



“Supporting Me”

A guide for Personal Assistants
employed by or for someone
who may behave in ways that
others find challenging



Contents

- | | |
|---|--------------|
| 1. Introduction | 1-5 |
| 2. Why do people behave in more extreme or challenging ways? | 6-8 |
| 3. Supporting me to prevent challenging behaviour happening | 9-15 |
| 4. Supporting me when my behaviour becomes more challenging | 16-32 |
| 5. Keeping safe | 33-34 |
| 6. Further information | 35-38 |

The photos and images in this guide may not be reproduced in any other format without permission.

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 is for Personal Assistants (PAs) who support someone who may behave in more challenging ways when they are anxious, stressed, frustrated, agitated, and/or angry. It may be useful for PAs supporting some individuals with a learning disability, Autistic Spectrum Condition, dementia or some mental health needs.



This is not a 'stand alone' guide to supporting me. It focuses on how to work positively with me to reduce or respond to more difficult behaviour. There will be lots of other things you will need to know to help you support me well.

Not all this information may apply to me. Please take time to find out what does.

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



Respect

It's important that you treat me, my family and friends with respect. Please respect the choices I make, my culture and the lifestyle I have chosen for myself, even if these are very different from your own. 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, needs, things that I want to achieve in my life and how to support me. If this is available to you, please make sure you read and follow it. There may also be specific guidelines for you to use to help me with my behaviour.



2. Why do people behave in more difficult, extreme or challenging ways?

Challenging behaviour is a means of communication - it always means something!

It doesn't happen "for no reason". It is often about needing to get control in situations that are difficult or stressful.

Lots of things influence our behaviour:

- Our history and life experiences
- The environment
- Other people's behaviour
- How we understand what's going on
- Our ability to get what we want or need

All of us can behave in ways that others find challenging at times, particularly when we are anxious, scared, distressed, frustrated, stressed, agitated and/or angry.

‘Challenging Behaviour’ is a term used to describe behaviour that people find challenging or difficult (e.g. hitting, grabbing, shouting, throwing things or self-injury).

Whilst someone may behave in challenging ways, they do not **have** challenging behaviour as a condition or diagnosis.



If we have difficulty making sense of what is going on or getting what we need in our life, it is likely we will use more challenging ways to communicate our wants, needs and emotions.

People who have the most severe communication difficulties may use extreme or challenging behaviour more often, because they have fewer other ways to express themselves.

Working out (with me if possible) what the behaviour means is very important.



3. Supporting me to prevent challenging behaviour happening

Your role

If I feel I am being supported well I am less likely to feel the need to behave in more challenging ways.

Help me avoid behaving in a challenging way, rather than just focusing on how to respond once I am.



Final 'triggers'

There is usually something that acts as a final “trigger” and provokes the challenging behaviour.

Triggers can be:

- a demand
- being told 'no'
- feeling scared
- not having control
- an internal sensation or sudden pain, a memory or thought
- being bored, not being given attention or being ignored
- an activity finishing or someone leaving.



Get to know what my triggers are and support me to avoid or cope with these.

Sometimes **you** might be the “trigger”! After a more difficult time, think about what you could have done differently and change your approach if necessary.



Communicate well with me

We will need to communicate with each other really well. You may have to learn new ways of communicating and be prepared to change how you communicate when you are with me (e.g. using signing, pictures etc). Your words, tone of voice, body language and facial expression need to communicate warmth and respect.

If you feel anxious or stressed when supporting me, your body language, facial expression and tone of voice may show this.



Support my choices and decisions – help me have control

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 law – the Mental Capacity Act 2005.



This right is backed by law – the Mental Capacity Act 2005.

The more choice and control I have, the less likely I am to behave in difficult or challenging ways.

Support me to make as many decisions myself as possible. If I find too many choices overwhelming, you might have to limit the options for me, particularly if I am anxious or agitated.





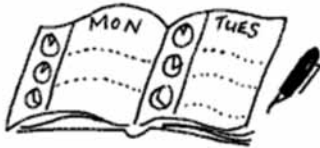
If I am not able to make a decision at the time it needs to be made, you might need to make the decision or act on my behalf. Any decision made or action taken must be in my best interests and the option that is least restrictive of my human rights.



