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The Rough Guide to Managing Personal Assistants

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"Having PAs enabled me to find out who I am and now enables me to be who I am." If you are a disabled person and about to start receiving a Direct Payment to employ your own personal assistants (PAs), this book aims to give you a flavour of what it is like; the joys and the challenges.

The book covers recruitment, managing, using PAs in social situations and at work, and dealing with problems. Put together by Sian Vasey with cartoons by David Shenton.

United Kingdom.

The Academic Network of European Disability experts (ANED) has [current data \(2016\) about personal assistance and IL in the United Kingdom](#).

The European Network on Independent Living (ENIL) has a [European survey on personal assistance with current data \(2013\) about personal assistance and IL in the United Kingdom](#).

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Introduction

By Sian Vasey

There is a new breed of human being now taking its place in the cosmos. It is a creature of the 21st century and as it blinks and looks around in the bright light of the unfamiliar day it is already beginning the search for its fellow travellers on planet disability. This modern creation has devised a support system for itself known as a Direct Payment and uses that means to surround itself with worker creatures often referred to as Personal Assistants (PAs). This is a guide written by the early settlers on the planet in the hope that the later arrivals can avoid some of the pitfalls, which may await them on their journey.

OR to put it another way, if you are a disabled person and about to start receiving a Direct Payment to employ your own PAs, people who in a distant era were called 'carers', this book aims to give you a flavour of both the joys and the challenges.

The kind of things you can employ a PA to do may be personal such as bathing and washing, getting dressed and eating and also domestic such as gardening, cleaning and driving. Visually impaired people can employ them to read correspondence and help in the shops. People with learning difficulties may use them to assist with organising finances and menus. PAs can also assist with parenting duties, going on holiday and taking up the hobby of your choice.

Direct Payments really represent a golden opportunity for disabled people. They are the means by which we close the chapter of disability history called 'Institutions' and move on to the part of the story where we get a crack at living just like everyone else. With the right facilitation any disabled person, whatever their impairment, can take control and be free to get on with life. It all seems so simple, but of course like so many things it is just a bit more complicated than it first

appears. This book is about those complications. It is about the business of finding, keeping, dealing with murderous thoughts towards and perhaps even getting to like the PAs without whom we are, as they say, up the creek without a paddle.

We are, all wrestling with the same issues. Everybody finds it an effort, at least some of the time, because it is basically management work that we are involved in here and management is rarely easy. In business, managers are paid large sums and then often do it badly. We get paid nothing and cannot afford to fail, not only because our living arrangements will instantly be in tatters, but because there is a view widely held by the powers that be that we are not up to the job. This book is a celebration of disabled people's undoubted ability to get on with a difficult job in order to get a life.

Primarily this book is about learning from experience, including dealing with problems, and I hope nobody is going to feel put off the idea of independent living because of this. It goes without saying that if life as a PA user was totally without hitches then there would be no need for this book. While you can rest assured however that, unless you are very unlucky, life with PAs can go very smoothly for great stretches of time, the fact is that this state of affairs doesn't give you much to write about....."I find that every day my PA turns up on time, makes my coffee just how I like it, works at right speed, gives me interesting nuggets of chat and sets me up perfectly for the working day".....the good news is that this is all true, but it does make an instruction manual for a washing machine seem gripping. Fear not, you will find that when you



have honed your PA using skills you too will breeze along and not even notice it going on around you.

Naturally NCIL would like to thank all the people, recruited in the main from a wide consultation exercise, who have bared their souls and written for this book. They all receive support packages, which is to say the money with which they pay their PAs, from either their local authority or the Independent Living Fund, or a combination of both. Money, as always, is a controversial question – not just how much you get from the local authority, but also how much you are expected to pay from your own pocket.

Some of the difficulties people describe in this book could be sorted out by a more substantial Direct Payment. Without enough money independent living becomes stressful and in some circumstances almost too stressful. Compared to the alternatives however, it is a day at the beach (with candyfloss thrown in). The collective struggle now is to find ways to make it easy for everyone. We have to stick together to keep the system working in the way we know is right. Money is one of the key factors in the crusade. It is both liberator and jailer and we have to resist all attempts to minimise care packages and maximise charging. If we fail then we will be in big trouble. We will have no money to pay for the other parts of our lives (mortgages, children, vehicles) or to pay for the other mammoth costs associated with significant impairment.

The other thing to say about the business of living and working with PAs is that it is truly a phenomenon, which sits right at the centre of disability culture and is something we must celebrate. Using PAs is a distinct disability experience of the liberating kind. We must make it known to the big wide world that this is our way of life. One reason for doing this is to make the presence of PAs such an unremarkable state of affairs that it can easily be assimilated into social situations. When I was talking to people about the book the awkwardness people experienced over this issue came up time and again as something that people found really exasperating. The disabled identity is still largely shrouded in mystery and misapprehension. This book is irrefutable evidence that disabled people can take control of and organise their own lives and as such it is a contribution to the efforts being made all over the world to rectify the way we are collectively perceived. We just have to keep telling it like it is until the truth is laid bare and people no longer feel they have to treat us like visitors from Mars.



A Few Thoughts on Independent Living and Taking Control for the First Time By Dave Morris

I often think that the term ‘independent living’ is an anathema. It changes something which is natural into a special state of being. It compounds the idea that ‘Crips’ are generally a passive,

dependent species, struggling to break out of their warped and dilapidated bodies; reaching out for a reflection of normality, grasping for independence as an alternative to the meagre fare of care and control which our society deems is what most people who need personal assistance should exist on.

I have always believed that living is about independence, control, spontaneity, personal, development, responsibility. Why should the fact that I need somebody to wipe my bum deny my aspirations to exercise independence and achieve whatever my potential may be? The fact is that independent living should be the starting point; a foundation on which to build; the development from child to adult. Of course we all know that it is not as easy as that.



Perhaps I ought to put these thoughts into context. I use, and indeed need, personal assistance in most areas of my physical life and always have done. I need someone to get me dressed, washed out of bed and into bed; someone to help me pee, wipe my bum, drive my car assist with the housework and so on.

When I was a kid this was all done by my mother and father, like it is for most kids I suppose. Well, at least until I was seven and shipped out to institutions. I'm not really sure when the transition from the ordinariness of using personal assistance as a child and the dependency culture of being a disabled person who needs personal assistance happens. I do know, however, that the front line of this transition is often located within the four walls of the residential establishment. It is here where being dependent on physical support becomes synonymous with being controlled. It is here where one's physical life becomes standardised, routinised, pigeonholed, organised, planned.

Bedtimes, mealtimes, bath-times, toilet-times. The clock rules and we become programmed. We use the loo according to schedule and spontaneity goes.

Sometimes I think about those institutional times and try to analyse the effect of the regimes I lived under for twelve years. Formative years in which I was in effect trained to be dependent/ I'd like to think it was like the metaphorical water off a duck's back, but I know somewhere deep within the clock continues to tick. I graduated from this background as a fully-fledged, severely handicapped' Crip. I was handicapped in many ways, the most striking being my retarded clothes sense. My suitcases, which filled the back of the St John's Ambulance driving me to university, bulged with neatly labelled, easy-fit, Velcro-fastened crimplene creations. I wore trousers about eight sizes too large, baggy Y-fronts, vests (to keep the chills out), striped pajamas for god's sake. I was eighteen, I'd never bought my own clothes and I was about to be released into an environment where clothing spoke volumes. The sad thing was that I believed the fact that I needed to wear these things. They were more comfortable for me, they were easier

for me, they looked better on me. Like hell, they just make me look like a prat; like a good, sexless cripple. At least I had fought off the surgical boots and braces I suppose.

My mentality was also distorted, disabled into accepting that I should maintain ways of dealing with my physical self which had been imposed upon me. One enduring memory is spending hours getting tied up in nylon slings and chains and dangling from overhead hoists feeling like meat from a butcher's hook,. Silently screaming as the nylon wrenched my legs apart or virtually castrated me. The feeling of cold, dank, nylon on my skin as I was winched swinging and dripping from the bath still sends a shiver through me when I think about it. The fact is that I thought I needed to use these contraptions; that there was no alternative. So I bathed sparingly and went to the loo inconsistently and braced myself whenever I did.

My first contact with a personal assistant was almost comical. Somehow I had ended up at university. Another institution yes, but at least it wasn't a Cheshire home. Now it would have been too much to ask for me to have chosen the university. In fact it was like almost delaying the inevitable permanent incarceration. I was told to choose this particular academic institution, not because of its excellence in the field of study which I wanted to pursue, or its varied social life, or because it had the third cheapest beer in the country, but because it accepted crips and provided personal assistants – only during term-time of course. I was probably the only person in the country who had the same university down five times on my UCCA form.



So there I was being wheeled out of the aforementioned ambulance and I was confronted by an ordinary looking bloke the same age as me, with a crew cut and a northern accent and this person would be wiping my bum. No uniform, no high pitched voice, just saying "hello" and not having an attitude problem. My parents believed him to be the electrician fixing the overhead hoist and went to look for matron. I have never looked back.

Taking control of one's personal assistance needs is not easy. We always say that we, the cripples, are the real experts. To be honest, however, I wasn't. I'd never done it before. I was used to being told what to do, when to do it, where it should be done and how it should be done. The PA had never really seen a Crip before and also didn't know what to do, thank god. So we actually learnt together. I suppose I should remember the freedom of having my first pee when I wanted it, but I don't. The transition from dependency to spontaneity just sort of happened.

1. Desperately Seeking - Recruiting your personal assistants



Every PA employer will know that sinking feeling when a good PA, or even a not so good PA announces that they are leaving. The prospect of the recruitment process looms and there is nothing to be done but bite the bullet and get an advert in the paper. Everyone has a tale of trying to interview the weird, the wonderful and the totally inappropriate. Here's Phil Miller.

I will never forget my feeling of total amazement when an applicant turned up on my doorstep with her Italian husband and her mother. The reason given for this was that they wanted to check me out to make sure that I was genuine. Her mother was a qualified nurse, so clearly she was just the person to spot whether my requirements were genuine or whether I was just a big old fraud! The interview was very difficult as I ended up being the interviewee. Needless to say, she did not get offered the job.

Kevin Caulfield recalls some of the daft things people have said to him in the interview situation.

"I've healed all my clients, usually in the first week."

"So I don't have to nag you then about taking your tablets and eating your food?"

"Can I bring my sewing machine to work?"

Andre Polanski is gay and has to grapple with this as an extra dimension to the art of being a PA user. On recruitment he says.

NO matter how much you try you always get applications that are wholly inappropriate. Some I have received include: students who think it is about taking me to the pub one night a week; people who mistakenly think assisting a gay man involves having sex with me; and people who are very, very interested in knowing all about my medical history (and seem to be smiling too much when they're asking these questions!). I've also had one applicant who was

really argumentative when I didn't offer her a job – disagreeing with my reasons for not employing her, which was really difficult to handle. I would never interview PAs on my own now, just for safety reasons. And I don't interview them in my home.

There are also those that lead you to expect a lot like this one Diana Nicholson interviewed.

Peter arrived one Saturday afternoon for an interview. A pleasant young man, immaculately dressed in a suit and tie. He seemed confident and not embarrassed by the fact that the client was a lady. The further the interview went the more jobs we discovered he could do; cooking, cleaning, driving, gardening, first aid, DIY. Willing to turn his hand to anything. All in all the Rolls-Royce of PAs. Referees were supplied. After two hours and cups of tea we were still talking. We knew his life history, his hobbies, everything down to his shoe size! He was asked to star the following Saturday and has never been seen from that day to this.

As it happens, while I was putting this book together I had to run an ad in the local paper seeking a PA to put me to bed three nights a week at 10.45pm. This pays £11 per visit, and perhaps for that reason I was inundated with calls, a week later and the phone was still ringing regularly. To be clear, I am able to organise my PA time, so they are with me for short periods, a maximum of two hours. I do not need them to be with me for long periods. This gives me the advantage that the personality of the recruitee is not quite such a make or break factor. Punctuality, staying power and being able to do my 'lift' are the key requirements for me. I think it is because of the lift that I particularly hate the interview process and I have difficulty applying myself to it properly. I approach it with the view that if they can summon the strength to hoik me from chair to loo then the person spec has been more than adequately matched. Even though it may be true that the interviewee speaks only Danish, with a smattering of conversational Japanese and that they like to be tucked up in bed with a cup of Horlicks and a thick paperback by 9.30 at the latest (a point I ascertain thanks to their considerable skills in the art of mime).

