

Supporting loved ones with health or care needs: your practical guide

The content in this ‘prototype’ guide was co-designed with working carers and carer organisations. This is not a live product and does not constitute government advice. This prototype aims to demonstrate how findings from the Carers’ Employment Digital Discovery and Care Choices project could be put into practice in the design of information aimed at potential carers.

Who is this guide for?

We've designed this guide for adults in England who have recently learned that an adult close to them needs care or support due to their health. This may be due to an accident, old age, illness, disability or other physical or mental health problem.

You might also find this guide useful if you have been supporting a loved one whose support needs are changing, or if you want to think about changing the support provided for any other reason.

We hope this guide can help you understand your options and connect you with resources and support that others in your situation have found useful.

We understand that this is likely a busy and emotional time with lots of new information and choices to make. That's completely normal. Please use this guide in an order that makes sense to you, and come back to it when you want. You can read it by yourself, or you might find it useful to talk about topics with friends or relatives.

This guide is for **adults thinking about caring for other adults**. If you are a:

- **young carer (under 24)** you can [get support from the Carers Trust](#).
- **parent of a child under 18 with care needs**, [NHS Choices has further information](#).

What is 'care' and 'support'?

There is a range of different ways someone might need care due to their health. The support they need could take a lot or little time to give, and might vary day-to-day. Caring can be done in person, over the phone or online. Many people might contribute to someone's care, or it might be given by just one person. Some examples include:

- **emotional support** like help with anxiety or keeping someone company
- **practical tasks** like cooking, housework or shopping
- **physical support** like lifting, helping someone get upstairs, or with physiotherapy
- **personal care** like washing, dressing or help with toileting
- **managing finances**, including budgeting, payments or applying for benefits
- **collecting prescriptions or giving medications**
- **managing appointments or services** e.g. with hospitals or paid carers
- **supporting the person to make sense of things, or make decisions**
- **advocating for your loved one's rights and access to services.**

Care often blends into family routine and relationships. You might not think of this help as 'care' or those providing it as 'carers'. You might view the support as part of being a partner, parent, son, daughter or friend. That's normal and **you don't need to think of yourself as a carer for this guide to help you!** But it can be useful to know that the term 'carer' is used by organisations that want to help you, and using it yourself might help you access support you are entitled to. The next pages outline guide contents.

Supporting loved ones with health or care needs

This guide includes 5 sections, each containing useful information, exercises and tools.

1

My loved one needs support. Where do I start?

- Understanding what your loved one needs
- Understanding your options & support
- Contacting Local Authorities
- Carer and Care Needs Assessments
- Understanding your entitlements

Pages #-#



2

Supporting my loved one: how might it affect me?

- Maintaining your wellbeing
- Support options
- Get support from your employer
- Financial guidance & support
- Connecting with others

Pages #-#



3

How can I talk to others about supporting my loved one?

Tips for conversations with:

- My loved one who needs support
- My family & friends
- My GP or healthcare professional
- My boss or co-workers

Pages #-#



4

How can I plan care & prepare for change?

- Making & reviewing a care plan
- Preparing for change
- Lasting power of attorney
- Checking if care arrangements are sustainable
- What can I do if things change?

Pages #-#



5

List of contacts & resources

- General information
- Support for carers
- Mental health support
- Financial & legal support & information
- Work & employment support
- Independent living equipment & advice
- Advanced illness and end of life care

Pages #-#



1 My loved one needs support. Where do I start?

Having a family member or friend who needs support due to their health is very common. You might feel uncertain or overwhelmed thinking about your loved one’s health and how things might change. You’re not alone. **A useful first step can be to get a clear sense of what support your loved one needs, what you need and who can help.**

Understand what support your loved one needs

You might start by clarifying what support your loved one needs, and who might help provide it. If you can, **write or share a care list with someone else**. This way someone else knows what help your loved one needs if someone providing care is no longer able to for any reason.

The below example care list is one way to start listing support needed for your loved one that could be shared with others involved in caring. A further template that also gives space to list how others might support you personally is provided later in this section. These are suggestions of different ways to stay organised if you choose to care, and you can choose the way that makes sense for you or your family, as caring arrangements can vary.

When thinking about the care needed, remember the ‘small things’. For example, keeping someone company or checking in with them makes a huge difference and takes time and energy. Below is an example of what an initial care list might look like.

Example care list: Support for Dad

Support needed	Who might provide this support?
<i>Remind and sometimes help Dad to microwave his meals.</i>	<i>Dad’s neighbour, Jack, might be able to nip over at lunch times.</i>
<i>Help Dad upstairs to the toilet, help him to sit down/stand up.</i>	<i>My daughter, Ann, works around the corner – could she go to see Dad before and after her shift?</i>
<i>Take Dad to his hospital appointment, and keep him calm if he gets anxious.</i>	<i>Dad’s younger brother, who lives down the road, might be available.</i>
<i>Do online food and toiletries shopping for Dad, and pick up his medicine from the pharmacy.</i>	<i>I can do this once a week on a Sunday evening.</i>
<i>Keep Dad company in the evening for an hour</i>	<i>Ann and I can alternate weekdays</i>

Care needs and personal situations can change, so it can help to **review your list or care plans from time to time**. Reviewing your list can help you think whether different arrangements could work better.

Further information on care planning is also available in **section four** of this guide. Carers First also offer further free [advice on care planning](#).

❑ Understand your options and reach out for support

Many people who care say that **finding and getting support early on can prevent getting overwhelmed or burning out**. Understanding what support is available can help you adapt care arrangements to suit you better, or manage if things change.

Getting advice from a GP, the NHS, condition-related websites, your local authority, charities, or from other carers (e.g. via a local carers centre) can be useful ways to learn about providing care and extra help. You can [find a local GP on the NHS.UK website](#).

You can **find local care support organisations and services using [Carers Trust's postcode tool](#)**. Others who care, or who have cared before, are often happy to share experiences and advice. Organisations like [Carers UK](#) and [Mobilise](#) offer online meetups and forums to enable carers to connect with each other. Further contacts and resources are listed in section five of this guide.

❑ Find your and your loved one's local authority

If you choose to provide care, to see what could make life easier for you and your loved one, you can **request support from your local authority**.

