



Shaping My Future

A guide for people with
physical disabilities in Essex

Delivered by:



Commissioned by:



Introduction to Shaping My Future:

a guide for people with physical disabilities living in Essex

Who is this guide for?

This guide should be helpful to anyone with a physical disability, impairment or long-term condition who would like ideas and information to help think through, and make decisions about, possible changes in their life.

It has been written for people living in Essex (see map on page 129), with links to both national and local services and organisations.

We hope the guide will be useful to a wide range of people living in a variety of situations, including:

- young people who are beginning to think about their adult lives and want to do some planning to feel positive about the future
- adults who would like to do some planning for a better future
- family members, friends and other allies who are keen to help with planning and making change happen
- people working in health and social care, as well as support organisations, to encourage practice that gives people choice and control about their life.







What the guide can give you

It can often feel as though choices are limited and there are many obstacles when you have a disability. Hopefully, this guide will help you find your way through some of the difficulties by giving you:

- ✓ **Information:** national and local information, as well as links to further sources of information and advice, to save you time and energy
- ✓ **Knowledge:** knowing about your rights and how systems work can help to get over some of the barriers that get in the way
- ✓ **Sources of support:** help with finding people and organisations to give support to achieve changes
- ✓ **Ways to solve problems and make decisions:** having both planning tools and practical information can help to make decisions and a plan of action
- ✓ **Optimism and choice:** having plans, and people on board, can help with feeling more optimistic that change is possible

What's in the guide?

Shaping My Future has been written to give you lots of information and tips in one place. The guide has six sections that talk about important aspects of life:

 Planning for change: getting started 4	 Family, friends and connections 36
 Learning and working 49	 My home 75
 Health and wellbeing 97	 Going out and about 113

Although they are written as separate topics there are many connections and overlap between them and you can use the links to find relevant content in other parts of the guide.

You may not need to use every section and are likely to go to topics at different times in your life. If you keep it handy it can be a useful manual for sorting out issues and moving things along when needed.


Versions of this guide


The PDF versions of the guide contain fillable text boxes that you can type into to save your ideas. You will need to download and save to create an offline copy and then save each time you write more. The coloured tint in the text boxes will not appear if you choose to make a printed copy.


Go to: www.essex.gov.uk/shaping-my-future


- to request a printed copy of the full guide
- to download the full guide and the six individual sections

Tips to get the most from the guide

 **Where to start:** It is probably useful to start with the first section 'Getting started with planning' as it gives techniques and tools to think about planning for change as well as an overview of the issues that are useful to think about. It also explains key pieces of legislation that help you to know your rights in many different situations.

 **What to do next:** You could then move on to any of the other five sections. You might decide to choose the one where you think change is most needed or you may choose an area where you could make changes more easily. Sometimes, sorting out something small can help with tackling more difficult things.

 **Talk with others:** You may want to get on and do the thinking and planning on your own but it is often easier to do it with other people who know you well or who have knowledge and skills you would find helpful.

 **Find a 'planning buddy':** If you think you might find it difficult to motivate yourself, try to get someone on board who is good at getting things done. Your thinking, plus their energy, should make a good team.

Language

The guide mainly uses the phrase 'people with physical disabilities' which we chose after important discussions about people's sense of their identity. We are keen the guide reaches as wide an audience as possible and hope the language feels inclusive to as many people as possible.

Section 1:
**Planning
for change:
getting
started**



**Planning for change:
getting started**



**Family, friends
and connections**



**Learning
and working**



**My
home**



**Health and
wellbeing**



**Going out
and about**

Information in this section

	Useful to me?
Thinking and planning tools	6
• How the tools can help	6
• Tips for planning	7
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• What's working well and what could be better	9
• Important <u>to</u> me and important <u>for</u> me	16
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Why this section might be helpful

This section could help you get started with planning in two ways:

- 1.** It describes planning tools you can use to think about aspects of life where you would like to make changes. The information you gather will help you to think about what these changes might be and which other sections of the guide to look at.
- 2.** It gives introductory information about three key pieces of legislation that will help you understand your rights and their implications for your day-to-day life. There are links to further information and advice lines, should you need to know more.

Although the information about the planning tools is given first, you could start by looking at the legislation and gaining an understanding of your rights if you prefer. It will work either way.

This is the first section of a guide called Shaping My Future. The guide has five additional sections covering different areas of life, but you don't need to look at them all. Choose the ones that you think might be useful to you at this point in time.



Where you see this icon there is space to write your notes and thoughts.

Thinking and planning tools

How the tools can help

Most of us find it useful to do some planning, to help things move on, at different points in our lives. Living with a disability can make this feel even more important as there are usually many additional issues to think about and plan for.

In this section you will find examples of tools that can help you with that thinking and planning. In the other five sections of the guide you will find ideas, resources and links to services that will help you to follow up on changes you would like to make. This might be solving problems, finding ways to ease difficulties or securing new opportunities.



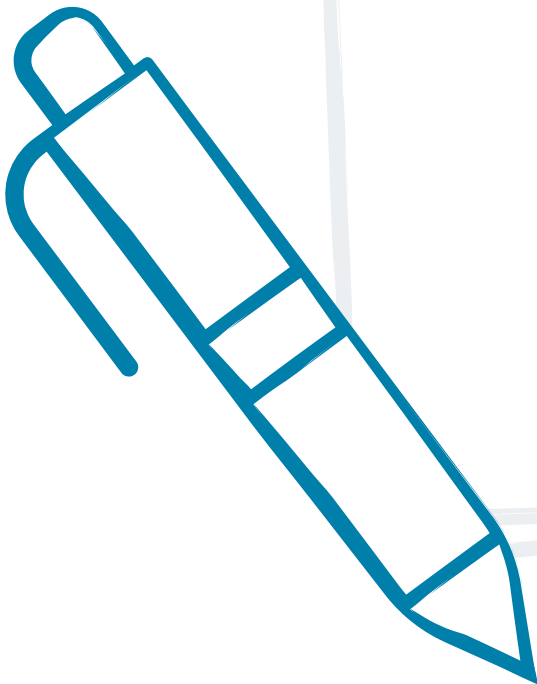
The tools can help:

- ✓ **To talk with other people** - looking at questions with family, friends and other people in your life can enable you to gain different perspectives and may also help broach subjects that can feel difficult or sensitive
- ✓ **To get things written down (on paper or electronically)** - it is much easier to plan if you write things down rather than just think about them and can help prevent worries going around in your head
- ✓ **To plan for change** - think about where you are now and where you would like to be in the next few months or years
- ✓ **To have better conversations with social workers and other practitioners** - they often use these tools and questions so, if you are familiar with them, you will have a better idea about what you want to tell them
- ✓ **To prepare for meetings** - by gathering information and evidence to take to health and social care meetings, such as assessments and reviews, and to inform other discussions, such as at work
- ✓ **To think about support** - to see whether you need more resources or support, either from statutory services, a not-for-profit organisation or more informal sources
- ✓ **To make planning for change more enjoyable** - they will help eliminate some of the stress and confusion when trying to work out what to do.






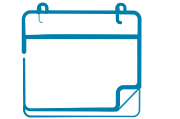


Tips for planning

- **Keep all your notes in a notebook or computer folder:** this will help you create a record for yourself and others of what you have talked about and the decisions reached.
- It helps to keep a note of who you have spoken to and what was discussed, and when people said they'd get back to you. **This makes it easier when following things up.**
- It's harder to plan on your own, so try to **involve people:**
 - who know you well
 - whose insights you value
 - who bring different perspectives from your own (perhaps through age or life experience).
- Use the information you gather to make a **to-do list**, a **mind map** or whatever you think will keep you going.
- **Finally, consider this information gathering as time well spent.** It can feel like another task to do but, in the long run, it should save you time and energy because you can use it in many different situations, such as asking for reasonable adjustments at work (see Section 3: Learning and working, page 66) or if you need an assessment for health or social care services.



Choosing which tools to use

You are likely to find some of these tools more useful than others. The table below gives a brief description of them to help you decide which ones you would like to try.

	Tool	Why you might use it	Page
	What's working well and what could be better	To gain an overview of how things are going in various areas of your life. To think about what you want to hold onto (or develop) and where you want to make changes.	9
	Important to me and important for me	To get the right balance between what's important to you (what you enjoy, gives your life meaning) and what's important for you (what keeps you safe and well). To get the right support for both aspects of your life.	16
	What makes a day (or week) go well/what makes a day (or week) go badly	If you are finding that things sometimes go wrong, particularly in your day-to-day routines, it can help to figure out what causes this and make changes to minimise the problems. You can also identify what makes the day go well and make sure this continues.	18
	My typical week	If you feel a bit stuck in your weekly routine, or don't have enough time to do the things you want to, mapping it out can help you work out where you could make changes. It may help you to think of different ways of using any support you get from others.	20
	Hopes and aspirations for the future	To hold onto your hopes, ambitions and aspirations and make plans to achieve them.	22
	Fears for the future	To identify what causes you concern or worry when thinking about the future, with the aim of taking steps to prevent those things happening and/or limiting their impact.	23



What's working well and what could be better

Why use it?

The main tool in this guide is a template to help you reflect on where you are now by looking at what is working in your life and what is not working or could be better.

Thinking about these questions can help you:

- identify your strengths and the good things around you
- make sure the things that are working well don't get lost
- look for opportunities to build on what's working well
- make changes to overcome what's not working or could be better
- get a sense about what is a priority
- make a plan to get from where you are to where you would like to be, for example in six months' time or in a year
- decide on which other sections of the guide will be useful to you.

All of this information will be very useful when you are planning for an assessment or review. It will help you to feel more in control of what is talked about and any support that is suggested.



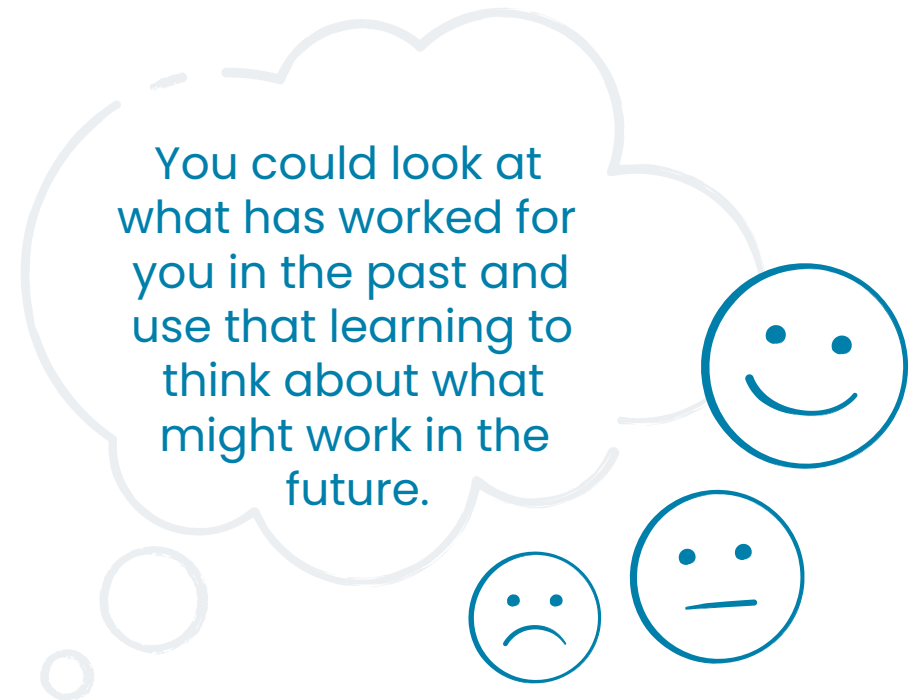
It could also help you to decide whether to contact social care to ask for an assessment or review.



How to use it



Start with the topics that seem most relevant to you at the moment.



If any questions don't feel relevant, just move on to the next one.

Use the information you have gathered to think about what needs to happen next, keeping in mind the idea of building on what's working and changing what isn't. Some of the solutions should be in the related sections of this guide.



	 What's working well	 What's not working/could be better
1. Getting started with planning		
Having people in my life who know me well enough to help me plan		
Getting the information I need to understand my rights and know the available options when making changes in my life		
Getting the advice and support I need to weigh things up and make decisions (this could be from people you know, an advocacy service, support organisations or a social work team)		
2. Being connected to people and places that are important in my life		
Carrying out parental and other caring roles		
Relationships (with a partner, children, parents, siblings and extended family)		

	 What's working well	 What's not working/could be better
Friendships (having friends, meeting up with friends, meeting new people)		
Community connections (knowing people in my neighbourhood, people who share my interests, people to do things with)		
Taking part in interests and/or developing new interests where I can meet people		
Feeling part of, and contributing to, my local neighbourhood, for example checking on a neighbour, volunteering, campaigning, taking on community roles such as school governor		
Knowing people locally I can call on , particularly when needing practical or emotional support		

	 What's working well	 What's not working/could be better
Having access to technology to talk and meet with other people, join online forums, find out what is happening locally		
3. Learning and working		
Going to college, university, adult education or having other learning opportunities		
Doing training, developing skills for work, volunteering		
Planning for work and/or fulfilling daytime activities		
Getting into, or remaining in, work and/or developing my career, including access to funding for work support		
Being challenged, having a change from everyday routines and/or a break from coping with day-to-day life		



What's working well



What's not working/could be better

4. My home

Where I live in Essex:



- close to people and places I need/want to be near
- having the shops and services I need nearby
- feeling safe to go out and about



Who I live with

Security of my housing situation
(for example tenure, ownership, affordability)

My home environment:

- comfort and ease of use
- safety
- equipment and adaptations I need
- technology to make things easier

	 What's working well	 What's not working/could be better
Carrying out day-to-day activities at home: <ul style="list-style-type: none"> • household tasks • personal care • leisure and interests (for example video games, painting, gardening) 		
5. Health and wellbeing		
Getting the support I need to manage my health as best as possible		
Being able to access the healthcare I need: <ul style="list-style-type: none"> • appointments • screening • tests 		
Being supported with my emotional wellbeing and/or any mental health difficulties I'm experiencing		

	 What's working well	 What's not working/could be better
Being able to have a healthy lifestyle through, for example, physical activity, exercise, diet, sleeping well		
6. Going out and about		
Being able to use my own transport or public transport to get to places that are important to me , such as visiting friends and family, health appointments and work		
Being able to travel to explore new places and interests		
Finding activities and places to go that are accessible to me		



Important to me and important for me

Why use it?

This tool helps you to think about two related aspects of life:

- Important to: what makes you feel happy or fulfilled
- Important for: what keeps you healthy, safe and well.

Living with a disability can mean that the focus often leans towards getting support to keep you safe and well. This tool can help to redress this imbalance.



Doing things that matter to you and make you feel happy are equally important. They give life meaning while also contributing to health and a sense of wellbeing.

Assessments and support providers may focus on safety and health but a good assessment and good support will do both.

The information you gather can be used to plan both informal and paid support. Take it to social care assessments and reviews to ensure your priorities are talked about and share it with practitioners to help them make suggestions that are more likely to work well for you.

How to use it

If possible, look at this tool with others, either an individual you are close to or a small group of people who know you well. If you do it on your own, you could talk afterwards to people who know you well and see if they have things to add.

You could put the **most important** points at the top so they don't get lost.



Important to me



What helps me have a good life: makes me happy, makes life enjoyable and interesting

Important for me



What helps me have a safe and healthy life: keeps me safe, physically and mentally well and makes my day easier

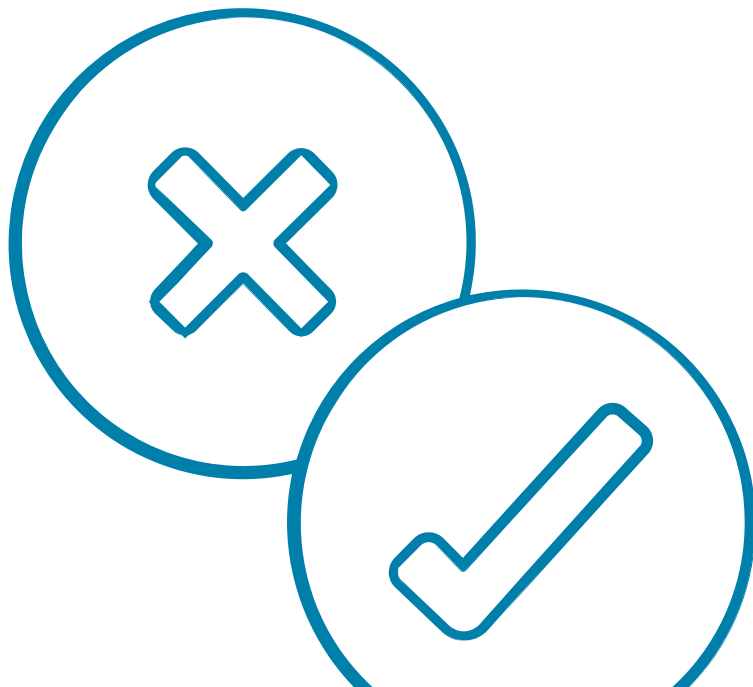


What makes a day (or week) go well/ what makes a day (or week) go badly

Why use it?

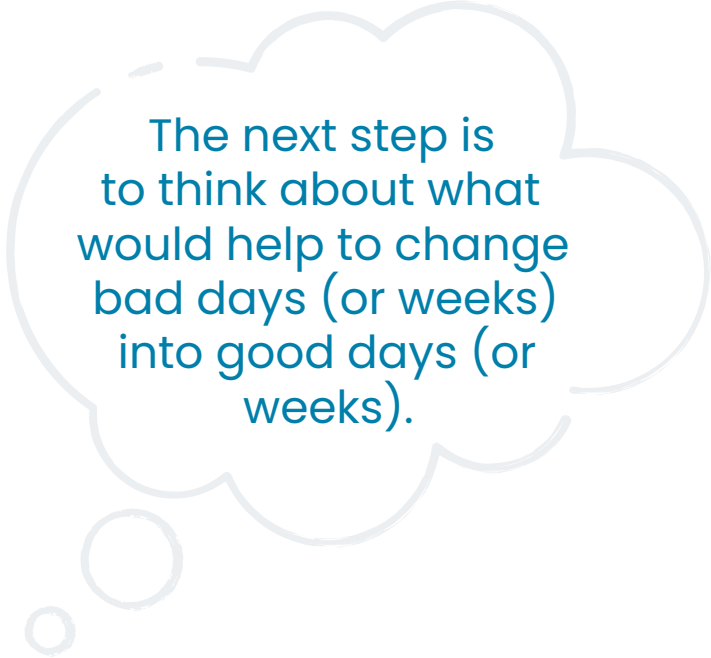
Thinking about what makes a day (or week) go well and what makes a day (or week) go badly is another way of gathering information about what is important to and for you, but with a greater focus on the details of day-to-day life.

There may be something that regularly happens to make your day go well or badly. This may be during daily routines or over the course of a week. Recognising these 'triggers' can often lead to small changes that improve your quality of life.



How to use it

Start with waking up in the morning and move on through the day, thinking about what makes your day go well or badly at each stage. Or start by noting all the things that help a day to go well from waking up to going to bed and then go through the day again looking at what makes it go badly.



The next step is to think about what would help to change bad days (or weeks) into good days (or weeks).



What makes a day (or week) go well



What makes a day (or week) go badly



What would help to make more days (or weeks) go well



My typical week

Why use it?

This is a useful tool if you think your week is quite limited in the variety of activities and opportunities it offers. It may also help if you feel rushed or exhausted at certain times of the day or week.

It's a simple tool that can highlight simple changes that can be made, such as using support funding differently, changing routines to start something new or reorganising activities to make the week more manageable.

How to use it

Go through the days making a note of what you do. There may be certain days of the week, or times of the day, that don't work well for you.

Think about where things could be improved and what changes could be made to achieve this. The other sections of the guide may provide you with ideas or you may want to rethink how you arrange your support.



	Morning	Afternoon	Evening/night-time
Monday			
Tuesday			
Wednesday			
Thursday			
Friday			
Saturday			
Sunday			



Hopes and aspirations for the future

Why use it?

This tool will help you think about what you would like to achieve in the next year or so.

This might be about aspirations, such as to be in employment or to find a more fulfilling job, or about developing friendships and relationships. It could also be about fulfilling a big dream you've held for a while.

