

LEARNING DISABILITIES TOOLKIT



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Every person with a learning disability is unique, and so your role as a carer will be unique too. What your caring role looks like will depend on the individual needs of the person you care for, and the support they need to maintain a good quality of life. Caring for someone with a learning disability can often be a lifelong role, and so it is important that you have access to the right information, advice and support to carry out your role as fully as you can, whilst still meeting your own needs long term.



WHAT IS A LEARNING DISABILITY?

A learning disability is a condition which affects the way someone learns new skills and processes new information. Most people are born with a learning disability, or develop a learning disability in their early years, although some people might be diagnosed much later than that. A learning disability can be classed as mild, moderate, severe or profound. Someone may have a very mild learning disability, meaning they can live independently with minimal support, whilst others may have a more severe learning disability and need full-time care. Living with a learning disability can affect someone's ability to look after their own wellbeing, access employment, maintain relationships and live independently.

WHAT IS A LEARNING DISABILITY?

Sometimes, but not always, people with other conditions like Down's syndrome, cerebral palsy or epilepsy can also have a learning disability. The same is true of autism; sometimes people with autism may have a learning disability, but autism is not a learning disability in itself.



Profound and multiple learning disability (PMLD) is when a person has a severe learning disability and other disabilities that significantly affect their ability to communicate and be independent.

[MenCap - What is a learning disability?](#)

[MenCap - Profound and multiple learning disabilities](#)



CARING FOR SOME WITH A LEARNING DISABILITY



What does caring for someone with a learning disability look like?

If you are caring for someone with a learning disability, your role will depend on the specific needs of the person you care for, and because a learning disability is a lifelong condition, this can mean they will need support throughout their lifetime. The level of support you offer can vary based on their individual condition, you might be offering minimal support so the person you care for can be as independent as possible, whilst helping them with practical tasks like organising their calendar, filling in forms, remembering specific activities, or managing their money. Alternatively, if the person you care for has a more severe or profound learning disability, you may be providing support with all aspects of their life, including personal care and support with communication and mobility.

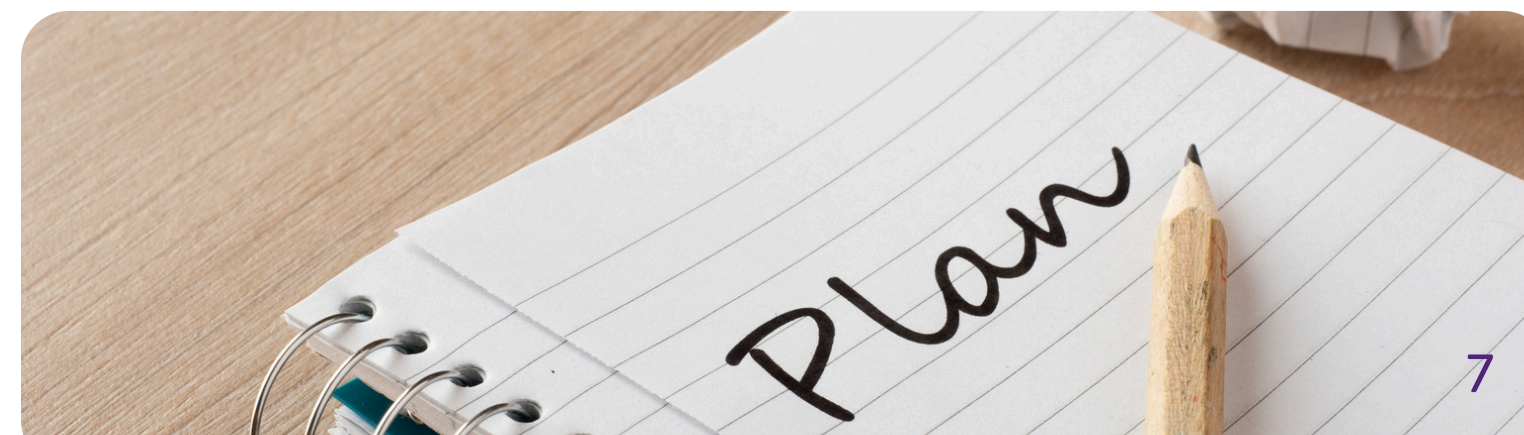
CARING FOR SOME WITH A LEARNING DISABILITY

Accessing support for the person you care for

You might begin by having an open and honest conversation with the person you are caring for, discussing their daily challenges and identifying areas where home adaptations or specialised equipment could make a significant difference.

