



ORIGIN

***Your Complete Guide
to getting the Best
from your Personal
Assistant***

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WHAT IS THIS GUIDE AND HOW WILL IT HELP YOU?

Many of us had our accident when we were young, e.g. I was 24. After the accident, like every tetra, I became dependent on a Personal Assistant/carer (abbreviated to PA hereafter) to help me with just about all practical activities. As a result of my age and jobs to age 24, I for one had had no experience or training in managing people and I suspect that a similar situation may be true for other ORIGIN clients. Over the more than 20 years since my accident, things have changed massively for the better regarding independent living, opportunities/expectations, access, funding, equipment and care provision.

One area that remains underdeveloped in the opinion of the whole ORIGIN team is that of practical advice from people who have learnt the hard way, i.e. by years of actually doing it

sometimes right/sometimes wrong, on how someone with a spinal injury can get the best from the PAs helping them – or putting it another way, how to manage their care package in the most effective way so as to achieve their personal goals.

This guide aims to aid ORIGIN clients in introducing best practice and ways that work into their care packages and advise clients how to avoid causing themselves and their PAs problems caused by inexperience, sheer lack of knowledge and/or certain personality issues.

The guide is made up of different sections which look at the issue from different standpoints and we hope this approach will be helpful to you in using and developing your care package.

Peter and Linda



BY AN ORIGIN CLIENT

In 1994 I broke my neck (C4/5) in a diving accident. I was faced with two options. Either I could return home and live with my parents, or I could have a go at living on my own and try and establish an independent lifestyle. I decided to live on my own and that was when personal assistants (PAs, carers, care assistants, care workers etc) entered my life. The nature and level of my injury has meant that I have had 24 hour care since my accident. On many occasions I have been asked what it is like to be dependent on someone else for so many things, and this is an attempt to shed some light on the experience.

On the 30th of June 1994 I was an independent, spontaneous young person in complete control of my day-to-day living. The next day on the 1st of July 1994 I was a tetraplegic entirely dependent on others for every aspect of my daily living, from getting up in the morning to going to bed at night and everything in between! Since that day I have had to ask for many things that people take for granted. I have to ask to get up in the morning, I have to ask when I want a drink, I have to ask when I want food, I have to ask when I want to brush my teeth, I have to ask when I need to go to the toilet, I have to ask when I want to go out etc etc etc. As a result everything takes that much longer to do. If someone else wants a drink from the fridge they simply go and get one, whereas I need to call somebody, explain which drink I want, how I want it served. This process probably doubles the time it takes to perform the simple task of getting a drink.

This dramatic change takes some psychological adjustment and can be frustrating at times. Even now more than 10 years after my accident I can get extremely frustrated. Sometimes those frustrations spill over and I can become quite short with people. Most of the time my PA will bear the brunt of this frustration, but it is important that they remember that the source of the frustration is not them personally but a lot more to do with my situation.

As a result of this situation I run my life on a pretty strict, almost military routine. Each morning I get out of bed in pretty much exactly the same way, and each evening I go to bed in pretty much exactly the same way. This serves two purposes. Firstly, the quicker by PA learns my routine the less I have to instruct them and as a consequence the less I have to consciously think about the mechanical processes other people take for granted. I often try to explain

to my PAs that while, say, getting me up in the morning is part of their job and if it takes all morning that's their job, for me it is simply getting out of bed. Something that needs to be done for me to get on with my life. So the less time it takes and the less I have to consciously think about it the more I can focus on the rest of my life. The second purpose served by my routines is that things don't get left out. It is much more difficult to go back a few steps and do something again for me than it would be with somebody without a disability.

Another issue that can arise as a result of me having to ask someone else to do so many things for me is the question of what is "reasonable" for me to ask them to do? Some people like gardening, others like



washing the car. Some people are happy cleaning all day, and some people really don't like cooking very much. So what is it reasonable for me to demand of my PAs? My rule of thumb in this regard is that anything to do with my body and my personal care is nonnegotiable, and everything else is open to negotiation. For example if I want to be repositioned in my wheelchair 20 times until I am sat just right, or if I want my face washed in a particular way and my hair brushed "just so" it is reasonable for me to ask that of my PA. I will not however demand that they wash the dishes in a particular way as long as they come out clean in the end!

However tetraplegics decide to organise their care (and each person does it differently) the bottom line is that we end up living with our PAs. This means that on a regular basis I invite complete strangers into my home and have to make them feel as welcome as possible. Inevitably I also entrust them with complete access to my home, car, bank pin numbers and all sorts of other aspects of my life -- usually within a very short time of having met them. This really is an act of faith and requires me to put my complete trust in relative strangers for my health, welfare and well-being. Occasionally this trust is betrayed (I have had things stolen from me, telephone bills run up and other unfortunate things) but I must say that in the 10 years since my accident it has only been broken on a handful of occasions. This represents a tiny proportion of the number of PAs I have known, but it does happen.

So here I am living with somebody out of necessity, not choice. And it's not like sharing a house with someone because we are pretty much together 24 hours of the day. In order for it to work good communication is essential. This sounds simple enough but given the complicated relationship that exists it is not always that easy. On the one hand I am the employer and therefore theoretically in a position of authority, but on the other hand I am entirely dependent on the other person for pretty much every aspect of my life, which gives them no small amount of power. So if I am not happy with something I need to communicate that in such a way that they don't end up storming out and refusing me the help that I need. Interesting.

So where does the relationship go? Well the employer/employee relationship is not enough in and of itself. There needs to be some element of friendship for it to work on anything like a long-term basis -- and in this sort of care work long-term not much more than a year. I remain friends with almost all of my past PAs and have even been invited to some of their weddings. That is why I prefer the term PA (Personal Assistant) to carer as I feel it better describes the nature of the relationship. On one occasion one of my PAs was asked by a friend of mine "Are you looking after Brian?" His response was enlightening. "No, Brian looks after himself, he just tells me what to do."

As I said earlier my PAs are privy to almost every detail of my life. They know what I do, where I'd do it and who I do it with. They know my bank codes and where I keep my spare house keys. They know what

radio stations I listen to, what TV I watch, who my friends are (and often what I think of them) how much I drink and so on and so on. It really is essential therefore that they respect my confidentiality and don't spread details of my life inappropriately. You would be amazed what has been blurted out in social gatherings by some of my less than guarded PAs. And it's not just confidentiality, discretion is a must. For example not many people appreciate what is involved for me in the simple process of getting out of bed. This can, at times take up to four hours. So when somebody phones me at 11 a.m. and my PA answers the phone and says "No, I'm afraid he is still in bed." the person on the other end may well simply assume that I am just a lazy person! While this may or may not be true a more discreet response would be that I am "unavailable".

