Planning for the future

Your helpful guide to care options for adults with support needs

lifeways group

When you've cared for a loved one into adulthood, we know that there's an unbreakable bond. Countless happy memories. And a true sense of pride for the person they've become.

But as you grow older as a parent, relative or sole dependant of someone with support needs who is still living at home, the future can start to feel a little uncertain. Everyone needs to fly the nest at some stage, but the idea of finding support you can trust is daunting, along with not knowing how it may change the relationship you have with your loved one.

On the other hand, caring for someone well into your old age could bring considerable challenges – you may develop health problems of your own, meaning you are no longer able to provide the level of care you once did.

As a supported living provider, we often see that older carers are reluctant to seek help until it becomes a real necessity, which unfortunately then adds stress and worry to an already difficult situation, and could result in your loved one moving to somewhere that wouldn't have been your first choice. It is therefore worthwhile to know your options and put plans in place before you need them.

We've created this guide as a starting point to help you explore and understand the support options available to you. We hope it helps you and your family to feel more informed and more confident to make plans for your future. We'll be covering the following:

- Understanding more about support
- Explaining the process of seeking support
- The different types of support available
- Finding someone you can trust
- Support with making the right choice

When planning for your family's future, there can be lots to think about and discuss. It's important to not rush such a big decision. Spending some time to think about your current family life and your hopes and aspirations will help you to explain your needs and wishes if and when you choose to seek support.

As a starting point, here are some questions to think about on your own or discuss as a family:

- What support do you currently provide to your loved one?
- Do you think you'll be able to continue this support over the next few years? The next three years?
- How could additional support improve their life?
- How could they benefit from leaving home?
- What are your hopes for your loved one in the future?
- Have you talked to your loved one about their future? If so, how do they see it looking?
- Do they currently have the level of independence you'd like them to have?
- If your loved one was to move away from home, where do you picture them living?
- Are there any skills or experiences you'd like to see them learn?
- Do you have any initial worries about seeking support that you'd like advice on?

Take some time to jot down any questions that come to mind

Our family's future:

What is social care?

Social care is practical, professional help funded by the government for people who need extra support with everyday life.

For adults with support needs looking to move away from the family home, social care can help fund support from providers (such as Lifeways) who offer a range of housing options along with personalised support designed to meet each person's individual needs.

Support can cover practical things, such as help completing everyday tasks. It can also be used to help with learning important life skills, such as money management and paying bills. And it can also cover more social aspects of a person's life, such as meeting up with friends and enjoying a favourite hobby.

With the right support, a move to independent living can lead to:

- Quality time with family and friends
- Increased independence
- New friendships
- Group activities
- Time spent enjoying hobbies
- Volunteering and work

"I'd never lived on my own before. I can do more independent stuff now. I like going to the cinema, shopping and going out.

Sam, who moved into supported living in his 40s

Finding out if you're eligible for support

In the UK there is a minimum threshold at which people are entitled to support from the government.

To be eligible, your loved one must be unable to do two or more of the following things:

- Manage and maintain nutrition
- Maintain personal hygiene
- Manage toilet needs
- Be appropriately clothed
- Be able to make use of their home safely
- Maintain a habitable home environment
- Develop and maintain family or other personal relationships
- Access and engage in work, training, education or volunteering
- Make use of necessary facilities in their local community, including public transport and recreational facilities
- Carry out any caring responsibilities they have for a child

Who do we contact if we think we are eligible for support?

If you believe your family may need support, the first thing to do is contact your GP or local authority. They will then allocate you a social care professional, usually a social worker, who will then be in contact to identify your loved one's needs and find out a little more about your family situation to decide if a full needs assessment is required.

Your local authority will be the local council in your area with a social services department. This could be a city council, county council or borough council. You can find your local authority by visiting **gov.uk/find-local-council**

The assessment process

The next stage of the process will be to have an assessment. This is usually a face-to-face meeting with a social worker, where they will gather all of the information needed to consider what plans could be put in place.

The assessment is an opportunity for you to share your needs and wishes for your loved one, and for your family. Where possible, your loved one will always be involved in the process and be supported to make their own decisions.

