Welcome to the Care and Support Planning Guide
This guide is designed for anyone who has health and care needs over time, or cares for someone who does.

It will help you to:

• understand what care and support planning is and how it might help you
• see how care and support planning works at each of the four stages
• find out about other people’s experiences of care and support planning and what they thought about it
• get started with care and support planning

To start using the guide, click on one of the boxes below.

You can get back to the previous section at any time by clicking on this icon: 

You can go to the next page or go back a page by clicking on the arrows: 

You can print pages of the guide by clicking on this icon: 

Watch some films about care and support planning
Read about what care and support planning is and why we need it
Find out how care and support planning could help you
See how care and support planning works at each of the four stages
Get extra information about care and support planning and how to get started
Find out what key words mean in the glossary
Some films about Care and Support Planning

Click on the images below to find out more about care and support planning.

Clicking on this links will take you to an external website. When you have watched the films, just close the webpage (or click the back button in your web browser if you are reading the guide online) to return to the guide.

This clip is about why we need care and support planning and the difference it can make

This clip provides an introduction to the four stages of care and support planning

This clip shows you what people have said about care and support planning

Do you have sensory loss?

Click here for accessible versions of this content

Clicking on this link will take you to a webpage on the National Voices website. Once you have finished, just close the webpage (or click the back button in your web browser if you are reading the guide online) to return to the guide.
Care and Support Planning: what it is and why we need it
Care and Support Planning: what it is and why we need it

What it is

• Care and support planning is about someone who needs support from health and/or social care over time, working together with a care and support partner.
• You should be able to talk about what matters to you and what you want to do or achieve.
• Together you should work out the best treatment, the right care and support and the actions you can take yourself to help you get there.
• It becomes a normal part of how you work with the professionals and/or supporters you are in contact with.

What it isn’t

• A document, drawn up by a professional and given to a person, without any discussion with them.

People are people, not conditions, disabilities or symptoms

Even if a person is diagnosed with exactly the same condition or disability as someone else, what that means for those two people can be very different.

Each person wants to do and achieve different things in their life and has different ideas about how they could get there.

By starting from your point of view, you and your care and support partner can think about what actions you can take yourself. You can also consider what it is that you want your care and support to do to help you.
Care and Support Planning: what it is and why we need it (2 of 2)

Making the best use of time and expertise

You...
- live with your condition and/or disability every day and make decisions about how to manage it. For example, taking medication, eating a healthy diet, taking exercise etc
- you learn what works best for you over time, what support and information you need and how your condition and/or disability fits into your life

The professional or supporter you work with...
- has a limited amount of time to spend with you
- has skills and knowledge to help you understand your condition or disability
- knows about the choices for monitoring, treatment and/or support

Care and support planning helps you and the professionals or supporters you work with to make the best use of your time together.

There are lots of different professionals or supporters who may work with you, but the key professional in care and support planning is the ‘care and support partner’.

Read on to find out more about the care and support partner.
More about the Care and Support Partner
A care and support partner is an individual who works with you on your care and support planning

The most important thing is having the right person to support you.

For many people, your care and support partner will be at your local GP practice. For example, it could be your GP or a practice nurse. It could also be another professional who is already working with you like a specialist nurse, social worker, physiotherapist and so on.

You should be able to say who you think would make a good care and support partner for you.

You may want to work with a peer supporter or trained volunteer, either as your care and support partner or as someone who can help you with the things you decide to do to manage your health and wellbeing.

Changes over time

Your care and support partner may change over time as your life changes.

For example, you may start off with your care and support partner being someone who works with you in hospital. Over time, if you change from getting care in hospital to getting support at home, it may be a good idea to change your care and support partner to someone who works at your GP surgery or in your local community.

The most important thing is that everyone knows who your care and support partner is, and what their role is.
The role of the care and support partner

The role of the care and support partner depends on how much support you want and need, and how much you feel able to do yourself.

A good care and support partner should

- **See you as an individual:** they should work with you, your family and carers to get a good understanding of you and what your life is like.

- **Understand and value your expertise:** they should understand that you are, or you could be, an expert on your condition or disability and how this fits into your life. They should encourage you to share this information, and use what you know as well as their own knowledge and expertise to make the best shared decisions.

