

Personal care and spinal cord injury



Table of contents

The role of a personal carer

— Caring for people with a spinal cord injury	1
— Sample job description	2
— Personal attributes	3
— Working with clients and their families	4
— Empowering clients	5

Rights and responsibilities	7
-----------------------------------	---

Job boundary management	9
-------------------------------	---

Communication and relationships	12
---------------------------------------	----

— Assertive communication	13
— Managing disagreements and conflict	15

Sexuality and personal care	18
-----------------------------------	----

Maintaining equipment

— Charging wheelchairs and electric hoists	20
— Adjusting and maintaining ROHO cushions	21
— Maintaining Jay cushions	25
— Adjusting an alternating air mattress	26

The role of a personal carer

Caring for people with a spinal cord injury

Delivering personal care services for people with a spinal cord injury can be one of the most challenging and physically demanding personal care roles. It can also be extremely satisfying because you can see the difference you are making to a person's life by giving them back some of the independence their injury took away.

In many cases personal carers work with clients, such as aged people with dementia, who may have limited capacity to direct their own care and make decisions about their day to day activities. In contrast, clients with a spinal cord injury – who have not sustained a brain injury – generally have a very clear idea of how they wish to live their life and what services they need to help them maximise their independence. However they may also need a high degree of mobility assistance.

Before you start working with a new client, your service provider will have made a thorough assessment of the services required. These should be clearly outlined in your job description and a specific service plan or agreement for the client.

Personal care services are generally only made available to people with a high level spinal cord injury – usually to the cervical area – resulting in complete or incomplete quadriplegia. They will usually have, at best, only limited movement of their arms and hands. People with very high level injuries may be ventilator dependent and will be dependent on carers to meet their day-to-day physical requirements.

Although someone might have high physical dependence, this does not mean that they are not independent. Independence is a frame of mind in which people see themselves as an individual with goals, set out plans to achieve those goals and seek out the services required to reach them. This independent thinking is to be respected and supported by personal carers both in the way you talk with your clients and in the way you deliver services to them. It is important therefore to discuss things with your client and ask for their opinion and preferences. Ensuring that clients are empowered to maximise their independence and live their chosen lifestyle is central to the philosophy of quality personal care services and a person-first approach.

Part of the principle of a person-first approach is to treat each client with dignity and respect. Notions of dignity are connected with how personal carers deal with a client's body. Keeping clients covered, respecting their feelings and their personal space, and handling their bodies carefully are all part of the dignity and respect that clients deserve. Another important part of an individual is their cultural background and the way in which they choose to express themselves. A competent personal carer should be mindful of these aspects of a person's life and keep their behaviour and communication within professional boundaries that will not cause offence or conflict.

As a personal carer, you need to be able to strike a balance between following a specific service plan and being flexible enough to take into account a client's preferences and changing day to day needs. If, at any time, you feel that services have deviated too far from plans or that you are being asked to do things that are dangerous or inappropriate, you should seek clarification from your supervisor.

Sample job description

Position title	Personal carer
Principal functions	<ul style="list-style-type: none"> ▶ Personal carers assist people with a disability to perform everyday tasks they would normally be doing for themselves in their home – this includes personal assistance and domestic services. ▶ Personal carers may also accompany the client outside their home to social functions, recreational activities or on holidays.
Personal assistance	<ul style="list-style-type: none"> ▶ Transfers in and out of bed, wheelchair, commode chair or car ▶ Showering or bed sponge ▶ Teeth cleaning ▶ Dressing and grooming ▶ Feeding ▶ Bowel care ▶ Bladder care ▶ Checking skin ▶ Assisting with medication ▶ Assisting with exercise or massage routines ▶ Care and maintenance of aids and equipment eg charging wheelchairs and adjusting cushions ▶ Accompanying client on social or recreational outings ▶ Assisting with personal administration such as correspondence, bill paying, banking and telephone calls ▶ Responding to medical emergencies and situations according to the agreed plan
Domestic services	<ul style="list-style-type: none"> ▶ General household cleaning eg, dusting, mopping and vacuuming ▶ Meal preparation and washing up ▶ Shopping ▶ Laundry ▶ Sewing or mending ▶ Dog walking ▶ General household maintenance eg cleaning windows ▶ Basic garden maintenance – provided the appropriate tools and safety equipment are available
A personal carer's tasks do not include	<ul style="list-style-type: none"> ▶ Any activity that requires manual lifting ▶ Any activity that involves climbing over 1 metre high ▶ Administering medication or injections ▶ Changing dressings ▶ Domestic or personal tasks for other household members

Personal attributes

The sample job description is task focussed. Although it is important for personal carers to be able to properly complete the required tasks, there is also a human element to the job. Clients confirm the importance of the personal attributes and communication skills of their personal carers.

The important qualities and attributes of personal carers include:

Good communication skills

Carers need to have good listening skills and the ability to clarify instructions and requests if they have not understood something. They need to be able to express themselves clearly and assertively and handle minor conflict. Communication between clients and carers should be friendly yet professional.

Flexibility

Personal carers need to be able to adapt to the changing needs and circumstances of their clients. Flexibility will allow clients to pursue their chosen lifestyle without being locked into a rigid provision of service that is disempowering.

Initiative

This is the ability to see what needs to be done without being directed every step of the way. It is important however that the client is consulted before jobs are completed – a personal carer's job is to assist, not take over someone's life.

Team player

In personal care work it is important that the client and carer can work as a team. This collaboration will empower the client to direct care services and promote safety because each party will know what the other is doing.

Non-judgemental

A personal carer works in other people's homes and may see behaviours and practices they are not used to. There may be expressions of culture that carers find strange. It is important not to judge other people – tolerance of diversity is an important part of a carer's competence. It is also important not to make assumptions about your clients based on their disability – adopt a person-first approach.

Respect for privacy

The privacy of clients and their families deserves to be respected. As a person going in to someone else's home, you are likely to find out intimate family details. It is important that you respect people's privacy and maintain confidentiality by not discussing those details with anybody else.

Efficiency

There are usually only limited hours in which to complete the required services. A carer who organises their work and manages their time well will be very valuable to a client and will get greater job satisfaction by feeling in control of their work.