Your assessor will gather information covering eight key areas where support may be required, all of which contribute to your loved one's well-being:

Make some notes here to help plan for your assessment

1 Communication and decision-making

What sort of decisions can your loved one make for themselves? How well do they communicate their feelings and wishes?

2 Health and well-being

Note down any health concerns your loved one has. What are things in their life that keep them happy and well?

3 Daily activities

What daily activities can your loved one do for themselves, and what are some things they might need support with?

4 Living safely and taking risks

Do you currently have any safety measures in place at home? Do you have any worries with your loved one having increased independence?

5 Relationships

Who are the people most important to your loved one? Do you have any hopes for them to make new relationships in the future?

6 Finances

Note down some of the ways you support your loved one financially. Do they need support with budgeting or paying bills?

7 Community access

What sort of decisions can your loved one make for themselves? How well do they communicate their feelings and wishes?

8 Emotions and behaviours

Note down any health concerns your loved one has. What are things in their life that keep them happy and well?

What happens after the assessment?

All the information gathered will be then given to your local authority for consideration, who will confirm their decision in writing and discuss the suggested support plan with you.

Will our finances be assessed?

Your finances or the potential cost of services are not taken into consideration during the assessment process. This means the local authority will only look at what the individual needs, not how much money you have or how much any services may end up costing.

Care and support plans

If it's agreed that support is to be provided, your local authority will discuss with you the type of services which could be the right fit, and from the information gathered in the assessment they'll create a detailed care and support plan, which sets out:

- **What services are to be provided**
- **When they will be provided**
- **Who will provide them**

Once in place, the support plan will be reviewed regularly by your local authority - at least once a year (or more often if necessary) and always when there is a change in circumstances. Your service provider will also keep you up to date with how it's all going, share successes and achievements with you, and build in new goals as and when needed.

It's important to know that you don't have to accept the support provider suggested by the Local Authority. Handing over responsibility for your loved one is a difficult decision no matter how old they are, so it's important that you are comfortable and clear on what you can expect from your chosen service provider.

What if we don't agree with the proposed support plan?

As part of the process of creating the support plan, you will have shared your thoughts for consideration with your social worker, therefore it's expected that support plans reflect the needs and wishes of an individual and their family. If at any point in the process you don't feel comfortable with something that's in the support plan, talk to either your social worker or your support provider who'll be happy to discuss your concerns.

Moving away from home

Leaving home is a natural thing for everyone to do at some point, but for adults living with support needs who've never lived away from their family home, it's a big step.

It's important to remember that if and when your loved one moves out of the family home, it doesn't mean that your family connection will be broken. Nor will it mean that you are no longer involved in their life. In fact, in our experience we've seen making the move can often lead to happier and more fulfilling family relationships once the aspect of care is reduced.

Support can cover practical things, such as help completing everyday tasks. It can also be used to help with learning important life skills, such as money management and paying bills. And it can also cover more social aspects of a person's life, such as meeting up with friends and enjoying a favourite hobby.

What is supported living?

Supported living is a service that helps people with a range of support needs retain their independence, whilst offering that extra physical and emotional support whenever it is needed to help them lead fulfilling lives in their own homes. Usually, people living in supportive housing have their own tenancy and live in designated housing provided by a specialist organisation, but still have full control over all their bills, household chores and other responsibilities that are involved with living in their own home. Support is provided separately to maximise their independence and if they have particular wishes or needs, to support them in achieving their goals.

What is residential care?

Residential care is for adults living with complex conditions who require 24/7 specialist support to care for their daily needs. Both accommodation and personal care and support are provided, and each person has their own private bedroom and access to shared communal areas such as the living room, dining room and kitchen. This allows residents to have alone time and independence in their rooms, but also the opportunity to enjoy spending time with others.

What's the difference between supported living and residential care?

- Residential care is for people who require specialist care 24/7, whereas supported living is better suited for people who require support to gain more independence to help them to lead completely fulfilled lives in their own homes.
- Both options offer support plans tailored to each person's needs and wishes, ensuring that everyone leads a fulfilling, enjoyable life learning new skills, making new friends and creating memories.
- Residents living in a residential care home won't be required to cover any costs as this will be covered by the individual's local authority or health board. In supported living the resident is a tenant that is responsible for their rent, bills and other housing costs. Housing benefit usually covers the cost of the rent, and other benefits can be put towards the cost of living.