Help me to plan ahead

Not knowing what is happening in my life or what is expected of me is likely to make me feel anxious and/or angry. I may find it particularly hard to cope when things change or my expectations are not met.

Help me to plan ahead and understand what is happening and prepare for future events (particularly for any changes).



Dealing with anxiety

We often have feelings of anxiety before we start to behave in more challenging ways. Help me to manage my own anxiety and learn better ways of coping with situations I find difficult.



4. Supporting me when my behaviour becomes more challenging

You also need to know how to support me when I do become more challenging.

When we become angry or upset our behaviour changes. This section describes what can happen when our behaviour escalates and how to support me.

Five stages of escalating behaviour

- 1 Calm.
- 2 Early signs that things are not OK.
- 3 Beginning to lose control.
- 4 Losing control.
- 5 Calming down.

Stage 1: Calm

I am calm, reasonably relaxed and seem my usual self. My behaviour is typical for me. It is important that I am supported in positive ways that help me to lead the life I want and feel secure and in control. This will prevent things becoming difficult (escalating).



Stage 2: Early signs that things are not OK

At this point there are warning signs that I am not calm and relaxed. There is a change in my behaviour and I may become restless, distracted, seem troubled, agitated or anxious. Generally it's clear that I'm not quite right and that I seem to be getting 'wound up'.



You can often stop the situation escalating at this stage. It's easier to help me now than when I am much angrier. Try and nip things in the bud!

- Try to empathise with me, acknowledge my feelings, show me warmth and let me know that you can tell that something is wrong.
- Be non-judgemental; don't criticise me.
- Check that I am not in pain, ill, tired, hungry, thirsty, too hot/cold or wet.
- Give me extra support and attention, or back off if that's what I want.
- Avoid audiences if possible.
- Remove any pressure on me.
- Remove or help me get away from the "trigger".
- Remind me of and help me to use any coping strategies.

If this hasn't helped me get back to my usual self, my behaviour may continue to escalate and you will need to change your approach.



Stage 3: Beginning to lose control

At this point I may appear highly anxious and begin to get angry, perhaps becoming confrontational and less rational. There may be a build up of tension. My behaviour might change dramatically – banging or throwing things, shouting, moving around quickly or erratically – as I begin to lose control.

This is your last chance to help prevent the situation getting out of control. You need to act confidently and be decisive. Even if you are not feeling calm you need to try to act as though you are. Don't Panic!

Due to my heightened emotional state I may interpret your communication as being controlling, critical or aggressive even if this is not what you intend.



Think about where you sit or stand.

Bear in mind that all of us need more “personal space” (this is the space all around us that we don’t like people coming into uninvited) when we begin to get anxious or angry.

- Keep out of my personal space and increase the space between us.



- Make sure you have a clear exit and can leave if you need to.
- Don’t stand blocking a doorway as this can appear threatening.

- Sit on a hard chair or the edge of soft furnishings or stand, so you can move quickly.



- Avoid cramped spaces or places with potential weapons (e.g. kitchens).



- Don't turn your back on me.

Think about your body language (facial expression, gestures and posture).

- Keep your body language relaxed and non-threatening. Avoid crossed arms or legs, don't clench your fists or jaw.



- Stand (or sit) at an angle to me. This is less threatening and makes you less of a target.



- Make eye contact from time to time, but avoid holding this as it can look threatening – consciously blink to stop you staring or looking scared.



- Don't make any sudden movements or gestures.
- Don't touch me as this might lead to physical aggression. If you physically restrain me you could be breaking the law.



Think carefully about what you are going to do or say.

- Talk less than you usually would. Speak slowly, calmly, simply and clearly. Use a relaxed, low tone. Never shout.
- Don't say 'no' and 'stop' or ask the question 'why'. These words can be provocative or sound controlling and may act as a trigger.
- Don't say "calm down" or "don't be silly" as this can also be provocative and suggests you don't understand.
- Offer me a simple choice and explain the consequences of each choice. For example "if you sit down I can look for the thing you've lost. If you don't I might need to leave".
- Tell me what to do, rather than what not to do (e.g. "please let go of me" rather than "don't grab me").
- Try to find ways to distract me or get me to do something more positive.