There are of course other social implications of having a PA. My friends all need to understand that if they invite me round to dinner they have to cater for two people. In addition to this many people don't fully understand the role of my PA, and this can make them feel slightly uncomfortable having these people around in a social context. Once again there is something of a balancing act required. On the one hand it is inevitable that my PA will join in my social occasions, but there may also be times when I want to spend time with my friends "on my own" and it is appropriate for my PA to discreetly withdraw.

Despite the frustrations that arise from living with a Personal Assistant the bottom line is that without them I would more than likely be living in an institution! They are fundamental in me achieving an independent lifestyle. I recognise that it is certainly not an easy job and were I still able-bodied I'm not sure I would be able to pull it off. So I really do appreciate the people who are willing and able to enable my life and I am extremely grateful for everything they do.

It is of course by no means all hard work and I have had some fantastic times with the people who have worked with me over the years. We have travelled to Africa and on to the continent and got stuck in some ridiculous situations which we have laughed our way out of -- you can either laugh or cry! As I said earlier I remain firm friends with lots of the people who have come into my life in this way, and I'm sure that there are plenty more friends to be made in this way.

INTRODUCTION

This extract is taken from the SIA Independent Living Guide

This factsheet is a guide to help you find a personal assistant and then to work effectively with him or her. Your personal assistant may make the difference between living in the community, where you have control over the decisions that affect your life, and living in an institution.

In the later stages of your rehabilitation we hope that you will have been thinking about YOUR needs and what YOU want. You may have been doing this formally by going through a Needs Assessment checklist with a key worker and discussing your needs and priorities with your nurse, physio, OT and social worker at goal planning meetings. Alternatively, you may have been doing it in a less formal way as part of your thinking about the future. Or you may already have been referred to an Independent Living Advocate.



Independent living is daunting because it means taking responsibility for meeting your own needs, and it is important to think realistically and constructively about what those needs are. Once you know what you want you can draw on the resources that are available to help you achieve your aims. If you want to live independently and require a personal assistant to help you do this, then you have a number of options. Firstly you could approach your local authority, who may be able to help you find somebody. Secondly you can go through an agency.

Your local Social Services Department can probably give you a list of agencies serving your area, or you can look in the Yellow Pages under "Nursing Agencies or Care Agencies". The advantage of using an agency

is that you pay the agency and the agency pays your personal assistant, so that you have no responsibility for the person's tax and national insurance and few other responsibilities as an employer.

However, you will have limited choice of who they send, and you will pay more for your assistant's services than if you employed him or her direct. A third option is to contact Crossroads Care, a charity that has over 150 local care attendant schemes. See the guide to "Useful Names and Addresses" for details of where to contact them. Fourthly you can approach Community Service Volunteers (again, see "Useful Names and Addresses") who may be able to provide somebody to work with you for up to 40 hours a week over a period of four to six months. Finally, you can choose to employ an assistant directly. This gives you the greatest control over selection of the person who is to work with you and over all the arrangements relating to his or her employment as your personal assistant, although it also involves taking on certain responsibilities as an employer.

Whichever of these options you choose, this factsheet will help you to work effectively with your personal assistant. If you are taking responsibility for the recruitment of your assistant it will also give you advice on how to go about this.

The first section of this factsheet helps you to look at exactly what you want from your personal assistant. The second section gives guidelines on the process of recruiting the right person [We have omitted this section as ORIGIN does all this for you]. The third section looks at how you can develop a good working relationship with your personal assistant. In the fourth section, we look at maintaining that relationship. Finally, in the fifth section we look at some of the practicalities and responsibilities of being an employer [We have omitted this section as ORIGIN does all this for you].

The full transcript, including the omitted sections is available at www.spinal.co.uk/pdf/independent_living.pdf

Have confidence in yourself - remember, you dealt effectively with many problems before your injury, and you have already successfully tackled a range of new demands and situations. There is no reason why you can't also meet this new challenge successfully. Seeking information and advice is an important way of helping yourself, which you are already doing by reading this.

SECTION I: IDENTIFYING WHAT YOU WANT FROM YOUR PERSONAL ASSISTANT

This section will help you

- Identify aspects of your life where a personal assistant can make you more independent
- Decide what sort of time commitment you need from your personal assistant
- Select a personal assistant who will be compatible with you

Identifying your Needs

Your first task is to identify exactly what you need a personal assistant for. This means analysing your lifestyle and needs carefully. There is a checklist at the end of this guide to help you do this in a systematic way.

The Checklist

The checklist is organised around possible areas of need, such as activities of daily living, skin checks, social activities and so on. Within each area there are a number of items, which describe specific needs or activities. For each item you should consider whether it concerns an activity you want your personal assistant to be involved with. If so, put a tick by it. So for example, you may want your personal assistant to wash your hair for you, but prefer to let it dry naturally. You may also want your personal assistant to take you to the hairdresser to get your hair cut. So, on the first page you would tick "washing hair" and "cutting hair".



In the second column on the checklist you should specify exactly what you require from your personal assistant in the activity. So for "washing hair" you might specify that you want your hair shampooed, towel-dried and combed, and for "cutting hair" you would specify that what you need from your personal assistant is transport to and from the hairdresser.

In the third column put down how long the activity will take (e.g. 20 minutes for hair washing, or 1 hour for a round trip to the hairdresser). Try to be as accurate as possible - if in doubt, time yourself next time you carry out the activity.

In the fourth column put down how often you want to do the activity in question (e.g. three times a week for hair washing, once every six weeks for haircutting).

The fifth column is a space for you to put down any other notes that are relevant to the activity. For example, you may want to make a note that you prefer to have your hair washed first thing in the morning rather than in the afternoon or evening. Or every three months you may want to have your hair coloured and not just cut, which mean allowing longer.

The sixth column, headed "Evaluation", is for you to use when you are assessing your personal assistant on each of the activities. We will discuss this further in Section IV.

When you have finished going through the checklist, work out, using the information in the third and fourth columns, what time commitment you need from your personal assistant. The easiest way of doing this is to work out a daily total for those activities you want to do every day, a weekly total for those activities you do once a week or more but not as often as every day, and a monthly total for the more infrequent activities. You can fill in the numbers at the end of the checklist as you work them out.