Working with clients and their families

Personal carers who work with clients living in the community will find they often have to deal with friends and family members who live with their client. Clients could be married, have children, live with their parents or share a house with friends.

When going into a home to do personal care work, you must take into account the needs and concerns of these other residents. Families are all different and depending on their general attitudes and cultural backgrounds they will respond differently to having a stranger come into their home.

These other family members want to be able to carry on their lives as normally as possible without having to be concerned with personal carers in their environment. Respect their privacy by not going into parts of the house that are not directly related to your work and not getting involved in family discussions or arguments. It may be important to maintain the schedule of your tasks so you don't interfere with the schedule of other family members.

As a personal carer, you will be in a position to observe and pick up information about clients and other family members. It is important that you do not repeat this information to anybody. Imagine how you would feel if somebody came into your home on a regular basis and then went and told members of the community about the intimate details of your life. It would probably make you feel angry and upset – and very exposed and vulnerable.

You may come across situations where you perceive that family members are having trouble letting go of certain tasks that you thought were part of your job description. This could be happening for a number of reasons. The spouse, parent or another relative of your client might have been doing all the personal care up to now and think that they will do it better than you. They may be genuinely concerned for the wellbeing of their loved one, wanting to make sure that care tasks do not have an adverse impact. It can be difficult to know where you stand or figure out how to negotiate in these situations.

Alternatively you could find yourself in a situation where other members of the household start to treat you like a general servant and leave many jobs for you to do that they are capable of doing themselves.

Here are some guidelines for dealing with some of these situations.

If you need to negotiate tasks in a family

- ▶ Check your job description – what are the tasks outlined in that?
- ▶ Do you see the request being made as a reasonable deviation from normal?
- ▶ From your observations, how are jobs generally shared in this family?
- ▶ Can you negotiate tasks with the family that will increase efficiency for all concerned?
- ▶ You may need to assertively communicate with the client or their family if you think something is unreasonable.
- ▶ Always talk to your supervisor if you find the situation is too hard for you to handle.

If you are faced with family members who are not letting go of tasks

- ▶ Is this an ongoing pattern of behaviour from the family member?
- ▶ Remember that clients and families have the right to vary how things happen in their home – reasonable and infrequent variations are okay.

- ▶ Talk to your client privately. How do they feel about the situation? What do they want?
- ▶ Report the situation to your supervisor. Some negotiation may need to take place with the family members or a re-assessment done of the services being provided.

If you are caught in difficult or conflict situations

- ▶ Don't get involved in conflicts between other people in the home – remove yourself from the room and don't comment on the situation.
- ▶ If any member of the household tries to talk to you later about the situation, tell them you would rather not be involved.
- ▶ If any member of the household wants to tell you personal or sensitive information, suggest that this is not appropriate and that it makes you feel uncomfortable or disloyal.
- ▶ If you do find out sensitive information, don't share it with anybody.
- ▶ If you have a conflict with your client or a close associate, try to discuss the situation calmly and find a workable solution. If you are unable to handle the situation talk to your supervisor.

It can be helpful to keep reminding yourself of the central purpose of your work. Personal care work is about assisting and empowering clients to live independently and pursue their chosen lifestyle. By focusing on the tasks that fulfill this purpose and behaving in a professional manner at all times, you are less likely to find yourself in difficult situations.

If you have examined your personal boundaries and worked on assertive communication, you will have the tools to deal with situations as they come up. If a situation is too difficult to handle on your own, always talk to your supervisor and allow the support processes of the service provider to deal with the situation.

Empowering clients

The central purpose of being a personal carer is to maximise your client's independence and help empower them to live their chosen lifestyle.

Empowerment begins with communication. People with a spinal cord injury are usually capable of making decisions about their life and expressing their needs and preferences. As a personal carer, you need to be a good listener – listening is a fundamental skill in good communication. By asking questions and listening carefully to answers and instructions, you will find out what a client wants and how they like things to be done.

A personal carer's attitudes to their client can also be empowering. Focus on your clients as people – rather than on a label or injury level. This will ensure that you set up a relationship based on team work and collaboration in which you work together to maximise your client's independence.

You should also refrain from making assumptions about a client's routine. You may have other clients with a spinal cord injury or similar physical disability but that doesn't mean they have the same routines or preferences. You need to be adaptable and use the skills you have learnt to deliver services in the way the client requests. As you are getting to know a new client's routines, ask questions and clarify how things should be done. Eventually you will become comfortable with the routine aspects of the care and you won't need to ask for direction as much. However, you should always ask about food and clothing choices and anything else the client needs to make a decision about.

Clients will want to direct their own care. In the first instance, it is their life and their body and they have the right to make choices about what is happening to them. You should follow your client's instructions unless you are being asked to do something that is unsafe or inappropriate. A client will know if there is a reason to change their daily routine and make decisions about what changes they want. For example, they know when they feel unwell, if they had a hot curry last night or if they have an appointment to attend. This kind of variation to routines is to be expected and carers need to be flexible enough to accommodate it.

Some clients can be very particular about how routines are carried out. They may talk through very detailed instructions each and every time the routine takes place. Some carers may find this annoying or feel as though they can never get to a point where they will be trusted to do anything by themselves. For the client, it is probably more an issue of maintaining control over what is happening to them and avoiding mistakes or time delays – rather than anything to do with the carer. This behaviour could also be a result of anxiety because either the carer or the client themselves are new to this.

Empowerment goes beyond personal care routines. It is very important for clients to have their environment set up to maximise their independence. They might have a range of equipment they need for their daily activities like drink bottles, magazines, remote controls and computers. You must make sure that these things are left in easy reach. Remember to put things back where you got them from unless the client directs you differently.

Personal carers can sometimes do things inadvertently that lessen the accessibility of the home.

For example, you might:

- ▶ Move things to the back of shelves and counters because they are tidier – with the result that the client can no longer reach them
- ▶ Move furniture into what seems like a more logical set up – eg four chairs around a table – with the result that the person using a wheelchair can't draw up to the table
- ▶ Put things away that appear to be lying around – but they are there because that is where the client can reach them.