A first step is **finding which local authority is responsible for 'social care' in the area of the person providing care and the area of the person with care needs**. [Gov.uk's postcode tool](#) can help you find your local authority website. If only one local authority is listed after you enter your postcode, it will be responsible for social care. If more than one local authority is listed, check which one mentions 'social care'.

If you live in a different local authority area to the person who needs care, enter both your postcode and your loved one's postcode to find both relevant authorities.

The next step is to **request a carers assessment and/or a care needs assessment** from the local authority. These assessments are explained below. You won't be charged for either assessment, but the things they recommend might not be free and funding may not be provided.

❑ **Get a free Carer's Assessment to identify support for you and/or others who are providing care**

A [carer's assessment](#) is used to recommend things to make your life easier when looking after someone. Don't worry, this isn't an assessment of how you look after your loved one, but of what help might be available to you. The assessment might recommend things like:

- someone to help with caring so you can take a break
- a gym membership or exercise classes to relieve stress
- help with taxi fares if you don't drive
- help with gardening and housework
- training on how to lift safely
- putting you in touch with local support groups so you have people to talk to
- advice about benefits for carers

❑ **Get a free Care Needs Assessment for the person who needs care**

A [care needs assessment](#) is focussed on what support or equipment could be provided to help your loved one live more independently and safely. It might recommend things like:

- equipment like a walking frame or personal alarm
- changes to your home such as a walk-in shower
- practical help from a paid carer
- day care for your child if either you or they are disabled
- access to day centres and lunch clubs

❑ **Exercise 1: Note your support options and network**

Now you've thought about what your loved one needs help with, and learned about carer's assessments and care needs assessments, you might find it useful to **think about who else can help you and your loved one.**

You could **use the template below to start listing your 'support network' of people or organisations that might be able to help.** It can help to note contact details and save them in one place so you can find them easily later. Create your own map or list if you prefer. Your support network could include family members, friends, neighbours, people at work, your GP, volunteers, social workers, your local authority, local organisations, or anyone else you can think of who might help. A list of caring organisations, resources and links are provided in **section five** of this guide and might help you think about who you might want to include in your support network.

It could be useful to do this exercise or share your support list with other people who can help you think about, plan or give the care. For example, you might ask friends or family, a GP, a social worker or carers centre to think about your support map or list. Speaking to them might also help you identify sources of support you might not have thought of.

My Care Support Contacts

Who?	Name and contact details	How might they help my loved one?	How might they help me?
<p>Family and friends</p>			<p><i>E.g. Pick my daughter up from school and take her to gymnastics on a Tuesday so I can help Dad</i></p>
<p>Organisations</p> <p><i>(e.g. Healthcare professionals, condition-related or carers-focussed charities)</i></p>			
<p>Work</p>			

❑ Understand what protections and support you could be entitled to

We might feel a responsibility to provide care, or that we have to care in a certain way. This might be out of love, expectation or even pressure we put on ourselves. Caring can be rewarding and demanding, while we also have demands on us from other parts of our lives. It can be helpful to learn about what legal protections carers can be entitled to.

You can get advice about entitlements to from your [local Citizens Advice Bureau](#), or on the [Citizens Advice website](#). Mobilise also provide [advice about carers' entitlements under the law, such as protections at work, as well as practical advice about how to assert your legal entitlements](#). If you care for someone, some things you might be entitled to could include:

- Requesting flexible working. This could involve changing the number of hours you work, the times or days you work or the location you work from.
- Taking time off work to care for dependents.
- Protection against discrimination under the Equality Act 2010.

Section Summary

There's lots of information out there. Keeping track and making sense of it can be hard. Here's a summary of what you've learned from this section, and things you might want to do next:

- Reaching out to others in similar situations early on can help you get valuable advice and support, helping make things more manageable down the line. Getting support early can prevent you from getting overwhelmed or burning out.
- Sharing care and reaching out to any friends, family, organisations or local services can help make caring easier for everyone. If you can, avoid doing all the care yourself, even if the tasks seem small or manageable.
- It can help to learn about legal entitlements and protections carers are entitled to.

Summary of things you could do

1. Search for local carer support services using [Carers Trust's postcode tool](#).
2. Connect with others who care for someone or have done so before, for example, through organisations like [Carers UK](#) and [Mobilise](#).
3. Find out more about [carer's assessments](#) and [care needs assessments](#) and consider getting support from your local authority.
4. Reach out to people who could support in different ways.

Reflections

Please feel free to use this space to write down any thoughts or ideas you have after reading this section. For example, information you've found useful or things you want to do or learn more about:

[PROTOTYPE CONTENT - LINES FOR REFLECTION TO BE INSERTED HERE]

2 Supporting a loved one: how might it affect me?

When a loved one needs help it can be easy to make them your focus. We might feel we have to put our own needs to one side for someone else. We may stop doing things we enjoy and keep us healthy. Sometimes putting others first is vital, but over time it can lead to burn out, being unable to provide the same level of care, or leaving work.

Regularly considering your own needs and wellbeing can help you stay healthy and notice if you need more support. You'll find exercises and links to help you below. It can help to make a habit of checking your own wellbeing, even if things feel manageable right now.

☐ Exercise 2: Check in with yourself

Recognising your own feelings, looking after your own health, and learning how others have managed when loved ones are in need can help protect your wellbeing. You might start by simply taking a few minutes to 'check in' with yourself.

Prototype: Space to insert lived experience quote and illustration

Below, you will find a visual to help you check in with how you've been feeling. Some feelings and emotions may seem familiar, others might not. You might have no idea how you've been feeling lately – and that's okay too.

Take a look through our examples, and have a go at circling any which you've been feeling lately. Add any that are missing. You can do this activity on your own, or you might find it helpful to talk about how you've been feeling with others.



You might be experiencing a range of things including anger, stress, worry or confusion. These feelings might be new to you, or you might have felt them for a while. You don't have to deal with them alone. It can help to reach out to friends, family or support groups, or go to the [NHS Every Mind Matters pages](#) for advice and support.

Recognising when we need a break or support is important. Some things you could do to help you feel better right now include:

- taking ten minutes to enjoy a drink or snack
- going for a walk
- calling a friend
- listening to your favourite music

You could also consider adjusting how much you have on your plate, and making bigger changes to deal with caring, work or other demands. Regular self-care and checking in is important for ourselves and those who depend on us. Caring can be both rewarding and demanding. To keep doing it in a healthy way over time, it's important to remember to eat well, sleep, get regular exercise, stay in touch with friends, and do things you enjoy.