Once you have done this you should think about how much additional time, if any, you want your personal assistant to be around on standby although not actively working.

Although completing the checklist may seem a rather laborious exercise at first, making the time to do it properly is an important investment in the future. As well as increasing your chances of establishing a successful relationship with your personal assistant from the start, it will also make you think about the areas of need that are taken into account in an application for direct payments.

How Many Personal Assistants?

Having established what your needs are and what time commitment you require, you can think about how you want to organise your care. If you live with a partner or other relative who provides you with some help you must define the scope of this support so that you and your personal assistant are clear about the extent of his or her responsibilities. You must also make arrangements to cover for time off, holidays, sickness and so on. If you need care for more than about 13 hours a day you will certainly need more than one permanent personal assistant, and in any event you may like to consider having several part-time personal assistants instead of one or two personal assistants who work full time. Or you may consider having a 24/7 live-in PA.



To some extent these choices will depend upon who applies for the post. However, a sensible option may be to employ one or two permanent personal assistants who work five days a week, and to use an agency for the other two days. By establishing a relationship with the agency, you will be able to use them with some confidence in emergencies, for example if your personal assistant falls ill. In addition you could contact your local social services department, community health services and voluntary services to see what help they would be able to provide in an emergency.

And don't forget that good neighbours may be your best resource in a crisis.

Compatibility with your Personal Assistant

Obviously a job description is an essential first step in recruiting your personal assistant, and by going through the checklist you are producing a job description at a good level of detail which will enable both you and your personal assistant to be clear exactly what is expected. However, if you are spending a considerable amount of time with your personal assistant, and particularly if you are sharing your home with them, it is also very important that you are personally compatible.

To help you clarify what is and isn't important to you in terms of your general lifestyle, there is a second checklist at the end of this guide. It consists of a set of statements about lifestyle preferences. Just put a tick in the column which indicates whether the statement is true for you always, usually, sometimes, rarely or never. Filling out the checklist will highlight what preferences in a personal assistant would be unacceptable to you. For example, if you never listen to jazz because you can't stand it you probably won't want to share your home with somebody who listens to nothing but jazz.

Once you have completed both checklists you will be able to write a detailed job description and to identify questions you need to ask prospective employees about their own lifestyle preferences. Now you are ready to set about recruiting your personal assistant.



SECTION II: DEVELOPING A WORKING RELATIONSHIP

Once you have recruited your personal assistant it is important that you develop a good working relationship with each other. Communicating effectively with someone who is intimately involved in your life does not necessarily come easily. However, it is a skill which can be learned and which it is important to learn. It is often tempting to avoid tackling little problems and irritations for fear of upsetting the other person or creating an uncomfortable atmosphere. But if you do not address the problems that are an inevitable part of any close relationship, you and your personal assistant may become alienated from each other. If your relationship has become uncomfortable for both of you, your personal assistant is unlikely to give their best, and may even leave. Developing good lines of communication is a way of maximising what you can both offer each other.

Understanding your Personal Assistant

Communication is a two-way process. It means actively trying to understand what is going on for the other person as well as making your own views and feelings as clear as possible.

If your personal assistant feels that you are making an effort to understand his or her point of view, s/he is more likely to make a similar effort with you. There are a number of simple skills you can develop to help you convey your interest in your personal assistant's worries and concerns.

Firstly, try to be aware that we all send out mixed messages at times. We may say one thing but feel another. The feelings we are trying to hide often come out in our body language - gritted teeth, clenched fists, tightly crossed arms, a particular tone of voice. These forms of non-verbal communication are also very powerful when we do not accompany them with words - an angry look or a deep sigh can convey a very clear and strong message. Being alert to these unspoken forms of communication and picking up on them, without being dismissive, negative or aggressive, will help to nip potential problems in the bud. If you can see your personal assistant is unhappy or fed up, even though s/he is not saying so verbally, try to find out why.

Secondly, if your personal assistant is trying to speak to you about something, make sure you give him or her your attention. Looking at the person as they are



speaking creates a very strong impression of interest. Keeping half an eye on the television or looking at your watch will not encourage the person to be open with you.

Thirdly, make some kind of acknowledgement of what your personal assistant is saying to you. It is often helpful to follow up things s/he has said in order to clarify what the issues really are. Asking specific or general questions will convey the fact that you are taking your personal assistant's views and feelings seriously as well as helping you to understand what is going on.

Expressing your own Needs

Just as you can't read your PA's mind, your PA can't read yours. You therefore have to learn to articulate your own needs. This may take practice, particularly if you are used to being independent and don't have a lot of experience of relying on others or asking them for help.

You may not want to share many of your feelings with your personal assistant, but sometimes it is important to do this. If you are feeling generally irritable or under the weather it is helpful for your personal assistant to know that s/he is not the specific cause of your mood. It may also help him or her to meet your needs more appropriately. If there is something about your personal assistant's behaviour that is annoying you, tell them about it as specifically as possible. So if s/he keeps interrupting you when you're trying to speak, say something like "That's the third time you've interrupted me", NOT "Do you have to be so rude?"

Feedback

Giving and receiving feedback is a particularly important part of your relationship with your personal assistant. If you are trying to give negative feedback about something that you didn't like there are some simple guidelines you can follow to help you do this constructively:

1. Give feedback as soon as possible after the incident has occurred.
2. Don't give feedback in front of other people.
3. Describe the action, not the person (as in the "interrupting" example above).
4. Be specific and just give one short example.
5. Don't bring up incidents from the past - stick to the present.
6. Give feedback to provide information, not to criticise.

Remember that positive feedback is just as important as negative feedback. If your personal assistant has done something well, tell them so - they need appreciation and encouragement just as we all do. They will also understand better how to meet your needs properly in the future if you tell them when they've done a good job.

You also need to receive feedback from your personal assistant. As well as showing respect for him or her, it allows you to gauge how effectively you are giving directions. Try to invite feedback when you have instructed your assistant in carrying out a task. This will help you to develop greater verbal independence as well as encouraging a good working relationship between you.

Instructing your Personal Assistant

Different personal assistants will learn at different rates. Some may be able to carry out a task from your verbal description of how it should be done others may need to be shown. When you are describing a task, explain the procedure step-by-step, explain it the same way each time to give consistency, and say why it is important to do it that way. If your personal assistant knows why s/he is doing something, s/he will find it easier to remember. Don't assume your assistant will know how to do something without being told, even if s/he has worked before for someone with a disability like your own. Different employers have different ways of doing the same thing, and you must help your personal assistant to learn what your own preferences are. At the same

time, consider any constructive suggestions your assistant makes - s/he may think of something helpful that has not occurred to you.