Briefly on my interview procedure, anybody who is new to this business should come and watch me in action to get a comprehensive idea of how not to do it. Instead of preparing myself, and my questions, I let them do all the talking and then wonder why, by the end of proceedings, I find I have learnt all sorts of fascinating facts about their grandson's pet rabbit and their deep passion for flamenco dancing, but have not acquired so much as a scrap of information about their previous work and whether punctuality may be one of their habits.

Victoria Brignell is much more sensible.

Before interviewing applicants, I find it helpful to draw up a list of questions which cover all the points I need to know. Having a set of questions in front of you during interviews ensures you do not forget to ask anything crucial. Questions I ask include "What experience of working with disabled people do you have?", "Have you had any lifting and handling training?", "Do you know how to use a hoist?", "What are your cooking skills like?" and "What does confidentially mean to you?".

The interview day went well with only one no show. Although, it was perhaps not so much an interview day, as a day for taking strangers into the bathroom, to instruct them on the mystic arts of getting sufficient pressure against my knees to be able to yank me into a semi-standing position, in order to pull my clothes down with one hand and bung me on the loo. After going through this process with four or five people I was fairly fagged out. The hardest work were the

ones who have never done anything like it before. I do not know why but they often develop a tendency to click into mysterious slow motion. I have to remind myself over and over that they do not know me from a bag of potatoes, that it must be really quite intimidating for them and that the process has to be given some time. However, I had to find miraculous restraint, when prior to launching into the lift routine I asked a really quite capable seeming older woman to put the cordless phone I happened to have on my lap, on the bathroom shelf. She picked it up as though it were a precious objet d'art, about to make an appearance on The Antiques Roadshow. Cradling it in both hands she gingerly placed it next to my spare loo roll, like a sacrificial offering to a minor deity. It was all I could do to hold back from shrieking "It's only a bloody phone, just put it on the sodding shelf like a normal human being."

I also tend to pre-judge the whole process, so having spoken to her on the phone I was instantly sure that the one with claustrophobia and two cats would get the job. At interview, she did indeed seem ideal, later got the offer and was very pleased. However, the next day she phoned to say she couldn't take the job after all. She had done a trial run of the walk to my house at 10:30 and said she found it too intimidating.

There were two lessons I learnt from this. One is stick to your guns over what you have decided is important. I was quite clear that I wanted someone with a car, or who was living no more than a couple of roads away. It is a late night call and people walking any distance or using the bus myself be deflected on that one because she seemed so pleasant and so keen. Luckily it wasn't a fatal mistake. The second thing is not to be too quick off the mark letting applicants know they haven't been chosen. Far better to give someone the impression they were your first choice.

My second choicer was not a particularly cheery soul, but she looked reliable. I had to ask myself whether I really need a relentlessly chirpy soul with me in the bathroom when I am cleaning my teeth and taking my vitamin pills? The question that bothered me though was whether I was only settling for her because of lack of time and energy to sort out someone else. Was I fooling myself that she looks like a stayer, etc.? Fingers crossed she works out.

One good thing I did this time though was to start a computer database of everyone that called, so I can go back to them in the future. At first I was determined to catch everyone who rang, wanting to get maximum value from my advert. This made the day fiendishly chaotic with the phone, the doorbell and my frantic typing of people's details. After about a day and a half I gave up with the database and just left a message on the machine saying that the job had gone. Even so I now have 78 names on the computer and 30 more still to transfer from my bits of scribble.

But enough about me in my urban setting. Recruitment is a very different business when you live in the country. Beverly Ashton, who lives in a Somerset town recounts her experience of looking for staff.

Being a PA user is not something I'm comfortable with or very good at. I struggle with the business of recruiting and managing staff. I am getting better as I have learnt from some bad experiences.

My care budget is only for ten and a half hours, spread over the seven days of the week. This would be enough to make a job for one person. Unfortunately it is not possible to employ just one person because it is not reasonable for anyone to work every day of every week. I also need to be able to arrange cover for when they are absent.

If I split the hours up the money is also divided and the resulting jobs are too low paid to be very attractive. Living as I do in a small rural town, there is no shortage of part-time work for women. Supermarkets, local factories and 'Home Care' agencies offer jobs which represent more hours and therefore a better wage. Few women want little bits of work timed exactly when their families need them – meal-times and early evening. WE have no student population.

I used to employ PAs directly myself, but because of the above problems the standard of applicants was poor. Most who applied were women who could not get shop or factory work – generally because of unreliability. I didn't understand this at the time. The difficulties I encountered mean that at the moment I am using an agency, rather than employing directly myself.

The first time I ran a recruitment campaign it was rather rushed. I received confirmation that I had the finances to employ my own assistants at the same time as the letter telling me that my statutory service were being cut off. I needed to find staff quickly and decided to run a press and Job Centre advert. The Job Centre applicants appeared better than the others because they got help with the application form.

I did ask for references on the application form I used but unfortunately I didn't make the best use of these. I was very short of applicants. I wanted two workers and only got two applicants who were potentially suitable. One was a young girl, who I will call Cheryl, with a long list of previous jobs on her form. She had worked for a reputable 'Home Care' agency but had not used the manager of the agency as a referee. Instead she had used two shopkeepers. At the interview I questioned this, knowing what a reliable referee this manager would have made.

She told me the woman didn't like her. Feeling frustrated, I nonetheless accepted this. I knew one of the shopkeepers she had quoted and followed her up instead. The shopkeeper said she was very busy and asked if I would accept a verbal reference.

The reference from the shopkeeper was so vague that I was not sure she remembered who Cheryl was. There were no recommending details except that she was honest with money. She became particularly vague when asked about punctuality and reliability and wouldn't really answer any other questions. I assumed this was because she could not remember Cheryl. She did say that she was a very nice girl. So on the strength of that and there being no negative answers, I employed Cheryl.

She turned out to be a completely useless employee who in the six months she was with me, drove me nearly bonkers. She lost my house key in less than 24 hours, she was constantly late, on the irregular days when she turned up at all. She was indeed a very nice girl who had had a difficult early life, but struggling without the help I needed and worrying about her problems nearly finished me off.

One moral of this story is that I will never take a verbal reference again, or at least not without agreeing the protocol. Another thing learnt was that it is very valuable to have a co-interviewer. Anybody else would have picked up that Cheryl was not a suitable employee. They would have picked it up because they were not facing a desperate period without a PA, the prospect of which made me throw all caution to the wind. Advertising in a small rural town I find I get a better quality of applicant by advertising in a newsagent and my local newsagent is best of all. However, everybody in the area knows it is me that is advertising. People

approach me in the street and ask if I have found anybody, and if I say yes they always ask who it is. They then offer their views on that person or their family members. There seems to be ample dirt to be dished whoever I employ and it is all enthusiastically shared. The only way to cope is to understand that there would be similarly negative gossip about anybody I cared to mention.”

Liz Briggs is one of the pioneers of independent living. She is one of the group of people who got themselves out of a Cheshire Home back in 1982. In so doing, she became one of the first people ever to receive a direct payment. She also lives in the country where, as she now writes, it is getting more difficult to recruit successfully.

I have been employing my own PAs for just over 17 years. I am single, now in my 40s, living in a housing association, bungalow, in the South of England over a hundred miles away from my family. I chose to live here after moving from a residential Cheshire Home in the same county as I had developed my support network, which was very important to my well-being in those early days. I have a neuro-muscular impairment, which has meant that my personal care needs have gradually increased.

My first two PAs came with me from the Cheshire Home, both were Scandinavian and the arrangement was that they lived in my bungalow. I soon discovered two things. Firstly my place just wasn't big enough for three women and secondly that I often felt the odd one out. So I decided to have one living in (another Dane) and one living locally. I advertised in Job centres, local papers and word of mouth.

As time went on I settled down to employing two women, both local young people who stayed approximately a year at a time working a two day on, two day off, three day every other weekend rota.

One good source of employees, I found, was a local riding stables. I likened looking after a horse to working for me – they needed to be reliable, patient and not mind mucking out!

I now employ a mix of people, as I have found it increasingly difficult to find the 'right' people to work for any length of time with me. I have completely changed the way I schedule them. Everyone is on a renewable six month contract, both for my sake and theirs. I have found though that the contract gives me no protection if someone walks out. In fact I could write a whole book on people walking out, not turning up for work walking off with house keys and so on. The good news is though that some of my part-time workers have been with me over ten years, so, occasionally, I must do something right!

I advertise mostly in local papers, but have used The Lady magazine and Disability Net website. I stopped using the Job centres when they stopped sending me people who actually turned up for their interview! I don't like using cards in local shops as this makes me feel rather vulnerable. I have found University Job-Shops a good source, though last time I advertised for women, two males applied!

The problem of finding people to recruit has become more acute recently. I believe this is because we have become victims of our success, the success of the independent living movement. Years ago, the only opportunity to do care work was to work in a residential or rest home, so any advert I ran attracted a lot of attention as I was living in my own place. It

was common for Jobcentre applicants to be astonished that I actually interviewed them myself, and ran their pay scheme, etc. They came to work for me as it was a novelty.

As this idea of independent living was our own, we had no rules to go by. Yes there were employment laws, such as they were then, but everything else was trial and error. Even what to put in an advertisement, and how to write a description of the job, was picked up as we went along. By 'we' I am referring to the group of us who took the initiative to move out of residential care, which started the whole independent living ball rolling in this country. We spent many hours on the phone trying to work out the best way to sort out a problem, which could have been anything from how to sack someone to how to arrange holiday cover. To say that 'I flew by the seat of my pants' was an understatement, but I survived. It was exciting, enjoyable, fresh, a challenge which helped me grow and expand as an individual.

Now it is common for disabled people to live independently and it is accepted as a run of the mill job opportunity. Potential workers are able to pick and choose who they work for, what hours they work and how much they work and how much they get paid. It is no longer exciting to seek new employees, it is stressful and a chore. Also, those of us on Direct Payment/ILF monies can only pay a certain amount per hour while local rest homes and agencies are paying more, which makes life even more interesting.

Is there an answer? I am not sure. I have seriously looked at other options for myself. I would like some help in recruiting staff, but then, at least at present, the whole choice is mine. I would like company, but need my privacy. I would love to live nearer to friends who give me mental and physical support, but I would hate to leave this place.

I am not sure what the future holds for me, I do find it sometimes is a great strain, always having to be a good and cheerful employer. (I never had designs to run a business.) I know what the alternatives are (been there, read the book, etc!) so I stay as I am. Perhaps I have higher expectations than before, perhaps it is no longer a challenge. Perhaps independent living has an expiry date?

Liz is obviously having a tough time and it seems to me that the real issue here is not about Liz being tired of it all, but that she does not have enough money to pay people properly. The issue of money is inevitably linked with the issue of recruitment. As a broad rule of thumb I think people flock much more to, and stay with, jobs that comprise a small number of relatively well paid hours that will fit in with their lives. As Liz says she has had some of her part-time staff for years. It is more difficult to get people on a 24 hour basis and to live in. This is partly because employing in this way often pays a lot less money per hour and also obviously requires that people give up much more of their life, which they will not do forever. Hence, leading to more regular recruitment stress and expense. It is worth pointing out that just because a disabled person needs continuous assistance it doesn't have to be provided in that way. There is no reason to exclude the idea of buying 24- hour assistance in small chunks just because it is expensive. It leads to a more stable and manageable life, the money has to be found. There is a political job to be done here. We have to maintain pressure on the government to ensure that care packages cover more than just the cost of survival and run to the full cost of independent living.

Equally in a small rural population there will be fewer people to choose from as both Beverley and Liz have described, so all the more reason to be paying a competitive rate. Social Services and the ILF must be made to acknowledge that packages have to be calculated taking these

empirical factors into account. The judgement as to whether an individual's package is set at the right amount has to be based on whether the individual can recruit and retain workers of the right calibre for the money they have available to them. If they cannot do this then independent living becomes a misery and perhaps impossibility.

Tom Brewer has a live in PA plus other part-time PAs. He has found a solution, which suits him.

