around to support them. Whilst this may be the case, it makes sense to balance this risk with the risk of not involving your relative in discussions and making decisions, which could be equally upsetting in the long run. The section on making plans in a person-centred way suggests ways of involving your relative.

Planning can feel overwhelming and is not always easy or straightforward. It can be difficult to find the time and energy to explore your options when you are providing day-to-day support and dealing with numerous other issues. Some families will find it harder than others – particularly if they are lone or elderly parents, or have a limited network of family and friends, or if their relative with learning difficulties has complex support needs. The involvement of other people can help to keep you going.

Sometimes parents feel they shouldn't involve their other adult sons and daughters as they 'have their own lives to lead' but siblings and other relatives can also bring helpful ideas and perspectives. Also, it's a good idea to contact local parents' support networks, carers' organisations or social services departments to find out about other families' experiences in your area and to ask what support is available to plan ahead.

Support from local authorities and organisations

We have held workshops so families can look at and use different sections of this guide. Parents have enjoyed talking together and learning from each other; many have said they found it supportive to be working with others and sharing their worries and ideas. Other families have appreciated individual support to think about how they might use it.

It is worth asking whether the organisation in your area, that supports carers of young people and/or adults with learning disabilities, might be able to run some workshops. Or you could ask the transition or adult care management team for advice about issues that arise from reading the guide. When your relative has a transition or annual review or you have a carers' assessment you could discuss the support you and your family need with making future plans.

A guide shaped by families

This content of this guide has been shaped by what families have told us. To find out what people thought about making plans for the future we arranged workshops for people with learning disabilities, parents and siblings and also carried out a national survey for parents. This is what people told us.

People with learning disabilities told us:

'You never know what is around the corner – you need to be ready' (said by a person whose parents had died and was now living with his brother, and was worried his brother might not come back from work one day).

'We shouldn't be wrapped in cotton wool – we need to try things otherwise how will we cope when our parents aren't there?'

'We need to hear about people being ill and people dying so that we learn how to cope – if we haven't got ideas about how to cope with death then it's very difficult when our parents die.'

'I need to go step by step and in my own time' (said by someone who found it difficult to talk about planning for a future without her mother).

'We need time to think things through, especially after someone dies – we need time and support.'

Parents told us:

'We want to know what is going to happen to our daughter so we need to plan with her.'

'I went to a meeting and there was an elderly couple there who were saying they didn't know what to do – it made me realise I didn't want that to happen so we made plans and now our daughter has her own place through a shared ownership scheme.'

'Having a plan has put my mind at rest – we have to think about things before they happen.'

'We want to know what is going to happen before we are too old – we want peace of mind.'

'We've done lots of planning as part of our son's transition from school- now we want to keep going.'

Siblings told us:

'My parents both died suddenly within six months of each other and I was left to try and sort out my brother's care without knowing enough about his needs, and having to cope with my loss at the same time.'

'How do I talk to them (my parents) about a time when they either can't cope any more or are no longer with us?'

'I wanted my brother to be used to other people supporting him before there is some sort of crisis like my mum going into hospital. He said he would like to go out at the weekends so he now has a personal assistant and they go out on Saturdays and do shopping and other bits and pieces.'

'I worry about what will happen in the future as my parents won't even allow my sister to go to respite.'

'I wanted to have a plan so that I know what to do when the time comes; I helped to get a circle of support together and we have begun to share ideas and information. I feel so much happier now we are all talking about my brother's future.'

'It has always been assumed that I will look after my sister, but nobody has ever asked me if I want to do this.'

The reasons parents gave for putting off making plans for the future	The benefits/reasons parents identified for planning for the future
<p>'We're burying our heads in the sand because we can't face thinking we won't always be here for our daughter.'</p> <p>'We don't know where to start – it's so confusing and there's no clear pathway.'</p> <p>'We're always let down – when we've asked for support to make plans nothing is ever followed up.'</p> <p>'There is so much uncertainty – when we plan something it all changes again.'</p> <p>'We have no one to help us plan – it's hard to think on your own.'</p> <p>'We're tired just trying to sort out day-to-day issues – where do we get the energy from?'</p>	<p>'No one else will do it.'</p> <p>'We are in the best position to do it – we are the people who know our son best and can spend time finding out what he wants to happen.'</p> <p>'The later we leave it the harder it gets.'</p> <p>'Our daughter doesn't like change so we need to start gradually putting things in place.'</p> <p>'If we take the lead we can go at the pace that is right for our son – it is not driven by someone else or by an emergency.'</p> <p>'Our daughter will realise we are behind her and supporting her to sort things out – we can't leave her or her siblings to do this on their own.'</p>

The reasons parents gave for not asking others to help them plan for the future	The benefits parents said they gained when they involved family, friends and support groups
<p>‘It’s our private problem and we can’t expect others to share the responsibility.’</p>	<p>‘A problem shared is a problem halved. It was such a relief to involve a few other people who weren’t so close to it all – my anxiety wasn’t helpful and stopped me from being able to think about the future.’</p>
<p>‘Other people are too busy – they have their own lives to live.’</p>	<p>‘We were reluctant to ask our friends for ideas but when we did we realised they brought a fresh pair of eyes – they helped us find the information we needed and decide on the steps we should take first. It was enjoyable for all of us.’</p>
<p>‘We’ve always managed on our own somehow so we will keep going. Whenever we have asked for help before we have felt let down.’</p>	<p>‘Talking to my son and his wife made me realise that my son (with autism) could have a good future living in his own flat and they would always do their best to keep an eye on things.’</p>

The information we have put in this guide is designed to help families overcome, or at least alleviate, the difficulties they face in planning for the future. It may not be an easy journey, but we hope the ideas and strategies suggested here will bring some practical solutions and a sense of relief.

How the Care Act can help families when planning for the future

The Care Act 2014 replaces a number of previous laws and good practice guidance and aims to simplify the framework for providing care and support. Personalisation as well as choice and control are central in the Act. Most of the changes came into effect in April 2015.

At the core of the Care Act is the principle of wellbeing. The concept of wellbeing includes specific areas such as protection from abuse and neglect; physical and mental health and emotional wellbeing; family and personal relationships; and suitability of living accommodation. However, the Act also states that the principle must be applied more broadly to help people achieve the outcomes that matter to them in their life. In addition, the Act says that local authorities must promote wellbeing when carrying out any of their care and support functions in relation to a person (such as an assessment, making a decision) and this applies equally to adults with care and support needs and their carers. Local authorities must establish the impact of caring on your wellbeing and whether you are able and willing to continue to provide care.

In relation to planning for the future, applying the principle of wellbeing could mean that during an assessment it is identified that putting things in place for the future would contribute to your relative's wellbeing (and yours, as a family carer). The wellbeing principle also applies when a local authority undertakes broader strategic functions: you could use this as an argument for the provision of peer support groups in your local area to help you and other families plan for the future.

In addition to this general principle of wellbeing, the Act specifies some other key duties and principles.

Prevention

Closely connected to the idea of wellbeing is the principle of prevention. The aim is to ensure that the care and support system does not wait for people to reach a crisis point before responding and to prevent low-level needs escalating into health and social care emergencies. This is a statutory duty, which means that the local authority must do it. Prevention also covers helping people to retain skills and reduce their dependency.

Supporting families to put things in place for the future fits well with this prevention duty as it reduces the risk of inappropriate decisions being made under pressure should an emergency occur. An example of the prevention duty being used would be helping someone to build up their natural support network as part of their current support plan – this could give them greater independence and also create a support option should an emergency arise.

Using natural supports are not only usually less distressing for the person but can also help to reduce support costs (which is also one of the aims of the prevention duty). This duty applies to both your relative and to you as a carer: support to think and plan for the future can be a preventive measure for both of you and could be a useful duty to refer to when making a case for resources.

Information and advice

Under the Care Act, local authorities have an increased duty to provide information and advice to make it easier for people to make well-informed choices about their care and support. Information and advice is to be provided at times when people need it and should include general details about the way the system works as well as more personalised information for

individuals. The Act says that local authorities should (rather than must) consider the people they are communicating with on a case-by-case basis to help them get the information and advice that is particularly relevant to them, which includes planning for their future care and support needs.

Again, this provision could be used to support families to have access to the information and advice they need to plan and put things in place for the future. The local authority must ensure information and advice services are available, but they do not need to deliver them themselves: it could be done by other statutory and voluntary sector organisations, so this could be a role for your local family carers' support group. If families receive information and advice about matters such as making an emergency plan and housing and support options then they will be in a better position to contribute good ideas to their relative's support planning.

Here are a few other points from the Care Act that may be helpful to consider when you are planning the future:

- The Act has a statutory requirement for local authorities to collaborate and integrate with other public services such as health and housing. It also requires seamless transitions for young people moving to adult social care services.
- Carers have a statutory entitlement to an assessment that is separate from that of the person they are caring for.
- Support planning services should consider how carers can be supported to look after their own health and have a life alongside caring.
- The Act introduces national eligibility criteria with the aim of having a common system in all areas of the country.
- At an assessment, all of a person's eligible needs should be identified, regardless of whether they are being met by a carer.
- When looking at eligible needs, the ability to maintain family or other significant relationships, and the impact of these not being maintained on an adult's wellbeing, should always be considered.
- There is a duty to provide an independent advocate for people who would have 'substantial difficulty' in engaging in Care Act processes, such as assessment or care and support planning.

1. Making decisions



Decision-making and planning for the future

Thinking about the future life of your son or daughter when you are no longer around to support them is one of the most difficult things, practically and emotionally. However, it is important to face this challenge, as decisions may need to be made regarding where they will live, how they may be supported, how their finances will be managed and who will be responsible for keeping an eye on things. If you do not broach the subject, then at some point someone else will, and they are less likely to do it with all the unique knowledge and understanding that you have gained over the years and that a formal assessment will probably not provide.

Parents and other family carers play a key role in decision-making, so it is helpful to have an understanding of the legislation and practice that relates to it. With this you will be in a good position to ensure that you are included in decisions and that the best decisions are made. It will also give you an insight into how and why professionals are making decisions on behalf of your relative. Decision-making usually works best when it is a partnership between the person, their family and people who are paid to support them.

People with learning disabilities have a huge variation in their ability to make decisions but the information in this section is relevant to all families, including those who feel their relative has a limited ability to express their views. Most people can show both positive and negative preferences to a person, a place or an activity and this ability can be invaluable when making decisions.

This section looks at:

- Decision-making under the Care Act
- an overview of the Mental Capacity Act;
- shared decision-making: involving your relative in making decisions;
- ‘best interests decisions’;
- challenging decisions;
- involving other people in decision-making;
- other people who have authority to make decisions (lasting powers of attorney and Court of Protection);
- advance decisions to refuse treatment.

Decision-making under the Care Act

In the Care Act, local authorities must involve people in decisions made about them and their care and support. Regardless of how complex a person’s needs, they must help people to express their wishes and feelings, weigh up their options and assist them in making their own decisions. If your relative has care and support needs and would have substantial difficulty in being involved in processes such as assessments, care and support planning and reviews, then the local authority must make sure there is an appropriate individual or independent advocate to support them. Often family carers will be the appropriate individual but if you don’t feel confident to do this you could say this to the local authority and ask for your relative to have an independent advocate to support them in the care and support planning process. An independent advocate must have the skills to involve your relative and cannot be someone who is already working with your relative in a paid capacity.

Overview of the Mental Capacity Act

The Mental Capacity Act, which covers England and Wales, was introduced in 2007.

'Mental capacity' is another way of saying the ability to make a decision. It is helpful to have an understanding of the Mental Capacity Act and the meaning of 'best interests decisions' as these underpin the way everyone working with people with learning disabilities should be approaching decision-making.

As a family carer the Act is relevant if you need to:

- support your relative to make a decision;
- make a decision or act on your relative's behalf (acting in their best interests);
- question or challenge a situation where someone else, such as a care manager or support provider, makes a decision or assessment of capacity that you do not agree with.

If you understand the key principles of the Act you will find it easier to make sure that your relative is involved as much as possible in decisions that affect them and that these decisions are the right ones for them.

The Act has five key principles that define the way decision-making should be approached:

1. It is assumed that a person has capacity to make a decision unless it is shown otherwise. It is also important to understand that the ability or 'capacity' to make a decision is looked at for each decision: no one is ever assumed to lack capacity for all decisions; before anyone can make a decision on behalf of someone, it needs to be shown that the person does not have the capacity to make that decision.
2. A person should be given as much support as possible to make a decision – this may involve thinking about different ways of asking a question or giving information (see section below on shared decision-making).
3. People have the right to make unwise decisions – the fact that someone makes a decision that seems unwise to others, or that others do not agree with, does not mean that the person lacks capacity.
4. Any decision made on a person's behalf must be made in their best interests.
5. Any decision made on a person's behalf should aim to limit their rights and freedoms as little as possible.

The Mental Capacity Act has a Code of Practice that provides guidance to professionals in health care, social care and housing as well as staff providing care. Whilst the Code of Practice applies less to family carers, it provides a helpful framework to guide everyone. It sets out the responsibilities of a decision-maker (see 'best interests decisions' below) and also guidance on assessing the capacity of a person to make a decision.

Finding out if your relative can make a decision

A person is assessed as being unable to make their own decision if they cannot do one or more of the following four things:

- Show some understanding of the information given to them to make the decision.
- Retain that information long enough to be able to make the decision.
- Weigh up the information and use it to make the decision.
- Communicate their decision – this could be by talking, using sign language or movements such as blinking an eye or squeezing a hand.

Shared decision-making: involving your relative in making decisions

It is important to always look for ways to support your relative to make decisions and to be involved in the decision-making process in whatever ways they are able. These decisions may be about their current life or the things they would like to happen in the future. There are several ways in which you can achieve this, depending on what might work for your relative and your family. Here are some ideas and suggestions that families have found have worked for them:

- Give your relative as many opportunities as possible to make decisions about smaller issues and to express their preferences: the more decisions they make, the easier they will find it.
- Break down big decisions into many smaller decisions which they might be able to make.
- Keep a written log of the situations and approaches that helped, such as time of day or environment, and which didn't, and then use what you've recorded when thinking about bigger decisions. This information can also be used by other people (and can continue to be used if you are no longer able to be involved).
- Learning about your relative's preferences may well begin to shape bigger decisions. For example, giving them opportunities to keep in touch with friends or meet new people may reveal who they get on well with. This information could influence a decision about who they live with.
- You may feel there is someone who is good at supporting your relative in making decisions. If so, your relative can ask for them to attend meetings, such as support planning or reviews, with them.
- If you feel your relative needs support from someone other than yourself, you could check whether there are any local advocacy organisations providing citizen advocacy or peer advocacy.
- Ask whether your relative is getting the right support with communication. If you feel there is a lack of knowledge and understanding about their communication, you could ask for a referral to be made to a speech and language therapy service.
- Try different resources such as the Books Beyond Words series or easy-read information such as the Housing Options booklet 'My Place to Live'.
- Look at the information in Section 2 on person-centred planning. This explains how to learn more about a person and what works for them.
- Use the ideas in the 'Involve Me' guide (details at end of this section) written for families and staff to include people with profound and multiple learning disabilities in decision-making and consultation.

Best interests decisions

The Mental Capacity Act sets out a process to ensure that a decision made for people who have been assessed as not having the capacity to make it themselves is made in their best interests. Best interests does not mean what you would choose if you were in their situation. Instead it is about knowing their values, wishes, aspirations—what you think they would choose if they did not lack capacity. This includes decisions made by families as well as social workers and care professionals.

If your relative lives at home with you, you will probably be the decision-maker for many of the day-to-day decisions. If they are in supported living or residential care, a paid worker is likely to be more involved in making day-to-day decisions.

However, for bigger issues such as finance, social care or health, it is likely that a professional, who should have expertise in Mental Capacity Act issues, will be the decision-maker. For example, for a decision regarding moving into accommodation funded by the local authority, it is likely that a care manager (social worker) would be the decision-maker acting for the local authority. For a health decision, such as whether to have a specific treatment, it is likely that a medical professional will be the decision maker.

The decision-maker is expected to get the views of people with an interest in your relative's welfare, including family members, paid staff and other people who know them or have specialist knowledge. If your relative has a deputy or attorney (see page 23-24), they must also be consulted.

These people might help by:

- supporting your relative in getting involved in decisions;
- giving their own views;
- giving expert advice.

As a family carer you may be able to help by providing information, or you may be the best person to find out more from your relative to contribute to the decision. A best interests meeting may be held for big decisions, such as deciding where your relative might live. This meeting would provide everyone with an opportunity to give their views.

The solicitors, Irwin Mitchell, have produced a leaflet to help anyone who feels they are not being appropriately consulted about the welfare of their loved ones. It includes two template letters to help family members who have not been involved or are concerned they will not be involved in a best interests decision-making process (see Information at end of section).

Challenging decisions

There may be situations where you wish to challenge a decision or need to find a way to resolve a dispute. This might happen:

- if you think you have not been consulted when you feel you should have been;
- there are disagreements about whether someone has the mental capacity to make a decision;
- a decision is made which you do not think is in the best interests of your relative;
- if there is disagreement, perhaps among family members or between family and a professional, about a decision such as what is in a person's best interests.

In these situations you could:

- keep a record of any disagreements;
- involve an independent advocate (not an Independent Mental Capacity Advocate) who can help to make sure your relative's wishes are properly understood;
- use the formal complaints process of the relevant service – for example the NHS, your local authority, a voluntary or private sector service (see page 106 for information about making a complaint);
- get advice from the Office of the Public Guardian;
- go to the Court of Protection.

Decision-making and person-centred planning

You may agree that your relative is unable to make a decision, but you disagree with the suggestions that are being made on their behalf. In this case, it is helpful to keep a written log of what works or doesn't work for them. This information can be used to back up or rule out the options that are being looked at. If you have gathered this information through person-centred planning (see Section 2) and have involved other people who are important to your relative, it is likely to have more influence.

Involving other people in decision-making about the future

It helps to consult with other people regarding future options. Although parents sometimes say they feel it is unfair to involve other people in decision-making as they think the responsibility sits with them, we have found that wider family and friends are willing to be involved and often appreciate being asked.

It may be that your son/daughter already has quite a few people involved in their lives, so it is not difficult to decide whom you might ask for support. You could consider asking your other sons or daughters, other relatives and family friends (especially if they are of the same generation as your son/daughter), your son/daughter's friends or people who have worked with or currently support them.

Why it helps to involve other people:

- Talking things through with others may throw up new options and ideas.
- You can get emotional and practical support as a family when it gets stressful: for example, if you are in disagreement with your local authority.
- They may know things about your son/daughter that you don't know; they may see them with different people and in different places.
- They can question your assumptions: for example, that another son or daughter will take on a certain role, or that siblings don't want to be responsible in the future. They need a chance to say what they can and can't do.
- They may welcome the opportunity to get involved and this may lead to long-term commitment and support.

For more ideas about involving other people look at 'Building a circle of support' in Section 3.

Other people who have authority to make decisions

Some of the ways in which other people can make decisions on behalf of your relative are outlined below. If you are considering using any of them, you should explore the additional sources of information listed at the end of the section and/or get professional advice.

Lasting powers of attorney

A lasting power of attorney (LPA) is a legal document appointing one or more people to be an individual's attorney, either to make decisions about their property and financial matters (called a property and affairs power of attorney), or their personal welfare, including medical treatment (called a health and welfare power of attorney). They can only be made by someone aged 18 or over.

A person needs to have the mental capacity to create an LPA. This means they need to understand the nature of what they are doing as well as the implications. A good test for this is to consider whether your relative is able to talk about their future and express their wishes. Most people with severe learning disabilities would not have this capacity so this option would not be open to them. A Court of Protection deputy would be the best solution in this case (see below).

Family carers may also wish to create their own LPA so that someone is already in place to help them, should they be unable to deal with their finances at some time in the future.

Attorneys must be over 18. Ideally at least one of the attorneys should be younger than your relative and live reasonably nearby; it could be a family member, friend, work colleague or a professional. It is not a good idea to choose family members who live abroad as this can cause delays in dealing with paperwork. Decisions made by an attorney must be made in the person's best interests and the attorney would be expected to involve family members in the process. Property and affairs attorneys must not be bankrupt and should be someone who can be trusted to make decisions about your relative's finances.

You can specify how the attorneys are to carry out the work: whether they make all the decisions together or whether they can act independently of each other. This will depend on the circumstances of the person creating the power of attorney and their ongoing needs.

A health and welfare LPA is set up in the same way as a lasting power of attorney for property and affairs. It allows the attorney to make some decisions about matters relating to the person's health and welfare if or when they are not able to make such decisions themselves. The decisions may concern the person's medical treatment, how their health care is managed, where they live and how their living arrangements are managed (particularly in a care home or supported living). They might also involve more detailed aspects of their life, such as daily care and diet.

To make an LPA the person needs to obtain the forms and guidance from DirectGov. These forms should be returned to the Office of the Public Guardian for checking and registration; an LPA can only be used once it has been registered with the OPG.