Sometimes a client will ask a carer to do something that they are capable of doing for themselves. This may be because they need something done quickly or it may be due to laziness. You should encourage your client to do things for themselves when they are able. You may be able to help them work out ways they could achieve certain tasks, especially for those times when there is no-one around to help.

It takes time and experience to develop a sense of what helps to empower your clients. Since each person with a spinal cord injury is an individual, what works for one will not necessarily work for another. People with a spinal cord injury will have different levels of intelligence, different problem solving skills, different inter-personal skills and different motivation. Above all remember that it is not the job of a personal carer to take over someone else's life, make decisions for them or tell them what they should do. Your job is to empower them to take control of their own life.

Rights and responsibilities

As a personal carer, you have certain rights from both a legal and moral perspective. Legislation such as the Occupational Health and Safety Act 2000 and Commonwealth and State Anti-Discrimination Acts establish certain rights for all employees in Australia. Employment conditions are governed by industry agreements, awards or contracts as well as the relevant state and federal legislation

In addition, every individual has certain universally accepted rights – such as the right to be treated with respect.

Your rights as an employee providing personal care services include the right:

- ▶ To a safe workplace free of hazards both physical and psychological
- ▶ To a workplace free of harassment, violence, discrimination
- ▶ To know what is / is not part of your job and job boundaries
- ▶ To know what standard of work is expected
- ▶ To have the information and resources to do the job to the expected standards
- ▶ To express reasonable concerns about work conditions and expectations
- ▶ To be listened to when you have a concern or suggestion
- ▶ To be treated with dignity and respect
- ▶ To be paid appropriately for your efforts
- ▶ To receive support from the service provider or employing agency

For every right you have, there is a related responsibility that can also sometimes be a legal responsibility. For example, we all have the right to a safe workplace. This comes with the legal responsibility to work in a safe manner and report any risk or hazard that may cause an accident or injury to yourself or others. Workers have the right to be treated with respect – the responsibility is to treat all clients and co-workers with respect.

Question: What other responsibilities do you think would result from the rights listed?

Professional behaviour

Your service provider should set out your responsibilities and the expectations of the organisation in a contract or code of conduct. Most employees are aware of what constitutes good conduct and are committed to the highest standards of integrity and ethics.

There are however aspects of professional behaviour that have particular relevance for personal carers because of their close working relationships with people with a disability.

Confidentiality

Clients have a right to privacy, dignity and confidentiality. This is explicitly stated in the Disability Service Standards. As a personal carer, you will have access to very sensitive information about your client. Personal carers and service providers have a responsibility to ensure that this information remains confidential and is only shared with people who are authorised to have it. It is not acceptable to discuss your client with other clients, carers or friends and family. Have a look for your service provider's policies on confidentiality so you understand the expectations of you as a personal carer.

Conflict of interests

People who work directly with clients should not place themselves in a position where they may be seen to be taking advantage of the client or exerting influence over the client's decisions – especially if you stand to gain from the decision. Often it is only the personal carer who will be aware of the conflict – so it is your responsibility to discuss it with your supervisor who will help you to try and resolve the conflict.

No personal carers should have a power of attorney or any other legal arrangement that would give them the opportunity to exert power or influence over a client.

Maintaining professional relationships

The relationship between a client and a personal carer is often an intimate one because of the nature of the work. However you need to maintain professional work boundaries. It can be difficult to establish friendly communication that doesn't cross these boundaries – but there is a difference between being friendly and being a friend. If professional boundaries are maintained, people are less likely to be hurt or feel as though they have been taken advantage of.

Make sure that you:

- ▶ Treat your client and their family with respect – you are going into their home and they need to maintain their privacy.
- ▶ Stay focussed on the work at hand – spending time chatting may hold up your client or make them feel annoyed.
- ▶ Ask questions if you do not understand something or if you need more information.
- ▶ Communicate assertively if you think a request is inappropriate or dangerous.
- ▶ Avoid using language that could be seen as rude or judgemental.
- ▶ Don't discuss your client's personal details with other people.
- ▶ Don't get involved with your client's family or business affairs.
- ▶ Contact your supervisor immediately if you can't resolve a problem directly with your client.

Job boundary management

The following exercise can be used in a facilitated session or as part of a self-paced learning manual. The scenarios have been designed to examine the rules set out by a service provider governing how certain situations should be handled, examine carers' personal boundaries, and work out how to deal with different situations.

There are often no clear cut right or wrong answers. It is important to gauge how personal carers would react and how they might deal with these situations. In all cases it is important to see that carers are not imposing their values on their client and have clear procedures for seeking help if they are unable to deal with anything themselves.

Sample responses for the following exercise can be found in Document 2 – 'Learning tasks and assessment tools'

Rights and job boundary scenarios

Try to answer the following four questions for each scenario. Remember your aim is to find a win / win situation.

- ▶ What is the issue in this scenario?
- ▶ Is the behaviour or request appropriate or inappropriate?
- ▶ What needs to happen from the client's perspective?
- ▶ What needs to happen from the carer's perspective?

1. Client has a dressing on a pressure area that was applied by a community nurse. The client asks the carer to remove the dressing and apply a new one.

2. Client has a supra pubic catheter that comes out during showering. The client asks the carer to re-insert it.

3. Client sometimes smokes marijuana to help with pain when carers are in the house.

4. Client's family often leaves wet towels and clothes lying around and carer is expected to pick up after everyone.

5. Client needs cash from the bank and asks carer to take his keycard and pick up some cash on the way back for the next shift.

6. Client's commode is broken making it difficult to control. Client asks carer to say nothing and not to report it because it will cost too much to replace or repair.

7. Client rings carer and asks if he will accompany him for a one week break to a coastal resort.

8. Client has a pet dog and asks carer to feed the dog each evening and pick up the droppings in the backyard.

9. Carer finds the client's kitchen is difficult to work in and decides to reorganise it to better suit his own work habits.

10. Carer has small children and often has trouble getting someone to mind them – so she brings them to the client’s house and lets them play in the house during her shift.