- **Build a trusting and supportive relationship:** they should be able to communicate well with you, be really good at listening, encourage you to join in discussions, check they understand what matters to you and encourage you to push yourself.

- **Work as part of a team:** they should work with other professionals or supporters who work with you, to make sure you get the best treatment, care and support and specialist advice. They should make sure that any treatment, care or support fits into your life in the best way for you.

- **Know about support in the local community:** they should know about support that you could get in the local community and help you to link into this.

“There are numerous different people involved in my brother and I’s care. We are fortunate that we have an excellent Respiratory Nurse Specialist at our local hospital who tries to coordinate the care. However, it is still often our Mum who arranges appointments and chases up results. Many families are not as fortunate to have a Mum that doesn’t have to work full time and is able to do this role.”

A person with Primary Ciliary Dyskinesia
• **Make sure agreed actions happen**: they should work with other professionals and supporters to make sure that the actions in your care and support plan happen as agreed.

“**When you have a long term health problem, you often have to manage your interactions with your healthcare professionals. Often you find yourself repeating your symptoms, test results, etc over and over again to different care professionals and sometimes several times within the same appointment.**”

A person with a long term condition
How can Care and Support Planning help me?
Care and support planning can help anyone with health, care or support needs over time.

This guide mainly talks about people with disabilities or one or more long term conditions but care and support planning can also help people who are recovering from illness or other problems. For example, it can help someone recovering from drug or alcohol problems.

**Care and support planning can**

- help you understand your condition or disability better
- help you feel more confident and able to manage your own health
- help you to play a role in managing your condition and get recognition and support from professionals in this role
- help to stop your condition or symptoms from getting worse
- help you feel more in control of your care and support
- help to build on your strengths and support you in doing or achieving what matters to you
- help to support you be as independent as possible
Care and support planning may also help your family and carers too. If your family and carers have a better understanding of your condition, they will be more confident about supporting you.

Click here to read some stories about other people’s experiences of care and support planning and what they thought about it.

Clicking on this link will take you to a webpage on the National Voices website. Once you have finished reading the stories, just close the webpage (or click the back button in your web browser if you are reading the guide online) to return to the guide.

“Each time I get a greater understanding of my condition and understand more about how I can go about maintaining and improving it.”

A person with a long term condition

“I know what is going on now which is a relief. I do feel more in charge both during the consultation and in managing my condition.”

A person with diabetes

“If I were a patient I would want to have this system in place. I think it respects people more as individuals. It gives people more rights.”

Practice nurse
How Care and Support Planning works at each of the four stages
How care and support planning works

Good care and support planning should have four stages. Click on the links below to find out more.

**Prepare – getting ready for the care and support planning discussion**
This stage is about:
- thinking about what matters most to you
- getting any useful and important information before the discussion
- taking time to think and talk to other people about the different choices you have

**Discuss – talking with the care and support partner**
This stage is about:
- you and the care and support partner working together
- talking about staying well and living well
- talking about what you are going to do
- talking about what care and support you might need from other people

**Document – writing down the main points from the discussion**
This stage is about:
- writing down all the main points that you have talked about with the care and support partner
- making sure that the plan belongs to you and is easy for you to understand and use

**Review – checking on how things are going**
This stage is about:
- seeing how you are getting on
- reviewing the plan with the care and support partner and making any changes
Stage 1
Prepare – getting ready for the Care and Support Planning discussion
It’s all about you

- Everyone has ideas about what they want to do with their lives. Only you will know how your long term condition or disability fits in with what you want to do in your life.
- You, and anyone who is important to you, should be part of deciding on your treatment, care and support and anything you can do to help you live and stay well.
- Having the right information means you can do things that help you to live and stay well.

Before your care and support planning discussion, your care and support partner should help you think about how you want to live your life. This includes the knowledge and skills you already have, the care and support you have now, and what you might need in the future.