Enduring powers of attorney

Before 2007, when lasting powers of attorney were introduced, it was possible to create an enduring power of attorney (EPA). This allowed an attorney to deal with someone's financial affairs, but not their health and welfare. The same test of mental capacity applied but the enduring power of attorney did not have to be registered until the person creating it became mentally incapable. It is advisable to ask a solicitor to check whether any enduring power of attorney that you or your relative may have is correctly executed and still valid.

Court of Protection

The Court of Protection is a specialist court for all issues relating to people who may lack capacity to make specific decisions. Where there is a disagreement about a person's capacity to make a decision that cannot be resolved informally, the Court can make a declaration about the person's capacity to make this decision. It can also make one-off decisions, for example in relation to the providing, withdrawing or withholding of serious medical treatment. The Court is also responsible for the appointment of deputies to make on-going decisions.

Court of Protection deputyship

If your relative does not have the mental capacity to either manage their own finances and property or to create an LPA, the only option available is to apply to the Court of Protection for a deputy to be appointed. This will not usually be needed where the person has no property or savings, because their benefits can be managed by an 'appointee' appointed by the Department for Work and Pensions. The Court will decide whether the appointment of a deputy is in the best interests of your relative.

Unless there is an emergency, the process of applying for a deputy to be appointed is lengthy, involves a lot of paperwork and can be costly. Usually it is a family member or close friend who applies to be appointed as a deputy, but if there is a significant amount of money or property involved, a solicitor can be appointed as a professional deputy. Only professional deputies are allowed to charge for the work they do; lay deputies may only reclaim out-of-pocket expenses.

The Court of Protection allows the deputy to manage your relative's money. A deputy can also make other decisions if these have been agreed by the Court of Protection; for example to sign a tenancy agreement on a rental property.

Deputies can also be appointed for health and welfare but this is much less common as most decisions can be covered by the best interests process.

Advance decisions to refuse treatment

An advance decision to refuse treatment (ADRT), sometimes known as a living will or advance directive, is a statement that a person writes specifying what medical treatment they would not want to receive at some time in the future. It is made whilst the person has the capacity to make such decisions.

There is no special form or format for an ADRT but you may want to get professional help from a solicitor or health care professional. Further details are available at NHS Choices <http://www.nhs.uk/Planners/end-of-life-care/Pages/advance-decision-to-refuse-treatment.aspx>

To make a valid ADRT the person must:

- be over 18 years of age;
- have mental capacity at the time of making the statement;
- state exactly what treatment they do not want to receive;
- explain why and when their wishes should apply;
- have made the directive without anyone influencing the decision;
- have not done anything to contradict the statement after signing it.

Your relative may appreciate support to think about and make an ADRT; they may have received a specific treatment that they would not wish to go through again, for example chemotherapy. An ADRT may be particularly important if they have a life-limiting condition or are in the very early stages of dementia.

Other types of advance statements can also spell out the kind of care a person would wish to receive in certain circumstances. These statements are not legally binding, but should be influential when deciding what treatment is in the person's best interests.



Questions to ask

Are there any organisations or groups in our local area that run classes that support people with learning disabilities to make decisions?

Is there someone in the health team who can support our relative with communication/developing a communication passport?

Is there someone who can advise us if our relative has the capacity to make a lasting power of attorney (LPA) or an advance decision to refuse treatment (ADRT)?

Is there someone who can look at the LPA or ADRT to advise us whether the person's wishes/decisions are clear?

Whom to ask

The learning disability community team, local Mencap or advocacy group should know if this is happening locally.

Ask whether health team practitioners, such as a speech and language therapist, can do this.

Contact the learning disability community team (care manager or health practitioner).

As above.

Notes



To find out more you could look at

Hft's Family Carer Support Service can provide free one-to-one support by telephone, email or letter on issues to do with decision making (Phone 0800 801 0448 or email familycarersupport@hft.org.uk).

Hft's **Using the Mental Capacity Act: a resource for families and friends of people with learning disabilities** (2011) is a very useful guide designed for families and includes video clips explaining specific issues. The link below provides details of how to order the booklet and DVD (which are free) or download them.
<http://www.hft.org.uk/mcaguide>

Mencap (with the involvement of the Challenging Behaviour Foundation) has produced information on the Mental Capacity Act for families of people with profound and multiple learning disabilities. There is a lot of useful information about health decisions. This is available as a download from the website.
<http://www.mencap.org.uk/news/article/keeping-within-law-mental-capacity-resources>

Office of the Public Guardian, **Making decisions. A guide for family, friends and other unpaid carers.**
<http://www.justice.gov.uk/downloads/protecting-the-vulnerable/mca/opg-602-0409.pdf/>

Involve Me is a project carried out by Mencap to find ways of involving people with profound and multiple learning disabilities in decision-making and consultation. There is a practical guide for family carers and paid workers, including video clips, which is available on the website.
<http://www.mencap.org.uk/node/13182>

A guide has been produced by SCIE and ARC for support staff and managers that includes information about LPAs, deputies, appointees and bank accounts: **Guidance on money management for people who may lack capacity to make some decisions about how their money is used** (2011). This is available from ARC's website: <http://arcuk.org.uk/publications/guidance-on-money-management/>

Best Interest Decision Tool produced by Irwin Mitchell Solicitors for individuals who feel that they are not being appropriately consulted about the welfare of their loved ones. A leaflet and template letters are free to download at <http://www.irwinmitchell.com/activities/best-interest-decisions-tool>

2. Making plans for the future in a person-centred way



Why person-centred planning helps when planning for the future

Person-centred planning is a form of life planning. It involves gathering information about your relative and then using this information to solve problems and to create more opportunities. It is usually families that have the most detailed knowledge about their relative; person-centred planning helps to make sure this does not get lost or ignored. It is also a way of involving other people who care about your relative to contribute their ideas. For many parents it has been the key to helping their son/daughter shape and enrich their own life.

Families can be put off because person-centred planning is sometimes presented in a complicated way. It doesn't need to be. There are a number of questions that can be used as 'tools' to help you gather person-centred information. Some of these are outlined below.

Person-centred planning starts with the person rather than with the services that are available. If you start by planning around the life of a person, you are more likely to come up with ideas and solutions that will fit the person, keeping them safer and happier, and that will be longer lasting. Of course, the plan can be adapted as a person changes and their life develops.

Person-centred planning can also be a gentle introduction to thinking about your relative's future. You can start with the here and now (perhaps looking at what is currently important to and important for them). When you all feel ready, you can gradually move on to thinking about your hopes for the future.

Person-centred planning should feel like a supportive and sociable activity that helps to alleviate some of the stress and confusion that is often a part of thinking about the future and making changes.

One family explains how person-centred planning is helping them to get started with planning for the future:

'We made a very difficult decision that we needed to start planning for our daughter, who has very complex support needs, to move away from home as we were not getting any younger. The care manager gave us the names of a few places to look at – the first one we went to was just not what we had in mind for our daughter and it put us off doing anything more.

Now that we have found out about person-centred planning we can see that this is where we need to start – looking at what is important to and for our daughter, and planning her support around this. We can now see a way forward.'

This section looks at:

- how person-centred planning can shape a care and support plan;
- how to get started with person-centred planning;
- why person-centred planning is different;
- getting other people involved with person-centred planning;
- how to make sure your relative is at the centre of the plan;
- using person-centred planning to make changes.

How person-centred planning can shape a care and support plan

In the Care Act, planning is called ‘care and support planning’ and this is defined as ‘part of the process for putting people in control of their care with the support that they need to enhance their well-being and improve their connections to family, friends and community’ (Guidance 10.1).

The process of assessment and care planning will vary between different authorities but if your relative’s assessment says they have eligible care and support needs then they should have a care and support plan. The Care Act says that the care and support plan should be person-centred and person-led (Guidance 10.5). It says that people should be involved in their own care and support planning at the earliest stage as possible. It also says that it should be about all of the person’s life and not just about their assessed need and what needs funding. It follows from this that having person-centred conversations and using person-centred tools (described below) help to gather very useful information to take to assessment and care and support planning meetings.

How to get started with person-centred planning

The joy of person-centred planning is that you can collect the information you think is needed, when it is needed – there isn’t a fixed order in which to do things. Through looking at what is happening in your relative’s life at the moment you will gather ideas and facts that will be useful when planning for the future. The aim is to gather information that tells people who your relative really is – what makes them feel good about themselves, motivates them or makes them unhappy.

Like and admire

A good question to start with is ‘What do we like and admire about.....?’ When we ask what we like about someone we are asking what qualities they have or what they do that we appreciate. When we ask what we admire we are asking about what the person is good at. This approach helps people who are planning to think about the positive attributes of a person rather than focus on their disability.

Then it is helpful to build on this picture by asking other questions:

- What is important to them (a good life)?
- What is important for them (a safe and healthy life)?
- What makes a good day?
- What makes a bad day?
- What are our hopes and wishes for the future?
- Who are the important people in their life?

Important to and important for

Understanding what is important to and important for a person is central to ensuring that they have a good life. 'Important to' means focusing on what they tell you, either verbally or through their actions and behaviour, about the things that matter to them. This could be having a specific duvet on their bed, eating foods that are familiar, watching their favourite football team, meeting up with a group of friends or taking their dog for a walk.

Looking at what is important to a person is a good way of making sure your relative's culture, religion, faith or spirituality doesn't get ignored; you might want to identify key foods, celebrations or community events.

Looking at what is important for a person gives a list of what keeps the person safe, healthy and well. This is likely to include medication, diet and therapy.

What is important to a person often gets overlooked by services as they focus on what is important for them. However, it's important to balance these two requirements; we all balance these different aspects of our lives. (See Section 7: Making a plan for emergencies for an example of a completed 'important to/important for' template.) Some things may be both important to and for a person; for example, they may enjoy eating healthy food and may also need to in order to maintain a healthy weight.

Deciding what is important to and important for is very helpful when planning for the future: it helps you to prioritise what needs to be put in place to make things work. The information you gather from asking these questions could be shared with people who meet your relative. In particular it will help paid support workers to work in a way that is responsive to your relative's personality and preferences, rather than to the label of 'learning disability'.

With the simple questions above and below you can collect ideas about what needs to stay the same and what needs to change in their life. You may also realise that there are some areas of your relative's life that need further thought, or that would benefit from other people's input. There is a blank template at the back of this guide that gives you the chance to think about how this information needs to be included in the support plan.

What makes a good day and a bad day?

Thinking about what makes a good day and a bad day is another way of gathering information about what is important to and important for them but is more focused on everyday life. Look at the details of their daily routine and what works/doesn't work for them. If they are not able to talk about this, you can get your family and any support staff to help with ideas.

In addition, you could also think about what makes a best day and a worst day. Both of these questions will give you information about what needs to be built into your relative's day and what needs to be avoided, which will be really helpful when planning for the future. There is a blank template at the back of the guide.

What are our hopes and wishes for the future?

Once you begin to gather information about your relative's current life you will start to get ideas about the changes they would like to make.

The questions you can ask at this point are:

- What are their hopes and wishes for the future?
- What are our hopes and wishes for the future for our relative? (Everyone close to them should be included in giving their ideas. Siblings, for example, may have different views from parents.)
- What would a good life look like?

When thinking about what a good life would look like, people may wish for things that don't seem possible at the moment, like finding a job or having their own place to live, but it is still important to write them down so they are not lost sight of. Over time, they may be able to work towards these goals with the right support.

Martha and Diana's story

Diana, who was 25 years old at the time, seemed unhappy with life. She was spending most of her time at her day centre in the garden (even when it was pouring with rain), and reluctant to go out of the house at weekends and had almost stopped speaking. Her family was very worried and she was being seen by services as having challenging behaviour.

A small group of people who cared about Diana got together to discuss some of the person-centred planning questions. When it came to the question about hopes and wishes for the future, Diana's mother said she had always hoped Diana would get some work in dancing or theatre as she had shown a lot of talent at college.

This led to a discussion about the groups and activities that Diana could be involved in to dance and act. Her family was supported through the process of applying for a direct payment so that Diana could go to creative activities she enjoyed rather than going to the day centre.

Over a period of months Diana became more like her previous confident self, joining in groups and trying new things with her support worker. Her family felt more hopeful about Diana's future and more able to plan for the years ahead.

This is a good example of a person-centred support plan.

Who are the important people in a person's life?

Thinking about who is important in your relative's life and how these people can help them to have more opportunities is central to person-centred planning. They could contribute by giving ideas and solving problems, making links with people or supporting them to take part in activities. You could start by drawing a 'relationship map' showing who is currently involved and who might get more involved (see template at the back of the guide).

Building a history/story of a person's life

It is really helpful to put together your relative's history or personal life story – some families may find this the easiest place to start in their person-centred plan. A personal history is useful because it:

- gives a sense of history that can be used to inform and shape the planning that you are going to be doing now as well as in the future;
- can be shown to people who meet your relative socially or through work and to people who support your relative (if your relative gives permission); this is especially important for individuals who have limited verbal communication as it enables them to let other people know who they are and the important things that have happened in their life.

Putting together the story of a person's life is closely connected to the ideas in Section 4 about making sure personal and family history and memories do not get lost through creating memory boxes and scrap books (see page 55).

Why person-centred planning is different

Most parents will have been involved with care planning and reviews for their son/daughter. This usually means identifying problems and then looking to see which services can be used to solve them. But this reliance on services can be a disadvantage because, for example, people can become isolated from places and activities in their local community. Person-centred planning involves a different way of thinking; it explores how a person would like their life to be and helps them to get the support to achieve this. This may be through services or paid support, but also from family and friends. Also, it can lead to doing more things in mainstream services and meeting people in the local area.

You can use person-centred information, gathered from the questions above, as a lever to make a case for what you think your relative needs; this could be funding for support or equipment or it could be the kind of place to live. When you go to a review or a meeting to look at a care or support plan you can use the information to back up what you are saying.

Person-centred planning is helpful because:

- the person is at the centre of any planning that takes place (rather than having to fit in with the services on offer);
- family and friends are seen as important people in the planning as they have the best interests of, and important knowledge about, a person;
- it identifies what is important to a person now and for the future and it builds support around this information;
- it helps a person to be involved in their community (rather than being isolated or spending all their time in services);
- it leads to action – making sure that things change in the way the person wishes and that this continues over the years;
- it can help to shape a support plan and provide evidence as to why funding is needed.

Getting other people involved with person-centred planning

Person-centred planning is a good way of getting other people involved in your relative's life – this could be people who already know them well or it could be a way of encouraging people who currently don't know them so well to become more involved. It can help build a group of people or circle of support around your relative.

Person-centred planning can bring together knowledge and skills from different generations. For example, parents often have a better idea about how services work, whilst people from younger generations, such as siblings, nephews and nieces, may have better knowledge of problem solving using technology or linking up with community activities. This range of perspectives can help identify different ways of creating opportunities or tackling problems.

Through involvement in person-centred planning, people may develop a commitment to your relative that may continue after you have died (see Section 8: Keeping an eye on things); this may be through keeping in contact, doing activities together, keeping an eye on things where they live, being an advocate or being a trustee for a discretionary trust (see Section 5: Making financial plans).

You may initially think that you don't know anyone who could get involved in planning, but don't let this put you off – use some of the 'tools' above and once you start to plan you may realise there are several people you feel you could ask. There are more suggestions about involving other people in planning with your relative under 'Building a network of friends or circle of support' in Section 3.

Everyone who knows your relative can share their knowledge of past events and experiences, but parents, siblings and other family members are most likely to have the largest input. The person-centred plan is a form of legacy for your relative, giving a sense of their identity and history.

How to make sure your relative is at the centre of a plan

Your relative may be able to say how they would like to plan: who they would like to be involved and where and when they would like to meet with people. However, if they would find this difficult, you can think about what would work for them and try out different ways of making them feel at the centre of what is going on.

Here are some suggestions for helping your relative to be as involved as possible in the planning:

- Let them lead as much as possible: choosing who they would like to plan with, where and when to plan, and doing it at a speed that works for them.
- Use drawings, pictures, photographs or any other media that work for them.
- Make sure the discussion is directed to them rather than around them (i.e. not talking about them in the third person).
- Give them space to think through their ideas about the future and support to say what they think – sometimes this may not be what you are expecting to hear.

Using person-centred planning to make changes

Person-centred planning can be helpful in making both small changes in a person's life and much larger decisions, such as planning living arrangements. It is good to practise first with small decisions. These could be about:

- meeting up with old friends or making new friends;
- getting involved in something that is happening in your local community;
- what to do at the weekend.

These smaller decisions contribute to planning for the future because they help develop a sense of involvement in decision-making about their own life (see Section 1: Making decisions) and encourage more confidence and assertiveness. Even if your relative is not able to make decisions you can learn from how they respond whether a decision was the right one. You will get to know more about their preferences and have a clearer picture of what they would like to see happen in the future.

A 'learning log' is a tool that helps you to gauge how well any changes have gone. It can be used by your family and by people supporting your relative, such as support workers funded through a personal budget. They can keep a log of your relative's activities based on their observations and use the 'learning' to plan further activities. The log helps to build on success and avoid repeating things that don't work well.

This tool is particularly helpful if you feel unhappy with the way your relative is being supported; it can also be used in a positive way to work with a service or support worker to make improvements.

Learning log

Date	What was the person doing?	Who was there?	What did you learn about what worked well?	What did you learn about what didn't work?
What have we learnt that we need to do differently:				
What have we learnt that we need to keep doing the same way:				

What is important to and important for...

Important to (a good life)	Important for (a safe and healthy life)	What this means for making a support plan



Questions to ask

In line with the Care Act, who in my area could help us to use person-centred approaches to help us shape a care and support plan?

How can we find other families who have experience in person-centred planning or are starting out and would like to share ideas?

Is support available to make a health action plan or a hospital passport?

If person-centred planning leads us to identify needs that have cost implications, how can we get funding for this?

Who in the area could help me to think about my needs as a carer and develop a support plan?

Whom to ask

Contact your local authority, family support groups or advocacy/speaking-up groups.

As above.

Contact your learning disability health team or GP.

Talk to a care manager about the needs that have been identified and use the person-centred information to make a case.

Contact your local carers' centre or family support groups.

Notes



To find out more you could look at

What is person-centred planning? This website gives detailed information about the questions to ask to gather person-centred information. There are also video clips showing how to use them.
<http://www.helensandersonassociates.co.uk/person-centred-practice/>

Christian's circle is a video clip about how Christian's circle has used person-centred planning to support him in his life, including moving home. His mother explains how helpful it has been to have others contributing ideas, especially as Christian has complex support needs.
<http://www.learningdisabilities.org.uk/our-work/changing-service-delivery/an-ordinary-life/>

For a template for a hospital passport you could look at
<http://www.easyhealth.org.uk/sites/default/files/Hospital%20passport%20-%20JBC.pdf>

We Can Dream is a booklet showing how person-centred planning tools can be adapted for people with autism, making allowances for their particular needs and preferences.
<http://www.learningdisabilities.org.uk/our-work/getting-the-right-support/we-can-dream/>

My Kind of a Future is a workbook for young people with learning disabilities to help them prepare for the future after school or college.
<http://www.learningdisabilities.org.uk/publications/my-kind-of-a-future/>

Guidance for Families of People with Learning Disabilities and Practitioners in Developing Culturally Competent Planning is a booklet for families to give ideas about how to include aspects of their culture in person-centred planning.
<http://www.learningdisabilities.org.uk/publications/reaching-out-planning/>

My Cultural Life Plan is an easy-read workbook for people with learning disabilities to think about important things in their life and culture
<http://www.learningdisabilities.org.uk/publications/my-cultural-life-plan/>

Delivering Care and Support Planning: supporting implementation of the Care Act 2014 gives lots of background information about care and support planning.
<http://www.thinklocalactpersonal.org.uk/Latest/Resource/?cid=10464>

3. Building friendships and support networks



Why friendship and support networks are important

We all need to have a variety of people involved in our lives. The Care Act recognises the importance of contact with family and friends as well as being connected with the wider community. One of the eligibility outcomes in the Care Act is 'developing and maintaining family and other personal relationships'.

A network of friends and family is especially important to people with learning disabilities who may outlive their parents or other close family. Some people with learning disabilities have told us that they would like to know that other people will be around for them when their parents pass away, to make sure they have a good life and are safe and well.

Parents usually say that they cannot expect anyone else to provide the same level of love, support and interest in the life of their son/daughter. One of their concerns is that their son/daughter does not have a support network of friends, colleagues and acquaintances and that this may make them vulnerable when they are no longer around. However, parents can help to create friendships and support networks around a person. If these people are also encouraged to be in contact with each other, they can work together to 'keep an eye on things', come up with new ideas and solve problems as they arise.

The more people involved in your son/daughter's life, the safer they are likely to be. For people who find it difficult to communicate their needs and wishes it is even more important that there are people who can speak up for them. Having a number of people involved helps to keep things going even when one or more of them face changes or pressures in their own lives which mean that they need to take a back seat. This will be inevitable but it doesn't mean they won't get involved again when they are able to.

