**GOOD PRACTICE in the CARE OF PEOPLE WITH DISABILITIES IN BED**

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I am a disabled man in my late sixties. A year ago, in September 2020, I had a major stroke that put me in hospital for several weeks. The stroke left me with a left hemiplegia, paralysed completely down the left-hand side of my body and very weak core muscle strength. It also meant that I was doubly incontinent and was fitted with a catheter. Full-time catheterisation meant that I was prone to bladder infections (which are not pleasant). It seemed that I was on a permanent prescription for bladder and urinary tract infections and the antibiotics added to the volume of pills and potions that I had to swallow every day. The problem is that, following the stroke, I found swallowing difficult and would often choke when eating or drinking. Thus, I had to have all my drinks thickened and avoid certain foods. The stroke also affected my speech and talking became something of an effort. Indeed, if I am emotional, or in pain, I cannot speak at all and have to resort to using Makaton sign language. As if not all that was enough, I found myself having to cope with lengthy periods of pain and incredibly poor post-hospital provision. All of this was during the Covid lock-down, which further compounded my nightmare. Having a stroke made me feel like Gregor Samsa, the salesperson in Franz Kafka’s surreal book (‘The Metamorphosis’: *Die Verwandlung*. Original in German, 1915), awakening one morning, only to discover that he had inextricably transformed overnight into a very different, somewhat repulsive, being. I awoke, knowing I would have to learn to deal with a new reality; one in which many people might view and treat me differently from now on.

On leaving hospital, I was provided with a manual wheelchair, a hospital style bed, a mobile hoist and sling, a commode (which I have never been able to use for its intended purpose), and a very poor quality over-the-bed style table that I used for just a few days before purchasing a much better version from Amazon. An interim care package was setup for me that involved four calls during a day but this provision only lasted for a short time until circumstances forced my wife to set up our own system of care. Such service provision was quite difficult to set up and proved to be frighteningly expensive. Having worked all my life and saved for retirement, no financial assistance for support was available; my retirement savings had to be used to cover all the cost of care. Yet, if I did not bother to plan for retirement, and had no savings, then the cost of care would have been virtually covered and the service almost free. My wife is planning on giving up work to help with my care very soon (Visser-Meily, Post et al 2009; Cameron, Cheung et al 2011; Cameron, Stewart et al2014; Bastawrous, Gignac, et al2015). She cannot cope with a job and having to meet my needs during the evening and the night. We applied for an Attendance Allowance; to offset some of the income we were losing, only to find that on the maximum level to which we were entitled is £89 per week. Further, my wife is entitled to a Carer’s Allowance of approximately £60 per week. These allowances, plus my state pension, barely cover the cost of the level of care (Rajsic, Gothe et al2019) that I now need on a daily basis. However, I am truly grateful for the help that I received. I am aware that, in other countries, I would not be provided with anything at all and would have to pay for every little bit of support. I thank the gods that I was born in the UK.

All my working life, I was involved, in one way or another, with People Of Disability (POD) and or learning difficulties. I also was involved in the provision of training for professionals and support workers. I worked alongside gifted Speech and Language Therapists, Occupational Therapists, and Physiotherapists as well as many talented teachers and support staff in many different countries. The focus of the training I provided concerned good practice in education and support provision for staff working with individuals experiencing special needs. It now seems somewhat ironic that I am in need of that support myself! The irony is not lost on me. I had become an I.R.O.N. (***I****ndividual totally* ***R****eliant on* ***O****thers for* ***N****eeds*)

The level of care provision both in hospital and in post-hospital settings varies wildly from the incredibly good to the unbelievably poor and, as an IRON, I thought that I should put down in print my experience and thoughts on the care I have received. What would I consider best practice? (MacKenzie, Creaser et al 2017) I should have some insight, after almost a year of daily care and a little, rather inadequate, post-hospital provision. When a person is ill, the last thing about which they should be worried is the level and standard of care provided. However, the realisation soon comes that, for ***I****ndividuals totally* ***R****eliant on* ***O****thers for their* ***N****eeds* (IRONs), the standard of care provided plays a major role in an individual’s quality of life (Mayo, Wood-Dauphinee et al2002; Opara & Jaracz2010; Van Mierlo, Van Heugten, et al 2016; Caro, Mendes et al2017)

As an IRON, I soon came to realise that my future was forever changed. I would, short of some miracle, always be totally reliant on the kindness of others and, if that kindness was, for some reason, to fade and the others chose to walk away, I would be helpless, trapped inside my own body: an IRON, a prisoner in virtual irons created as the outcome of a stroke. I understand why so many, in my position, become depressed and even suicidal (Parikh, Eden et al 1989; Parikh, Robinson et al1990; Van de Weg, Kuik, et al1999; Kneebone, & Dunmore2000; Pohjasvaara, Vataja et al2001; Berg, Palomaki et al 2003; Cassidy, O'Connor, & O'Keane2004; Niedermaier, Bohrer et al2004; Suh, Kim et al2005; Mitchell, Teri et al2008; Hadidi, N., Treat-Jacobson, D.J., & Lindquist, R. 2009; De Man‐van Ginkel, Gooskens et al 2010;Srivastava, Taly et al2010; Cameron, Cheung et al2011; Herrmann, Seitz, et al 2011; Schmid, Kroenke et al2011; Salter, McClure et al 2012; de Man-van Ginkel, Hafsteinsdóttir et al2013; Broomfield, Quinn, et al 2014;Mitchell, Sheth et al2017; Sarfo, Jenkins et al2017; Towfighi, Ovbiagele et al 2017; Das & Rajanikant 2018). Life without hope is not life at all. If post-stroke provision is poor, it is easy to lose hope because, the little support given, gradually starts to fade away, the individual is left alone, waiting for something of significance to occur, and constantly experiencing setbacks that only lead to further periods of waiting. I am currently waiting for an alternative to my catheter (waiting three months already) with which I have an ongoing problem, waiting for an electric wheelchair assessment (waiting over a month so far and a year post=stroke ), and waiting for my virus inoculation (why, when all my able-bodied friends have been inoculated already, am I still waiting?). If the wheelchair assessment finds me competent, I, no doubt, will have another long wait to learn to what I am entitled. Do I want special treatment? No. Am I deserving of more attention because of my stroke? No, I realise I am not special but I would like just a little more understanding of my predicament. Having no electric wheelchair virtually ensures that, without the help of others, I must spend day after day in the same position, in the same bed, in the same room. Others come to see me and typically talk of the weather outside, such conversations only serving to reinforce my feeling of being shackled, unable to escape. Not that I complain about the topic of conversation, I do not want to risk visitors electing to refrain from communication with me. I am still able to laugh at my situation and the events that happen. If I could not, I think that I would go quite mad! C’est la vie, n’est-ce pas? When I feel low, I try to take my mind to a different place. I might start writing a little more of this paper, for example!