If you've noticed changes in the way you are thinking or feeling over the past few weeks or months that concern you and cause you distress, you could consider seeing your GP or accessing [NHS mental health support services](#).

[PROTOTYPE CONTENT - LINES FOR REFLECTION TO BE INSERTED HERE]

Maintain your wellbeing: support options

Many people who have cared for someone say that **connecting with local support services and networks is key to staying healthy while caring**. [Carers Trust's postcode tool](#) can help you find services near you, including carers centres and hubs that provide advice, information, peer support and carers' breaks. Many charities offer advice on maintaining wellbeing while caring, such as [Carers UK](#), [Carers Trust](#) and [Mind](#).

❑ Get local support

People who provide care and those who need care can request an assessment for support from their local authority. Find out what support might be recommended with a [carer's assessment](#) and [care needs assessment](#) (see **section one** for more information).

❑ Take a break

As or when you need to, you might be able to take a break from supporting your loved one while someone else helps out. You might hear this being called 'respite care', and it allows you time to take care of yourself. The support available is based on what you and your loved one need. Find out more about carers' breaks on the [NHS website](#).

❑ Share care

If you can, **share care with family, friends and neighbours, or get support from organisations. Sharing care to ease the pressure on yourself isn't selfish: it can be in everyone's interests**. It can help the person who needs care to get the support they need, and help those around them to stay healthy too. Those providing care can find it easier to make time to look after themselves, and to combine caring and work if they want to. Talk to family and friends to see if they can help. You can find tips for having these conversations in **section three** of this companion.

❑ Get support from your employer

If you're employed, it's useful to **find out about support your employer might offer**. Ask your employer what they offer or check your employment contract and policies. For example:

- You are entitled to ask for flexible working. Flexible working means a way of working that suits your needs, for example having flexible start and finish times, working part-time or working from home more. You can find out more information from [Carers UK](#).
- You're also allowed to take [time off work for an emergency](#) involving your dependents, for example, if someone depending on you has a fall, or other care support is cancelled last minute.
- Some employers have support groups for employees who look after someone or may agree for you to take a career break.

- Some employers may be part of the [carers passport scheme](#) or may be willing to use one. A carers passport is a document to help carers be recognised and supported by those around them in a range of settings, including work.

You can get free, impartial advice about support you can expect from your employer from carers charities, [ACAS](#), [Citizen's Advice](#) or the [gov.uk Job Help pages](#). You can also find tips for having conversations at work about care in **section three** of this guide.

More resources and organisations you can speak to about support at work can be found in **section five** of this guide.

Explore financial guidance and support

Caring can come with financial impacts, from extra travel costs, needing to make home adaptations or by affecting your paid work. It can be useful to explore financial support and guidance. Some useful resources to be aware of include:

- [Money Helper](#) which gives free guidance about managing money and care.
- [GOV.UK: Benefits and financial support if caring for someone](#) (including Carer's Allowance and Universal Credit)
- [GOV.UK: Benefits calculators](#)
- [GOV.UK: Cost of living support](#)
- [Midlife MOT: Check the status of your work, health and money](#)
- The [Carers UK Upfront tool](#) can also help you understand what benefits and support you may be entitled to.

Connect with others who have provided care

Other people who care for someone, or have done so before, are often happy to give practical advice to people in situations they've been through. **Caring organisations like [Carers UK](#) and [Mobilise](#) offer online meetups and other forums for carers to connect and share experiences.** NHS.UK lists a number of [telephone helplines](#) for people providing care or support for a loved one. A further list of resources is available in **section five**.

Exercise 3: Take note of the things you enjoy and try to protect them

You can use the space below to write down things that you enjoy. This can be anything that supports your wellbeing, or helps you stay healthy and active. Don't forget the things that make you happy or bring you meaning and purpose like your family and relationships, hobbies and leisure, or your career.

You could also think about whether anything else this guide mentions might help you to continue doing the things you enjoy. For example:

I really enjoy going to my knitting group on Tuesday evenings, but Mum needs her medicines at this time. Could a neighbour pop in to help her on that night each week?

It's important that I'm at my son's football matches on a Sunday and around afterwards to spend time with him. Could my sister be on call on a Sunday if our brother with care needs has a fall or otherwise needs urgent help?

[PROTOTYPE CONTENT - LINES FOR REFLECTION TO BE INSERTED HERE]

Section summary

- You may feel like you have to take all the care on yourself. Seeking help from others and making time for the things that support your wellbeing can put you in the best position to be there for your loved one.
- Finding local services and connecting with others in similar situations can help you unlock valuable support.

Summary of things you could do

- Search for local carer support services using [Carers Trust's postcode tool](#).
- Connect with others who care for someone or have done so in the past, for example, through organisations like [Carers UK](#) and [Mobilise](#).
- Talk to your employer, friends, or family members to see if they can help.
- Find out more about [carers' breaks on the NHS website](#).

Reflections

Please feel free to use this space to write down any thoughts you have after reading this section. For example, information you've found useful or things you want to learn more about:

[PROTOTYPE CONTENT - LINES FOR REFLECTION TO BE INSERTED HERE]

3 Talking to others about supporting a loved one

Talking to others about care can help everyone involved get the support they need. Talking about care can be tough sometimes and you might feel nervous. Don't worry, that's completely normal.

Prototype: Space to insert lived experience quote and illustration

Look at our care conversation guides for tips

We've developed these conversation guides to help you get the most out of important conversations with the person with care needs, family, friends, healthcare professionals and your manager or colleagues at work. These might help you think about who to talk to, and what you might talk about. Some tips might also apply to other important conversations about care, e.g. with social workers, trade union representatives or other organisations involved in your loved ones' care.

Tips listed in the boxes are just suggestions, and you can think about what makes sense for your relationships and situation. For example, you might have regular conversations with family members and the person with care needs, while conversations with healthcare professionals might be rarer so you might want to cover more topics in one conversation. These tips cover four types of conversation that you might have, but might be useful to consider with others too.

You may be surprised to learn what options others can make available through these conversations. If you want more support, or to connect with others in similar situations, reach out to local carers centres or services through [Carers Trust's postcode tool](#). You might also search for condition-focussed support via charities like [Age UK](#).