Developing friendships and an informal support network (i.e. not paid people) is not meant to be a substitute for services and paid support, but rather a complement. The two should work together to improve the person's life.

Sometimes these support networks develop naturally; some people with learning disabilities are natural social connectors and draw lots of people into their lives. Others find it difficult to meet new people and to go out to new places. So how you go about developing this will depend on your son/daughter's personality and preferences.

This section looks at:

- building friendships with other people with learning disabilities;
- involving siblings;
- building a network of friends or circle of support.
- peer advocacy and citizen advocacy

Building friendships with other people with learning disabilities

When we talked to people with learning disabilities about who helps them to get by they told us about their friendships with other people with learning disabilities: 'Our friends are an important support – we need help to make these strong'.

Friendships between people with learning disabilities are often undervalued and the importance of peer support is not always recognised. Yet they are important because:

- they provide mutual support, both practical and emotional;
- they boost confidence and self-esteem, making people feel safer and open to exploring new opportunities;
- having genuine friends prevents people from feeling lonely; they are less likely to be abused by people who pretend to be friends and take advantage, for example by asking for money.

Latif and Abdul's friendship

Latif and Abdul share a house and receive 24-hour support. When you meet them you soon realise that their friendship is very important to both of them and helps them to achieve the lifestyle they like.

Abdul does not use words to communicate and finds it difficult to say whether he is happy or not about something. Latif uses some words and Makaton (sign language) to communicate and is very good at speaking up about whether support staff are doing their job properly. Latif has spoken up for Abdul when his support has not been good enough.

Abdul's family are very happy that they are sharing a house as they get on well together, and they also feel it helps Abdul to have a better quality of life and keeps him safer. Latif enjoys living with Abdul as he likes his calm nature which creates a peaceful atmosphere at home.

Parents usually know who their son/daughter is friendly with at activities they attend (day centres, colleges, etc), but they do not always create opportunities for them to meet outside of these places. If they stop attending the activity, they often end up losing contact. Parents can support friendships by:

- inviting friends to be part of family activities: celebrations, day trips, etc;
- providing opportunities for them to meet outside of organised activities: at each other's houses, or meeting up to do something together (with any necessary support);
- giving information to paid supporters about past and present friends so that connections are not lost and having an expectation that paid supporters will maintain and build friendships;
- involving friends in a circle of support (see below);
- looking at how technology, such as a mobile phone, PC or laptop, as well as social media, such as Facebook and Skype, could help to keep in contact with friends and to make arrangements to meet up.

Involving siblings

Parents who have other children sometimes find it difficult to involve them in planning for the future, or to gauge to what extent they should do so. This can be because they want them to 'get on with their own lives'. On the other hand, sometimes there is an assumption that another son/daughter will take over their role. Many siblings have told us that they want to discuss this with their parents so that they can have an honest conversation about what they can realistically do or not do. Some siblings say they do not know how to broach this as their parents are reluctant to

discuss the future, yet they are very worried about what is going to happen when they become too ill to provide care.

It is important that these discussions do not happen without involving your son/daughter with a learning disability as it can be assumed that they would like to live with their sibling, for example, whereas they may prefer to live with friends or on their own.

The involvement of siblings and other family members is backed up by the 'whole family approach' within the Care Act. The care and support plan should think about all the family and make a plan that works for everyone.

How siblings can help

Siblings can make many positive contributions:

- They will usually have grown up alongside their brother/sister so they will share a family history and understanding.
- They are of a similar generation to their brother/sister so are likely to make different suggestions from their parents.
- They can help to broaden the social network of their brother/sister and help them to connect with members of their extended family and/or take up new activities.
- They will hopefully still be fit and healthy when you are no longer around and will therefore be able to continue providing a family link and have a 'checking' role to make sure your son/daughter is being well supported.

It is helpful if any arrangements, such as financial planning or accommodation, are discussed and wherever possible written down so that siblings can plan their lives around the commitments they want to have to their brother/sister. However, siblings are not the only people who can take on these roles, so it is still worth involving other people in your son/daughter's life.

Building a network of friends or circle of support

Most of us have to cope with the loss of our parents and it is our network of family and friends that help us through this difficult time. People with learning disabilities may need extra help to deal with the loss of parents or main family carer as they may be more dependent on them than other adults who are likely to have had greater opportunities to leave home to go to college, find work or get married. Therefore it can be helpful to actively develop a support network or 'circle of support' around your son/daughter whom they can get to know and trust whilst you are still alive.

A circle of support is simply a group of people who have a commitment to a person to help them to have a good life. Families often say how helpful a circle is as it means other people contribute ideas and think of things from a perspective other than that of a parent. Some circles are informal, perhaps just coming together once or twice a year to catch up and celebrate something like the person's birthday. Others may meet more regularly and contribute to developing a person-centred plan and making sure things happen in a person's life.

The make-up of a circle of support will vary, depending on you as parents (what you would like people to help with, how much you are willing to ask), your son/daughter (what they need to happen in their life, who they would like to be involved) and the people you invite (what they are good at, how much time they have). When considering whom to invite to be part of a circle, ask people who you think have the knowledge you need to make things happen. For example, if your son/daughter likes sport, ask someone who shares this interest or who works in this field. They may be able to make new connections in your son/daughter's life.

If your son/daughter has many health problems you may want to include someone who could help to think about how to get round some of the limitations that can be caused by poor health. This could be somebody in a paid role, but it does not have to be. Other circle members may be family or friends who have a natural commitment and may well be involved in their lives for many years. You may also find there are past or current paid workers who your son/daughter gets on well with who may be keen to be involved.

What a circle of support can do (now and in the future)

A circle of support can help to make things happen now but they can also play an important role in the future when you are no longer around. A circle of support could be involved with all the areas discussed in this guide pack:

- Help with planning small and large changes – contributing ideas, knowledge and information (including, for example, planning a move from home—see Section 6).
- Help with making new connections to people and places.
- Providing friendship and a sense of belonging.
- Acting as trustees or executors to make sure after your death that your money is spent as you wish or that your letter of wishes is respected (see Section 5).
- After your death, providing continuity in your relative's life and keeping memories alive (see Section 4).
- Keeping an eye on things and speaking up for your relative (see Section 8).

Use the relationship map (see template at back of guide: 'People in my life') to help you decide whom you can ask to be involved. Parents often worry that it will be seen as an imposition if they ask people to be part of a network, or they fear they may be turned down. Yet many parents who have been reluctant to ask family and friends to get involved in person-centred planning have been pleasantly surprised that people feel valued and honoured to be asked: 'Why didn't you ask us before? We've always wanted to be of help' has been a common response. In our everyday lives we all ask people to get involved with us – 'would you like to come round and have a cup of tea', 'would you be willing to feed the cat

whilst we are on holiday', – it's the way we have built up our own support networks. If you think the worst that can happen is that they politely say no then it's worth asking. If someone does say no, then it does not necessarily mean they are rejecting you or your relative; they may have other commitments that mean it is difficult to be involved.

When getting started, you could:

- make it a sociable and informal occasion: invite people round for a drink and a bite to eat, or a small birthday celebration or meet at a comfy spot so everyone feels at ease;
- explain to people that you want to get a circle together and that you would value their ideas and support (you are not asking people to do what you see as your 'job' but to bring new things to your son/daughter's life);
- use some of the ideas in the section on person-centred planning (Section 2) to gather knowledge and ideas;
- start really small if you feel worried about doing this; you could involve one person at a time (a circle doesn't need to be big and many start small and grow).

Keeping a circle going

The circle you develop will have its own life and shape – the most important thing is to involve people in your relative's life and see what this brings. Some families use a paid facilitator to do some of the work to organise circle meetings and keep things moving. This can be helpful, especially when there are lots of changes going on in your relative's life or if you don't have the time or confidence to lead this yourself. If you would like a paid facilitator you could look at putting this in your relative's support plan and asking for their personal budget to cover the cost. This can be presented as a need, if you feel your relative requires a circle in order to prevent isolation or reduce vulnerability.

In some areas of the country there are support networks where people involved in a circle can meet together and share problems and ideas. If not, you could get together with others to start one. Alternatively, you could offer to be involved in someone else's circle in exchange for them being involved in your relative's and then support each other to keep going.

Peer advocacy and citizen advocacy

Some parents feel very isolated and they do not know whom they could ask to be involved in their son/daughter's life. If you are in this situation then you could talk to the care management team or family support groups to find out whether there is a citizen advocacy, peer advocacy or befriending scheme in your area that they could be involved with. This might help them begin to make connections with new people.

Jim's circle of support

Jim was 41 years old and living with his mother who was in her eighties. She was worried that they hadn't talked about where Jim might live in the future so when she heard about circles of support at a workshop, arranged by her local council, she thought this might help.

A circle meeting was arranged involving Jim's brother and sisters as well as a support worker who knew him well. Someone from the local church who knew the family also came. Jim was supported to talk about what he wanted to change in his life. He said he would like to feel more independent; he felt he needed to do more things with people other than his mum.

The church member offered to call on Sundays so they could go to church together and to look at other church activities they could join in. The support worker talked to the care management team and a direct payment was agreed for Jim to be supported once a week to learn to cook an evening meal at home. After a few months, Jim's mother could see that he seemed safe in the kitchen and she let him make more snacks and simple meals.

At another circle meeting the question of the future was discussed and both Jim and his mother both felt the best idea was for Jim to be able to stay in the flat where they lived and to have daily support. His mother contacted the housing association about succession of tenancy (see page 81) for Jim and the support worker helped Jim and his mother write down their ideas about the help he would need when living on his own. This was given to the care management team so they knew about their wishes.



Questions to ask

Is there any local help to develop a circle of support?

Is there any local support for people with learning disabilities to meet new people and make new friends?

Is there a community connecting scheme in our area?

Has the local authority got the contact details of siblings and other relatives, and how will they involve them in care and support planning to reflect the 'whole family approach' of the Care Act?

How can we get funding for a circle facilitator?

Whom to ask

Your local learning disability community team (care manager or health practitioner), Mencap or advocacy group should know if this is available.

As above.

As above.

Check with the learning disability community team or care manager.

When your relative has a review you could ask if this cost could be in their personal budget.

Notes



To find out more you could look at

A Guide to Circles of Support is a booklet to help families and people with learning disabilities get started with setting up a circle of support.

<http://www.learningdisabilities.org.uk/publications/guide-circles-of-support/>

Christian's circle is a video clip showing how Christian's circle has helped to make changes in Christian's life. Christian has complex health and support needs, so the circle has contributed ideas about how to use his personal budget and give him choice in his life.

<http://www.learningdisabilities.org.uk/our-work/changing-service-delivery/an-ordinary-life/>

4. Talking about difficult subjects



The importance of talking about difficult subjects

Talking about subjects of a delicate or intimate nature with offspring can be uncomfortable for any parents, and it can be even harder if your son/daughter has learning disabilities. You may feel a stronger need to be protective, and find it difficult to know how and when to broach particularly sensitive or complex subjects.

However, it is important to communicate openly about these issues, so that your son/daughter develops the confidence to talk about them and knows it's okay to do so rather than 'bottling it up' and getting anxious. In the long term, this will help them to talk to the right people and keep safe if there comes a time when you are no longer around to support them.

For parents of young people we have included some suggestions about changes that take place as they go through their teenage years and become adults. Planning for the future also involves having difficult conversations about a time when you might no longer be there to provide support, so it's important to talk about death and loss.

In this section we talk about ways of approaching the following subjects:

- puberty;
- relationships;
- sexuality;
- dependency;
- getting older;
- ill-health and ageing in loved ones;
- bereavement;
- end-of-life planning.

At the end of the section there is information about gathering memories and life stories: this can provide both an opportunity to talk about things together and a legacy for your son/daughter of their family life.

Puberty

As young people approach adolescence, they sometimes feel frustrated and confused by the changes in their bodies. If they do not understand what is happening to them, they may become worried. It is important to find ways of explaining these changes in straightforward terms and to help them understand that everyone experiences them as they begin to grow up.

The timing of these conversations is important. If you broach it too early it might not make sense and/or seem frightening. If you leave it too late the changes will already be happening and you will have missed the opportunity to prepare your son/daughter and to have made the process a little less overwhelming.

Girls need to be taught about menstruation and how to manage in a practical sense when they have their periods. They will need support to understand why they are bleeding and how to cope with physical symptoms such as cramping and bloating, and reassurance that what they are experiencing is normal. They may also require support to understand and manage their mood swings at this time. If toileting is an issue and your daughter wears an incontinence pad, you may want to ask your GP how to handle the hygiene issues related to menstruation.

Masturbation is another sensitive issue that may need to be dealt with. The best approach is to explain that it is something that should be done in private and not in front of other people. You can tactfully move your son/daughter into their room if they start to masturbate in front of others; this will help to establish the bedroom as the appropriate place for this activity.

Relationships

We all learn about ourselves through our relationships with others. Your son/daughter will have made a fine start with this through their relationship with you and other members of their family. They will also have developed relationships with other people such as friends, teachers and support workers.

From our relationships and interactions with other people we learn:

- that other people are interested in us – this builds our self-esteem;
- to be interested in others – this extends our interest in the world around us;
- to negotiate and compromise;
- to be caring and kind;
- to be assertive and not let people do things to us that we do not want;
- what we like and don't like in other people.

Helping young people and adults learn how to build and sustain relationships of all sorts will stand them in good stead throughout their lives. It will help them establish good friendships beyond their family and keep them safe as they learn to recognise and reject exploitative relationships.

It is important to know that we are loveable beyond the loving relationships that we have with our immediate families. Young people and adults should be helped to learn how to form romantic relationships when they feel ready for them.

Sexuality

Young people with learning disabilities need to be able to think about and discuss sexual feelings in order to explore their own sexuality and the possibility of having safe, consenting sexual relationships. Not talking about these issues can leave them feeling very isolated and vulnerable to people wishing to take advantage. It is often easier for a sibling or peer to have these types of conversations, rather than a parent. Alternatively, you could ask a health professional for assistance/advice.

Dependency

For many people with learning disabilities there is a slow realisation that they are not becoming as independent as other young people around them who don't have learning disabilities. This is especially the case if they have siblings. This dawning recognition of difference and in particular of dependency can be very painful and difficult to manage if it is not mentioned or acknowledged. Helping your son/daughter recognise their strengths as well as their dependencies can be one way of addressing this.

Person-centred planning (see Section 2) involves looking at the positive attributes of a person; questions such as 'What do we like and admire about.....?' and 'What are your hopes and dreams for the future?' can be a starting point for discussion and exploring how they might gain more independence. You could use the template on this page to talk with your son/daughter about this subject and decide what steps to take.

Steps to gain more independence

I would like to gain more independence with these things	Who can help me?	What will we do?
I would like to get more confident about being with other young people and make new friends.	My sister, my cousin	Find out about youth clubs and groups and what they do. Check whether they are physically accessible. My cousin will come along with me.
I would like to get used to staying away from home without my parents.	My friend, our parents	My friend and I will stay at each other's houses more often. Our parents will help us to look for and plan a supported holiday to go on together. I'll need a lot of reassurance from my parents and sister.
I would like to learn to look after my clothes.	My mum	Sort through my laundry basket every few days and wash some of the things with advice from Mum. I don't want to use the iron.

Getting older

Many people with learning disabilities miss out on the usual milestones of growing older: having a career, getting married, bringing up a family, having grandchildren, retiring and drawing a pension. It can often be difficult for people with learning disabilities to recognise that they are becoming an older person themselves. Sometimes they can be so well protected by family members that they continue to feel like the child in the family and have no sense of being an adult at all.

It is important to help a person with learning disabilities to learn about becoming older. It is a transition just like that of growing from a child into a young adult, and likewise it has its challenges. As your relative gets older they may need your support to understand why they no longer have the energy that they once had. Body changes and loss of agility may be frustrating for them. Women will also have to contend with the physical changes and symptoms as well as any difficult emotions that come with the menopause. It is helpful to explain all these changes as it can be very worrying to experience them without understanding the reason for them.

Here are some practical things you can do:

- Ensure your relative has an annual health check with their GP as well as regular health screenings which should include sight, hearing and cancer screening.
- You can ask your GP for a double appointment so that your relative is given time to talk and explain how they are. This will also enable the doctor to develop a relationship with them in preparation for a time when they might need to see each other more regularly.
- Dementia can affect people with learning disabilities at a younger age, particularly those with Downs syndrome. You can ask health professionals to take a 'base-line assessment' (assess their skills now to use as a benchmark) whilst your relative is young and healthy so that they can keep an eye out for any signs of dementia as they age, since it can be harder to detect in someone with learning disabilities. The earlier it is detected the more easily support can be put in place to minimise anxiety and distress for everyone.

Ill-health and ageing in loved ones

It can be difficult for people with learning disabilities to see their parents and other close family members getting older and frailer, especially if no one is talking with them about the changes that they see. Many older people with learning disabilities who live at home with their parents worry about what will happen to them if their parents are no longer able to support them.

They often keep this concern to themselves but, when asked, feel relieved to talk about it and to make some sort of plan for the future so that they know what will happen. It is preferable to have these conversations before there is a crisis so that time can be taken to discuss, consider, plan and put into place some of the practical things that might need to change. (Section 7: Making a plan for emergencies gives some suggestions for how to make a start with this.)

It can be particularly distressing if a parent or another relative develops a serious condition such as dementia. They may do confusing things and a parent may be unable to recognise their son/daughter. It is very important to explain the changes to the person.

A proactive approach to providing information on emotional and sensitive matters is always best. Here are some ideas for tackling sickness and ageing:

- Talk about story lines regarding serious illness in favourite television programmes or films. They provide an opportunity to discuss the practical things that are happening and the different characters' emotional responses, and to help your relative recognise their own responses to what they have seen.
- If a friend or more distant relation becomes unwell it is a good idea, if at all possible, to get your relative to understand what is happening. It is less distressing for them to learn about serious illness for the first time if it does not involve a close relation.
- If a parent or sibling does become seriously unwell it is important to answer the questions that your relative poses honestly and straightforwardly. It is also important to involve them in visiting and caring for the person, in a way that they are comfortable with. This will help them notice the day-to-day changes and not be taken by surprise if the person declines. It can also help them feel that they have played a useful part and done all that they could have done, which will help them with their grieving if the person dies.

Bereavement

Most people with learning disabilities will experience bereavement at some point in their lives. They may outlive their parents and the pain of this experience is likely to be harder to work through if it is the first death they have been involved with.

People can experience bereavement at any point in their lives and many people with learning disabilities may have experienced more childhood bereavements than their peers because they may have been to school with children with life-limiting conditions. Schools are not always good at supporting the school community with grieving and so many of these losses may have gone unacknowledged. Memories of previous unresolved losses may be triggered by a current loss, thus exacerbating the grief and getting jumbled into discussions about the current bereavement.

Breaking the news about a death can be a challenge, not only because it is an emotional issue, but also because it can be difficult to know how to explain to a person with learning disabilities something that is so hard to understand. It is important to know that breaking bad news is a process, not an event.

People will need time to talk and time to get on with other things. There will be times when they do not want to think about their loss at all. Sometimes it may seem as if they have not heard, but this can be a way of coping: it may take a long time for the person to really register even the smallest part of the reality that is being told to them. Most people will need to be given information more than once in order to take in such enormous news; they will need time to process what they have been told and to ask questions. Visual aids such as photographs or resources such as the Books Beyond Words series (see information at end of section) may be helpful.

Dealing with bereavement is usually made a bit easier if talking about death and dying has been a normal part of life for your relative. It is important to prepare and plan ahead for the inevitability of losing people who matter. This can be done in a number of ways: as suggested above, under 'Ill-health and ageing', by talking about deaths of characters in television programmes, or by involving the person in discussions and rituals on the death of family members, friends, acquaintances or even pets. This will help them to know that death is part of life even though it is sad and painful.

End-of-life planning

Talking about end-of-life and funeral arrangements can be very difficult, but involving your relative will make them feel more connected with what is happening and thus better able to cope with their grief. In Section 5: Making financial plans you will find further information on this subject. Your relative may also wish to plan their funeral and have their thoughts put in writing.

You may also want to consider what would happen if your relative developed a life-limiting condition or became terminally ill. People with learning disabilities have produced some uplifting resources about end-of-life planning (see end of this section). With support, they may be able to think about how they would want to be cared for. If they lack the capacity to talk about it themselves, you may wish to discuss it with other relatives or friends, based on what you know is important to your relative. If you have begun to look at person-centred planning, the information you have gathered could be used as a starting point. See 'Advance decisions to refuse treatment' in Section 1.

Gathering memories and life stories

Sharing life stories and memories can help people with learning disabilities to develop and affirm their sense of identity. Parents and other close relatives can really help with this by finding ways to support their relative to remember important life events, significant people and everyday memories. These memories become even more important when the person moves away from the family circle, for example, when leaving home, or when their parents die.

One way of doing this is to create a memory book or box with your relative.