I type this paper using an on-screen keyboard, controlled via a wireless trackball, picking out one letter at a time. It is not as fast as I would like. Prior to the stroke, I was faster, typing with two able hands. I am grateful for both the technology and the software that enables me to type, while in bed, with half of my body not functional. If I have to be disabled, I am glad it is in 2020 and not in 1920! Life, for someone in my position, must have been terribly difficult a century ago. It is not pleasant just thinking about it. I imagine, in 2120, things will have advanced even more and, perhaps, none of what I have written below will be relevant any longer. However, as I will not be around to benefit, I have to deal with my life as it is today. ‘Helper robots’, programmed to meet my every need, only exist in fiction. Until they become reality, people must fulfil that function for, at least, a small part of my day. During the night, my wife was, and still is, ‘on call’ to provide my care, even at three in the morning, although she has to work during the daylight hours and needs to sleep well to be able to function. When she had a daytime job (she was a teacher), I would lay in my bed, often in some pain, during the night, trying not to call her, so as not to disturb her sleep to come and help me. However, after a while, sometimes, I could not stand being in pain any longer and simply had to wake her. This remains the situation today and I do not see it changing significantly in the near future. I have a button, by my bed, downstairs that rings a bell upstairs in the bedroom. One particularly bad night, I had to summon her three times. I feel awful doing it once during the night; imagine how I felt having to do it three times. Typically, each ‘call’ keeps my wife fully occupied for around thirty minutes and so, she loses approximately forty minutes of sleep each time I have to awaken her. I am usually awake throughout the night. My doctor prescribed medication to help me sleep but it did not work. Apparently, a doctor may not prescribe anything stronger or more effective. Such a thing must exist because they put Patients to sleep in seconds to perform surgery. As I do not sleep at night, I tend to fall asleep during the day for short ‘naps’ of perhaps an hour or two. I have fallen asleep while holding a drink in my good hand with obvious consequences! A very wet bed and more work for those having to care for me. I try not to sleep at all during the day such that I have a better chance of sleeping at night. However, my body has a will of its own and it is often stronger than my will to remain awake.

The experience I had in hospital after my stroke was not a good one overall. I scribbled notes in a jotter, throughout my stay, in rather poor quality handwriting; it is hard to write with just one hand while lying in bed with a notebook resting on the blanket, perched precariously on my remaining good raised knee. In reviewing my notes, on one page I had written, ‘*I hate it here’* and on another, ‘*some nurses nice, some nurses mean*’. I particularly found some of the night staff I encountered to be ‘mean’. It seemed like they resented having to help me. Perhaps, having to work throughout the night is a chore and staff resent it. I can empathise with that but it is no reason to treat Patients any differently. I grew accustomed to long waits of fifteen minutes or more after pressing the nurse call button. I am aware that nursing is a busy and demanding occupation. I have nothing but respect for the job that nurses do and believe they deserve a significant pay rise to reward their dedication. However, a few are not deserving of such recognition. One night, after waiting for nearly twenty minutes for someone to answer my call, a nurse finally came to my bedside, she switched off the call light, which was flashing on the wall by my bed, and then walked away without saying or doing anything at all to or for me. My wife wrote to the Patient Experience Team to raise this issue but things did not improve. Another time, I was in a bed with a faulty bed control. It was night and the lights were out. I was very uncomfortable but could do nothing to help myself except to try to use the bed control to reposition my body a little. In the poor light, I hit the ‘raise bed’ function thinking that I was raising the top of the bed just to sit up. When I realised that I had raised the whole bed by mistake, I tried to lower it but that particular function was faulty and not working on my control so the bed remained raised in its highest position. A while later, a night duty nurse, on seeing my elevated position, came up to me and started to scold me like a little child. I tried to explain but my speech was bad following the stroke and I struggled to speak. The nurse made no effort to listen and comprehend my poor communication and continued to berate me. He used the separate bed control at the foot of the bed to lower the bed. He told me that I should go to sleep and stop messing with the bed control as it was not safe to be “way up in the air.” He then took my bed control and positioned it behind me such that I could not reach it and had to spend the remaining part of the night without any control over my position whatsoever. He said that *he* would be in trouble if I were to fall out of bed so high up (where was the concern for me?). Fall out? I could not even roll over on my own let alone fall out of bed. The side railings were in use and in the up position! How could I possibly fall out of bed even if the bed was atop a mountain? That particular nurse showed no understanding of my condition or my predicament. I was just a ‘naughty child’ messing with the bed control in his mind. On yet another night, I had been moved from the main stroke ward to an individual room, for a reason that I do not remember, and I really was really in need of a drink. I was so dry. I pressed the nurse call button and waited. Twenty minutes later (I got into the habit of timing my ‘waits’), I heard nurses talking outside my room; “Who’s buzzing?” “Oh, it’s just the man in room x. He can wait.” I waited another fifteen minutes before I got a drink. It got so that I dreaded the night. I was not sleeping well and would lie awake becoming more uncomfortable because I was unable to adjust my position sufficiently. It is unnatural to remain in the same position for long in bed, recordings of sleep patterns show regular body movement throughout the night (*https://www.23andme.com/en-gb/topics/wellness/sleep-movement/*). I lay awake for hours, much of the time, trying to move my body a little, using a combination of the bed control and my one good leg, to make myself more comfortable and ease the increasing pain, particularly in my bottom. I lay, waiting for the daybreak when, just before breakfast, nurses would arrive to wash me and make me comfortable, ready for the day to come. Time passes slowly when there is little to do to occupy the mind. I was very reluctant to use the nurse call button because my previous experiences were less than positive. I would lie, in some degree of discomfort, longing for someone who would come and help me. Some nurses were fantastic and nothing seemed too much trouble for them. One nurse sat by my bedside one day when I was feeling particularly low. She took the time to talk to me and tell me of other people she had met who had a stroke like mine and made an amazing recovery. She even held my hand. She was positive and caring. I wish all nurses were like her.