How do we decide between supported living or residential care?

When making the decision between supported living and residential care, there are several things to consider - most importantly, the type and amount of support required. Both supported living and registered care can provide support 24/7, but for people with more complex needs who require constant 24/7 care and support, residential care may be a better choice. For both services, you will need a referral from your local authority who will help determine which service is best. You will never be required to decide for yourself or your loved one alone. Local authorities will often have a list of preferred providers of supported housing, but you can also contact service providers directly to see whether they can help.

If you decide to start the process through Lifeways, we will be here every step of the way, making sure you have all the information to make the right decision and putting you in contact with your local authority.

What is a CQC report?

The Care Quality Commission (CQC) undertakes regular inspections of all registered services to ensure they meet government standards. It can be useful to take a look at their reports for any supported living or residential housing you're considering. Their reports can be found on their website **www.cqc.org.uk**

Seeking support – the process explained

By now you'll hopefully be feeling more informed about how to seek support and the type of support that is available. We've summarised the full process below with some helpful tips and advice along the way.

1 Seek support

If you'd like to seek support for your family, and think your loved one will be eligible, contact your GP or local authority who'll organise an assessment to agree what type and amount of support you need.

Our tip – It's reassuring to have done some research beforehand and understand the options that will be available. Along with this guide, we've added some further reading resources at the end for you to have a look through.

2 Connect with a service provider

Once an assessment has been completed and your local authority has agreed support is needed, you'll be connected with a service provider (such as Lifeways) to discuss the accommodation and support options that might be suitable.

Our tip – It's good to write a list of things you'd like to ask, such as:

- What are the other residents like?
- What hobbies and activities are done as a group?
- What are the facilities in the local area?
- What is the local transport like?

3 Meet with service provider

Your new service provider will arrange a meeting to have an in-depth conversation about your family's current situation, your loved one's support needs, and your hopes and wishes for them in the short and long term.

Our tip – It's important to be open and honest and share any worries you might still have. And remember you don't need to be alone on this journey - family, friends and neighbours can offer a useful perspective.

4 Visit properties

You'll visit available houses and apartments in your chosen location to have a look around, see if they feel like the right fit, and meet the support team.

Our tip – Take with you a list of any questions you have to discuss with the support team. Choosing the right place is a big decision, so take your time, it needs to feel right for everyone.

5 Create a support and funding proposal

Your service provider will create a support and funding proposal which will be sent to your local authority for approval. You should expect to be kept up to date throughout the whole process.

Our tip – If anything doesn't feel right, even at this stage, let your local authority or support worker know and they'll work with you to address any concerns.

6 Moving in

Once funding is approved, a moving in date can be set, and your service provider will work closely with you to make sure the whole transition process is as smooth as possible.

Our tip – The moving-in process should happen at a pace that's right for your family, without any pressure. As a service provider, we know that keeping to a routine can be really important to many people living with a condition, and so we make sure to keep disruption to a minimum.

7 Settling in

Once the move is complete, take time to settle into your new routines. You'll have regular reviews with your loved one, your support team and social workers to make sure everyone's happy with the progress.

Our tip – Your involvement in your loved one's life will not stop after the move. Moving forward, you can be as involved in their support as you wish to be, and your views will always be taken into consideration.

Success stories

Hear from families who have made the move to supported living in later life.

Annie, *Mum of Ross, who moved to Lifeways aged 37.*

"When Ross turned 37, we started to realise it might be time for Ross to leave home. We were both in our 70s, and as we were getting older it was becoming increasingly difficult to look after Ross, even with the support of a carer for a few hours a week. One of the managers of the day centre Ross attended had said that it was probably time for me to 'cut the apron strings', which I didn't really like to hear. Everyone around me was telling me the same, but it was hard to think about.

"It was a very hard decision to make, as we didn't think anyone could look after him the way we did."

Eventually I plucked up the courage to contact a social worker, who put me in contact with Lifeways. It was a hard conversation to have, but Launa (one of the Enquiry, Referral and Assessment Managers) helped us make up our minds that it was time. We can't thank Launa and the team enough, who assured us everything would be fine.