Life story or memory book

The best format for a memory book is a loose-leafed folder which can be added to over the years as new memories are created. You do not need to start at the beginning of someone's life; in fact, it is better to make each page as and when a particular event or person comes to mind or into conversation. The pages can be put in chronological order at a later date.

Family photos can be copied and added to the book. It is a good idea to write names and captions for photos and cuttings. Capturing small details of the memory in the accompanying words can help the person to reminisce and share their experiences with others. One person's memory book had a photo with the caption 'This is my family and I am having a picnic tea at my Aunty Mabel's. It was funny that day because our dog "Patch" ran off with the cake and Mum got very cross with him'.

Memory boxes

Another way to help your relative reminisce is to create a memory box. For some people with learning disabilities a box can be more appropriate than a book as it can be multi-sensory. A memory box can take many forms: it could be a small case, a box file or a cardboard stationery set of drawers.

First think which senses are particularly important for your relative and how they might best experience and remember key events and people. Then consider how you might capture this in a memory box. For example it may be through smell – the favourite perfume of a particular person; or through taste; or perhaps the feel of an item of clothing, a soft toy or pebbles from a beach. Add to these items some instructions and connected memories, so that your relative can be supported to reminisce in an enjoyable and sensitive way.

Further information about making a memory box is available in Talking Together (see information at end of section).

An alternative or addition to a memory box is a Talking Photo album in which a message or further information can be recorded to accompany a photograph or picture.



Questions to ask

Where can we get help for our relative who needs support to cope with feelings of loss and bereavement?

Whom to ask

Your local community learning disability team or your GP.

Notes



To find out more you could look at

The National Autistic Society has produced information for parents to help them talk with their son/daughter about puberty, sex and relationships. It is written for parents of people with an autism spectrum disorder but is also very applicable more generally.

<http://www.autism.org.uk/living-with-autism/communicating-and-interacting/sex-education.aspx>

Books Beyond Words is a series of books that tell stories in pictures to help people with learning and communication difficulties explore and understand their own experiences. The books are a helpful resource for all sorts of difficult topics including love and relationships, health, death and bereavement. They cost approximately £10 each.

Some titles include: **Susan's Growing Up** by Sheila Hollins and Valerie Sinason, **Falling in Love** by Sheila Hollins, Wendy Perez and Adam Abdelnoor, **Loving Each Other Safely** by Helen Bailey and Jason Upton, and **Ann has Dementia** by Sheila Hollins, Noelle Blackman and Ruth Eley.

<http://www.booksbeyondwords.co.uk/>

We're Living Well but Dying Matters is a film produced by CHANGE for Dying Matters and the National End of Life Care Programme, about including people with learning disabilities in discussions around death, dying and bereavement.

<http://www.dyingmatters.org/page/were-living-well-dying-matters>

Breaking Bad News is a website, written by Irene Tuffrey-Wijne, that gives guidance about how to support someone with learning disabilities to deal with bad news, which could be regarding health, family relationships such as divorce, someone important who provides paid support leaving, or a pet dying.

<http://www.breakingbadnews.org/ten-top-tips-for-breaking-bad-news/>

Easyhealth is a website that has accessible (easy words and pictures) information about health. It has hundreds of leaflets as well as video clips that help to explain different illnesses and health problems.

<http://www.easyhealth.org.uk>

Talking Together: Facilitating peer support activities to help people with learning disabilities understand about growing older and living with dementia provides lots of ideas for talking about these subjects

<http://www.learningdisabilities.org.uk/our-work/getting-the-right-support/talking-together/>

5. Making financial plans



Why financial plans are important

Making decisions about leaving your money and possessions (assets) is an important part of planning for the future. If you are able to leave something for your relative with a learning disability, this could provide them with additional choices and flexibility in their life and enable them to spend money on things as their needs change. This should be done in a way that will be recognised in law rather than relying on a friend or relative to informally put it in place.

The following information only provides an overview of what you may want to consider; there is more detailed information in the publications listed at the end of the section. It is recommended that you get additional advice from a legal professional who specialises in this area of work in relation to disabled people.

This section looks at:

- making a will;
- discretionary trusts;
- leaving your property in your will;
- disabled persons' trusts;
- lifetime trusts;
- appointeeship and suitable persons.

Making a will

This checklist sets out the different things you need to think about:

	What you want to achieve in your will
	Choosing a solicitor
	Choosing your executors
	Choosing your trustees
	Choosing guardians
	Making gifts
	What you want to happen with everything you own
	Funeral arrangements
	Letters of wishes

What you want to achieve in your will

You need to start by thinking about what you own in terms of money and possessions, either broadly or in detail. If you want to look at it in detail, it may help to make a list and then decide what to leave to whom.

There are various options:

- Leave everything to one person.
- Leave everything to one person except some itemised gifts.
- Divide everything between two or more people.

When you are dividing things you need to decide on the share/percentage you wish to allocate to each person.

It is also helpful to think about what you would want to happen if the people in your will died before you (this can be covered in what is sometimes called a 'catastrophe clause').

Choosing a solicitor

It is best to get the advice of a solicitor to draft a will. You need to find a solicitor who has experience and knowledge of drawing up wills and setting up trusts for families with a disabled relative. You could ask Mencap for their list of specialist legal professionals who have this knowledge (see contact details at the end of this section) or you could ask other family carers or local carers' groups whether they know of a local person.

When you phone a solicitor, ask if they are familiar with preparing wills that look after someone with a learning disability and their fee for doing this. If the solicitor is familiar with this kind of work, they should be able to give you a quote there and then. If they are hesitant, it may indicate that they do not have enough experience of this type of work and you should therefore look for someone else. You should feel confident that they understand your requirements.

If you feel you might be more comfortable talking to a solicitor at home, ask whether they will make a home visit and if there is any additional charge for this. A home visit could give the solicitor the opportunity to meet your relative – this could be beneficial when drafting your will.

Choosing your executors

An executor is a person you officially choose to make sure the wishes in your will are carried out. Their role is to find out what there is in money terms, check if there are any outstanding debts, apply for a grant of probate, collect any money or assets and pay debts and then deal with your estate as set up in your will.

You can choose up to four executors, but two are usually sufficient. You need at least two if you are setting up a trust and the executors are also going to be the trustees. The combination of people will depend on your circumstances. They can be family, friends, colleagues or professionals, but it is a good idea if at least some of them are younger than you and geographically close. It is also advisable to include a solicitor if a significant amount of money is being left.

Choosing your trustees

Trustees are responsible for looking after any trust that arises in the will; this could be a discretionary trust (see definition below) or a trust for any children under the age of 18. Your executors can also be the trustees; it's advisable to include someone who knows your relative well. If you have set up a circle of support (see Section 3: Building friendships and social networks), you could ask circle members to be trustees and, in addition, select a solicitor (or another professional such as an accountant).

When asking people if they would like to be a trustee you should explain that it needs to be both a long-term and an active commitment: there is no point your relative having resources in a trust if the money doesn't get spent. It is important to have at least one trustee who is not also a beneficiary of the trust.

Choosing guardians

If your relative is under the age of 18 you may want to think about choosing guardians who would look after them until they reach the age of 18. You would need to discuss this in detail with anyone you were considering appointing. If you have set up a trust, guardians need to understand the role of your trustees in managing the trust for the benefit of your relative. If you do not appoint guardians yourself, the Court of Protection would be involved in doing so, should the need arise.

Making gifts

Making a will gives you the opportunity to leave special things to your relative; this could provide them with precious memories of their family and family life and give them a sense of connection with their past (see 'Gathering memories' in Section 4: Talking about difficult subjects). They could be items such as photographs, jewellery, objects or furniture from your home. You could talk to your relative about it and ask what is special to them. Everything not left as 'gifts' is sold with the house and the proceeds are put into the estate. You might want to leave something to people whose friendship you have valued or to an organisation or charity that you have been involved with. These can be gifts of money.

What you want to happen with everything you own

When you are thinking about how to leave your estate, you may find it helpful to start by considering who you are morally obliged to. Most married couples want to provide for the spouse who is left. If there are likely to be inheritance tax issues, it is advisable to get professional advice.

Your next consideration is how your estate is to be divided after the death of the surviving spouse. You can divide it into however many shares or percentages you want. If you have other children without disabilities, you may want to consider their needs (for example how financially independent they are) before deciding on the percentages to leave to different people. It is not advisable to ask another person to look after the share bequeathed to your relative with a learning disability: it can lead to arguments between family members and a possible failure to carry out your wishes.

If your relative with a learning disability is receiving local authority funding or means-tested benefits, you need to protect their inheritance by setting up a trust with your will. If you do not leave a 'reasonable' amount to your relative, your will could be open to a challenge from the local authority and you would need to be able to provide a good reason for your decision.

Funeral arrangements

Your executors are responsible for organising your funeral; family members can also be involved if they are not the executors. Whoever organises your funeral needs to know what your wishes are. In a letter of wishes that goes with your will (see definition below) you can give any instructions for your funeral, including your preference for burial or cremation, your preferred location for the scattering of ashes, details of the ceremony and how you would like your relative to be involved. It may be a good idea to discuss your funeral plans with your relative, as it may help them to cope better at the time, especially if they have little or no experience of funerals.

Your relative may like to contribute to the planning: for example, at a Christian funeral they could select a hymn or reading.

Letters of wishes

A letter of wishes is a way in which you can give instructions and guidance on your affairs. It is not a legal document so there is no guarantee that it will be followed: it is important that you choose executors whom you trust to act on your wishes. However, because it is not a legal document, it is easier and less costly to update as and when circumstances change.

Discretionary trusts

A discretionary trust can be used to ensure money, property or investments are protected so that they are still available for your relative. It involves the legal transfer of the assets to trustees who then have a discretion (choice) as to how to deal with these assets. The discretionary trust would need to name more than one beneficiary but this can be achieved by naming a group of people that would include your relative. Trustees decide which of the beneficiaries receives help from the trust using the guidance you have left in your letter of wishes (it is important to choose trustees whom you believe will respect your wishes).

Discretionary trusts are worth considering because they can be used as a way to:

- leave an inheritance to your relative;
- set up a group of people to manage your assets (money or property) for your relative;
- prevent your relative from losing means-tested benefits and care funding from being stopped.

There are two ways of using a discretionary trust:

- To own, manage and look after a property;
- To give money that can be used to pay for things that would not otherwise be affordable for your relative.

For both purposes, the trust can be set up to be used in your lifetime (see lifetime trusts below) or in your will for your relative to inherit after your death.

In a letter of wishes you can tell the trustees how you would like them to use the money in a discretionary trust to benefit your relative with a learning disability. The money can be used for anything that the local authority would be unlikely to fund, such as holidays, equipment and additional support, as long as this does not set up a pattern of regular payments as the Department for Work and Pensions or the local authority could argue that it was income and take it into account when carrying out a financial assessment. In the letter of wishes you could say that you would like the trustees to involve your relative in discussions about how the money is used.

Leaving your property (house) to your relative in your will

You may wish to leave your house or flat to your relative with a disability with a view to them having their own home. A number of problems might arise if you leave it to them directly rather than in a trust:

- The value of the house will usually be included in any assessment for means-tested benefits or local authority funding and this may lead to your relative losing their rights to benefits and funding if they should need residential care in the future. The Care Act proposed new ways long-term care fees would be paid for but this has now been put on hold for a number of years.
- They will also need income to be able to run and maintain the house. This may not be a problem if there is enough money in the inheritance to cover these costs, but usually it is helpful to have trustees who are responsible for managing payments for maintaining the property.

Some parents try to get around these problems by leaving their property to another son/daughter and asking them to make sure that their disabled sibling has a place to live. This arrangement would not affect their benefits but it could lead to awkward situations between non-disabled siblings and there is no guarantee that a non-disabled sibling would carry out your wishes. Their family or financial situation might change over time and they might need to sell the property.

Putting the property into a trust is a way around these problems. The trustees could either keep the house as part of the trust or sell it and buy somewhere more appropriate for your relative to live. For further information about leaving property in a trust, see the Housing Options booklet listed at the end of this section.

Lifetime trusts

If your relative already has an amount of money, say, from an inheritance from a grandparent, or if you wish to put money aside in your lifetime, it can be put in a lifetime trust. Provided that the amount put into the trust is not more than the tax rules allow, it can be topped up, for example with birthday and Christmas money.

A lifetime trust can be a discretionary trust and would therefore name several beneficiaries. You would need to appoint at least two trustees to look after the assets (money or investments) that you put into the trust. It would be up to the trustees to decide how to use the assets, but you could prepare a letter of wishes setting out how you would want your relative to benefit. You should take specialist advice before setting up a lifetime trust.

Disabled persons' trusts

This is a special type of trust that can be created for or by a person with a disability but it is more restricted in the way it can be operated than a discretionary trust.

There are also detailed rules relating to disabled persons' trusts and taxation so if you are considering this form of trust you should talk to a solicitor. Discretionary trusts are usually viewed as being more suitable for someone with a learning disability.

Appointeeship and suitable persons

If a person has been assessed as lacking capacity to manage their money and receives benefits, the Department for Work and Pensions can appoint someone to take responsibility for managing this income.

If you are the appointee for your relative, you should think about who would take over this role should you no longer be able to carry out your responsibilities (which are to sign claim forms, notify the DWP about any changes affecting how much your relative can claim, ensure the money is spent in their best interests and to notify the DWP if you stop being appointee.)

Many older family carers arrange to give up appointeeship if they have a younger relative who could take up this role. In this way, they avoid a situation where their relative could be left without benefit income whilst a new appointeeship is set up. This could take several weeks. New applications can be accompanied by a letter from the original appointee which explains their wish to stop being appointee when/if the new applicant is authorised.

If you are acting as the 'suitable person' to manage a direct payment on behalf of your relative, the local authority will generally require you to have a separate bank account to handle this funding. If you are holding funds or contributing financially to a support package in any way, remember that if something happens to you, accounts in your name will be frozen and the money stops being available (for example to pay towards support workers, bills or for daily shopping).

To avoid the probate process blocking access to money that is relied on, you can set up an account with more than one signatory. The joint account should not hold an amount that will bring the savings a person with learning disabilities has access to above the lower capital limit for means-tested benefits (currently £6,000 but this may change in future financial years: you can check at www.gov.uk)

You could also find out whether there is a local organisation, such as a Centre for Independent Living, that could take over the payroll, timesheets and any other responsibilities to keep your relative's support system running smoothly.



Questions to ask

Are there any local solicitors who could provide advice about making a will and discretionary trusts?

Whom to ask

Phone Mencap Direct on 0808 808 1111 or ask other local families.

Notes



To find out more you could look at

For further information about house ownership and discretionary trusts, see
<http://www.housingandsupport.org.uk/ownership-through-a-discretionary-trust>

Mencap, **Wills and trusts: leaving money to someone with a learning disability.**
http://www.mencap.org.uk/sites/default/files/documents/2011.095%20Wills%20and%20trusts_V2.pdf

Mencap provides a list of specialist legal professionals in local areas. You can request this list and other publications about financial planning on the website.
<https://www.mencap.org.uk/webform/order-wills-and-trusts-publications>

6. Housing and support



Why it's important to think about housing and support in advance

Planning for the time when your relative leaves the family home can be challenging. Not only is it hugely emotional but it can also be difficult to get all the information you need to make a proper choice about what would work best. There is no 'one-size-fits-all' solution.

- Thinking and planning enable you to shape things around your relative and so put things in place that will work – it is not left up to someone else who may not have the same insight or dedication.
- Thinking about it doesn't necessarily mean your relative will move in the near future, but the sooner you think about it the more time you have to come up with good solutions.
- If you have started to plan you can jump at an opportunity when it comes up: for example a new house/flat that has the right facilities or is in the area where your relative wants to live.
- Thinking about where you are going to live as an adult is part of growing up and it's good if this is part of family conversations.
- It can often take some time to find or set up a suitable place to live and this is especially true for people with complex needs who often require very specific solutions.
- It often gets harder to think about such a major change as you get older.

If your relative does move away from the family home it does not mean that you won't be involved in their life. You can continue to give support by:

- using your energy to make sure the new living arrangements work;
- helping with practical things, especially if they are setting up a new flat or house;
- helping them to feel confident and safe in their new place;
- expressing your pride that they now have a place of their own; showing your approval (even if you are worried).

This section looks at:

- why it's important to think about housing and support in advance;
- ideas for getting started;
- the funding responsibility of a local authority;
- housing and support – how it works;
- family investment, including inheriting the family home;
- capacity to rent or own a property;
- succession and tenancies;
- tenancies and licences.

Ideas for getting started

Before you look at specific options, there are some general points that it may be helpful to think about:

- If you can avoid it, try not to start by asking your local authority or a provider where there is a 'space' – this could lead to your relative having to 'fit in' to something that may not be suitable.
- The starting point for choosing housing and support should be your relative's needs and wishes: where and how they want to live and whether their living arrangements will allow them to continue doing the other things they enjoy in their life (see Section 2: Planning in a person-centred way for suggestions about how to do this).
- Families usually find it helpful to talk to other families who have already supported their relatives to leave home because they can share their experience and ideas. If you don't know anyone, you could contact your local family support group or care management team to ask if they can put you in touch with other families.
- You may know, or get to know, other families who are in a similar position and you can work together; your relative may have a friend or friends with whom they'd like to live. You could get together with their families to approach your local authority.
- You can discuss your ideas with someone in your local authority (such as a care manager) or an organisation that provides services. They may be able to give advice or support to shape something new.

- If your relative will need funding for support it is advisable to talk to the local authority about your plans to ensure that adequate funding will be available.
- It's always a good idea to make sure your relative's name is on the local housing register so that the local authority knows about their potential housing need.
- Finding a good place to live does not have to be the family's responsibility: you may not feel able to do the research and planning, or your relative may wish to do it with someone else.

The funding responsibility of a local authority

If your relative will require funding from the local authority for their housing and support they will need to have an assessment of their needs. Under the Care Act an assessment needs to be appropriate (the person is asked how they would like to be involved and it takes into account what works for them) and proportionate (it should be as detailed as is needed to establish the person's needs). It should always be person-centred so information gathered from ideas in Section 2 should be taken into account.

Eligibility for support should only be decided after the assessment has taken place. The Care Act introduced the same eligibility criteria across the country to make a fairer and clearer system. Local authorities have a duty to provide an independent advocate for people who would have 'substantial difficulty' in engaging in Care Act processes, such as an assessment (see page 17).

Housing and support: how it works

There are many different ways of organising housing and support. They may be provided together as a package, or independently of each other by different organisations. When they are provided independently it can give more flexibility as you can try to match the best housing option with the best care and support option. In the past, support was usually provided by social services, but nowadays it is more likely to be delivered by private or not-for-profit care providers/organisations, or people use their funding to arrange their own support.

A personal budget means that funding can be used to pay existing services to provide support, for someone to arrange their own or a mixture of both. Similarly, this gives flexibility to 'mix and match' depending on your relative's needs and can include options such as Assistive Technology (e.g. a call button) or a support tenant. It is usually helpful to get advice, either locally from your adult social care team or from an organisation such as the Housing and Support Alliance or the Family Carer Support Service at Hft (details at end of this section), to think through the pros and cons of different ideas.

We've arranged the information about the various options in two tables to show the differences between what may already be available in your area (Table 1) and what you could consider setting up yourself, with help, if necessary (Table 2).

If you are considering options in Table 1, you need to ask whether:

- the service is in the right geographical area;
- the service has the right level of support attached;
- there are people your relative wants to share with and who want to share with your relative if it's not self-contained accommodation;
- your relative is likely to get offered a place.

You are likely to hear the term 'supported living'. Although this term does not have a legal definition it is used to mean a housing and support arrangement where someone owns or rents their home and has a say over who they live with if it is shared accommodation (they could live on their own), the support they get and how they live their lives. It can be a confusing term as it is sometimes wrongly seen as offering less support than residential care. In fact, the model of supported living is based on the assumption that all people with learning disabilities can live in their own home with the appropriate level of support. There are many examples of people having 24-hour support with staff sleeping in or being awake at night, including people with complex health and social care support needs.