If your personal assistant has difficulty remembering the details of a task, particularly if you are not present when it is being carried out, write the procedure down in the form of a step-by-step checklist that s/he can refer to as s/he goes along. This may be especially helpful during the early stages of your relationship when the person has a lot of new information to absorb at once. Keep the instructions even when your personal assistant is completely familiar with the task - they may come in handy if you have to train someone else in the future.

Remember that feedback is particularly important when your personal assistant is still learning. Acknowledge the things s/he does right, and mention anything that is not quite the way you want



it. You might like to try a daily feedback session during the training period to help your assistant consolidate what s/he has learned during the day.

Dealing with Conflicts

Using the communication skills we have just discussed will help you to avoid some conflicts with your personal assistant altogether. However, it is inevitable that disagreements will arise from time to time.

Conflicts are usually best tackled head-on. If you don't express your annoyance or anger at a situation it is likely to fester into long-term resentment that is much harder to deal with. But in speaking about it to your personal assistant, remember to describe the behaviour or the issue, NOT his or her personality. Instead of saying "You're so lazy", try something like "I'm furious that you haven't done any washing up today!"

This describes the behaviour and leaves room for improvement.

If there is a persistent problem that is threatening your long-term relationship with your personal assistant, you could try to problem-solve together. The steps in problem solving are:

1. Perceiving a need: in other words you must both agree there is a problem and that you will have a go at finding a solution to it.
2. Defining the problem: you must each describe what you think the problem is without mentioning personalities. You may find that there is in fact more than one problem needing to be addressed.

3. Generate solutions: have a brainstorming session where you both think of all the possible solutions you can and make a note of them. Anything anyone thinks of is valid at this stage.
4. Evaluate the solutions: discuss first the positive, and then the negative, aspects of each suggested solution. This avoids the "my idea is better than yours" syndrome.
5. Select a solution: select the suggestion that seems the best solution to the problem.
6. Making a plan of action: discuss what is going to be done by whom, where, when and how, in order to solve the problem.

[NB – PLEASE CALL ORIGIN BEFORE THINGS GET TO THE CONFLICT STAGE IF AT ALL POSSIBLE AND WE WILL SORT THINGS OUT FOR YOU]

SECTION III: MAINTAINING A BALANCED RELATIONSHIP

Depending on your particular circumstances and the amount of time you spend together, your personal assistant may become the person who knows you best in the world. This may present you with the problem of maintaining an appropriate balance in your relationship. You have a business arrangement with your personal assistant, yet he or she may also in some respects be a friend. Keeping both these elements in harmony can be difficult. Two ways of helping yourself to achieve the necessary balance are firstly to draw up comprehensive Conditions of Employment [ORIGIN has done this], and secondly to develop good supervision skills.

Reviewing the Job Description

You should also review the job description on a regular basis. Your needs may have changed, or certain activities may take less or more time than they used to. Make the appropriate amendments and make sure both you and your personal assistant have a copy of the revised job description.

Part of maintaining a balanced relationship with your personal assistant is ensuring that you do not ask him or her to do anything that you could do yourself. Your personal assistant is there to facilitate your independent living, not to be a servant or domestic. By limiting your personal assistant's responsibilities to those things with which you really do need his or her help you will foster a sense of mutual respect.

Evaluating your PA's Performance

You should regularly evaluate your personal assistant's performance on the different aspects of

his or her duties. This is a structured way of giving feedback, both good and bad, and you can use the "Evaluation" column on the checklist to do it. A simple evaluation scale, for example "Good", "Satisfactory" and "Needs Improvement", will be adequate - the really important thing is to discuss your evaluation of each activity with your personal assistant. You should also make sure that both you and your personal assistant sign each sheet after the evaluation to indicate that you have agreed upon it. If you feel your personal assistant is not performing a duty adequately, note this down in the Evaluation column and tell your personal assistant you want to see some improvement. Make sure that you then give regular feedback to help him or her achieve this improvement. If at the next evaluation you are still not satisfied with your personal assistant's performance give a written warning and, once again, make sure that you and your personal assistant both sign the evaluation sheets.

Evaluating your own Performance

It is important that you also evaluate your own performance as a PA user. This is difficult to do, as we seldom see ourselves as others see us, but try to do the following:

- 1 Regularly ask your personal assistant for feedback.
2. Go through your agreement with your personal assistant asking yourself whether, you are meeting your obligations towards him or her.
3. Ask yourself how you would like working for yourself.

TRAINING YOUR PAS IN THE WAY YOU WANT THINGS DONE

This extract is taken from SIA Moving Forward 3

It's important to train your assistant to do things in the way you want. Even if s/he has previous experience, it will probably have been with someone else with different needs or who liked things done differently. It's also important to establish that irrespective of any medical or nursing knowledge or training your assistant may have, you are the expert in your body needs. Your assistant is emphatically not a nurse, and you are not a patient.

If you are replacing a previous assistant, it may be possible to arrange a few days overlap between them, so that your old assistant can help to train your new one. For practical reasons this arrangement could be less stressful for both you and the new assistant. You may find it very tiring to explain all your needs as you go along, as well as chatting to and getting to know your assistant. If you are to be alone together, you may also feel vulnerable and unsure about having a stranger in your home and about being reliant on them to assist you with everything.

In terms of developing a good relationship with your new assistant, you may choose not to have a 'handover' period. This is an important time of getting to know each other and establishing good communication, especially if you will be working on a one to one basis. Assistants are individuals, with different skills and ways of doing things. The new relationship will inevitably be different from how you worked with and related to your other assistants. You may also want to make a few changes to the way things are done for you. This will be easier if you train your assistant yourself. You need to plan a 'handover' to suit your needs.

You must be very clear about what needs to be done and the assistant's role. As the employer, it is your responsibility to give them all the information they need to carry out their duties and to fit in with your lifestyle. You are in control and need to take the initiative at all times in your working relationship.

Always explain why it is important to you for them to do something in a particular way. This will help them to understand your disability and needs. Explaining all the little things – such as; because of your limited hand movement, you can only pick up a mug not filled above the handle line and with the handle turned to one side - can avoid the



misunderstanding that you are just being fussy. The more your assistant understands about the way your body works, the more able they will be to assist you with confidence.