I started to believe that hospital is the worst place to be when ill. My hospital was charging £10 per day just to watch TV. I refused to pay such an exorbitant amount and, as listening to the radio was free (when it was working), I would do that instead. My wife came to see me every day. How I looked forward to her visits. I asked her to buy me a DVD player and to scour the local charity shops and purchase any films on disc she found that she thought I might like. Doing all of that was much less expensive than paying for the ‘privilege’ of watching hospital TV. I passed the long days and nights watching film after film, even though I had seen most of the films before. I longed to go home from hospital so that I could recover. It would be weeks before my wish came true and then a completely new set of issues with post-hospital provision and care teams would arise. Do staff receive training in basic Patient / Client care? If they do, some attending must be sleeping throughout the course or the course is not fit for purpose. My experiences prompted me to write this paper to give those in a caring or administrative role a basic guide to good practice written by someone with first hand and current experience of care / Patient provision; an insider’s view.

I wish to make it clear that although this paper may appear like a criticism of Carers and Nurses, it would be mistaken to conclude that I have a negative opinion of people working as either Carers or Nurses. Far from it! I have encountered many outstanding Carers and Nurses. I believe both deserve a higher status for the essential function they play in society. Where would I be without them? In a very bad situation without doubt. No matter how good a Carer/Nurse is, there is always some room for improvement. Client feedback is therefore important (Tasa, Baker, & Murray 1996; Vingerhoets, & Grol 2003;Bastemeijer, Boosman et al 2019; Berger, Saut, & Berssaneti 2020). I hope this paper helps.

Below are sixty something points I have noted/experienced as an I.R.O.N confined mostly to bed and with knowledge gained through my earlier work (as a TAB – **T**emporarily **A**ble **B**odied person) in supporting special needs across the world over many years. The points made are grouped together under subheading categories. These are not in any particular order of importance. Some points deal specifically with my time spent in hospital and relate to the nursing provision. Others relate specifically to post-hospital care provided at home. Most are equally relevant to both forms of provision. I use the term ‘Client’ throughout this text to refer to the person in need of assistance. A ‘Client’ may be a service user, a customer, a Patient, or some other term of reference, depending upon your specific area of provision. ‘Carer’ is used throughout to denote the provider of care be it a qualified nurse or a person working in a caring role for a care provision company. I use the term ‘Patient’ if the experience directly relates to my time in hospital although the point made might equally relate to both areas of provision. The acronym POD is used to represent a **P**erson **O**f **D**isability or **P**eople **O**f **D**isability depending on context.

**The Goal Is Control**

1. The goal is control. That means giving the Client control and not taking it away from him or her. If remote controls are in use, the Carer should not take control but pass the control of the situation to the Client (Barlow, Wright et al2002; Greene & Hibbard 2012 ; Foot, Gilburt et al2014; McDonald C., 2014). If the person is not capable of operating the control, you should always ask for permission to use it and state clearly what you are about to do. Ask permission before each action: “Is it OK if I lower your head? “ Even if the person is physically incapable of performing some function, ensure that the person is always in control. Never take the bed control without permission and subsequently ask, “Is it alright to raise the bed?” The former act negates the latter. When a Carer takes control by removing Client control, this also removes Client dignity. Ensure the Client remains in full control when s/he is alone. Do they have the TV remote? Is the bed control accessible? Is the call button available? I found myself, on numerous occasions, without a means of summoning assistance. It is very worrying, especially if you are in a room on your own. I soon learned to check that I had access to a call button before staff left and I was on my own. That situation is not as threatening for more able Clients (who are not helpless and can get out of bed and move around to do things for themselves), but I was an IRON, a prisoner within my bed, held captive by my disability. I was not in control. Early in my first period in hospital following the stroke, I had to call a nurse to look at my catheter bag, which was full. The nurse said, “*Oh Christ*!” and hurried to get a disposable bottle in which to empty it. I then asked the nurse for the bed control. She gave me a quizzical look and asked, “*What do you want that for*?” I explained that I wanted to raise the top of the bed. She asked, “*Do you want to sit up*?” and using the bed control herself proceeded to raise the top of the bed saying, “*Tell me when*.” I protested, “*No, give the control to me*.” My speech was poor, affected by the stroke, and the nurse just carried on in control saying, “*Too high*?” and began lowering the top of the bed! I repeated, as clearly as I was able, “*No, give it to me*.” This time the nurse appeared to understand me and passed me the control stating, “*Fine, do it yourself*.” She was not pleased as she walked away. Carers like to be in control.It is not the Carer that needs to be in control, it is the Client. An example will illustrate this concept further. I had been saving some dental chewing gum on a little piece of tin foil on my bed table. I had a piece of gum every day and I had saved it over a week. It may not have been too hygienic but it was my choice. One morning a Carer spotted the gum on my table and, without asking me, picked it up and threw it in the rubbish bag! I was angry that she had taken away my control. **The goal is control.** Control over health. Control over Carers. Control over the environment. Control over the gadgets in the environment. Control is empowering.
2. Stop banging. One time, while in hospital, I found myself with no access to a nurse call button. Needing assistance, I improvised and used the bed control to bang on the bed frame. The unorthodox technique worked in that it got attention but I was scolded (banging was ‘inconsiderate of other patients’) and I had the bed control taken away and moved out of my reach. However, the nurse did give me the nurse call button but at the cost of losing my bed control. Ensure the Client always has an acceptable means of summoning assistance. Never punish a Client by removing control.
3. Going up? Ensure the hoist is in good working order (Health and Safety Executive 2011; Bainbridge 2019).If the Client is capable, put control of the hoist in the Client’s hands. Give control of the hoist to the person to be hoisted. The Carers can ensure that hoisting is undertaken safely even when they are not directly holding the hoist control. If the individual is physically and cognitively competent, the role of the Carer is to empower the Client and enable him / her to do it for him / herself. If there is no other option but for Carers to operate the hoist, it is important that they allow the Client to take charge of the situation by asking the person to give instructions on what actions to take and when to take them. Client instructions need not be verbal, sign or gesture are equally as good; these modes of communication still allow the Client control of the situation. Do not take control away from the Client, allow the Client to take control away from you.
4. I’m in charge. Who is in charge? (Haug & Lavin 1981; Veatch2008) A Carer entered my room while I was watching a film. She took the TV remote off my bed and paused the film without asking. I was somewhat annoyed! Her actions implied that she was in charge of the situation and, now that she was present, I was subject to her will. The question of who is in ultimate control of a situation can be contentious. If a Client is saying one thing and the Client’s spouse (or Significant Other) another and the Carer’s belief is yet a further option, whose rule is correct? Sometimes this can be problematic. As a general principle, the Client should always have the guiding voice, although it may prove very difficult to ignore the spouse! Suppose the Client is not cognitively competent, should the spouse’s wishes prevail? The answer is not a simple ‘yes’. The Client’s wishes should always be a priority but an other’s wishes may overrule a Client if the Client’s wish is D.U.B.I.O.U.S:
* **D**angerous,
* **U**nreasonable (impartial others would judge it to be so),
* **B**ad (for the Client),
* **I**mpossible to undertake,
* **O**utside your remit, (there may be rules that do not permit Carers to perform specific actions. This includes any directive written into the Client’s Care Plan),
* **U**nintelligible or **U**nworkable,
* **S**pecialist (require a professional – a person specifically qualified for that role)

If any of the above are a ‘dubious’ feature of the Client’s request, it may prove necessary to follow an alternative path. The goal is control unless control is *dubious*.