Tips for a conversation with my loved one who needs support

1. Consider whether you need a private conversation between you both, or whether involving other trusted family or friends might be helpful.
2. Try to **find somewhere quiet** where you're comfortable and won't be interrupted. Think about where and how you can all feel safe to share what's on your mind.
3. **Start by sharing what you hope to get out of the conversation.** Share any concerns you have and how you're feeling.
4. Remind your loved one that **you want them to have the best possible care**, while also looking after your own wellbeing.
5. **Try not to rush.** Allow time for each of you to share your views. You may be surprised to learn that they share your feelings or have already thought about what support options would work best!
6. **Pause and listen** to how they're feeling. Validate their feelings and give reassurance. Remember, some of the things you, or they, want to say might be hard to hear and you might each be feeling emotions of guilt, sadness, anger or frustration. Take your time, and take a breath or sip of water if you need. Reinforce that you just want to work together to explore the best care arrangements for everyone involved.
7. If you're feeling stressed or overwhelmed, **try using "I" statements and specific examples** to help them understand how you feel. For example, "I find it hard to look after myself and spend enough time with my children while also coming over every evening. It's affecting my wellbeing. I want to make sure you're well looked after, so we're going to have to explore different options."
8. **Share ideas for different support options** that might benefit both of you. Some of them, like getting a care needs assessment, are mentioned in this guide – feel free to discuss any of these. Encourage your loved one to express their honest feelings about the options, but remember that finding the best solution for everyone might involve making some compromises.
9. Finally, don't forget you can **get professional advice** if you need it. If you or your loved one are overwhelmed or you're struggling with finding suitable care arrangements, speak to your GP, a carers charity or local authority. They can provide further support and guidance, resources, and advice for your situation.

Tips for a conversation with family or friends

1. **Try to find somewhere quiet**, where everyone is comfortable and won't be interrupted.
2. **Start by sharing what you hope to get out of the conversation.** Share any concerns you have and how you're feeling.
3. Remind them that **you want your loved one to have the best possible care** while looking after your own wellbeing too.
4. **Pause and listen** when they want to share their own thoughts and feelings. Remember that people can have very different personal circumstances and points of view. Try to be considerate and constructive whilst also making sure your views and feelings are heard too.
5. **Discuss what care is needed**, talking through a care list or plan if useful. Talk through the tasks that need doing, how often they're needed and how long they take, and how you might share them between you.
6. **Talk about how extra support could help**, even if things feel manageable now. Share any concerns, for example about your life and wellbeing.
7. **Discuss different options** for caring. Consider discussing ideas from this guide. Someone might surprise you by sharing ideas which you hadn't thought of. Even if your friends or family members don't live close by there are still things they might be able to do from a distance (e.g. take care of an online shop or help manage finances). Be sure to share availability, experience and skills to make a plan – feel free to use templates or exercises in this guide to help.
8. If you're overwhelmed, or family members are unable to offer support, **consider speaking to your GP, local authority, or carer charities.** They can provide resources and guidance tailored to your family's situation.
9. Finally, **revisit and adjust your plan with friends and family regularly.** Remember that every care situation is unique, there is no one right way to approach it, and circumstances can change quickly. By working together and communicating frequently you can help the arrangements work for everyone involved.

Tips for a conversation with a GP or other healthcare professional

1. **Schedule an appointment** with your GP or other healthcare professional.
2. **Prepare a list of the caring needed, any problems you're experiencing, and if or how it's affecting your physical or mental wellbeing.** You could also write down a list of questions to ask the GP. For example, about how your loved one's care needs might change and whether there is anything to help manage change. GPs might have limited time or availability, so it can help to prepare in advance to make the best use of time and cover everything you want to.
3. **Try to be open, honest and direct.** Share specific examples, and don't be afraid to make your doctor aware of how you're feeling both physically and mentally. This information will help them understand your situation and suggest the right support.
4. **Ask for advice and support in managing your own health and wellbeing.** If it's not directly offered, ask about specific self-care strategies and techniques that can help with stress, or even information about local support groups.
5. **Discuss alternative care options or adjustments** to your current care plan. You might ask for further advice on how to involve family members, friends, or paid carers.
6. Remember, **you know yourself and loved one best.** If you feel something isn't right, trust your instincts and raise concerns.
7. Finally, **don't be afraid to ask for referrals** even if this hasn't been offered. Arrange a follow-up appointment if it's needed. Remember that GPs and other professionals are there to help both you and the person who needs care.

Tips for a conversation with my boss, co-workers, or other people at work

1. If you can, **arrange a chat with someone you trust** at work. This can, but doesn't have to be, your boss. It could be a trusted colleague, HR representative, wellbeing champion, or a member of a workplace carer's network (if your organisation has one). Choose a time and private place where both of you are comfortable, not rushed, and free from distractions and interruptions.
2. **Prepare by writing down what care is needed, and how it may impact your work now or in future**, for example needing time off at short notice. You don't need to talk about your loved one's condition, but you can if it helps.
3. **You could prepare a list of questions to ask**, for example about company policies, entitlements and protections while caring, employee support networks, whether your employer is part of the [carers passport scheme](#) or open to using one, or information you could be signposted to for support. You may be surprised at what's on offer.
4. Express that you want to **find arrangements that suit you and your employer and mean your loved one gets the care they need**. If you're having this discussion with a manager, consider suggesting solutions, or asking about what flexibilities they might offer. You might read more about [benefits of flexible working on Carers UK](#) for ideas.
5. **Be open and honest about how you're feeling**. If you're feeling stressed or overwhelmed, try using "I" statements and be as specific as you can. For example, "I was late to a meeting yesterday as I had to answer an urgent phone call from my Mum's doctor. I'm worried that colleagues will think I'm not committed or competent, especially if it happens again."
6. **Discuss the impact of caring on your work**. Express any worries you have and pause to listen to any comments or thoughts from the other person.
7. **Consider talking about emergency plans** should you need to leave work urgently to look after your loved one, for example if they have a fall or other arrangements are cancelled last minute. Find out more about [time off for family and dependents on GOV.UK](#).
8. Finally, try to **arrange follow-up chats**, or consider arranging a chat with a manager if you did not initially. Keep in contact regularly and be open and honest if anything changes. Remember, you can get free, impartial advice about support you can expect from your employer from carers charities, [ACAS](#), [Citizen's Advice](#) or the [gov.uk Job Help pages](#).