It is natural to feel anxious about how well they will be able to do the job and how well you will get on together. Remember that they are also likely to feel anxious. It could be helpful to be honest about your feelings, establishing a common bond between you.

Evaluation

However good your relationship with your employee, it can still be difficult to say if you are not happy with something your assistant has done. It is a good idea to set aside a regular time to discuss any re-evaluation of your working arrangement. This is the time for a two way discussion between you about any changes that need to be made and how you both feel. Be assertive about issues that are important to you and encourage your employee to also be assertive about their own needs. Explain that this is an opportunity to air any difficulties and to find a workable solution.

It is always best to separate the times when you are receiving personal care and when to discuss any grievances that may arise, however pressing they may feel at the time. It is also important to recognise that compromise and negotiation is necessary in any relationship.

The working relationship

Be sure to respect your assistant. Show that you value them. Notice the good things they do for you and show your appreciation. Treating them with positive regard means that they will find the job more rewarding and enjoyable and are more likely to want to stay in the job.

It is natural that you are sometimes going to feel frustrated about things you cannot do for yourself and also how someone else does it for you. If these feelings are explained to your assistant, they are much more likely to understand and empathise with you. You having the right attitude is essential for a good, friendly working relationship.

You are likely to have chosen your regular assistant for their potential compatibility with you, as well as their ability to do the job. You may rely on them as a companion for socialising. Make sure that you both have acceptable boundaries. Establish who pays for their cinema ticket/drinks etc. and how much they 'join in' with what you are doing. Your assistant will inevitably form their own relationship with your friends, family and other assistants. It is up to you to ensure that your needs are not compromised by these relationships, whether friendly or in conflict.



It is also your responsibility to ensure that you get the privacy you want, whether on your own or with friends and family. Respect privacy for your assistant as well. Establish the difference between time off and being on call if needed. If they live in, make sure that they do have privacy in their room.

If you become their direct employer, e.g. if you take on a permanent carer that you employ, keep to the conditions of employment set out in their contract of employment. Refer to them if they are not being met to your satisfaction. Discuss any changes that

may be necessary. It may feel easy at the time to 'let little things go', but you may regret this later. Think carefully about any consequences that may affect you. Boundaries are important, however friendly you are. You are still their employer. THIS POINT IS NOT NEEDED FOR ANY PA EMPLOYED BY ORIGIN.

Good communication is important to be able to negotiate and maintain the complex working relationship between yourself and your assistant. You need to take responsibility for your behaviour and attitude and how you get your needs met. It is not acceptable to be either aggressive or to be taken advantage of. Be firm, but fair, tactful and polite at all times. If you feel that you need to develop these skills, there are many books on how to be assertive. It could be a good investment for maintaining the assistance you require.

Good assistants can be difficult to find. Make sure that your expectations are not too high or too low. Work out your priorities. You may find someone who doesn't cook or clean to your standards or expectations, but you may get on very well with them and they are good with your personal care. If practical and worth the investment, look at providing training for the skill or you could re-arrange duties for someone else to provide the service. Utilise the strong points of each assistant and work out or negotiate how best to utilise what they find difficult. Be honest about your expectations. Don't put up with something that you are really unhappy about. Change the situation. Be reasonable and sensible about what can be achieved. Be as flexible as you can, but be aware of your levels of tolerance and what you are able to live with.

You may find it useful to talk to other S.I.A. members who employ personal assistants. They can share with you their experiences and offer advice and support if needed. Phone the S.I.A. Information line on 0845 678 6633 or visit the S.I.A. website at www.spinal.co.uk You can also visit the Chat Room at the website and contact other members for advice.

How you manage your assistants and get your needs met is your personal choice and you will work out how best to do this with every different assistant. The relationship and the role they have in your life will be as rewarding as you make it. Employing assistants will enable you to experience as much independence and freedom as you choose.

Having a good carer, I believe, brings me as much

independence as possible given the fact of a C5/6 spinal injury. It removes my total reliance on family and friends which can become wearing for all concerned, and most importantly it allows me to choose how I wish to live.

In addition to giving me freedom of choice in how and when I do things, I also find having a care assistant an interesting and rewarding experience which allows me to see people from walks of life and other countries who I would not otherwise meet. Many of those who have worked as my carer have gone on to become good friends with whom I stay in touch long after they finished working here.

However, I have found the working relationship between me as a disabled person and my carer to be a complex one; part employee, part friend, part family member and part stranger. The carer's job involves intimate personal care and long periods together, but control and authority for the carer's work remain with me. I discovered from experience that getting to grips with organising this complicated relationship in a fair and sympathetic way takes some doing, particularly as I had had no previous experience and the 'employee' is living in my own house. Eventually I learned that the care assistant needs to be managed – like any other employee. I discovered that a team approach was beneficial: with my carer and me working together as a team where both people have a part to play in making arrangements work best for both of us rather than me simply giving 'orders' to the person providing my personal assistance.

One of the keys to success is communication, i.e. talking to each other openly and patiently, particularly if asking my carer to do something differently. Another key to success is flexibility and yet another is being reasonable. My carer must respect my right to control my life and his/her duties, but I must not abuse this authority or become overly demanding or uncaring. It is important to remember that my carer is a person doing a difficult job, and needs time off, space, sleep and support as much as anyone.

I came to realise that it was important for me to take active control of and responsibility for my life, and therefore, my care assistant. In the early days, I experienced problems when the control and responsibility drifted towards the carer – confusion arose over who was working for whom.

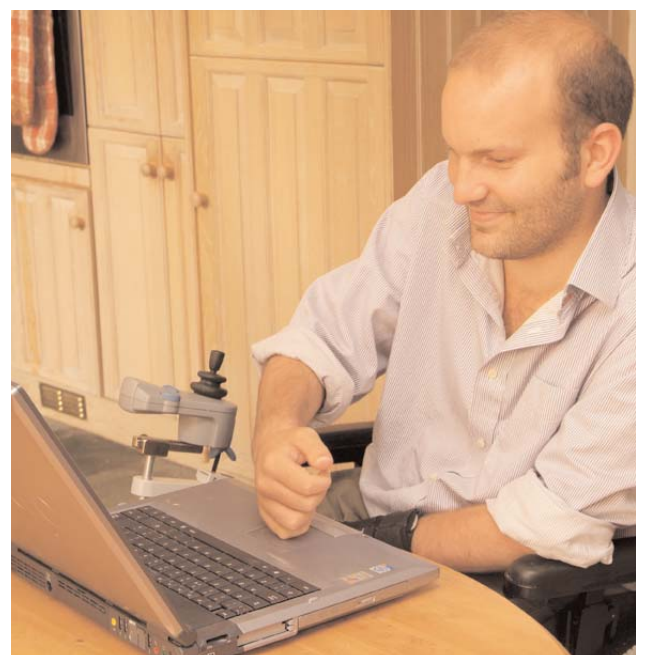
Occasionally, in these circumstances, I felt somewhat beholden to the one or two people carrying out my care work and had hesitated to say anything critical, fearful that they would leave and I would be left without a carer. To overcome this worry of not being able to find good care assistants when required, I need to know that sources of carers exist.