How to use it

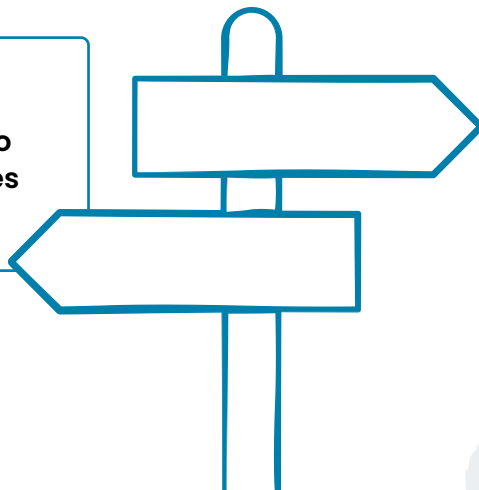
You could draw a large thought bubble and use it to record your hopes and dreams. Alternatively, you could use a bubble for each different aspect of your life where you would like to make changes, such as where you live, work opportunities, hobbies and interests.



Hopes and dreams



You could think about when you would like to achieve these changes and add a date.





Fears for the future

Why use it?

You may feel concerned or worried when thinking about the future.

Sometimes we try to ignore these worries as they can be difficult to think and talk about. But writing things down and sharing them can open up conversations with other people in your life, who may also be worrying about similar things, and help you find solutions.

You might be able to make changes that would reduce the likelihood of what you fear occurring or lessen its impact should it occur.

One of the aims of the Care Act is for support to be offered at an early stage rather than left until people are in crisis. Some of the worries you identify may fall within this idea of prevention (see page 29).

How to use it

Use the left-hand column to write down worries or concerns about the future. You could think about this with someone you trust or do it on your own first and then share your thoughts with one or two people, if you feel comfortable doing so.

Think about where you might get relevant advice. If a worry is related to one of the subjects covered in this guide, you may find helpful information or links to advice lines in the relevant sections.



You might be able to make changes that would **reduce the likelihood** of what you fear occurring or **lessen its impact** should it occur.



My worries and concerns



What might help

Legislation and your rights

Referring to legislation can be useful when you are looking to solve problems and take practical steps to get the right support, whether at home, in education, at work or elsewhere.

In the following pages, you will find a brief explanation of the Human Rights Act, the Equality Act and the Care Act and some of their key points that could help you to advocate for your rights and any support you need.

The Human Rights Act 1998

The Human Rights Act 1998 sets out the fundamental rights and freedoms that everyone in the UK is entitled to.

The Act requires **all public authorities** (such as government departments, councils, hospitals, the police and those acting on behalf of public authorities) to act in a way that respects and protects an individual's human rights.

These are some of the articles in the Act that it could be particularly useful to know about:

- **Article 3:** the right not to be treated in an inhuman or degrading way. This means that everyone has the right to receive care and support that is dignified and respectful. A public authority must intervene if a person deliberately inflicts mental or physical harm on a person with a disability, which

includes physical and/or psychological abuse in a health or care setting. The state has a duty to protect people from such treatment and investigate allegations.

- **Article 8:** the right to respect for private and family life, home and correspondence. This means that people with disabilities have a right to live their life privately, to enjoy family relationships (including the right to live with their own family) and live in their home peacefully without interference from public authorities.
- **Article 14:** the right not to be discriminated against (being treated unfairly because of who you are) in relation to any of the human rights. This article requires all rights and freedoms set out in the Act to be applied without discrimination (direct or indirect). This means that people should not be stopped from enjoying any of the other rights in the Act because of their disability.



For more detail about the Act and the Articles go to: www.equalityhumanrights.com/en/human-rights/human-rights-act.



Citizens Advice has produced a practical guide that talks you through what you could do if you think you are being denied a human right:

www.citizensadvice.org.uk/law-and-courts/civil-rights/human-rights/taking-action-about-human-rights.

The Equality Act 2010

The Equality Act 2010 protects people with ‘protected characteristics’ from discrimination. It gives them the right to challenge discrimination when they think it is taking place. The ‘protected characteristics’ include having a disability, the definition of which is quite broad.

The Act says you are disabled if you have a physical or mental impairment which has a substantial and long-term adverse effect on your ability to carry out normal day-to-day activities.

The law protects people, who fall within its scope, from discrimination carried out by:

- healthcare and support providers,
- services providing property to buy or let, such as housing associations and estate agents
- education providers, such as schools and colleges
- employers
- businesses and organisations that provide goods or services, such as shops, banks and utility companies
- transport services, such as buses, trains and taxis
- public bodies, such as government departments and local authorities.

The Act also covers ‘discrimination by association’, which means, for example, that family members are protected from being treated unfairly because of a person’s disability.

Reasonable adjustments

A key part of the Equality Act is the duty it places on public bodies to make ‘reasonable adjustments’ for people with a disability. When thinking about possible changes in your life, or in the support you receive, consider how asking for reasonable adjustments might help to achieve what you need.

Reasonable adjustments are changes that organisations and people providing services or public functions (see list above) must make for you to ensure you receive the same services, as far as this is possible, as someone who does not have a disability.

The duty to make reasonable adjustments applies if a person with a disability is at a substantial disadvantage compared to a person without a disability, or a person who does not share the same disability.

There are three things people or organisations may have to do to make it easier for you to access or do something:

- Change the way things are done
- Change a physical feature
- Provide extra aids or services

It is clear in the Equality Act that the person using a service cannot be asked to pay the cost of making the reasonable adjustments.

Additionally, organisations have an 'anticipatory duty', which means they must plan in advance to meet access needs of people with disabilities and not just respond when requested to make adjustments.



Citizens Advice has produced a more detailed explanation of reasonable adjustments, as well as sample letters to challenge organisations and services: www.citizensadvice.org.uk/law-and-courts/discrimination/what-are-the-different-types-of-discrimination/duty-to-make-reasonable-adjustments-for-disabled-people.



There are also some helpful links to advice lines on page 34 of this guide. For more detailed information about discrimination and reasonable adjustments in specific areas of life, such as employment and housing, please go to the relevant sections of this guide.



This video explains reasonable adjustments: www.youtube.com/watch?v=Wb5tM6CrkIs&t=377s.



The Care Act 2014

The Care Act 2014 introduced many changes regarding the way in which care and support is provided by local authorities. In this guide we have provided a summary of the key points but you may need more detailed information.



Disability Rights UK has written a guide that provides more details called 'Your guide to the Care Act: What you need to know about social care in England': www.disabilityrightsuk.org/sites/default/files/pdf/CareActGuide24january2017.pdf.



Disability Rights UK also has a helpline where you can get information about the Care Act (see page 34).



It's useful to be aware of some of the key principles and duties in the Care Act as they can help you to understand how and why decisions are made. They can also help you to describe the kind of support you might need.

Some of these duties are 'statutory', meaning they are things a local authority must do and you have a right to expect.

Below you will find information about:

- wellbeing, which is the underpinning principle of the Care Act

- three of the key duties: personalisation, prevention, and providing information, advice and advocacy
- the key processes of assessment and care and support planning, with links to sources where you can get more details.

Wellbeing

The Care Act says that a person's wellbeing must be central to all local authority decision-making and social care work. Wellbeing is broadly defined so that it can take into account people's different needs but includes:

- physical and mental health
- emotional wellbeing
- family, personal relationships and community connections
- suitability of living accommodation
- being in education, employment and taking part in leisure activities
- protection from abuse and neglect.

This guide aims to help you to think about how the principle of wellbeing may be relevant to you in these different areas of your life. During an assessment you could say how support with planning, and/or putting things in place, for a better future could contribute to your wellbeing. You could also think about anything that might have a negative impact on your wellbeing and what needs to be put in place to prevent it from happening, for example some additional support hours.

Personalisation

The duty of personalisation or being person-centred is central to the Act. This will mean different things to different people as it is about each person having choice and control over their social care support, as well as in life more generally. The focus should be on what works for you and not on what services are available or what other people might want in a similar situation.

Social work teams should spend time finding out about you, what your support network looks like and what your thoughts and wishes are. **The planning tools on pages 6–24 are all ways of collecting person-centred information which can help with planning personalised support.**

Prevention

Local authorities must prevent, reduce or delay the need for care and support for all local people. They need to make sure the care and support system does not wait for people to reach a crisis point before offering support. Services should act to prevent low-level needs escalating or turning into health and social care emergencies. They should also help people to retain existing skills and learn new ones, maintain their independence or reduce their dependency.

It may be helpful to think about what prevention and early intervention could mean for you. It covers a wide variety of support options, but a couple of examples are a befriending scheme to overcome isolation or a telecare system, such as a personal alarm or motion sensors, to reduce the risk of harm at home and elsewhere.

If you are unsure, or putting off, whether to ask for support in relation to something you are struggling with day to day, it's worth thinking about the principle of prevention. Local authorities often find it easier to provide this low level of support and it may also suit you better; for

example, it may feel less intrusive and disruptive to your life. Trying out low levels of support can be helpful if you are worried about needing increasing levels of support over time.

Putting things in place for a better future also fits well with this prevention duty. This guide aims to enable people to think about areas in their life where they would like to have more control or feel more independent. This might be about making day-to-day life easier or having more opportunities. It could also help with thinking about ways to slow down the loss of independence as a result of a degenerative illness or ageing. Support to think about and put things in place for the future can be a preventive measure and a useful duty to refer to when making a case for resources.

Information, advice and advocacy

Under the Care Act, local authorities must provide information and advice to make it easier for people to make well-informed choices about their care and support. It should include general details about the way the system works as well as more personalised information so that people receive the information and advice that is particularly relevant to them.

Local authorities are required to provide information and advice to people even if they don't have eligible needs or aren't receiving funding for care and support.

Local authorities also have a duty to provide an independent advocate for people who would have 'substantial difficulty' in taking part in Care Act processes, such as assessment or care and support planning. An independent advocate must have the skills to involve a person. They can't be someone who is already working with them in a paid capacity.

In Essex, this independent advocacy support can be provided by Rethink Essex (see page 33).

Assessment

Local authorities have a legal duty to assess any adult who appears to need any level of care and support. This should happen regardless of whether the person seems to have 'eligible needs' (needs that will be met by the council). This is because the assessment should be looking broadly at what might be helpful and not just cover care and support. It may be that your needs would be better met by services and organisations other than the council.

All your 'eligible needs' should be considered, even if they are currently being met by a family member, friend or neighbour. It may be that they are unable to continue to offer support in a particular area, or you may not want them to. If you would like to be less dependent on informal support, think about what this might look like for you and talk about it at your assessment. Your assessment should take into account your thoughts about gaining more independence.



If you have fluctuating needs (that is, they change from day to day, week to week or at different times of the year), then your need for support should be considered over a period of time and not just on the day of assessment.

Think about what a 'bad' day or series of days prevents you from doing and what support you need or already get from others. Share this information so it's reflected in the assessment. Information about what helps you to have a good day could help people understand what good support looks like for you (see page 18 for a planning tool to help with looking at good days and bad days).

The assessment needs to be 'appropriate and proportionate' to your needs. This means it must be carried out in a way that works for you and goes into the right amount of detail to help you achieve the things that are important to you. If your situation means that the assessment needs to be carried out in a certain way, let people know. For example, pain or fatigue may mean you need it to be done at a certain time of day or completed over a number of sessions.

The Care Act promotes a strengths-based approach in relation to assessment and care and support planning. This means that social workers or other practitioners should find out about a person's strengths, knowledge and relationships so they can be built upon when planning support. A strengths-based approach is more likely to lead to support that is person-centred and consequently more likely to work well.



If you want to find out more about the strengths-based approach you may find this video useful: www.scie.org.uk/strengths-based-approaches/videos/what-is-sba.



Having an assessment in Essex

To ask for an assessment, you should call or email Essex Adult Social Care (details on page 33). If you prefer, you can ask a family member or friend to do this on your behalf or ask your GP to refer you.

The early intervention team will be the first people to get in touch with you and their assessment may be all that you need. If you need a more detailed assessment, they will refer you to the right person. If you need a care needs assessment, they will refer you to a social worker or an occupational therapist. They can meet you in your home (or somewhere else if you prefer) or organise an online call on TEAMS. They will talk to you about your support needs in more depth, in a way that works for you.

Try not to think of an assessment as a test but as a way for you to explain how your needs affect your wellbeing and your thoughts on what could be helpful to you. The information you give helps the practitioner to make suggestions or let you know about support that could be useful.

If you have an assessment, you have the right to decline the support that is offered and can ask about alternative ideas you think might be helpful. If your situation changes or worsens, you can ask for a reassessment at any time and don't need to wait until things feel very difficult.

Care and support planning

If you're assessed as needing social care and support, they must help you to develop a care and support plan. The process of developing your plan should include discussing how you want to be supported and providing information about different options and local service providers. You can get help with support planning from other people: this could be a family member, an advocate (see page 29) or an advice worker (see Disability Rights UK helpline on page 34).

They will also talk to you about a financial assessment to work out how much you may need to pay towards the cost of the support. There is more information, including a calculator to get a rough estimate of your possible charges, here:

www.essex.gov.uk/do-i-need-to-pay-for-care

The money you are allocated by the council to pay for your support is called a personal budget. You can use it to:

- arrange your own care and support using direct payments
- ask the council to arrange care and support for you
- arrange some care and support yourself, and have the council arrange some for you.



There are lots of options around direct payments so it may be useful to read the Disability Rights UK guide to the Care Act (www.disabilityrightsuk.org/how-we-can-help/benefits-information/factsheets/independent-living-factsheets) or get advice through the helpline mentioned in the paragraph above.



ILG Community is a group for people employing Personal Assistants (PAs). It's free to join and gives access to ideas and support: <https://ilgcommunity.com>

Carers

One of the big changes introduced in the Care Act in 2014 is that carers (family, friends and neighbours giving unpaid support) have a right to an assessment that is separate from that of the person they are supporting. They can request an assessment even if the person they support hasn't had an assessment. The principles of the Care Act, such as wellbeing and prevention, also apply to assessment and planning support for carers.

Young people

The Care Act also requires 'seamless transitions' for young people moving to adult social care services. A local authority is expected to look at building on a person's transition assessment to draw up a plan to achieve a smooth transition. This plan should make clear what's going to happen, when it will happen and what role different people will have.

If the transition assessment identifies needs that are likely to be eligible for adult care and support, the local authority should (rather than must) look at giving an indication of how much funding will be in the young person's personal budget. This is to make it possible for young people, and their families and supporters, to plan their support before they move on to the adult social care system.

The Care Act requires 'seamless transitions' for young people moving to adult social care services.





Organisations in Essex



Essex Adult Social Care


Monday to Thursday, 8:45am to 5pm
Friday, 8.45am to 4.30pm

 Telephone: **0345 603 7630**,
Textphone: **0345 758 5592**
For out of hours queries contact the
Emergency Duty Service.
Telephone: **0345 606 1212**

 You can also email the Adult Social
Care team and someone will get back
to you.
Email: socialcaredirect@essex.gov.uk

Healthwatch Essex

Healthwatch Essex runs an independent
and confidential information service to help
you understand and find your way around
health and social care in Essex. There is
more information about Healthwatch Essex
in Section 5: Health and wellbeing.


 Telephone: **0300 500 1895**:
Monday to Friday, 9am to 4.30pm

 Email: info@healthwatchessex.org.uk

www.healthwatchessex.org.uk

Rethink Essex

Rethink Essex is funded by Essex County
Council to run an advocacy service to
support people with disabilities when
making decisions about their health and
social care. Advocates can support you to
understand your rights and to have a say if
you are faced with difficult decisions about
your care.

 Telephone: **0300 7900 559**

 Email: essexadvocacy@rethink.org


www.rethinkessexadvocacy.org

National information and advice lines



The personal budgets helpline, telephone and email service is run by Disability Rights UK. You can use the helpline to get information on the national eligibility criteria for social care funding, care needs assessments and care and support planning, as well as non-residential community care charges.

It can also help you to understand how personal budgets work in relation to care and support services and how to access social care funding.


 Phone: **0330 995 0404**

 Email: **personalbudgets@disabilityrightsuk.org**



The Equality Advisory Service has a helpline that can provide advice and information on human rights and disability issues.

www.equalityadvisoryservice.com

 Phone **0808 800 0082**



#Social Care Future is a movement of people committed to bring about change in social care. Their shared vision is “We want all people to live in a place we call home with the people we love, in communities where we look out for one another, doing things that matter to us”.

To get involved, join their mailing list to hear the latest news and events:

socialcarefuture@gmail.com

Its website has more information and resources: **<https://socialcarefuture.org.uk>**



Advicelocal, developed by Rightsnet, is a search facility to find out where you can get advice on specific issues in your area. Its aim is to help if you have a social welfare law problem. This might be regarding disability and social care; welfare benefits and tax credits; debt and money advice; housing and homelessness; or employment issues.

<https://advicelocal.uk>



Think Local Act Personal is a group of organisations working together to share information and ideas about personalisation. It has a variety of resources on its website. Its **jargon buster** may help you to find your way around the different terms you are likely to hear when talking about care and support.

www.thinklocalactpersonal.org.uk/Browse/Informationandadvice/CareandSupportJargonBuster



My notes

Use this page to make a note of anything you're interested in following up from this section.
Do this in whatever format works best for you to make sure your thoughts and ideas don't get lost.



Section 2:
**Family,
friends and
connections**



Planning for change:
getting started



Family, friends
and connections



Learning
and working



My
home



Health and
wellbeing



Going out
and about

Information in this section

	Useful to me?
What the Care Act says	38
Ideas to build your network	40
• Peer support	42
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Why this section might be helpful

This section gives ideas for people who want to strengthen their ties with family and friends, widen the circle of people in their lives or increase their involvement in their local community.

Most of us need to have people in our lives, whether family, friends or a wider social network, otherwise we can feel isolated and vulnerable. Also, the people in our lives can often provide ideas and information that help with planning and making changes in our lives. Being connected with others is about contributing to other people's lives and to the local community too.

Some people are natural connectors and draw lots of people into their lives, and many people with a physical disability have a rich social life. Others find it more difficult to go out to places and meet new people, whether due to physical access issues and/or loss of confidence. There are more ideas in other sections to help with building connections.

In Section 6 there is information about inclusive activities and finding accessible places to go to. Section 3 talks about places where you can learn new things and meet people with similar interests.

This is the second section of a guide called Shaping My Future. It has five other sections but you do not need to look at them all. Choose the ones that you think might be useful to you at this point in time.

What the Care Act says

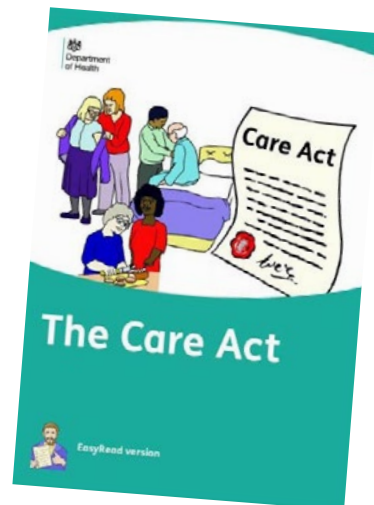
Social connections are an eligible need

There is a recognition in the Care Act of the importance of contact with family and friends and of being connected with the wider community.

One of the needs that is eligible for support is 'developing and maintaining family and other personal relationships'. What this means in practice will vary from person to person but could be about relationships with partners, children (including adult children) and extended family. For people without family, other personal relationships will have more importance.

The Care Act recognises the contribution from family, friends and support networks to people's physical and mental wellbeing; it is well known that connections with others generally help to keep us healthy, active, safe and well. Informal support networks can also help to minimise some of the difficulties that can lead to a loss of independence.

The building of informal support networks when developing care and support plans is not meant to be a substitute for services and paid supporters but should be complementary: the two should work together to make life better or easier.



Assessments and support planning

Try to think of assessments and care and support planning as being about your whole family and support network.

This includes both people who live with you and those who live elsewhere: anyone who helps with your support and/or is important in your life. Consider what is needed to help your network of people to work in the best way possible.



If you have family or friends who provide care for you, they can ask for a carer's assessment, whether or not you have requested an assessment or receive funding for support. They may be eligible for support in their own right. This support could help them to meet other carers or connect with others more generally if they are feeling a bit isolated. **Carers First** gives support to carers in Essex: you can phone them on **0300 303 1555** or email hello@carersfirst.org.uk to find out how they can help.



More information about carers' assessments can be found here www.carersuk.org/help-and-advice/practical-support/getting-care-and-support/carers-assessment. This link tells you how to request a carer's assessment in Essex: www.essex.gov.uk/topic/support-for-carers.

If you have children who have a caring role, you may want to find out what support they can be given. The Youth Service in Essex provides different kinds of support for young carers, including one-to-one support, information, training and recreational breaks.



This link gives you more information about how it can help and how to access its services:

<https://youth.essex.gov.uk/schools/young-carers-services/young-carers-service>.