11. Carer has two different clients and frequently talks to each client about what happens in the other client’s home.

12. Carer goes in for their shift with mobile phone switched on, expecting to receive an important call. Phone rings when client is halfway through a hoist transfer and carer answers the phone.

Communication and relationships

What are the benefits of having a good relationship with your client and keeping the lines of communication open?

- ▶ You get along better
- ▶ There is less stress or conflict – a psychological hazard
- ▶ You can talk things through before they escalate
- ▶ You can solve problems, such as workplace hazards
- ▶ You can get help and support when it's needed
- ▶ Everyone knows what's happening and what's expected
- ▶ You enjoy your work more

Improve your performance as a listener

1. Stop talking, especially chattering and interrupting. Let the speaker finish. Hear them out, in silence. We tend to finish other people's sentences for them or work out our reply on the assumption that we know what they are going to say.
2. Relax. Research shows that tension and anxiety reduces the effectiveness of the auditory receptive centre.
3. Put the speaker at ease by showing that you are listening. Facing the speaker and making eye contact signals that you are focussed on them. The good listener does not look over someone's shoulder or do something else while they are listening.
4. Try to choose an appropriate time to communicate problems or difficulties when the person is likely to be receptive.
5. Be aware of personal prejudices and assumptions – they can be serious barriers to good communication.
6. Listen with empathy as well as reason. Try to get a sense of the underlying feelings behind what is being said – this will give you a deeper understanding of what the speaker is telling you.
7. Ask questions to clarify anything you didn't understand or try paraphrasing what the speaker has said to check that you understood what they meant.

Assertive communication

Being assertive is about standing up for your own rights while still respecting the rights of others. Assertive communication allows two people to explore solutions to a problem without blaming or defensiveness. It helps you to come to a win / win solution. This is one that allows both parties to feel that their needs are being heard and understood.

The following two communication techniques – 'I' statements and how to say 'no' – will help you to tackle difficult aspects of communication.

I statements

'I statements' are a useful tool to help you broach a potentially difficult situation. When you have a problem or want to talk about something that may be a bit tricky to approach, 'I statements' help to open up communication and allow both parties to find a workable solution that respects both their needs.

Using 'I statements' means that you put things forward from your own perspective. The receiver is likely to react in a more positive way when you try to solve the problem – rather than blaming or accusing. There is an easy formula that you can use to give an 'I statement' but the main ingredient is using words like 'I', 'me' and 'my' rather than 'you'.

- ▶ When... describe the situation or behaviour
- ▶ I feel / it means... describe from your perspective
- ▶ I'd like it if / can we... offer a solution or alternative.

It can be as simple as just saying 'I feel a twinge in my back when I move that way, for my safety I need to do it differently' rather than 'You made me do it that way and now my arm hurts.'

Some additional examples are:

Negative communication

You can't ask me to do that, it's really unreasonable, you should know better.

Assertive communication

When I'm asked to do things that are not part of my job, I feel uncomfortable about saying no. I'd like it if we could sit down and look at exactly what my job description is so we're both clear.

Negative communication

Don't shout at me, I can't think straight. I'm still new here and you're not helping when you get angry.

Assertive communication

When you get upset with me I find it hard to concentrate. I am still trying to learn the ropes and I would like it if we could calmly discuss my work and you could make suggestions for improvement.

Negative communication

You can't ask me to pick up dog poo from the garden, are you crazy? Get someone else to do it.

Assertive communication

I would find that task too hard to handle and it is not part of my job description. I would appreciate it if you could find someone else to do it.

Saying no

Some people have trouble saying 'No'. If you are being asked to do something that you find unacceptable or if you are unable to fulfill a request, this technique can help you to express your refusal without blaming or over explaining your reasons. Follow the four step formula to say no when you need to – without feeling guilty.

Acknowledge the request or reason for asking

However never 'but'

Refusal say no without justifying or explaining

Olive branch what can you offer eg another time, a referral to someone who can help or other alternatives

Managing disagreements and conflict

Personal care, by definition, involves getting to know a client at a very intimate level and working with them in their own home. As a result, clients and carers will often develop a very strong bond. However the blurring of distinction between 'carer' and 'friend' also has its disadvantages.

Difficult situations for carers can arise due to factors that have nothing to do with them – such as a client's marital problems, grief, frustration or anxiety. The carer must nonetheless deal with the effects of the person's issues and emotions.

Sometimes a client may gossip about the carers to each other and create bad feelings among them. Other difficulties may arise if the client thinks that the personal carer is trying to 'take over' or not listening to his or her requests and preferences.

Some situations that can lead to misunderstanding or a breakdown in the relationship between a client and a carer include:

- ▶ The carer not listening to or ignoring the client's directions about personal care because they (the carer) think they know best how it should be done.

For example, 'I worked in a nursing home for 18 years. I know what to do.'

- ▶ The carer not listening to or ignoring the client's directions about domestic tasks because they feel the directions are misguided.

For example, a carer has been asked to buy sausages and returns with lean beef '...because it has less fat'.

- ▶ The client not listening when the carer is expressing a concern or problem with a work request.

For example, the carer says 'This seems to be hurting my back. I need to find another way to do this' and the client replies 'Nonsense it doesn't hurt anybody else, just get on with it'.

- ▶ The carer taking on a friend role in addition to their carer role.

For example, the carer now finds that the client is constantly asking for favours 'as a friend' and infringing on the carer's personal time or sense of ethics.

- ▶ The carer overstepping the boundaries into the client's personal space.

For example, the carer helping themselves to a cup of coffee or to food in the fridge.

- ▶ The client overstepping the boundaries and asking the carer about personal information they don't want to share.

For example, the client asks questions about the carer's husband and his business concerns.

- ▶ The carer talking about the client to other people, including to other clients.

For example, a client asks the carer how another client manages his bowel and the carer tells him.