Table 1: Looking at options that may already be available

Option	What this means	How support will be organised	Things to think about	How to take this further
<p>Shared house (sometimes called a group home)</p>	<p>An ordinary or purpose-built house which is shared with other people with learning disabilities. Each person has their own room and shares communal areas.</p> <p>The person should have a proper tenancy or a licence (see tenancies and licences below).</p>	<p>There is usually one provider organisation managing the support to people in the house – generally some shared support for all the tenants plus some individual support, depending on the person’s needs.</p> <p>Support is usually provided by a separate organisation from the landlord. The landlord could be a housing association, a not-for-profit provider or a private organisation/individual. The person will usually receive a personal budget through the local authority to pay for support.</p>	<p>Shared houses often work best when people know each other and choose to live together.</p> <p>There should be flexibility to increase/decrease support as needed or to change organisation/workers providing support.</p> <p>Look into the process for finding new tenants when people move on.</p> <p>Find out how the rent and bills will be split and paid.</p>	<p>Ask your local authority about the shared houses that currently exist, for example, their geographical location, which organisations provide support (then you can find out a bit more about these) and the level of core support (is it 24 hours?)</p>
<p>Shared lives (also known as adult placements)</p>	<p>A regulated service (run either by the local authority or a provider organisation) in which an individual or a family offer a place to live and support in their own home.</p>	<p>Carers are paid a fixed amount (rather than an hourly rate) for an agreed level of support.</p> <p>The person could receive additional support from someone else or a service for other activities in their life.</p>	<p>Matching the person and the carer is critical to success.</p> <p>Carers are selected and trained by a regulated shared lives scheme.</p>	<p>Ask your local authority whether there is a local scheme and how referrals are made.</p>

Option	What this means	How support will be organised	Things to think about	How to take this further
<p>Shared lives (also known as adult placements) (continued)</p>			<p>Being part of a non-biological family works well for some people but not others.</p> <p>Carers can have up to four weeks' paid breaks per year; the person living with them receives 'respite care' during this time (meaning they have to go somewhere else).</p> <p>No security of tenure as technically the person is a lodger.</p>	
<p>Residential care</p>	<p>A 'home' providing accommodation with 24-hour care. An overall fee is paid.</p>	<p>Definition of a care home is that it provides personal care: washing, dressing and giving medication.</p>	<p>Check how a care home would provide access to ordinary activities outside of the home.</p> <p>It may not be local and so it might be harder to maintain contact with friends and family.</p> <p>If you think your relative may need a higher level of support (nursing care) in the future, look for a home that provides this as well. Check whether the care home is specifically for people with learning disabilities.</p>	<p>Find out from your local authority whether your relative would be eligible for funding for a care home.</p>

Option	What this means	How support will be organised	Things to think about	How to take this further
<p>Intentional community</p>	<p>Set up for people to live together as part of a supportive community – sometimes based on social or religious ideas. Often set up as a village or with a small farm but also in urban areas.</p> <p>Well-known examples of this are Camphill and L'Arche. Can be either registered care or supported living.</p>	<p>Support is provided by the community.</p> <p>Some support is often provided by people without disabilities who live as part of the community.</p>	<p>Check the type of accommodation being provided and how secure the tenure is.</p> <p>Sharing of beliefs can be an important part of life there.</p> <p>People are usually encouraged to contribute practically to the community.</p> <p>Not usually suitable for people who find it hard to spend a lot of time with others.</p> <p>Useful to find out how much contact there is with the external community – there may be limited opportunities to meet new people.</p>	<p>You could look on the internet, ask other families or your adult social services team what is available within a reasonably local area.</p>
<p>Core and cluster</p>	<p>Self-contained flats on a single site with support on site. May have communal areas. Can be either registered care or supported living.</p>	<p>There is usually one provider organisation managing the support to people in the house.</p> <p>The support may be 24 hour or specified hours in the day.</p>	<p>Good for people who want their own front door but also want other people nearby.</p>	<p>Check if this option is available locally. If not, are there other people who may be interested in setting this up?</p>

Option	What this means	How support will be organised	Things to think about	How to take this further
Core and cluster (continued)		Support is usually provided by a separate organisation from the landlord. The landlord is likely to be a housing association or a not-for-profit provider.	Also good for people who don't need someone living in the same house/flat, but can call on support when required.	
Network	<p>A small network of people living in properties in walking distance of each other.</p> <p>Keyring is a national organisation that sets up these networks in different geographical areas.</p>	<p>There is usually a low level of support to help with things such as budgeting, maintaining a tenancy and social contact. It is provided by a support volunteer who lives nearby.</p> <p>The network of members in the area may also support each other and provide friendship.</p>	<p>Good for people who want their own front door but also want other people they know to live nearby.</p> <p>The person could look for a property in an area where a network already exists.</p>	<p>Check if this option is available locally. If not, are there other people who may be interested in setting up a network?</p> <p>Contact Keyring http://www.keyring.org/Home for more information.</p>

If none of the above options are available, or if they are not suitable, you may wish to think about setting something up from scratch. This may require more time and effort as you will have to plan for setting up the housing and the care and support individually, i.e. they will not be provided as a package. The help you get from your local authority will vary depending on the type of arrangement you are setting up, whether or not the authority has a duty and the resources available locally.

The table below outlines your main options for setting up something new. They are suitable both for people who want to share and for those who want to live alone, and can work with any support arrangement. Support could be flexible depending on a person's needs and include anything from low-level visiting support to very intensive 24-hour care and support.

Table 2: Options for arranging something new

Option	What this means	How support will be organised	Things to think about	How to take this further
<p>Renting a flat/ house on own</p>	<p>An individual can rent from any type of landlord. They could apply to their local housing register for social housing, go direct to a private landlord or use a specialist housing provider.</p>	<p>Once the person has had an assessment and been given a personal budget, the funding can be used to arrange the most appropriate support.</p>	<p>Will there be enough support via paid personal assistant, family, friends and volunteers/ voluntary group activity, to meet the person's needs and ensure they don't get lonely?</p> <p>Is the property in the right geographical area (for example, for friends, transport, shops, safety)?</p> <p>What sort of tenancy is being offered (see below)?</p>	<p>Check your relative's name is on the local housing register.</p> <p>Look at what is available in local estate agents.</p>
<p>Shared or outright ownership</p>	<p>Buying somewhere using money you already have or apply for support for mortgage interest. This can work for people wishing to share or live alone.</p>	<p>As above</p>	<p>Maintenance of property.</p>	<p>Contact My Safe Home www.mysafehome.info/</p>
<p>Family investment including inheriting the family home</p>	<p>Families can use existing property or specially bought property to provide housing for their relative.</p>	<p>As above</p>	<p>How will the property be managed now and in the future?</p> <p>Do we need to charge a rent to cover costs, repairs and maintenance?</p>	<p>See below and list of resources at the end of the section for further information.</p>

Option	What this means	How support will be organised	Things to think about	How to take this further
New build	Using housing association or private money to build specially designed properties.	As above	<p>A good option when you want a type of property you can't easily find to rent or buy, for example, for someone with mobility problems who needs ground floor accommodation, tracking hoists etc.</p> <p>Can take a long time: not a quick solution.</p>	<p>Find out if there are any new-build opportunities locally or if there is any private development or Homes and Community Agency money that can be used.</p> <p>Get adult social care team to talk to their housing colleagues.</p>
Specialist buy-to-let	Specialist disabled people's housing providers who are able to buy properties on the open market to rent on to disabled people.	As above	<p>Good choice of property as bought from open market.</p> <p>You can get works and adaptations done as well. Rents can be high so you need to check if they are affordable with housing benefit or other income.</p>	<p>Check with adult social care team how this is managed locally.</p> <p>Contact Housing and Support Alliance to find out who might be able to do this in your area.</p>
Private sector leasing	Private sector rented housing is managed by a registered provider.	As above	<p>A good option if you can't get enough housing benefit to rent directly from the private sector.</p> <p>A good option if you want a longer-term tenancy agreement than you would normally get in the private sector.</p> <p>Need to check that the overall rent is affordable.</p>	<p>Check if there is a local scheme.</p> <p>See H&SA factsheet: www.housingandsupport.org.uk/renting-privately</p>

Use the information from the tables to think about which options could work for your family

Options	Do we want to find out more?	What questions do we have?	Whom are we going to ask?
Table 1			
Shared house (sometimes called a group home)			
Shared lives (also known as adult placements)			
Residential care			
Intentional community			
Core and cluster			
Network			
Table 2			
Renting a flat/house on own			
Shared or outright ownership			
Family investment including the family home			
New build			
Specialist buy-to-let			
Private sector leasing			

Family investment, including inheriting the family home

Some families support their relative into housing, either by using inherited property, by investing in property using capital or funds raised by a mortgage (for example buy-to-let), or by extending the existing family property. They may make the property available to the disabled relative alone or to an identified group on a shared basis. Whichever option is chosen, families need to consider how and by whom the property will be maintained in the future and how much money might be required to keep it in good repair.

If a family wants a designated individual or group, other than themselves, to look after the property and charge a rent to cover repair and maintenance costs, they will need to either:

- put the property in trust, or
- lease to a third-party landlord.

If considering these options, families need to find out whether there will be any housing benefit restrictions and look carefully at tenancy arrangements. It is important to choose the right type of trust. Discretionary trusts are often recommended since the property is not taken into account when assessing the person for benefits. A discretionary trust can also manage property maintenance and repairs. It is always advisable to get legal advice from an expert in this area.

The following links go into more detail about this subject:

<http://www.housingandsupport.org.uk/discretionary-trusts>

<http://www.housingandsupport.org.uk/discretionary-trusts-and-tax>

<http://www.housingandsupport.org.uk/family-investment-in-housing>

Capacity to rent or own a property

Families often ask whether their relative is legally able to rent or own a property. See 'Mental capacity' in Section 1: Making decisions, for an explanation of the process for assessing a person's capacity to make a decision and the process for making decisions on someone's behalf (known as a best interests decision).

Renting a property

The procedures and issues relating to decision-making and tenancy agreements where somebody does not have the capacity to decide whether or not to accept a particular tenancy offer are complex. In particular there is ambiguity about when and why it may be necessary to apply to the Court of Protection for authorisation to have a tenancy agreement on behalf of the person who lacks capacity.

This is explored in detail in Chapters 3.8 to 3.10 of Choice, Contracts and Mental Capacity <http://www.housingandsupport.org.uk/site/hasa/templates/general.aspx?pageid=196&cc=gb>

Owning a property

Mortgage papers for someone lacking capacity to understand them will require the signature of a deputy appointed by the Court of Protection.

Succession and tenancies

When families live in rented housing they often ask whether the tenancy can pass to their relative. The process of passing a property on to a relative is known as succession, and it is not always straightforward. It is therefore advisable to check with the landlord well in advance.

However, you should first consider whether your relative would actually want to remain in the property. For some people the memories and familiarity would be comforting, but for others they may be upsetting. On the other hand, if they moved away from the family home, would it mean losing a local support network? Would the house be too large or too expensive for them to run on their own?

If you feel staying in the property would be a good option for your relative, you need to find out if your tenancy agreement would permit them to do so. This will mainly depend on which type of landlord you have.

Your relative would have the right to succeed to the tenancy in local authority housing as long as there had not already been a succession. For example, if a tenancy was in the name of the father, it could pass to the mother if he died. In such a case, the son or daughter would have no absolute right to stay in the property as there would already have been one succession. One way round this would be to ask whether your relative could become a joint tenant now. They would then be able to remain in the property if the other party to the joint tenancy died. If the original agreement was signed as a joint agreement between mother and father, and mother died, the son or daughter could request to be a joint tenant on the new succeeded tenancy offered to the father.

If you have a registered social landlord there is no right to succession, although guidance indicates that if all of the following criteria are met the relative should be granted a new tenancy: the property is the person's permanent home, they have lived there for at least a year and they have a housing need.

With a private landlord, who has granted an assured short-hold tenancy, there is no right to succession and no guidance to say this should be the case.

It is always worth discussing succession with your landlord as they may agree to grant a new tenancy to your relative. However, a landlord may require the person to move from a larger property to a smaller one.

It is also important to discuss succession with your local authority to find out whether they would provide any funding for support that your relative may need.

Tenancies and licences

It may be helpful to know about the different kinds of agreements that your relative may be offered and the implications of them. If your relative rents their property they will probably be offered one of three tenancy types:

1. Assured or secure tenancy: these are mainly offered by registered providers (housing associations), specialist not-for-profit providers and on properties that are managed or were previously managed by the local authority. They offer the highest level of security as any action to end the agreement by the landlord can be taken only in very tightly defined circumstances, meaning that such action is rarely, if ever, taken.
2. Assured short-hold tenancy: these are mainly offered by private landlords and in some specific circumstances by registered providers and specialist not-for-profit landlords. The agreement will be for an initial fixed period (usually 6 or 12 months but can be longer), offering either the landlord or tenant the opportunity to end the agreement for any reason at the end of the period.

If neither party gives notice, or if the original terms are not explicitly renewed, the agreement reverts to a 'periodic', which allows either party to end the agreement giving two months' notice.

3. Licence to occupy: these do not have the same security as an assured or an assured short-hold tenancy as they allow the landlord to serve immediate notice to quit at any time and for any reason. They also allow the landlord unrestricted access throughout the offered accommodation.

As well as being risky to the tenant they create potential problems in relation to the regulation requirements of the Care Quality Commission (CQC) (see Glossary). When personal care is provided in someone's own home the service provider should be registered as a 'domiciliary care' provider. However, if the property is not the person's own home, the arrangement has to be registered as 'residential care'. A licence may well be used as evidence that the accommodation is not a person's own home.

The type of landlord a person has may determine how much housing benefit they will be entitled to. If they rent privately, they will be restricted to a locally determined capped figure regardless of how much rent is actually payable. This is called local housing allowance (LHA). However, if the person rents from a registered provider (housing association) or some types of not-for-profit landlords, they may be able to have more or all of their rental costs met, even if they are higher than LHA. More details on this can be found here <http://www.housingandsupport.org.uk/housing-benefit-tenancies-exempt-or-excluded-from-restrictions>



Questions to ask

Does our local authority have written information about housing and support options for people with learning disabilities?

Is there Easy Read information or a DVD that our relative could look at?

Whom in the adult social care team can we ask to explain the different local housing and support options for people with learning disabilities and/or the process for moving this forward with our relative?

How can we find out whether there are other local families or individuals in a similar situation who might be interested in planning or setting something up together?

Whom to ask

Ask a care manager or another member of the local learning disability community team, the housing section of your council or a family support organisation.

As above.

As above.

The local care management team might know about this but it is worth talking to family support organisations such as local Mencap groups.

Notes



To find out more you could look at

The Housing and Support Alliance is a charity, working mainly in England and Wales, that specialises in housing and support. They provide information and resources on housing, supported living and rights as well as independent advice to members. Membership currently (2015) costs £25 for an individual family or £100 for a group of four or more families. Email enquiries@housingandsupport.org.uk
<http://www.housingandsupport.org.uk/home>

Choice, Contracts and Mental Capacity (2005). This is a guide written mainly for paid staff but families may find it both useful and interesting. It is available at:
<http://www.housingandsupport.org.uk/site/hasa/templates/general.aspx?pageid=196&cc=gb>

For further information about house ownership and discretionary trusts, see
<http://www.housingandsupport.org.uk/ownership-through-a-discretionary-trust>

Hft's website has useful information about using Personalised Technology (sometimes known as Assistive Technology) to help people do everyday things more easily, live more independently and stay safe. Examples of this include big picture phone to make it easier to call people, medication dispensers and alarm buttons <http://www.hft.org.uk/Supporting-people/Our-services/Personalised-Technology/>
Hft's Family Carer Support Service can provide free one-to-one support by telephone, email or letter on issues to do with housing and support (Phone 0800 801 0448 or email familycarersupport@hft.org.uk).

In Section 8 of this guide 'Keeping an eye on things' there is a checklist with questions to ask if you are looking at possible providers of housing and support.

7. Making a plan for emergencies



What is an emergency plan?

An emergency plan sets out the best way of supporting your relative in case of an emergency. An emergency plan should contain the information that helps to stop an emergency turning into a crisis.

Family emergencies can take many different forms. The need for emergency support may arise because you or another family carer:

- suddenly becomes ill or has an accident;
- needs to go into hospital as an emergency or a planned short-notice admission;
- has to be elsewhere for some other reason, for example to care for another family member or friend.

Emergency plans are often seen as tools for family carers whose relative lives at home with them, but they can be equally useful if your relative lives in their own flat and you are part of their support network.

Family emergencies may result in either temporary or permanent changes in the life of your relative. This means that planning for emergencies is very closely linked to planning for the future (see Section 9: Making a plan for the future).

Why is an emergency plan helpful?

- The nature of emergencies means that often there isn't time to stop and think about the best thing to do; an emergency plan can be drawn up when you have time to think and discuss ideas with family, friends and paid workers.
- Without a plan, decisions may be made by someone who does not know your relative well and is perhaps not the best person to do so. They may be decisions that take your relative away from the people and places that are familiar: this can make someone feel they have no one to talk to, become anxious, distressed or depressed and even be labelled as having behaviour or mental health problems as a consequence.
- If your relative has complex support needs it could be especially helpful to have a plan in place as there are often fewer available options and therefore more planning can be needed. Without this planning your relative may have to move from their local area or to somewhere unsuitable.
- It reduces anxiety as people with learning disabilities and family carers feel more in control if they have a plan that they are happy with – for this reason, it will be helpful even if you never use it.
- It's a good way to begin to think about longer-term plans; thinking about what works in an emergency can help you to determine what needs to be planned for the future.

How to make a plan

If you regularly provide a substantial amount of care, you have the right to request a carers' assessment and a local authority has a duty to respond to that request. You can have this assessment whether or not the person you care for has had a community care needs assessment or if the local council has decided they are not eligible for support. As part of this assessment you should be asked about emergencies and offered help with planning for them or signposted to an organisation who is responsible for this. If your relative has a care and support plan, an emergency plan should be included in this; an annual review could be used to develop or review an emergency plan.

The arrangements for making and using emergency plans vary between local authorities and some are better than others. If you contact your local council they should be able to tell you about the way in which this is done locally. The development of emergency plans is usually the responsibility of:

- a care manager or reviewing officer
- a carers' centre
- a local Mencap group or other learning disability support organisation, or
- an organisation that might also provide emergency care.

Most local areas have a Carers Emergency Alert Card scheme and some also have a service that provides short-term replacement support.

You may want to find out what happens in your local area before you start to develop a plan for your relative. You can then decide whether you think those arrangements would

work for your family or whether you would prefer to develop your own plan using the ideas outlined below. If you decide to use the format below it is a good idea to share it with the care management team and make sure there is an alert on your relative's records to say that they have an emergency plan and where it can be found. If your relative has a care and support plan the details of the emergency plan should be included in this.

If you are giving support to more than one relative with a learning disability, it is best to make a separate plan for each person as they are likely to have different support needs and different people involved in their lives.

We have produced a template for an emergency plan at the back of this guide. It suggests which information you should include in it. Here are some things you may wish to consider to get you started:

1. Think about who might help you to draw up an emergency plan.
2. Think about possible emergencies that might arise.
3. Put 'cushions' in place before an emergency happens.
4. Think about who might help out in an emergency.
5. Look at the support options in an emergency.
6. Make a list of what is important to and for your relative to keep them safe and well in an emergency.
7. Make a 'to do' list to put things in place now.

1. Think about who might help you to draw up an emergency plan

You could get a small group of people together – family, friends, paid workers, neighbours – and share ideas. Or you could start by sitting down with your relative and talking about your ideas together and then share the ideas with others as the next step.


2. Think about possible emergencies that might arise

An emergency that you cannot plan for or predict may arise. However, there may be some events that you think are more likely to happen because of your family situation, your own health needs, or you may have other caring responsibilities, such as for an elderly parent. You may want to think about what could possibly go wrong and use this as a basis for your planning.

What might happen?	What do we need to think about in that situation?

3. Put 'cushions' in place before an emergency happens

Putting things in place before an emergency happens will make your arrangements go more smoothly and may prevent a crisis. We have made a checklist of things to think about. You may want to add to it or amend it.

Tick box	Suggestions for what to put in place	Further information
Letting people know you have caring responsibilities		
	ICE (In Case of Emergency) number on phone. Emergency services look for this.	On your contact list on your phone type ICE and add phone numbers of people you would want to be contacted. They can alert people to the fact that you are a family carer. You can put more than one number (ICE1, ICE2 etc).
	Carer's card	Most councils or carers' centres produce a card for carers. In some areas a carer's card is part of a scheme to provide emergency support for a short period in your own home.
	Message in a Bottle 	The Lions 'Message in a Bottle' scheme is for carers to put details of the person they care for on a standard form and in a common location – the fridge. A sticker located on the outside of the fridge indicates to paramedics that a message in a bottle can be found in the fridge. Your carers' centre should know how you can get hold of the 'bottle'.
Calling for help		
	Would a Telecare call button be helpful?	Local councils usually run a Telecare scheme: trained operators are alerted when a call button is pressed following an accident or emergency and carers will come to the house (using an external key safe). There is a small monthly charge for this service.
	If you have a Telecare button, does your relative know how to use the button to call for help?	
	Does your relative know how to use a phone to call for help?	You could put emergency contacts into the 'contacts book' on your phone. Also, there are phones in which you can put the photo of the contact with their number: the photo is pressed to dial the number.