Your care and support is about

- your physical health needs, like losing weight or managing your blood pressure
- your mental health needs, for example, if you need support with depression or anxiety
- your social needs, like keeping in touch with family and friends
- your communication needs

Your care and support partner helps you to think about all of these things. They should help you in the way that works best for you. For example

- they may use questionnaires or send you a list of things to think about
- they may give you information, or tell you about information or learning sessions, to help you find out more about your condition or disability.
Here are some things that you might like to think about before the care and support planning discussion:

- What you enjoy doing most
- What you would like to do in the future
- Your strengths and abilities
- Your family and friends
- Any medical, social, sensory or psychological issues
- Your home environment
- If you can get to local shops and other community facilities
- Employment, volunteering, education or training that you would like to do
- Your religious, philosophical or cultural beliefs or values
- Any lifestyle changes that you have been thinking about like losing weight or doing some exercise
- If and how assistive technology might help
- Any problems you have faced in getting care and support

Thinking about these topics will make sure you get to talk about what matters most to you.

**Key points**

- You, and your family and carers, are the best people at understanding how your condition or disability affects you and fits into your life

- Before you meet with your care and support partner, think about what matters most to you
Information is important because it helps you think about what you would like to talk about in the care and support planning discussion. Information also helps you to make decisions and choices.

You and your care and support partner work together to get information from other people who work with you. For example, your GP, your social worker and any other services you use.

This might include finding out about other plans about you and your care and support. For example, plans about your health, social care or housing.

Your carer might also have a plan about their support needs and it might help you to know what is in this plan.

Here are some examples of the information you might get at this stage:

- Information about your condition or disability
- Test results and what they mean
- Information about treatment, care and support choices
- The results of any assessments. For example social care or special educational needs assessments, and any care or support you have had as a result
- Information about patient decision aids. These help you to make choices
- Information on lifestyle like what you eat, exercise or smoking

Your care and support partner can help choose the information that may be most useful to you.
Any information should be easy for you to understand. For example, translations, Braille or easy read if you need them.

You can choose to share this information with important people in your life, like your family or carer.

**Key points**

- **Having the right information will help you get ready for the care and support planning discussion**

- **Your care and support partner should help you find the information that is important and useful for you**
Taking time to think

Why is having time important?

- You may find out some new information and need time to think about it.
- You may want to talk to important people in your life, like your friends, parents, partner or children.
- Taking time to think will help you get ready for your care and support planning discussion. You can have questions ready and be clear about what you want to talk about.

Carers

A carer is someone who looks after an ill, frail or disabled family member, friend or partner. They do not get paid.

If you have a carer, they can take part in your care and support planning if you want them to. They know you well and any care and support should be organised in a way that fits with any support they already provide.

Caring for someone can also affect a carer’s own life and health. If a carer feels that they need support themselves, local authorities can carry out a carer’s assessment and develop a carer’s support plan.

Some people’s family members or friends may choose not to provide care and that’s ok. Some people may not have family or friends to support them. Both these things should be noted and thought about as part of the care and support planning discussion.

Key points

- Having time to think through information and talk with family, friends and carers will help you think about what it means for you
- If you want them to, family, friends and carers should take part in your care and support planning from the start
Stage 2
Discuss – talking with the care and support partner
You and your care and support partner have information and expertise to bring to the discussion:

- **You know what it is like to be you!** You know what it is like to live with your disability and/or health condition and what effect it has on your life. You also know what your strengths and skills are and how you want to live your life.
- **Your care and support partner has the skills and knowledge to help you understand your condition or disability.** They can help you find out about options for monitoring, treatment and support. They can also help you to find support from other people or services.

The care and support planning discussion is about the person and their care and support partner working together to share this information and expertise.

The discussion should:

- **Focus on staying and living well:** The discussion should be about your life now and how you can stay as well as possible and feel good about the future.
- **What you can do for yourself:** The discussion should be about what you want to do or achieve and the steps you can take to get there. This should include talking about support to help you develop the confidence, knowledge and skills to help you live as well as possible. It should be about what you want to do or achieve and the steps you can take to get there.
- **What care and/or support you might need from others:** The discussion should also be about what care and support is available to you. You and the care and support partner should discuss which options you think might work for you and which you would like to try. From this discussion, a ‘package’ of care and support will be drawn up.
Communication

Good communication helps you to feel comfortable and confident to talk about what matters most. Your care and support partner should:

- let you know roughly what the discussion could cover
- ask you questions in a way that helps you to say what you think
- listen closely and carefully to what you say
- focus on the issues that are most important to you
- check that they understand what you are telling them

You may want to ask other people to come to the discussion like a friend, family member or supporter.