Strategies to prevent and manage difficult situations

- ▶ First and foremost, recognise that both you and your client are only human. You will not always get along with your client. We are all affected by our life experiences. Conflicts will occur.
- ▶ There are no absolute 'rights' and 'wrongs'.
- ▶ Be conscious at all times that your primary role is that of a paid personal carer, not that of a friend. Try to maintain clear boundaries in the relationship.
- ▶ Be clear about your personal boundaries and communicate assertively with your client when you feel those boundaries have been crossed.
- ▶ Usually the client will be the expert in their own care and, if not, it's still their body and their life.
- ▶ Remember that you are in someone else's home, so don't take liberties.
- ▶ Address potential problems when they first appear, rather than waiting until the situation gets out of hand. If possible, discuss the problems first with the client – then with your supervisor.
- ▶ Try not to take the client's issues and emotions on board. Quite often their problem will not be about you – but you happen to be the person around that they can take their frustration out on.
- ▶ Recognise that the person with the spinal cord injury may still be learning how to manage their disability and their carers, and may not always handle certain situations well.
- ▶ Avoid using racist, sexist or homophobic language – no matter how well you think you know your client.
- ▶ It is OK not to feel comfortable in some situations – how you handle them is the key. Talk to your supervisor if you need help to handle a difficult situation.
- ▶ Sexual harassment is sexual harassment, whether it comes from a person with or without a disability. Be assertive – tell your client you feel uncomfortable. If it continues, report it.
- ▶ Don't violate the service provider's policy for the sake of a client who has asked you for a favour 'as a friend' – it's not worth it.

Here are some ideas for solving problems that could occur while doing personal care work

- ▶ Talk to your client
- ▶ Listen to your client's feelings
- ▶ Let your client know that you understand and respect their feelings
- ▶ Use assertive communication to express your feelings
- ▶ Work with your client to try and think of ways to solve the problem
- ▶ Think about each idea and how it would work
- ▶ Choose the idea that will work best for both of you
- ▶ If you can't reach an agreeable solution talk to your supervisor

Talking about a problem is often difficult. It can be even more difficult if you think your client will become angry, upset or even cry. If you are worried about this, think about what will happen if you do not talk about the problem. Saying nothing might mean that you will be working when you are upset about what is happening. This could create problems for you by making you feel unwell with anxiety or making you very distracted –and therefore more likely to have an accident or make a mistake. We would all prefer to feel satisfied and happy in our work so there is a lot to be gained from sorting problems out rather than leaving them in the hope they will go away.

As a personal carer, a time may come when you feel that you can no longer stay in your work situation. If you are thinking of quitting because of a problem on the job ask yourself these questions.

- ▶ Have I talked to my client about this problem?
- ▶ Am I being too sensitive to criticism?
- ▶ Is there any way to work out this problem so that I do not need to quit?
- ▶ Am I angry? Making good decisions is not easy when you are upset.
- ▶ Have I thought about it for a day or two? Thinking about a problem overnight – sleeping on it – can help you to think more clearly.
- ▶ Have I discussed this problem with my supervisor? Sometimes someone else's perspective can be useful.

Conflict resolution

It is important that you feel you are able to bring your concerns to your supervisor or manager, especially if you have tried to resolve issues but have not succeeded.

When working in a one on one situation under time pressure, being directed by a client who can tell you about the task but not demonstrate it for you can be frustrating. By the same token, being a client who needs to manage their hours efficiently and not being able to get your message across to your personal carer can also be aggravating. Look for the real problem, rather than the outburst or irritation. Is it that the client needs to explain tasks better? Is it that you don't have the skills required to do a task? Are you finding it difficult to comply with requests in the time allowed?

Communication is extremely important – between client and personal carer, and also with the service provider's staff. If you don't communicate about the difficult situations, they tend to continue to cause frustration that builds until the job is no longer satisfying or rewarding.

Take your time with communication in a conflict situation. Saying the first thing that comes into our head is seldom a good thing to do. Consider what you need to say and how you are going to say it. Bring the subject up at an appropriate time – having a discussion while your client is in the middle of a care routine may not get you a receptive audience. Try to look at both sides of the story. Sometimes hearing why someone did or said something or how they felt at the time can make you feel differently about the situation.

You may feel you need some training to help you with communication or that your client needs some help in managing carers. If this is the case, speak to your supervisor and the service provider can put measures in place to help.

Sexuality and personal care

After a spinal cord injury, the person with the injury continues to be a sexual being with normal sexual thoughts and feelings and a need for intimacy with other human beings. Your client still has a need to express their sexuality through their clothing and grooming choices. They will also often have sexual relationships with partners, friends or sex workers.

As a personal carer, you may find that your client expresses their sexuality more overtly than they would have done before their spinal cord injury. This can be for a number of reasons. After their injury your client may feel less attractive and may attempt to compensate for this by behaving in a more sexual way. Clients often compensate for their embarrassment over being naked or the experience of an involuntary erection during care procedures by talking about intimate things or making remarks that they would otherwise reserve for their significant other.

Although it is important for carers to understand why their clients may be behaving in an inappropriate way, this does not make it alright. It is important that you be as honest as you can with your client – tell them how their behavior makes you feel and ask that they are sensitive to your needs. While it is important to be able to discuss your personal boundaries, it is not appropriate to judge your client or express your disapproval of their choices. If you encounter materials – like videos or magazines – that you find unacceptable, you should discuss how they make you feel and ask that they be stored out of the way and not used while you are in the house.

If your client continues to act in an inappropriate way, then you should report their behavior to your supervisor so that they can intervene without any further embarrassment to you.

Sexual function following SCI depends mainly on the client's level of spinal cord injury, the completeness of the injury and how long it has been since the injury occurred.

A person with a SCI may experience:

- ▶ Alterations to their ability to feel sensation in the genital area
- ▶ Inability to ejaculate in male and achieve lubrication in females
- ▶ Inability to achieve or sustain an erection that is capable of penetration
- ▶ Prolonged erection.

Involuntary arousal response in male clients

You may have noticed that sometimes your client will get a spontaneous erection while you are attending to his care needs. This can be very embarrassing for both you and the client. It is important to remember that this response is the result of an involuntary reflex activity caused by stimulation of the reflex centres – rather than by erotic thoughts.

After an injury to the cord above T12, the reflex centres responsible for reflexic bladder, bowel and sexual function are often not affected. They function as they did before the spinal cord injury – only now the brain can't override the response. The simple act of sheets gently touching the genital area may be sufficient to cause a reflex erection. Removing the stimulus is often enough to allow the erection to subside.