1. Empathy. Anyone’s life can change, in an instant, overnight. It could be you lying naked in the bed unable to care for yourself, unable to move without assistance. How would you feel? How would you want to be treated? (Raab 2014; Svenaeus 2015)
2. Mr Stretch and Mrs Bendy. Unless very special, a person’s elbows only bend in one direction. Why, then, do some Carers place items, such as the bed control, TV remote, etc., in positions that require the Client to perform superhuman contortions in order to be able to access them? Placing items in impossible to reach locations is removing Client control. Removing control is removing dignity. Maintenance of the Client’s dignity is extremely important (Cairns, Williams et al 2013; Higgins 2020; Hammar, Alam et al 2021). The goal is control. The goal is Client control. (Examples of removal of Client dignity can be found in a Unison publication available here: https://www.unison.org.uk/content/uploads/2015/06/23070.pdf)
3. Enable with the cable. Controls for hospital-style beds are usually attached to the bed via a spiralling cable. This cable has a habit of becoming snagged down the side of the bed such that only a small amount is available to the Client in attempting to control the bed’s position. The Client ends up fighting against the spring of the spiral to gain control. Carers have stood and watched me struggle with the bed control fighting against the springy cable and not asked if I needed help. It is a simple matter to ensure the bed control is within reach, easily accessible, and the cable is free from snagging on the side of the bed. The Client should be able to use the control after Carers leave without any problems.
4. Assess not Assume (Ryden & Knopman1989). Do not assume because ass-u-me makes an ass out of u (you) and me (pun originally attributed to Oscar Wilde). Do not assume that a Client cannot comprehend questions or instructions. Do not assume that a Client is incapable of performing a task even if the Client’s ability is unclear. Rather, clarify the situation by asking the person. Never perform an action on ‘behalf of an individual’ assuming the person cannot do it for him / herself. Take away a Client’s control and take away a Client’s dignity. Under time constrictions, it is often easier / quicker to ‘do for’. This is not good practice.

Do for = poor practice.

Do with = better practice.

Enabling the Client to do for him / herself = best practice.

**Communication**

1. Sign of the times. All Carers should know some basic (Makaton) signs, such that they will be able to understand if a Client is trying to communicate, or to be able to demonstrate to a Client how to make basic communication; for example, how to sign ‘yes’ and ‘no’. If sign is not known to the Carers, ask the Client to demonstrate some basic signs. I was signing ‘I don’t know’ this morning slowly several times. The Carers, rather than see my signs as an answer to the question they had just asked of me, decided that I was pointing out that my chest needed washing They hadn’t a clue and seemingly preferred to remain ignorant of ways to make any communication between us a lot better. Communication matters - Always attempt to establish a meaningful means of communication for and with the Client. It may be that the Client utilises an alternative form of communication (for example, a sign or symbol system). In which case, attempt to learn how able s/he is in its use. If you are not competent in sign language, ask your Client to show you how s/he makes basic signs. For example, yes, no, please, thank you, pain and any others that it might be useful to know. Be a little wary of copying a Client’s signs without checking that the sign is correct. While it is acceptable for a Client to use idiosyncratic signing (for example, I only have use of my right hand and so I have adapted my knowledge of Makaton to work with only one hand) (Note: I believe Irish Sign Language only requires the use of one hand), idiosyncratic signing is not acceptable for the Carers! Playing Chinese Whispers with sign language is sure to result in very strange hand movements recognisable by no one. Learn to recognise the signs as used by the Client. It can be very frustrating for a Client, when signing, if the Carers do not comprehend the message. A good place to learn some basic (Makaton) signs is to search for ‘Mr Tumble’ videos on YouTube. ‘Mr Tumble’ is not just for children. Everyone should know some signs: schools should teach sign language. Sign language should be an option on the curriculum alongside French and German. If the Client has apparently no recognisable means of communication, and a significant cognitive impairment, it is possible to attempt to turn an already existing behaviour into a meaningful mode of communication (Ware 2012). For example, if the Client is able to move any part of his / her anatomy purposefully, it may be possible to associate that particular movement with a specific concept by always responding to it in exactly the same way. Moving a hand slightly to the right (or slightly lifting a finger) might be taken to mean ‘yes’, for example. The consistency of the response establishing a relationship, over time, such that a movement, which a Client was already capable of performing, becomes an idiosyncratic sign for the word. It is very important that all involved with the Client respond consistently, in the same way, to establish the link. Significant Others should be aware of all that is attempted. Where a Client has an existing method of alternative communication, it is very important that Carers do not impede its access for any longer than is essential. A symbol book or chart may need to be out of the way, while rolling, for example, but the Client should have access to it as soon as possible after. Do not deprive the Client of a means of communication for longer than is necessary.
2. Don’t ask her, ask me. As previously noted, questions on care should be addressed to the Client and not to some other member of the Client’s family. It is truly demeaning to Clients to ignore them completely and address questions to others. It is the old ‘*does he take sugar?*’ issue (Wagner 1991; Hogg & Wilson2004). Radio 4 (UK) used to broadcast a weekly series entitled ‘*Does He Take Sugar?*’ (It started in 1977 and ran for about twenty years) in which it covered the treatment of the disabled. The title of the program refers to an all-to-frequent occurrence, in which a person asks another (other than the person with the disability) a question about a topic avoiding talking to the person with the disability. People often discuss items concerning someone with a disability, while s/he is present, and do not include the person even though s/he can speak for him / herself. The radio series made this type of thing explicit and gave People Of Disability (POD) a voice. My wife has replied to people, behaving in this fashion, on several occasions, “*I don’t know. Why don’t you ask him?*” Always address questions to Clients. Even if incapable of verbal communication, the Client may still be able to respond using an alternative methodology. If another family member is around, they are likely to respond on the Client’s behalf if they know the Client is unable to answer for himself / herself for any reason. The Client will always appreciate that the Carers directed question at him / her even though s/he is not able to reply in a comprehensible fashion in the situation. Bypassing the individual completely is both demeaning and very poor practice. If a Client responds in a manner that is incomprehensible, never denigrate the Client’s response system, “*Oh, I don’t understand those stupid signs, can you write it down?*” Rather say, “*I am sorry John, I never learned any sign language, but perhaps you could teach me how you say some basic things when I come the next few times and you will help me to understand you better*. *Is that OK with you?”*
3. Inclusive talking. I have found that Carers in pairs tend to talk to each other most of the time and not to me! Talk should always be inclusive; that is, involving the Client. Even if the Client is a poor communicator, that is not an excuse for excluding him / her. If the Client cannot speak at all, try to involve the person in conversation and expect signed, symbolic, facial, vocal sound, or body language responses. Try to talk about topics in which the person is interested: their previous job or pastime, favourite TV programme or films or music, the local or national news, a sporting event, family matters, etc. Do not talk over them, talk to them. Never talk about a Client unless you are talking to the Client. Never discuss matters about another Client in the presence of a Client. That is unprofessional. It is acceptable practice to ‘tell by indication’ (pointing to or touching very gently) especially if the Client has learning difficulties or is in any way intellectually impaired and has problems in understanding spoken language. Thus, when informing a Client of the need to move his arm, it is acceptable to enhance the likely understanding of spoken language by pointing to or, if required, gently touching the arm briefly. If a Client does not communicate, it may be necessary to contact the local speech therapy service for support. The Client’s Care Plan should detail the Client’s Speech and Language Therapist if one is already supporting the Client. The SLT may be able to advise on a suitable AAC (Alternative or Augmentative Communication) system should it prove necessary.
4. Talk to me. If a Significant Other is present while performing care duties, ensure that any conversation is with the Client and not with the Other without including the Client. It is not good practice to talk about the Client with another while the Client is present and can overhear especially if the talk refers to something negative. Do not discuss, with the second Carer, the details of the coming day. Do not talk about other Clients (their information is private). Even if your Client is not very talkative, you should still talk to them and include them in the conversation. The main topic of conversation amongst the nursing staff in hospital (conversations that did not include me) appeared to be concerned with details of shift rota or the details of their next break. Nurses would typically carry on a conversation concerning shifts while working with a Patient, talking between themselves across a Patient. The Patient may as well not have been there!
5. A dumb person. As a result of the stroke, my speech was impaired. Sometimes, I can hardly speak at all: when I am emotional, when my mouth and throat are dry (usually following sleep), when my throat needs clearing (since the stroke, I cannot cough on demand (I have to wait until it happens naturally)) and, at other times, for reasons I cannot explain. At each of these times, I resort to single-handed sign language until I am able to speak once again. Just because I am ‘struck dumb’ occasionally, it does not follow that I become periodically intellectually incapacitated. Never talk to a Client as though s/he is cognitively deficient, presume intelligence until confirmed otherwise. Even then, always be respectful and communicate with the Client in a manner suited to, and commensurate with, her / his abilities.