Tick box	Suggestions for what to put in place	Further information
Phone numbers		
	Does the local authority have the phone numbers of people who need to be contacted in an emergency?	You can ask the council to keep their numbers on the electronic records for your son/daughter – but you should first check that they are happy to be included on the database.
	Do the people mentioned in your plan have each other's phone numbers?	If an emergency occurs it is easier if you need to phone only one person. That person can then contact all the others on the list to make arrangements.
	Do you, and the people who will help in an emergency, have the contact number for the learning disability team and the out of hours service?	You may want to put these numbers on your fridge or noticeboard, or in your phone contacts. The out of hours number is usually reached through the main council number.
Essential information about your relative		
	Does your local authority know that you have written a plan and where it can be accessed?	You should make sure the plan is part of your relative's care and support plan. You may want to give a copy to key people, including any daytime or short breaks services that your relative uses.
	Have you written an important to/important for sheet (see below: point 6) to show what would help to keep your relative safe and well?	See point 6 for an example.
	Have you written information to describe how your relative likes to communicate and how others can best communicate with them (this is sometimes called a communication passport)?	This is particularly important if your relative finds it difficult to communicate. You could include information that would be helpful if your relative was upset or anxious.
	Have you prepared a sheet with any essential health information?	
Making sure people can get in and out of your home		
	Who has spare keys to your house?	It's helpful to say who the key holders are in the emergency plan.
	Have you shown your relative (if it's appropriate) how to unlock the front door – especially at night when you may have additional locks?	They may need to let a neighbour or the emergency services into the house if you are unwell.

4. Think about who might help out in an emergency

Some families will know immediately who might help in an emergency. Others may initially think they have no one, but will often find people who are willing to be of assistance by using some of the tools outlined in this guide (see 'circles of support' in Section 3). The more people involved in your relative's life, the easier it will be to organise support in an emergency.

People can help by doing practical things such as cooking a meal or driving your relative to hospital at visiting times. Or they can provide direct support by going to stay with them, having them to stay, or providing help at certain times in the day. They can pick up the phone to have a chat and provide reassurance.

You can use the template at the back of this guide to create a 'relationship map' of the people in your relative's life. These might be:

- family members who may live nearby or further afield (they can give support by phone);
- friends: these could be your friends or your relative's;
- paid supporters – people working in services or people employed through a personal budget. Short breaks (also known as respite) services may be able to provide support, or alternatively you may be able to get funding for some additional support from a person already working with your relative;
- community organisations – this may be a faith group you belong to, a community centre or a lunch club.

You can put the name (or a photograph) of the person whose plan it is in the centre of the map. The names of people who are more involved in your relative's life go in the ring nearest to the

centre and the people who are less involved go in the outer ring. Write beside the name who they are or how they are related to the person in the centre.

When you have filled it in you can think about how different people might help. You might also need to ask people if they are willing to be part of the plan (for example ask a neighbour whether they will keep a spare front door key or keep your relative company whilst waiting for other arrangements to be made). Use the 'to do' list (see example below) to note what needs to be done.

In the options we have included natural supports (family, friends and other non-paid people who are part of your lives) as well as paid support. Natural supports may be more within your control and your relative may be more comfortable with them. However, a paid support worker already involved in their life could play a very helpful role. If your relative is receiving social care funding, you could think about how this could be used to provide support in an emergency, for example, if they have a direct payment it could be used to fund individual support.

Making a visual emergency contact list

One family used a 'relationship map' to make an emergency contact list. They put everyone's phone numbers and photographs alongside their names. They gave copies to everyone in the plan and also put a copy on the fridge. This meant that in an emergency everyone had each other's contact details so could phone around and implement the plan. Anyone looking at the plan knew the names of the contacts closest to the person as they were nearest to the centre.

5. Look at the support options in an emergency

You may have a clear idea about what you would like to happen, but this may also depend on the nature of the emergency. Here are some things to think about when looking at the options:

- Is there a scheme for emergency replacement support in your area? This is likely to be someone coming into your home for up to 72 hours and it may be a generic service rather than specific to people with learning disabilities.
- You may need to think about immediate support and also slightly longer-term support; for example you may have a family member who would need to travel to get to your home.
- Is there a friend or neighbour nearby who might be willing to 'hold the fort' until other arrangements can be put into place?
- Think about whether your relative could stay at home, even if they would need support all the time. It is often easier to arrange support than to find a place to stay (for example a residential short breaks service) and may be less stressful for your relative as it will be more familiar.
- Does your relative have a personal budget that they are using for individual support? Would any of the workers providing support be willing and able to provide additional support in an emergency?

You can use the emergency plan template at the back of this guide to think through some of these options and then decide which work best for you.

John's story

John lives with his elderly mother in a flat owned by the local authority. John has lived in the area all his life and knows many local people. His mother is not well and may need to go into hospital for treatment. Before an emergency plan was written, John and his mother had not talked about what would happen in the future.

Through looking at the best options in an emergency, John and his mother talked about future plans and are keen that the tenancy passes to John. John said that he did not feel confident about cooking meals but would like to start doing this for himself and his mother.

The local authority agreed that John could use some of his personal budget on a worker who is supporting him to learn to cook. This worker would be able to give more time to support John if an emergency arose, such as his mother going into hospital.

6. Make a list of what is ‘important to’ and ‘important for’ your relative to keep them safe and well in an emergency

An emergency can be stressful, especially if the person who provides most of the day-to-day support is not around, perhaps because they have been rushed to hospital. There may be lots of changes to a normal day and disruptions to usual routines, causing worry and anxiety.

A few pieces of key information can prevent problems arising and help a person to feel less anxious. So it is really helpful to write down as much information as possible – particularly in the case of a person who has difficulties expressing what they want or need.

This sheet can be used as a checklist for someone who knows your relative well and only requires a reminder, or it can provide essential information for someone less familiar with their needs and preferences.

The sheet has two columns:

- What is important **to** me: here you can write all the things that your relative likes, are important in their life and that helps their day to go well.
- What is important **for** me: here you can write all the things that help to keep your relative safe and well.

Some people may have a person-centred plan (see Section 2) which will include a lot more detail, but it is always helpful to have a sheet summarising what is important in a person’s day-to-day life.

Things that are important TO me to make my day go well	Things that are important FOR me to keep me safe, healthy and well
<p>I like to start the day by being woken up gently and having my breakfast somewhere quiet.</p> <p>I speak to my brother Darren most evenings – he lives a long way away but we enjoy chatting about what we have been doing. If my dad was unwell this would be even more important to me.</p> <p>I hate showers but enjoy having a bath.</p> <p>If I have to stay somewhere away from home I like to take certain things with me. These are: my headphones and MP3 player, photos of my family, a fleece and slippers.</p>	<p>I get very anxious when anyone close to me is in hospital and need people to explain to me what is happening.</p> <p>I would need someone to arrange for me to visit my dad if he was in hospital otherwise I would go out and look for him.</p> <p>I need a reminder to take a tablet for my blood pressure every morning before I have breakfast.</p> <p>I get upset if people I don’t know touch me or hug me.</p>

7. Make a 'to do' list to put things in place now

You can use a 'to do' list, like the one below, to make a note of things you need to find out and arrange for the emergency plan. As you work through the suggestions above you could make a note of things you want to follow up.

To do	Who will do it?	Tick when completed
Check whether the neighbour at No. 46 will have a spare set of keys.		
Check whether a friend would be willing to come to the house for a few hours until a paid supporter arrives.		
Show my son how to use the phone to call for help.		
Find out about a direct payment: ask if my son could have one to one support to go to places on a Saturday afternoon.		



Questions to ask

What arrangements does my local authority have for helping families to develop an emergency plan?

If we write a plan, how can we make sure that the local authority knows about it and uses it when an emergency arises?

If the implementation of the plan costs money, how can I find out whether funding will be available in an emergency?

Whom to ask

Contact your local authority or the carers' centre.

Ask a care manager/duty care manager to arrange for an alert to be put on your relative's file to say they have an emergency plan. If you do not receive a satisfactory answer raise the issue with your local Mencap group or carers' centre.

Find out whether your relative's personal budget could be increased if an emergency arose to cover the cost of additional support, or discuss the plan with a care manager and see whether they agree that it is a realistic plan.

Notes



To find out more you could look at

The Foundation for People with Learning Disabilities has produced a booklet for older family carers that includes information about planning for emergencies. There are also booklets for siblings and people with learning disabilities.

<http://www.learningdisabilities.org.uk/publications/supporting-you-older-family-carer/>

Hft's website has useful information about using: Personalised Technology (sometimes known as Assistive Technology) to help people do everyday things more easily, live more independently and stay safe. Examples of this include big picture phones to make it easier to call people, medication dispensers and alarm buttons.

<http://www.hft.org.uk/Supporting-people/Our-services/Personalised-Technology/>

8. Keeping an eye on things



Keeping an eye on things

In this planning guide we have suggested different ways in which you can help make your relative's future settled and secure, ensuring they have choice and control over their lives as well as keeping them safe from harm and abuse. Families often say that these are the issues that cause them most concern when they think about a time when they won't be around to keep an eye on things.

Throughout this guide we've emphasised the importance of planning and taking steps to build a safe and happy future for your relative. These include:

- Creating as many opportunities as possible for them to make decisions and speak up for themselves: this includes putting together information about the best way of supporting them to make decisions and understanding their way of expressing what they prefer.
- Making sure that person-centred information about them has been put together (by your relative, you, and any other close family and friends) in a format that will help other people to understand who they are and what is important to them. This will help them obtain services and support that match their needs rather than having to fit into what is offered.
- Involving as wide a group of people as possible in your relative's life so that they know there is someone who they can talk to if they have any worries and who will 'keep an eye on things' when you are no longer able to do so.
- Involving your relative where possible in discussions about when you may no longer be around so that they are better prepared to cope with loss and bereavement – this should make them feel less vulnerable when they have to go through difficult times.

This section gives additional information about what to look out for when your relative is moving from the family home:

- What to consider when choosing somewhere to live and/or support;
- Keeping an eye on things after a move;
- What to do if you have concerns.

What to consider when choosing somewhere to live and/or support

Using the information in Section 6 you may have decided on the model of housing and support but still need to decide between different providers of that model. Don't be afraid to ask questions: the more information you have, the easier it will be to make an informed choice and to avoid any unexpected problems. Service providers should welcome families who are interested and informed.

Not all of the questions in the table below will be relevant to your relative – it will depend on whether they are living on their own, in shared accommodation, moving to a place where housing and support are provided together etc.

	Do we need to ask about this?
Overall impression	
<p>The questions below are suggestions to be considered, but you should also trust your gut reaction when you visit.</p> <p>Is there a welcoming and homely atmosphere?</p> <p>Does the physical environment seem to be well looked after and reflect the culture and interests of the people living there?</p> <p>Do tenants/residents appear to be confident and relaxed and at the centre of things, behaving as though they know it is their home?</p> <p>Is there plenty of choice of things to do?</p> <p>Do the staff seem motivated and respectful towards the people they are being paid to support?</p> <p>Do they communicate with people in an adult and warm manner?</p>	
Organisation(s) providing the housing and/or support	
<p>Find out as much as possible about the organisation(s) – is it local, regional or national?</p> <p>Is it a private company or a not-for-profit organisation?</p> <p>Does it only provide support to people with learning disabilities?</p> <p>Does it offer any specific expertise such as communication, complex health needs, positive behaviour support or building community connections?</p>	
<p>Look at its website and any information leaflets it produces – are they written in a person-centred way?</p> <p>Does the organisation produce accessible versions of its information?</p> <p>Has it produced any documentation, such as a personalisation charter setting out the standards you can expect around individualised support or a family charter saying how it involves families?</p>	
<p>Ask to see its policies on quality improvement, making complaints and safeguarding – are these written in a person-centred way?</p> <p>All housing and support providers should have a complaints procedure including an easy to read version if they are providing a service to people with learning disabilities: you will be able to gauge the provider's attitude to improving their service from the way it is written. Find out how they support someone with a learning disability to understand the process.</p> <p>Do they welcome complaints as a way of improving the service they provide?</p>	

	Do we need to ask about this?
<p>Ask the care management team about the reputation of the organisation, the history of the service you are thinking about and, if registered, how it has performed in relation to Care Quality Commission (CQC) standards. Ask them for the link to recent CQC reports on services you are considering.</p> <p>Find out whether it mainly provides a service to local people or out-of-area placements as this can influence how many other residents/tenants have family keeping an eye on things.</p>	
<p>Most importantly, ask local families involved in bodies such as the Learning Disability Partnership Board what they know about the reputation of the organisation and the specific service you are considering. Talk to individuals and families who currently use the service for their views and experiences.</p>	
Location and safety of property	
<p>Would your relative know people in the area and would they be able to travel safely to visit people and places they know?</p>	
<p>Does the area feel safe to live in and to be out and about in?</p> <p>What are the security features in the house (for example door and window locks) and is there good lighting in the area around the house?</p>	
<p>Is there a sense of local community – for example a Neighbourhood Watch Scheme, corner shop, community hall?</p>	
House sharing	
<p>Does your relative know the other people they would be sharing with?</p> <p>Do they get on with them and are there plenty of opportunities to get to know other tenants/residents before a move?</p>	
<p>What support is provided if people find they do not get on together?</p>	
<p>If someone wanted to move out, how would they be supported to do so and how would the other tenants/residents be involved in choosing who would move in?</p>	

	Do we need to ask about this?
<p>Are meetings arranged so that tenants/residents can talk and make decisions together about what they would like to happen in their home?</p> <p>How often do these meetings happen, what might be discussed and who would be responsible for making sure they lead to changes or improvements?</p>	
<p>What bills are there and how are they shared?</p>	
<p>Do the tenants buy shared furniture and equipment? If so, what happens if something gets broken or someone moves out?</p>	
<p>How support is arranged</p>	
<p>You may want to ask about how support is planned – would it be regularly discussed with your relative so they could make changes when they wanted or needed to do something different?</p> <p>Is support only reviewed at an annual review or more frequently, and how would families be involved in this?</p>	
<p>Would your relative have a say in who supports them?</p> <p>Would they be involved in interviewing new staff (whether for shared or individual support)? Would they be encouraged to describe the kind of people they like to be supported by (and those they don't)?</p> <p>Would they be able to change a support worker if they were not happy?</p> <p>Would the organisation be willing to recruit a specific worker who shared an interest or skill that would be important to your relative?</p>	
<p>How many hours of support would your relative receive?</p> <p>How many of these would be shared with others they live with and how many would be individual?</p> <p>How would you be informed of this (for example, weekly diaries, regular written reports)?</p>	
<p>Is there overnight support and, if so, how is it arranged?</p> <p>Are overnight support workers seen as part of the main staff team?</p> <p>If there is not 24-hour support, is there a 24-hour emergency number?</p> <p>If there is not 24-hour support, is there a 24-hour emergency number? How does this work and who runs it?</p>	

	Do we need to ask about this?
Quality of support	
<p>When you go with your relative to see a potential place to live or to meet a support organisation, take the person-centred information you have gathered and share this with them. See whether they respond positively and seem keen to meet your relative's needs in a creative way.</p>	
<p>Ask how the service is externally monitored. If it is done by the Care Quality Commission (i.e. residential homes and domiciliary support organisations) ask to see any reports. Do they have an independent quality-checking service and are people with learning disabilities and families involved in it?</p>	
<p>Ask how people at a senior level in the organisation find out about the views and experiences of people with learning disabilities and family carers. Are people with learning disabilities or family carers on their Board?</p>	
<p>Ask how the service is monitored and managed by the organisation – who is the responsible manager and how much time do they spend there?</p>	
<p>Find out about staff turnover – is there a mixture of people who have worked for the organisation for a while as well as new people who have brought fresh ideas?</p> <p>You could ask how long support workers usually stay. You might want to find out how staff are contracted – do they have permanent or temporary contracts?</p> <p>Do they have 'zero hours' contracts where they are paid only if there are support hours available for them to work? Some people like flexible work hours but for others it creates uncertainty and they will not be committed to the organisation.</p>	
<p>Ask how the organisation provides support, training and personal development to staff who would be working with your relative.</p> <p>If your relative has specific needs, will the organisation pay for staff to have training to meet those needs?</p>	

If you feel hesitant about any of these matters, talk to other people (friends, other family carers, a carers' support group or a care manager) and find out what they think. It is always best to look at a few organisations and places to live before making a decision as you can then make comparisons. If you do not feel positive about a support organisation or place to live that has been suggested by a care manager let them know your reasons: this should help them to understand what would work better for your relative.

Keeping an eye on things after a move

If your relative moves away from the family home, you, other family members and their circle of support still have a valuable part to play in making sure things are going well. You are likely to see your relative try new things and feel confident about their achievements: your new relationship will probably be a combination of worry about the challenges and risks they are facing and pleasure at seeing them cope in their new situation. We all have to balance taking risks and trying out new things.

The key is to try new things in a way that minimises risk. It will help your relative if you can combine expressions of pleasure and respect for their new achievements and decisions they have made for themselves (even if you don't always agree with them) whilst also keeping a watchful eye for any signs of unhappiness or worrying changes in behaviour.

You may find that your relationship will gradually change. How you shape this different involvement in your relative's life will depend on how much you feel able to do, where your relative has moved to, the level of support they need to make decisions and what you and your relative feel would work well.

Using person-centred information to shape their support

After a move families can continue to be involved with person-centred planning and are often central in keeping it going. Your relative may also choose new people in their life, those they are living with or being supported by, to contribute. They will hopefully bring new ideas and connections. If your relative has a circle of support aim to keep it going after a move; people involved can help to make a move go well and think of new opportunities.

If your relative has difficulty communicating verbally it is important to make sure they have a 'communication passport' that describes their communication and how to support them to make decisions and also explains how they express emotions and feelings such as pleasure or pain.

You can help your relative to choose photos and items to take with them to their new home: these can trigger conversations with new people providing support. A life story book can capture important times in your relative's life and these can be shared in future years (see pages 32 and 55 for more information and ideas).

Keeping in touch

Try to arrange for your relative to have regular contact with family and/or family friends. This helps to give the message to support providers that, as a family, you are still committed to your relative having a good life and also that there are people who are keeping an eye out. There shouldn't be any restrictions on when you can call in and sometimes it is good to call in without advance warning (especially if you are concerned about something). Between visits you can keep in touch by

phone, emails or Skype – a method of making video calls which means that you can connect with your relative even if they have little or no verbal communication. When you are visiting you should try to have some time on your own together so that your relative can talk about any worries (however small). Although you would not expect to go into other people's rooms, no other areas in a nursing or residential home should be 'out of bounds'. The situation is different if your relative is sharing a house as a tenant as you will need to respect the fact that it is also somebody else's house.

If there are no family members or friends that could visit your relative, you could consider putting money in a discretionary trust to pay an advocate or other interested person to visit.

Building a relationship with people supporting your relative

A good support provider will welcome the involvement of family and friends and create opportunities for you to meet in a variety of ways (for example they could support your relative to invite you for a meal). Communicate regularly with the provider and let them know how you would like to be involved.

Give positive comments when you see something good happening; it is demoralising only to receive criticism. If you have established a good relationship with the support provider, it will also be easier to raise concerns and ideas for change. Discuss any concerns with support providers at an early stage as that should make them easier to resolve. Your involvement in raising concerns will depend on how able your relative is to speak out about things they are not happy with. If they are able to explain the concern themselves you could support them to think about the best way of doing so and who could help them.

Making decisions

If your relative has difficulty making some or most decisions you will want to keep an eye on how decisions are being made on their behalf (see Section 1: Making decisions). After a move, an organisation providing support must (under the Mental Capacity Act) still involve family members in the process of assessing whether someone has the capacity to make a specific decision and in making best interests decisions. If this is not happening or you feel decisions are being made that do not seem to be in the best interests of your relative and you are not being listened to, you should ask for an independent advocate to be involved who could help to make sure your relative's wishes are properly understood. Alternatively, you could follow the complaints procedure described below.

Quality checking

In some areas, or in some organisations, there is a quality-checking service that employs people with learning disabilities and sometimes also family carers. A quality-checking service that asks residents and tenants their views about the support they receive helps to give people with learning disabilities a sense of their right to good support and to speak up. Quality-checking teams usually use a set of standards such as the REACH standards (see glossary) against which services are monitored. It may be helpful to look at the REACH standards (see glossary) to know what is realistic to expect.

Knowing how to keep safe

It's important that your relative feels safe where they live. Some considerations are door and window locks, regular smoke alarm and fire safety checks. Tenants should also know to check for ID badges when there are callers to their house. As long as they know the basic rules to follow, the internet

offers a safe way for people to keep in touch and make arrangements with friends and family. (see <http://www.learningdisabilities.org.uk/content/assets/pdf/publications/staying-safe-online.pdf>)

Your relative also needs to know about the procedures that exist to help them keep safe and secure. Most local authorities have produced an Easy Read guide to help people understand about keeping safe or 'safeguarding' (see below), and housing and support providers should have an Easy Read complaints procedure.

It is important that your relative feels safe when they are out and about too. Do they know how to ask for help if they go out on their own? Is there a Safe Places scheme in the area? Under this scheme, local shops and businesses train to be a 'safe place' and put a sticker in their window to alert people with learning disabilities that they can ask for help. There is a lot of information on the internet for people with learning disabilities about how to keep safe when they are out and about; for example travelling on public transport, getting in a taxi, being out at night and looking after valuables. (see <http://www.learningdisabilities.org.uk/publications/safeoutandabout/>) Alternatively, you could talk to a local advocacy group which is likely to have Easy Read information on keeping safe.

