



“Supporting Me”

A guide for Personal Assistants
employed by or for someone
with a learning disability





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1. Introduction

You have been employed to support me to live my life as I choose. I may employ you through my Direct Payment that I manage myself, or people close to me may employ you on my behalf through my individual/ personal budget.

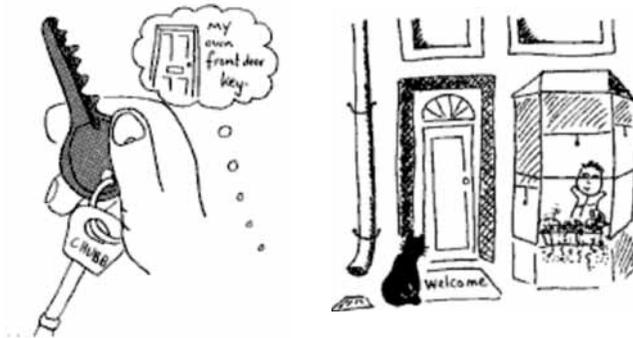
This guide contains information about what it means to have a learning disability and how to provide good support. Not all of this information may apply to me. Please take time to find out what does.

There is a copy of this guide that can be tailored to suit me. My photos can be added to it. The local Independent Living Advice Service has this. (See back page.)



Respect

It's important that we get on well, and this is more likely if you treat me, my family and my friends with respect. Please respect the choices I make, my culture and the lifestyle I have chosen for myself. Don't impose your lifestyle, choices, opinions or beliefs on me.



Treat my home and possessions with consideration. Don't assume that you can do things in my home without checking.



Whilst you may encourage, support, advise and guide me, please don't be 'bossy'. I am an adult and you cannot (and should not try to) **make** me do things.



Remember it's my life not just your job.

Don't 'gossip' about me to your friends and please get my permission (or the permission of those close to me) before you give other people personal information about me.



Getting to know me

It's really important that you get to know me. Take time to find out what I like, need and want. Don't assume. If I can't tell you myself, ask the people close to me. I may have a person-centred plan that will give you some useful information about my preferences, abilities, support needs and the things that I want to achieve in my life. If this is available to you, make sure you read and follow it.



2. Having a learning disability

I have a learning disability. Everyone with a learning disability is an individual with their own strengths, abilities, personalities, needs and aspirations.

Having a learning disability means that I may find it more difficult to learn, understand and remember new things. I may need support with day-to-day activities, communication, social situations and keeping safe. I have always had my learning disability (or I have had it since I was a child). It is not an illness. It has been caused by the way my brain developed before, during or after my birth. With the right support I can lead a full and active life.

3. Communication

We will need to communicate with each other really well. You may have to learn new ways of communicating and be prepared to change the way that you communicate with me. Check what I am able to hear, see and understand; adapt your communication to this.



One thing you may need to change is how you speak.

Don't talk too much!



I probably don't understand as much verbal communication as you think I do. Lots of 'chatting' may not help me to get on with my life. It may even be distracting and stressful for me, especially if you talk about yourself too much.

I may find it more helpful at times if you show, guide and help me to be involved in the activities in my life rather than just talk to me.



Verbal communication

Tips on talking to me so that I understand:

- ⇒ Keep your words simple and specific to the activity we are doing.
- ⇒ Don't be afraid to remain silent if no words are needed.
- ⇒ Speak slowly and clearly and stress the keywords.
- ⇒ Use an ordinary intonation – don't use a 'sing-song' voice as this sounds patronising.
- ⇒ Don't talk to me as though I were a child.
- ⇒ If I can respond to them, ask open questions – ones that need more than a short factual or yes/no answer.
- ⇒ If I struggle with open questions, ask closed questions (e.g. "tea or coffee?").
- ⇒ Find things to talk about that interest me.
- ⇒ Start a conversation with a comment, rather than firing questions at me. Have a conversational focus (e.g. a photo).

Helping us communicate well

It may take time for you to get to know and understand me. Here are some general communication tips that will help:

- ⇒ Get my attention before you start.
- ⇒ Make sure I can see your face and we have good, comfortable eye contact (but don't insist on eye contact if I don't want it).
- ⇒ Watch my body language, gestures and facial expressions.
- ⇒ Your body language, gestures and facial expressions need to support your verbal communication.
- ⇒ Give me time to understand and to respond – don't leap in and finish my sentences or anticipate what I am going to say. Only speak for me if you really have to.



