

Shaping My Future

A guide for people with
physical disabilities in Essex

Section 5: Health and wellbeing



This is the fifth 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

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.



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

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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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