A child can self-refer or be referred by a family member or a practitioner, such as a GP.

If you are a carer yourself, make sure you mention it in your assessment, so that you can be supported in this role.



Tapping into local community resources

Care and support plans should also support people to make the best use of their local community.

You might want to look at how support hours can be used to build social connections in your local area, such as help with joining or taking part in a local club or group.



If you employ personal assistants, you could look for people who live locally or have strong ties with your local community. You could also think about finding someone who is good at connecting with others and building links, especially if you don't find this easy.

The benefits of building local community-based support are being recognised more and more by health and social care services. Local councils are doing more to build local community-based support to reduce loneliness and isolation and help people live as independently as they can. See pages 46–47 for examples of this kind of support available in Essex.

Ideas to build your network

Here are a few ideas to help you consider whether you would like to develop or strengthen the network of people in your life and how you could go about this.

People will differ in which approaches they find useful and this may change at various times of their life. If your circumstances have recently changed, you may need or want to adapt your friendship group. On the other hand, there may be times when you don't particularly want to socialise.

Often, looking locally and thinking about the people and places you already know can be a good place to start. However, you may feel you'd like to look more widely to connect with a more diverse group of people and interests. In Section 6 you will find information about travel which may help to make this a bit easier.

Although some people may be apprehensive about making connections over the internet, online groups can be a very helpful way to connect with others who don't live nearby or when going out and about is difficult. In Section 3 there is information about courses where you can learn digital skills.



Many local community groups were set up to connect people and offer help during the COVID pandemic, and some of them, such as Colchester's 'Anti Loo Roll Brigade' Facebook page, have continued to operate: www.facebook.com/groups/202461331008256.



Karen's thoughts on building social connections



"Reaching out can be one of the scariest things to do. Someone may be naturally introverted or in the early stages of coming to terms with their identity as a person with a disability because they are young or have recently acquired a disability. I wasn't always social but this changed as I began to follow various disabled 'influencers', research disabled role models and get into disability politics. I then became open to the idea of social connections, although this is still difficult for me.

Making friends, having partners and managing familial relationships with a physical impairment is complicated due to a barrier in communication between non-impaired and impaired individuals. However, the digital age has allowed for 'othered' people to find each other across the world. The internet helped me find places to go that I never thought existed, places which were purely organised on the basis of human acceptance. It allowed me to make friends with people I might never have met in my immediate community, yet we have deep connections because we're able to share meaningful and specific aspects of ourselves with each other, for example poetry, fashion and gaming."

Another message from people who contributed to this guide was that it's not always easy to maintain or build friendships but it helps if you do some planning and are upfront about what you are able to do and what you need. When making arrangements, explain what would work for you so there is the opportunity to adjust things to enable you to be included.

Emma's suggestions to build and maintain friendships



- I used to meet friends regularly to go for meals and try new places but now everything has to revolve around me and my needs. I am uncomfortable with that. So, when we are planning something, I try to quickly suggest somewhere I know that we will all enjoy but will also work well for me.
- You could think about writing down what works best for you and share your ideas with family and friends. Sometimes it's easier to write things down than say them face to face. You might want to explain that sometimes you just want to be at home in your own surroundings but you are still grateful for support and friendship, and are not being rude if you say no to suggestions.
- Think about writing your own blog to share with friends and any groups you join. It can feel therapeutic to voice your feelings and can also attract conversations with like-minded people.

Peer support

Peer support is when people with shared experiences meet together to be of help to each other, whether face to face or online. It can help them feel less isolated about their experiences. It can also be a way of gaining information, ideas and motivation.

Some peer support groups will have been set up by services or individuals who may also take responsibility for running them. Others may be more informal and evolve from a few people thinking it would be helpful to meet regularly to support each other around specific issues. They could be local or national groups. One-to-one peer support may develop from meeting someone with whom you have things in common and arranging to meet regularly to talk things over and give mutual support.

The nature of peer support will vary depending on who has organised it and its purpose. What is important is that it should be a safe space in which to give and receive support and where people feel accepted and understood. No one person is seen as the expert, and how much support you give and receive can vary depending on what feels right for you at different times.

It should be a safe space in which to give and receive support



Peer support may be about meeting other people who have the same condition as you, or a similar one. You could contact relevant organisations or look at their websites to find out what they offer.

Or you may be more interested in talking with others who are going through a similar experience, such as planning for post-school opportunities, or people who share a similar cultural background. You could contact relevant groups or practitioners to find out what is available.

Some peer support groups are based on doing something relaxing together, such as a creative activity, where people can chat, get to know each other and share experiences.

Many peer support groups – both formal and informal – are now online. Facebook, for example, offers many closed groups that can give access to support, information and friendships in a fairly protected environment. See the section below about online communities for more information.

You may also be able to find out about peer support groups through libraries, GP surgeries, social workers, organisations for specific disabilities such as the MS Society and Headway and the community organisations mentioned on page 46.

Online communities

The internet has enabled many people with disabilities to access information, connect with peers and engage with specific communities all over the world in a way that wasn't previously possible.

Being able to engage via an online space with like-minded people can offer a sense of community that many people find difficult to access on a geographical basis. Online communities often remove a lot of the barriers that exist in the outside world because you can choose when to engage depending on how you are feeling that day, and without having to consider physical accessibility.



If you are new to using a computer and want to learn the basics or develop your skills, you may find some useful links in Section 3: Learning and working, pages 57–58. If you are worried about using the internet, there are lots of resources on how to keep safe, such as this one made by Sussex police: [little-leaflet-of-cyber-advice.pdf \(sussex.police.uk\)](#).

There are many private Facebook groups where you can get information and ask questions. A well-run group will have admin people who make sure rules are kept to in relation to members' behaviour.

Other social media spaces such as Twitter and Instagram allow the use of hashtags, which means you can quickly find and follow people with similar interests to yourself. Certain hashtags have a specific community and language surrounding them. An example of this is #spoonies, which enables people living with constant pain and fatigue to connect with one another.

YouTube and TikTok show videos created by people with a wide range of conditions. These can be informative, funny or relatable.

The links below have been suggested by people with lived experience of disability who helped to develop this guide:

-  **Disabled UK: Time to unite together and be heard** is a closed group that aims to share information with the aim of helping disabled people, their families and their carers: www.facebook.com/groups/Uniteasonedisableduk
-  **Wheely Brits** provides support, friendship and advice to UK wheelchair users and their carers: www.facebook.com/groups/wheelybrits
-  **Direct Payment and Personal Health Budget (CHC) Users** is a closed group for users of the Direct Payment system, individual budget scheme, and personal health budget for continuing healthcare scheme: www.facebook.com/groups/417727481673353
-  Websites with chat rooms and forums for people with disabilities, such as www.disabilities-r-us.com and <https://ablehere.com>
-  Websites for anyone wanting to connect with others with shared interests such as <https://www.meetup.com>

Circles of support

A circle of support is a small group of people you bring together to think and plan with you. The idea is that it is easier to plan when others are on board.

It can lead to new ideas and opportunities, and help with decision-making and problem-solving. You may have a number of people who are already part of your support network but don't meet together or know each other. Bringing people together can generate conversations and give you the chance to hear different perspectives. This can be particularly helpful at times of change in your life, but can also build your confidence around being more involved with people and places.

People organise their circle of support in the way that works best for them but generally it is about encouraging family, friends and others you know, to put their heads together to help you achieve what's important to you. You could think about local people who perhaps share your interests, culture or religion or who have specific knowledge or skills that you would find helpful, including any paid supporters. It's about involving people who are important to you and can help you achieve what you are setting out to do. The people in your circle could meet up in a way that works for everyone – this might be online, or in person, for example at your home, or in a café or pub.

A circle of support can help you to:

- get to know more people
- do new activities/develop new interests

- think about and plan for work opportunities
- get support at times of change, such as leaving school, moving home or looking for work
- get support when dealing with changes resulting from a recently acquired disability or a progressive illness
- have a group of people you can call on in emergencies or when needing practical and/or emotional support.

You may also find that support becomes reciprocal, providing opportunities to help and contribute ideas to other people.



It can sometimes feel difficult to get started with a circle of support because we feel awkward asking others to help us. However, remember that, by the same token, people are often keen to help but don't know how to ask. It may be easier to start by asking people to help you plan for something specific as this will give them the opportunity to see how a circle might work.

If you are eligible for funding from Adult Social Care, you could ask whether you could use some of the money to pay for someone to help with facilitating a circle of support.

Community mapping

Sometimes it can be helpful to map your local community to get a clearer idea about what is going on, especially if you don't know the area well. This can give you ideas about where you might meet new people, get involved in activities or find opportunities to contribute your ideas and skills.

Community mapping can be very useful if you have recently moved home (or are planning a move to a new area) or when young people are finishing education and thinking about what they could do next. You could do this on your own but it may be easier and more enjoyable to do with one or two others. Try to choose people who know the local area or, like you, are keen to find out more about it.

Start by taking a screenshot or printing a map (preferably A3) of your area from Google Maps, then mark on it different community resources that you would like to learn about, such as:

- places (for example libraries, cultural and religious centres, colleges, community centres, leisure centres, as well as outdoor spaces, such as parks, community gardens, sports grounds)
- community services (for example transport services, foodbanks, mutual aid hubs and services/activities provided by the places noted above)
- businesses that provide local jobs (this will be more relevant if you are thinking about looking for work)
- people (for example someone who organises Neighbourhood Watch, street barbecues).

Some of these may show up on Google Maps but others you will need to add. One of the advantages of Google Maps is that you may be able to use Street View to check the outside of buildings for accessibility or to do a virtual walk-through to find the easiest way to get somewhere.



A lot of this searching can be done on the internet, looking at Facebook groups, neighbourhood network groups such as Nextdoor (www.nextdoor.co.uk) and local newsletters.



Joining a Facebook group for your local area (such as Colchester Community Group: (www.facebook.com/groups/1467660470227405)) can lead to other pages where people living nearby share your interests. You could also try visiting places such as community centres, where you could talk to people with a development role.

The next step is to use the map to think about what might interest you, in terms of taking part in activities or offering to help out. Sometimes living with a disability can knock your confidence but there are places that will value your contribution. This could be about your understanding of disability and inclusion or sharing your interests and what you are good at.

Organisations in Essex

Here are some of the community organisations in Essex that may be helpful if you want to reach out to make more connections and build your support network.

This can be a difficult step for many people, but these organisations have been set up to address the isolation and loneliness that can affect many aspects of people's lives and help build local connections.



Community Agents


Across Essex there is a network of 'community agents' who have good local knowledge and can help people to make links with others and with activities in their area. The community agents may be paid or volunteers.

The support they give is only short-term (about six weeks). It aims to help with feeling more confident about living independently and to find solutions from within the local community.

They mainly work with people over 50 but they do also support younger people and informal/family carers. You can refer yourself to their service or contact them to talk about the short-term support you think would be helpful and they can let you know what they can offer.

To find out more: www.communityagentsessex.org.uk

You can refer yourself by:

 Phone: **0300 303 9988**

 Email: livewell.linkwell@nhs.net



Essex Time Bank Network

Time banking is a way for people to share their skills and time without any money changing hands. You can use any passions or expertise you have to offer help to others and earn credits for when you need help with something you might find difficult.


Time banking works flexibly in that you can decide when, and how often, you volunteer. Your credits go into a central time bank. For every hour you volunteer you gain a 'time credit' and you can use this to ask for help in return.

Some of the examples on its website of giving or receiving support are shopping, using a computer, teaching a language, companionship and DIY.

It is free to become a member and open to everyone, regardless of skills or availability to regularly commit time. Time banking in Essex is supported by Community 360 and Timebanking UK with local groups in most districts.

You can use this link to find your local time bank in Essex:
<https://tol2.timebanking.org/essex>

To find out more:

 Phone: **01376 550507**

 Email: timebank@community360.org.uk



Essex Connects

Essex Connects is a website to help you:

- find information about local activities such as a club or group
- get in touch with local charities, voluntary groups and community services based in different areas of Essex

Go to www.essexconnects.org.uk to search for local information.



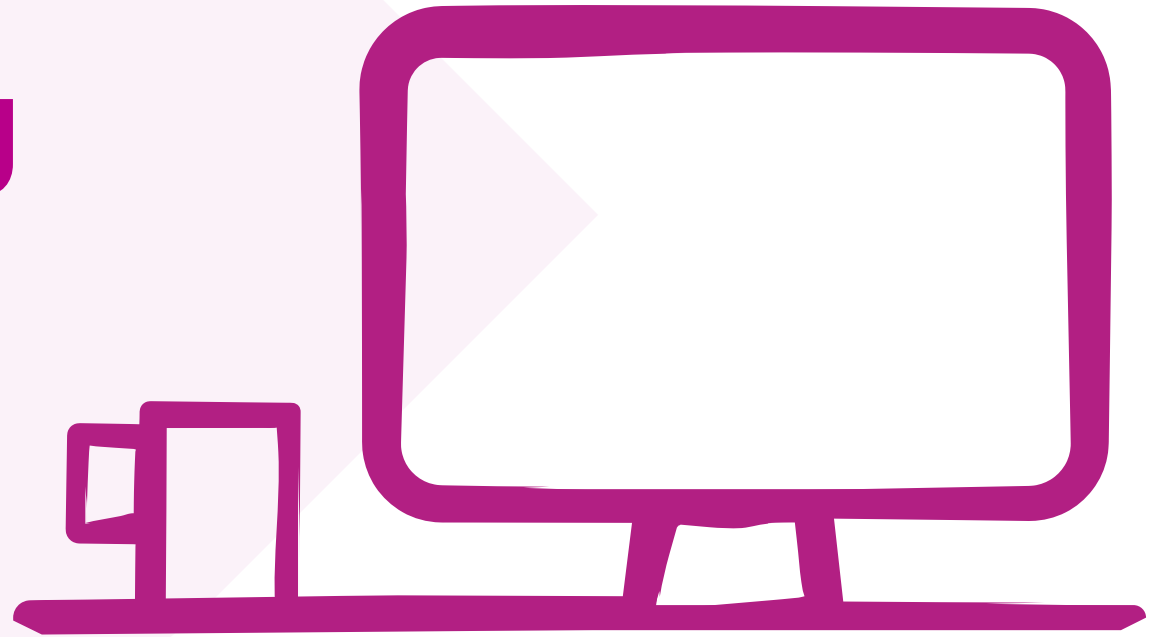


My notes

Use this page to make a note of anything you're interested in following up from this section.
Do this in whatever format works best for you to make sure your thoughts and ideas don't get lost.



Section 3:
**Learning
and
working**



**Planning for change:
getting started**



**Family, friends
and connections**



**Learning
and working**



**My
home**



**Health and
wellbeing**



**Going out
and about**

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Why this section might be helpful

In this section you will find information about learning new skills, exploring new interests and being in work. You will also find information about support available and sources of funding that may help with taking up education and employment opportunities.

Finding new opportunities for learning and working are important at all times of life. You may be planning for leaving school in the next few years, starting out as a young adult, or looking to change direction during adult life in response to the impact of your condition, or simply for a challenge.



It may be helpful to know about your rights in relation to education and employment. As well as reading the information in this guide, it's worth looking at this factsheet from Disability Rights UK.



'Understanding the Equality Act: information for disabled students' (Factsheet 56). This covers rights in relation to both education and employment: www.disabilityrightsuk.org/understanding-equality-act-information-disabled-students.

This is the third section of a guide called Shaping My Future. It has five other sections but you do not need to look at them all. Choose the ones that you think might be useful to you at this point in time.

Post-16 planning

Between the ages of 16 and 25, you will usually need to make some significant decisions around education and employment as you plan for adult life. Many of the ideas and resources in this section will help with this planning.

Essex County Council has a **Preparing for Adulthood** (PfA) service, delivered by teams in different areas of the county. Its advisers work with young people (aged 14 to 25), who have an Education, Health and Care Plan (EHCP), and their families. They support people at key points during this time to help with deciding on education options, employment and community links (see page 72 for contact details).



The national **Preparing for Adulthood** website, funded by the Department for Education, has resources and ideas to help young people with disabilities to achieve paid employment, independent living, housing options, good health, friendships, relationships and community inclusion: www.ndti.org.uk/resources/preparing-for-adulthood-all-tools-resources



Another resource that could be useful, if you are in secondary school or college, is Disability Rights UK's Get Ahead toolkit and resources, which are co-produced with and for disabled young people. You can sign up to receive the newsletters and magazines, which will help you to build up a picture of how things work and give lots of ideas about what is available across post-16 education, training and work. It is also a place where young people can contribute and share their ideas and talents. Here is the link to their information and signing-up form: www.disabilityrightsuk.org/get-ahead

One of the newsletters explains different routes into work for young people, such as apprenticeships, traineeships and supported internships: www.disabilityrightsuk.org/sites/default/files/Get%20Ahead%20Magazine%20%20-%20issue%202_0.pdf



Learning

There is a huge variety of learning opportunities available for everyone, which can be tapped into at different times of life, depending on your interests and what you want to achieve.

Wherever possible, information has been included about funding that may be available, as well as ideas for free, online ways to learn new things, whether for pleasure, to gain skills or for career development.

Online courses can help to reduce costs and remove concerns about physical accessibility.



If you are choosing a college or other place of learning, make a visit to check you can access all the relevant areas of the buildings. If you are aged 16 to 25 and have an EHCP, you should be able to get support from a practitioner, such as an occupational therapist, to do this.

Further education

Further education is post-16 education that is below degree level.

It is offered by schools and academies with sixth forms, further education colleges, independent learning providers and special post-16 institutions. The Education and Skills Funding Agency provides funding for young people between the ages of 16 and 19 years and up to the age of 25 for those with an EHCP. After the age of 19, for funding to continue, the benefits of remaining in education needs to be stated in your EHCP.



Disability Rights UK has a leaflet with more information about funding for further education courses. Factsheet 26: www.disabilityrightsuk.org/funding-further-education-disabled-students

Apprenticeships

Apprenticeships provide learning and training, as well as hands-on experience, in a specific area of work.

The benefit is that you can gain a qualification while being in paid employment. You'll find more information here: www.apprenticeships.gov.uk/apprentices/becoming-apprentice.

You can do an apprenticeship at any age and at different stages of your working life. The four levels of apprenticeship are set out below:

	Level	Equivalent education level working for
Intermediate	2	GCSE
Advanced	3	A-level
Higher	4,5,6 and 7	Foundation degree and above
Degree	6 and 7	Bachelor's or Master's degree



If you are thinking about apprenticeships, have a look at the Amazing Apprenticeships website: www.amazingapprenticeships.com. It talks about the benefits of going down this route and provides a good range of resources that explain how apprenticeships work.



There is also information about apprenticeships at degree level on the UCAS (Universities and Colleges Admissions Service) website: www.ucas.com/understanding-apprenticeships.



In Essex, there are a number of organisations who can help with finding apprenticeships. Adult Community Learning has a programme of apprenticeships for people between the ages of 16 and 18 and 19 or older: www.aclessex.com/apprentices.

Higher education

Deciding whether to go to university or college to gain a higher education qualification can seem like a major step for anyone – and even more so for people living with a disability – but helpful information is available to support you to weigh things up and make choices.

The main message we've heard from people who have studied at college or university is that it's important to plan early (at least the year before you might be going), collect as much information as you can and visit beforehand (this can sometimes be virtually but it's preferable to go in person). You could visit as part of an open day or arrange to go at a different time if that works better for you.



UCAS has a checklist to help you prepare for open days and suggests booking early as places can get filled up. It also recommends making an appointment with the Disability Support Team (DST):
www.ucas.com/undergraduate/applying-university/individual-needs/disabled-students/disabled-students-preparing-open-days-and-visits.

On each university website, you should be able to find details of their DST and what is available within the university and from external agencies, such as paid supporters. As well as looking at this information, you should speak to the team before deciding to apply, as their response could help with making a decision.



There is information on the UCAS website about using DSTs:
www.ucas.com/undergraduate/applying-university/individual-needs/disabled-students/speaking-disability-support-team-or-mental-health-adviser.



It's important to plan early, collect as much information as you can and visit beforehand.

Karen's experience of higher education



"I wanted to go to university because I realised this would be a good way for me to get my independence as a young person and to live the full human experience to the best of my abilities and opportunities. Little did I know how much planning this would need but, looking back, it turned out to be a decision that gave me what I was looking for.