Lastly, I find having a care assistant is a means of bringing spontaneity, opportunity, choice, control and fun back into life – but living with another person is not always easy. On balance, this method of living is a big improvement for all involved on the alternative courses of having to rely on my family and close friends, and it is infinitely preferable to institutional care and the benefits far outweigh any difficulties.

•SIA member - C5/6

Emergencies

You will need adequate back-up assistance to cover holidays. You also need to have, planned in advance, people whom you can call on in an emergency. Assistants may be too ill to work, need compassionate leave or even just leave or give notice unexpectedly. If you receive direct payments from Social Services, they may be able to supply temporary help if all back-up fails. Ask your social worker what they could provide in an emergency. It is very important to try to cover all eventualities with a choice of possible back-up people to call on. This may not be easy, but it will save a lot of anxiety about being left with no assistance.



How To Get The Best From Your PAs - (or how to make life simpler!)

Over the time ORIGIN has been in business, we inevitably notice that some care packages work very well and others less so, some methods/routines are easy for PAs to learn and others are less so. This guide is being produced with the aim of disseminating good ideas – if they're not for you then fine but it never hurts to think about things.

Experience has shown that with some thought and just a little effort, taking on a PA usually works well, enhances clients' independence and can also be fun!



- 1 Decide to take responsibility for your own and your PAs' best interests: the need for you to take the lead in things is intrinsic to independent living. We know no-one is always bright and cheerful and you are not expected to organise entertainment for your PA. We have found, though, that a care package is most likely to succeed in a generally positive, active environment.
 - 2 Your health – maintaining the best health possible is obviously good for all aspects of life and taking care of skin condition, weight and general well-being with help here too as there seems to be some truth in that old cliché, 'healthy body, healthy mind: healthy mind healthy body'.
 - 3 To all intents and purposes the client is the PA's manager – and all good managers should well understand the importance of planning, communication, teamwork, patience and occasionally, compromise.
- a It is very helpful to define the work and write it down as clearly as possible in a job description. The PA must know what his/her work involves and the need for attention to detail, so that nothing of importance in your daily/weekly requirements is missed.

b Communication and teamwork are at the heart of all successful care packages. Working together is a team effort where client and PA are able to talk openly, with the shared aim of both gaining greatest benefit from their association. PAs cannot read your mind and no matter the level of training, new people will invariably require some explanation of the way you like things done, or why you require things done in a certain way. Many misunderstandings can be avoided if you make these explanations as clear and concise as possible. Always try to be consistent in the way you do things as this helps your PA to remember your routines more quickly. What is it reasonable to ask a PA to do? Generally, if in doubt you should ask if your PA is happy about doing a particular request and if he/she is reluctant, please try to avoid pressurising them. Never ask a PA to do anything that could be construed as being unreasonable, potentially dangerous or even worse, illegal. Sensible, honest communication is important at all times and in particular a few words of praise are always appreciated for a job well done.

- 4 Clients should recognise that every PA is different - that they are people, not machines. It is natural to expect a lot from your PA, but please remember that no-one has infinite reserves of patience, stamina or ability. They are all decent people trying their best to do a difficult job and if they are sometimes asked to compromise, occasionally you may also be asked. Patience is always a great virtue - but perhaps rather more in you the client, than your PA!

Finally, it is worth noting that the UK Home Care Association states that a PA (and any agency involved) should always act - "to promote and safeguard the wellbeing and interests of clients" - "behave with honesty and integrity" - "respect the privacy and property of clients" – "recognise that clients have a right to make their own choices". In return, we suggest that clients should consider their PA as a combination of employee, friend and considerate relative, as well as providing a healthy and safe working environment in which you can both operate to greatest mutual benefit.

Some specific points

- No badmouthing about old PAs – criticising previous PAs causes an atmosphere, upsets new PAs as they think, 'if he's saying that about X, what will he say about me'?
- Help the PA to help you
- Plan out things as much as possible and try to avoid dropping last minute changes of plan/'surprises' on your PA to reduce stress/problems. Have clear written guidelines. Have a cleaning/weekly task plan. Even if you are not a planning sort of person, some structure really does make a big difference.
- Often PAs are from overseas or very different backgrounds from you. Even though they may speak good English, they may not understand colloquial/slang English and/or the English sense of humour which is often based on sarcasm, irony or taking the mickey. Foreigners frequently take jokes seriously and get upset. This issue can easily be addressed with a little thought and consideration – think too, how you would get on living overseas and using a foreign language for your work 24 hrs a day...
- It's a team – both you and the PA must get something from it
- Give your PA regular time off
- Driving – give them a practice drive before you need to drive – even experienced drivers get shaken if constantly criticised – try to help them and reduce their nervousness.
- Many of us struggle to say to PAs that we want some time on our own. Try something like 'could you excuse me for a while, I'd just like some time on my own and I'll give you a shout if I need anything'. No-one will then feel awkward in this situation.