What to do if you have concerns

It is natural to worry when your relative is living away from home and it is always best to raise any concerns you may have at once, even if it is over a minor issue, for peace of mind and to prevent the problem from escalating.

Likewise, it is important to listen to any concerns that your relative may express and trust them if they indicate that something has happened to them or to others. This may be through words or through changes in their behaviour; they may seem more anxious, or be avoiding people or places.

You can take different levels of action, depending on the nature of the concerns. You may feel that something specific is not working well, support is of a generally poor quality or you may have noticed something that makes you worried that some kind of abuse is taking place. You should not hesitate to raise any concerns: it is through openness and discussions that serious harm is prevented and the quality of services is improved. Family carers often worry about raising concerns as they fear it will be 'taken out' on their relative. This should never be the case and would be cause for serious concern in itself. If you are fearful that this might happen, you should ask a carers' support organisation or the care management team to help you raise your concern.

There are two main routes you can follow. If you think your relative, or someone else, is at 'risk of harm', the Safeguarding of Adults procedure should be used. Otherwise you can use an organisation's complaints procedure.

Safeguarding of adults

If you have a concern about the safety of your relative and you feel they are in immediate danger or have been the victim of a crime, the police should be contacted. If you think they are at risk but not in immediate danger, you should report it to your local authority's safeguarding adults team, who can be contacted through the main council phone number.

The Care Act puts adult safeguarding on a legal footing and states that local authorities are responsible for any adult in its area who:

- has needs for care and support
- is experiencing , or is at risk of, abuse or neglect, and
- as a result of those needs is unable to protect himself/herself against the abuse or neglect or the risk of it.

The Care Act recognises the key role of carers in safeguarding particularly in witnessing or reporting abuse or neglect.

Abuse can be of various kinds: physical, sexual, psychological, financial, material, discriminatory or institutional, or to do with neglect and acts of omission. Local social services are the lead coordinating agency for Safeguarding Adults Boards. Other organisations, such as the NHS, independent (private and voluntary) social and health care providers, housing providers, the police, the Crown Prosecution Service (CPS), the Probation Service and the Benefits Agency, also have responsibilities and they should all work together and share information as appropriate. When you contact your local authority to raise a concern, you will speak to a member of the safeguarding team who will have been trained to deal with concerns in a sensitive manner. They have responsibility for investigating concerns, so you only need to provide them with information about your concern and they will follow it up.

Making a complaint

Before deciding what action to take, you may find it helpful to write down your concerns and talk them through with other family carers or people who know your relative well. This should help you decide the best way of approaching the issue and provide you with a written record if needed. If you do make

a formal complaint, it is advisable to keep a record of phone calls, letters and conversations with staff. Wherever possible, it is best to support your relative to be involved, so that they develop the skills and confidence to speak up for themselves.

Complaints can generally be made at three levels:

- Talking to the service provider/organisation or the care management team;
- Using a complaints procedure;
- Going to an independent regulatory body or ombudsman, if the complaint hasn't been resolved at the first two levels.

Talking to the service provider: if you have already established a mutually respectful relationship with people working in a service it will be easier to raise any worries. You should feel that both you and your relative are being listened to and your worries properly addressed. They should also tell you about their complaints procedure in case you feel you have not been listened to.

Using a complaints procedure: every NHS, social care organisation and housing provider must by law have their own complaints procedure. You may want to use this if it doesn't feel possible to resolve your concern through discussions or if your concern is with the management of a service and you feel you need to take it higher. You can ask for independent support when making a complaint – contact your local authority or the NHS to ask who may be able to help.

Going to an independent body: if you are not satisfied with the outcome following the complaints procedure, you can ask the local government ombudsman to review the way the complaint has been dealt with (if it is a council service) or contact the regulatory body such as the Care Quality Commission.



Questions to ask

What advocacy support is available locally for people with learning disabilities?

Is there locally produced, accessible information about making a complaint or about keeping safe?

What support/ advocacy support is available for family carers when their relative is going through the safeguarding process?

Whom to ask

Contact your local authority, family support groups or advocacy/speaking-up groups.

As above.

Contact your local authority.

Notes



To find out more you could look at

The National Family Carer Network (NFCN) and other organisations worked together to produce three levels of resources about safeguarding for families with an adult relative who has learning disabilities: a 4-page 'Top Tips' guide, a more detailed 'Essential Guide' and a Resource Pack which includes video clips featuring people's stories. Visit the website for more information about all three.
<http://www.hft.org.uk/safeguarding>

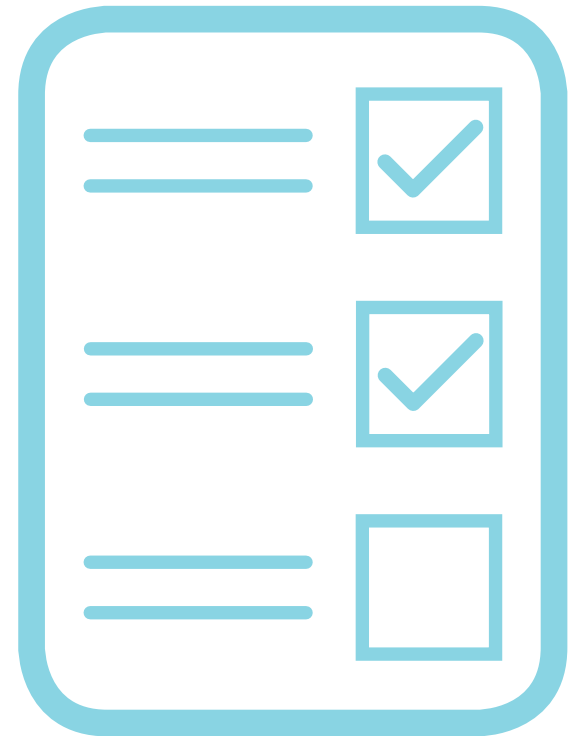
Making Safeguarding Personal is a programme of work led by the Local Government Association to make sure safeguarding investigations lead to the changes the person wants in their circumstances (rather than focusing on the process). Information about this programme could be helpful in making a safeguarding investigation personal to you relative.
<http://www.local.gov.uk/documents/10180/5854661/Making+Safeguarding+Personal+-+Guide+2014/4213d016-2732-40d4-bbc0-d0d8639ef0df>

Staying Safe on Social Media and Online is an easy read guide for people with learning disabilities.
<http://www.learningdisabilities.org.uk/publications/safeonline/>

Staying Safe Out and About is an easy read guide for people with learning disabilities.
<http://www.learningdisabilities.org.uk/publications/safeoutandabout/>

The **11 REACH standards** set out the ways in which people can have choice and control in supported living.
<http://www.paradigm-uk.org/wp-content/uploads/2014/07/Slide1.jpg>

9. Making a plan for the future



Making a plan for the future: a checklist

This checklist can be used to help you plan which areas you want to do further work on, either now or in the future. There may be sections that are not applicable or do not need to be considered at the moment. You can fill it in over a period of time and put things in place when you feel ready or have the time.

Topics in the planning guide	Does not apply	This is in place for now and we will update/think about it further on (add date)	We have not started this but it seems like a priority to begin now. We will (add steps)	We have started working on this but need to do (add next steps)	We're not ready to look at this now but will think again in (add date)
1. Making decisions					
<ul style="list-style-type: none"> • We have an understanding of how the Mental Capacity Act and best interests decisions would apply to our relative. • We have thought about how to involve our relative in making decisions. • We have decided who else we would like to get involved in making decisions. • We have set up a lasting power of attorney for property and affairs (if applicable). • We have set up a lasting power of attorney for health and welfare (if applicable). • We have set up a Court of Protection deputyship (if applicable). • We have checked the enduring power of attorney (if you had one). • We have discussed our planning with the local authority and asked for it to be recorded and/or discussed at annual reviews. 					

Topics in the planning guide	Does not apply	This is in place for now and we will update/ think about it further on (add date)	We have not started this but it seems like a priority to begin now. We will (add steps)	We have started working on this but need to do (add next steps)	We're not ready to look at this now but will think again in (add date)
2. Making plans for the future in a person-centred way					
<ul style="list-style-type: none"> • We have gathered person-centred information using questions such as 'what is important to/for?' or 'what makes a good day/bad day?' • We have identified our relative's hopes and wishes for the future as well as our own. • We have asked other people who know our relative to help with these questions. • We have thought about the best ways of involving our relative in developing a person-centred plan. • We have identified some changes our relative would like to make now. • We think a learning log would be helpful when making changes. 					

Topics in the planning guide	Does not apply	This is in place for now and we will update/ think about it further on (add date)	We have not started this but it seems like a priority to begin now. We will (add steps)	We have started working on this but need to do (add next steps)	We're not ready to look at this now but will think again in (add date)
3. Building friendships and support networks					
<ul style="list-style-type: none"> • We have completed a relationship map to help us think about who is part of our relative's life and who we would like to be more involved. • We have looked at how our relative's friendships with other people with learning disabilities could be strengthened. • We have talked with other relatives (for example our relative's siblings, cousins, nieces and nephews) about how they might help us to make plans. • Our relative has a circle of support helping him/her to have a better life. • We have thought about the support we need to keep the circle going (such as a paid facilitator). 					

Topics in the planning guide	Does not apply	This is in place for now and we will update/ think about it further on (add date)	We have not started this but it seems like a priority to begin now. We will (add steps)	We have started working on this but need to do (add next steps)	We're not ready to look at this now but will think again in (add date)
4. Talking about difficult subjects					
<ul style="list-style-type: none"> • We have looked at how our relative could be supported to be more independent. • We have gathered ideas about how to support our relative to have a better understanding of death and dying. • We have considered whether our relative is getting the health care they need as they age including annual and other health checks. • We have decided on the best way to leave memories for our relative and have begun to put this together. 					

Topics in the planning guide	Does not apply	This is in place for now and we will update/ think about it further on (add date)	We have not started this but it seems like a priority to begin now. We will (add steps)	We have started working on this but need to do (add next steps)	We're not ready to look at this now but will think again in (add date)
5. Making financial plans					
<ul style="list-style-type: none"> • We have had discussions about what we have to leave in our will and how we want to leave it (covering money, property and gifts). • We have found a solicitor to help us with our will. • We have looked at whether we need to set up a discretionary trust. • We have agreed who will be trustees. • We have got a will in place that considers the best way of leaving money, property or gifts (as appropriate). • We have set up a discretionary trust. • We have considered a future benefit appointee. • We have set up a joint bank account for personal budget and/or direct payment money. 					

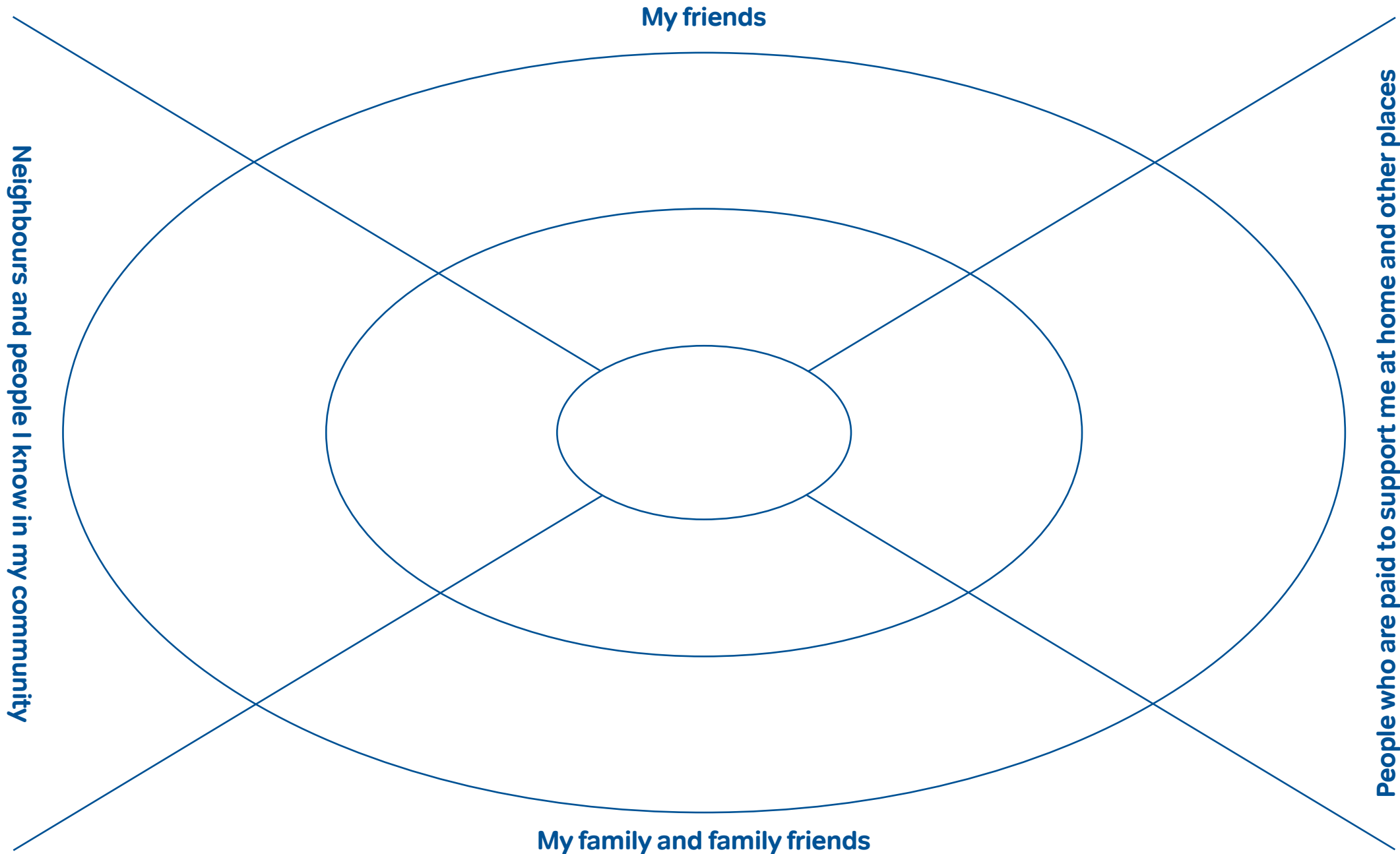
Topics in the planning guide	Does not apply	This is in place for now and we will update/ think about it further on (add date)	We have not started this but it seems like a priority to begin now. We will (add steps)	We have started working on this but need to do (add next steps)	We're not ready to look at this now but will think again in (add date)
6. Housing and support					
<ul style="list-style-type: none"> • We have gathered person-centred information (see Section 2) that will help us, as a family, to have an idea about the kind of housing and support that would work for our relative. • We have looked at whether there are any other families who may want to look at housing and support options with us. • Our relative's name is on the local housing register. • We have got the information we need about the local options. • We have had a discussion with someone in our local authority about funding and process. • We have got information in an accessible format for our relative and/or have identified who will support them to think about this. • We have looked into whether our relative could have succession on our tenancy. • We have looked at whether we could leave our property to our relative. 					

Topics in the planning guide	Does not apply	This is in place for now and we will update/ think about it further on (add date)	We have not started this but it seems like a priority to begin now. We will (add steps)	We have started working on this but need to do (add next steps)	We're not ready to look at this now but will think again in (add date)
7. Making a plan for emergencies					
<ul style="list-style-type: none"> • We have found out about the local arrangements for emergency support and contacted the relevant people. • We have thought about who might provide support in an emergency (paid support or family/friends) and what would need to happen. • We have put this information into a written plan and given a copy to the people we want to have a copy (local authority, support services, relatives, neighbours). • We have looked at what needs to be put in place before an emergency occurs ('cushions'). • We have made an important to/important for list for an emergency situation. 					

Topics in the planning guide	Does not apply	This is in place for now and we will update/ think about it further on (add date)	We have not started this but it seems like a priority to begin now. We will (add steps)	We have started working on this but need to do (add next steps)	We're not ready to look at this now but will think again in (add date)
8. Keeping an eye on things					
<ul style="list-style-type: none"> • We have put together ideas about how our relative can keep themselves safe. • We have put together information that helps other people to support our relative to keep safe. • We have talked with our relative about being part of a speaking-up group or looked at them having an advocate. • We have an understanding of safeguarding policies and know the questions to ask when looking at support providers. • We have other family and/or friends who have agreed to 'keep an eye' when we are no longer able to. • We have introduced family/ friends to the local authority and shared their contact details. 					

Templates

People in my life (Relationship Map)



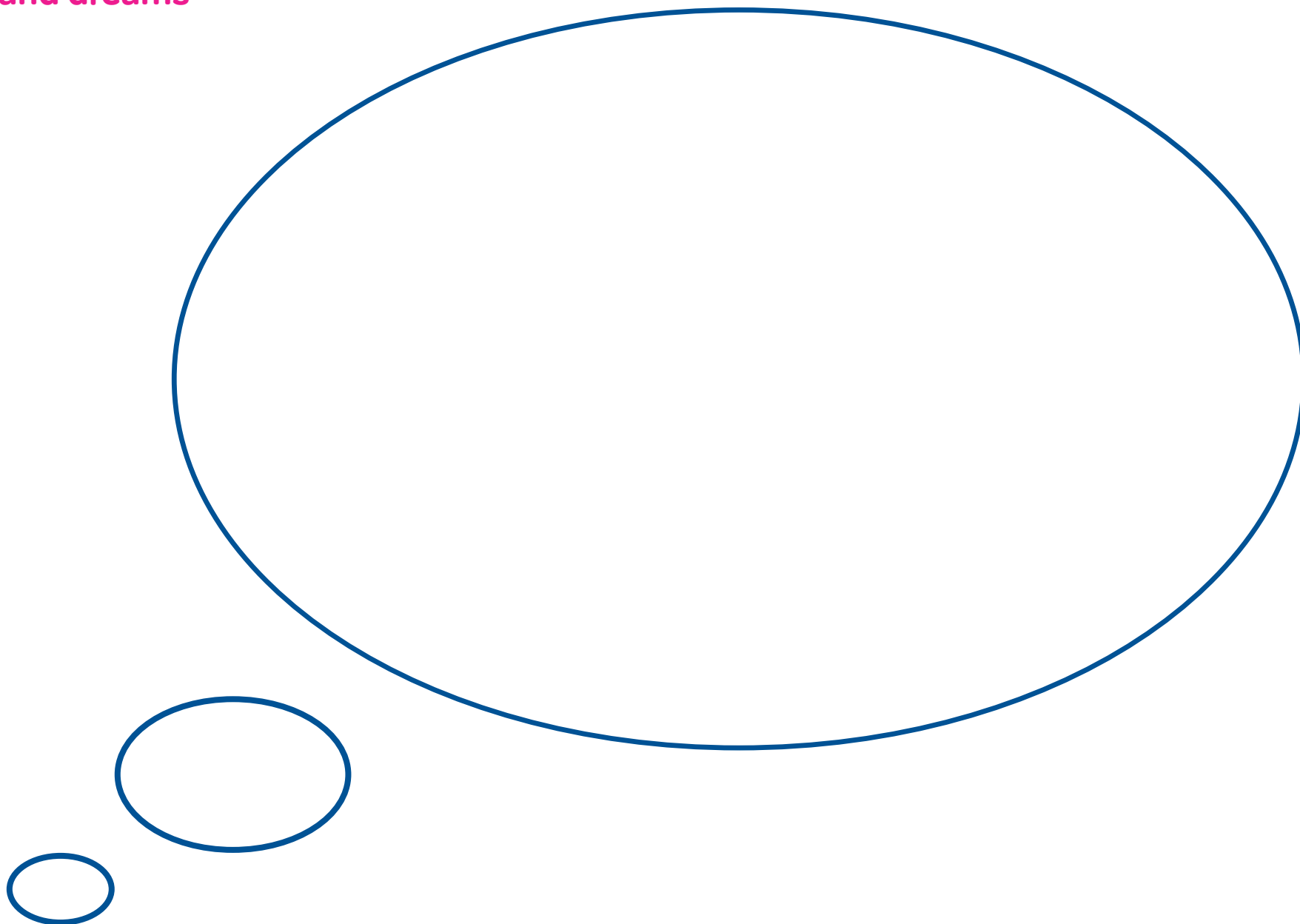
What is important to and important for...

Important to (a good life)	Important for (a safe and healthy life)	What this means for making a care and support plan

Good day–bad day

What makes a good day? Think about what needs to happen to make the day go well	What makes a bad day? Think about what needs to be avoided to prevent the day going badly
What makes a best day?	What makes a worst day?

Hopes and dreams



Learning log

Date	What was the person doing?	Who was there?	What did you learn about what worked well?	What did you learn about what didn't work?