During my studies, I stayed in halls of residence with a live-in carer. Achieving this wasn't easy as most of the buildings my mother and I visited prior to enrolment were inaccessible. Eventually we found a room with potential for adaptations and made the case for this to be done as reasonable adjustments to enable me to study. The university was in a neighbouring county which made sorting things out more complicated but my social care team didn't change and social workers and occupational therapists worked with Cambridge City Council regarding my needs. As part of my reasonable adjustments, the university recruited note takers to help me during lessons. This was funded by my Disabled Students' Allowance.

All of these arrangements meant that my start date was deferred by one year. Nevertheless, I made it to university, and I got to experience what it's like to be young, wild and free!

But even with all of that planning in place, I still faced many difficulties, mainly because higher education does not have enough experience of students with a physical impairment.

Being a young adult undertaking higher educational studies while dealing with social stigma and prejudice can all lead to high levels of stress. Making good use of the university's wellbeing services and the extensions programme helped me to get by and I would advise any disadvantaged minority to do the same. I'd also suggest putting energy into making friends as having supportive people around can be very helpful.

Over time, I began exploring and practising self-advocacy by letting people such as lecturers, librarians and canteen staff know about my needs. I went on to become a student rep to improve the situation for other disabled students."



**My message is that it's all worth it,
and with tenacity it becomes possible!**



A more general resource, **Know Before You Go**, produced by **Student Minds**, is an e-guide intended for sixth-form students looking to go to university, as well as their families and education practitioners who support them, to help them think about and prepare for some of the changes that university life might bring: www.studentminds.org.uk/knowbeforeyogo.html.

Student Minds has also produced **Transitions**, a guide to help people through university life and find their way round some of the difficulties. Both guides acknowledge the anxiety and stress going to university and college can cause, and point to sources of support to make it easier: www.studentminds.org.uk/transitionintouniversity.html.



The **Open University** (OU) provides a different option, with most learning taking place at home. The OU was set up to make higher education more accessible and, because of the flexibility it offers, it is the largest provider of higher education for disabled people – according to its website, 28,000 disabled students studied with the OU in 2020: www.open.ac.uk/courses/do-it/disability.

There are also other colleges and universities that offer distance learning options. This website has a search function to find online courses: www.distancelearningportal.com.



28,000
disabled students
studied with the
OU in 2020

Opportunities to keep on learning

If you have been away from education for a while it may be worth thinking about teaming up with one or more people you already know to enrol on a course. This may give you more confidence and reduce the worry about starting something new.



Essex Adult Community Learning (ACL)

ACL provides lots of different online and face-to-face courses. On its website you will find a list of what is currently available. It also runs taster sessions so you can try out some new things.

Courses cover:

- English, maths, science and digital skills
- creative subjects, such as art, crafts, photography and jewellery making
- wellbeing
- qualifications and skills for employment

Adult education classes provide many benefits: meeting people who share your interests, building confidence, reducing stress and gaining qualifications.



ACL has learning support co-ordinators in local areas who you can talk to before or during a course to find out what support might be available (such as study skills support if you have not undertaken formal learning for a while or specialist assistive or enabling software and resources).



More information about learning support and the contact details of the co-ordinators can be found here: [**aclessex.com/learning-support-information**](https://www.aclessex.com/learning-support-information).



You can sign up for its newsletter to hear about new courses: [**www.aclessex.com**](https://www.aclessex.com).



A list of the different centres can be found here: [**aclessex.com/centres**](https://www.aclessex.com/centres).



FutureLearn

FutureLearn is an online site where you can sign up to do free courses run by universities and organisations at your own pace. Most of the courses last 6-10 weeks but there are also short 2-3 week courses that can be a good starting point.

One of the good things about FutureLearn is that you can study at a time of day that works for you and do as much or as little at any one time. The courses are designed to be easy to follow and a fun way to learn, often with videos, quizzes, downloadable transcripts and chat rooms so you can share ideas with other students (often from around the world).

You need to be comfortable doing things online but apart from that the structure is very supportive. You could ask a friend or supporter to sign up for the same course and then support and motivate each other. As they are free, there's nothing to lose. You can upgrade to get additional features but there's no need to do so.



There are courses that can help you get into work or move on in your career, help you think about what you might like to study at college or university or just learn about new things. Some are introductory taster courses while others are more in-depth or specialist.

You can sign up for their newsletter to hear about new courses:
www.futurelearn.com.



OpenLearn

OpenLearn is a website where you can find all the free courses available from the Open University. They have been developed for informal learners, as well as people who are wanting to build their confidence or knowledge to start more formal study. Some of the courses can also be found on FutureLearn.

www.open.ac.uk/about/open-educational-resources/openlearn



Financial help for studying

Disabled Students' Allowance (DSA)

DSA is support to cover study-related costs because of a disability, long-term illness or a mental health problem. You can receive this funding on its own or in addition to any student finance (see link below) that you get.

The level of DSA that is given is based on a person's needs. It is not affected by household income and does not need to be paid back. You can get help with:

- specialist equipment, for example a computer if you need one because of your disability
- non-medical helpers, for example a British Sign Language (BSL) interpreter or specialist note taker
- extra travel costs to attend your course or placement because of your disability
- other disability-related study support, for example having to print additional copies of documents for proofreading.

You can find information about eligibility, funding levels and how to apply on the government's website: www.gov.uk/disabled-students-allowance-dsa.



Here is a link to a video of a young student talking about her experience of applying, with lots of practical tips: www.youtube.com/watch?v=Pk8hyrfYsb8.

The more general costs of doing a higher education course at college or university can be off-putting but support is available. Also, tuition fees don't have to be paid in advance; you can obtain a loan from the government that only needs to be paid back once your earnings reach a certain level. There is more information at: www.gov.uk/student-finance.

Student finance and Disabled Students' Allowance are explained in this leaflet: www.disabilityrightsuk.org/fundinghighereducation.



Funding from charitable trusts

If you can't get the money you need to do a course from statutory sources, such as the ones above, charitable trusts may be able to help you. Each trust has its own eligibility criteria, which you can check out on their websites before applying. Some trusts only help disabled students, while others help students more generally. Most trusts help young disabled students but some will also consider funding mature disabled students.

Trusts usually receive more applications than they can support so, even if you meet their criteria, you may not get funding, but it's worth trying. The **Disability Rights UK** factsheet about charitable trusts can help with your application: www.disabilityrightsuk.org/funding-charitable-trusts. Part A gives advice about how to apply, while Part B lists trusts that may help with funding, information about who they help and the amount they give.

The **Snowdon Trust** is an example of a charitable trust that gives grants to people with physical disabilities to support them in further or higher education or vocational training.



This video of a conversation with Tanni Grey-Thompson and Lord Snowdon gives examples of how the fund has helped people fulfil their aspirations: www.snowdontrust.org/our-founder.

Adjustments and support for learning

Under the Equality Act, education and training providers have a duty to anticipate the adjustments that disabled students may need.

But in order to make the most of your course, you may require more specific adjustments. To get adjustments in place, you will need to let the provider know of your impairment and maybe also share your thoughts about what you think would be helpful.

The **Disability Rights UK** guide (link below) has a comprehensive list of specific adjustments in relation to different conditions. This list can help you be aware of possible options and prepare for meetings about your needs. Remember: you are the expert in your condition and any information you share will be invaluable to others.

You could speak to a course organiser, tutor, the DST and the exam office. One of your concerns may be dealing with pain, fatigue or a fluctuating condition that can make it difficult to predict how your studies will be affected. You need to explain this to make sure it is taken into account, for example, in relation to organising your study, arrangements for delivering coursework and doing exams.



Make sure the people you speak to put in writing the arrangements they have agreed and you can use this as a checklist to make sure it happens.

More information is available here: www.disabilityrightsuk.org/adjustments-disabled-students.



And finally, to help with learning-related queries, Disability Rights UK has a student helpline that may be able to help you.



Advisers can advise and support disabled people who are studying or wish to study at any level on full-time or part-time education or training courses if:

- the course is in England and
- they are over 16 years old

The helpline can also be used by parents and/or carers of disabled students and professionals working with disabled students.

The student helpline is sponsored by the Snowdon Trust (see above).

Open: Tuesdays and Thursdays, 11am to 1pm

Email: students@disabilityrightsuk.org

Working

Having work, whether through a job or self-employment, is an important part of many people's lives.

Yet it can feel as though there are many barriers and hurdles to finding suitable work or remaining in work, particularly when living with pain, or with a progressive or fluctuating condition.

This section outlines some of the sources of support that are available. It includes links to leaflets and advice provided by organisations, such as **Citizens Advice**, **Disability Rights UK** and **Scope**, as well as details of helplines that may be able to answer more specific queries.

Some of the people involved in writing this guide felt they had had to be persistent as some agencies and schemes had not been able to help.



They found it helpful to get support from family or friends when going to meetings and in thinking through options to find sustainable employment.



Self-employment

Much of the information in this guide focuses on being an employee but self-employment and having your own business can be a way of doing a job you like with more flexibility about how and when you work.

- Follow this link if you're interested in finding out more about working for yourself: www.gov.uk/working-for-yourself.
- You'll also find information to help you think through the pros and cons of self-employment on Scope's website: www.scope.org.uk/advice-and-support/self-employment-pros-cons.
- A good place to get information about business funding, support and guidance is your Local Growth Hub. The BEST Growth Hub covers Essex, Southend and Thurrock: www.essexopportunities.co.uk/employers/best-growth-hub.

Karen's experience of self-employment on the internet



"As a teenager, I wanted to be like my peers who were earning money doing things like paper rounds. I began exploring jobs on the internet for me to do in the comfort and accessibility of my home. I was able to create products to sell within a virtual world and make real-life profit from the creating, designing and marketing of digital goods.

I still work for myself on the internet as a content creator, writer, producer, and spoken word and digital artist, while being a full-time postgraduate student.

Self-employment seems a helpful alternative to more traditional jobs that require travel and accessible workplaces and it enables more people with physical and sensory impairments to use their personal strengths and contribute to the economy."

Emma's experience of exploring self-employment as a way back to work





"Although my newly acquired disabilities stopped me from returning to my previous career, I felt I still had much to offer – a decent brain that functions perfectly well, many adaptable skills and an abundance of enthusiasm!

Unfortunately for me, none of the numerous agencies and scheme organisers I saw were able to assist me in finding employment which took my physical needs into consideration. So, I began buying and selling on eBay as I could do this from home, taking my time with it and stopping if I was having a bad day. But there was so much work for very little reward.

Luckily, I then found a company who gave me work on a self-employed basis. I worked a couple of days a week for them, with extra days added when they needed more done. There was also flexibility if I needed to attend medical appointments. I learned how to make reading glasses, making and cutting

the lenses and putting them in frames, and I also did lots of admin work. Then COVID came along and that job came to an end.

So, I began making art and craft items. This has been highly therapeutic (and addictive!) and I have had a fair amount of success in selling my creations, though this needs to increase. I found that once Christmas fairs are over, there are few outlets, so I started hosting monthly craft and gift markets."

 I feel I've found the ability in my disability, which isn't always easy, but I'm now using my passion and talent, which has brought me income and feels extremely positive. 

Your rights at work

Section 5 of the Equality Act 2010 protects people from discrimination in the workplace at all stages of employment, including recruitment and access to training and career development.

Examples of discrimination could be:

- an employer withdrawing a job offer when they learn of your condition
- your employer firing you due to disability-related absences
- workplace bullying because you are disabled
- your employer not providing reasonable adjustments that would help you to do your job.

If you feel you are being discriminated against at work, there are places where you can seek independent advice to help you decide what to do about it. **Citizens Advice** has a guide you can go through to check if you are being discriminated against in your workplace and the steps you can take to address any issues: www.citizensadvice.org.uk/work/discrimination-at-work.

One of the dilemmas can be whether to tell an employer about a disability. **Scope** has a guide to help you think about the timing and how to go about it: www.scope.org.uk/advice-and-support/talking-to-employer-about-disability. If you want adjustments to be made at work, you need to tell your employer about your impairment or condition and, once they know, they must consider your request for support.

Most organisations are positively keen for employees to be open with them about any disabilities or health conditions so that they can then put in place the necessary support to help them to do their job.

Organisations providing support around specific conditions may have information on their websites about approaching employers with suggestions for adjustments. For example, the **MS Society** provides templates and factsheets covering issues such as 'Telling your employer decision', 'Return to work after time off sick' and 'Understanding your work situation'. They could be useful to people with other conditions as well: www.mssociety.org.uk/care-and-support/everyday-living/working-and-ms/work-toolkit.



Reasonable adjustments at work

It is useful to know about reasonable adjustments at work whether you are looking for a job or struggling in the one you currently have.

In the Equality Act there is no set definition of what is 'reasonable' as it depends on the type of job and employer.

It could include:

- ✓ flexible working,
- ✓ different duties,
- ✓ changes to policies,
- ✓ working practices or physical layouts
- ✓ providing extra equipment or support.



Don't be put off asking for adjustments as they may make a significant difference to your working life and yet be relatively easy to arrange.

If something is easy and inexpensive to do, and your employer has not done it, this could amount to disability discrimination. (There is general information about reasonable adjustments and discrimination in Section 1: Planning for change: getting started, page 26.)



The following organisations have produced helpful information on reasonable adjustments at work:

Citizens Advice has information that takes you through the steps of approaching an employer about changes to help you at work: www.citizensadvice.org.uk/work/discrimination-at-work/taking-action/asking-your-employer-for-changes-to-help-if-youre-disabled.



Scope provides a clear explanation of reasonable adjustments, including examples of what can be asked for and a template letter to send to your employer if they have not responded to your request: www.scope.org.uk/advice-and-support/reasonable-adjustments-at-work.

When talking to an employer or others about reasonable adjustments or discrimination, it is helpful to record details of the people you speak to, what you discuss, meetings you have had and actions you have taken in a notepad or computer folder.

This will make it easier to keep track of what you have done and what needs following up.



Access to Work funding

Another way to get practical support to carry out your job is through Access to Work.

This is a government grant scheme for people who are disabled or have a physical or mental health condition. Before you apply for the grant, you need to have talked to your employer about the reasonable adjustments they can make. The other conditions are that you are aged 16 or over and have a paid job or are about to start or return to one. You can also be self-employed, in an apprenticeship, internship, on a work trial or doing work experience (but not voluntary work).

The grant can pay for things such as:

- ✓ aids and equipment in your workplace, including a wheelchair
- ✓ money towards any extra travel costs to and from work if you can't use available public transport, or if you need help to adapt your vehicle
- ✓ an interpreter or other support at a job interview
- ✓ other practical help at work, such as a job coach or note taker


The funding can include support at home if you work from home, some or all of the time. It can also be used for practical support to move into self-employment or to set up a business (but not for business start-up costs). The grant is not means tested and does not need to be paid back.



All the details about Access to Work are on the government website: www.gov.uk/government/publications/access-to-work-factsheet/access-to-work-factsheet-for-customers.

You can apply online at www.gov.uk/access-to-work/apply.

Access to Work helpline:

 Telephone: **0800 121 7479**

 Textphone: **0800 121 7579**



Ben's story about adjustments and support in his job as a corporate tax assistant manager



"I joined a large, international accountancy firm as a graduate trainee after leaving university and during my first three years there I studied for my Chartered Accountancy qualification. I had always had an interest in accountancy, which was strengthened after speaking to careers advisers at university. The ethos of the firm towards their employees seemed to stand out and they showed a strong willingness to work with me in relation to issues associated with my disability.

Throughout my employment, I have had full-time support workers to assist me in the office with administrative tasks and some personal care that I require during the day. This is funded by the government's Access to Work scheme. My employer also purchased a few small pieces of equipment for me (for example a cordless telephone, which I find easier to use than a standard desk telephone).

They have established an internal disability network for employees in 2005, part of which I now lead. I feel that this has helped to change the organisational culture in relation to disability. I have consistently been provided with all the support I need in relation to my disability, which has been built on effective two-way communication between my managers and me: there has rarely been any misunderstandings on either side. One of the best examples of support and flexibility was the help I received during the process of transferring from the Southampton to the Cambridge office even though there was a lot of uncertainty around the timescales for my move.

My advice for others:

- **Don't have any preconceptions regarding a particular organisation or a particular job:** roles can often be adapted where necessary and potential hurdles overcome with methods that you may not even be aware of (for example the latest advances in technology).
- **Be open and honest with your employer about your disability,** but remain positive and focus on everything that you can do, as opposed to areas that you may find more difficult.
- **Don't be afraid to ask your employer for practical help where necessary.** Recognising that you need some assistance to be able to work more effectively should be viewed as a strength, rather than as a weakness."



Ben's blog on Purple Space (a networking and professional development hub for disabled employees, networks and allies) gives more information: www.purplespace.org/home?myhub&selected=1749.

Getting individual employment advice

There are a number of organisations that give individual advice on a wide range of issues, including work, over the phone or by email. These include Disability Rights UK and Scope, who are mentioned above with links to their websites. In addition, there are organisations that specialise in work issues.



The Advisory, Conciliation and Arbitration Service (ACAS) provides free, impartial advice on all workplace issues for both employers and employees. Its website includes information on disputes, redundancy, flexible working and reasonable adjustments: www.acas.org.uk/advice.

It also has a helpline:


 ACAS helpline: **0300 123 1100**

Monday to Friday, from 8am to 6pm

You can talk through your options without needing to give any personal details (ACAS is not able to give legal advice).



Working Families is an organisation that provides free advice and information to parents and carers to support them with issues they may face in the workplace. If you are a parent, it can help with understanding your rights, for example to flexible working, which could enable you to juggle your different roles alongside your disability: <https://workingfamilies.org.uk/advice-information>.

 You can get support by phone: **0300 012 0312**
(open Monday to Friday from 11am to 2pm)

Alternatively, fill in an online contact form:
workingfamilies.org.uk/contact-us-for-advice.

Support with looking for work

There are national and local organisations that give support to people looking for a job, returning to work after a break, changing jobs or exploring different career pathways. Details of a number of these are given below.

Finding disability-friendly employers

You should find that most large employers are aware of their duties under the Equality Act. However, you may want to look out for signs that an organisation has a particularly positive approach towards recruiting people with disabilities.

Disability Confident is a government scheme to encourage employers to recruit and retain disabled people through good practice. (It replaced the Positive about Disability 'Two Ticks' scheme.) When you're searching for work, look for the 'disability confident' symbol on adverts and applications.



This symbol means the employer is committed to employing disabled people and you'll be guaranteed an interview if you meet the minimum criteria for the job: www.gov.uk/government/publications/disability-confident-guidance-for-levels-1-2-and-3/level-1-disability-confident-committed.

There is also a list of employers who have signed up: www.gov.uk/government/publications/disability-confident-employers-that-have-signed-up.

Evenbreak is a social enterprise providing a platform that advertises work opportunities with employers who are actively aiming to attract disabled candidates. You can register for job alerts and also look on their website to get an idea of organisations who have signed up to use the platform, many of whom are household names: www.evenbreak.co.uk.

When you're searching for work, look for the 'disability confident' symbol on adverts and applications.

Intensive Personalised Employment Support

This is a government-funded scheme that provides one-to-one support and training to help people into work. To apply you must have a disability or health condition that affects the work you can do, be unemployed and be between school leaving age and state pension age.

Under the scheme, a dedicated support worker helps with:

- identifying what work you're able to do
- matching skills to work that's available
- getting training to help with finding work
- building a personal support network
- managing work around your specific disability or health condition
- giving support during the first six months of work.

Intensive Personalised Employment Support is usually for 15 months but you can get an additional six months of on-the-job support if you find employment. If you have a job coach, they should be able to tell you if you're eligible. If you don't, you can go to your local Jobcentre Plus and ask to speak to a work coach about the scheme. Find out more here: www.gov.uk/intensive-personalised-employment-support.

Supported employment

Supported Employment is an established model for supporting people with significant disabilities to secure and remain in paid employment. At its heart is the idea that anyone can be employed if they want to be, as long as sufficient support is provided. One of the key tools is 'vocational profiling', which means spending time finding out about a person's aspirations, learning needs, individual skills, former experiences and job preferences. It's accepted that someone may not have all the skills necessary to do a job but will learn them while at work, often with the help of a supporter through Access to Work. Less traditional recruitment methods, such as work trials or a working interview, are usually used to reflect this.



The website of the **British Association of Supported Employment** (BASE) has more information:

www.base-uk.org/what-supported-employment.


Although it is chiefly a member organisation for supported employment services, you can find out more about supported employment and search for BASE members in your area.

Essex-based support



Preparing for Adulthood service (PfA)

Support young people between the ages of 14 and 25, who have an Education Health and Care Plan, with planning for education, work, housing and connections.