*Think on these words*

*As these pages you thumb, for*

*Speechless is not Thoughtless*

*And Voiceless not Dumb*

(Jones 1996)

1. Terms of endearment. Always call the Client by his / her given first name or by their preferred name. Never use terms such as sweetheart, darling, flower, petal, my love, duck, ducky, hun, etc. Carers are not in a romantic relationship with the Client so they should use the Client’s preferred name at all times (Comerford 2015; Laskowski-Jones 2015). Use age appropriate language at all times. “*Good boy*” is not appropriate for an adult male.
2. Questions, questions. (Ward, Kibble et al2013; Myers 2019; Institute for Healthcare Improvement 2021) When talking to a Client only ask one question at a time. When more than one person is asking questions, it can become terribly confusing for the Client who does not know which question, from which person, to answer. Only one person should be asking simple questions, one at a time, and the person should wait for a response before asking another. A frightened, bewildered, or in-pain Client requires calm, not a barrage of questions from over-anxious Carers. “*Where’s it hurting*?” - “*Is it your leg*?” - “*Do you want me to get the doctor*?” - “*Do you want us to move you*?” - “*Are you feeling sick*?” - “*Do you feel hot*?” - “*What can I do to help*?” --- “*STOP asking so many questions!”*
3. Deaf and dumb? (Birbeck Nevins 1895) Some Clients may be hard of hearing. It does not follow that this is a licence to shout. Rather, the Carer should get in a position such that the Client is able to see her / his face clearly. The Carer should not stand with her / his back to a window such that the light coming in puts the Carer’s face in the shade (De Weerdt & Kusters 2016). The Client may be able to gather information to comprehend the situation from body language and the movement of a Carer’s lips and mouth. If Carers know a little sign language, please use it. Even if the Client does not know how to sign, your use may assist understanding as well as teaching the sign.