My local CIL has set up a recruitment agency. We are listed in a book about working holidays in the UK that is published in Germany. We are also registered in jobcentres through Germany. We get prospective PAs applying all the time. If they are from an EU country they do not need a work permit. I carry on doing this because it is getting harder to recruit good people locally.

The process is like normal, really. You have an application form, you have to decide from that if the person is on your wavelength, look at the reasons they are applying, how long they can stay for and whether they like dogs? You use letters or phone calls or e-mail to exchange more information. I'd say eight or nine times out of ten it has been OK. The only problem I had was when I needed to recruit really fast, so I took the first person who was available.

When they arrive it can be a bit difficult if they are not fluent in English. The older I get the more impatient I get. But you have got to be accommodating, provide a sense of warmth and welcome. Some get really homesick. Some are quite young and some are more streetwise. I try not to employ anybody under 21 these days – the younger ones get more homesick.

One woman, who came to be one of my best PAs, could hardly speak any English when she arrived, we had to communicate via body language, facial expressions and so on. But I could tell that she was committed to the job and we stuck at it, she ended up being brilliant. You could sense from the beginning, there was an underlying current of communication, even though the language wasn't there.

It can be frustrating. I remember sending one woman out with a shopping list who came back with totally the wrong stuff. You just have to take it slowly. It can be tricky for the fiddly things, like positioning in bed, so I usually get another PA to show them the basics.

Finding the right people for you is, I believe, the secret of success as an employer of PAs. When you are right for each other a mutual loyalty develops and people will not let you down. Recently a PA who does some of my nights did the work while unbeknownst to me feeling really ill. She just made it home in time to be violently ill. The next morning the PA who gets me up had to yank me off the loo so that she too could throw up. Even so she managed to finish off the job to recuperate. This is not intended to show that working for me makes you queasy, but that when you have the right person they do not let you down in a hurry.

Quick tips

- The general view is that the best place to advert is in the local paper. But here are some other options: local sports clubs, local stables (both on the grounds that strong fit people were required), local churches (if you want helpful people who share your beliefs), notice boards at the local university or college (young, flexible workers). Press wise there are: national papers (usually chosen by people with larger packages, as cost is much greater than local), foreign magazines or those aimed at travellers (e.g. TNT) for those looking for a live in worker. Experience of using jobcentres, however, has not been particularly good.
- Think really clearly about the person that you want. Some of us like people of a similar age and background. For some, knowledge of our culture or faith is a very important factor. Others just want someone cheerful and strong. You will get to know the sort of person who works well for you.
- You might prefer to do the interviews somewhere other than your home. Most local Personal Assistance Support Schemes can offer a room for this purpose.
- Keep it legal- the ILSA handbook has more on this (See the Book List at the end).
- You may find a particular type of person works well for you. Perhaps there is some natural law at work that makes you recruit in your own image.
- Don't feel you have to plump for applicants who look good on paper, go for the ones you feel comfortable with in your private moments.



- Try and have someone, whose opinion you value, with you when you do your interviews, not to ask the questions but to talk it through with afterwards.
- When you are organising the interviews leave enough time between them to give yourself a break and remember it is unlikely that all the applicants will turn up on time.

2. Getting To Know You - The induction process

Training a new PA into your routine is always a challenge.

Dave Morris gives a clear picture of how it feels.

Every so often I come across old articles in magazines or books on library shelves about how to manage stress. Invariably there is a table of stressful things with points allocated, so that you can play a fun quiz adding up how stressful your life is and how urgently you should make that appointment with a councillor or just simply change your lifestyle. By my reckoning such an event should certainly come along side moving house, starting a new job, or losing a close relative.

Now I know that I often go on about the fact that as a fully-fledged card-carrying cripple I know best how to tell people how to do those things that I need doing. However, let me let you into a little secret. At seven o'clock on a cold January morning as I lie in bed awaiting the arrival of a new PA, I often think how nice it would be if one came fully trained and practice perfect in the art of me.

The simple fact is, however much I like it or not, this is never going to be the case. However much I have prepared in advance, life will be disrupted big time for a few days. Everything will take twice as long. Inevitably there will be that strange psychological stand-off in the bathroom for a brief instant as the reality of wiping another's backside kicks in. That moment of doubt as you move perilously from shower chair to bed. Reconciling oneself to being just slightly undressed and out of position. Having to explain the bloody obvious. Gently persuading that I am not a porcelain doll that will shatter into a thousand pieces, or making sure that I don't. Playing the driving school and offering a short prayer to St Christopher. And that constant accompanying commentary. The soundtrack of new personal assistance. A little more to the left, no up, over to the right, higher, push, pull, backwards, forwards, no its OK you are doing fine. It is a patter that is so familiar. I hear myself saying these things again and again. The same jokes, the same nervous embarrassment, the same explanations, the same reassurance, the same muted frustration. Now it's off to the real world to earn my crust. The level playing field, no concessions – equality, autonomy, independence. God I'm knackered.

The relationship with one's personal assistance is a vital one. It reverberates in every corner of one's life. It shares intimacy, it oversees success and failure, it is one with your dirty underwear and hears you singing in the shower. It is an interaction that is virtually unique. It is as intimate as a marriage. By its very nature it is very physical and breaches strong social taboos. It is a relationship that is under constant flux: mutating as individual replaces individual on a cyclical basis, changing as each individual moves on and is replaced.

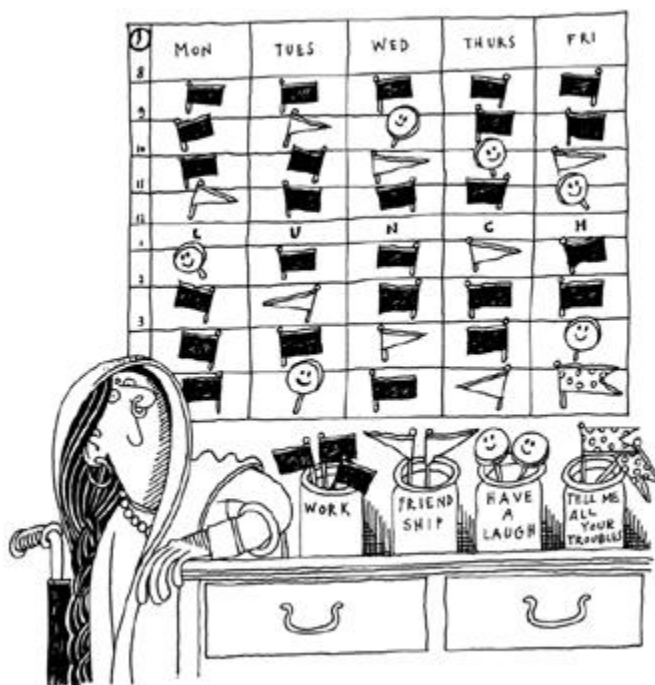
I have shared my live with many people. So many in fact that memory blurs and names merge into one another. I have developed so many short-term relationships. Each one of these

relationships is fully rounded and individual, capturing a period, a space, a moment. Some are intense and shrouded in emotion, some are peripheral, a few have ended in confrontation and consternation and others have developed into strong long-term relationships.

Sometimes some small element within me resents having to go through the anxiety of building a new relationship with a personal assistant. When I think about it carefully, however, the stress is vital. It is a bonding process, communication across the vast expanse of difference. Somehow I have known instinctively since I started using personal assistants that my autonomy and control is directly caught up in the quality of the relationship I have with those individuals providing personal assistance. Understanding and mutual respect is so much more effective a way of being in control than trying to play master and servant or pretending that Bicentennial Man already exists. There is absolutely no point in pretending otherwise. I welcome the uncertainties and the stresses. I welcome the hassles and frustration. It is normal, it is ordinary, and it is part of me.

Quick Tips

- Give your PA a list on paper of your routine to help them build up speed.
- What about making a home movie of how you have things done – there is at least one PA user who has done this.
- Always try and organise a handover between PAs. It gives the new PA confidence and saves you the bother of having to go through the same stuff time and time again.
- Start as you mean to go on – be very businesslike at first and then you can become more relaxed when you have set the general precedent for how things should be done.
- Make sure people know when they are going to be paid.
- Be clear at the outset – make a list of things you do and don't want to happen (for example on use of your telephone) - you may find that gradually it helps to put everything in the contract. This may make the contract a bit bulky though and it is certainly a good idea to go through things verbally as well.



3. We Can Work It Out - Managing the relationship with your PAs

There are certain things that you need to organise as a PA user. For example your PA has to be given a contract and a job description. If there is a Personal Assistance Support Scheme (PASS) in your area it should be able to give you some help getting these nuts and bolts into place. If there is no PASS where you live then contact the National Centre for Independent Living for

advice. NCIL also has a website, which contains a list of all Personal Assistance Support Schemes, sample contracts, job descriptions and other useful information.

At NCIL we don't think you should have to struggle with these issues, information and advice should be at hand. A local PASS should be the source of this help. Some of the best local PASS schemes have been set up by disabled people, often those who have pioneered using personal assistance; others are run by a variety of voluntary organisations. If there isn't one in your area, you might like to push for one to be set up. NCIL has a leaflet on how to get started. If your local PASS is not offering all the services you need, ask why not, encourage them to do more.

The other major thing you have to think about is how to organise a payroll for your PAs. If you feel up to it you can do this yourself and need to get in touch with the Inland Revenue to get all the relevant stationary and instructions. Alternatively you can take the lazy way out and use a payroll service which should not be very expensive. If you are lucky your local PASS may offer a payroll service.

For more information it may well be worth your while getting hold of a book published by ILSA entitled The PA Employers Handbook. Once you have got this personnel administration sorted out then you can concentrate on how to manage your relationships with your Pas, which is the main concern of this chapter.

First up is Beverly Ashton on not becoming so wrapped up in their lives you can't get on with your own.

Over the years I've caused myself a lot of difficulty by listening to, worrying about and taking on the life problems of Pas. I now know, without a shadow of a doubt, that the best response when somebody tearfully spills out some terrible problem is to say "Oh dear! I'm so sorry. That must be awful...but how could you just look to see whether the vacuum cleaner bag needs emptying".

In the past I have been repeatedly involved in really desperate things, martial violence, partner infidelity, teenage pregnancy right down to the death of beloved pets. I find it very difficult to feign lack of interest, because I'm fascinated. These are real life soap operas. However, getting involved kills the 'Employer/ PA relationship' stone dead. Before it dies, it's very stressful and I always reach a point where I dread my PA coming.

I have found that I don't have to like my PAs for this arrangement to work, but I do have to feel comfortable with them. For PAs who are going to give me personal care, I have to feel comfortable without any clothes on. I have a sixth sense and I know before I take my clothes off whether I'm going to feel comfortable with an individual.

I currently get my workers through an agency. Agencies have difficulty understanding that you may not feel comfortable having personal care from somebody who you are quite happy to have do your housework.

One interesting and very good PA relationship I had was with a woman who early on told me she had great interest in spiritualism. Each evening she would tell me the messages she was getting from 'the others side'. The spirits talked about all sorts of things, sometimes about me and would say extraordinary things, but strangely this did not damage the PA relationship. She was good humoured, amusing, efficient, an extremely effective worker and I would be

employing her today if the spirits hadn't told her she had to go and live in Yorkshire, which she did.

Victoria Brignall takes up the theme.

The PA/ disabled person relationship is unlike any other because, when it is successful, you become very close to the other person very quickly. Within a few hours of a PA starting to work with me, I have to ask them to help with very personal tasks. After a week with a new PA, I feel closer to them than I do to with most of my relatives whom I've known all my life but see only a few days every year. As a result, when a PA decides to move to a new job, it is like suffering a bereavement. One minute they are with you every day, the next minute they have gone. A good PA often becomes a friend and you keep in touch long after they finish, for example, next year I have been invited to two weddings, one by my current PA and one by an ex-PA.

However, it is also important not to expect too much from the relationship because that way you will avoid being disappointed. Although some PAs may treat you as a friend (for example, asking you out for a drink when they are not on duty), others may follow a policy of keeping their work and private lives separate. Although it may be difficult to accept that you are simply a job to them when you feel the relationship is more than that, this can have the advantage of making the relationship less complicated.

