

Shaping My Future

A guide for people with
physical disabilities in Essex

Section 2: Family, friends and connections



This is the second section of a six-part guide. For details about accessing the full guide and the other sections go to the back page.



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



**2. Family, friends
and connections**



3. Learning and working



4. My home



5. Health and wellbeing



6. Going out and about

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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

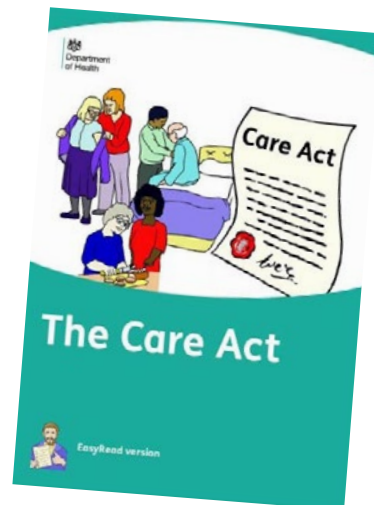
Social connections are an eligible need

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.



Information about Shaping My Future

Shaping My Future 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, with links to both national and local services and organisations. In the introduction to the full version there are tips to get the most from using the 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

Acknowledgements

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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@togethermatters.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@togethermatters.org.uk.

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