



“Supporting Me”

A guide for Personal Assistants
employed by or for someone
with a mental health issue



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1. Introduction

You have been employed as a Personal Assistant to support me to live my life as I choose through a direct payment. This guide is to help you understand how you can best support my recovery from mental distress.



Showing respect

It's important that you treat me, my family and friends with respect. Please respect the choices that 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 you can do things in my home without checking.



Be careful with the language that you use. Ask me how I'd like to be addressed. Don't talk about me as a "patient" or "a schizophrenic". Everyone in life has challenges but we don't want to be defined by them.

Remember it's my life, not just your job.

Don't 'gossip' about me to your friends and get my permission before you give other people personal information about me.



Keeping boundaries

We will be spending a lot of time together in my home or doing activities. Over time, if things are going well, we are likely to develop a comfortable, relaxed relationship with each other. In fact, there may well be times when it's hard to distinguish our relationship from that of friends.

At these times, we both have to remember that this is a working relationship. You have a responsibility to take on the tasks which we've agreed and I have a responsibility to treat you properly as an employer. We need to keep to our agreed goals and times of work. Be punctual and remember that I may find you being early as difficult as being late.



If you are a friend or family member

If you're a friend or family member who I'm paying to support me, the formal element to our relationship may feel particularly strange to both of us at first. We need to keep in mind that for the hours I'm paying you, the focus is on my agreed goals. Understand that if there are problems I will need to address these with you, just as I would with anyone else. If you are finding it difficult at any point, it's important that you let me know.



My family and friends

Be aware that there may be a partner or spouse, children, other family members or friends living with me. It is their home too so be sensitive to their views and feelings. They may have a significant role in caring for me in my life - show respect for this in how you respond to them.



2. Having a mental health problem

I am a person with a whole range of interests, strengths, abilities and aspirations. I am also someone with a mental health problem. One in four people will experience mental health difficulties at some point in their lives so I am not particularly unusual or different.

Mental health problems can affect anyone, of any age and background. They can be short-lived or enduring, mild or severe. I need support from you because my difficulties continue to affect the quality of my life.



Some common forms of mental health distress

Mental illness or emotional distress can take very different forms. Some common experiences are outlined here.

They will not all apply to me – please take the time to find out the ones that do.



Unusual thoughts or experiences

I may hear voices or see things which other people do not see or hear. I have no control over these and to me they are very real. Voices can often be insulting, undermining, controlling and frightening. Sometimes they make me distrust other people. Other voices may be comforting or inspiring. If I reply or react to my voices in company, I can appear odd or distracted. Medication may be helpful in controlling my voices but I have a right not to take such medication if I don't want to.

- You can help me by showing acceptance of my experience of the voices or delusions and acknowledging the impact that they are having on my life. This doesn't mean you have to pretend that you experience them too.



Depression and mania

Although everyone feels down at times, I may become so depressed that I completely lose interest in life and I am unable to carry out the usual daily activities of looking after myself. For example, I might not want to get out of bed or to eat and I may have difficulty concentrating on simple tasks. Sometimes I feel so hopeless that I may have thoughts about suicide.

- Understand that I'm not being lazy and that this isn't a matter of needing to "pull myself together". If I'm in this state, you can help me by encouraging and supporting me in my daily tasks until I feel well enough to pick them up again for myself.



- I may find it hard to ask you to do things for me, so this is a good time to use your own initiative, for example, washing up or making lunch. Don't try and force me to do something which I'm not yet ready for. If you are worried about my safety, refer to the section below on "Keeping Safe".

Some people swing from depression to 'mania'. In this state, I may be excited, talking fast and coming up with grand schemes which may involve spending lots of money. I might be insensitive to the impact I'm having on others and hostile to anyone who tries to calm me down.



- You can help me by understanding that this is as much a part of my mental health problem as my depression. I can feel ashamed and embarrassed when I learn how I behaved during a manic episode. This might make me want to cut myself off, so be sensitive to my feelings and take care to be non-judgmental. If you become aware that I'm behaving in ways that aren't in my own best interests, such as getting into debt, make sure someone knows – see my plan later in the booklet.



Anxiety, phobias and compulsions

I may suffer from extreme anxiety in relation to certain activities or objects (for example, crowded places, socialising, dirt or spiders). Experiencing anxiety is very distressing. At its worst, I may experience terrifying panic attacks where I think that I'm having a heart attack or dying. I may develop a phobia, going to great lengths to avoid having to face the thing I'm anxious about. This avoidance can severely limit my life, especially where it relates to social situations.



I may experience obsessive thoughts and need constant reassurance that everything is OK. I may experience compulsions, such as the need to wash my hands over and over again, to touch or count things in a certain order, or to hoard belongings.