If you are a person with a learning disability or mental health problems you may want to use an advocate. This is something that should be available to you. Advocacy may also be useful for other groups that find it difficult to speak up for themselves.

You should be able to communicate in the way that works best for you. Let your care and support partner know if you need support to do this.

**Remember: you don’t have to cover everything in one discussion.**
Focus on staying well and living well

It is important to talk about what will help you to stay as well as possible now and in the future. It’s important to think about what gives you a good quality of life.

You and your care and support partner should think about any potential issues which might be affecting your health and could be stopped if you got some extra support. For example, stopping smoking or changing your diet now will help you to have a healthier life in the future.

It might be helpful to talk about times in your life when you have felt really well and what was going on in your life at that time.

It’s also important to talk about when things did not go well and what could have been done differently. For example, if you had to have a stay in hospital.

You might want to think about any changes you or other people can make to help you to stay as healthy as possible.

If you have a condition that changes over time like arthritis or multiple sclerosis there may be times when you need more care and support and times when you need less. Talk about how any changes to the care and support you need can be made part of the package you get.

There may be groups or services near you that can help you stay well and live well. For example:

- Support groups to help you stop smoking, lose weight or keep fit
- Transport services to help you get around
- Buddying and befriending services.

A personal budget can also help people think about their own ways to stay and live well.

Key points

- The discussion should be about how you can stay well now and live as well as possible in the future
- You might have some ideas about what could help. Your care and support partner should be able to tell you about services and support in your area
What would you like to do or achieve?

You and your care and support partner may want to think about what you would like to do or achieve in future. For some people, this may be about finding ways to keep things as they are now. For example, staying comfortable living at home or not having to give up work.

You are looking for things that will happen because of an action, not an action itself.

If you decide on something you want to do it should be manageable. It might help to say when it will be done by.

You might want to score the things you want to do from 1 to 10, with 1 being the most important. This will help you decide how important doing or achieving this thing is to you.

Here is an example of deciding on a change and setting a timescale.

Mrs Smith is a grandmother. She is overweight, has high blood pressure and mild depression. During her care and support planning discussion, she tells Mr Bashir, her GP, that she would like to lose about half a stone. Being overweight is getting her down. She can no longer fit into her favourite clothes and is struggling to keep up with her grandchildren. She will be going to a family wedding in 6 months’ time. Mrs Smith decides that she would like to use the wedding as motivation to lose half a stone so she can fit into her favourite outfit for the wedding.
How can you get there?

You then need to think about what actions you can take to do or achieve what matters to you.

Here is an example of deciding on the actions to take.

Mr Bashir asks Mrs Smith about what she would like to do to lose the weight. Mrs Smith says that she would like to start doing some exercise. Mr Bashir asks what sort of exercise she would be interested in. Mrs Smith says that she would not feel comfortable in a gym but enjoys walking. She would also like to meet some new people. She remembers that her daughter talked about a local walking group and thinks that this might be a good action to take.

The next few pages include some extra information about support for self management – support to help you develop the confidence, knowledge and skills to help you to feel in control of your life and live as well as possible.
What is support for self management?

You make decisions about how to live with your condition or disability every day. For example, taking medication or deciding to eat a healthy diet are both examples of self management. Self management means doing what you can to look after your health and wellbeing.

Support for self management is all about helping you develop the confidence, knowledge and skills to help you to feel in control of your life and live as well as possible.

Self management will vary depending on each person’s situation but it may include:

- supporting you to think about what is important to you or what you would like to do or achieve
- deciding what you can do to achieve this
- identifying what to do to deal with any issues you might face from day to day, including dealing with any unforeseen ups and downs or changes to your health or condition

“Learning self management was a revelation to me. It taught me to recognise the triggers and early warning signs that might precede an episode of illness, and what action to take in order to stop it in its tracks. I am now able to work, maintain and enjoy a healthy marriage with my wife and be a good father to my three children. My only regret about self management is that I didn’t discover it earlier.”

A person who uses mental health services
How can self management help me?