An erection that lasts for an extended period of time is called a priapism. Priapism can be potentially dangerous for your client as stasis of blood in the corpus collosum for extended periods may cause the blood to clot. This client will require hospitalisation to remove the clotted blood. If the client has an injury at or above T6, they may experience life threatening dysreflexia from a prolonged erection.

There are several ways that you can help your client to manage priapism. Lying your client down will reduce the amount of blood available to the genital area. Another strategy is to give them a warm shower. The heat from the shower will cause blood to travel to the skin's surface to attempt to cool down and also reduce the amount of blood available to the genital area. If neither of these strategies are successful, the client will need medical attention so you should call an ambulance to take them to hospital.

Unfulfilled sexual needs

If a client confides in you that they are feeling sexually frustrated or have a need for intimate contact with another person, it can be a little shocking at first to hear that information. It is good to remember that it is an act of enormous trust from the client to actually discuss these issues with somebody else – so whatever your initial reaction try not to judge the client or tell them how they should behave.

There are a number of services that provide sex workers to people with a disability and they are often skilled and caring people who take their job seriously. Your supervisor or service provider may know of services in your local area that the client could be referred to.

If you feel unable to cope with this kind of discussion, let the client know in a non-judgemental way and suggest that you could talk to your supervisor or they might have someone else they could discuss this with. People with a disability are still human beings with sexual needs like anybody else. Often it is the barriers in our society and the attitudes of people around them that prevent them from fulfilling their needs. As a trusted carer you are in a unique position to help someone with a fundamental human need.

Maintaining equipment

Charging wheelchairs and electric hoists

Electric wheelchairs are best maintained if they are charged each night after use. Nightly charging ensures the batteries last longer.

The procedure for doing this is:

1. Put the wheelchair in 'free wheel' and move it in front of the charger.
2. Put the lead from the charger into the socket in the front of the hand control of the wheelchair.
3. Turn the battery charger on at the power point.
4. Check that the light on the charger comes on – indicating that the wheelchair is being charged.
5. When the wheelchair battery is charged, turn off the power point.
6. Disconnect the lead from the wheelchair hand control and place it securely around the battery charger or through the handle of the battery charger. This is so it doesn't drop to the floor and possibly get squashed when the wheelchair is moved.

Electric hoist batteries vary according to the make of the hoist. It is best to read the manufacturer's instructions about battery charging. As a general rule the battery should be put on the charger each night like a wheelchair.

To charge the battery:

1. Remove the battery from its connection on the hoist – if it is a removable battery.
2. Fit the battery into the charger – make sure it has clicked in fully. If it is not a removable battery then connect the charging lead to the battery in the hoist.
3. Plug the charger into the power point and make sure the charging light is on. Most chargers will have an indicator that the battery is charged eg the light might go off or change colour.
4. Leave the battery to charge overnight. In the morning, turn off the charger at the power point and remove the battery or unplug the lead if it's not a removable battery.
5. Replace battery in hoist. Store the charger in a safe and convenient place.

Adjusting and maintaining ROHO cushions

Goal – to successfully position, test and adjust all styles of ROHO cushion.

Expected outcome – client to be sitting on a correctly positioned and adjusted cushion.

Many clients with spinal cord injuries use a ROHO cushion for pressure relief. ROHO cushions are interconnected air filled neoprene cells. They are inflated with a pump and deflated with a valve.

There are different types of ROHO cushion. They can be one or two inches high and vary in width and length depending how many rows of air cells they have. All ROHO cushions originally come with a soft, 4-way stretch cover to provide optimum pressure relief. Commode seat cushions are not used with a cover.

The different types of cushion are:

Height:	Low profile 5cm high (2 inches) High profile 10cm high (4 inches)
Type:	Single valve cushion (1 valve) Dual valve cushion (2 valves) Commode cushion (hole in the centre) Quadro cushion (4 compartments with a red/green control valve) Enhancer cushion (short cells in centre back, high cells at front and sides) Nexus spirit cushion (foam base with short air cells at the rear)

It is important to know what style of cushion your client uses so that you can check and adjust it correctly.

Positioning the cushion in the chair

1. Always handle the cushion with the yellow rope located on one of the cushion corners. Do not hold the cushion with the valve as this might cause the cushion to leak.
2. Always have the valve/s at the front of the cushion in the chair. This allows for easy adjustment while the client is sitting on the cushion. It also ensures correct cushion positioning once the cushion is replaced in the chair.
3. Place the zip at the back of the chair to prevent it rubbing the back of the client's legs.

Enhancer cushion – position lowest cells at the centre back

Nexus spirit cushion – put the foam at the front.

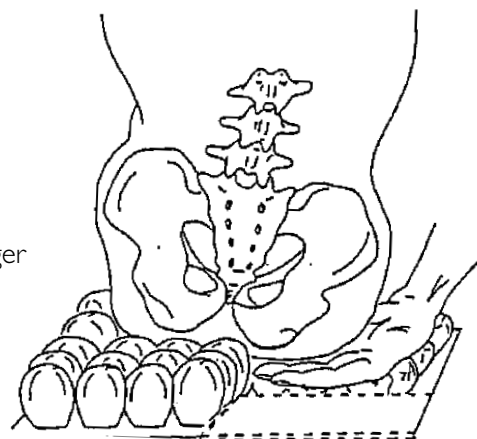
Before the client sits on the cushion, check the cushion has a cover and make sure you have positioned the cushion correctly.

Do not put sheepskin, blue sheets or towels over the cushion as this decreases its pressure relieving properties.

Transfer the client onto the cushion and then test the cushion to check it is not deflated.

Testing a ROHO cushion

1. Place a plastic glove or plastic freezer bag over your hand.
2. Slide your hand underneath the client's buttock from the side or front to feel under the bottom bones (ischial tuberosities) or the lowest bony prominence.
3. Always test both sides. For example, some people may have one bone that sits lower than the other and there must be a one finger width clearance.
4. There should be one finger thickness of air between the client's bottom and the base of the cushion – see diagram.