**Client Care and Care Practice**

1. Phone protocol. Never make or take a phone call while with a Client unless calling for medical aid (or in an emergency) and then only with the Client’s permission. Taking a personal call is unprofessional; wait until not with a Client and then call back, if the call was important. Turn off phones while with a Client. I have witnessed Carers taking calls from family members, friends, and even the Care Company during the time I am paying for care! Care Companies should not ring staff during the time that they are attending a client. It is completely unprofessional. They should develop a system such that they are able to contact staff between Client calls.
2. Idle hands. It is bad practice to stand around Idle not doing anything or chatting with a colleague. This is especially true if the Client is paying for the service. While waiting for the Client to complete a task, Carers should be productive. Are there cleaning or tidying tasks? The Client can tell the Carers when s/he has finished the task. In that way, Clients are in control. This morning, two Carers stood idly chatting to one another while I washed my face with a flannel using my good arm. I take my time when washing my face because I don’t shave. The left side of my mouth feels like it used to after a visit to the dentist and given an injection to numb the pain. It feels like that except it never wears off. When I eat, food tends to escape from the left half, unbeknownst to me and gets trapped in my beard and dries hard in place. As such, it takes a while for me to clean when washing. I noted the time that the Carers did nothing but chat as I washed my face. After five minutes had elapsed and they still were Idle, I stopped what I was doing and asked, “*Why are you just standing there*?” They ‘explained’ that they were waiting for me to complete washing my face! I have to pay for this service. It is not free. While five minutes does not sound much, the call is only for thirty minutes total. The Carers could wash my legs and my abdomen whilst I wash my face. Attached to my legs are my feet yet, my feet were not washed at all and, two quick wipes of my legs hardly qualifies as ‘washing’. Five minutes idle and other things performed poorly. This is not good practice. Later, in that same session, I informed the Carers that this is the day that I have my hair washed. The Carers did not like this and asked my wife if ‘tomorrow’s Carers’ could do it instead. Asking my wife, and not me, is simply poor practice, let alone not wanting to do what their Client had asked! What I was asking did not break the ‘dubious’ rule (see point 4) and, therefore, the Carers ought to have performed the task.
3. A good listener. Give the Client the opportunity to provide feedback on your practice. Towards the end of the session you might ask the question,”*John We would like to know how we have done this time. Would you tell us anything that we can do better or concerned you with what happened during our visit?*” Do not be defensive during any feedback, rather listen attentively and not interrupt. Thank the Client for the feedback and say that you will take on board the comments for future practice. Remain calm even if you believe the Client’s comments to be false. Anger and or sarcastic comments will not help the situation. Attempt to act on the feedback during subsequent sessions.
4. Incontinence is not just inconvenience. Being doubly incontinent is a pain, both figuratively and literally. It is more than an inconvenience; it is annoying, bothersome, costly, demeaning, embarrassing, painful, potentially harmful, odorous, time-consuming, troublesome, and worrying. I used to be able to ‘*skip to m’ loo’* whenever the urge arose, now I have such poor control over these functions that I require a catheter for one and a daily suppository for the other (number two, pun intended). Since having my catheter, it has caused me nothing but pain and problems. The stroke has messed up my bowels. An event that normally is a very private affair became very public overnight. It requires a-n-other to clean up the mess (literally) and that is both demeaning and embarrassing. Carers are usually very good in this role. It cannot be very pleasant and, as I can attest, the Client does not relish the process either; it is something I would much rather do all by myself if I could. It is very good practice to perform such duties as quickly and with as little fuss as possible for both the Carers and the Client. The Client is not happy that others have to perform this duty and will be very grateful if Carers can make it as routine as possible. Prepare all that is likely to be needed in advance such that time is not taken searching for a necessary item and slowing the process. Remember, continual wiping with a wet-wipe may result in making an area sore. Be as gentle as possible.
5. Bling. When interacting with a Client, do not wear jewellery. Leave large rings and watches at home for the day; wedding rings are usually OK. Why this rule? Because, during physical interactions I have been ‘caught’ by jewellery many times. Jewellery can have sharp corners and edges which, when brushed against my skin, is painful and likely to evoke a spasm even in a completely different part of the anatomy. For Carers, it is not noticeable unless the Client reacts in pain or starts to spasm. Some spasms can be very subtle and, if not watched for, may go unnoticed. A wristwatch brushing against a Client’s skin surely is not a problem, is it? It is! Watches can scratch and cause unwanted Client reactions. The same applies to rings that have gemstones attached. A gemstone is both hard and sharp. Carers’ hands (even while wearing gloves) are in physical contact with Clients a lot of the time. It is likely that rings are going to make contact with skin. If the ring scratches a sensitive area, it can be painful for the Client. Even a necklace may be problematic. A Carer leant over me and her necklace was dangling such that the medallion on the end came in contact with my skin. The medallion was cold. It did not scratch but I am super sensitive to anything cold in contact with the hemiplegic portion of my body. It sent a spasm down my leg and into my left foot. All spasms are uncomfortable and some are painful. A cold medallion, just touching me gently, caused pain. This was unnoticed by the Carers, who carried on regardless. Leave jewellery at home! There is also a chance that Clients, who cannot control movement of hands and arms, could accidentally catch and pull on loose items of clothing or jewellery such as a tie or a necklace. People experiencing learning difficulties may also become attracted by such things and make a grab for them. I stopped wearing a tie after struggling with a person who had taken a firm hold and pulled it and would not let go! I have witnessed staff with long hair in quite some pain while struggling to get free from the grasp of a person who found their hair irresistible.
6. Religion and politics. While it is important that Carers engage the Client in all conversations in an appropriate manner, they should avoid the topics of religion and politics unless the Client initiates a discussion on those areas. Then, listen politely to the person’s views on the matter and, if you disagree, you might steer the conversation gently in a different direction. Do not upset the individual needlessly by arguing or ridiculing any of your Client’s beliefs. If you simply have to talk about either of these things then adopt an explorative stance by asking your Client, “*What do you think about…?*”, “*What are your views on…?*” Try to find some common ground from the person’s responses as the area for discussion.
7. Grabbing control. It is not good practice to take a hold of any part of a person without first gaining their permission. Many of the actions you need to perform will necessarily involve physical contact. It is not necessary to seek permission every time for all physical contact involved in a specific task. That is only required until the person understands what is involved in the performance of the task. It may only require explicit explanation for the first couple of times. After that, all that is necessary is to let the Client know what task is about to take place: “*John, we are going to roll you now, OK?*” Never grab a person by any part of their body. Remember the mnemonic ‘*paws not claws*‘. Use the flat of your hand not your fingertips, which can be very painful especially if you have long fingernails even if you are wearing gloves. Remember, it may be construed as physical abuse if you touch any part of a Client without their permission. Carers will sometimes attempt to pull on my good right arm when rolling me onto my left side. This is not good practice. Pulling an arm, may result in a strain, making the Client’s life a little more uncomfortable. Having to use the right hand only for things, normally achieved using two, places a strain on your fingers, wrist, arm and shoulder after a while. When only one arm is functional, it pays to take good care of it! To experience it for yourself, try going through an entire day without using your left arm and hand for anything at all. Then, imagine having to do that without being ambulant. It is not fun! Do not pull on a Client’s arm. Avoid grabbing and pulling – paws not claws.