- You can help me by showing compassion for and acceptance of my behaviour, even if it is something you've never felt yourself. Don't try and push me to overcome the thing that I'm frightened of unless I've asked you for help. For example, if I hoard newspapers, don't throw these away without my permission as this could make things worse for me. You may encourage or support me, but please respect the limits which I set.



- If I have a panic attack in your company, the best thing that you can do is to take the lead from me, remain calm, and sit with me until it passes. I am likely to be feeling bad about myself, so it is helpful for you to emphasise my good qualities and coping strategies.



Self-harming

I may harm myself on a regular basis, for example, cutting my skin or taking an overdose of tablets. I do this because I'm very distressed and it helps me to feel better in that moment. It gives me a sense of relief from feelings that otherwise feel unbearable. It doesn't necessarily mean that I want to die, although I may put myself at risk.



- You can help me by understanding that self harm is sometimes the only coping mechanism which I may have. Please don't be punitive. It will make a lot of difference if you can be supportive and non-judgmental towards me. Wherever possible, allow me to get my own medical help or to tend to my injuries myself. Show that you care, but don't over-focus on my self-harming. However, if you are worried for my safety, then always call for medical assistance.



Cycles of wellness and illness

Having some of the above experiences – or others not mentioned here - does not mean that I'm always unwell or distressed. My health is likely to fluctuate over time. Please don't take it personally if I'm inconsistent. I will have good days (or weeks) and bad days (or weeks). When I'm in a good phase, this doesn't mean that I don't need your support. It is often at that point that I can most use your help to have a life worth living and to prepare for the next difficult time.



Overcoming other people's prejudices

In addition to my mental health problem, I have to cope with the reaction of people around me which is often negative. Many people don't understand much about mental ill health and get a bad impression from the media.

For example, some people think that if I hear voices I must have a 'split personality' and be dangerous. This isn't true: in fact many people hear voices, and the number of people killed by someone with a mental illness is very low - fewer than those under the influence of drugs and alcohol. We are far more likely to be victims of violence and to harm ourselves than to harm others.



Having a mental health problem means it's also much harder for me to get work or to be accepted in any area of life. Because people focus on my problems, they don't see the qualities and attributes I bring. For example, they often assume that I'm not intelligent or that I could only do unskilled work. This lack of understanding greatly increases the challenges and distress which I face.



3. Supporting me on my recovery journey

A life as good as yours!

My goal, and my human right, is to lead a fulfilling and satisfying life, alongside any mental health symptoms or emotional distress which I may continue to experience. This is my 'recovery journey'.

Recovery is about believing that life can be good whatever my particular struggles, having hopes and dreams for the future, and taking part in life as actively as anyone else. This might mean being a parent, a volunteer, an employee, a friend, a gym member and so on. The only difference between me and anyone else is that I need additional support to have the skills and confidence to do this.

I'm employing you to support me on this journey. I would like you to see us as equals and our working relationship as a partnership. I'm not looking to you to 'make me better' - there are professionals who I can turn to for treatment if and when I want it. I'm not looking for you to 'look after me' as a 'vulnerable patient'. I'm the expert in my own condition, and know what I need. I see you as my supporter, working alongside me to help me achieve my goals.



Maintaining hope and optimism is a vital part of my recovery. Focus on my strengths and coping strategies rather than the things I can't do and believe that I can achieve my dreams and goals, however badly I'm affected by my mental distress. This is particularly important for those times when I lose hope myself.

The quality of my relationship with you will be a big factor in how well my recovery progresses. Small things like facial expressions matter, as I can be very sensitive to how others respond to me. Be honest on those occasions when you may be feeling tired or low whilst at work so I don't think I'm doing something wrong.



4. Understanding mental health services

As I am eligible for self directed support, I am likely to be under the care of a community mental health team (usually called a CMHT or Recovery Team). The team includes doctors (psychiatrists), nurses (sometimes called CPNs or Community Psychiatric Nurses), social workers, support workers (often called STR Workers or Support, Time and Recovery Workers), occupational therapists and psychological therapists. One of these will be my allocated worker, sometimes called a Care Coordinator. I may see other team members also at different times depending on my needs.



My Care Coordinator helps me to assess my own needs and plan my care and support. This is called the Care Programme Approach (CPA). What we decide is written up into a CPA care plan and is reviewed at regular intervals. One of the options in a CPA Plan is to receive a direct payment or personal budget to spend on meeting my social care needs as I see fit. This is what allows me to employ you. I chose this option because it gives me choice and control over how my support is provided.



In addition to my CPA Plan, I may also have written my own Recovery Plan (sometimes called a Wellness Recovery Action Plan or WRAP©). This plan highlights my personal strategies for staying well and supports my self-management. I may decide to share either plan with you or to invite you to my CPA review.

My mental health team provides specialist expertise to support me with my mental health problems. I may also get advice, advocacy, self-help and support from a number of other people, including voluntary sector agencies, family and friends. At times of crisis I may go into psychiatric hospital or be supported at home by a crisis team.