When you need a PA to live with you, it makes it even more important that you both have a good relationship with them and compatible relationships. Telephones and TVs can be potential sources of contention and you need to come to an arrangement about their use from day one. My PA can use my phone whenever she wants and she pays for any calls she makes. I have an itemised phone bill to allow us to calculate how much each of us must pay. She knows that I will do my best to avoid interrupting her conversations but sometimes it may be necessary to ask her for help while she is on the phone.

Although I only have one TV in my flat, this is not a problem because neither of my PAs or myself watch much TV and we have fairly similar tastes. My PA is happy to give me first choice in what we watch. However, when I was undertaking my postgraduate course, my PAs had wildly different tastes to myself. They would want to watch every single soap opera imaginable.

Privacy and confidentiality are extremely important to me. When you use PAs, you have to come to terms with the fact that you are never going to enjoy the same level of privacy as an able-bodied person. It is virtually impossible for me to do anything without my PAs knowing about it. I therefore treasure the privacy that I have. For example, my telephone is in the hall

of my flat so that if my PA is in the living room or in her own room I can talk without being overheard. My PA's contract is typical in including a confidentiality clause.

Ali Kashmiri finds that he has to prime his PAs to say nothing because his family sometimes sees them as a source of information.

My mother worries about what I eat. Sometimes I find that she will ask my PA something like what I have had for breakfast. This may sound like a small thing but it gets on my nerves. I make a point to my PAs to respond to all enquiries with a clear 'I don't know'.

Some final thoughts on friendship and privacy from Anne Pridmore.

I often question myself and the question I ask is "Do I expect my PAs to be all things to me?". By this I mean there are times when I am working or socialising with my friends when they sit in the background and other times when a bit of friendly banter would be welcome. How does a PA know what role she/he should take? Am I expecting too much of her/him?

Experience has taught me that PAs come and go and if you have become too friendly with them it can be devastating when they leave. However it is very easy to fall into this trap because many disabled people are isolated from their friends.

For me it is not a very good idea to become too friendly because it shifts the balance of power. How can you tell a PA that she has not cleaned your sink properly for days if you sat up until 1 o'clock drinking and discussing the meaning of life with them the night before?

My induction training and supervision talks about the very nature of the role of a PA. The training looks at privacy and confidentiality and how difficult it is to achieve this is for many disabled people. If you 'share' your innermost thoughts with your PA how can you even begin to talk to them about the rights to privacy?

There are also issues around race to which a PA employer has to be sensitive as Anne Wallis has experienced.

As a white woman who has friends from myriad backgrounds, I perhaps should have been more prepared for the distortions that the employer/ employed relationship brings about. Never having been an employer, however, I am afraid I learnt the hard way. For instance one black, African PA interpreted my responding differently to different personalities as racism. She was part of the scene when a PA who I nicknamed 'Speedy Gonzales' was around. The



latter would whizz through work and then say 'What should we do know?' Once we went shopping and another time we even went swimming. The African woman in contract was quiet and slow in a majestic sort of way. I enjoyed this and made use of the peace she created to read and rest. It emerged, however, that she thought I was reserving the exciting things for the white woman. (She told this to a friend of mine who happened to be from her own community.)

What have I learned? The biggest thing is to lay things out as clearly as possible from the start. Some of that will be familiar to disabled readers; this is the bit where you lay down how you want to be helped, and what you don't want to happen.

Also, it helps to be aware, even if nothing is said, of the power imbalances between myself and my PAs. That way I can try to reduce the gaps, either by behaving as powerfully as it takes to assert myself, or by trying to learn from them and let them show me new and different ways of going about things, or letting them simply feel able to be themselves.



But, in addition, these days, if I have a black helper I say 'Look. I intend to treat you with respect and I truly hope I will not be racist in any way. But if I am, please tell me straightway' I say this to empower my PAs to be open with me. I find it very unhelpful to hear things second hand. However where these relationships worked well, they were really a blessing to be whole family. For example, my daughters are of mixed heritage and I was taught how to plait their hair; I was introduced to wonderful new dishes; one woman helped me carry my babies the African way (perfect for my particular impairment) and we gained some fantastic friends.

Paul and Sarah Robinson's team of PAs have all got to know each other, which somehow to me spells disaster. I like to keep mine well away from each other.

Talking to PA employers in Bristol, however, this topic got a mixed reaction. Some people would not even consider giving PAs each other's phone numbers, whilst at least one person didn't mind if they rearranged their shifts, as it saved her having to make a lot of phone calls. Here is the Robinson's experience:

One advantage of having PAs knowing each other is that they tend to support each other and cover a PA who is sick or on holiday. However you need to be careful if your PAs get together regularly, as we have sensed that they sometimes exert influence on each other, which can work to over disadvantage.

For instance, we wanted to go away at Christmas and in the days before they got together we think it is likely that one of them would have agreed to the trip without too much cajoling from us. In this new phrase we sensed that that the 'job's worths' among them tried to encourage the more amenable ones to see the disadvantages of a long shift over Christmas. We cannot stop them talking to each other but it can be very frustrating if the end result is that you can't get the cover you need. The only solution we found was to fall back on what is required of them in their contracts as regards working over public holidays, changing shifts, etc.

Another consequence of PAs getting on very well with each other is that we had to start being very careful about inadvertently passing on information that one PA told has told us, to the next PA on duty. Not because we are gossiping, but simply because it is natural to share news with a close team of people. However, sometimes this can go badly wrong if a PA doesn't want to hear this information or by asked about it later on by another member of the team. We now take great care to ensure that we are always discreet about any personal information that a PA tells us, and assume it's private unless we are told otherwise! We also have to be careful now with thoughtless remarks such as telling one PA that we think another PA is 'being a bit slap-dash'. The chances are this comment will find its way to the PA in question! So know we are careful, and 'if in doubt, say nowt!'

Ian Basnett has been a PA-user for fourteen years and has a 24-hour care package.

The issues that I find most difficult are interpersonal ones where you are not getting along with your PA or somehow things are not working, personal hygiene problems or performance. All this can be helped by being explicit as possible both in my written material and what I say about the job. I like to have a degree of separateness from the PAs in the day. It is also important that everybody understands that the PAs are there to facilitate me and undertake tasks I can't otherwise do. I make it clear that what I am seeking is a friendly working relationship. To help achieve this I require that PAs use a separate room for reading and relaxing when they are not working with me. I have a small TV, which I put in this room so that they tend to use that when there is ironing or other similar tasks to be done. This way of working suits my lifestyle better. It probably means that I miss out on developing relationships with some really good people. However it does also mean that people who might be good PAs but whose friendship wouldn't be welcome, understand the situation clearly.

It's worth knowing that not everybody finds that relationship an easy one. I think it makes it difficult for some PAs to relax and there are others some find the boundaries difficult, particularly as they are inevitably a little wavy. However, most of the time it works for me.

I have had to tackle problems such as poor personal hygiene. This is never easy, however, having it written down in advance in the job description makes it easier. I point out the importance of that in this particular job and say that I understand that there may be occasions where we all 'slip up'.

Kevin Caulfield sometime worries about not being a good enough employer and is also that very rare beast, someone who actually enjoys the paperwork.

I worry about things like not providing adequate provision and often avoid it because I find it difficult. Although I do deal with most problems that arise eventually. Not giving enough praise I know is a difficulty for me. As a woman/man cannot live on air alone. I generally enjoy all the paperwork and the dealings with the tax people, but that is just who I am! I still

think that the Inland Revenue believes that I am running a Marks & Spencer or a similar concern.

Andre Polanski has had problems with supervision as well, sometimes with regard to finding a suitable location for the sessions.

Several times I have come home from work totally knackered, and still had to find the energy to do a review with a PA who needed practical guidance. Sometimes it is really hard to think clearly when you are doing personnel stuff in the evening or at odd hours. I remember once, the only chance I got to do a review while I was away working at a busy conference, was by doing it in a locked adapted toilet. It was simply the only place I find where we wouldn't be interrupted! My PA thought it was unusual, but coped with it admirably. Some issues just won't wait, they have to be dealt with quickly.

If it all goes horribly wrong you may find that you just have to do the sacking deed. I once took on a driver who had not the vaguest idea of timing or even that it would be the good idea to let me know if she could not make it. There was nothing for it but to take the plunge. I phoned her up and said 'Sorry, but I do not think that it is working out between us' I did not have to argue my case as she immediately hung up. The next day however she took a little revenge and stole the van keys that I foolishly kept under one of the tyres, for the different drivers to pick up. I found them about eighteen months later in a water tub that is next to the van. I think the moral code here is do not make yourself unnecessarily vulnerable – I could have easily have got another set of keys cut. Also watch out for PAs who you think may have the potential to be dodgy, trust your judgement and simply do not take them on in the first place.

Suselle Boffey has also had to 'let someone go'.

This is probably the most stressful part of the employer/ manager role, but hopefully not an everyday trauma. Again it helps enormously to think through your communications strategy well before you confront a worker; this begins with a clear statement of your disciplinary procedure in your contract, a copy of which should always be given to the PA at the start of employment.

To minimise the possibility of being taken to an industrial tribunal by your soon to be ex-employee, it can be useful to offer her/him a final interview to review the facts of misconduct and your reasons for dismissal. Doing this I actually managed to avoid the final act of dismissal on one occasion. After going 'round the houses' for 40 minutes in this interview with an employee who had committed a serious misconduct, but still felt that her personal circumstances condoned her behaviour, she eventually conceded that her circumstances failed to match my needs and agreed that we should part company!

You could say that the fundamental advantage of a direct payment is that it gives the disabled person power in the relationship they have with their PA, which is not the case when an agency or local authority is directly supplying the support. The power means that the PA/ employer relationship can be truly symbiotic. The PA needs your job and you need their labour, a recipe for the perfect balancing act, as long as neither party decides to misuse their power. Do not forget that you have this power and or give it away or feel reluctant to use it. Never be a bully, but PAs will respect you if you make it clear how you want things to be between you.



Quick Tips

- Have occasional reviews where you both get the opportunity to say what's working and what's not.
- Dealing with the issue of finding cover when people are on ill or on holiday.
 - a. It is a good idea to spilt the time you have an employ a number of PAs so that they can cover each other. Try not to put all your eggs in one basket. You could build this into their contract (NB decide if you want to share phone numbers, so they can organise this themselves, or if keeping full control is important to you).
 - b. Former PAs- keep in touch with the good ones, use them as standby where you can.
 - c. Research local agencies- ask other people which are reasonable ones-make contact before you need them, so they know your requirements if an emergency does arise.
 - d. Friends who also use PAs- ask if they have any suitable contacts to add to your emergency list.
 - e. Friends and family- sometimes they are the nearest answer.
 - f. If everything else fails, your local authorities still has a duty of care to you- so keep their emergency number sometimes.
- Be friendly, but do not be friends while the PA is in your employment. You lose control over your situation if you try and have a dual relationship of both friend and PA.

- Have a contract in place. In every contract the statutory minimum on things such as annual leave and sickness applies. The contract can be added to as time goes on and tailored to your needs. Also remind your PAs of the agreements should they be straying from their job descriptions.
- A list of what MUST go in a contract is available from NCIL, there is also advice on contracts in the ILSA handbook. (See the Book List at the end).

4. Its My Party - PAs and your social life

How do you deal with PAs in the social context? This is the question that everyone wants to talk about. A hot date with three people at the table presents an immediate challenge to the social norms. How do we cope with that challenge and how do we develop the skills to minimise the intrusion of the PA presence?

Ruth Bailey tackles this hefty question and also the more practical, but nevertheless major issue of dealing with the cost of taking a PA with us wherever we go.

I've been using PAs for the last 10 years, but it is only in the last year that I have needed, and crucially have had the funding, to enable me to have PA support when I go out. Yes, this is liberating; less stress about access, as I know, for example, if there is a step at the front

entrance I can send a PA inside to find the side entrance. I do not have to restrict my menu choices to what I can manage to cut up/carry or have to metaphorically cross my legs for hours on end. Yet liberation, of this sort at least, brings its own headaches...

The question I constantly grapple with now is how to manage my relationship with my PAs, so that, on the one hand I get the help I need and on the other get the space to be alone with my friends. Or simply to be 'alone', in the sense of not having to talk! If only this were an academic question! In fact daily it sometimes seems to stressed old me, I have to deal with its practical manifestations. Here's a taste of some of them...