If adaptations to their home, specialist equipment or extra personal care to live as independently as possible is required, the person you care for is entitled to request a Care Needs Assessment from their local authority, or you can do this on their behalf. Following an assessment, a care plan is drawn up with the specific needs of the person you care for in mind. This means they will be connected with the most appropriate people and places tailored to their needs. This might include peer support groups, places where they can enjoy their favourite activities, or support with accessing education or employment.

[West Sussex Council -How to get adult social care support](#)



PLANNING FOR EMERGENCIES

Creating a communication plan for use in emergencies in collaboration with the person you care for can help everyone feel more confident and secure. You might have emergency contact numbers in an easily accessible place or programme those numbers into their mobile phone. A Carers Emergency Contact Card can give you some peace of mind if you were to experience an accident or sudden illness. For times when the person you care for is out and about, you might want to encourage the person you care for to carry an ID bracelet or an ID card that communicates information about their condition and specific needs simply and discreetly.

You can also book a free Safe and Well check with your local Fire Service. A team will come to visit, providing the person you care for with actions and advice to help make their home as safe as possible. They can also provide specialist equipment and draw up the best fire escape plan for use in case of an emergency.

[Carers Support - Carer Emergency Contact Card](#)

[Sunflower - Hidden Disability](#)

[This is me - My Care Passport](#)

[West Sussex Council - Home Safety](#)

Planning for when/if you are no longer able to care

Whilst it might be difficult, it is also important to consider what would happen if you were unable to provide care, either in the short or long term, or after your death. Having a conversation with the person you are caring for about their needs and desires if you were not around to support them can bring peace of mind to everyone involved.

Drawing up an advance care plan will also ensure the person you care for has a say in their future care, and regarding any support they might need when you are not there yourself.

[MenCap - Webinars](#)

[Thinking Ahead Guide – a planning for the future guide for families](#)



ACCESSING SUPPORT FOR YOU AS A CARER

We offer a range of services to carers, including emotional support, one to one discussion around your needs, signposting and referrals to relevant services as well as access to our monthly online learning disabilities carer groups, skills training, carer events and help with accessing funding and grants.

Our dedicated web page offers details of our services:

[Carers Support - Learning Disabilities](#)



Especially for families and unpaid carers of adults with learning disabilities, Carers Support have a monthly online group on 2nd Tues of month, at 10.30am or 5.30 pm.

This is a friendly group to meet other carers, share experiences and support for each other.

We also have a regular [LD carers newsletter](#).

Just email us at info@carerssupport.org.uk or call 0300 028 8888 if you'd like to be added to the mailing list.

For parent carers of children with a learning disability, you can also access up-to-date information:

[Reaching Families](#)

[West Sussex Parent Carer Forum](#)



ORGANISATIONS AND SERVICES

Support for you as a carer is also available through these organisations:

Organisation/Service	What they do	Link
Mencap	<p>Leading UK charity for people with a learning disability and their families and carers. Their website contains information, guidance and resources on a host of different topics. They also have a helpline and an active online community for peer support, and regular 'Planning for the Future' webinars.</p> <p>Mencap – Learning Disability Helpline (for family/friend carers as well as people with a learning disability. Phone: 0808 808 1111 from 9am to 5pm, Monday to Friday. Email: helpline@mencap.org.uk.</p>	<p>Webinars</p> <p>Mencap</p>
Challenging Behaviour Foundation	<p>Information, support, advice and workshops for families of people with learning disabilities and challenging behaviour. Their website has lots of information and resources around behaviour and a Family Support Service offering peer support, carers email network, Carer-Catchups, the CBF Family Forum and 'Listening Ear' Calls.</p>	<p>Challenging Behaviour Foundation</p>

Organisation/Service	What they do	Link
BILD - British Institute of Learning Disabilities	<p>BILD offer a variety of training and coaching for services working with and for people with learning disabilities and have a variety of resources on a range of relevant topics, including Positive Behaviour Support.</p>	<p>BILD</p>
Scope	<p>Scope is the disability equality charity in England and Wales. They aim to provide practical information and emotional support when it's most needed, including online advice and support, a telephone helpline, family services and online community.</p>	<p>Scope</p> <p>Scope Family Services</p>
HFT – Family Support Service	<p>HFTs Family Carer Support Service is a free information and support service for family carers of someone with a learning disability, who is over 16 years old and living in England. They offer support via telephone or email and resources designed to simplify complex topics and workshops.</p>	<p>HFT – Family Support Services</p>