Hints

- ▶ If your fingers are squashed there is not enough air.
- ▶ If you can wriggle your fingers up and down easily, there is too much air.

Adjusting ROHO cushions

For single valve, high profile, low profile, commode and Nexus Spirit

Test cushion as described above.

If it is too flat – use the ROHO pump to pump more air into the cushion. This is easier if the client is not on the cushion, but can be done with the client on the cushion if necessary.

If it is too high – with client sitting on the cushion, loosen the valve at the front of the cushion and let air out for 2-5 seconds. Test after each deflation and repeat both steps until at proper level – one finger width.

For dual valve ROHO cushions

Make sure that both valves are at the front – unless instructed otherwise by the client. Test cushion on both sides of the client's buttocks or the lowest bony prominence.

Adjust each valve as above. It is important to continue testing both sides of the cushion under the client's bottom until the correct level of air is reached – one finger width.

For Quadtro ROHO cushions

A Quadtro ROHO cushion has four separate compartments – with air either flowing between them or locked off individually. It has a red / green control valve and a separate thin valve.

The control valve works in the following way:

Green end in / red end out = open. Air flows between all compartments

Red end in / green end out = closed. Each section is locked off separately

To adjust the cushion:

1. Position in chair with the two valves facing the front.
2. Check position of red / green valve and make sure valve is open – ie put green end in.
3. Allow for the air to travel between compartments – approx 30 seconds.
4. Feel with hands on four quarters of cushion to check air is equal. Push to equalise if not – you will hear a hiss.

5. Transfer client on to cushion.
6. Follow above directions to test under bottom with hand – both sides.
7. Adjust using small valve as necessary. Wait 30 seconds for air to equalise before retesting each time. This sets the cushion up like the single valve ROHO.
8. If the cushion was prescribed to be used with the cells locked off, wait until you have completed the hand test – one finger width of air – and then push red end of control valve in to lock.
9. Be careful not to let out too much air – it is slow to move between cells and you don't want the patient to bottom out through the cushion.

For ROHO enhancer cushions

ROHO enhancer cushions have air cells that are two heights throughout the cushion. The high cells are at the side and front and the small cells at the centre back.

They have two valves next to each other. The outer valve controls the short cells in the middle of the cushion and the inner valve controls the higher cells around the outside.

Test the cushion. Always test the low centre back cells. This can be done from the back of the cushion with a flat wrist, or from the side of the cushion. There should be one finger width of air between the client and chair.

To adjust the cushion:

1. Open outer valve and inflate cells using ROHO pump until cushion fills.
2. Repeat to fill cells using inner valve.
3. Transfer client onto cushion if not already sitting on cushion.
4. Place hand in plastic glove or freezer bag under client's bottom bones.
5. With hand in place, open outside valve to deflate to one finger width of air. Close valve.
6. Check that client is comfortable sitting on high outside cells. If not, let a little air out of inner valve.
7. Always do a final test under each buttock. If the client is sinking through the cushion, inflate the inner valve a little.

If you are unsure about how to set up any of the cushions, you should contact an occupational therapist who can retest the cushion.

Care of ROHO cushions

1. ROHO cushions can be punctured or torn. The best way to protect the cushion is to use the cover provided.
2. ROHO cushions have a yellow rope attached to one corner. This is designed to be the handle. Using the rope avoids tears in the cushion. Do not pick up the cushion by the valve or the control valve on a quadro select. This could tear the cushion.
3. Sharp objects will puncture the neoprene.
4. Cigarettes will burn holes in the neoprene, though it will not ignite into a flame.
5. Dirt and grit can wear the neoprene at the base of the cells. Using a cover or heavy duty cover will prevent potentially dangerous material getting in between the cells.

Cleaning and disinfecting ROHO cushions

Always wear gloves and an apron when cleaning ROHO cushions.

To clean the cushion:

- ▶ Deflate the cushion, close the valve(s) and place in a large deep wash basin or bath.
- ▶ Use a soft plastic bristle brush, sponge or washcloth to gently but thoroughly scrub all the air cells and the spaces between them. Use the edge of the basin to spread the air cells open for good access to the base.
- ▶ Rinse completely and towel or hang from yellow cord to dry.

You can use liquid dishwashing detergents, liquid laundry detergents or general purpose housekeeping cleaning products. Do not use automatic dishwasher detergents that are too caustic for personal safety.

Dilute following the product label directions for surface cleaning. After cleaning, the basin or bath must be disinfected.

Cushion covers

Always clean the cushion cover when cleaning the cushion – especially if the cover is soiled by spills or body fluids.

Soak the cover in cool water for an hour and then put it through the washing machine on normal cycle. Please wash separately, There is no need to disinfect the cushion cover.

Disinfecting

Periodic cleaning is all that is recommended unless there is a known infection or an open wound. If you need to disinfect the cushion, use a solution of 40ml of household liquid chlorine bleach in 4 litres of water. Always follow manufacturer's safety guidelines on the product label. Soak the clean cushion in the diluted bleach for 10 minutes, rinse completely and allow to dry.

Deodorising

To deodorise ROHO cushions, mix one tablespoon of baking soda in one litre of water or a solution of 1 part vinegar in 10 parts water. Soak for several hours, rinse and let dry. This may need to be repeated several times. Clean product frequently or use an incontinence covering to avoid strong odours and staining.

Repairing ROHO cushions

All ROHO cushions come with a repair kit. This can be used to fix small punctures or holes. Follow the instructions in the kit or in the information booklet.

Larger tears or damage needs to be assessed by a manufacturer. Ask the client who supplied the cushion and follow up repairs with them.

The information about ROHO cushions was sourced from the ROHO group website – www.rohoinc.com 4 February 2004.

Picture used with permission from Mal Turnbull, Seating Dynamics, 2004.

Maintaining Jay cushions

Jay cushions, Jay 2 and Jay Deep Contour, are cushions made from foam and a gel like material called a fluid pad. The cushions provide pressure care for people at risk of skin breakdown.