Being a keen cinema/ theatre goer, should I get my PA a ticket, or, given that I don't need assistance once settled in the auditorium, tell them to come back at the end? At first I did the former, but I soon realised that this was expensive- and it didn't feel right in terms of my relationship with my PA. If I'd shelled out £20 for a ticket and they didn't seem interested or wouldn't discuss it with me afterwards, I felt pissed off. I knew this was unreasonable on my part, because her job was to assist me, not be my companion. It also made me lazy, I'd think, oh I won't ring so and so and see if she wants to come to the pictures, I'll go with my PA. So now I don't get my PA a ticket, but tell them to bring a book and come back for me at the end of the performance. True, this does lead to some raised eyebrows- 'isn't your friend coming with



you' ask the trying-to-be friendly and actually being patronising box office staff. 'No' I reply, without explanation, which isn't helpful but a girl's gotta have a rest...

I do have exceptions to my no ticket policy- or perhaps, more honestly, I should say that my policy is inconsistent. Some of my PAs are also good mates, and if there is a particular film that we both want to see, I arrange to go and see when they are working and pay for their ticket. This can lead me into tricky situations, such as feeling under pressure to go out with my PA, because from her point of view, a night out to the cinema is preferable to doing my ironing. At one stage I'd give my PAs a choice. I'd say if she were interested in the play she could come if she wants, provided she buys her own ticket. But I'm beginning to realise even that it only feels OK if I'm fairly friendly with the PA and she knows the friend I'm with. Why? Well on a precious night out with a friend, to share him or her with a PA who I have little in common with- and who I spend more time with than friends anyway, just isn't what I want.

It has taken me a while to find the confidence to say this, and will probably take even longer to feel OK about it!

More complicated than the ticket question is that of my handling of the role of PAs when I am with other people, say going out for a meal or at a party. When I first started using PAs, I tried to include them into the conversation, 'putting them in the picture' as it were about whatever it was my friends were talking about. But this was very trying for me, and it felt the PA was getting to know too much about me and my friends- either that or the conversation never ceased to flow beyond the superficial and for me, that isn't satisfying.

I can remember feeling full of despair that I would never again experience the intimate dinners with friends where we talked and talked about really personal stuff. I felt that I would lose my sense of being an individual, that I was becoming one of a couple, yet my partner was a PA whom I had no particular knowledge of, or feelings for, and vice versa. (Interestingly when I am in a relationship, it has always been important to maintain my other relationships, to see friends alone as well as with my partner.)

My next strategy was to try to ignore my PA when I was in social situations, talking with her only as far as necessary for her to assist me. After all, that is the theory, that is a PA's role is to facilitate, and therefore in any social situation, such as when I go out for a meal with friends, they should ideally remain stumm unless talking with me about my needs. This does work... up to a point, although I am still at that stage of feeling quite uneasy about chatting about away to a friend and ignoring the person sitting next to me, cutting up my food, holding my drink, or whatever. And, of course, it is not easy for the friend- still less the stranger, who may have never come across the concept of facilitation. I have yet to come up with a formula of words to explain to those friends and strangers why I am ignoring the person helping me. My fantasy, my fear, is that people think I'm rude, and an ungrateful crip, but hopefully in time I'll get over that, as I convince myself that what I'm doing is OK and I'd quite like them to do the same!

I do try and talk openly with my PAs about all this. Recently, when discussing the role of a PA with an interviewee she said "I can be a very good broomstick". My liberal instinct nearly made me say "oh you're a human being, not an inanimate object" but then I realised that actually, this was a pretty good way of describing how I wanted to be in a particular situation, and I needed to have the confidence to acknowledge this. As an aside, I offered this person the job- but her broomstick skills (and I do think being a 'broomstick' that is being self-effacing,

without appearing bored or sullen, is a skill, and one that doesn't come easily to a lot of people) do sometimes slip.

Once when this happened, I sat there in quite a stew, trying to decide if she was being patronising and intrusive or if it was just me being oversensitive. Then the friend I was with, a non-disabled woman with no knowledge of PA issues, commented that my PA was a bit OTT motherly. Time to act!

Another problem area for me is my tendency to worry too much about whether my PAs are bored. This had led me to some sticky situations. For example, I swim regularly, and while in the pool I tell my PA to go up to the café and come back to the poolside in 20 minutes. However, some people just don't have a sense of time. On one dramatic occasion, after 30 minutes there was no sign of my PA and I was freezing and seizing up, so I commandeered the help of my friend to get me out and stick me under the shower. Now, my friend has epilepsy, and if he's swimming, he gets sufficient warning of a fit to jump out. Unfortunately while he was being an emergency PA and pulling me up the ramp, he got a warning, but he just tried to keep on going, hoping he'd get to the top without passing out. He didn't, and things got hairy for both of us. When my PA came back, I was pretty angry. It took a friend of mine to point out, that to send my PA off for a coffee was for their convenience, not mine, and I wasn't really taking due care of myself. It would be perfectly OK for my PA to sit by the pool and read a book, which would then give me the freedom to get out whenever I choose.

As I become a more experienced PA employer/user, I hope that perhaps I can 'let go' a bit and not worry so much about what might my PA might or might not say in any given situation. I need to recognise that I cannot control a PA – and, more importantly I don't have to- but what I can do is give a clear instruction as to my expectations and needs, and then trust them to get on with it. Then I will be able to enjoy myself even more, and probably have a much better, more professional, relationship with my PA. Certainly in the early days I craved for somebody to be at my side, teaching me how to be a PA user. That would be good, but in a way one has to learn by doing, but testing things out yourself. After all we are talking about relationships here, and these have to be shaped by one's own needs and personality – and that of the PA. What feels 'right' with one PA, may not feel so good with another. A book like this will be invaluable, giving reassurance that "it's not just social inept me" who struggles with these questions and also gives a framework for considering them.

Ruth's experience shows that you have to find your own way with this issue. There was a time back in the seventies when some people experimented with the idea of regarding a PA as a disabled persons arms and legs. A macabre metaphor, but it is not surprising that the idea was run up by the flagpole. However, as it infers on the PA the approximate status of a sideboard, lowlier even than the broomstick, it did not really stand the test of time. At first the idea was taken very literally and they may still be some PA employers who operate in this way but nowadays most of us try and find a slightly more sophisticated strategy.

The real trick is to treat a PA like a human being and not lose your own humanity in the process.

One problem with adopting a single approach at all times, such as invariably introducing your PA as a hologram from the planet Stumm, whose programme will instantly cease to function should they be directly addressed by an earthling, is that you are denying yourself the benefits that a PA with good social skills can have. Being one of the laziest people in the world, I have found that the sort of social occasion which involves people that I do not know very well, can be

eased along tremendously by the right PA, who can chat merrily, leaving me plenty of time to think my thoughts and read the menu.

If you have PAs who are more capable in a social setting then try and take them with you as opposed to the ones who yawn a lot and insist on asking your friends if they are enjoying themselves every time there is a lull in the conversation. Don't think you have to give everyone a crack at your social calendar. Of course if you can only get a yawner then my advice is to stick with the "please don't chat to the android" line.



There is a difference between the arms and legs philosophy and being civil with people while firmly relegating them to the wings of your social stage. People have to understand that on most occasions if PAs are not simply left in the background to facilitate when the need arises, then our enjoyment of a social situation can be greatly diminished. A work colleague of mine once got very uppity because a disabled person visiting our office did not include his PA in the chat. We could not get her to understand the need of the disabled individual to have a life which did not forever involve introducing PAs to whoever was with her and then letting them get to now each other.

He, like all of us, wanted his share of attention in a social setting. If a PA starts taking up the social space there is obviously less to go round and unless the disabled person has a truly huge personality they will be relegated time and time again. If my co-worker started flirting with the PA, which in this case was a real possibility, it would have profoundly affected the group dynamic, probably to the detriment of Mr Wheelchair. It had to be pointed out to her that at the end of his shift the PA would go on his chosen social way without giving a thought to the social needs of Mr Wheelchair, who would then be doomed to entertain the next shift of workers.

Perhaps we could learn from our relationship with waiters, which of course is as much about how the waiter behaves as how we behave. You know where you are with waiters – they are doing a job, they are there to help you, but they will never try and start genuinely social chat with you. A PA code of conduct should be devised to allow them to indicate easily that they are on duty and do not need or want to be included. Another thing about waiters is that they often wear a uniform, not that it discourages one friend of mine from flirting her socks off when she orders her food but of course the rules allow them to ignore her without giving offence. In all seriousness I wonder whether the idea of PAs wearing something to signal that they are not present in a social capacity could become recognised.

The problem with PAs in a social context is that you cannot control how your relationship with them is perceived by others as Anne Wallis has found.

One woman, who remains a friend to this day, come to me very soon after leaving her home in Jamaica. Our only problems lay in how others perceived our relationship. On her first day working for me it happened that I was due to visit an old friend, also black and from the Caribbean. My friend found the situation almost intolerable...it reminded of when her family used to have servants. Although she tried to tell herself there was nothing I could have done differently. It seems to me that it started a rot in this my oldest and dearest relationship, which withered away within two years.

There have also been two white friends who, I have found out indirectly, thought I was racist in my dealings with my black PAs. It seems to me that, as an Asian friend put it one evening, I was on a hiding for nothing. As any of you who have PAs for most, or all of the time will know, your relationship with them is public, whether not either of you wish it to be so. As such it is open to as many different interpretations as you have different friends and relations.

Andre Polanski's social life makes me feel tired just thinking about it. He has discovered that there are plenty of pitfalls to using PAs on the gay scene as he now describes.

I am really lucky living in a city and being able to recruit personal assistants who know how to behave in lesbian and gay company. I met a PA user recently whose male PA kept making comments about women in a gay bar- it was really upsetting for them, and for us to be forced to be in this guy's company. On another occasion I have had to have a stern talk with one new PA who thought it was OK for him to flirt and get chatted up while he was supposed to be working i.e. assisting me!

Because the gay scene can be so small (or seem that way) a lot of the time when I go out, my PAs will have people they coming up trying to socialise with them, not understanding that they're working. It takes a lot of effort to try and deflect them. I've even had one guy physically threaten me when I asked him to stop disturbing my PA. It was really frightening.

I remember being told by a social worker early on that disabled gay men and lesbians didn't deserve, as she saw it, 'special treatment'. She didn't think it was part of her job to make her assessment with any thought for gay issues and was concerned that if I had assistance to go out to gay venues, it would be seen by other people as 'sex on the rates'. If only she knew how many times I've been out and been completely ignored by people trying to chat up my PAs.

As Ruth touched upon, the PA user/ PA relationship also impinges on your time alone – your thinking and creative time. Only the other day I was luxuriating in the bath, a place where most people get struck with ideas for novels or develop major themes of their symphonies. No visitations from the muses for me however, instead it was a case of knuckling down to my PA's long description of her meal at Harvester. I spotted the danger signs as soon as she plonked herself conversationally on the loo lid. Each vegetable was lovingly described, the texture of the meat exactly delineated. I even learnt that her sister had chosen butterscotch sauce in preference to strawberry, on her ice cream that is. I will only say that I am led to wonder whether this could be why there is such a paucity of disabled novelists and composers and perhaps the National Disability Arts Forum should look into it.

Victoria Brignell also finds she wrestles with the issue of how to be alone.

Able-bodied people often do not appreciate how stressful it can be to use PAs. As I am tetraplegic, paralysed from the neck down, I rely on PAs (and often two) around me most of the

day. Luckily I am a fairly gregarious person and I like other people's company. However, there are still times when I would like to be on my own and this is difficult to achieve. I feel that I am 'on show' all the time and this can make it difficult to relax. A few weeks ago a friend from school days said to me that she felt tired after entertaining her university friends all weekend. This is what it is like to have PAs with you all the time. You constantly feel that you are 'entertaining' people. You cannot just shut your door on the outside world.

Private time can also be romantic time. This usually involves at least one other person. Andrew Bruce prefers this to be his wife Maureen. They have developed the art of canoodling in spite of being surrounded by a huge team of PAs.