Stage 4: Losing control

This is the stage when my behaviour becomes the most challenging, as I lose control. I may shout, break things, make threats and/or be physically aggressive or violent.

At this stage, safety (yours, mine and anyone else's) is the most important thing. Keeping calm and not overreacting are essential.



Everything mentioned previously about where you stand and your body language applies at this point as well, but the best thing you can do now is:

- stop talking
- increase the space between us even more
- follow any agreed guidelines
- get out if you need to.

I may be angry, shouting (etc.), in a way that is scary but it may still be safe for you to stay in the same room. Being able to 'vent' feelings may be important to me. Try not to take this personally if it is not aimed at you.

It may not be safe for you to stay in the room if I become threatening or violent towards you.



Stage 5: Calming down

People don't usually behave in the more extreme ways just described for long. As they start to calm down from the more challenging behaviour they start to regain control and become more rational.

At this point I may be feeling tired and emotional. I might cry, apologise, withdraw, want to make things better or want to be alone.



At this stage you need to:

- reassure me. Praise me for calming down
- provide whatever support I need, give me space if that's what I want
- behave in a non-judgemental way, even if you might not be feeling like that.

Don't discuss my angry behaviour with me at this point, unless I want to.

Support me to continue to recover and calm down. This usually takes longer than it does to get angry – and much longer than most people think. This is a very sensitive time and I can become angry again very quickly if you are not careful.



When you support me through a challenging behaviour you may go through a ‘fight or flight’ response (a release of adrenalin and other chemicals) and experience some strong emotions (e.g. fear or anger).

After the incident you may feel tired, upset or exhausted. This is perfectly natural and may help you to understand some of my experience.

If possible, talk to someone else about what happened and try to get it out of your system. Try not to show me any difficult feelings you have about the situation or me and try not to let those feelings affect your support.



At a point afterwards

When I am completely calm, recovered and back to my usual self it will be helpful to review how you support me and things that might need to change. (This may not be the same day.) If possible talk to me about my coping strategies and help me to think of new ones. We may need a new agreement about how you support me in the future and/or what I will do myself.



It is not ok for you to 'tell me off' or 'punish' me for behaving in a challenging way. (This could include how you talk to me, withdrawing your positive attention or pleasurable activities.) This could act as a trigger now or in the future.



There may be some natural consequences of my behaviour. I may have broken something I like, and have to wait while it is mended until I can use it again. I may not have got what I wanted. I may not be able to go back somewhere (e.g. a shop). You may feel that it is too risky for you to support me in some activities or in some environments. This is something you will need to talk to me (or those close to me) about.

Only talk to me about the natural consequences of my behaviour if I can understand and make use of what you say. Only talk to me about this when I am calm.



5. Keeping Safe



I have the right to live my life free from abuse (this includes bullying). If I tell you something or you see something that you think may mean that 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.

6. Further 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 that 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
- Active support and skills teaching
- Supporting people who can behave in ways that are challenging
- Positive behaviour support (learning disabilities)
- Safeguarding vulnerable adults from abuse
- Choice and capacity
- Understanding learning disability
- Understanding mental health
- Understanding dementia
- Autistic Spectrum Condition



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

Valuing People 2001 & Valuing People Now 2009 www.valuingpeople.gov.uk (The government’s plan for making the lives of people with learning disabilities better)	
British Institute of Learning Disabilities www.bild.org.uk	Mental Capacity Act www.dca.gov.uk/menincap/mca-act-easyread.pdf
Mental Health Foundation www.mentalhealth.org.uk	Mind www.mind.org.uk
Alzheimer’s Society www.alzheimers.org.uk	National Autistic Society www.nas.org.uk
The Challenging Behaviour Foundation (learning disabilities) www.thecbf.org.uk	Suzy Lamplugh Trust (UK charity for personal safety) www.suzylamplugh.org

Challenging behaviour

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).