The cushion has a foam base and the fluid pad sits on top to provide cushioning. There may also be accessory parts that fit between the foam base and the fluid pad(s). When removing these for cleaning, it is essential they are replaced in the same position. If you are unsure, contact the health professional who prescribed the cushion or an occupational therapist.

Placing the cushion on a wheelchair

When positioning someone in a wheelchair that has a Jay cushion, always ensure the fluid pad is positioned with the fluid pad(s) or softest part at the rear of the seat. If you are unsure this is written on the foam base and the fluid pads. A Jay cushion – once prescribed for a person – does not need any further adjustments.

Maintaining a Jay cushion

Monthly cleaning and regular maintenance is recommended as it may help extend the life of the cushion. During cleaning, component inspection is recommended. Check the cover for tears and excessive wear and inspect the fluid pad(s) for punctures or any other abnormalities. Check the foam base to ensure that any accessories are still in position.

When checking the fluid pads, if you ever feel the fluid is firmer in one area, simply knead the fluid back to its original consistency and/or call your local authorised supplier.

Cleaning a Jay cushion

Cover – Remove the cover from the foam base. Turn the cover inside out, zip closed and machine wash in warm water and drip or tumble dry on low heat. No ironing required. Ensure the cover is completely dry before refitting.

Foam base – Remove cover, fluid pads and any accessory parts from the foam base. Wipe with warm water and soap. Wipe off with a clean cloth, ensuring there is no excess moisture. Do not submerge the foam base in water.

Fluid pads – Remove cover from the base. Remove fluid pad or pads and wipe with warm water and soap. Wipe off with a clean cloth, ensuring there is no excess moisture.

Accessory parts – Wipe clean the accessory parts with warm water and soap. Dry with a clean cloth.

Refitting

Reinstall any accessory items, then the fluid pad(s) and then fit the cover back over the foam base. Make sure the back of the cover matches up with the back of the cushion. If you are unsure this is written on the underneath of the foam base.

Please refer to the specific instruction manual for any additional cleaning, maintenance or assembly instructions.

Adjusting an alternating air mattress

Goal – to successfully maintain an air mattress or overlay and find the source of any problems

Expected outcome – air mattress or overlay properly adjusted for client.

Types of air mattress

There are two types of alternating air mattresses used by clients with a spinal cord injury – a mattress replacement system or a mattress overlay.

A mattress replacement is a full size air mattress that sits on the base of the bed instead of a standard mattress. A mattress overlay is a thinner air mattress that is used on top of the standard mattress and is approximately 10 cm high.

Both styles of alternating air mattresses need a power connection to operate the mattress. This cord plugs into a power point. The cord should be attached to the underside of the bed – to ensure the floor space is clear of the cord so, for example, the hoist can pass freely under the bed.

The control box should be attached to the end of the bed. This control box is attached to the mattress by air hoses through which the air flows.

Each mattress also has a 'CPR' plug so that the mattress can be deflated quickly in case of an emergency where CPR needs to be administered. The plug can also be used for quick deflation.

All styles of air mattress are designed to alternate, so that adjoining cells are alternatively hard or soft. This relieves pressure for the client when lying on the mattress.

Some mattresses automatically adjust to a person's weight and any changes in their position eg changing from lying down to sitting up at 90 degrees. Others need to be adjusted to the correct weight of the client – via a dial on the control box – so that they inflate correctly. Always refer to the manufacturer's user manual to check which style of mattress each client has. If you are unsure, contact the supplier or the health professional who prescribed the mattress.

Air mattress setup

All air mattresses should be set up and installed by a health care professional or the supplier when they are first delivered to the client. Each air mattress or overlay will be set up differently according to the manufacturer and supplier instructions. It is a good idea to make sure the instruction manual is available.

Air mattresses or overlays have straps that attach the air mattress or overlay to the bed base or mattress. It is important to secure this to stop the mattress from sliding if the bed is tilted or the head of the bed is elevated.

Correct air mattress set up includes checking that:

- ▶ The air hose at the bottom of the mattress or overlay is not kinked.
- ▶ The air hoses are attached to the control box.
- ▶ The mattress or overlay is lying flat and not folded over at either end – unless indicated by client that this is authorised by supplier.
- ▶ The power plug at the wall is plugged in and switched on.

- ▶ The button on the control box is on.
- ▶ The mattress or overlay is securely attached to the mattress or bed base by straps to stop it rolling around.
- ▶ The CPR plug is clicked in.

Making the bed

It is important to take care with the sheets when making the bed over an air mattress or overlay.

- ▶ Always use a flat sheet instead of a fitted sheet over an air mattress or overlay. This allows it to maintain its pressure reducing properties.
- ▶ Keep the CPR plug free and easily accessible in case of emergency.
- ▶ Make sure the air hose is not kinked or squashed between the mattress or overlay and control box.
- ▶ Do not put sheepskin or lots of blue sheets on top of the mattress or overlay surface – unless authorised by supplier and health professional – as this makes the mattress or overlay ineffective for pressure relief.
- ▶ Blue sheets can be used as required during certain procedures such as bowel and bladder routines.

Trouble shooting

Most air mattresses have a flashing light or alarm that goes off when the mattress has no power supply or is not inflating properly.

If the alarm goes off or the mattress is flat, there are several things you can check.

- ▶ Check the mattress is plugged in and turned on at the wall.
- ▶ Check the switch on the control box is on.
- ▶ Check the air hoses are attached properly at the pump box and to the mattress. They should be firmly connected
- ▶ Check that the air hoses between the pump box and mattress or overlay are not squashed or kinked.
- ▶ Check the CPR plug is hooked up and has not been pulled or knocked out accidentally.
- ▶ Check if one of the cells is punctured or broken.
- ▶ Check whether the mattress or overlay is a weight-adjustable one. If so, is the dial set at the right weight for the client? Follow the instruction manual for this.

If the mattress stays deflated, is punctured or the alarm stays on, call the supplier hotline phone number. This is usually on the control box. The mattress will need to be fixed as soon as possible.

Please also call ParaQuad for advice on interim care for the client.

If an air mattress deflates or punctures and stays flat, the client with a spinal cord injury is at a high risk of developing pressure areas if they continue to lie on it. Pressure areas can begin to develop even after a short time.