Retaining privacy when, as a couple, both of you are using PAs, presents a genuine problem at times. We have a PA with us for the best part of 18 hours a day. Therefore, even if they are in a different room of our not very large home, it is not an ideal environment in which to 'whisper sweet nothings' or similar to your partner. We find PAs are always sensitive to our need for privacy, but unless you talk it through with them in advance it can make for an awkward atmosphere, as well as an absence of 'nooky' at home!

As a married couple we have found it best to discuss this matter with each of our PAs, once they have settled into their job, and feel comfortable with us. This then creates the mutual trust necessary to share our personal life and needs. That way, whether we wish them to go for a long walk, or assist us getting into bed, it would have been talked about openly and agreed between us. Then, when the actual time arrives and you crave some privacy our PAs should be able and willing to move into action without any fuss or embarrassment. If there are going to be any issues for the PA then they need to be dealt with in advance, and not when we are just in the mood for a cuddle!

The issue of being with your family and having PAs in tow can perhaps be more tricky to manage than being with friends. Amarit Desai finds it a challenge.

The fundamental difficulty I have with my mum is that she feels guilty because she is not doing everything for me and that the Asian community thinks badly of her because I am living away from my parents. I try very hard to organise things so that my PAs are not there when I am with my family- my nephew in particular has said he likes it more when it is just the two of us.

I have to supply them with a lot of food, which takes some doing. I really enjoy our days together but I am certainly flaked out for a long time afterwards. I like to make sure that my mother gets some time to enjoy just being with me. When I am at my parents' house I find my dad does not really talk to my PA very much, which makes things uncomfortable and my mum keeps whispering "are they going yet?" Not surprisingly the conversation gets a bit stilted.

And finally there is the issue of being with your children. Currently it is quite unusual to get a Direct Payment entirely for the purpose of facilitating parenting tasks, but it can be done. Certainly there are some visually impaired people who have been successfully getting payments for this purpose. We can only keep battling on to ensure that parenting is fully recognised as one of the activities with which disabled people sometimes need facilitation.

Operating as a parent, dealing with the fairly recent acquisition of a PA team and also with the relationship of a PA team and also the relationship between your children and the team can be a lot to take on board.

Anne Wallis describes her experience of getting to grips with it all as a parent of twins, employing PAs.

Having someone, who starts out as a total stranger helping you in your home, is worrying enough. Will you like each other? Will they understand your needs? Will they patronise you? Will they bully you? Will they do things the way that you like having them done? But when that person arrives to support you in your role as a parent, any number of other issues enter the arena. Now you not only need all the ordinary things to go right, but you also need this person to respect your wishes about how you raise your children. It is much easier receiving help from friends or family from one perspective at least – which is that usually there is between you something that is shared culture; may it be class based, racially-based, to do with religion, or perhaps with a set of values. When any or all of these are shared, it leaves everyone free to concentrate on detail.

When, however, little or even nothing of the background and culture is shared, there can be any number of power gaps – in both directions (you are more powerful than your help or your helper is more powerful than you) and these can lead to either wonderful learning and new relationships, or disasters. I've had my share of both and learnt a lot in the process.

I am white, English (but with African beginnings) of Jewish descent and from a middle class family. I knew what my values were and was very clear about some things I did not want to happen. I did not want my children hit or physically hurt ever, by anyone, and I did not want them to be shushed if they cried. I needed my helpers to work directly with children because I had twins.

One of my best helpers, who has become a friend, was a black working class Christian woman, newly arrived from Jamaica. Motherhood and earning our own livings were the absolutely only thing we had in common, in terms of culture and roles. We didn't hit it off in any astonishing way, we just proceeded slowly to get to know each other. But we are both fundamentally respectful and caring people and it is difficult not to warm to someone who is gentle and loving towards your children.

One difficulty I hit was that my babies took to her so much that I had to confront, not so much jealousy (because they loved me that much too) but fear that they might not know who was really their mother. This came to a head one night when we were all staying at a friend's house. She slept in one room with one daughter and I was in another with the second. The latter woke up and in the night and began to cry. She was inconsolable and repeated the same syllables over and over. I was convinced that she was calling for my PA, and to this day I don't know definitely whether it was her sister or really the PA she wanted. But it rattled me and the next day I decided I had to raise the issue with my PA. I could, however, do no more than tell her that I was upset and yet couldn't possibly fault her. I needed her to be loving with the girls and yet I needed them to feel they knew I was their mother. This young woman listened, but had nothing to say. It appeared unresolved and unresolvable ... yet it was never again any kind of problem. I'm glad I told her what was bothering me, because otherwise it could have really festered and poisoned all our relationships. How and why it sorted itself out I have not the faintest idea!

Quick Tips

- Do not feel guilty about not including PAs in social activities, particularly when there is a cost involved. Remember your package only covers their wages.
- Try and train your PAs to take a backseat – talk to them beforehand about the type of social occasion that is coming up and work out your joint strategy.
- You need to give them an allowance if you are out a day, or remember to tell them to bring a packed lunch if you can't afford that.
- Contact the Disabled Parents Network for support and advice on the subject of parenting. Tel: 0870 241 0450

5. The Sting - Guarding against dishonest PAs

Forewarned and forearmed so they say and the aim of this chapter is to forewarn readers, of things to look out for if a PA is ripping you off. This happens very rarely, but it's as well to bear it in mind. One incident happened to me and the other story is Penny Pepper's. Her tale is probably more sinister than mine, going beyond petty theft. Penny lost power in her PA set up and it took a new husband to come along and point this out. We both consider ourselves to be reasonably savvy, we were both conned right rotten in different ways.

I had money going missing, which I found being a weird experience. It became very important to me to find out who was guilty, because I felt that until I established this categorically then nobody was. The explanation had to be that I was just imagining my money was going missing. I must have spent it or it wasn't there in the first place. If this ever happens to you I recommend you try and get a grip quicker than I did, as it will certainly help your bank balance.

It is obvious that I just have not read anything like enough Agatha Christie, because I immediately took the view that absolutely everyone who came into my flat was under suspicion. I could not seem to take the logical view that someone who had been with me for thirteen years was less likely to be the culprit than a person I had known for only six months. When I at last came to my sense and realised that my trustiest old allies were not likely suspects, I eventually caught the thief red-handed. Let's call her Lilly Liar.



She didn't have a regular slot with me but did a lot of filling in gaps, particularly at Christmas. I told my brother how available she was for ad hoc work and he pointed out that given the financial benefits this was hardly surprising.

Once I had her in my sights I got her round at lunchtime for the loo, first loading my purse with four tens and two fives. Sure enough when she was gone one ten was missing. Strangely I found

this quite shocking, although with the benefit of hindsight I can now see there were plenty of sighs that all was not right with Lily. A major one was her desperate attempts to persuade me to take out a loan for her to get a new car, as she was too young to get a loan herself. I very much regret not giving her an instant “not on your nelly” response. It was not a situation where assertiveness was difficult. I think I fell genuinely prey to the idea that as it would not be hard for me to get a loan, and as I trusted her, what was the harm in thinking about it?

She also borrowed £400 from me, and so far I’ve only had £250 back. The loans were given in the form of payments I made for her on my credit card over the phone, which were made in the form of a bouncing post-dated cheque (so watch out for that one). Talking to a friend of hers who she also ripped off and lied to, it became clear that most of what she told me about her life was a pack of lies intended to make me think she had money, so that I would get her the loan. She was also inventing all sorts of stories that seemed to give her no advantage at all. For example why bother to say that I become disabled in an accident ten years ago and that she and I often went clubbing together? For the record I have been disabled since birth and frankly the idea of going clubbing with an eighteen year old, well I would rather spend an evening stuck in a lift with Dr Kevorkian.

The point of writing about this is to point out that a torpor can overwhelm you, which stops you spotting what afterwards seems so transparently obvious. This I suppose can happen in all sorts of circumstances, but I’m sure in my case it was somewhat fuelled by the fact that she was a good PA who I didn’t want to lose. If you’re aware this can happen you are less likely to succumb.

Here Penny Pepper writes about her experience of this phenomenon.

Before my relationship with my husband, Gabriel, began I was surfing along with my PAs. I had a relaxed attitude to my staff and did them favours, which I did not initially perceive as a problem. With hindsight I would say this easy-going approach is a tactic I adopted to avoid conflict because I hate conflict. I have needed ‘care’ from early childhood and have come to see that many of the ambiguous interpersonal dynamics between myself and my PAs reflect this past.

It was in to this backdrop – and my rather lax mind-set – that Gabriel arrived. He is fairly newly disabled and is still learning about disability rights and politics, yet as a post graduate doing his doctoral thesis when I met him, he has a very sharp mind and an ability to grasp matters quickly.

With the heady rush of our relationship, I believe that he remained silent about what he saw as exploitative practice from my PAs, initially out of deference to me. When he eventually tempted to voice his dismay, I was immediately wary. He didn’t understand about PAs and independent living schemes I would argue; he was still a ‘novice’, I knew better and so on... When he continued to express his concerns about one of them, Mrs T- who had been a very ‘faithful’ PA for four years – I insisted she was above reproach, and became quite distressed when he suggested otherwise.

As Gabriel had support needs of his own my workers were asked separately if they were comfortable giving him cover. They would naturally be paid more as appropriate- while I would ensure my local authority acted quickly to assess Gabriel’s needs to extend the funding. The PAs agreed without any complaint- maybe they were just trying to be nice to me or were

desperate to remain employed- in fact they seemed enthusiastic, saying that they were pleased. None voiced anxiety about changing to supporting both of us and I was happy.

I confess that I find it painful to write about this situation with hindsight, as my mind does truly boggle at the level to which I had let the professional boundaries blur. One issue that Gabriel brought home to me almost immediately was how much time I had spent with Mrs T doing nothing other than chatting i.e. every morning on her five hour shift, she and I would spend perhaps three hours simply idling as though we were friends. It was a long time since I had stopped to think whether this was using my time (and my PAs) effectively. I had lived this way for a while and just jogged along with it.

Gabriel pointed out gently that it seemed to him this was one reason I was constantly groaning that I never had sufficient time for my writing- and now there were the needs of our personal time together if our relationship was to continue smoothly. I admit I was shocked into a period of re-evaluation which led us both realising that the structure of shifts I had had for some time now suited the PAs considerably better than me. It was also obvious that changes would need to be made for the scheme to work for us as a couple.

Also difficult during this period came the slow realisation that I was indeed being exploited as Gabriel feared.

While I was reluctantly accepting this I went through a very difficult period with my PAs which eventually made the truth clearer. They started to play off against each other, taking the opportunity to hold whispered conversations when a shift change occurred. They would then individually report back to me with choice morsels of these conversations- which of course all contradicted each other- but all creating a feeling of instability and confusion.

I believe now that Ms T's active – yet initially hidden dislike of Gabriel arose because she saw that he would be the conduit through which I would reassess the cosy set-up in which I lent her money, my car, my clothes- and was ridiculously lenient over her slack time keeping. While I accept that PAs and users will not inevitably like each other, I believe this was a matter of jealousy that she would no longer be able to manipulate me to her own devious ends. She resigned when we told her we were getting married. Her parting shot was to steal various items from us, to fix it for her husband to fleece us over a decorating job, and for her to land me with an unwanted mobile phone contract – then to coax me into fiddling the amount of holiday pay she was owed.

Much of her exploitation of myself (and Gabriel) came to full light after she had left. The sense of betrayed trust caused me enormous hurt, from which I still feel bruised and wary.

The problem is that when you start to talk about this sort of thing people start describing you as 'vulnerable'. I find this hugely irritating. We are no more vulnerable than anyone who mixes with other members of the human race, some of whom, as we all know, are a pain in the bottom. If we start taking on board the notion of ourselves as vulnerable we are going to get into a very miserable state. As a PA employer from time to time you have to be quite steely. Always keep your needs at the forefront and in the nicest possible way do not let them mess you about.

If you are sure or reasonably suspect that a PA is up to no good sack them as quickly as you legally can.

The point I really learnt from Lily is that, at the risk of sounding like your local neighbourhood beat bobby, it is a bit stupid to leave temptation too much in the way of people, particularly people one does not know well. When it comes to money, if you've got it do not flaunt it. I should have kept my purse in the bag on the back of my chair at all times, so it would have been in the loo with me and I should keep the cash in my drawer locked up. As it happens I think Lily was more than just succumbing to temptation shoved in her face. As a girl who was filching from her friends, fantasising from fit to bust, getting into credit card fraud and stealing from a clothes shop where she briefly worked, it would have taken Fort Knox to keep my cash safe from her. In fact I think I got off lightly.