Section Summary

- Speaking to others about your situation can be daunting, but it can be really helpful for planning and managing care.
- You can get support from local carer centres and charities. Other carers, contactable through e.g. carers centres or [online forums \(e.g. Carers UK\)](#) who have had similar conversations, are often happy to support and share experiences and advice.
- Try to be open and honest when having conversations to ensure the people you speak to have an accurate view of your situation and can give the right support.

Summary of things you could do

- Search for local care support services using [Carers Trust's postcode tool](#).
- Think about if any conversations could help support you or the person who needs care.
- Use the conversation guides to help get the most out of your conversations. Note down what you want to get out of the conversation. Afterwards, write down any next steps or agreements.

Reflections

You might find it useful to write down any thoughts or ideas you have after reading this section, for example, information you've found useful or things you want to learn more about:

[INSERT LINES FOR REFLECTION HERE – PROTOTYPE CONTENT]

4 How can I plan care and prepare for change?

□ Make or review a care plan

Making and reviewing a care plan can help you manage your time and help your loved one get the care they need. Sharing the plan with others also makes it easier for your loved one to continue receiving the care they need in an emergency or if someone providing care can no longer provide it.

Using information in this guide as a prompt, you could begin writing down a care plan with your loved one and anyone else involved. Remember that situations change over time, and you can return to this section whenever you need to.

[Lived experience quote and illustration]

Below you will find some examples of how you might lay out a care plan. The aim of a plan like this is to make things clear for everyone who is helping out, and so that your loved one can continue to receive care in an emergency or if things change. [Carer's First](#) and [The Charity for Civil Servants](#) also offer detailed templates for emergency care planning.

In case the care plan might be used by someone other than yourself, it can be helpful to note particular details about what your loved-one prefers, enjoys or makes them more comfortable, as well as any irregular appointments that aren't part of their regular routine. Examples could include their preferred name, how they like their tea or coffee, any social gatherings they attend, or things like hospital appointments which happen every few weeks. There's no detail too small. If it's important to them or to you, write it down.

Once you have a plan in place, keep it somewhere accessible and try to update it regularly. **If your loved one currently has no support or you're the only one looking after them and you would like help, please speak to your GP or local authority. They can help you and your loved one get support.**

Example care plan

In this example, Samira and Zayn help look after their dad Malik.

<u>Malik</u> 's Care Plan	
Name and DOB of person with care needs:	Malik Smith 1/1/1953
Preferred name:	"Mal"
In an emergency please contact (in order of preference):	#1 Mal's daughter Samira: xxxxx
	#2 Mal's son Zayn: xxxxx
	#3 Mal's neighbour Jim: xxxxx
<u>Malik</u> 's needs, wants and preferences:	Medical history: Mal has recently been diagnosed with dementia, which means he struggles to remember more recent things. Mal has asthma, which he has a blue inhaler for. He also has urinary incontinence. Mal is allergic to bee stings.
	Further relevant information: Mal uses glasses, otherwise he struggles to see close-up. Listening to Frank Sinatra really calms Mal down if he gets agitated.
	Communication needs: As a result of Mal's dementia, he often needs to be reminded of things multiple times. Please be patient with him and speak calmly and kindly when repeating things otherwise he can get agitated and upset.
	Mobility: Mal can get around with a walking frame, but needs help standing up and sitting down.
	Anything else: Mal's favourite foods are rich tea biscuits and rice pudding. A chat with a cup of coffee (with milk and two sugars) really helps him calm down.

PROTOTYPE – NOT GOVERNMENT ADVICE

Mal's daily support:	
Morning:	<p>Mal usually wakes up around 07:30. He needs help to stand up out of bed and can then walk to his en suite using his walking frame. He can wash himself and undertake personal care if wash supplies are provided and then just needs support to put on fresh clothes (found in wardrobe) and conven (under sink) before breakfast. Please also give him his teeth, which are kept beside his bed.</p> <p>For breakfast, Mal likes 3 Weetabix, or two slices of toast and a cup of coffee (milk and two sugars). He needs support to make breakfast but can eat and drink independently.</p> <p>After breakfast, Mal likes to go to his living room and watch television. He can walk there with his frame, but will need support to stand and sit down. Please make sure Mal's table is within reach, with the remote, a fresh drink and his mobile phone.</p>
Afternoon:	<p>Mal likes to have lunch between 12:00 and 13:00. He will choose from the ready meals in his freezer. He will need support to microwave them but can eat them independently.</p> <p>While his meal is cooking, Mal needs to be supported to the toilet, where he needs help to sit and stand. Empty conven as needed.</p> <p>He likes to eat lunch at his dining room table, and will have another coffee. When he is finished, please rinse the pots and put them away. Mal then likes to return to his sofa, where he may have an afternoon nap or watch more TV. Please make sure his table is within reach with the remote, his glasses a fresh drink and his mobile phone.</p>
Evening:	<p>Mal likes to eat tea between 17:00 and 18:00. He will choose from the ready meals, or from ingredients he has available.</p> <p>Please help him to the toilet again and empty conven as needed.</p> <p>He can eat independently and likes to sit in the kitchen to chat as it is prepared, and will help where he can (like chopping food for example).</p> <p>With his evening meal, Mal likes a cup of Horlicks or glass of water.</p> <p>After eating he will decide whether he would like to get in bed to watch TV, sit in his reading chair or return to the living room. He will need support to stand and sit. Please make sure he has a drink, mobile phone and glasses within reach.</p>
Night:	<p>Mal usually goes to bed around 21:00, but some nights may go earlier after his tea.</p> <p>Mal can manage these things independently, but will need reminding to: take his teeth out and place them in the green pot next to his bed remove his conven</p> <p>He will then need a little support to get changed into his pyjamas (top drawer) and incontinence pants (under sink). Please make sure his mobile phone, a fresh glass of water and his TV remote are within reach.</p>

Mal's weekly support	
Monday	Samira helps in the morning Zayn pops over for the afternoon, and usually either takes Mal shopping, or provides some company. Evening and night: Layla (paid carer – company and number)
Tuesday	Samira helps in the morning, and takes Mal to Carers centre for midday. Mal stays there until 16:00. Zayn collects Mal from the Carers centre and helps with evening and night routine.
Wednesday	Morning and afternoon: Layla (paid carer - company and number) Evening and night: Samira
Thursday	Morning: Samira Afternoon: Zayn Evening and night: Layla (paid carer – company and number)
Friday	Morning and afternoon: Zayn Evening and night: Samira <i>Please note: Mal has the Physio at the outpatients' clinic every 2 weeks at 11am. Zayn takes him to this.</i>
Saturday	Samira stays for the whole day (and night) and takes Mal out shopping.
Sunday	Zayn stays for the whole day and night.