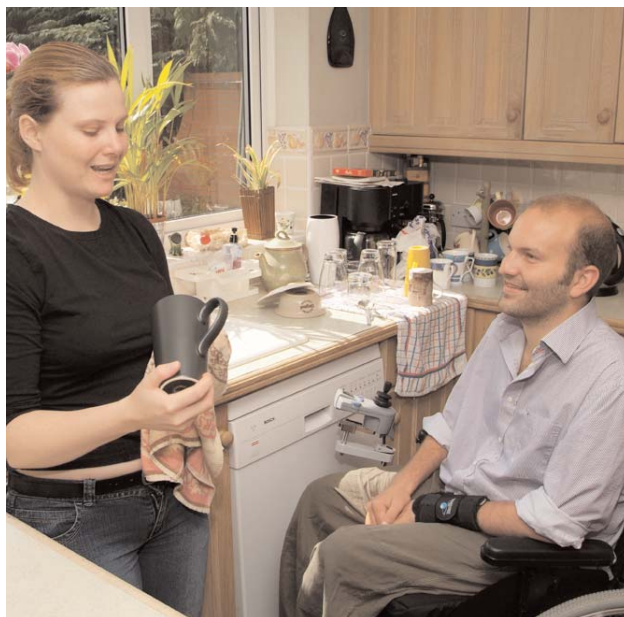
- Ask them what more you could do to make their work with you work as effectively as possible
- Develop and improve your routine constantly – things/equipment/you/everything changes. If your routine has not changed at all in a year or two, it probably could work better for you.
- Far be it from us to tell you how to live your life – that is 100% up to you – but getting out of the house regularly – anywhere at all, even just a regular trip to the shops – is good for both parties. If you choose to go out, explain that because doing so is at your behest, you will pay for meals/drinks etc. Also, to those clients who drive, let your PA know early if who will drive after a trip out, i.e. if you have a drink, you may ask your PA to drive home.
- Holidays – PLAN, PLAN, PLAN. Begin early, check everything, hope for the best but prepare for the worst. We have provided a packing list idea in the appendices.
- Welcome them into your home – PAs do not HAVE to help you/me/anyone; they do so because they WANT to. I understand that you would far rather not have to rely on a carer to help you but, given a spinal injury, that's unavoidable and HOW you adapt to working with another person has a significant impact on your quality of life at home.
- Learn from your PAs – if you think about it, we are privileged to meet all these interesting people from all over the world each of whom has their own story to tell. As Elzbeth, one of my PAs says, you can see 'another person's reality' and they can see yours. Interesting.

The reason ORIGIN exists is to provide the very best live-in care we can for people with a spinal injury. We have long felt that an overlooked side of things is client training on the issue of managing the people actually delivering their care on a daily basis.

We hope this collection of articles and assorted jottings is of some help to you in getting the very best from your care package, avoiding the common pitfalls and so, perhaps, improving everyday life.

This guide will itself evolve and we will update it from time-to-time. If you have any observations or suggestions for future editions, please do let us know.

The ORIGIN Team.



APPENDIX A - Quick Tips

The induction process

Even though ORIGIN trains all our PAs and they will probably have experience, you may find these points help.

- Give your PA a list on paper of your personal and household 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 over 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.
- Be clear at the outset – make a list of things you do and don't want to happen (for example on use of the telephone/internet).

Managing the relationship with your PAs

- Have brief reviews where you both get the opportunity to say what's working and what's not – this is useful even on short placements.
- Dealing with the issue of finding emergency cover when people are ill or on holiday.
 - a. It is a good idea to split the time you have and employ a number of PAs so they can cover each other. Try not to put all your eggs into 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. Make sure you have ORIGIN's number to hand.
- d. Ensure you have a list of your neighbours phone numbers.
- e. Friends who also use PAs – ask if they have any suitable contacts to add to your emergency list.
- f. Friends and family – sometimes they are the nearest answer.
- g. If all else fails, your local authority still has duty of care to you – so keep their emergency number somewhere.

PAs and your social life

- Do not feel guilty about not including PAs in social activities, particularly when there is a cost involved. Remember your package only includes their wages.
- Try and train your PAs to take a back seat – 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 all day, or remember to tell them to bring a packed lunch if you cannot afford to do that.

Guarding against dishonest PAs – although this happens rarely

- 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. IN THIS CIRCUMSTANCE, YOU MUST INFORM ORIGIN IMMEDIATELY
- It is an 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 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 working with an agency brings real benefits.

Holidays

- Sort out who is paying for what in advance.
- Check if your PA needs a visa and that their driving licence is OK for where you are going.

- Don't expect your PA to take responsibility for the packing. It's 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.

It's off to work we go

- You can get money for PA support at work from the Access to Work scheme. Contact the DEA (Disability Employment Advisor) base 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 that your PA has or can develop a skill which can really help you with your work then use it.

APPENDIX B - PERSONAL ASSISTANT ACTIVITY CHECKLIST NEED ACTIVITY HOW LONG? HOW OFTEN? COMMENTS EVALUATION

FEEDING	ORAL HYGIENE	SKIN CARE	DOMESTIC TASKS
Help with eating	Brushing teeth	Checking skin	Laundry: washing
Special diet	Flossing teeth	Relieving pressure	Laundry: drying
	Mouthwash	Turning position	Ironing
DRESS/UNDRESSING	Denture care	Positioning pillows	Sorting clothes
Complete assistance		Checking for in-growing toenails	Dry cleaning
Some assistance	BLADDER MANAGEMENT	Treating skin breakdown	Mending
	Toileting		Preparing meals
PERSONAL HYGIENE	Catheterisation	MOBILITY AND MOVEMENT	Preparing snacks
Cleaning face	Condom drainage	Stretching joints	Washing up
Showering	Leg bag	Transfers	Drying up
Bathing	Cleaning equipment	To/from bed	Cleaning oven/cooker
Drying body	Other	To/from shower/bath	Defrosting fridge
Combing hair		Transfers	
Washing hair	BOWEL MANAGEMENT	To/from car	
Drying hair	Aperients	Wheelchair to car	
Cutting hair	Suppositories		
Shaving	Digital checking		
Make-up	Cleaning after toilet		
Ear care	Transferring to toilet		
Menstrual care			
Nail care			
Other (e.g. Deodorant)			

APPENDIX C - REGULAR ACTIVITIES

To ensure things are done in the most efficient way and in the manner you like write simple notes for your personal assistant to follow. For example, getting up, going to bed, getting into a vehicle.

Morning Routine - Getting up...This is how it's done!