 **Mid Essex** (Braintree, Chelmsford, Halstead and Maldon):
03330 131421

 **North East Essex** (Colchester and Tendring): **03330 321641**

 **South Essex** (Basildon, Billericay, Brentwood, Castle Point, Rochford and Wickford): **03330 131424**

 **West Essex** (Epping, Harlow and Uttlesford): **03330 321984**

Targeted Employment team

Help young jobseekers with Special Education Needs and Disability (SEND) on their journey into employment through supported internships, inclusive apprenticeships, traineeships and social enterprise.

 [**targetedemployment@essex.gov.uk**](mailto:targetedemployment@essex.gov.uk)



Papworth Trust

Provides a service called Community Connections that supports people with a disability, or long-term health condition to move into work, training or active job searching.

www.papworthtrust.org.uk/work/community-connections



Realise Futures

Offers personalised employment support to think about options, gain skills and take steps towards a job or training. Work and health programme to help people manage their health and wellbeing and get into employment.

www.realisefutures.org/employment

Benefits and work

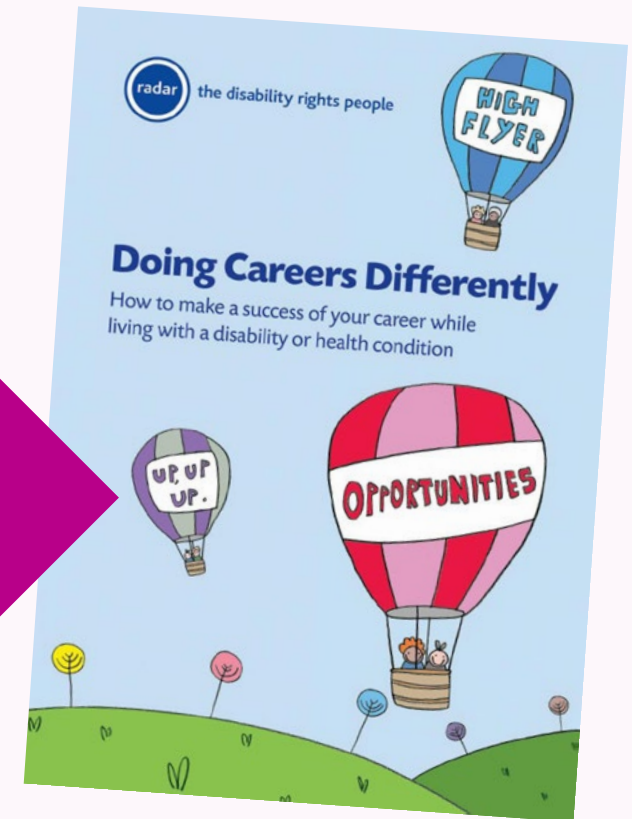
It may be helpful for you to know how working could affect your benefits.



This leaflet explains about 'permitted work': www.scope.org.uk/advice-and-support/permitted-work.



And finally,
a guide from
**Disability
Rights UK** full of
practical ideas:



Doing Careers Differently: How to make a success of your career while living with a disability or health condition is an informative and motivating guide, written by and for people with disabilities. It covers all stages of working life, from finding your first job to rethinking your career or simply wondering what to do next. It's presented in a question-and-answer format and includes lots of stories of personal experiences. It has a positive outlook and promotes the idea of turning your disability into an advantage in the world of work.

www.disabilityrightsuk.org/how-we-can-help/publications/doing-life-differently-series/doing-careers-differently



My notes

Use this page to make a note of anything you're interested in following up from this section.
Do this in whatever format works best for you to make sure your thoughts and ideas don't get lost.



Section 4:
My home



**Planning for change:
getting started**



**Family, friends
and connections**



**Learning
and working**



**My
home**



**Health and
wellbeing**



**Going out
and about**

Information in this section

Useful
to me?

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Why this section might be helpful

Where we live has a key bearing on our lives. Feeling safe, secure and comfortable at home can make all the difference to the way we cope with our situation. It can also have an impact on other aspects of life, such as our health and wellbeing and our ability to take up study and work opportunities, as well as any care or support we need from others.

This section provides information about the different options to help you achieve the best accommodation for your situation. It may be fairly easy to make your housing work better with pieces of equipment and some small adaptations. On the other hand, you may be thinking about major adaptations or looking for somewhere more suitable to live.

Knowing how the system works, and the terminology and organisations involved, should help to make it easier. It's advisable to plan as much in advance as possible as it can take time and effort to get the right things in place. If you are thinking of doing this planning on your own, it may be helpful to involve one or two people who would be good at thinking it through with you, or helping with practical tasks, such as viewing properties. Also, it's worth talking to people in services and organisations who have expertise in housing as they can help you to look at the pros and cons and make the best decisions.

This is the fourth section of a guide called Shaping My Future. It has five other sections but you do not need to look at them all. Choose the ones that you think might be useful to you at this point in time.

Your rights in relation to housing

Housing is an important part of the Care Act 2014. It gives local authorities a clear duty to promote people's 'wellbeing' (Section 1: Planning for change: getting started, page 28) when carrying out care and support roles and gives the 'suitability of accommodation' as one of the nine points defining wellbeing.

Related to the idea of wellbeing is the central aim of preventing needs from developing or increasing: housing has an important part to play in this respect, for example, in the provision of suitable equipment and adaptations. Also, it states that the information and advice supplied by local authorities should include details of housing options to help people make informed decisions.

The Human Rights Act does not give the right to a home or to any particular type of accommodation. However, when a person has a home, they are entitled to respect for both it and for their private lives within it. If a social landlord unreasonably refuses or delays making changes that a disabled person needs to continue living in their home, this may amount to a failure to respect their tenant's home.

The United Nations Convention on the Rights of Persons with Disabilities states that: 'Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement' (Article 19).

It may be helpful to refer to this statement if you feel you are being pressured into a shared house or a sheltered housing scheme when you would rather live in an 'ordinary' or 'general needs' tenancy.

Under the Equality Act, councils and housing associations have a duty to make 'reasonable adjustments' (see Section 1: Planning for change: getting started, page 26) in relation to all their processes, including those relating to housing applications.



Shelter has information on reasonable adjustments that should be made in relation to housing: https://england.shelter.org.uk/legal/housing_options/people_in_need_of_care_and_support/reasonable_adjustments_for_disabled_people.

Eviction and discrimination are the only housing-related legal issues that are covered by Legal Aid. You can also find more information about this on Shelter's website: https://england.shelter.org.uk/housing_advice/complaints_courts_and_tribunals/legal_aid_and_free_legal_advice.



The Equality Advisory and Support Service (EASS) can help if you think you might have been treated unfairly and want further advice.



Telephone: 0808 800 0082



Textphone: 0808 800 0084



Email using the contact form on the EASS website: www.equalityadvisoryservice.com/app/ask

Summary of some of the housing options

Description	Advantages	Disadvantages	More information/ideas to help
<p>Renting from the private sector</p> <p>When your landlord is an individual or a private company</p>	<p>Lots of homes are available to rent privately so there is likely to be more choice.</p> <p>May be easier to find it near to where you want to be, such as closer to family and friends, workplace, health services.</p> <p>Usually able to find it more quickly – this can be particularly helpful if moving to a new area or waiting for social housing.</p>	<p>Less security of tenure than in social housing – this means it is easier for a landlord to ask you to move out, even if you have been a good tenant.</p> <p>Adapted and fully adapted properties can be difficult to find.</p> <p>May be difficult to make changes to make it more accessible. Would be unlikely to get consent from a landlord if the alterations fundamentally and irreversibly changed the nature of the property.</p> <p>Rent is likely to be higher than for social housing.</p> <p>Housing Benefit or the housing element of Universal Credit can be used to pay rent but may not cover the full cost.</p>	<p>The Equality and Human Rights Commission’s Your rights when you rent from a private landlord: information for disabled people: www.equalityhumanrights.com/en/publication-download/your-rights-when-you-rent-private-landlord-information-disabled-people</p> <p>More information on page 83.</p>
<p>Social housing</p> <p>Owned by a:</p> <ul style="list-style-type: none"> • housing association, also called a registered provider • council, also called a local authority • housing co-operative • charity (less common) 	<p>When compared with private renting:</p> <ul style="list-style-type: none"> • cheaper rents • more security of tenure • generally easier to have adaptations made. 	<p>Shortage of properties and particularly ones that have been adapted or are wheelchair accessible.</p> <p>Can be difficult to be placed in a band high enough to qualify for any property.</p> <p>Often there are geographical restrictions and, if you don’t have a tie to a local area, the council may not put you on their housing register.</p> <p>Often long waiting lists and restrictions on choice and size of housing offered.</p> <p>How long you wait will depend on a number of factors, including the band you are in, the size of home you need, the area of Essex you wish to live in and available housing.</p>	<p>Equality and Human Rights Commission’s Social housing and your rights: information for disabled people: www.equalityhumanrights.com/en/publication-download/social-housing-and-your-rights-information-disabled-people</p>

Description	Advantages	Disadvantages	More information/ideas to help
<p>Specialist housing associations</p> <p>Housing associations providing accessible properties</p>	<p>High standard of specification and clear description of level of accessibility.</p>	<p>Limited availability, therefore a lack of choice about properties and geographical locations.</p>	<p>Habinteg is a provider in Essex. There is a 'Find a home' tab on their website: www.habinteg.org.uk</p>
<p>Sheltered housing/ supported housing</p> <p>A type of 'housing with support', which you can buy or rent. Usually for people aged 55+. Sheltered housing schemes may include both wheelchair and mobility housing</p>	<p>A way of living independently if you find you need a bit more support, or if you want to live in a smaller and easier-to-manage home.</p> <p>May have facilities such as a warden or alarm system to give reassurance and support.</p>	<p>Very few sheltered housing schemes exist for younger disabled people.</p> <p>May be more restrictive than having your own home.</p> <p>Can sometimes charge fees for support whether it is used or not.</p>	<p>Independent Living in Essex is a partnership between ECC and local councils. Its website gives information about local schemes: www.independentessex.co.uk</p>
<p>Residential care</p>	<p>Can provide somewhere to live if you're no longer able to stay in your own home, after considering other options such as adaptations and extra help.</p> <p>Provides 24-hour help with personal and medical care but you can still get healthcare from GPs and district nurses as you would if living in your own home.</p>	<p>Living in a care environment rather than your own home.</p> <p>Loss of independence and autonomy.</p> <p>Not many residential homes for adults with physical disabilities so accommodation may not be in your local area and you may not be living with people of a similar age.</p> <p>No choice about who you live with.</p>	

Description	Advantages	Disadvantages	More information/ideas to help
<p>Shared ownership</p> <p>Through a housing association where you buy a share of your home (between 25% and 75%) and pay rent on the rest</p>	<p>Gives more legal protection and rights than rented accommodation.</p> <p>Makes owning a property more affordable.</p> <p>Can own up to 75% of your home.</p>	<p>Need to be able to save up for a deposit, which can be difficult on a low income.</p> <p>Limited choice of property type and particularly of fully adapted properties.</p>	<p>The government website has information explaining shared ownership: www.gov.uk/affordable-home-ownership-schemes/shared-ownership-scheme</p>
<p>HOLD (Home Ownership for people with Long-term Disabilities)</p> <p>A government-backed shared ownership scheme specifically for people with a long-term disability</p>	<p>Compared with the scheme above, it gives more choice as it allows you to buy on the open market or choose a new-build property.</p> <p>Can own between 10% and 75% of the home's value.</p> <p>Once you own the home you have security of tenure.</p> <p>Adaptations can be carried out using a Disabled Facilities Grant (DFG) (see page 94).</p>	<p>Need to meet eligibility criteria, such as receiving certain benefits or having a low income from employment.</p> <p>Qualifying benefits are:</p> <ul style="list-style-type: none"> • high or middle-rate care Disability Living Allowance (DLA) • Personal Independence Payment (PIP) • Attendance Allowance for over-60s <p>Also need to save up money for a deposit and set-up costs.</p>	<p>The government website Own Your Home has information: www.ownyourhome.gov.uk/scheme/hold</p> <p>Advance, a provider of HOLD, has more information on its website: www.advanceuk.org/services/shared-ownership</p>
<p>Buying a house on the open market</p>	<p>More choice re properties and freedom to make adaptations.</p> <p>Adaptations can be carried out using a DFG.</p> <p>Long-term security and freedom to move if you need/want to.</p> <p>DWP benefits can be included in your income, for example, if you have been awarded PIP on an indefinite basis.</p>	<p>Requires a deposit, which can be a significant cost if on a low income.</p> <p>Can be difficult to secure a mortgage if your income consists solely of benefits – will need to pass mortgage affordability tests when applying.</p> <p>Additional costs of home buying, such as legal fees and insurances.</p> <p>If the property needs adaptations, there may be a wait for planning permission to carry them out.</p> <p>May be in the position of buying without knowing whether permission will be given.</p>	<p>This government website explains about getting a mortgage if you're disabled: www.moneyhelper.org.uk/en/family-and-care/illness-and-disability/getting-a-mortgage-if-youre-ill-or-disabled</p> <p>Check whether there are any planning restrictions, for example if the property is in a conservation area.</p> <p>Tell your solicitor at the start of conveyancing about the adaptations you are hoping to make.</p> <p>More information on page 83.</p>

Description	Advantages	Disadvantages	More information/ideas to help
<p>Social housing mutual exchange</p>	<p>A housing swap aims for both parties to have their housing needs met.</p>	<p>Need to already be in social housing to qualify. Not many properties available – may not be any that are accessible in your area. When you swap, you take the home as seen so can't ask for additional adaptations. But if your condition changes, you can apply for a DFG: contact your local council for more information (see page 94).</p>	<p>Information about swaps can be found on these websites: HomeSwapper: www.homeswapper.co.uk UKhomeswap: www.homeswaps.co.uk Always view a property to make sure it offers what you need.</p>
<p>College or university accommodation</p>	<p>Provides an opportunity for young people to live away from their family home while studying.</p>	<p>Only temporary while studying. Can be difficult to find adapted student accommodation.</p>	<p>Plan ahead, talk to the university and their Disability Support Team. Talk to them about reasonable adjustments. See Karen's story in Section 3: Learning and working, page 55.</p>
<p>Shared Lives This is a scheme in which carers provide accommodation and support in their home</p>	<p>It aims to match a person needing care and support to a compatible Shared Lives carer. You live in a family home environment.</p>	<p>No security of tenure. There may be difficulties around living in someone else's home.</p>	<p>To find out more about the Shared Lives scheme in Essex, contact essex.sharedlives@essex.gov.uk If you do not have access to email, you can phone Adult Social Care who will pass on your enquiry: 0345 603 7630.</p>
<p>Supported living For people with disabilities who want to live independently but need some help and support. Can share with others or live in own flat in a building where others are also supported</p>	<p>More independence than residential care. Have your own tenancy. The landlord and the support provider are separate organisations so you can change your support without needing to move home. Should have a say about who you live with. Possibility of sharing a house with friends.</p>	<p>Currently little supported living available for people with physical disabilities in Essex.</p>	<p>More information about supported living can be found here: www.essex.gov.uk/housing-options-and-care-homes/supported-living-for-people-with-disabilities One of the aims of the new ECC accommodation strategy is to develop supported living as an option.</p>

Ideas to help with finding a property

Social housing

Demand for social housing significantly exceeds its availability so it's important to be clear about what you need and to understand the local system.

In all areas of Essex, housing association and council properties are let through a 'Common Housing Register'. This is to create a single point of access to social rented properties, making the system much simpler to navigate. Councils must allow disabled people, those with health or welfare needs and homeless people to join the register. Make sure you are on this register if you want to apply for a housing association or council property. Do this well in advance if you are looking to move from a less independent setting so that your move is not delayed.

These are some points to help you through the process:

- Find out how the allocation system works in the area you live in/need to move to. Use this link: www.essex.gov.uk/housing.
- Read the allocation policy or scheme to find out the rules and method for ranking the urgency of people's needs. It will explain which bands or points apply to different sorts of housing circumstances in your area.
- If you want to move to a different local authority or council district you will need to be able to show you have a connection or requirement to do so; for example, to live closer to family or other people who will be part of your support network. Give as much detail as possible and explain how it could reduce your current or future need for social care services.
- If your disability or medical condition is the main reason for moving, you will need to explain in detail why your current housing situation is causing you difficulties. Use the same terms as the scheme does, for example 'significant hardship' or 'increasing the risk of an emergency'. Include any other information about how your housing is affecting your independence or your physical and mental health. Collect as much evidence as possible, ideally from practitioners such as doctors, consultants, social workers, occupational therapists and physiotherapists.

Renting privately or buying a property

Although many people's first choice would be renting social housing, because of the severe shortage, it may be worth thinking about renting privately or buying a property on the open market, if you can afford it.



Disability Horizons has produced a free guide to finding an accessible home, whether renting or buying. It provides practical information and explains the various terms you are likely to come across.

The Ultimate Guide to Finding an Accessible Home can be downloaded from its website: <https://disabilityhorizons.com/2021/07/accessible-housing-download-your-free-2021-guide-to-finding-an-accessible-home>.

Looking at properties, whether to rent or buy, can be time-consuming and is often made more difficult by the lack of information about accessibility provided by most estate agents.

Some specialist organisations have been set up to help people find accessible properties for both renting and buying. It's worth looking at these sites to see what they offer, although property numbers may be limited:

- www.accessible-property.org.uk
- www.thehouseshop.com
- www.branchproperties.co.uk



Tips for viewing properties

Being clear about what you need

Think about the different aspects of a property and the different rooms and start by making a list of what you need (what is essential) and what you would like to have (but can compromise on). For example: are the ceilings strong enough for ceiling track hoists? Is there adequate storage space? A level-access shower? Make your list on a computer so you can fill one in for each property you view to help you decide which would be the closest to what you want.

Disability Horizons' housing guide (see page 83) includes a checklist of access requirements which you could download or use to create your own list. It could be useful to have a look at the checklist before you have an assessment about your housing needs.

Some access issues will be insurmountable and rule out a property. A property may be a listed building which precludes some adaptations being made. However, it may be possible for equipment and/or adaptations to be made to achieve some of the changes you need so take this into account when you view. Adaptations are likely to be easier in properties you buy, or rent from social landlords, but may also be possible with private renting, if you intend to stay there for five years or more, at the discretion of the landlord. It can be more difficult to make adaptations in communal areas as planning permission will also take into account the needs of others in the building.



Also, think about external access and the surrounding environment: issues such as location of shops, leisure facilities, public transport options and/or parking for yourself and for carers.

Build a relationship with estate agents

Estate agents do not usually include information about the accessibility of properties for either private lets or houses for sale. However, they are required under the Equality Act to make reasonable adjustments, for example, to make property details and property viewings accessible.

If you are looking to rent or buy on the open market, it may be useful to build a relationship with a few estate agents. You could let them know your key access requirements and, if they do not have enough details about a specific property you are potentially interested in, you could ask them to check with the landlord or vendor. If you use a wheelchair, it might be a good idea to take a portable ramp with you as agents may overlook external steps that would prevent you from viewing.



Estate agents are required to make reasonable adjustments, such as making property details and viewings accessible.

Moving from one area to another

There are additional things to think about if you are moving area, either within your local authority or to a new one. Think about the availability of support services you may need in the area you are looking to move to. If you have personal assistants, think about whether the area you are considering would be more difficult for them to travel to. If you would need to find new care providers, check good-quality services are available in the new area.

The Care Act introduced the idea of 'continuity of care' with the aim of making it easier for an adult to move from one local authority to another. This should be done through the sharing of care and support plans and information about personal budgets. The transfer of direct payments and any other sources of funding between different local authorities should be planned to ensure uninterrupted provision of care.

If you have been provided with equipment and subsequently need to move area, the Care Act guidance says that the equipment should move with you, if you want this to happen and it is the most cost-effective solution.



Think about the **availability of support services** you may need in the area you are looking to move to.

Help with housing costs

Some discretionary housing payments are available towards housing costs for people who are claiming Housing Benefit or Universal Credit.

For more information check out the government website:

www.gov.uk/government/publications/claiming-discretionary-housing-payments/claiming-discretionary-housing-payments.

Since 2013, social housing tenants (with the exception of pensioners and/or those living in supported housing) have been affected by the removal of the spare-room subsidy. This is often referred to as the 'bedroom tax'. Benefit payments no longer cover the cost of unoccupied rooms. But if you can supply evidence that your disability means that you need the 'spare' room, you may be eligible for a Discretionary Housing Payment from your council. Examples of evidence could be the need for an overnight or live-in carer, a disabled child who is not able to share a room or the storage of medical equipment.



It's also worth looking to see whether any Council Tax reductions might be available.