- ⇒ Check I have understood (e.g. ask me to tell you what I have understood). Do not assume that 'yes' always means I understand or agree with you.
- ⇒ Give me one piece of information at a time.
- ⇒ Use a calm and quiet environment.
- ⇒ Demonstrate where possible.
- ⇒ Adapt information and present it in different ways if this helps.
- ⇒ Repeat things several times (perhaps on different occasions) if it helps me.
- ⇒ Humour may be important to me but only use humour that I can understand and can take part in. Avoid sarcasm and never ridicule me.



Communication tools

I may use different things to help me communicate e.g. pictures, photographs, symbols, objects and signing.

Use and value all the different communication tools I have. It is disrespectful if you don't. There's no point in having them if they are not used.



If I have a Communication Passport or book please make sure you follow what it says.



4. Supporting me to live my life



I may employ you to support me to do my daily living tasks, such as cooking, cleaning, shopping, laundry, budgeting. I should be involved in everything that happens in my life; always think about the best way to do this.



If you are supporting me with my personal care (washing, dressing, using the toilet, eating and drinking etc...) please do so in a sensitive and respectful way that maintains my dignity. Be patient; don't rush me.



My relationship with you is important. If I like being with you I am more likely to take an active part in the things we do together.

Help me to have meaningful and fun things to do, be healthy and achieve my dreams.





What type of support do I need?

The support you give me must be at the right level. Too much support and I may become dependent on you and de-motivated. Too little support and I may not experience success – this may damage my confidence and make me reluctant to try this activity (or other new activities) again.

Ask me, or find out, how I want you to support me.



A good way to work out how much support I need could be to start by **asking** me to do something (e.g. “can you put the kettle on?”). If I’m not able to respond to this prompt, then **show** me what to do. If I’m still unsure what to do or I don’t respond, then **guide** me with the task.

When I am tired, anxious or stressed, I may need you to help me with decisions and tasks more than at other times.





Engaging me

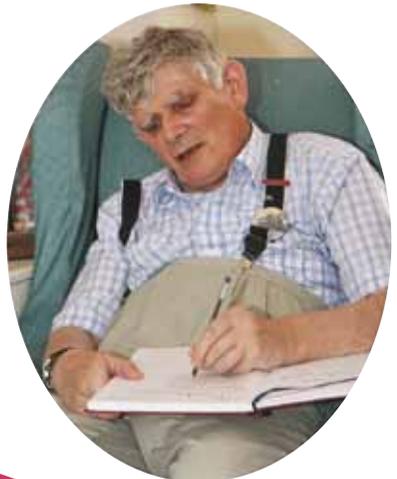
For me to be truly involved in my life I will need to be engaged in the activities we do together. If I am quite independent, this might mean that I take part in the activity. If I am less able, this might mean that I look captivated, interested or absorbed (for a moment or for longer). It is important that you understand when I am engaged in something and when I am not.

I won't necessarily need to be engaged in something all the time from start to finish. This is ok and will depend on my needs. You may be **helping** me with parts of an activity or you may be **doing** the parts that I am initially anxious about or find difficult to do.



Getting organised

It may be difficult for me to understand time and to plan ahead. I may not understand words like today, tomorrow, next week. I may have difficulty in working out sequences of events and predicting what is happening next. This might make me anxious and upset.



Having choice and control over what happens and when is important to all of us. We all like to be able to look forward to things, but I may need help to know what is coming up. Try to explain time, sequences and events as simply as possible. Use timetables and planners (with pictures etc) to help me know what is happening and when. This may help to lessen any anxiety and make life more predictable.



Remembering things

We can all have trouble remembering things but my learning disability may make this more difficult. For example I may find it more difficult to remember information I have only been given verbally. Be patient and prepared to repeat and explain things. There may be some things that I will always need to be reminded about.



The following tips may help:

- ⇒ Break information into ‘chunks’ and only give me a little at a time.
- ⇒ Give me a cue to help me remember my intention to do something – e.g. “After breakfast you said you wanted to...”
- ⇒ Help me to use diaries, calendars and timetables. Adapt these so that I can use and understand them (e.g. use pictures).
- ⇒ Help me to write notes, make lists.
- ⇒ Use the alarm on my watch or mobile phone as a prompt.
- ⇒ Help me to put things somewhere I can’t miss them (e.g. by the front door).
- ⇒ Help me to get into good habits (e.g. always put keys in the same place).
- ⇒ Check what I have remembered/understood.