ORGANISATIONS AND SERVICES

Organisation/Service	What they do	Link
Foundation For People with Learning Disabilities	For information on circles of care, LD and mental health and the Thinking Ahead guide, developed for families and people with learning disabilities to help talk about and plan for the future. Particularly helpful in preparing for times of change such as leaving education, moving home, looking for new opportunities and emergency situations	Foundation for People with Learning Disabilities Thinking ahead
Ability Net	Ability Net help children and adults with disabilities to use IT, computers and access the internet. Offer free technology support.	Ability Net
Disability Rights UK	Run by and for disabled people. Promotes equal participation for all, providing information, advice, resources, helplines and campaigns on independent living and careers.	Disability Rights UK
GP Surgery Learning Disability register	The register is a list of all the people with a learning disability that the surgery looks after. Being on the register means that the GP surgery should offer things like an annual health check, certain vaccinations, easy read letters or extra time in appointments.	Learning Disability Register

Organisation/Service	What they do	Link
West Sussex Disability Register (Ages 0-25)	WSSCC collects information about children and young people age 0-25 with Special Educational Needs and Disabilities (SEND) to help plan and deliver their services. Benefits of being on register are: <ul style="list-style-type: none"> • Help influence services and plan events. • Receive regular eNewsletters with local events, activities and information. • Access discounts on local and national attractions – via the Max Card 	WSSCC Register Max Card
Community Hubs	Community and outreach services delivered by different organisations across West Sussex. Check sites for individual services, locations and drop-in sessions. For advice/support on many issues (wellbeing, activities, work, benefits, getting funding support). Also, Groups, online and phone support for cared-for person and advice for families/carers.	Arun & Chichester Connects Support - Aldingbourne Trust Worthing-Buddys Social Hub and Information Centre MidSussex Signposts (Mid Sussex) Ltd Horsham & Crawley About Outreach 3 Way Dimensions
West Sussex Learning Disability Health Facilitation Team	A team of nurses who are specialised in facilitating health care for people with Learning Disabilities.	Health Facilitation Team

ORGANISATIONS AND SERVICES

Organisation/Service	What they do	Link
Sussex Health and Care	Information about Health and Care Services including Annual Health Checks, Care Passport and Easy Read resources.	Sussex Health and Care
Annual Health Check	Annual Health Checks are for everyone over the age of 14 who is on their doctors learning disability register. The check should be carried out once a year by the persons doctor or a nurse. It can help people stay well by talking about their health and finding problems early so they can be sorted out. You do not have to be ill to have a health check. Everyone having an Annual Health Check should be given a Health Action Plan.	Mencap – Annual Health Check Guide (easy read): Annual Health Check Guide for family/friend carers
Community Learning Disability Team	CLDTs are multidisciplinary teams who support adults with a learning disability and their carers. Specialist health professionals, including speech and occupational therapists provide support to people with a significant learning disability who, even with reasonable adjustments cannot access generic services and/or require specialist health assessment and treatment.	Information about what CLDT do and contact details
My Care Passport (Also called a Hospital Passport)	A document that tells medical staff about a person's healthcare, their learning disability, how they like to communicate and how to make things easier for them to feel comfortable. Can help with contingency planning.	This is Me – My Care Passport Booklet (PDF)

Organisation/Service	What they do	Link
Health Screening Information	Sussex Health and Care website containing information about annual health checks, cancer screening, and other health screening for people with learning disabilities. Also, information for family/friend carers, easy read information and short films.	Support for people with a learning disability - Sussex Health & Care
Easy Health Website	An online library of accessible health information with simple words, clear pictures and films.	Easy Health
Mental Health and Wellbeing	People with learning disabilities can be more likely to experience poor mental health. Mental health and wellbeing should be discussed during annual health checks. Sussex health and Care also have a Feeling Down Guide in easy read format with information about how to keep feeling well, and what to do when you are worried about mental health.	Feeling Down Guide Resources from Mencap CSWS - Mental Health Toolkit
Healthy Brain and memory assessments	People with learning disabilities are more likely to get dementia. So, NHS in Sussex now offer Healthy Brain and Memory Assessments to help find the early signs of dementia. A healthy brain assessment is a screening program for individuals with Down syndrome who are over 30 years old. A memory assessment is a specialist assessment for the older population of people with a learning disability who are experiencing signs and symptoms of dementia.	Healthy Brain Assessment Leaflet Memory Assessment Leaflet