A Good Morning! And remove the covers, pillows and socks

Lift night bag from hook and put bucket away in cupboard

Rest night bag on bed, logroll to check skin, put moisturiser if needed

Deodorant under arms

Detach night bag from day bag after closing tap, empty into toilet and rinse bag with water from tap in sink (wash your hands afterwards)

Put on socks, attached day bag to left leg

Put underwear and them trousers on (pull up as high as possible, logroll minimum of 3 times)

Shoes on

Pull XXX up on all the way, so that he balances on his own hands, twist lower body to side of bed by grabbing hold of his feet

Get into right position, SLIDE to chair

Put board and sheet away

Put blinds up

Once in chair, put on shirt

Re-arrange underwear/trouser until comfortable on chair

Belt

Jumper

Give razor to have and help choose a tie in weekdays

Downstairs to Breakfast



APPENDIX D - SPECIMEN HOLIDAY PACKING LIST

THINGS TO DO BEFORE AND TO TAKE ON HOLIDAY

TICK WHEN
DONE

THINGS TO DO

- LOCK HOUSE WINDOWS
- ARRANGE TAXI/LIFT TO AIRPORT
- ARRANGE CAT FEEDING
- DISPOSE OF OLD FOOD, CANCEL MILK/PAPERS, TURN HEAT/HW OFF
- LEAVE LIST FOR CARER AT HOME IF NEEDED
- ENSURE SUFFICIENT MEDICAL SUPPLIES REMAIN FOR WHEN YOU RETURN HOME ...
- CHECK CARER'S PACKING BEING DONE EARLY - NO RUSHING AT THE END
- BUY GUIDE BOOK - CHECK TOURIST ATTRACTIONS ETC

CAR

- SERVICE
- QUOTE FOR CAR HIRE - CHECK PRICES/FUEL ANY EXTRAS ETC.
- IF NEEDED, 'GREEN CARD INSURANCE FOR RELEVANT DRIVERS
- CALL CAR HIRE LOCAL OFFICE TO CHECK SUITABILITY OF VEHICLE
- AA COVER.....
- DRIVING LICENCES OK?

PLANE

- QUOTE FOR FLIGHTS
- INFORM THEM I AM IN CHAIR
- CONFIRM IN WRITING OVERWEIGHT BAGGAGE/MEDICAL EQPT OK
- CONFIRM APPROPRIATE SEATS BOOKED - BULKHEAD SEATS ONLY
- CONFIRM WHEELCHAIR NEEDED AT TRANSFER AIRPORT WITH
BOOKING STAFF AND FLIGHT CREW

WHEELCHAIR & OTHER EQUIPMENT

- CHECK CHAIR IS OK
- TIGHTEN ALL BOLTS
- REMOVE SIDE/CLOTHES GUARDS BEFORE TRAVELLING
- CHECK ALPHABED INFLATES OK.....
- CHECK LOO CHAIR OK

TICKETS

- HAVE THEY ARRIVED?
- ARE THEY RIGHT?.....
- CONFIRM UNDERSTANDING OF WHEELCHAIR.....

ACCOMMODATION

- IS THERE ADAPTED ACCOMMOTION/HOTEL IN THE AREA?.....
- CHECK MINIMUM DOOR WIDTHS - CHAIR IS 28"/70CM WIDE
- AND 48"/120CM LONG.....
- CHECK IF ANY STEPS
- CHECK BED HEIGHT - IDEALLY 60-65CM
- CHECK NEED TO TAKE BEDDING/TOWELS

PASSPORT/MONEY

- PASSPORT - DATE OK?
- CASH/TRAVELLER'S CHEQUES
- CREDIT CARDS - DATES OK?.....

TICK ONLY WHEN ACTUALLY PACKED & CHECKED

THINGS TO TAKE

TICK WHEN PACKED

- DOCUMENTS, SUPPLIES & EQPT.
- ADDRESS BOOK
- ADDRESS LABELS FOR CASES
- AFTERSHAVE
- AFTERSUN
- ALARM CLOCK - CHECK BATTERY
- ALLEN KEYS/RING SPANNER
- ALPHA BED & PUMP
- ANKLE SOCK
- ANTIBIOTICS!
- ASPIRIN
- AUTAN
- BAG FOR UNDERNEATH SHORTS
- BATH PLUG
- BATTERIES
- BED HEIGHT ADJUSTERS!
- BELTS
- BIG BAG STRAPS
- BLANKET FOR LONG FLIGHTS
- BOTTLE OF WATER
- BROWN/GREEN BOTTLE 2L
- CAMERA - SPARE FILM
- CAR SHEEPSKIN
- CAREX SOAP
- CLEARASIL/COTTON WOOL
- COMPACT MIRROR
- COMPUTER/CHARGER AND CABLES
- CONDOMS/FOAM STRIPS
- CRANBERRY PILLS
- DAKTARIN SPRAY - CHECK FULL
- DAY BAGS
- DEODORANT
- EARPLUGS
- ELECTRIC ADAPTORS/BLOCK
- ELECTRIC EXTENSION CABLE
- EMERGENCY BAG
- EYE DROPS
- FLANNELS
- GEL - 2 TUBES PER WEEK
- GLOVES/TALCUM POWDER
- GUIDE BOOK
- HAIRBRUSH
- HEADACHE PILLS
- INCO SHEETS
- KEYS
- LOO CHAIR/BUCKET
- MAP
- MOBILE PHONE AND CAR CHARGER
- MOISTURISER
- MONEY
- NIGHTBAGS - CHECK SIZE
- NOTEPAD/PEN
- PASSPORT
- PLASTERS
- PLASTIC BAGS FOR ABLUTIONS

- RAZOR/3-PIN ADAPTOR
- RENNIE
- RINSTEAD PASTILLES
- RYE BREAD
- SAFETY PINS
- SCISSORS
- SENNA PILLS
- SEWING KIT
- SHAMPOO
- SLIDING BOARD/SLIDING SHEET/PILLOW
- SPARE BAG CONNECTORS
- SPARE CUSHION LINER/COVER
- SPARE FUSES
- SPARE LEG STRAPS
- SPECIAL PILLOW FOR LONG FLIGHTS
- STRAWS
- STRING
- SUN OIL
- SUNGLASSES
- SUPERGLUE
- SUPPOSITORIES
- TAPE
- THERMOMETER
- THIGH STRAP
- TICKETS
- TOE STUFF
- TOOTHBRUSH
- TOOTHPASTE
- TORCH
- TOWELS
- TRAY
- URINE SAMPLE BOTTLES
- WATER SPRAY
- WEE BOTTLE
- WIPES
- LIST OF DUTY FREE
- CLOTHES & GENERAL ETC.
- BOOKS
- DRAWING STUFF
- JUMPERS
- LEATHER JACKET
- RUCKSACK
- SHIRTS
- SHOES
- SHORTS
- SMART JACKET
- SOCKS
- SUN HAT
- TIES
- TROUSERS
- T-SHIRTS
- VESTS/LONG JOHNS
- WARM JACKET AND HAT
- WINTER BOOTS