Ross's personal care and eating was our main concern, but since he's been here, he's eating really well and has put on weight. He's really enjoying his life here - he's happier, has made friends, and loves his support team. Of course we miss Ross being at home, but we can visit him whenever we want, plus we have time to ourselves now to spend as a couple – so it really feels like we've got the best of both worlds."

> **The team go above and beyond here and we are eternally grateful.**
>
> Gillian's sister-in-law

Gillian's story

Gillian suffers with cerebral palsy and severe learning difficulties. Until early 2018 she had lived with both her parents in the family home and attended a local day centre. Sadly, Gillian lost both her parents and moved in with her brother and his family, who felt that Gillian might actually be happier in her own home.

Gillian's sister-in-law shares her experience with Lifeways:

"In a word – brilliant! After family discussions we realised we wanted to give Gillian the chance to live more independently in her own home for the first time in her life. We took a lot of time looking and researching for somewhere close to us. From the start the local Lifeways service appeared to be the perfect place. The manager spent so much time with us and Gillian, ensuring that every need and concern was considered.

"Recently we celebrated Gillian's 60th and I had the pleasure of seeing her with residents and staff socialising in her new home. I could not be happier!"

As a family we are so grateful for all the help we have had from every member of Lifeways. All the staff at Gillian's service are an absolute credit to the organisation."

You can browse the resource section at **lifeways.co.uk** to watch and read more success stories about the people we support.

Considering your loved one's financial future

As well as considering whether your loved one could benefit from support, it's also important to have your family's financial affairs in good order to make sure it's not something they'll need to worry about in years to come.

Is leaving an inheritance a good idea?

Leaving gifts outright can cause a number of problems for people who are receiving funded care and support. Even a small inheritance can affect means-tested benefits and support packages funded by the local authorities, leading to the inheritance being used to pay for these services until it runs out. A new application for benefits or support packages will then have to be made with no guarantee the individual will receive what they were previously entitled to.

Inheriting a large amount of money, particularly at such an emotionally distressing time, can cause other problems. Your loved one may become susceptible to financial abuse from others or may lack the ability to deal with their new-found wealth.

Creating a special needs trust

If you wish to leave an inheritance, setting up a trust will provide them with more secure protection and allow provision for them during their lifetime without affecting their benefits. You can put savings, investments, properties, and other possessions into your trust, and it can be accessed immediately.

Even if you're unable to pay into a trust right now, you can set one up anyway. When you write your will you can make sure that your assets are left to the trust and not to your loved one. This way, you can make the trust the beneficiary of any inheritance and ensure that they are protected.

Naming a Trustee

A trustee is the person who will be responsible for managing the special needs trust after your death. It can be a family member, a friend, an independent professional trustee, or even a bank or lawyer. The trustee ensures that the money in the trust is spent only on your loved one and only on services that you've specified or that are appropriate to their needs.

The trustee also supervises how the money in the trust is invested. The person who is caring for your loved one (the guardian) cannot spend any money in the trust without the trustee's approval.

Further reading

We've added links below to useful organisations and charities for more information related to the topics we've covered in this guide.

The Foundation for People with Learning Disabilities
learningdisabilities.org.uk

The Association of Directors of Adult Social Services
adass.org.uk

The Princess Royal Trust for Carers
carercentre.com

Age UK
ageuk.org.uk

PohWER - A charity providing free advocacy, information and advice
pohwer.net

Access Social Care - provides free legal advice to people with social care needs
accesscharity.org.uk

About Lifeways

Lifeways has been a provider of supported living and residential care since 1995, and empowers nearly 5,000 adults across the UK who live with autism, learning disabilities and a range of other conditions to lead more independent and fulfilling lives.

We provide support from our dedicated team of experienced support workers, as well as partnering with specialist housing providers to offer individual and shared housing. You canfind out more about our support and browse the types of housing we offer at **lifeways.co.uk**.

If you're interested to find out more about what we offer, you can eithercontact us directly or we may be one of several providers approached by the council on your behalf once your assessment has been carried out.

When the time's right, we're here to talk.

If you'd like to talk, at Lifeways we're here to listen.
There's never going to be any pressure, any obligations, or any rush - we can simply offer advice and guidance to help you find out more and to feel confident about your family's future.

Call **0333 321 4881**
Email **referrals@lifeways.co.uk**
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