Other support

Who's available to take __Malik__ to hospital appointments:

- Samira: Monday, Tuesday and Thursday mornings
- Zayn: Monday, Tuesday and Thursday afternoons, Friday all day
- Layla: Wednesday

Power of attorney: Samira and Zayn

Manage money and direct debits: Samira

Other useful contacts: Jim (Dad's neighbour at no. 19), GP, physio, local carers centre, social care team at the council

❑ Exercise 4: Make a care plan of your own

You can use the template below to fill in your loved one’s weekly plan of support. Try to think about your options from previous activities in this guide, and don’t be afraid to ask others for help.

Make sure to draft or share your plan with someone else, particularly with other people involved in providing care so everybody understands what care is needed. If it’s just you who is providing care at the moment, sharing the plan with someone else is still important so that others can help if you become unavailable for any reason.

_____’s Care Plan	
Name and DOB of person with care needs:	
Preferred name:	
In an emergency please contact (in order of preference):	#1
	#2
	#3
_____’s needs, wants and preferences:	Medical history:
	Further relevant information:
	Communication needs:
	Mobility:
	Anything else:
_____’s daily support:	
Morning:	
Afternoon:	
Evening:	
Night:	

_____’s weekly support	
Monday	
Tuesday	
Wednesday	
Thursday	
Friday	
Saturday	
Sunday	

Other support to consider:

Who’s available to take ____ to hospital appointments:

- xx
- xx
- xx

Power of attorney [if relevant]: xxx

Manage money and direct debits: xxx

Other useful contacts: xxx

[INSERT LINES FOR REFLECTION HERE – PROTOTYPE CONTENT]

❑ Prepare for change

Change can't always be predicted. Your loved one's care needs might increase or develop in different ways. Changes in your support network might mean some might no longer be able to help with caring, or become more able to help than before. Thinking about support and flexibilities in advance can help you manage better if and when changes or emergencies do occur.

Learning about your loved one's condition can help you prepare for possible future changes. Depending on their diagnosis/diagnoses, charities like [Age UK](#), [McMillan Cancer Support](#), [Mind](#) or [Parkinson's UK](#) could help you understand how your loved one's needs might develop or change over time. They can also offer opportunities for learning from others in similar situations. Mobilise lists a broader range of condition-related charities on their [website](#).

You could use our 'sustainable care checker' below to think about if and how to make care arrangements more manageable and adaptable. Remember, any decisions you make now are not set in stone. Your options might change in the future, and that's okay!

❑ Consider if you need a lasting power of attorney

You may want to talk to the person with care needs about setting up a lasting power of attorney for themselves (you may even wish to set up one for yourself). A lasting power of attorney is a legal document that allows someone to make decisions for you, or act on your behalf, if you're no longer able or no longer want to make your own decisions.

In England, there are two types of lasting power of attorney:

- One covers decisions about finances and property. It can start working while the person still has capacity to make their own decisions.
- The other deals with decisions about health and welfare. This only comes into force when the person loses capacity to make their own decisions.

You need to plan ahead for this as the person making the LPA must have the mental capacity to consent to getting an LPA.

If the person who needs care doesn't have the capacity to make a lasting power of attorney, it is still possible to get the legal agreements needed to make decisions for them by applying to the Court of Protection.

Find out more:

- [GOV.UK: Power of Attorney](#)
- [Carers Trust: Managing someone's affairs](#)
- [Carers UK: Managing someone's affairs](#)

❑ Exercise 5: Check if your care arrangements are sustainable

Everyone’s situation is unique. There’s no one right way to provide care. The below exercise includes questions and actions you might find helpful to consider.

Things to think about	Tips and things you could do:
<p>If you or someone else involved in helping wants to take a break (for example, to go on holiday), is there someone else who can help out for a short period of time?</p>	<ul style="list-style-type: none"> ❑ Try asking friends and family if they would be able to help. ❑ Speak to your GP or local authority about respite care. ❑ Find local carers support services through Carers Trust's postcode tool.
<p>Have you spoken to healthcare professionals about how your loved one’s needs may change in the future?</p>	<ul style="list-style-type: none"> ❑ Speak to your loved one’s healthcare professionals and condition-related charities to see if they can give you any information about how your loved one’s needs may change in the future and what you can expect. ❑ If your loved one's condition is getting worse over time, it can be difficult to think about the future. It's important to remember you don't have to do this alone, though, so make sure to reach out to your GP for support. You can also speak to others in a similar situation through support groups run by charities like Carers UK, Carers Trust or Mobilise. ❑ If you have information about how things might change, start thinking about how your care arrangements could adapt to meet your loved one’s needs.
<p>Do you regularly review your care arrangements with those involved, to check no one is overwhelmed or that the plan still works for all involved?</p>	<ul style="list-style-type: none"> ❑ Set a date in the diary (perhaps the first week of every month or every few months) to review your arrangements and check in about how everyone is feeling.
<p>Have you connected with a local carers centre to find what support they might offer e.g. with care planning?</p>	<ul style="list-style-type: none"> ❑ Search for local carer support services using Carers Trust's postcode tool. ❑ Ask your GP or healthcare professional if they can recommend local support services.

	<input type="checkbox"/> Contact your local authority to understand what support they provide.
Do you, or anyone who might be involved in caring for your loved one, have enough time for yourselves? For example, for any activities that you would normally do to relax or to maintain your physical or mental wellbeing?	<input type="checkbox"/> Read about what could help you make more time for yourself and the things that are important to you in section 2 of this guide.
Do you know what burnout is and how to spot early signs?	<input type="checkbox"/> Burnout is a state of emotional and physical exhaustion, often caused by long-term stress or being overwhelmed and not having the time needed to care for yourself or do things you enjoy. Early signs can include feeling drained of energy, irritable, or physical symptoms like headaches. <input type="checkbox"/> If you or someone you know shows early signs of burnout, speak to your GP to get support.
Can you speak to someone if you feel overwhelmed?	<input type="checkbox"/> If possible, try having a designated person in your life who you can trust and ask for help if needed. <input type="checkbox"/> If you don't feel comfortable talking to family or friends, try to speak to your GP.