When people are supported to self manage, they are more likely to:

- experience better health and wellbeing
- have greater confidence and sense of control over the care and support they get
- feel that their symptoms are less severe, including pain
- have fewer visits to accident and emergency
- have fewer unnecessary stays in hospital, and fewer days spent in hospital
- be able to stay living in their own home
- have better mental health, e.g. less depression.

Can everyone self manage?

Everyone with a long term condition or disability is already doing some self management. Most people with long term conditions say they would be interested in doing more. Many people say that they would feel more confident about self management if they had support from a professional or someone who has or has had similar experiences.

In some places, the NHS or charities run self management support services that can help people get started.
Support for self management

The role of family, friends and carers

Family, friends and carers often play an important role in supporting self management.

For example, many family members support people by reminding them to book appointments or manage their medicines.

Friends and family can also support you to change your lifestyle such as changing the family’s diet or getting involved in more exercise.

It is important that your family and carers get the right information to help them to support you.

Key points

- You make decisions about how to manage your condition or disability everyday
- Support for self management is about helping you develop the confidence, knowledge and skills to help you feel in control of your life
The care and support planning discussion lets you and your care and support partner discuss the care and support choices that you have. You can also think about how these can be provided in a way that is best for you.

The choices you have will vary depending on your circumstances but could include some of these:

- Information for you, your family and carers
- Medication and/or medical treatment
- Specialist services such as a dietician, physiotherapist etc.
- Emotional or psychological support like counselling or a support group
- Support in the local community like support groups, activity groups, exercise classes, befriending services etc.
- Home care and independence support services
- Housing - adaptations to your home or specialist housing
- Respite (short breaks) services
- Education or employment support
- Assistive technology

You and your care and support partner will also need to think if there is anything that could stop you getting services, facilities or support and how this could be sorted out.

You should also talk around choices you are making to make sure you know what these may be and what can be done to reduce them as much as possible.
**Personal budgets**

A personal budget gives you more control over the care and support you get.

A personal budget is money to pay for your healthcare or social care support. Care and support planning helps you think about what matters to you and what you want to do or achieve. You decide how you would like to spend your budget and agree this with your health or social care team.

Local councils have been using personal budgets to help people have more say about their social care support since 2008. Personal health budgets are now being introduced.

Joint health and social care budgets are now also being looked into. This would mean you have one personal budget which can pay for the support you need from health and social care.

Your care and support partner can talk to you about having a personal budget. If you have a personal budget, your care and support partner should make sure that you know what this budget is. They should also make sure that you have the right information and support to plan and manage your budget.

You can find more information about personal budgets via the ‘Other information about care and support planning’ pages on the National Voices website. Once you have finished reading this information, just close the webpage (or click the back button in your web browser if you are reading the guide online) to return to the guide.

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**Key points**

- Your care and support should be about the things that matter most to you
- Discussions should cover all the care and support choices that you have
Stage 3
Document – writing down the main points from the discussion
The care and support plan is a record of the main things that you talked about with your care and support partner. You can use your plan as a guide to what you want to do and to check how you are working towards what is important to you.

The care and support plan should be written up in a way that makes sense to you.

You decide with your care and support partner what is written in the plan. Often the plan will include:

- **A summary of the actions that you will take for yourself:** This would be about what you said was important to you and what you will be doing.
- **A summary of the care and support that you will get from other people:** This could include any information that might be useful for you in your day-to-day life. For example, details of the services you can get after being discharged from hospital, information about what to do in an emergency or useful contact numbers.

Your care and support partner might write up the discussions and share a copy with you. You may prefer to do this yourself. The most important thing is that you have a copy of the plan and you feel that it belongs to you. The professionals or supporters who work with you must also know they are important to the plan working. They need to take responsibility for doing their part to make things happen.

A summary of the discussion should also become a part of your health and/or social care record. That means you won’t have to go through what is important to you every time you meet professionals or supporters.

The plan can change over time, as your life changes.
Sharing the information

Your care and support partner should find out who you are happy to share the plan with. This may include family members, carers and other professionals or supporters you might be working with. Your decision about who can see your plan should be written down in your records.