5. Helping me to learn

I may take longer to learn new things and need more time and repetition.

I may find it harder to concentrate on things for the same amount of time as you. I may be more easily distracted or get tired more quickly. I'm likely to find it harder to concentrate if I am uncomfortable, tired, bored, uninterested, or I am finding the activity confusing or hard to do.



To help me learn:

- ⇒ reduce possible distractions
- ⇒ help me get organised and have ready the things I need
- ⇒ divide the activity into segments or shorter tasks
- ⇒ show me a model of the end product so I know what I am aiming for
- ⇒ show me how to do things as well as telling me
- ⇒ let me do things in my own time and pace (don't rush me!)
- ⇒ take a break or be prepared to stop if I am getting too tired or frustrated.



When we are doing a task or activity, try to do things the same way each time. This will be less confusing for me and will help me to learn. It might be useful for you to work out with me the exact order I need to do an activity, including the words/prompts we use, and write it down, so we can both follow it.



6. Helping me to have relationships in my life

It is important to have people in our lives that care about us, and people we can do things with. You might help me to have good relationships, to find new friends and keep the ones I have already. I may need to learn new skills to do this. You may be able to help me to develop a 'Circle of Support'; people who will help me to live the life I want.

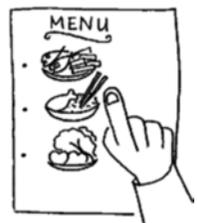


7. Choices and decisions

I have the right to make choices and decisions and to have control over my life and what happens to me. This right is backed by a law – the Mental Capacity Act 2005.



If I am able to make decisions for myself, respect my right to do so, even if you don't agree with the decision I then make, or think the decision is unwise. Please don't assume that just because I have a learning disability I don't have the ability to make decisions.



Support me to make as many decisions as possible for myself. This might include:

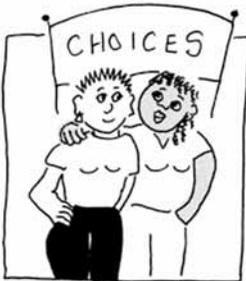
- ⇒ giving me time to think about the decision
- ⇒ presenting the information I need in a clear and simple way
- ⇒ explaining the options available to me and the consequences of different decisions several times and/or in different ways
- ⇒ using different communication aids (e.g. pictures, symbols, film, audio tapes etc)
- ⇒ trying different times of day or a different place in which to talk about the decision etc.
- ⇒ checking my understanding by asking me to tell you what I have understood.



If I am not able to make a decision, then you might need to make the decision or act on my behalf. Anything you do must be in my best interest and be the option that is least restrictive of my human rights.

Try to think about what I would decide if I could make the decision myself.

The Mental Capacity Act has a 'Code of Practice' that you are legally required to follow if you are making a decision on my behalf (see page 39).



Help me to take risks safely

We all learn and develop by taking risks. I want to be able to try new things. Some of the choices I make may involve risks. This is ok. Making mistakes is often how we learn to do things better next time. I need you to support me to take reasonable risks without putting myself (or anyone else) at undue risk of harm.

I (or the people close to me) will tell you if there are any situations where I need particular support to keep safe (e.g. crossing roads, in the kitchen or bathroom etc). If I have a support plan, this should give you details of the support I need.



Speaking up for me

Although you should always support me to speak up for myself, there may be times when you need to speak up (advocate) on my behalf. This is very important if my rights, choices and wishes are not being respected or I am being discriminated against. Please do this in a way that helps me to keep a good relationship with the person/people concerned, if possible.



(Photo from Southdown)

8. Keeping safe



I have the right to live my life free from abuse (this includes bullying).

There are some things that can place me at particular risk of abuse. These may include; being more dependent on others for help, finding it difficult to communicate what is happening, not understanding that it is not ok or that it can be stopped. Many people with a learning disability say they experience harassment when out and about.

Changes in my behaviour, the amount of money or possessions I have, my physical or emotional state or unexplained injuries are some possible signs that I am being abused or neglecting myself in some way.



If I tell you something or you see something that you think may mean I am being harmed, seriously neglecting myself or I am at risk of this, you have a responsibility to report your concerns.

Do not:



- press me for details
- assume someone else will report it
- contact the alleged abuser
- promise to keep what I have told you a secret.

Do:



- make a note of what you have seen or I have told you
- help me to preserve any physical evidence – or do so yourself
- report it – and tell me you have done so.