Remember, this checker exercise aims to help you find opportunities to make caring arrangements more sustainable. There's support available to help you plan care. Please speak to your GP, local authority, local carer centre, or carer charities for support. You can find contact details for these organisations in **section five**.

Exercise 6: What can I do when things change?

When things change, some people can feel rushed to adjust or respond as quickly as possible. It's tempting to take on everything yourself to meet an urgent need. Try to find time when you can to make sure you're also considering your own needs and life alongside the person who needs care. Ask for support and try to find time to think about options to make arrangements manageable over time.

This activity is a handy checklist to help you respond to change. Feel free to return to it as a reminder of key bits of advice from this booklet when things change or you want to consider adapting care arrangements.

Things that might help	Questions to think about:
<input type="checkbox"/> Understand the change	<ul style="list-style-type: none"> • What is the change – a change in your loved one’s care needs? A change in the support available to them or you? A broader life event like a house or job move that will impact on your caring? • Is it a temporary or permanent change? • Is it definitely happening or still just a potential change at this stage?
<input type="checkbox"/> Talk to others about it	<ul style="list-style-type: none"> • Family • Friends • GPs • Paid carers • Charities like Carers UK, Mobilise or Age UK etc
<input type="checkbox"/> Revisit exercises and suggestions in this guide	<ul style="list-style-type: none"> • Section 1 helps you think through what’s happening and what support is available • Section 2 helps you check in on your feelings, and how you might be impacted • Section 3 helps you talk to those around you • Section 4 helps you make care arrangements sustainable • Section 5 lists further resources and organisations and websites that might help you
<input type="checkbox"/> Learn from mistakes and mishaps	<ul style="list-style-type: none"> • If possible, can we reduce the chances of any negative or unhelpful events happening again? For example: <ul style="list-style-type: none"> ○ Your loved one has a fall and might need extra equipment to get around safely. ○ Someone who helps becomes overwhelmed and pulls out of providing support, so you have to cover the gap in care this creates for a while. • Think about what you, or those around you could do to prevent the same happening again.
<input type="checkbox"/> Test new arrangements first	<ul style="list-style-type: none"> • You might be able to test some changes out before they become permanent. For example: <ul style="list-style-type: none"> ○ If you’re offered a new job promotion you could ask your boss for a trial period first, ○ You want to try paid carers, but your loved-one who needs care isn’t sure about how they feel about it, so you start with a few trial sessions.

<p><input type="checkbox"/> Remember to protect yourself</p>	<ul style="list-style-type: none"> • You may feel a sense of duty or morally obliged to look after your loved one, but you are entitled to choose whether or not to provide care, as well as how.
--	--

Remember, you're not obliged to give up parts of your life to care for someone. There are options available to try to adjust care arrangements. For example, sharing care, paid carers, or support from local authority. It can also risk being unsustainable to put your life on hold and prevent changes you want while looking after your loved one. Caring for someone doesn't have to come at the cost of our wellbeing. Looking after ourselves is important if we want to care effectively long term.

Protect your wellbeing

It's important to remember **you are always entitled to make or adapt choices that work for you** and your loved one. If providing support becomes too much, or if it's something you can't manage, it's perfectly okay, and sometimes for the best, to take a step back and ask for help. Your wellbeing matters too, and it's in both your and any dependent's interests for you to protect your own health and life. It's important to consider whether over-committing in the short term could put you at risk of burnout or being less able to provide care later on – **it's not selfish to say no to things and protect your health!**

Your entitlement to choose whether to care or not applies no matter what arrangements you might have already agreed to. There is other support available, like paid carers and community services. Your kindness and compassion show no matter what, and it isn't measured by the number of hours you give. Just remember that it's okay to seek help, or make choices to put your own wellbeing first – you can do this at any time.

Summary

- Be prepared for change and think about adapting care arrangements to help you manage changes.
- Finding time to plan or adapt care arrangements can be difficult. But having sustainable care arrangements in place can reduce the risk of crisis situations.
- Change in life is often inevitable. Planning ahead and having support to rely on is important.
- You can reach out to your GP, local carers centre, local authority, or carer charities for support.
- Remember that considering your own needs and life alongside those of others isn't selfish, and it can often be in everyone's best interests.

Summary of things you could do

- If you don't have one already, try writing down the care arrangements that are in place for your loved one. You can use our example plan to help you.
- Use our 'sustainable care checker' exercise to see if there's any opportunities to make your current plan more sustainable.
- Revisit the exercises and templates in this guide to help you understand the change and how it might impact you.
- Search for local carer support services using [Carers Trust's postcode tool](#).
- Consider connecting with others who care for someone or have done so in the past, for example, through organisations like [Carers UK](#) and [Mobilise](#).

Reflections

Please feel free to use this space to write down any thoughts you have after reading this section. For example, information you've found useful or things you want to learn more about.:

[PROTOTYPE CONTENT - LINES FOR REFLECTION TO BE INSERTED HERE]

5 Contacts and resources

General information and support:

Age UK provides information and advice for people in later life through their advice line, local centres and website.

Age UK Contact: 0800 678 1602

Age UK Website: www.ageuk.org.uk

In Wales,

Age Cymru Contact: 0300 303 44 98

Age Cymru Website: www.agecymru.org.uk

In Northern Ireland,

Age NI Contact: 0808 808 7575

Age NI Website: www.ageni.org

In Scotland,

Age Scotland Contact: 0800 124 4222

Age Scotland Website: www.agescotland.org.uk

Condition-related charity websites like [Age UK](#), [Mind](#), [Parkinson's UK](#) and many more are listed on Mobilise's website: www.mobiliseonline.co.uk/condition-specific-support

FirstStop a fair service that provides guidance and information to older people, their families and carers about accommodation and care choices for older age.

Tel: 0800 377 7070

Website: www.firststopcareadvice.org.uk

Homecare Association the Homecare Association is the umbrella organisation for groups that offer social care, including nursing services, to people who live at home.