Single-person discounts are available to anyone living on their own. You could be moved down by one band in the Council Tax 'gradings' if you need to use a wheelchair indoors, although there are several additional criteria for receiving this.

Ask your utility company, too, if they have any schemes for disabled people. Sometimes they have specific rates or the offer of a reduction if you need to use additional resources due to a disability.

If your condition means you have additional waste, such as incontinence products, you can request an increased allocation to be collected.



If you need advice about help with housing costs, contact **Citizens Advice**. You can use this link to find your local branch: **www.citizensadvice.org.uk/about-us/contact-us/contact-us/search-for-your-local-citizens-advice**.

Ask your utility company, too, if they have any schemes for disabled people.

Equipment and adaptations

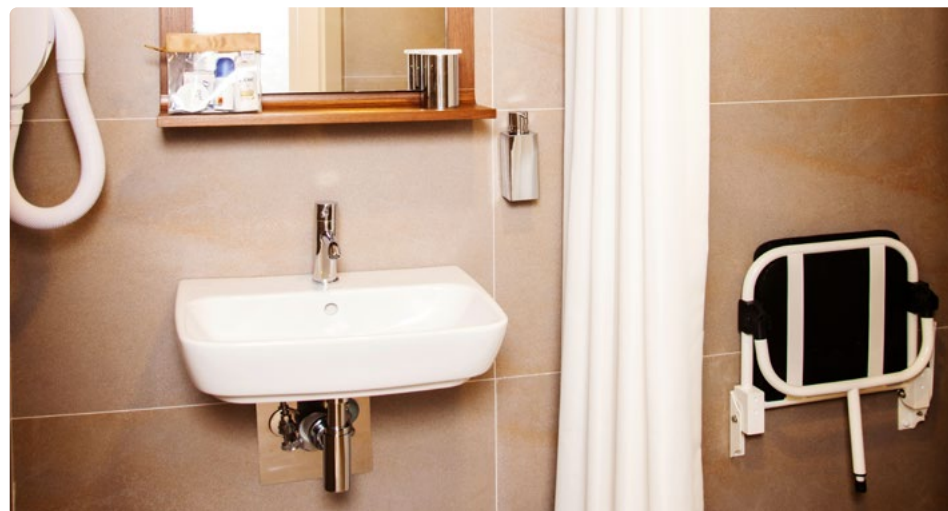
This section will give you information about:

- the different routes to find the right aids and adaptations for what you need
- possible sources of funding, including the Disabled Facilities Grant (DFG)
- local and national services and organisations that can help you get what you need.

Community equipment and adaptations can help you to cope more easily and safely where you currently live or enable you to move to a new home. They can range from a small piece of equipment (such as a grab rail or toilet frame) or technology, through to major structural changes (such as creating a level-access toilet and shower room). What is important is getting the right solution for your needs and the property you live in.



It's helpful to understand the terminology that is used, the organisations and services that play a part and the different routes to access funding.



How to get the right equipment and adaptations for your needs

You may have become aware that you are struggling with certain tasks or roles at home. Don't delay in thinking about how to address them as it can take a while to go through the process and in the meantime you may find things get harder.

Think about the different rooms in your home and/or the tasks you do each day and write down where you are finding it difficult. This may fluctuate day to day or vary at different times of the day, so make a note of that too. Think about your strengths as this will help practitioners, such as occupational therapists (often referred to as OTs), suggest the best equipment and adaptations for you.

It can be hard to think about all of this on your own so, if possible, ask someone you feel comfortable with to talk it through with you. It can mean thinking about issues you would rather ignore but it will help you to get the equipment and adaptations that will make your life easier now, and be better prepared should things become more difficult in the future.

You can also think about equipment and adaptations that would help family members and others who are caring for you.

If you have not already had a care and support assessment (which you are entitled to under the Care Act), then this is the time to ask for one. You can arrange one by getting in touch with Adult Social Care by phoning **0345 603 7630** or emailing socialcaredirect@essex.gov.uk (see Section 1: Planning for change: getting started, page 33 for more information).

Alternatively, you can go through your GP surgery. If you have had a care and support assessment, you may just need to contact Adult Social Care or your Children with Disabilities team and ask for an occupational therapy assessment (see below, page 89). This will be a discussion about how equipment and/or home adaptations might improve your ability to carry out everyday tasks at home.

There are also local and national organisations that specialise in giving information and advice about adaptations and equipment:

- **The Disability Living Foundation** (DLF) has a searchable online catalogue of independent living equipment, called Living Made Easy, which can be found at: <https://livingmadeeasy.org.uk>. DLF also runs a free online, guided self-assessment tool, with links to product suggestions and help and advice. This tool, called Ask Sara, may be a useful starting point but may not be right for everyone. If you need advice over the phone, DLF also has a helpline. Its advisers are available Monday to Friday, 9am to 5pm, on **0300 999 0004**.
- Some of the charities and support organisations for specific conditions provide specialised information about which aids and adaptations may be of particular help. Also, they may have forums and Facebook pages where you can ask questions. This information can be shared with assessors as evidence of need.

- It may be helpful to visit showrooms, such as the **Wecan** digital centre at the Harvey Centre in Harlow where you can look at care technology: www.yourharlow.com/2022/06/03/wecan-digital-centre-opens-in-the-harvey-centre.
- **Essex County Council** have information about daily living equipment on their website: www.essex.gov.uk/get-equipment-to-stay-independent/types-of-equipment.

Looking through the information provided by these organisations can give ideas about what might be of help, and you will then be better prepared for an assessment. Under the Care Act, local authorities have a duty to prevent, reduce and delay needs as well as to promote independence: equipment and adaptations play an important role in fulfilling this duty.



When you are considering what might be helpful to you, try to think how it might prevent a need for more support or give you a more independent lifestyle, and share this information with anyone carrying out an assessment.

Equipment and adaptations are sometimes provided free of charge, so it is worth checking what you are entitled to before buying anything yourself.

However, buying your own removes the need to wait for an assessment, and a wider range of products is likely to be available privately. If you are looking to buy your own equipment, make sure you get expert advice through one or more of the organisations mentioned above.

Help from occupational therapy

Occupational therapists help with developing, recovering or maintaining daily living and working skills when people have physical, mental or cognitive impairments.

Their knowledge can be invaluable when thinking about equipment and/or adaptations. OTs can also bring in other experts where necessary, for example a property surveyor in the case of any structural home alterations.

Their service is free of charge from the NHS or social services (through Adult Social Care). There is often a wait for an OT assessment, so when you ask for a referral, try to find out how long the wait is likely to be. Then you can plan how to manage in the meantime or let them know if your need is urgent and a delay will put you at risk, for example, of falling.

If possible, do some preparation before an assessment. Think about different rooms and tasks and what you are not able to do or are finding difficult. This will enable you to get the aids and adaptations that will help you now and if things become more difficult.

You could also use an independent OT but they will charge for their service. The advantage is that they usually do not have waiting lists and can offer services that the state does not fund.



You can find a private OT by searching here: www.rcot.co.uk/about-occupational-therapy/find-occupational-therapist.

Emma's experience of OT support for equipment and adaptations





"At my PIP assessment, I was fortunate to be interviewed by someone who was very helpful. Up until that point, I had fought against making any changes, even though I knew I desperately needed to get things in place to make my life more comfortable and less of a strain. And safer! My PIP assessor said she felt I needed an occupational therapy assessment as soon as possible.

Once home, I decided to get straight on to it as I knew that, if I thought about it too much, I would talk myself out of it. I searched the internet to find out how to go about it and saw you can simply call your county council and request one, so this is what I did. A few days later an OT called to get an idea of my needs. She then made an appointment to visit me at home.

The appointment was relaxed and unrushed. She listened to all the information about what I struggled with, what I was concerned about and what I felt I needed help with going forward.

Very quickly I was given raised toilet seats and soon after someone was sent to fit grab rails and a second bannister on my stairs. I tried out an electric bed raiser but did not get on with it so a different type of grab rail was fitted next to the bed instead, along with bed raisers on the legs of the bed.

I was given a bath board to try as I could no longer get in/out of the bath. This did not work for me. I was then assessed for having my bathroom converted into a wet room. This was a relatively simple and swift process and work was soon underway."

 I am not one to ask for help so I'm glad that the PIP assessor gave me that nudge because these additions and adaptations do truly help me! 

Understanding the different categories of equipment and adaptations

Term	Description	Funding and access	More information
<p>Equipment</p>	<p>Equipment is generally portable (although it also includes fixed items such as toilet frames). It may be loaned for a period of time and would be returned if no longer needed.</p> <p>It could be taken by a person to another property (although this may not be possible in some situations, such as moving to residential care).</p> <p>Examples might include: a raised toilet seat, a bath or shower seat, grab rails, adapted kitchen utensils.</p>	<p>Usually provided free of charge if you are assessed as needing it by a practitioner such as an OT or social worker working for the local authority, or a health professional (GP, hospital clinician, district nurse, community physiotherapist).</p> <p>There are some pieces of equipment that ECC does not provide, such as perching stools.</p> <p>Contact Adult Social Care to find out if you can get support with equipment.</p> <p>Telephone: 0345 603 7630 or email: socialcaredirect@essex.gov.uk</p>	<p>The equipment is usually provided by the local community equipment store.</p> <p>If the equipment is complex, in that it will require regular servicing and maintenance (such as mobile hoists), it will be delivered and fitted. Ask about maintenance contracts.</p>
<p>Care technology</p>	<p>Care technology is an umbrella term that covers a wide range of equipment that uses information technology and software to make life easier and give people more independence. It can be used for many different purposes, depending on what a person wants to gain from it.</p> <p>It is often described under these groupings:</p> <ul style="list-style-type: none"> • telecare • assistive technology • remote monitoring • apps for mobile devices 	<p>Same as above.</p>	<p>There is more information about the variety of care technology on page 93.</p> <p>ECC has more information about equipment and care technology on its website: www.essex.gov.uk/get-equipment-to-stay-independent/care-technology</p>

Term	Description	Funding and access	More information
<p>Minor adaptations</p>	<p>Changes that are made to the home and usually cost less than £1,000.</p> <p>Examples might include:</p> <ul style="list-style-type: none"> • a short ramp and/or some grab rails • a door-release intercom system 	<p>The assessment for these is carried out by ECC. The funding is provided free of charge under the Care Act, irrespective of tenure.</p>	
<p>Major adaptations</p>	<p>Typically cost over £1,000 and up to £30,000 and require substantial or structural works to your home.</p> <p>Examples might include:</p> <ul style="list-style-type: none"> • installing of a wet-floor shower room • widening of doors • installing ramps or a stairlift • replacing kitchen units with adjustable worktops • building an extension to the property and/or a ground-floor bathroom • providing a heating system suitable for your needs 	<p>You may be eligible for a DFG to carry out major adaptations to your home.</p> <p>A DFG will not affect any benefits you get.</p> <p>DFGs are not means tested for people in receipt of certain benefits, such as Universal Credit/Income Support, Housing Benefit and Guarantee Pension Credit. It may be worth checking you are receiving all the benefits you are entitled to as this may reduce or remove your assessed contribution.</p> <p>They are also not means tested for children and young people under the age of 20 and in full-time, ordinary, non-advanced education.</p> <p>When DFGs are means tested, your income and savings (as well as that of a partner) are taken into account. The first £6,000 of household savings are not taken into account for the means test.</p> <p>If you move within five years you can be asked to repay a proportion of the funding. If you have a degenerative condition, or if your needs change, you can make further applications.</p>	<p>If the cost of adaptations is over £30,000, you will usually be asked about looking for charitable funding or a bank loan but there is also a fund to which you can apply.</p> <p>Councils cannot provide a DFG for work which has already been completed, so it's important not to start any work before a DFG has been approved.</p> <p>For more information: www.disability-grants.org/disabled-facilities-grant.html www.essex.gov.uk/adapt-your-home-to-work-for-you/Get-help-with-home-adaptations</p> <p>More detailed information on DFG on page 94.</p>

Care technology

Care technology covers a wide range of equipment that uses information technology and software to make life easier and give people more independence.

The examples below give an idea of how it can be used. If you think it might be useful to you, it's worth speaking to a practitioner who can help you find the right equipment and give you lots more information about the options and funding.

It is a growing and changing aspect of care and therefore funding arrangements are still being developed. It may be possible to use Disabled Facilities Grant (see page 94) or discretionary funding from your local housing authority for some of the technology mentioned. Examples are: environmental sensors that can help with controlling sources of power, light and heat; smart thermostats that can automatically learn the preferences of the user and self-adjust when they enter or leave a room and automated light switches that can be activated using voice commands, a smart phone app or via a sensor triggered by movement or a timer.



Detailed government information about funding arrangements can be found here: shorturl.at/dFNU3.

Telecare can help with safety and wellbeing through equipment such as digital pendant alarms, which can alert others if you have a fall. An Oysta watch is a variation of a pendant but also includes GPS tracking and has two-way communication, similar to a mobile phone, and can be useful when you're out and about.

Assistive technology covers a range of technology to give more independence, such as medication reminders, communications aids and virtual personal assistants. Examples of this include a vibrating wrist watch, which gives alerts when medication is taken, and a Memrabel, which can be set for a variety of reminders.

Remote monitoring, such as Echo Show, can be used for video calling, news, weather and music, and can also give support with reminders.

Apps for mobile devices can be used to help you look after yourself and to make aspects of daily living easier. Spoonzy is an example of an app that can simplify meal planning and grocery shopping. Headspace is a meditation and mindfulness app to support health and wellbeing.

West Essex Community Action Network has a programme called TEC Mates which supports the use and uptake of digital technology and technology-enabled care products and services. It provides support to help people understand digital technology. There is more information on its website: <https://westessexcan.org/tec-mates>. You can email the network at admin@westessexcan.org. It also runs digital showcase centres called Living Smart Homes, which you can ask to visit to experience digital technology and learn more about its potential: <https://westessexcan.org/our-work/living-smart-homes>.

Disabled Facilities Grant (DFG)

To qualify for one, either you or the person you're applying for must:

- own the property or be a private tenant
- intend to live in the property during the grant period (which is currently five years).

A landlord can apply on behalf of a disabled tenant.

If you rent from a housing association or are a council tenant, find out from them how to apply for a major adaptation. A DFG cannot be used by council tenants and housing associations vary in their practice.

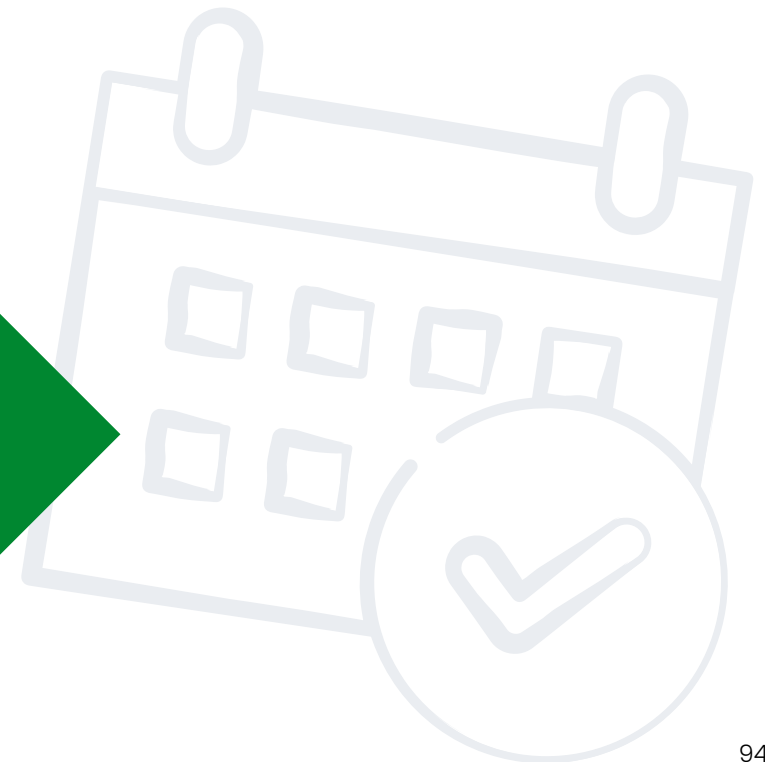
Your council has a responsibility to make sure the adaptation is:

- 'necessary and appropriate' to meet a person's needs (this will be assessed by an OT)
- 'reasonable and practicable', given the age and condition of the property (assessed by housing).

There can be delays in the DFG process, which are often due to long waiting lists for assessment with an OT. The law says the local authority must make a decision about your application 'as soon as reasonably practicable' and no later than six months after the date your application was made. Keep a note of when you applied and let them know if your situation has got worse.

As well as providing a mandatory DFG, some councils also offer a range of discretionary housing assistance grants. Details of each council's Housing Assistance Policy should be on their website.

The local authority must make a decision about your application 'as soon as reasonably practicable' and no later than six months after the date your application was made.



Role of Home Improvement Agencies (HIAs)

Many councils provide support to disabled people with applications for DFGs.

This support may be provided by the council itself or by an independent agency. Services providing such support are often called HIAs. All HIAs provide help in two key areas:

- individual advice provided in your own home
- expertise in making changes to the physical fabric of the home.

They can help with planning and arranging home improvements, as well as with applications for DFGs and any other discretionary grants that your local council provides. They can be particularly useful when working on a larger project and may well help you to save money, especially if you are not confident about the work you are doing and/or finding the right tradespeople. They may also help you access other grants or loans available for home repairs. Your local council may provide other services to support elderly or disabled people, such as handyman schemes or help with gardening.



More information about HIAs in your area can be found at: www.findmyhia.org.uk.

Not all councils provide (or commission) an HIA. Instead, they may direct you towards independent organisations that can provide you with help and support in arranging adaptations to your home, such as DG Accessible Designs, an accredited HIA though not specifically commissioned by any councils in Essex. Further information about how it may be able to help you with the tasks described above can be found at <https://dgadesigns.org/index.php> or by phoning **0800 193 3110**.

Adapt My Home (<https://adaptmyhome.org.uk>) has a self-assessment tool to help you think about whether adaptations may be relevant to you. There is also a tool you can use to see if you are likely to need to contribute towards any DFG-funded adaptations.

If you get turned down for DFGs for adaptations, there are some alternative funding sources, for example, small grants from a charity. **Turn2Us** has an online search tool you can use to find out what help might be available from a grant-giving charity www.turn2us.org.uk.



Age UK's factsheet 'Disability equipment and home adaptations' gives more detail on many of the topics covered above.



www.ageuk.org.uk/globalassets/age-uk/documents/factsheets/fs42_disability_equipment_and_home_adaptations_fcs.pdf



My notes

Use this page to make a note of anything you're interested in following up from this section.
Do this in whatever format works best for you to make sure your thoughts and ideas don't get lost.



Section 5:
Health and wellbeing



**Planning for change:
getting started**



**Family, friends
and connections**



**Learning
and working**



**My
home**



**Health and
wellbeing**



**Going out
and about**

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Why this section might be helpful

Getting the right support with health and wellbeing can make a huge difference with coping day to day and making other areas of life go well. This section provides information and ideas to get you thinking about what might be helpful to you. There are many reasons why people living with a disability may need additional support around health. You may find:

- you have additional health or wellbeing needs specific to your impairment
- your physical disability impacts on your general physical and emotional health, which may get overlooked
- it's hard to discuss any mental health difficulties you're experiencing
- there are barriers to accessing the health services you need.

Covid has caused an additional stress on people's health and wellbeing. Many are still living with the after-effects of the virus, while others have found that the support they had been relying on before the pandemic is no longer available. The principal aim of the Care Act (see Section 1: Planning for change: getting started, page 28) is to improve people's wellbeing, which includes supporting their physical, mental and emotional health. You may feel that the demands of day-to-day living with a disability mean that you are not managing to look after your health and wellbeing as well as you would like to. If so, make sure you talk about it if you have a social care assessment and when thinking about the support hours you need.

This section should also be useful to family and friends who have a caring role, who can often forget to look after their own health.

This is the fifth section of a guide called Shaping My Future. It has five other sections but you do not need to look at them all. Choose the ones that you think might be useful to you at this point in time.

Getting the healthcare you need

Access to healthcare

The Equality Act says that all health services are required to make ‘reasonable adjustments’ (see Section 1: Planning for change: getting started, page 26) so that they are accessible to everyone.

This means that GP and dental practices and hospitals have a duty to anticipate the needs of disabled people and, where possible, make adjustments to provide the same level of service as for non-disabled patients.