5. How to support me when I'm unwell

There may be times when you become worried that I'm behaving differently from usual. Perhaps I start cancelling sessions or being out when you call or appear depressed, upset or agitated. You may want to help me but not be sure how best to go about it.

Everyone is different, so it's about learning what the particular issues are for me. It can be good to talk this through at the beginning of working together. Not everyone is comfortable writing, but if I am, I may jot down some notes below which could be helpful to you or share with you other plans which I have already written. Or I may prefer for us to have a chat about it when the time seems right.



How I am when I'm well

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How I am when I'm unwell

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.....

Things that can trigger a worsening of my mental health

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My early warning signs

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How I want you to respond

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Who I want you to contact

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6. Keeping safe

If you're worried about my safety

The pre-planning described above may not always be sufficient to reassure you that I am safe. There are different ways that I may be at risk:-

- I may be so low that I'm thinking about killing myself
- I may be self-harming in such a way that I could accidentally kill myself
- I may have friends, family or neighbours who are exploiting my vulnerability, for example taking my money or belongings, abusing or bullying me



- I may be neglecting to look after myself – not eating or drinking sufficiently or living in unhygienic conditions
- I may be spending thousands of pounds I don't have because I'm in a manic state

It is important to act on these concerns

Where possible, try and talk to me about why you are so worried and get my permission to contact someone for help and advice. Hopefully, we can agree the right course of action together.



However, there may be times when I won't want to hear your concerns or will be adamant I don't want your interference. In these situations you will have to make the decision to act against my wishes. Keeping me or someone else safe is the only time that this applies. It is always difficult and you may worry that it will damage our relationship. But if you are acting in my best interests, then once I return to a state of wellness I'm likely to understand why you took the action you did and even be grateful to you.



If you're worried about someone else's safety

I am much more likely to be a victim of violence than to be someone who carries out violence. However, some people do at times behave in ways which frighten or put other people at risk. This could include verbal or physical aggression and threats or it may involve possible risks to the wellbeing of a child.

It is important to act on these concerns



If I behave in an aggressive or violent way to anyone, then do something about it. I am responsible for my actions at all times, unless I am so unwell that I am deemed not to be responsible – in which case I need to be in hospital. If it feels safe to do so, pick up minor incidents with me, making it clear that you will not tolerate any bullying, threats or violent behaviour. If you feel scared whilst you are with me, your first responsibility is to your own safety. If necessary, call the police. You do not help me by protecting me from the consequences of my actions.



Who to contact

If anyone is in immediate danger of physical harm, call the police on 999.

If you are worried that I am a risk to myself or others, contact my Care Coordinator or, failing that, my G.P. They are the professionals who know me best.

My Care Co-ordinator's name and contact details:

.....

My G.P's name and contact details:

.....



Sussex Mental Healthline: 0300 5000 101 provides out of hours telephone support, information and advice to service users, carers and healthcare professionals. Lines are open Monday to Friday 5pm – 9am, weekends and bank holidays 24 hours.

If you are worried about my safety out of office hours, contact the emergency duty service and say that you have a safeguarding concern:-

**Brighton and Hove and East Sussex:
07699 391462**

West Sussex: 01903 694422



If you are worried that a child is being abused or neglected, then contact the Children's Safeguarding team:

Brighton and Hove:

Central – (01273) 294470
East Team – (01273) 295200
West Team – (01273) 296272

East Sussex:

East – 01424 724144
West – 01323 747373
Out of hours – 07699 391462

West Sussex:

Monday to Friday – 01243 642555
Out of hours – 01903 694422



7. Useful Information

Developing your skills

As your employer I am responsible for making sure that you can develop the skills and knowledge you need to support me. Much of this will come from you learning from me as I explain how I want things done. You may also find it useful to receive some mental health training. 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. MIND in particular provides a wide range of useful information.



Useful websites

- **MIND**
www.mind.org.uk
- **Rethink**
www.rethink.org
- **In Control**
For information on self-directed support
www.in-control.org.uk
- **Mental Health Recovery**
For information on WRAP©
www.mentalhealthrecovery.com
- **Sainsbury Centre for Mental Health**
www.scmh.org.uk
- **New Horizons**
The government's plan for improving the lives of people with mental health problems
www.newhorizons.dh.gov.uk/index.aspx
- **Sussex Partnership NHS Foundation Trust**
For information on Sussex statutory mental health services
www.sussexpartnership.nhs.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



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Other 'Supporting Me' guides, including copies that can be tailored to me, are available from the local Independent Living Association or by contacting seregion@skillsforcare.org.uk

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

Sussex Partnership 
NHS Foundation Trust



Photos

Thank you to staff and services users from the Allen Centre "New Horizons" service for agreeing to be photographed. Other photos are from the NHS Photo Library and Skills for Care.