Quick Tips

- Be hard nosed about this and if you think someone is taking your money then make checks i.e. count it before and after each PA comes and goes and then take action.
- It is obvious thing to say, but do not leave temptation in the way. Be careful about who knows your PIN numbers and keep a check on the whereabouts of bank cards. On the other hand, you could take the view that if you cannot trust them completely, you may have the wrong people on board.
- Do not take it too much to heart if this happens. This may be an area where the advice about not becoming friends could come in very useful. Getting a bad or dishonest employee does not make you a bad employer – just an unlucky one.

6. We're All Going on a Summer Holiday - Don't forget your PA

Some people are able to choose to manage without PAs in social situations, but even those with the mightiest of bladders generally have to take them on holiday. Holidays deserve a chapter to themselves because it is quite easy to get your PA arrangement wrong when going away, if even you have a little trouble at home, but there are some very clear things you can do to avoid difficulties. It is never cheap to go on holiday and it's even more expensive to go with a PA. If you find that your precious days away are not working out well then the cost is reason to make you feel doubly cross. On holiday the relationship between PA and user becomes more intense, because they are with you all the time.

For me the basic problem boils down to a conflict between them wanting to do something such as sleep or shop at a time when I have no desire to do either and want to do something completely different. I am talking about there the type of holiday that involves a lot of sightseeing and activity. I want to get up and out and they just want to hang around. It is fact that you do learn a lot about the ways of other people being a PA user. I have been amazed by people who I think would have happily spent a fortnight sitting in the hotel room watching the TV if they hadn't had me to get them going. I think it helps to drum it into them before you go

that it is going to be very tiring for them. Get them mentally prepared for action and exhaustion. The other thing I could certainly do, but as yet have never really managed to is to give them at least time off in the day.



I have found that even fully adult PAs can suffer from homesickness. Try and take one who is not too family orientated, or at least used to the idea of 'travel' - Australians are a good idea. The last time I went I took an Australian nurse. She was extremely capable, but had a bit of a bossy nursery way with her. The only time this became irritating was during the getting up ritual, which we both loathed, basically because the access in the hotel made it difficult. We ended up apologising to each other profusely for being ratty in the mornings and apart from that got on extremely well.

Ali Kashmiri likes to go and see his family in Pakistan. The last time he went was five years ago.

I find it difficult to get people who want to go to Pakistan and who will fit in the culture, men and women not mixing and so on. I have been trying to make this trip for two years, but I do need a person who

is on the ball, particularly during the plane trip and I would rather go with someone I know. Last I took a white PA- it was quite isolating for them-they read a lot. We also had to deal with the fact that where I come from people are idolised for having white skin and strangers would be buying him drinks and fags.

Here Maureen Bruce gives you the benefit of her first experience of taking PAs on holiday and how she and her husband Andrew learnt the hard way. It is crucial to point out that this holiday took place before Andrew and Maureen had a care package in place, so while the PAs had all their expenses paid for, from the Bruce personal pocket, there was no money for wages. I do not think you can underestimate how this reduces the power of the disabled person in the relationship. It is not only about power, paying someone also gives them a clear message about the nature of the relationship between you. Having said that I have dim memories of not paying people when I was younger and things going very well. I think it can be easier to fall in that sort of arrangement when you have youth on your side.

Our first PA using holiday taught us how important it is to make it clear to the PA that for them it is a 'working' holiday. We also learnt how a PA who had been an ideal employee on her own, changed completely when paired with the second PA who happened to be her sister. You can extrapolate from this that group dynamics can sometimes do strange things when far away from home.

Lesson number one- be very careful when employing relatives to work together! Our original PA had been a delight on her own, but when mixed with her sibling the duo formed a volatile cocktail! There was so much sulking when one PA's partner sent a huge bunch of flowers to his beloved, while the other one didn't make contact at all!

Lesson number two- from the outset, make it clear in writing, what is expected of your PA. Our holiday had been planned in minute detail, three weeks in California sightseeing. However, because we had not categorically set the goal posts, our PAs thought it was their holiday too.

Another point that we seemed to fail on with the pre holiday clarity was the assistance they were expected to give to Andrew, who at the time was not a PA user in his own right. However we thought we had made it clear that when on holiday, Andrew also had personal assistance needs. As these were far less than mine, for some reason my PAs decided not to take him at all seriously. He was made to feel a nuisance when requesting help, and when they did help him in the shower, they thought it hugely funny to grab their camera and take a picture of him! In other words, they were blurring the role of a PA and a friend. This was totally unacceptable behaviour from a PA.

Lesson number three- be wary of taking away PAs who have young kids. Throughout the holiday, they kept going on about how they were missing their offspring, and at every moment stopped at roadside stops to buy any rubbish to take home for them. Unfortunately, as they were doing all the driving, we lost an element of control, and were often left strapped in the van in sweltering heat waiting for them to come back from their shopping forays!

Lesson number four-make sure your PAs have stamina. We could never quite understand why they were always so tired. On the way to Hollywood we wanted to stop and do some sightseeing. This didn't go down well, and we were told in no uncertain terms that they were worn out, and all they wanted to do was get to the hotel to take advantage of the swimming pool. It was funny that they were never too tired to sunbathe.

Jane Campbell learnt this the hard way when she went to Canada. Jane likes nothing better than to go on extremely long rambles, which of course involve the Herculean effort of keeping a finger on the control stick. The PA can be staggering along beside her, feet red and raw, perspiration squirting from the brow. Symptoms to which Jane was blissfully oblivious until the PA was almost too tuckered out to beg for a breather. Now Jane makes a point of stopping for a coffee every so often. She really is all heart.

On a serious note, we as employers should recognise that it can be tiring being 'on duty' for long hours when away from home, and ensure that proper rest breaks are built in. Our PAs have told us that even when they are not on shift on holiday, it is hard to 'switch off' or 'get away' when we are all living together for a couple of weeks. So bear this in mind when deciding who to take on holiday.

Lesson number five- clarify who is paying for what. When on holiday it can be very costly to pay for a PA's meals as well as your own. For instance, what happens if you decide to go to a swish expensive restaurant? Do you consign your PA to demolishing the contents of the bread basket, or bite the bullet and dig deep into your purse? Money can be a very thorny subject, and budgeting for meals is an essential element when planning a holiday. Again, it is very important to get this clear from the outset. This can also apply to who's paying for phone calls.

Lesson number six- do not lose control of your PA. Yes, I'm sorry to say, as you have probably gathered, we did! This was our first experience of taking a holiday with PAs. Had we been at home and in familiar surroundings no doubt we would have sacked them. However we were thousands of miles from home and felt very vulnerable. When one is relying on a PA for everything from getting up in the morning to going to bed, it can be very difficult to start asserting oneself. As it was, all the tension erupted in a huge row, which had us in te bothars. We spent the last week of the holiday keeping our relationship with the PAs on as businesslike a basis as possible and keeping as far apart from them as we could manage.

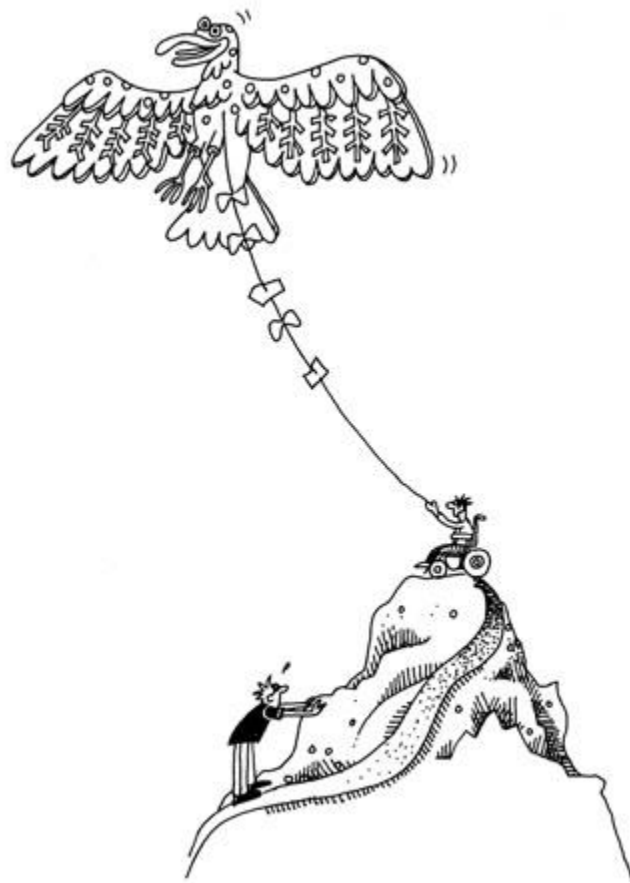
However, we're happy to say that we have learnt from this first experience as employers. Since then we have had some really great holidays with PAs, which have been positive and enjoyable experiences.

I have to say that any friend whose idea of fun was taking a photo of me naked in the shower would very soon be an ex-friend, but maybe I'm just being a misery again. At the risk of repeating myself on the issue of cost we really do have to keep banging on about this to the people who pay the packages. At the very least it may make them think twice about charging policies that mean working disabled people have to pay a huge amount of their wages towards their basic package. Preferably, they will in time get their heads round the idea of actually increasing packages to cover these massive expenses.

Finally on the subject of holidays here is Roy Webb with a story which amongst other things teaches us that there is nothing wrong with a bit of honest calorie counting.

This is about the first time I flew on an aircraft. I was flying to Edinburgh. One difficulty arose because our seats were well to the back of the aircraft. I managed to get the airline to swap these to four seats in business class, as some of these were empty. This meant that my seat was nearer to the aircraft door. The next problem was that I needed to transfer my 'big bum' from my wheelchair to a tiny seat that only looked about half as wide as my bum! The little trolley, with me precariously strapped to it, had to be wheeled down to where my seat was and then somehow I had to transfer from this tiny thing onto my seat.

Luckily, I had three of my regular workers with me at the time and somehow they managed between them to do it! Thanks to the uncomfortable aircraft seats, by the time we reached the other end we all needed a massage and a rest.



The moral here is that if you have good workers that you have built up trust with, then anything is possible! Even fitting an oversized bum into an undersized seat.

Quick Tips

- Remember the European Working Time directive when going on holiday. It requires that rest breaks are built into the working day. Employees can opt out of the maximum hours part of the directive if they choose. For more information call NCIL.
- Sort out who is paying for what in advance.
- Do expect your PA to take responsibility for the packing. It is a good idea to make a checklist of all things to be packed. Check all your stuff into the bags at both ends of the operation.
- Have a good time.

7. Hi Ho Hi Ho - It's off to work we go

The PA phenomenon has hugely increased the employment prospects of disabled people, but it is one thing to worry about how PAs will affect the social dynamic when one is pubbing and clubbing and yet another to cope with the omnipresence of a PA at work. The situations people describe here are often about colleagues making difficulties for the PA user. I think the professional environment is a place where we can expect and will soon get more understanding, or at least better treatment. As ever staff training must be part of the answer and I am sure this chapter will provide some useful material for all those consultants out there. The Department for Education and Employment's Access to Work scheme does now provide a serious source of finance for PAs at work and so it should follow that PAs at work become a more familiar sight and less cause for consternation.

Alice Maynard recounts her experience of using PAs while she does her job at Railtrack.

I work with a PA, paid for by Access to Work. I need them when I go out of the office on business- sometimes just for a few hours or a day, and sometimes overnight. One of the problems that I find is how other people at business events – strangers and colleagues – relate to my PA.

All of us work with our PAs differently. Some like their PAs to function as individuals, and some just as an adjunct to them- their arms and legs. And then there's a whole spectrum between, and I'm somewhere in there, but pretty much towards the 'arms and legs' end. I don't need my PA to take an active part with me in meetings- in fact they'll often go out for a couple of hours till I need them again- but I don't want them to be totally isolated from the rest of the group, especially if it is something like a business dinner.