Tel: 020 8661 8188

Website: www.homecareassociation.org.uk

Independent Age offers advice and help on living and financial arrangements, travel and accessibility for older people, their relatives and caregivers.

Tel: 0800 319 6789

Website: www.independentage.org

NHS provides information on NHS services and condition specific advice in their Health A-Z.

Website: www.nhs.uk

Social care and support guide: www.nhs.uk/conditions/social-care-and-support-guide

Carer's assessment: www.nhs.uk/conditions/social-care-and-support-guide/support-and-benefits-for-carers/carers-assessments

Care needs assessment: <https://www.nhs.uk/conditions/social-care-and-support-guide/help-from-social-services-and-charities/getting-a-needs-assessment/>

Find your local GP: www.nhs.uk/service-search/find-a-gp

Carers' breaks and respite care: <https://www.nhs.uk/conditions/social-care-and-support-guide/support-and-benefits-for-carers/carers-breaks-and-respite-care/>

Scope offers advice and information on living with disability. Also supports an independent, UK-wide network of local Disability Information and Advice Line services run by and for disabled people.

Tel: 0808 800 3333

Website: www.scope.org.uk

The Silver Line An anonymous, free phone service that offers support, companionship and guidance to elderly people.

Tel: 0800 470 8090

Website: www.thesilverline.org.uk

Support for those who help, or care for, loved ones:

Carers Trust works with local carer organisations to provide access to the right support, advice and resources.

Contact: Call 0300 772 9600 in England or 0300 772 9702 in Wales or email info@carers.org

Website: www.carers.org

Postcode tool: www.carers.org/help-and-info/carers-services-near-you

Carers UK provides information and advice on caring, offers a telephone listening service and helps carers connect with each other through local support groups.

Contact: Call 0808 808 7777 or email advice@carersuk.org

Website: www.carersuk.org

District Provision Tool provides national and county-specific links to carer support.

Website: www.gov.uk/guidance/district-provision-tool/carers

Mobilise provides support and advice to unpaid carers through their online service and offers virtual meetups.

Website: www.mobiliseonline.co.uk

Emotional and mental health support:

British Association for Counselling and Psychotherapy (BACP) helps people learn about counselling and find appropriate services in the UK. You can also search for a certified counsellor on their 'How to find a therapist' page.

Tel: 0145 588 3300 (Mon to Fri, 10am to 4pm)

Website: www.bacp.co.uk

Mind offers guidance, help and assistance to anyone who has a mental health issue.

Tel: 0300 123 3393

Website: www.mind.org.uk

Relate provides relationship counselling and support across the UK

Tel: 0300 100 1234

Website: www.relate.org.uk

Samaritans offers private and unbiased emotional help, anytime of the day or night, all year round, for people who feel troubled or hopeless

Tel: 116 123

Website: www.samaritans.org

UK Council for Psychotherapy (UKCP) maintains the national list of psychotherapists and psychotherapeutic counsellors, showing practitioners who meet high standards and training requirements

Tel: 020 7014 9955

Website: www.psychotherapy.org.uk

Financial support and legal information:

Carer's Allowance Unit handles state benefits in England, Scotland and Wales. You can find information online or through its helplines and apply for benefits.

Tel: 0800 731 0297

Website: www.gov.uk/carersallowance

Citizen's Advice offers free advice and information on various issues, such as debt, benefits, consumer rights, housing, immigration and legal matters.

Tel: 0800 144 8848

Website: www.citizensadvice.org.uk

Disability Rights UK provides information on benefits and disability rights in the UK. Has several helplines for specific support, including getting back to work, direct payments, human rights issues, and advice for disabled students.

Tel: 0330 995 0400 (not an advice line)

Website: www.disabilityrightsuk.org

Equality Advisory Support Service (EASS) supports fairness and educates people on their legal entitlements in England, Scotland and Wales.

Tel: 0808 800 0082

Website: www.equalityadvisoryservice.com

GOV.UK UK Government website provides information on government services such as benefits, jobs and pensions.

Website: www.gov.uk

Carer's Allowance: www.gov.uk/carers-allowance

Find support through your local authority: www.gov.uk/find-local-council

Turn2Us a charity that assists people who are struggling financially to get welfare benefits, charitable grants and other financial support.

Tel: 0808 802 2000

Website: www.turn2us.org.uk

Work and employment support:

ACAS gives employees and employers free, impartial advice on workplace rights, rules and best practice.

Website: <https://www.acas.org.uk/>

Access to Work offers guidance and assistance to people who have chronic health problems and their employers. This helps cover the cost of practical support, so you can perform your work.

Tel: 0800 121 7479

Website: www.gov.uk/access-to-work

Job Help offers information for people working and supporting someone with care needs.

Website: jobhelp.campaign.gov.uk/ways-of-working-that-fit-around-you/working-and-caring-location-menu/

WorkSmart source of information on work rights, wellbeing at work and money issues. It belongs to the Trades Union Congress (TUC).

Website: www.worksmart.org.uk

Independent living equipment and advice:

British Red Cross provides various health and social care services in the UK, such as home care, a service to borrow medical equipment, and a transport service.

Tel 0344 871 11 11

www.redcross.org.uk

Disabled Living Foundation (DLF) offers unbiased guidance on all kinds of disability equipment and mobility products.

Tel: 0300 999 0004

Website: www.dlf.org.uk

Living Made Easy offers unbiased, free guidance on various kinds of mobility products and disability equipment.

Tel: 0300 999 0004

Website: www.livingmadeeasy.org.uk

Advanced illness and end of life care:

Compassion in Dying helps people to plan ahead and write Advance Decisions ('Living Wills') and discuss their wishes and preferences when facing a life-changing illness.

Tel: 0800 999 2434

Website: www.compassionindying.org.uk

Dying Matters encourages and supports people to communicate more freely about dying, death and grief.

Website: www.dyingmatters.org

Hospice UK offers guidance on coping with serious illness. Also offers free pamphlets and a list of hospice services in the UK.

Tel: 020 7520 8200

Website: www.hospiceuk.org

Marie Curie Marie Curie nurses offer end-of-life care at no cost in the UK. They look after people in their own homes or in Marie Curie hospices, around the clock, every day of the year.

Tel: 0800 090 2309

Website: www.mariecurie.org.uk