TO REPORT SUSPECTED ABUSE

If you witness abuse, or think someone may be abusing me, you need to alert Social Services and report your concerns. Do this by calling:

East Sussex: 0845 60 80 191

(Out of hours: after 5pm, at weekends, on bank holidays, call: 07699 391462)

West Sussex: 01243 777100

(Out of hours: after 5pm, at weekends, on bank holidays, call: 01903 694422)

Brighton and Hove: 01273 295555

(295550 if I have a learning disability)

(Out of hours: after 5pm, at weekends, on bank holidays, call: 07699 391462)

If I, or someone else, is in danger, you suspect a serious crime may have been committed, or I require medical attention, phone 999.

9. Useful information

Developing your skills

I am (or those close to me are) responsible for making sure that you can develop the skills and knowledge you need to support me. Much of this will come from me – as I (or those close to me) explain how I want things done. If you think it would be useful to learn more skills to support me better, talk to me (or those close to me). I can contact the following people for advice about training that may be available to you:

East Sussex: Brian Andrews tel: 01323 463114
email: Brian.Andrews@eastsussex.gov.uk

Brighton and Hove: Kevin Murphy tel: 01273 295279
email: Kevin.Murphy@brighton-hove.gov.uk

West Sussex: Gill Brady tel: 01903 839453
email: Gill.Brady@westsussex.gov.uk

It may be helpful for you to gain knowledge and skills in the following areas. Which areas are useful will depend on my needs, the hours you work and the tasks/activities you support me with.

- Person-centred approaches
- Communication and Makaton
- Active support and skills teaching
- Autistic Spectrum Condition
- Supporting people who can behave in ways that can be challenging
- Working with the senses
- Safeguarding vulnerable adults from abuse
- Choice and capacity



Some training providers run courses on these subjects. The council may run some free courses, other providers charge and we would need to work out if and how we can pay for this. You can also find out more by reading – e.g. looking at websites.

Useful websites

- **British Institute of Learning Disabilities (BILD)**
www.bild.org.uk
- **Mencap**
www.mencap.org.uk
- **Foundation for People With Learning Disabilities**
www.learningdisabilities.org.uk

- **Valuing People 2001 & Valuing People Now 2009**

(The government's plan for making the lives of people with learning disabilities better.)

www.valuingpeople.gov.uk

- **In Control** (a website promoting self-directed support)

www.in-control.org.uk

- **Mental Capacity Act 2005:** Dept of Constitutional Affairs
Easy Read version

www.dca.gov.uk/menincap/mca-act-easyread.pdf

- **Mental Capacity Act 2005:** Code of Practice
www.dca.gov.uk/legal-policy/mental-capacity/mca-cp.pdf
- **Circles Network** (a charity that promotes Circles of Support)
www.circlesnetwork.org.uk
- **Sussex Multi-agency Policy and Procedures for Safeguarding Vulnerable Adults**

These are available on the websites of each local authority. Type the above into the following search engines:

www.westsussex.gov.uk

www.eastsussex.gov.uk

www.brighton-hove.gov.uk



Learning disability

This Personal Assistant guide has been developed in 2009 by Southdown Housing Association on behalf of Sussex Skills for Care, with funding from Skills for Care.

Other guides/leaflets in the “Supporting Me” range and copies that can be tailored to me are available from the local Independent Living Advice Service:

Brighton & Hove: Federation of Disabled People
Tel 01273 229264 Email: bhfederation@bhfederation.org.uk
Website: www.bhfederation.org.uk

East Sussex: A4e
Tel: 01323 414674 Email: ilss@a4e.co.uk
Website: www.a4e.co.uk/ils

West Sussex: Independent Living Association
Tel: 01903 219482 Email: info@ilawestsussex.org
Website: www.ilawestsussex.org

Southdown

Southdown Housing Association
2 Bell Lane, Lewes, East Sussex,
BN7 1JU 01273 405800

www.southdownhousing.org

Southdown Housing Association is an exempt charity, Registered with the Tenant Services Authority/TSA, the Regulator of Social Housing (L1829) and The Industrial and Provident Society (20755R)



www.skillsforcare.org.uk

Part of the Sector Skills Council
Skills for Care and Development

Photos and images

Most photos are from Southdown. Black and white photos courtesy of Skills for Care. Drawings courtesy of Change (tel 01133 880011 www.changepeople.co.uk).