ORGANISATIONS AND SERVICES

Organisation/Service	What they do	Link
STOMP	STOMP stands for 'stopping over medication of people with a learning disability, autism or both with psychotropic medicines'.	Short video from our Sussex Specialist Pharmacist talking about STOMP And resources if you are concerned: STOMP - easy read (PDF)
West Sussex Adult Services	For Adult Social Care Support and Assessment	Adult Services
Life-long Services Transition Team	Guide to moving from having support from Children's Services to Adult Services. For people who have a lifelong disability and eligible social care needs, acquired before the age of 25 years. This can include physical, sensory, learning disabilities and autism. These people will typically have grown up with their disability, which has had lifelong effects.	Life-long Services Transition Team
West Sussex Connect to Support	Information and advice to help with independence and wellbeing with links to services, products, groups and activities.	Connect to Support
West Sussex Local Offer	You can use this website to find out about services, support groups and leisure activities that are available in West Sussex for children and young people (age 0-25) who have special educational needs and disabilities and their families.	Local Offer

Organisation/Service	What they do	Link
Independent Lives	Information, care and support services for people with care needs, including personal budget support and payroll service. And a separate website devoted to the management of Direct Payments and the recruitment of personal assistants.	Independent Lives PA Pages
Reaching Families	Provide information, training, support and groups for parents and families of children and young people (up to aged 25) with SEND (Special Educational Needs and Disabilities) in West Sussex. They also have a comprehensive Making Sense of It All guide to SEND and directory of services and support – available to download or hard copy of book.	Reaching Families Making Sense of it all - Guide
West Sussex - Blue Badge Service	Government guidelines allow people with visible and non-visible disabilities, including learning disabilities, to apply for a Blue Badge.	Blue Badge For a postal application call 01243 777653
Disabled Persons Rail Card	There is a cost for this, but people can get up to a 1/3 off rail travel.	Rail Card
West Sussex Disabled Person Bus Pass	For free/discounted Bus Travel	Disabled Person Bus Pass

Organisation/Service	What they do	Link
Changing Places toilets	Fully accessible toilets with an adult changing bench, hoist and space for carers – see website for locations.	Changing Places
Sunflower Lanyard Scheme	Businesses taking part in this scheme offer sunflower lanyards to people with hidden disabilities. Staff are trained to offer people extra assistance.	Sunflower
Supported Employment	Provide employment support to individuals in West Sussex with lifelong disabilities, physical and sensory issues, acquired brain injury and those who are carers.	Supported Employment
Respite and short breaks Short breaks are incredibly important - caring, even for someone you love, can be an exhausting experience, which can leave you little time for yourself or other members of your family.	West Sussex Care Guide : Information about support and services in West Sussex to stay well and remain independent in the home, plus a list of organisations that provide care in the home, Day Care services, supported/assisted living and care homes for respite and short breaks.	Care Guide Childrens Services - Short Breaks & Respite

Contingency Planning

As carers we like to think that we will always be there when needed but sometimes this is not possible. This could be for many reasons, including becoming unwell, a domestic or family emergency or changes to your usual work routine, such as a need to travel away from home/work base. A Contingency Plan is there so that the person you are caring for is supported at the earliest opportunity and you have peace of mind that there is something in place.

Download our contingency planning form at www.carerssupport.org.uk/contingency-planning