Some of it depends on the PA themselves. Some PAs are better being polite and friendly to colleagues without getting involved in conversations or activities that are unrelated to me, as this tends to make them feel less available to me if I need them. I quite often have agency PAs from the town where I am visiting, and I genuinely just meet them just a few minutes before the meeting or whatever. So there's rarely time for a 'proper' briefing. Once I had someone who was doing agency work whilst training as a doctor. She was very lively- but you would have thought this was her meeting not mine! She was very difficult to shut without putting her down in front of other people.

Other PAs are so reserved, that I have to be very explicit when I want their assistance. Subtle hand signs mid meeting don't work, so I can have a situation where I ask my PA, say, for a cup of coffee, and my colleagues leap into the breach- eager to help. Very nice of them, but it does tend to disrupt the business, which is generally what I want to avoid by my ineffective subtlety!

I have had an experience where I was using my husband as a PA for work (not through Access to Work, I hasten to add!) and the group we were with very friendly and welcoming and insisted he took his own place in the workshop, even though we had only paid for me to be involved. He was put into a different group from me and that was very awkward- several times that afternoon I wanted his help, but he was elsewhere and involved on his own, and so I was stuck. That taught me a lesson about keeping my PA 'to hand'. But that nearly backfired on me the other day. We were off in the New Forest for a team building session (very nice indeed) and after dinner we had a quiz. My PA that day was my regular for work and she is quite well known by my work colleagues. She had been getting something for me when I was allocated to a team, and when she came back, she was allocated to a different team. She is very easy going, and a brilliant PA. However she wasn't aware of what I would want in the situation and didn't want to make waves. When I found out, I insisted that she was with me – and my colleagues started to 'rib' me, including one of my own team, who I thought would really know better. I found it really hard – I didn't really have an opportunity to explain, but it was like saying no to a visually impaired person 'no you can't have large print'. Although my PA did join the team I was in, it was a very uncomfortable moment, and one of those that leaves me feeling unreasonable and demanding. It seems we have a lot of education to do!

Andre Polanski has had similar experiences.

On a couple of occasions in the past I've been in meetings where people have insisted my PAs leave the room and refused to continue if they don't. I didn't have any choice but to leave as well.

Once at a lesbian and gay conference I was told I couldn't bring any heterosexual PAs with me – effectively stopping me participating. I don't live in a fantasy world where I can pick up PAs to suit other people. I tried to explain to people why we don't always have the choice over the sexual identity of the people who assist us, but even though my PAs weren't assisting in the group, they decided that only lesbians and gay men could be in the room.

I got told today by a group of occupational therapists (who I was giving a presentation to) that I was 'very lucky' to have personal assistance and to be able to do what I want, and that other disabled people weren't that 'lucky'. And these are the people that will be deciding who gets assistance and adaptations!

Not on the subject of inter-personal relations but very much on the subject of work I lost two jobs last year because I'm a disabled PA user; one city didn't have any accessible accommodation available for me to move into and the other refused to take on my PA package. And the government says we should embrace employment!

Susan Maynard-Campbell, as it happens, is Alice's sister. She encountered some fairly naked opposition to the way she organises her life.

I use a PA for the purpose of work only. My husband picks up the rest. I have only one PA and we have a brilliant working relationship. I describe her as 'my arms and legs' but sometimes now she is my brain too! We have been working together for over three years. However, she is more than happy to take the 'melt into the background' position that many of us feel is right for our PAs.

My main work is disability consultancy and training. In general, at some point during a training event, I will introduce her as a means of educating participants on the issue. Despite this I have had major problems with just a few people who cannot accept this is the right approach. I have been told that slavery ended in the 19th Century! Even when I get my PA to say her own bit about her being totally comfortable with the situation, it still happens.

Often I am required to name my PA 'for security reasons' at an event I go to. The other day I was doing a workshop at a conference. I had had to name my PA and then she appeared on the participant's list, which was alphabetical. They then split us up alphabetically and we were assigned to different places for lunch! Another danger in acknowledging your PA as an individual is, as I am sure you know, that people take it as a release to speak to them not you. Even 'right-on' people fall into this trap. A nameless person in the background is less likely to attract attention.

I have now just about cracked it by explaining the situation as being like a 'minder' or the civil servant who shadow ministers. However, I think we PA users need to do more work, as a group, to help people who are not in our position, to understand the situation. We need to find ways of showing we value PAs, but that they are there for us, not as participants in whatever we are doing. Any ideas?

I have spent quite a lot of time working at the BBC's Disability Programmes Unit where they have a team of PAs known as access workers. On film shoots access workers have to be alert at all times to needs that may arise from anyone- from contributors to cameramen-while simultaneously being invisible to the extent that they could teach David Attenborough a few tricks about blending into the undergrowth.

The fact is that access workers need some different skills to those found in PAs you recruit for home use. Access workers have to have the usual attributes of common sense, physical stamina, etc., along with a dash of media savoir faire. PAs probably need extra skills in any work context.

Twice I have made the mistake of taking PAs from home into the BBC environment. One of them got caught up in a fire evacuation exercise, which included Esther Rantzen amongst those congregated outside the White City Building. The PA was immediately in awe at the sight of the great broadcaster, loudly sharing with us her desire to put an arm around Esther to protect her. Hard to imagine that anyone could have such a scary thought, but she did and my opinion rather blew the cred of the DPU by telling everyone this so loudly.

The other occasion when I had no choice but to take a domestic PA up to Elstree where soaps are made, also ended in my blushes. I had a feeling it was going to be a bit dodgy, so I very clearly told her that she was not to speak to any Eastenders actors if she happened to run into them. I had a vision of Barbara Windsor being 'out-Windsored' by this particularly effusive PA.

One thing we have to acknowledge is that it is a competitive old world out there and when we are at work it is extra important to fit in, be cool at all times and not look like a wally, even by

association. At the BBC the entire workforce is crazed by ambition and even researchers on a two-day contract bulge with their own self importance and of course a bit of this rubs off. You can imagine how pleased I was when I heard, as I was buzzing down the corridor past a man dressed the surgical scrubs, her limb little voice innocently piping up, as if she didn't know the answer perfectly well "Are you from Holby City?" Let's just say I was not pleased.

Jane Campbell also has her image to think about. Any amount of power dressing will not compensate for those occasions when a PA decides to let your side down.

Attending professional conferences and seminars, usually, as a guest speaker is part of my job. Imagine my horror when I spied out of the corner of my eye, my PA/driver for that day, filling his pockets with chocolate biscuits laid out for conference delegates! Not one or two for later, but hands-full. I frantically attempted to distract the delegates' attention with witty stories and profound insights, hoping they would not notice. A telling-off later was, alas, to no avail. Later that month, in fact on every similar occasion since, the refreshment table has proven to be too much of a temptation for this hungry man.

Solution? Give him a fiver to go down to the fish and chip shop? Ask function organisers to place some PA refreshments in a side room? Send him on a long errand?

The point here is that you have to make the right decision about which PAs are going to do what for you. Some PAs are good at ironing duvet covers and some are discreet in the workplace. Your job is just to try and not get the two muddled up.

Quick Tips

- You can get the money for PA support from the Access to Work scheme. Contact the DEA (Disability Employment Advisor) based at the Jobcentre.
- Think about the different qualities you may need from a PA in the workplace when you are recruiting.
- Always try and arrange for them to have their own space to sit in and somewhere for them to relax if you do not need them.
- Remember that it is YOUR job, never let the PA take over.
- If you find your PA has or can develop a skill, which can really help you with your work then use it.

8. Reasons To Be Cheerful - This is the life

There is absolutely no doubt Direct Payments mean real freedom for disabled people. Employing your own PAs means you will be in control of who is in your life doing whatever it is that you need doing. You are in control of when they are there, what they do and how they do it.

Angela Smith is about to start receiving Direct Payments, but at the moment uses an agency.

In the morning they come in and open the curtains even though I have no clothes on- I just can't wait to get my own PAs.

I can remember a time when I used to rely on district nurses to get me up in the morning- one week I was left off the rota by mistake and nobody came at all, the following week the same thing happened because the rota had been copied from the week before. If you use services, whether

they are provided by the local authority, by an agency or by the man in the moon you are highly unlikely to get the level of flexibility or fine-tuning that is essential for a good quality of life. There are many reasons why people have difficulties getting Direct Payments, but Nick Danagher sees one barrier as a basic disbelief in disabled people's ability to manage.

Disabled People are forever being cast as vulnerable, hence the services that support us tend to be overprotective. Direct Payments are about the right to take risks, to learn, like everyone else does, from our mistakes and to develop into wiser, stronger people. That is independent living.

Perhaps it goes without saying, but a good PA set up allows disabled people to get on and do things –work, rest and play- to coin a phrase. You do have to make compromises sometimes, but the advantages vastly outweigh the difficulties and when all is said and done your ability to move around the world becomes so hugely advanced that – hey who cares about the tricky bits!

For some of us having PAs means more than just being able to live a life. This is Jane Campbell's experience.

For me, having any control over who assists me and how that assistance is given is crucial to my survival. PAs to me are the only 'healthy option'. My impairment throws up a few challenges choking, chest infections and asthma which prevents me breathing, are a few choice examples! In order for me to feel safe or 'breathe easy', I must feel confident that my PA can manage to assist me when the old lungs can't. This is literally a life and death situation.

When I had to rely on care workers and district nurses my physical health was not only compromised but at sometimes I was in grave danger! I think the worst occasion was when a nurse refused to tilt me over a pillow to cover and I nearly choked to death. This is a simple manoeuvre that my PAs can easily manage. I know what it takes to stay alive and managing this with my PAs is for me, the ultimate gift.

Perhaps the value of having PAs best summed up by Rowan Jade, so she will get the last word.

Having PAs enabled me to find out who I am and enables me to be who I am.

Book List

Personal Assistance Support Schemes Complete List

Published by and available from:
The National Centre for Independent Living (NCIL)
250 Kennington Lane
London SE11 5RD
020 7587 1663

Controlling Your Own Personal Assistance Services

Produced by NCIL/ BCODP
Available from:
The National Centre for Independent Living (NCIL)
250 Kennington Lane
London SE11 5RD
0207 587 1663

Pointers to Control- People with Learning Difficulties using Direct Payments

Available from:
Values into Action
The National Campaign with People who have Learning Difficulties
Oxford House
Derbyshire Street
London E2 6HG
020 7729 5436

Facing Our Futures- the short report Independent Living Seminar/ Conference Summer 1999 England An European Network on Independent Living event

Available from and produced by:
The National Centre for Independent Living (NCIL)
250 Kennington Lane
London SE11 5RD
020 77587 5436

in association with Hampshire Centre for Independent Living,
Dublin Centre for Independent Living and the Independent Living Institute

Personal Assistant Employers Handbook

Published by and available from:
Integrated Living Scheme Advice and Support Service (ILSA)
West of England Centre for Independent Living (WECIL)
Leinster Avenue
Knowle
Bristol BS4 1AR
0117 903 8900

Personal Assistance Training Pack

Independent Living Project
Disability Gateshead
John Haswell House
8-9 Gladstone Terrace
Gateshead NE8 4DY
0191 477 3558

Independent Living for People with Learning Difficulties – Sample Trust Deed

Published by and available from:
Values into Action
The National Campaign with People who have Learning Difficulties
Oxford House
Derbyshire Street
London E2 6HG
020 7729 5436

Users' Ability to Manage Direct Payments

A pack developed by Changing Perspectives
Produced by and available from:
The National Centre for Independent Living (NCIL)
250 Kennington Lane
London SE11 5RD
020 7587 1663

Selecting Personal Care Assistance – What You Need To Know

By Lyn Rucker & Gary Nield
Published by the National Development Team
Albion Wharf
Albion Street
Manchester M1 5LN
0161 228 7055

Make your Move- Video and Information Pack

By Andrew Holman
Produced and available from
Values into Action
The National Campaign with People who have Learning Difficulties
Oxford House
Derbyshire Street
London E2 6NG

Guide to Receiving Direct Payments

Available from:
Department of Health
PO Box 777
London SE1 6XH
Or fax 01623 724 524

Quote code DPP/E

Direct Routes to Independence – A guide to local authority Implementation and management of direct payments

Hasler, Campbell and Zarb
Published by the Policy Studies Institute
Available from:
Central Books 99 Wallis Road London E9 5LN
020 8986 5488

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This book is dedicated to all those disabled people who are struggling with the system in whatever way. Hang on in there!

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