It might be important to give a copy of the care and support plan to other people that work with you. This can help everyone deal better with a crisis and avoid you having to go into or stay in hospital.

Key points

- Your care and support plan is about what was talked about in the discussions between you and your care and support partner

- It should be clear and accessible and only shared with the people you want to share it with
Stage 4
Review – checking on how things are going
Your care and support partner will talk with you about ways to follow up on how you are getting on. This means that if you are having trouble making progress, you can discuss why this is. For example, if a goal is unrealistic or if there is something getting in the way of achieving it.

If you have achieved what you included in your plan, you can talk about how to make sure things carry on working well or what you want to do next.

For example, if Mrs Smith loses the weight faster than she thought she would, she might want to think about doing more exercise too, as she starts to get fitter.

If you think that follow up would be useful, it is up to you and your care and support partner to decide how this is done. This could be a chat over the phone or by email with your care and support partner. You may find ways to track your progress yourself. You might also discuss how you are getting on with peers via a local support group or a peer supporter.

You and your care and support partner can decide if this is a regular catch up, like a phone call every two months, or if it should happen at the same time as certain actions should have happened.

**Why do we need a review?**

Your life, health and what matters most to you may change over time. The review gives you and your care and support partner a chance to think about what has worked well for you, what has not worked, and what might need to change.
What should be in a review?

What is in a review might be different for each person but it might include talking about:

- how you are getting on with achieving or doing what you said was important to you
- if and how your health (mental and physical) and wellbeing has changed in any way
- if and how your situation has changed in any way
- if you have needed any unplanned or emergency care since the last discussion. For example, a trip to A&E or a stay in hospital
- how your care and support is working for you
- how confident you feel about living with your condition or disability day to day and what might help you feel more confident
- any changes that might need to be made to care for and support you in the best way

When should a review happen?

How often you have a review will depend on your situation and how confident you are about managing your condition or disability day to day.

You and your care and support partner should talk about when a review should happen. Your care and support partner should make sure that you are offered at least one review a year.

When people have conditions that can change, often it is particularly important to take a flexible approach towards reviews, as the support they might need is more likely to change over time and/or following a stay in hospital.

Key points

- Follow up might be helpful to make sure you feel supported in working to achieve what matters to you
- Care and support planning is not a single discussion, but something that happens over time. The review makes sure that the care and support that you are getting and the actions that you are taking fit in with how your life is
Extra information about Care and Support Planning and how to get started
You can click on the links below to find out more information about care and support planning and how to get started. Clicking on these links will take you to a page on the National Voices website. When you’ve finished reading, just close the webpage (or click the back button in your web browser if you are reading the guide online) to return to the guide.

- Read some stories about other people’s experiences of care and support planning and what they thought about it
- Read some common questions and answers about care and support planning
- Find out what you can do next if you want to get started with care and support planning
- Get information about how care and support planning might work in different parts of your life
- Other information and materials about care and support planning
Glossary
**Advocate**
An advocate is someone who can help people to speak up and make decisions about things that are important to them.

**Assistive technology**
Equipment that helps you be independent.

**Carer**
Someone in your family, a friend or partner, who looks after you but is not paid.

**Care and support partner**
A care and support partner is an individual who works with you on your care and support planning. This could be your GP or a nurse or it could be another person who is already working with you like a specialist nurse, social worker, physiotherapist.

**Disability**
A physical or mental impairment that has a significant and long term adverse effect on a person’s ability to carry out day-to-day activities. Examples include difficulties with your hearing, sight or having a learning disability. Disability may be linked to one or more long term conditions.

**Long term condition**
A physical or mental health condition that cannot currently be cured but can be controlled and improved by how you are supported in your community, as well as by medication and traditional therapies.
Peer
Someone who has personal experience of the same disability or condition as you and can provide knowledge, experience, emotional, social or practical help.

Personal budget
A personal budget is money to pay for your healthcare or social care support.

Philosophical beliefs
Any belief that isn’t religious, which affects the way you live your life e.g. your decision to be a vegetarian or vegan.

Psychological issues
Any issues with your mental health e.g. depression or anxiety.

Sensory issues
Any issues with your physical senses e.g. if you are deaf, blind, hard of hearing, have a visual impairment or are deaf blind.