What have we learnt that we need to do differently:

What have we learnt that we need to keep doing the same way:

Emergency plan

Your relative's details

Name

Address

Telephone number

Mobile number

Date of birth

About you

Relationship to person above

Name

Address

Telephone number

Mobile number

Emergency plan summary (complete this after you have filled in pages 4-7)

Main person/people who would make arrangements/speak up for your relative in an emergency:

Name	Relationship to your relative	Telephone and mobile number

What do you think would work best in an emergency?

What we would like to happen	What needs to be put in place to make this work?

Is there anything you would not like to happen/anyone you would not wish to be contacted?



Thinking about the options

Fill in these boxes to identify what you think would work best.

In an emergency could your relative stay at home either on their own or with support (support could be either paid support or a family member/friend)? If yes, indicate for how long and what support would be needed:

Length of time	On their own	On their own with low level of support e.g. phone contact, short visit	With significant support e.g. help with daily tasks, overnight support	With 24-hour support
1-4 hours				
All day				
Overnight				
A few days or longer				

Family, friends or neighbours your relative could stay with in an emergency:

Length of time	Name(s)	Contact details	Support they would need
1-4 hours			
All day			
Overnight			
A few days or longer			

Support worker(s) paid through a personal budget who may be able to help in an emergency:

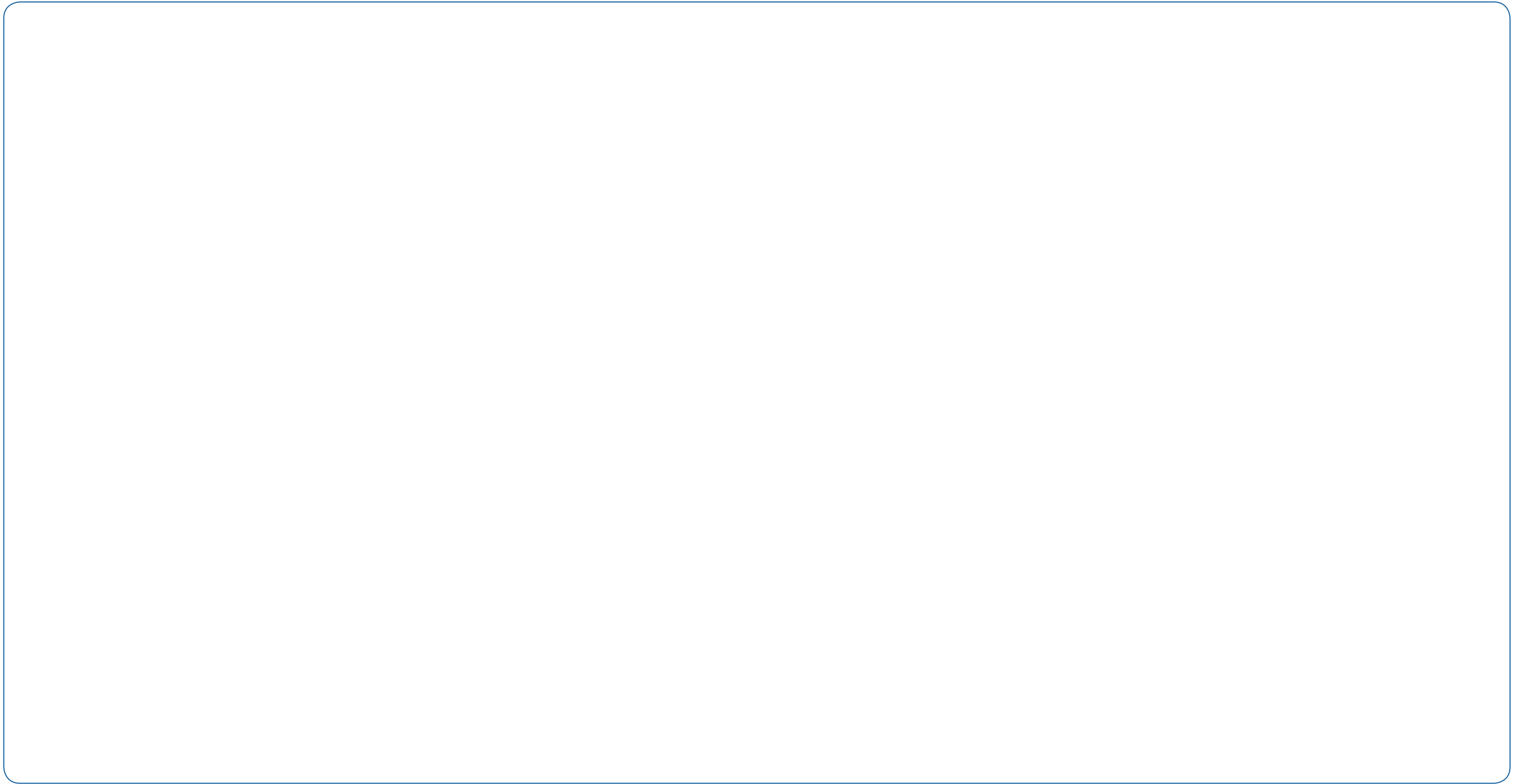
Name of person	Do you employ them directly? If not, name of organisation that employs them	Telephone number	What support do they give now?	What support might they give in an emergency?

Services/support organisations that may help in an emergency (e.g. short breaks/respice, community support, personal assistant provider):

Name of person	Organisation that employs them	Telephone number	What support do they give now?	What support might they give in an emergency?

Is there any other information you want to add to this plan?

This could include information about what would be important to your relative to help them feel less anxious, health needs, best ways to support them, dietary needs, cultural needs and anything else that would help someone else to step in and support your relative with particular emphasis on essentials - for example medication, calming activities, favourite routines?



To do list: things we want to do now

To do	Who will do it	Tick when done

Does your relative know about this plan?

Glossary

Advance decision to refuse treatment

An advance decision to refuse treatment is a statement that a person writes explaining what medical treatment they would not want to receive at some time in the future. It is made whilst the person has the capacity to make such decisions and authorises someone to make decisions on their behalf if they were to lose the capacity.

Attorney

A person, usually a lawyer, appointed to act for another in business or legal matters.

Befriending scheme

Befriending schemes can provide friendship and learning opportunities for people with learning disabilities. They are usually run by voluntary sector organisations and develop befriending relationships through recruiting, vetting, training and supporting volunteers. These friendships can provide opportunities to go out to places and meet new people, and link people around a shared interest.

Best interests decision

The Mental Capacity Act (see below) sets out a process to ensure that a decision made for people who have been assessed as not having the capacity to make that decision themselves is made in their best interests. Best interests decisions should be made with the involvement of people who know the person well.

Care and support plan

A care and support plan is a document prepared by the local authority which sets out a person's needs, which of the needs meet the eligibility criteria, what needs the local authority will meet and how. It will also set out the personal budget and how this will be used. The process of developing the care and support plan must involve the person themselves, their carer (if they have one) and anyone else the person requests.

Carer's card

In some areas carers' card schemes have been set up by the local council or a carers' centre. A card can be carried that identifies the person as having caring responsibilities for another person. The card has the telephone number of the carers' scheme as well as a unique identification number to avoid any personal details appearing on the card. The schemes vary, but they are sometimes linked to an emergency care scheme which draws up an emergency plan with the carer and provides a 24-hour response service.

Care Quality Commission

The Care Quality Commission (CQC) is the independent regulator of health and social care in England. It covers adult social care in registered care homes and personal care provided by domiciliary care services. The government has set standards for these services and CQC monitors how well services are being provided against these standards.

Circle of support

A circle of support is a group of people who meet together on a regular basis to help somebody achieve the things that are important to them in their life. The circle acts as a community around a person and may include family members and friends as well as paid workers. They can vary in how they meet and what they do but they usually help with planning in a person-centred way, and help to make changes. This may be for day-to-day things, such as going out in the evening and meeting new people, but may also be for bigger issues, such as moving home.

The members of the circle of support are involved because they care enough about the person to give their time and energy to help that person overcome obstacles and increase the options that are open to them. However, circles of support are usually sociable and give everyone involved a sense of being connected to each other.

Circle facilitator

The circle facilitator is the person who keeps the circle of support running, arranging meetings and helping choose people to be involved. Sometimes the person with learning disabilities will facilitate the circle, but often parents are the facilitators. Independent facilitators can be paid to develop a circle and support it to keep going.

Citizen advocacy

Citizen advocacy involves an unpaid volunteer working in partnership with a person with a learning disability for as long as the person needs support to address specific issues or to empower them to have more choice and control over their lives.

Community connecting

Community connecting is a term used to describe an approach that supports individuals, who are often marginalised, to get to know people and become involved in things that are happening in their area. People with learning disabilities often miss out on opportunities to become involved because they are chiefly meeting others through services. Community connecting uses a person's special qualities and interests to find people and places that would value what they would bring. The aim of community connecting is to develop a person's social and support networks and to give a sense of participating and contributing, leading to greater confidence and well-being.

Complaints procedure

A person who uses health or social care services (the service user) has the right to complain about their own experience. They might want to complain, for example, about the quality of service or a refusal to provide a service. A complaint can be made by another person, who is known as a representative, on behalf of the service user, if the service user is unable to make the complaint themselves.

In many cases a problem can be dealt with quickly by speaking directly to the person involved in providing the service, without the need to make a formal complaint. However, if the matter cannot be dealt with in this way it will need to be investigated as a complaint. A complaint can be made verbally, in writing or electronically. Where the complaint is made verbally, the responsible body must make a written record of the complaint and provide a copy to the complainant.

Court of Protection deputyship

If your relative does not have the mental capacity to either manage their own finances and property or to create a lasting power of attorney (see below), the only option available is to apply to the Court of Protection for a deputy to be appointed. The Court of Protection allows the deputy to manage your relative's money. A deputy can also make other decisions if these have been agreed by the Court of Protection. See Section 1 for more information. A deputy is usually a close friend or relative of the person who needs help making decisions. A deputy can also be a professional, such as an accountant or a solicitor.

Direct payment

Direct payments are cash payments given instead of community care services that the person has been assessed as needing, and are intended to give greater choice over how the person receives care and support. The payment should be sufficient to enable the person to purchase services to meet their eligible needs, and must be spent on services that meet these needs. It is usually spent on employing people, often known as personal assistants or support workers, or on buying support from a home care agency. It can also be used to buy other services for needs that have been assessed, such as activities or equipment. Most areas have a direct payment support service, either provided by or commissioned by the local authority; these are sometimes user-led organisations.

Direct payments are means-tested so their value is also dependent on a person's income and assets. Direct payments cannot be used to purchase residential care or services provided directly by local authorities.

Discretionary trusts (see Trusts)

ICE number

ICE stands for 'in case of emergency'. People are encouraged to store the number of the first person to be contacted in case of any emergency on their phones under the 'name' of ICE. It is useful to store this number on your home phone as well as your mobile.

Independent mental capacity advocate

The role of an Independent Mental Capacity Advocate (IMCA) is to represent a vulnerable person who lacks capacity to make important decisions about serious medical treatment and change of accommodation, if they have no family and friends available for consultation about those decisions.

Learning log

A learning log is a tool that helps to gauge how well any changes have gone. It can be used by family and other people supporting a person with learning disabilities, such as support workers. They can keep a log of the person's activities based on their observations and use the 'learning' to plan further activities. The log helps to build on success and avoid repeating things that don't work well. This tool is helpful if a family is unhappy with the way their relative is being supported but is also beneficial when used in a positive way to work with a service or support worker to make improvements.

Letter of wishes

A letter of wishes expresses your wishes and tells readers about specific things that you want to happen after your death,

for example how you would like trustees to use the money in a discretionary trust (see below) to benefit your relative with a learning disability. Since a letter of wishes isn't a legal document, it is easier and less costly to update as and when circumstances change. However, this also means there is no guarantee that it will be followed.

Life story or memory book

Compiling a life story book can help you support your relative to remember important life events, significant people and everyday memories. You can collect family photos, cuttings and stories in a loose-leafed folder which can be added to over the years as new memories are created. It is a good idea to write names and captions for photos and cuttings. See also 'memory box' below.

Memory box

For some people with learning disabilities a box can be more appropriate than a life story or memory book as it can be multi-sensory. A memory box can take many forms: it could be a small case, a box file or a cardboard set of drawers and could contain items that are particularly important for your relative, such as objects that have a scent or texture that will trigger a memory, as well as photos.

Mental Capacity Act

This Act, which covers England and Wales, was introduced in 2007. 'Mental capacity' is another way of saying the ability to make decisions. See Section 1 for details of the Act.

Peer advocacy

Peer advocacy is a relationship based on people sharing similar experiences or difficulties, such as having a learning disability. People feel united because of a common cause. Usually, one person feels more able to speak up for someone else and uses their understanding from having similar experiences

to do so. The relationship is based on mutual support and empowerment and has the added benefit of a special insight and close rapport being developed between the people involved. The primary qualification is their own experience of disability, exclusion or using services.

Personal budget

Personal budgets are an allocation of funding given to a person after an assessment. It should be sufficient to meet their assessed needs. Users can either take their personal budget as a direct payment, as a payment for a service or a combination of the two. They are intended to give people more choice and control over the support they get without necessarily having to take on the responsibilities of managing a direct payment. See also care and support plans.

Person-centred planning

Person-centred planning is an umbrella term for a variety of approaches to gathering key information about a person: who they are, what is important to them and what would work for them. Person-centred planning helps with planning the support that someone would need but it also helps to look more broadly at how the person would like to live their life now and in the future. Person-centred planning sometimes focuses too much on making a written plan. A written plan is a useful tool as it can be shared with others and help to make change happen in a person's life, but it is the implementation that is important. People who care about the person's future, such as family and friends, are often key in making sure that this process of planning continues during a person's lifetime.

Power of attorney

A power of attorney is a legal document appointing one or more people to act on an individual's behalf, either to look after their property and financial matters (called a property and

affairs power of attorney), or the handling of their personal welfare, including medical treatment (called a health and welfare power of attorney).

Enduring power of attorney

Before 2007, when lasting powers of attorney (see below) became valid, it was possible to create an enduring power of attorney. This allowed an attorney to deal with someone's financial affairs, but not their health and welfare. The same test of mental capacity applied but the enduring power of attorney did not have to be registered until the person creating it became mentally incapable.

Lasting power of attorney (property and affairs)

Attorneys must be over 18, not bankrupt and, equally importantly, people who can be trusted to look after your relative's finances. Ideally at least one of the attorneys should be younger than your relative and live reasonably nearby; it could be a family member, friend, work colleague or a professional. It is not a good idea to choose family members who live abroad as this can cause delays in dealing with paperwork.

Lasting power of attorney (health and welfare)

This allows the attorney to make decisions about matters relating to the person's health and welfare if or when they are not able to make such decisions themselves. These decisions must be made in the person's best interests and the attorney would be expected to involve family members in the process. The decisions may concern the person's medical treatment, how their health care is managed, where they live and how their living arrangements are managed (particularly in a care home or supported living). They might also involve more detailed aspects of their life, such as daily care and diet.

REACH standards

An organisation, called Paradigm (<http://www.paradigm-uk.org/>), developed the Reach standards as a national framework for assessing the quality of support received by tenants in supported living. The 11 REACH Standards aim to identify whether tenants have choice and control over how they are supported and how they live their lives (<http://www.paradigm-uk.org/wp-content/uploads/2014/07/Slide1.jpg>). Similar sets of standards have been developed in some local areas.

Safeguarding adults

Safeguarding means protecting vulnerable adults from abuse or neglect and putting systems in place to prevent abuse or neglect from happening in the future. The Care Act puts adult safeguarding on a legal footing and states that local authorities are responsible for any adult in its area who: has needs for care and support; is experiencing , or is at risk of, abuse or neglect, and as a result of those needs is unable to protect himself/herself against the abuse or neglect or the risk of it. The Care Act also recognises the key role of carers in safeguarding particularly in witnessing or reporting abuse or neglect.

Safe Places schemes

The Safe Places scheme was set up to enable people with learning disabilities to deal with any incident that takes place whilst they are out and about in the community. Incidents could range from harassment or bullying to just needing directions. Local shops, organisations and businesses place a sticker in their window (following training) so people know they can call in for help. Voice UK, the organisation that promotes this scheme, can provide training for people with learning disabilities and for professionals.

Skype

Skype is a service that allows users to communicate by voice using a microphone, by video by using a webcam, and by instant messaging over the internet. You can download Skype for free on your PC.

Supported living

Supported living is a term used to mean a housing and support arrangement where someone rents or owns their home. They would also have a say over who they live with if it is shared accommodation (or they could live on their own), the support they get and how they live their lives. It is based on the assumption that all people with learning disabilities can live in their own home with the appropriate level of support. There are many examples of people having 24-hour support with staff sleeping in or being awake at night.

Support tenant

Some organisations use support tenants to provide live-in company or help to people living on their own or in a shared house. They live as a friend or 'flat-mate' and usually share household tasks and bills just like anyone sharing a house might. Support tenants are usually supervised by the support provider who has an agreement to be available for an agreed number of hours or to provide support with certain tasks.

Trusts

Disabled person's trust

This is a special type of trust that can be created for or by a person with a disability but it is more restricted in the way it can be operated than a discretionary trust (see below). There are specific rules relating to disabled persons' trusts and taxation so if you are considering this form of trust you should talk to a solicitor. Discretionary trusts are usually viewed as being the most suitable for someone with a learning disability.

Discretionary trust

A discretionary trust is a way of putting money aside for your relative. It involves a formal transfer of assets which could be property, investments or money to a number of people (beneficiaries). The trustees have the discretion (choice) as to how they deal with the assets that are in the trust. The purpose of having a number of beneficiaries is that the disabled person is not seen as owning the assets when being assessed for benefits or care funding. In your letter of wishes (see above) you would say how you would like the money to be spent.

Lifetime trust

A lifetime trust is a type of discretionary trust and would therefore name several beneficiaries. If your relative already has an amount of money, say, from an inheritance from a grandparent, or if you wish to put money aside in your lifetime, it can be put in a lifetime trust. Provided that the amount put into the trust is not more than the tax rules allow, it can be topped up, for example with birthday and Christmas money.

Trustee

See trusts above. A trustee is a person given control or powers of administration of property or affairs in trust with a legal obligation to administer it solely for the purposes specified.

Useful organisations

Foundation for People with Learning Disabilities

Carries out action research and development work to improve the lives of people with learning disabilities and their families. From this work it produces a range of practical resources that are available free to download. Key areas of work are planning personalised support, health, employment, family support, friendship and community connecting.

Website: www.learningdisabilities.org.uk
Email: fpld@learningdisabilities.org.uk
Telephone: 0207 803 1100

Hft

Provides a free national Family Carer Support Service (FCSS) for families and carers of people with a learning disability which includes: one-to-one support by telephone, letter or email; workshops for family carers (for example carers' rights, support planning, housing and support options, money matters, personal budgets, the Mental Capacity Act, safeguarding) and a news digest with useful information. It has also carried out innovative work on using Personalised Technology, sometimes called Assistive Technology. Its website has a virtual Smart House that demonstrates how these technologies can be used to support people at home, helping them increase independence and safety.

Website: <http://www.hft.org.uk/>
Email: familycarersupport@hft.org.uk
Telephone: 0117 906 1751

Housing and Support Alliance

Produces information and resources on all aspects of housing and support with many free resources on their website. Also provides additional support to its members (currently costs £25 for family carers) who receive a monthly newsletter and access to individualised information and advice.

Website: www.housingandsupport.org.uk
Email: enquiries@housingandsupport.org.uk
Telephone: 0845 456 1497

Mencap

Campaigns for the rights of people with learning disabilities as well as directly providing support, including through a network of local affiliated groups. It has a wills and trust service with an in-house solicitor who can provide free phone and email advice.

It provides Mencap Direct, a national advice line for people with learning disabilities, families and carers, covering all issues concerning the lives of people with learning disabilities, including individual budgets and self-directed support.

Website: www.mencap.org.uk
Email: help@mencap.org.uk
Telephone: 0808 808 1111

Respond

Works to reduce the effects of abuse and trauma, including bereavement, on people with learning disabilities, their families and supporters. It provides psychotherapy for people with learning disabilities, advice and support for staff and families and training for carers and professionals.

Website: www.respond.org.uk

Email: admin@respond.org.uk

Telephone: 020 7383 0700

Sibs

Supports brothers and sisters of disabled people. It has a phone and email service for adult siblings for help with any adult sibling issue. It provides practical and emotional support, a buddying service and runs workshops. It has supported many siblings of people with learning disabilities, including those keen to make future plans.

Website: www.sibs.org.uk

Email: info@sibs.org.uk

Telephone: 01535 645 453

Social Care Institute for Excellence (SCIE)

Aims to improve the lives of people who use care services by sharing knowledge about what works. It produces practical guides, examples of good practice and video clips that help to explain social care. Safeguarding and person-centred support are two of its priorities.

Website: www.scie.org.uk

Email: info@scie.org.uk

Telephone: 020 7024 7650

Updated 2015

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changing
lives



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