8. Leave well alone. Leave the Client’s room as you found it but give the Clients control by asking them questions: “*Would you like me to turn off the light?*”; “*Do You want these tissues back on your bed?*” If anything has to be moved, for any reason, ensure it is repositioned prior to leaving the Client. When returning items for a Client, ensure that they are within the Client’s reach and accessible. It is very frustrating to need a tissue, only to discover that, when the Carers put the box back on your bed, they placed them just out of reach and there is nobody at home to help.
9. Smoke screen. Try to refrain from smoking immediately before working with a Client. The Client will be able to smell the smoke on clothes. It is not a pleasant smell. Avoid smoking during the working day if possible. Clients will be able to tell. For a similar reason, avoid wearing strong perfume. While it may seem pleasant to you, it can prove to be quite overpowering for the Client especially when up close by the bedside. The use of a spray-on deodorant for a Client may also be quite overpowering. If in doubt, ask the Client!
10. TV stops work. If a Client is watching something on TV, do not become distracted by it and stop working. See bullet point 4. There is no reason to stop working and stand idle. The Client is likely paying for the service or, at least, somebody is, and your labour is not free. There is no such thing as care without cost; there is always some form of cost to someone somewhere. It is possible to notice what is occurring on TV while providing care, there is no reason to stop working. Chatting, with the Client, about what’s on the TV is good practice. There is no reason to ignore the TV completely. A Carer should never take control and turn off the television or adjust the volume without the Client’s permission. The TV does not prevent work. Although, a loud volume may interfere with some aspects of practice, the Client may have hearing loss and require the additional volume. Refrain from turning down the volume or making any change without the Client’s express permission.
11. Remove glasses 👓 Before rolling, ensure the Client’s glasses are removed. Always ask for permission before removing anything from a Client. Glasses can become an issue and may cause a Client an injury whilst in the act of rolling. If anything has been removed from a Client ensure it is returned immediately on completion of the task. Do not attempt to roll a Client without removing their glasses, if they wear them. It may prove rather uncomfortable if glasses remain in place whilst rolling. There is also a possibility of damage to the glasses. If Carers have removed glasses from a Client for whatever reason, it is their responsibility to ensure that they are back with the Client before they leave. Never leave a person on their own without returning their spectacles. Imagine being alone and virtually blind for hours before the next care visit. Unlikely? Well, it happened to me! Without my glasses, I was virtually blind and could not do anything other than wait until the Carers came for the next visit some four hours later. Why didn’t I tell my Carers that I needed my glasses? It did not occur to me until they had left. Do not not rely on the Client reminding you of a particular need; it is a Carer responsibility.
12. Flesh and bone. When holding a Client to perform an action such as rolling ensure that the person is held by the bony bits of their body, the knee, the hip, the shoulder or the elbow. Never take hold of flesh. The fleshy areas of the body are most likely to be painful and be hurt. Remember the earlier reference to the use of ‘Paws not Claws’. Claws (fingertips) dig into the flesh and may bruise or leave marks. Paws (flat hands) do not. Flesh causes stress, use bone alone.
13. If asked – do. If the Client asks for something to be done, then do it immediately unless in the middle of some process for the Client that cannot be stopped. There are not many things that cannot be put on hold until later whilst acting on the Client’s request. It can be very frustrating for a Client to be told, ‘just a second’, ‘in a minute’, ‘just let me do this job’, ‘I’ve only got one pair of hands’, ’when I have done this’, or any other such euphemistic phrase, which usually means the Client will have to wait for much longer and, perhaps, the request never gets fulfilled. Of course, there will be many times when things are very busy and everything just cannot be dropped to perform some action to comply with the request of a Client but, Carers should remain calm and attempt to do that which has been asked as soon as possible. The Client is in control; Carers are there to serve. Do not become stressed, stress can affect the rest of the day and other Clients may suffer as a result. When I was in hospital, I became aware that ‘just a second’ rarely meant a literal second and I could be waiting a very long time. That awareness did not contribute to my recovery one little bit! Try to imagine the Client’s position; s/he probably has realised, whilst lying in a hospital bed, the independence, once taken almost for granted, has forever been snatched away because of some stroke of bad luck (pun intentional). By giving Clients control over their situation, it is helping a little to restore some dignity. That is a worthwhile role!
14. Don’t patronise me. Do not tell a Client to “Calm down” if s/he becomes annoyed at some part of your practice (that the Client has been found to be wanting) (Bernstein 2017). Rather, apologise and ask the Client, in a calm manner, to explain what was wrong and to indicate how s/he would prefer the issue to be resolved. Keep a record of the Client’s preferences such that, in future, the routine can be performed to the Client’s specifications. Remember, the goal is control. The Client is ‘in the driving seat’. I was recently told to “relax” by a Carer after the second Carer had sent my left leg and good right arm into spasm by being a little too rough with a particularly sensitive part of my anatomy. When I pointed out that the remark was unprofessional, a Carer informed me the second Carer was new and did not know about my situation. That was no excuse for unprofessional behaviour. Always pair new Carers with one having experience such that the latter is able to advise, educate and guide the novice appropriately. All Carers should read the Client Care Plan before attending a Client.
15. Don’t look back in anger. If a Client is being difficult, do not aggravate the situation further by making a facetious comment such as, “*who got out of the bed on the wrong side this morning*?” Ask the person to try to explain what is upsetting him / her. Let the Client know that Carers are willing to help. The Client should come to understand that everything, within your power, would be done to resolve the issue. Clients should trust Carers and feel safe in their care, welcoming their arrival throughout the day. Returning a Client’s anger will only make a difficult situation worse and can affect future visits negatively. Remain calm and let the Client know that s/he is in charge and Carers are there to help.
16. I swear I didn’t. It is very unprofessional to use profanities in the presence of a Client. Even if a Client is using vulgar language whilst communicating, do not be tempted to reciprocate. Maintain your professionalism.
17. Punctuality is timely. Presumably, attendance to provide care for a Client is at established times throughout the day. It is good practice to inform the Client if there has been a delay and the team’s arrival is going to be late. I have been expecting support to arrive, at a specific time, only to be kept waiting for long periods not knowing what has happened or if I am going to get the care, for which I pay, at all. There have been many occasions on which Carers have failed to arrive at the usual time and I have not been informed. Having to wait for long periods, perhaps in pain, for a service and the team have not even bothered to inform the Client that they are running late, is not something about which anyone would be very happy. Even worse, if the Carers do not turn up at all!
18. Go with the flow. If the Client has a catheter, double-check the night bag. Is the night bag properly attached to the leg bag? Is the leg bag’s valve in the open position such that urine can flow freely from the leg bag? A leg bag alone may not have sufficient capacity to handle the volume of urine passed during the night. A leg bag, full to capacity, will prevent the Client’s bladder from emptying and may cause serious pain (Herter, & Kazer 2010)