When you are making or attending health appointments, remember that while health practitioners will have expertise in the specific area of health you need addressing, you are the expert in your disability. You may have your own ideas, from your day-to-day experience of living with your condition, on how your needs can best be met. Let health practitioners know so they can give you choices about managing your healthcare.

Health practitioners may have limited experience of physical disability and making healthcare accessible. Lack of accessibility cannot be given as a reason for not offering health checks, screening, tests or treatment. The experts by experience involved in producing this guide gave the following advice:

- ✓ Let people know in advance about your accessibility needs, for example whether you have difficulties with steps, the width of doors or require a hoist.
- ✓ If you think you might need more time for an appointment, ask for it at the time of booking.
- ✓ Check accessibility beforehand as otherwise it could be a wasted journey and may result in a delay in getting the right treatment. You may need to go to a different hospital where your accessibility needs can be met, for example, where they have scanning facilities that would work for you.
- ✓ Hospitals usually have a number of specialist beds – tell people what you need rather than relying on them to ask you.
- ✓ Health workers should not use General Data Protection Regulations (GDPR) as a reason for not sharing information about your accessibility needs – let them know what information you are happy to be shared.
- ✓ If possible, when you go to health appointments, take someone with you who can make notes and help with thinking about questions you might want to ask. They may also remind you about how things are on a bad day as you are more likely to make it to appointments on a better day.

Healthwatch Essex

Healthwatch Essex, a charity set up under the Care Act, works across the county to learn about people's experiences of health and care services and uses this information to make improvements. It also provides an information service.

Information and Guidance Team

The team provides information and guidance to help people find health, social care and wellbeing services in Essex that are right for them.

You can contact them to ask about:

- health and social care services in your area
- how to access the support you need
- what to do if you have a concern or complaint

When you speak to a team member, you don't need to give them your name, your address or any other information you don't want to share. The information you give will not be shared with other organisations unless you give permission.

 Email them for support at info@healthwatchessex.org.uk

 Telephone **0300 500 1895** on weekdays from 9am to 4.30pm.

 Message on **07712 395398**, Monday to Friday, 9am to 4.30pm.

On Monday, Wednesday and Friday, 10am to 2pm, they are available on live chat – look for the icon in the bottom right corner of the screen on their website.

The Healthwatch Essex website also has a directory of services, such as dentists, opticians, pharmacies and GPs, available in your area. You can see how they are rated by other people who have used them and also give your own feedback about your experience of using a service: <https://healthwatchessex.org.uk/services>.

Many national and local charities for specific conditions provide relevant health information on their websites. If there isn't a specific charity for your condition, look for one which addresses similar health issues to your own.

The Healthwatch Essex website also has a **directory of services**, such as dentists, opticians, pharmacies and GPs, **available in your area.**



Jade's approach to getting support with her health



"The practice manager at my doctor's surgery has been a good source of practical help around making it easier for me to attend appointments. To get an appointment for a specific day you need to phone at eight o'clock but my condition makes mornings very difficult for me. Also, I need to have a PA for appointments but don't have one every day. I contacted the practice manager and explained my difficulties, and she put a note on the system that I could pre-book appointments in advance. This has made a huge difference and means I can have the appointments I need and make sure support to attend is in place.

My condition causes a lot of severe pain and fatigue. I have regular massages that I managed to get funded through my personal budget. The massages don't cure me but give me a bit of a break whilst I have some reduction in pain. This makes a massive difference, both physically and mentally. On bad days, knowing the treatment will reduce some of the pain helps get me through.

A lot of the time, I find it difficult to leave the house and, with my condition being rare, I hadn't got to know many other people with it. I've found it so supportive to join Facebook groups for people with my condition. Knowing there are others out there that understand helps so much."

“ I've really connected with some of the people I've met – they have become my friends and I speak with them almost every day. ”

Emotional wellbeing and mental health support

There are a number of local and national organisations that can help you improve your sense of wellbeing or provide assistance with concerns you may have around your mental health.

Essex County Council (ECC) has a website page giving details of mental health support that is available, an explanation of various mental health problems and what to do in a crisis:

www.essex.gov.uk/mental-health/get-help-and-support.

The Essex Wellbeing Service (see page 108 for further information and a link to their online assessment) offers support with both physical and mental wellbeing. It covers areas of lifestyle that can affect your mental health, including social isolation, smoking, alcohol use and weight management. This kind of support can help with handling difficulties such as stress and tiredness and help to build confidence. There are also news articles that give advice and guidance around mental health:

www.essexwellbeingsservice.co.uk/services/mental-health.

Every Mind Matters, a website that's part of the NHS Better Health campaign, gives advice and practical tips to help look after your mental health and wellbeing. It has a quick quiz you can do to get a free plan with tips, often in the form of short videos, to help you relax, improve your sleep, boost your mood and feel more in control:

www.nhs.uk/every-mind-matters.



Many of the ideas in the other sections of this guide can also contribute positively to your wellbeing, for example, looking at ways to build more connections with others (Section 2), to learn something new (Section 3) and get involved in activities that interest you (Section 6).

Adult Mental Health and Wellbeing Team

Essex's Adult Mental Health and Wellbeing Team, which is made up of social workers, support workers and an employment specialist, provides short-term early intervention support.

They work with people who are experiencing low-level mental health problems such as anxiety and depression, which are causing a social care need. They usually support people for around three to six months to help them improve their mental health by working on what's important to them. This might involve finding ways to help with mood management, getting out and about without feeling anxious or stressed, returning to work or education, connecting with community services or meeting new people.

Anyone living in Essex who is aged between 18 and 65 can refer themselves to the team if they have mental health concerns or feel emotionally distressed and have a social care issue, or care for someone who does: www.essex.gov.uk/mental-health/adult-mental-health-and-wellbeing-team.

NHS psychological therapy

If you have a problem that you think could be helped by a mental health therapy, you may be able to get support through an NHS psychological therapies service, often known as Improving Access to Psychological Therapies (IAPT). You can ask your GP to refer you or, if you would prefer to refer yourself, use this link to find your nearest service: www.nhs.uk/service-search/mental-health/find-a-psychological-therapies-service.

IAPT services usually offer:

- talking therapies such as cognitive behavioural therapy, counselling and guided self-help
- help for common mental health problems such as anxiety, depression, obsessive-compulsive disorder, social anxiety and phobias.



Relationship support

Relate is a national organisation providing support with different aspects of relationships with partners, friends and extended family. It has ideas about building new relationships, going through difficult times, arguments and conflicts and developing confidence around relationships. There is a chat window on its website to access a free 30-minute conversation with a trained counsellor about day-to-day issues and concerns: www.relate.org.uk. There is also a search facility to find a Relate centre: www.relate.org.uk/find-your-centre?id=619

Student support

If you are at university or college, or planning to go, you may find information from **Student Minds** useful (see Section 3: Learning and working, page 56 for more information). Experiencing mental health difficulties at university can feel overwhelming but there are lots of different types of support that might be available to you. This link gives you information about the support programmes that Student Minds offers, as well as services available at your university or college: www.studentminds.org.uk/supportatyouruniversityandfurther.html.

Domestic abuse

Healthwatch Essex's Information and Guidance Service (see page 100) is a registered J9 Domestic Abuse Reporting Centre. This means it can offer confidential help if you think that you may be experiencing domestic abuse.



It can help you find support tailored to your needs and wishes and access local and national specialist services: <https://healthwatchessex.org.uk/2021/02/healthwatch-essex-becomes-a-domestic-abuse-reporting-centre>.



Telephone **0300 500 1895**



Email info@healthwatchessex.org.uk



Text/WhatsApp on **07712 395398**.

Alternatively, you can contact **Compass**, a single point of access funded by ECC in partnership with the Office of Essex Police, Fire and Crime Commissioner to support victims of domestic abuse across Essex. You can speak to a trained member of staff who will do an assessment and put you in touch with the most appropriate support service.



You can call the Essex Domestic Abuse Helpline on **0330 333 7444** or, for further information and an online self-referral form, go to: www.essexcompass.org.uk.

Self-help and self-care

Disability Horizons' website has a section on wellbeing and fitness covering a wide variety of topics. An article on self-care shares tips to get you through difficult days and help you feel more positive and in-control. The article can be found here: <https://disabilityhorizons.com/2022/09/5-self-care-tips-how-to-manage-on-difficult-days-if-you-have-a-disability-or-health-condition>. Further articles on wellbeing can be found here: <https://disabilityhorizons.com/category/wellbeing-fitness-and-disabled-sport>.

Side by Side is a 24-hour, online community moderated by **Mind**, a national mental health charity, where people can connect with others over shared experiences. It has community guidelines to make it a safe place where people feel comfortable: <https://sidebyside.mind.org.uk>.

There are a variety of apps for mobile devices that promote health and wellbeing for which you may be able to receive funding. An example of this is **Headspace**, a meditation and mindfulness app created to help with stress, anxiety and sleep issues: www.headspace.com.



Karen's thoughts about the value of self-help



"I was diagnosed with a major depressive disorder in my teens after I had actively sought counselling from CAMHS services, GPs and so on. A diagnosis didn't help me as much as I thought it would. Since then, I've been practising 'self-help' which to me means drawing on my expert-experience as a disabled person, being open to help and challenging myself at every given opportunity.

It doesn't get any easier – I just get better at managing my physical impairment, its symptoms and the psychological stress that comes with it. I think it is important to note that life is hard for everybody, but somehow, most of us adjust well enough to forget how hard it is. Which is the same for living with a physical impairment.

Life with a physical impairment is hard, but you can and will adjust to the challenge, especially if you get all the finances and services you're entitled to and continuously make positive personal decisions towards a better, healthier life."

Having a healthy lifestyle

It can sometimes be difficult to take steps to lead a healthy lifestyle when there are many day-to-day issues to deal with but there are a number of services and organisations that aim to make this a bit easier.

The **NHS Better Health** website has a range of free tools and apps that can be used to improve aspects of physical wellbeing such as losing weight, quitting smoking, reducing alcohol consumption and becoming more active:

www.nhs.uk/better-health.



Physical activity

There is widespread recognition of the importance of people with disabilities and long-term conditions being offered support to be physically active to help both body and mind.

However, they may face a range of barriers to becoming more active. These may be physical, including pain and fatigue, but a lack of confidence or information about available support can also prevent participation.



If you experience access problems, for example at a sports or leisure centre, you have a right to ask for reasonable adjustments and expect them to be made (see Section 1: Planning for change: getting started, page 26) to enable you to use the service.

You can also get support with finding the right activities that would be safe and beneficial to you, and that you'd feel motivated to do. Healthcare practitioners can help you with this or you could get in touch with **Sport for Confidence** (see below).

Sport for Confidence is a social enterprise in Essex that employs occupational therapists and coaches who work individually with people to help them find physical activity that is meaningful to them and takes place at the right time and place for them. It also provides a weekly sport and physical activity programme at different centres in Essex that includes running, trampolining, boccia, curling, netball, community swimming, aqua aerobics and tennis. In addition, it offers a variety of walking sports and an exercise referral programme.



You can find out here what is available at your local leisure centre here: www.sportforconfidence.com/our-services/leisure-centres.

All Together is an **Active Essex** campaign that promotes the opportunities available for people with disabilities or long-term health conditions to participate in sport and physical activity across Essex.



You can search for local inclusive sport and physical activity opportunities using its interactive map: www.activeessex.org/all-together-activity-finder.

Activity Alliance (previously known as the Federation of Disability Sport) has published a friendly guide called **Being Active: An everyday guide for people living with an impairment or health condition**: www.activityalliance.org.uk/how-we-help/resources/1729-being-active-guide. It encourages regular exercise to make it easier to complete everyday activities such as getting up and dressed in the morning, as well as boost self-confidence, improve sleep, help memory and reduce stress.

Doing Sport Differently is a guide, written by and for people with lived experience of disability or health conditions, to inspire involvement in sport and fitness and improve access to grassroots sport: www.disabilityrightsuk.org/doing-sport-differently.

There are lots of free videos demonstrating home exercises and gym-free workouts on the internet. **Parasport** has created two videos – one of a stretching and mobility routine and the other of an aerobic routine – that do not require any equipment. Their aim is to help people who are unused to doing physical activity to get started: <https://parasport.org.uk/inclusive-home-workout-zone>. It also has a tool called Find a Sport where you can search for activities local to you or for a specific sport that you are keen to try: <https://parasport.org.uk/find-a-local-activity>.

WheelPower has lots of resources for wheelchair users, such as workouts for young people and physical activity after a spinal cord injury. Its website also has information about events, including weekly online exercise, dance and yoga classes: www.wheelpower.org.uk/resources.

Essex Wellbeing Service (EWS)

EWS is funded by ECC and delivered by Provide CIC in partnership with a number of specialist organisations.

It is open to anyone who is aged 16 or over and registered with a GP in Essex (excluding Southend-on-Sea and Thurrock). It can help with:

- | | |
|---------------------|---------------------|
| ✓ health checks | ✓ sleep |
| ✓ weight management | ✓ physical activity |
| ✓ stopping smoking | ✓ mental health |
| ✓ alcohol reduction | ✓ social isolation. |

Online assessment

EWS has an online assessment form that could help you get a clearer picture of your general health needs and suggestions to make lifestyle changes to improve your health and wellbeing. One of EWS's aims is to reduce risks for illnesses such as cardiovascular disease. Completing the questionnaire could give you:

- a better picture of your overall health needs
- tools to help you keep going with improving your health
- access to trained lifestyle coaches
- additional support from specialist organisations in Essex.

You can take the assessment online or, if you prefer, call a team member on **0300 303 9988** who can help with completing the assessment over the phone. More information about the online assessment can be found here: www.essexwellbeingsservice.co.uk/begin-your-journey.

Live Well Link Well

EWS works closely with existing organisations in Essex, each with expertise in their specialist areas. You can look at the list here: www.essexwellbeingsservice.co.uk/link-well/community-1. If you feel you would benefit from some extra support from services on the list, you can go through EWS to get support to connect with the right ones for you: www.essexwellbeingsservice.co.uk/contact. Live Well Link Well can also find local groups, organisations and clubs in your community that can help you take steps to being healthier and make positive social connections.

Volunteering service

EWS recruits and connects volunteers with Essex residents in need of support with everyday tasks (such as medicine collecting, food shopping, transport to medical appointments and social isolation). You can use this form to request support: www.essexwellbeingsservice.co.uk/volunteering/support-request.

Funding

There are a several ways that people with complex or high levels of healthcare needs can receive funding for their support.

Personal health budget (PHB)

A PHB is an amount of money to support a person's health and wellbeing needs. It isn't an additional pot of money but a different way of spending health funding based around what matters to a person and their individual strengths and needs.

A PHB can give a person more choice, control and flexibility because they receive an upfront indication of how much money they have available for their healthcare.



If you feel the local commissioned services are not working very well for you or don't meet your needs, you could ask about having a PHB.

You have a right to one if you receive Continuing Healthcare funding (described below) but you can also request one by speaking to your local Integrated Care Board (ICB) as they are being encouraged to offer them to other patient groups.



Peoplehub, a not-for-profit organisation created and led by people with lived experience of PHBs, is a useful website with information about eligibility, people's accounts of how they are using PHBs and resources to help manage them: www.peoplehub.org.uk.

PHBs are similar to personal budgets for social care funding (see Section 1: Planning for change: getting started, page 31). They involve working with a healthcare professional to create a care and support plan that reflects your health and wellbeing goals. Agreed funding can be used for a variety of support, such as therapies, personal care and equipment. There is more information on the NHS website, including a short video explaining PHBs and a search button to find your ICB: www.nhs.uk/nhs-services/help-with-health-costs/what-is-a-personal-health-budget.

Personal wheelchair budgets

You will be able to have a personal wheelchair budget if you are referred and meet the criteria of your local wheelchair service.

You will also be eligible if you are already registered with the wheelchair service and need a new wheelchair either because of your changing needs or the condition of your current chair. A personal wheelchair budget should give more choice and flexibility over the chair and related equipment.

Local information about PHBs and/or personal wheelchair budgets for mid/south Essex, west Essex and north east Essex can be found here:

www.midandsouthessex.ics.nhs.uk/health/personalised-care/budgets

<https://hertsandwestessex.icb.nhs.uk/funding-care/personal-health-budgets-2/4>

https://www.neessexccg.nhs.uk/uploads/files/phb_a5_leaflet.pdf

A personal wheelchair budget should give more **choice and flexibility.**



Continuing Healthcare

NHS Continuing Healthcare is the name given to a package of ongoing care that some people, aged 18 or over, are entitled to receive as a result of disability, accident or long-term illness.

It can be received in any setting outside of hospital, including your own home. People who are eligible for Continuing Healthcare have the full cost of their care and accommodation funded by the NHS and, unlike local authority funding, it is not means tested.

To qualify it must be proven that your care requirements are primarily for health, rather than social or personal care. There is no clear definition of 'primary health need': it is not based on a diagnosis but on the nature and extent of your care needs. It is usually given to people who have particularly complex or unpredictable care needs.



More information can be found in these FAQs:
www.beaconchc.co.uk/faqs/general.

The application process involves an initial screening checklist which, if you meet the criteria, will be followed by a full assessment. The process is lengthy and quite complicated but an organisation called **Beacon**, funded by NHS England, can offer support by providing:

- an information and advice service where you can get up to 90 minutes of free advice from trained staff
- a toolkit to help navigate Continuing Healthcare; it gives a detailed explanation of the system, what to do at each stage, and the pitfalls to look out for

You can fill in Beacon's contact form www.beaconchc.co.uk/talk-to-us or phone **0345 548 0300** to leave a message and somebody will return your call. Further information about what they offer can be found here: www.beaconchc.co.uk/what-is-nhs-continuing-healthcare.

Responsibility for Continuing Healthcare lies with ICBs. See below for the contact details in your area.

West Essex

<https://hertsandwestessex.icb.nhs.uk/funding-care/nhs-continuing-healthcare>

Email: hweicbwe.thecontinuinghealthcareteam@nhs.net

Telephone: **01992 566137**

Mid and south Essex

www.midandsouthessex.ics.nhs.uk/health/personalised-care/all-ages-continuing/nhs-continuing-healthcare

Email: meccg.chc@nhs.net

Northeast Essex

<https://suffolkandnortheastessex.icb.nhs.uk/your-health-and-services/continuing-healthcare>

Email: sneeicb-nee.northeastessexchc@nhs.net

Telephone: **01206 918681**



My notes

Use this page to make a note of anything you're interested in following up from this section.
Do this in whatever format works best for you to make sure your thoughts and ideas don't get lost.



Section 6:

Going out and about



Planning for change:
getting started



Family, friends
and connections



Learning
and working



My
home



Health and
wellbeing



Going out
and about

Information in this section

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Why this section might be helpful

Being able to go out and about means much more than just getting from A to B. Lack of mobility and/or accessible transport can prevent you from meeting up with family and friends, connecting with people and being involved in things that you enjoy. It can also limit options in relation to work, housing and healthcare. You have a right to be able to get out and about so, if you need additional information or advice, talk to your GP or a health or social care practitioner to get the support you need.

In this section, you will find information and ideas about getting around, including mobility aids, driving, different forms of public and community transport and air travel. There is also information about finding accessible places to enjoy leisure time.

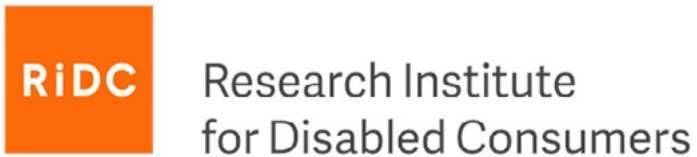
This is the sixth section of a guide called Shaping My Future. It has five other sections but you do not need to look at them all. Choose the ones that you think might be useful to you at this point in time.



Travel

Advice

The websites below give general advice and useful starting points for thinking about what might be helpful to you.



The Research Institute for Disabled Consumers (RiDC) has unbiased reviews, information and guidance on products and services based on its research with disabled and older consumers.

It's worth looking at its website to see if it has carried out research that addresses queries you have; for example, it has recently done a survey of motability scooters (see below). You might find that there are areas of research that you want to participate in too. RiDC uses its findings to raise issues, for example, regarding accessibility of electric vehicle charging points.

RiDC also has a car search database to help people find cars with flat, easily accessible boots that have room for a folded wheelchair or have lots of leg room and high seats. www.ridc.org.uk

Email: mail@ridc.org.uk

Phone: **020 7427 2460**



Motability is a not-for-profit scheme that enables people to hire a mobility scooter or car for up to three years. To qualify you must receive a government-funded disability allowance – either the Disability Living Allowance (DLA), if you already receive that particular benefit, or the Personal Independence Payment (PIP), if you are applying now. You will receive your wheelchair or mobility scooter in exchange for all or part of your allowance.