Benefits advice

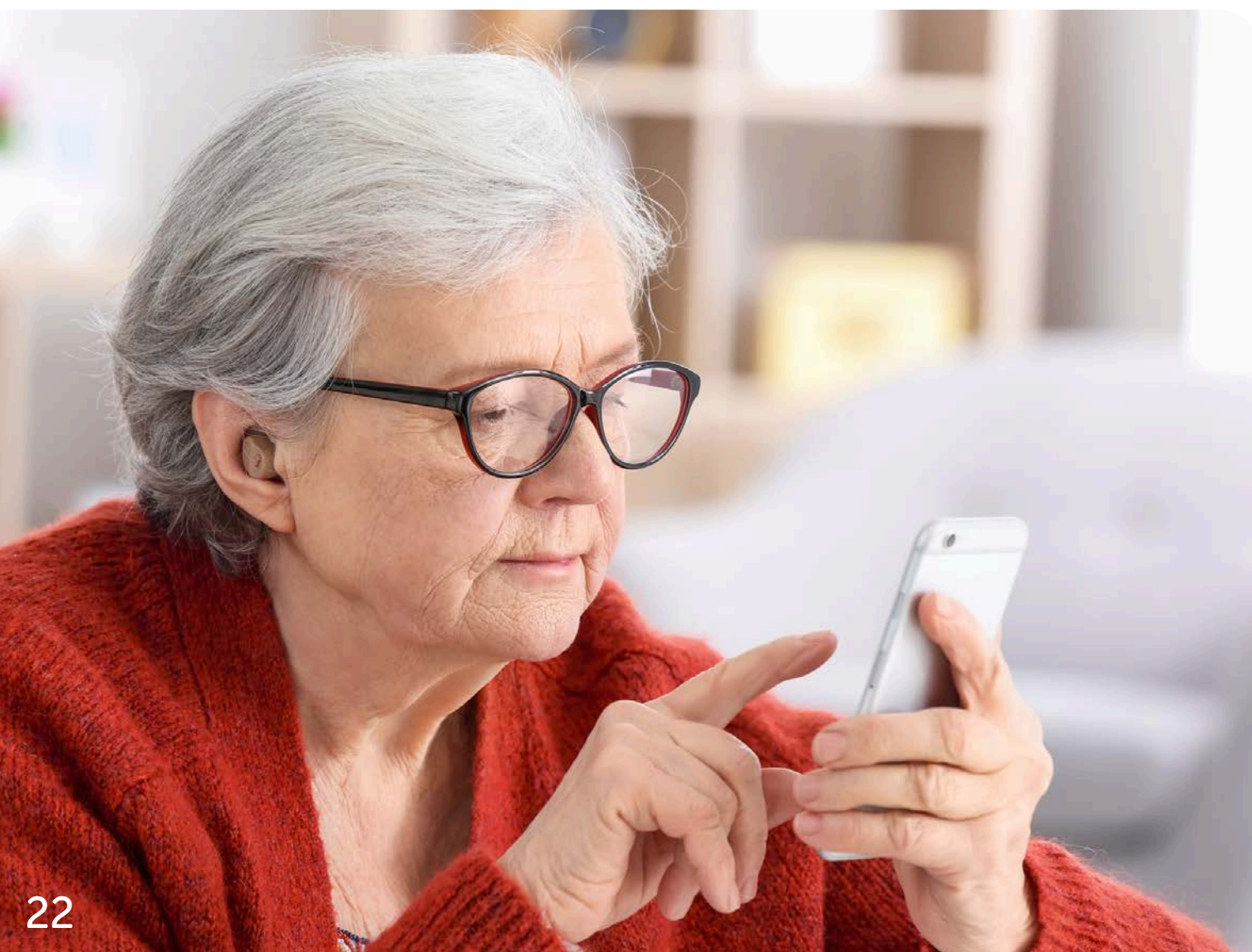
A recent Carers UK survey revealed that 68% of carers regularly use their own income or savings to pay for care or equipment for the person they care for. It may improve your financial situation if you have an understanding of the benefits you are entitled to. We offer a one to one benefits service.

Find out more and book an appointment with our adviser at [Carers Benefits & Toolkit Services](#) | [Benefits For Carers](#)

Digital champions

If you feel you are missing out on all you should because you do not have access or are not confident about using the internet you can ask for support from one of our digital champions, who will gently support you to get access and confidence for shopping, online meetings and other services you would like to use.

Call us on 0300 028 8888 and ask to be referred to a champion.



Emergency/discount card

You may be concerned as to what will happen to someone you provide care and support to, should you be involved in an accident or be suddenly taken ill yourself. Our Carer Emergency Contact Card (CECC) offers peace of mind to family and friend carers and supports them to develop a carer contingency plan, in advance, in case of an accident or an emergency. The card also doubles up as a carer discount card, giving carers a range of exclusive offers and discounts within West Sussex.

Apply for your card at www.carerssupport.org.uk/carers-emergency-contact-card/

Grants, funding and equipment.

Carers Support offers resources to improve carers' wellbeing, including a list of low-cost equipment with links. The Carer Health and Wellbeing Grant can support you to purchase items or services to improve or maintain your health and wellbeing. There is a criterion for this fund and more details can be found at <https://www.carerssupport.org.uk/grants-funding-and-equipment/>.

Carer Assessments

Carers Support provide Carer Assessments on behalf of West Sussex County Council. A Carer Assessment carried out by Carers Support West Sussex is for adults caring for another adult.

A Carer Assessment aims to explore your needs as a carer to ensure you receive the appropriate assistance and resources for your vital role, and determines what help and support can be provided to you, which may include access to services provided by Carers Support West Sussex or services offered by the Council, as well as information about other support which could benefit you or your family. There is more information about carer assessments at <https://www.carerssupport.org.uk/carers-assessments/>.