Further information can be found here: www.motability.co.uk.

There is also a tool to check eligibility for the scheme: www.motability.co.uk/about/check-your-eligibility.




East Anglian Driveability provides a regional transport hub which gives free individual advice to people who are finding it difficult to get out and about. This advice is for both people who are no longer able to drive and those who have never driven but whose needs have changed. The advisers combine their local knowledge about what is available with considerations about an individual's accessibility needs. They can help with journey planning and thinking about which schemes may be of benefit to you. This service is linked to Driving Mobility (see page 118).

More information about this service can be found here:

www.eastangliandrivability.org.uk/regional-transport-hub.

 Telephone for general enquiries: **01842 753029**

 Telephone for booking an appointment: **01787 222873**

You can also go through Motability to get a powered wheelchair but the best place to start is by contacting your local wheelchair service (see page 117).

Transport for All
Access, Rights, Advice


Transport for All is a disabled-led organisation that gives individual advice and campaigns for better access to transport and street space (for example clear pavements). There are two different categories of advice: one-off enquiries and casework.

One-off enquiries may be advice on how to apply for concessions (such as the Freedom Pass, Blue Badge or a Taxicard), advice about your rights when travelling, or how to complain if you've had a problem on a journey.

 For this sort of enquiry phone **020 7737 2339** or

 email contactus@transportforall.org.uk.

A casework enquiry is usually more involved and could include appeals if an application for a concession was turned down unlawfully, persistent issues with a transport provider or instances where you feel discriminated against on transport due to your disability.

 The phone number for casework enquiries is **020 7737 2339** and the email is casework@transportforall.org.uk.

Membership is free. If you sign up, you will receive email updates and have the opportunity to get involved with transport campaigns: www.transportforall.org.uk/membership.

Support with mobility

There are a number of websites where you can read about what to consider when choosing mobility aids.

If you are considering getting a walking stick, walking frame, wheelchair or mobility scooters, there is information on Essex County Council's website: www.essex.gov.uk/walking-and-mobility and also on the NHS website: www.nhs.uk/conditions/social-care-and-support-guide/care-services-equipment-and-care-homes/walking-aids-wheelchairs-and-mobility-scooters.

You may be entitled to a manual and/or an electric wheelchair depending on your needs. Ask your GP to refer you to your local wheelchair service for an assessment to find out if you need one and, if so, what type. You can use these links to see your local service:

- **Braintree, Witham, Chelmsford and Maldon (Provide Wheelchair Service):**
www.provide.org.uk/service/wheelchair-service
- **Epping, Harlow, Uttlesford (NHS):**
<https://eput.nhs.uk/our-services/holly-wheelchair-service>
- **Colchester and Tendring (NHS):**
www.esneft.nhs.uk/service/wheelchair-services
- **Basildon, Brentwood and Thurrock (NHS):**
www.nelft.nhs.uk/services-brentwood-wheelchair-special-seating

In Section 5: Health and wellbeing, page 110 there is information about personal wheelchair budgets which can give more choice and flexibility when choosing a wheelchair.



Which? has published a review of different walking sticks and rollators and gives advice about making the right choice: www.which.co.uk/reviews/mobility-equipment/article/buying-the-best-walking-stick-frame-or-rollator-aUxbU0H2gpLr.



The **RIDC** website has information about powered wheelchair assessments and funding: www.ridc.org.uk/features-reviews/out-and-about/getting-powered-wheelchair/getting-assessed-powered-wheelchair and also, as mentioned above, about mobility scooters, including a checklist to help you decide which scooter is right, covering comfort, ease of use and what you want to use it for: www.ridc.org.uk/features-reviews/out-and-about/choosing-wheelchair/mobility-scooters/mobility-scooters-checklist.

ShopMobility UK is a scheme that co-ordinates a network of local centres that hire out mobility scooters, powerchairs and wheelchairs so you can enjoy your independence while out and about.

You can use this link to find centres in Essex and elsewhere: www.shopmobilityuk.org/find-a-centre.

Driving

Many people with different forms of disabilities are able to drive independently and, where necessary, highly sophisticated specialist driving systems can be fitted to vehicles and tailored to meet individual needs.

These include automatic 'tie-down units' to allow someone to drive while seated in their wheelchair, electronic and infra-red controls for brake/accelerator, a joystick for steering the vehicle, or a combination of any of these. The Motability scheme, mentioned above, can be used to cover most of the costs of these adaptations.



The process of applying for a provisional licence can take a long time and involve completing medical information forms. Therefore, it's advisable to start as early as you can.

There is more detailed information about having a driving assessment and applying for a provisional driving licence under **Disability Grants** below. It may be useful to know that if you are in receipt of the higher rate of the mobility component of DLA/PIP you can apply for a provisional licence and start learning to drive from the age of 16.

Carers who need to learn to drive to give lifts to the person they support may be able to obtain funding by arranging a carer's assessment with Adult Social Care (see Section 1: Planning for change: getting started, page 33 for contact details).



Driving Mobility

Driving Mobility, an umbrella charity supported by the Department for Transport, co-ordinates 20 independent driving and mobility assessment centres across the UK.

The Essex centre provides:

- car driving assessments
- high-tech driving adaptations (including driving from a wheelchair)
- driver and passenger access and seating assessments
- wheelchair and scooter loading assessments.

The centre's aim is to help people retain or gain their independence with getting around, build confidence and share information about what is available. Its assessment is not a test but a way of finding out what you need and trying out different options and adaptations.

The main centre in Essex is in Colchester:

www.drivingmobility.org.uk/information-centres/view/colchester



Phone: **01787 222873**



Email: **kimb@eastangliandriveability.org.uk**



Disability Driving Instructors is an independent, not-for-profit Community Interest Company (CIC) that works closely with Driving Mobility. The company provides a 'one-stop shop' to help disabled people get impartial advice about how to start to learn to drive, how to return to driving after an accident or illness and how to keep driving safely. It has an accessible online register of specialist driving instructors who are specially trained and have adapted cars for lessons:

www.disabilitydrivinginstructors.com.

Phone: **0844 800 7355**

Email: admin@disabilitydrivinginstructors.com

disability grants

Helping you Find the right grant

The **Disability Grants** website has information about applying for a provisional licence and possible funding for driving lessons: www.disability-grants.org/funding-for-driving-lessons.html.



The **Blue Badge** scheme is a national scheme to allow people with disabilities to park closer to their destination because they are less able to walk long distances or take public transport.

You can use a Blue Badge as a driver or passenger.

Some people will be automatically eligible, for example if you get the higher rate of the mobility component of DLA, or the mobility component of PIP and score eight points or more on the 'Moving Around' activity of the mobility component.

You may also be eligible if you are unable to walk, or have considerable difficulty in walking, such as (but not limited to), heart or breathing conditions, arthritis and other joint conditions, pain or balance issues.

It's worth looking at the details to find out whether you might be eligible and how to apply at: www.essex.gov.uk/topic/blue-badge.

Email: blue.badge@essex.gov.uk

Post: Blue Badge team, Essex County Council, Essex House, 200 The Crescent, Colchester CO4 9YQ

Ben's experience of learning to drive



"From an early age I was always very interested in driving – maybe it was the idea of being able to travel much further independently than I could ever manage in my wheelchair! Due to the nature of my disability, I knew I would need some highly specialist vehicle adaptations to achieve my dream.



When I was 18, I visited a driving centre that had numerous different types of vehicles and control systems that I could try out on its private road network. At first, it felt very strange but eventually we found a model of van and range of driving adaptations that seemed to work for me. Given that I use an electric wheelchair at all times, I need a van that I can enter and drive whilst remaining seated in my chair. I have a remote control that presses a button to electronically open the back door of the van and deploy a lift or ramp for me. Once inside, I position myself behind the steering wheel and over an electrical system on the floor that secures my wheelchair in place. On my left hand, I wear a glove with a metal peg going into the steering wheel and with my right, I operate a lever for the brake/accelerator. My head operates a pressure pad to control switches, such as indicators and windscreen wipers.

Buying a vehicle and installing these specialist adaptations doesn't come cheap. I approached

Motability and provided them with a copy of the report from the driving centre. They assessed my case and then approved me for funding. It took a while but eventually my new van was delivered to my home.

The next step was for me to have formal lessons in it and to pass my driving test in the same way that anyone else has to do. Over time my skills and confidence grew and, after six months of lessons, I was ready to sit my driving test. I passed first time and within the space of a few months I was happily doing journeys of over 100 miles, often on busy motorways!

More than 20 years on, I have my third adapted vehicle, held under a lease with Motability. It is paid for through the mobility component of my statutory PIP benefit. Fuel is my only ongoing cost as Motability meet the cost of all repairs, maintenance and insurance. I enjoy travelling and have driven around the majority of the UK and many European countries."

 **Learning to drive and passing my test has had a revolutionary impact on my independence and, without any doubt, I feel that it is the biggest achievement of my life to date.** 

Public transport

Rail travel

You may be eligible for a Disabled Persons Railcard, which will entitle you to one-third off the price of a rail ticket for both you and a companion. The card currently costs £20. More information can be found at: www.disabledpersons-railcard.co.uk. Check here to see if you are eligible for a pass: www.disabledpersons-railcard.co.uk/are-you-eligible.

→ You can find information on the National Rail website about buying tickets, planning journeys, receiving assistance and accessibility of specific stations: www.nationalrail.co.uk/stations_destinations/passenger-assist.aspx.

Bus travel

You may be entitled to an English National Concessionary Bus Pass. Information about who is eligible and how to apply can be found on this website: www.essexhighways.org/getting-around/concessionary-fares. You can also collect an application form from your local library. Alternatively, phone **0345 200 0388** to obtain one or for assistance completing it.

For information about accessible bus travel, you can contact your local bus company or visit its website. The main bus companies in Essex are Arriva and First Bus Essex.



Arriva's website has information about its policy towards customers with disabilities and its assistance card: www.arrivabus.co.uk/help/customers-with-disabilities.



First Bus Essex has information about the steps it takes to make its services accessible: www.firstbus.co.uk/essex/plan-journey/bus-accessibility and a card that can be used to ask for extra help when using its service: www.firstbus.co.uk/essex/extra-help-travel.



Community transport

There are a number of schemes that come under the umbrella of community transport that provide additional travel options to help people who either have restricted mobility, live in rurally isolated areas or find it difficult to access conventional public transport.

The local community transport organisations in Essex offer a range of transport services, such as social cars, dial-a-ride and group travel. They vary in what they offer to people who use wheelchairs. Below are links to the groups in different areas of Essex with information about what they provide.

District	Organisation	Contact
Basildon	Basildon Community Transport - www.basildoncts.co.uk	01268 465858
Braintree	Braintree District Community Transport - www.braintree.gov.uk/info/200300/community_transport	01376 557883
Brentwood	Brentwood Community Transport - www.brentwoodct.co.uk	01277 228080
Castle Point	Wyvern Community Transport - www.wyvernct.org.uk	01268 754936
Chelmsford	Chelmsford Community Transport - www.chelmsfordct.org	01245 477750
Colchester	Colchester 360 - www.community360.org.uk/services/community-transport	01206 216600
Epping Forest	Epping Forest Community Transport - www.efcommunitytransport.co.uk	01992 579556
Harlow	Harlow Community Transport - www.efcommunitytransport.co.uk	01279 446871
Harwich	Harwich Connexions - www.harwichconnexions.co.uk/cms/community-transport.html	01255 552010
Maldon	Colchester 360 - www.community360.org.uk/services/community-transport	01621 843164
Rochford	Wyvern Community Transport - www.wyvernct.org.uk	01268 754936
Tendring	Tendring Community Transport - www.dial-a-ride.org	01255 436962
Uttlesford	Uttlesford Community Travel - www.uttlesfordcommunitytravel.org	01371 875787

There may be other community transport schemes in your local borough or district.

For more information phone **03457 430 430** or email passenger.transport@essex.gov.uk.


Additional information about accessible transport options in Essex can be found here: www.essex.gov.uk/accessible-transport.

Taxis

If you need accessible taxis, you can contact the taxi licensing office at your local council to get advice about what is available. This link will help you find the details of the relevant council: www.gov.uk/find-local-council.

Taxi and minicab drivers must not discriminate against you and cannot treat you less favourably than other customers. They should also make any 'reasonable adjustments' (see Section 1: Planning for change: getting started, page 26) to their service to enable you to make your journey. Assistance dogs must be allowed into the vehicle, unless the driver has an exemption certificate (which will be displayed on the windscreen) and you cannot be charged extra. More information about the law can be found here: www.gov.uk/transport-disabled/taxis-and-minicabs.

Uber has three services to assist people with disabilities: Uber Access for those using wheelchairs, Uber Assist for those with assistance dogs and UberX for those in need of extra help because of their mobility issues. Further details can be found here: www.uber.com/gb/en/ride/uberwav.



Taxi and minicab drivers must not discriminate against you and cannot treat you any less favourably than other customers.

Air travel

If you are thinking about flying but feel anxious about the practicalities, Queen Elizabeth's Foundation for Disabled People has an Accessible Aviation Team to support people who have concerns or need practical help and advice.

The foundation runs Tryb4uFly assessment centres where someone guides you through the journey in a realistic cabin environment and you can try equipment and look at options for comfort during a flight. There are centres in Surrey, Birmingham and Leeds.

→ Further information can be found here: <https://qef.org.uk/our-services/accessible-aviation>. It also has online flight video guides that you can watch at home (www.qef.org.uk/service/accessible-aviation/flight-video-guides-your-guide-to-flying-with-a-disability).

→ The **Equality and Human Rights Commission** has produced a list of FAQs and top tips for disabled and less mobile passengers. Follow this link to find out about your rights and what to do to make sure you have the best chance of a smooth journey: www.equalityhumanrights.com/en/advice-and-guidance/top-tips-disabled-and-less-mobile-air-passengers.

It's important to be aware that even with plenty of planning, people still experience difficulties, including damage to electric wheelchairs. However, the information in the link above helps to put the right things in place to reduce risks and help you decide whether you want to travel by air.

Accessible activities

Inclusive activities

A range of activities specifically organised for people with physical disabilities is available in Essex.

These activities create opportunities for people to meet others, keep fit and active and explore new interests. Some are provided by disability organisations, while others have been set up by generic services with the aim of offering accessible activities. You will find links to a variety of these activities in Sections 2 and 5 of this guide.

One organisation that was frequently mentioned by contributors to this guide for giving confidence to go out and take part in organised activities was **Sport for Confidence** (more information about what they provide in Section 5: Health and wellbeing, page 107). In her story to the right, Emma describes how an activity organised for people with disabilities gave her motivation to get out and make new friends.

There are also services in Essex that provide information about activities where people can meet up with others who have similar interests. **Essex Connects** is an online directory where you can search for social activities, such as a local group or club, in your area. You can also use it to get in touch with local charities, voluntary groups and community sector services: www.essexconnects.org.uk.

Emma's story about going along to Sport for Confidence



I have never been sporty or competitive. I never played a sport as a hobby when I was able to. But with limited mobility and wishing to do something that was at least a bit active, I was interested when I saw an ad for Sport for Confidence activity sessions at my local leisure centre.

I did not want to try the swimming sessions as I was not confident about getting in and out of the pool or showing my body. Racket sports did not hold any interest for me. But having played boules on many occasions, I was excited at the prospect of learning to play boccia, which has fewer physical demands. I never regretted it one bit! There was a vast difference in the abilities of the people who attended, but everyone was accepted and each person's game was adapted according to their needs. There was never any pressure to attend every week and with a pay-by-session system, there is no upfront payment and subsequent loss of money if sessions aren't attended. I very rarely missed a session as I loved it so much! My husband was welcome to stay with me and we very quickly formed bonds with many of the other players and also the coaches.

COVID put a stop to all of it, yet the friendships formed from it have continued throughout and we have had social gatherings when permitted and safe, showing that wonderful things came from being brave enough to just go to that very first session. I am not a particularly confident person so I feel anyone can do it if I can. I would strongly urge others to give things a go. One hour out of your life can change so much and if, for whatever reason, it's not right for you, there's probably something else that is!

Finding accessible place to visit

Planning visits and days out can take a bit of work but there are plenty of places that provide access for people with disabilities or mobility issues. Below are some examples of websites that give information about accessible places.

Accessible Countryside for Everyone (ACE) provides information and promotes accessibility to the English countryside for people with mobility issues, their carers and families. You can follow ACE on Twitter at @access4everyone to get up-to-date news about events. Its website has a specific Essex page: www.accessiblecountryside.org.uk/essex.

AccessAble has access guides with detailed information gathered by trained surveyors who check inspect and review every place in person. The user community decides which information they collect. You can use the information to plan where to go to or use the app or website while you are out and about. It has a specific Essex page on its website: www.accessable.co.uk/essex-county-council.

Accessible Travel Club is a Facebook group where questions can be asked about accessible travel anywhere in the world: www.facebook.com/groups/AccessibleTravelClub.

Disability Horizons' website has lots of interesting and fun ideas for getting out and about, such as information about all-terrain wheelchairs, travel accessories for disabled adventurers and preparing for a festival as a wheelchair user: <https://disabilityhorizons.com/category/travel-and-disabled-holidays>.

Euan's guide is a website with lots of reviews, written by people with disabilities, about the accessibility of a variety of places. You can use it to look for local places to visit or plan a trip away. The guide also provides access information about events and venues, such as sports stadiums. You can sign up to the newsletter to receive the latest reviews: www.euansguide.com.

The **Rough Guide to Accessible Britain** aims to give inspiration and practical advice to help plan a day out. As well as covering physical access, it includes information about other facilities such as quiet spaces, small group tours and free admission for carers. More information here: www.motability.co.uk/news/rough-guide-to-accessible-britain.





Many places that receive visitors have wheelchairs available to hire, which can be helpful if there's a lot of walking involved in the visit or you're feeling less mobile than usual. Some venues hire out motorised vehicles for wheelchair or mobility scooter users. These are likely to be better suited to the terrain of the venues and may also save you the job of cleaning mud off your own wheelchair or scooter –and car boot – once you get home! You may need to phone, before you set off, to reserve a wheelchair or scooter.



Accessible toilets

And lastly, but often most importantly, accessible toilets!

There is information about where to find them and how to apply for a **RADAR** key at this link: www.essex.gov.uk/disabled-toilets-and-changing-facilities.

To use the toilet in safety and comfort, many people need to be able to access a **Changing Places** facility, which has more space than an accessible toilet and additional equipment, such as a height-adjustable changing bench and a hoist.



The Changing Places website has a search facility and also a list of motorway service stations:
[www.changing-places.org/
find_a_toilet.aspx](http://www.changing-places.org/find_a_toilet.aspx).





My notes

Use this page to make a note of anything you're interested in following up from this section.
Do this in whatever format works best for you to make sure your thoughts and ideas don't get lost.



Acknowledgements

This guide was commissioned by Essex County Council and written by Christine Towers at Together Matters (www.togethertomatters.org.uk). An Expert Reference Group was set up at the start of the work to shape the guide.

The Reference Group met regularly and members brought their knowledge, skills and time to contribute content ideas, personal stories and thoughts on how to make the guide relevant to a diverse audience.

In addition, other people with physical disabilities gave ideas about information to include, commented on drafts and wrote about their personal experiences.

A number of practitioners brought specific knowledge and expertise from their work in Essex.

Particular thanks to:

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- Karen Mutsatsa, Expert Reference Group member
- Leslie Lodge, Expert Reference Group member
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- Care managers in the physical and sensory impairment teams in the south and west of Essex.

Thanks also to the many information, advice and support organisations whose websites and guides provided invaluable ideas for developing the content. Particular thanks to Disability Rights UK and the Equality and Human Rights Commission.

Feedback

Please let us know how you have used the guide, ways in which it has been helpful and suggestions to improve it. We are also keen to hear people's stories about how it gave support with shaping the future so that stories, ideas and learning can be shared. Please send any feedback to [**christine@togethertomatters.org.uk**](mailto:christine@togethertomatters.org.uk).

Disclaimer

Every effort has been made for the information in this guide to be as accurate and up-to-date as possible. If you see something that needs amending, please email [**info@togethertomatters.org.uk**](mailto:info@togethertomatters.org.uk).

January 2023
© Christine Towers



Map of Essex

Essex County Council is divided into twelve local councils, which are referred to in the guide. Some services and organisations are Essex-wide, whilst others will vary depending on where you live.

Further copies of this guide can be downloaded from www.essex.gov.uk/shaping-my-future

Find out more about Together Matters at www.togethertomatters.org.uk

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