19. Don’t strain yourself. If the Client watches TV or has a monitor for any other purpose, ensure s/he has an unobstructed view of it before leaving. Position the Client’s bed such that the screen can be viewed without having to strain. The Client should be able to see the monitor whilst in a comfortable and natural position. Ensure that your Client has access to all the gadgets s/he requires to be in control. The remote for the TV should be in easy reach, for example. I am frustrated when items that I may need are placed just slightly out of my reach. I will strain to reach them, often failing, as a little more than half of my body is not functioning correctly.
20. Naked and cold. The Client may prefer to be naked while in bed and may not wear any bedclothes. When the covers are removed, the covers that were keeping your Client warm, remember s/he is now exposed the elements and may start feeling Cold. While Carers might be quite warm, fully dressed and active, the Client might be having a quite different experience. Try to imagine being naked in a room in the presence of strangers tasked in a caring role; what should happen? Feeling exposed and embarrassed would be natural. Within a short time, it is also normal to feel cold. What should occur? Perhaps Carers could temporarily cover up parts that may be embarrassing and get on with the job efficiently such that the Client can be back under his / her blankets as soon as possible. A person should not be naked for longer than necessary.
21. Come in from the cold. Some Clients with disabilities may be super sensitive in specific areas of their body. A paralysed limb resulting from a stroke, for example, may not be immune to sensations. In fact, the limb may be super sensitive. If cold hands come into contact with such a limb, it may be felt like an electric shock resulting in painful spasms in several areas of the Client’s anatomy. Simply forewarning (and apologising to) the Client that your hands are cold and then proceeding to touch the Client’s body anyway is very poor practice. Always warm your hands. There is usually a sink and hot water available.
22. Wash and dry. If washing a Client, ensure that the wash is done properly. Ensure that whole limbs or any parts, requiring daily cleaning, are not missed (Burns, & Day2012; Lawton, & Shepherd 2019). After washing, ensure the Client is dried properly. Carers will probably be wearing some form of rubber or plastic protective gloves whilst with a Client. In which case, it will be more difficult to tell, by touch, whether a specific area of the Client’s anatomy is completely dry. Always ask the Client if s/he feels dry. Ask, also, about deodorant and talcum powder, do not just assume or completely forget. Isn’t all this just common sense? Not so! I have experienced a daily ‘wash’ for almost a year and the difference in standard between the arriving Carers is huge. First Carer: “*Do we wash with any soap?*” Second Carer: “*Oh, don’t bother with that, just use plain water*.” Common sense? It obviously is not ‘common’ as not all have the same basic level of practice. Neither is it ‘sense’ because, if it was, it would be natural and all would do it, at least in a basic manner. This morning, one of my Carers appeared as though she had a stroke resulting in a right side neglect. She only washed the left side of my right leg and the left side of my chest! I, long ago, gave up trying to tell Carers about washing; they either become very defensive, angry, or claim they were going to do it anyway and “*You must be more patient”*. The reward for my ‘patience’ is typically a wash that is more like a quick wipe. I very rarely receive a good wash; Carers wipe some areas of my body and neglect others. I calculate that Carers have only washed the left side of my abdomen four times in the last nine months. When Carers roll me on to my right side, they have access to my left side but they usually neglect washing this area. I used to bathe every day before I had the stroke. I cannot have a bath now because there is no way of getting me upstairs, no means of getting me into the bath and, no means of preventing me from slipping under the water and drowning whilst in the bath! Nearly a year without a shower or a bath. How would you feel? Now add to that, washes that are mostly inadequate. I am going to suggest that, one day a week is ‘good wash day’. On this day, the Carers would have to take more time to wash me thoroughly. Carers often do not wash my groin properly if at all. I suppose Carers are embarrassed to go ‘down there’. However, it is one area requiring special attention. It often becomes sore and painful due, I suspect, in some measure, to a lack of personal hygiene.
23. A pain in the bum. It is common for people, remaining motionless in bed for long periods, to develop bedsores. Bedsores are incredibly painful. Cleaning the skin of my bottom several times a day with wet wipes does not help. This only tends to make the skin sore. The skin on a person’s bottom requires a gentle touch. At the first sign of soreness, the nursing service should be informed. I have found that some creams, used to prevent further infection, sting so badly that I refuse to let anyone apply them. Sitting in urine or faeces, for any length of time, without immediate cleaning, can compound the situation. Seek medical advice as soon as the first signs of any soreness appear. Notify Significant Others of the concern. Never pull through a sheet or anything that could cause friction (even slide sheets cause friction) between the skin of the bottom and the surface of the item removed. While it may be believed the item is smooth (for example, a bed sheet) and unlikely to cause any problems, believe me, it is felt by the Client as it is pulled through under his / her body and it can be very painful especially to an already sore posterior and may break the skin. The sling, used in hoisting, is especially problematic in this area. It is not smooth and, with incorrect use, the resulting friction burns can cause excessive pain. I have an ongoing problem with pressure sores. ‘Pressure sores’, ‘bed sores’, or ‘pressure ulcers’ (variant names for the same condition) are damage to the skin and underlying tissue, caused by a sustained pressure on the skin due to the weight of a body over time. People that are unable to change position in bed or in a chair readily are especially vulnerable. Sustained pressure on an area of the skin can impair the blood supply, which can lead to the condition. Sores are painful things especially as the Client has to lie / sit down on them again. Carers should be very gentle in cleaning areas containing a sore. This morning, the Carers cleaned my bottom with a wet-wipe as is normal. It was very painful. Wet-wipes can feel very harsh on sensitive skin especially with repeated wiping. As moisture on the skin can increase the risk of developing pressure sores, areas that are washed, or cleaned with a wet-wipe, should be thoroughly but gently dried afterwards. Clients with a pressure sore should not be in a seat for more than 2 hours without some form of repositioning (DeFloor and Grypdonck, 1999). If the Client exceeds this time, return the Client to bed, with suitable pressure management, for no less than 1 hour (Gebhardt and Bliss, 1994; Defloor and Grypdonck, 1999). Thus, if a Client (sitting in a chair) is indicating that his / her bottom hurts, take it seriously and make every effort to reposition the Client and, if possible, return the Client to bed. I have found that, hoisting slings can contribute towards becoming uncomfortable. Remove the sling, immediately after use, if possible, should a client be likely to remain in a single seated position for more than twenty minutes. If the client already has a pressure sore, this is true for ‘stay in place’ slings as well. Additional products to help with the management of pressure sores (beyond those that the NHS is able to supply) can be beneficial (Cullum et al, 2000; McInnes and National Institute for Clinical Excellence, 2004). However, there is no clear evidence, which are the best products to use in the effective management of sores (McInnes and National Institute for Clinical Excellence, 2004). If a Client has a sore or anything that might possibly develop into a sore, contact the nursing services immediately. Do not assume that someone else is sure to do it, ensure that someone will. On a following call, check that the matter is now with the nursing service and that, at least, weekly monitoring is in place. Do not attempt to treat the sore yourself, unless medically qualified to do so, always seek medical advice from the local nursing provision. The nurses will treat and maintain a record of the sore, ensuring that it will not become worse. They are likely to dress an open wound. A dressed area should be treated carefully.A dressing should not be removed by other than the nursing team managing the situation, without their express permission, even if soiled. Rather, report observations immediately to the proper authority. Effective management and debridement of stores is the key to returning a Client to better health and reducing the risk of the sore developing into a greater danger (Romanelli and Mastronicola, 2002; Cutting and White, 2004). Details of Pressure sore practice should be in the Client’s Care Plan.
24. A weighty matter. Often, when Carers are performing some routine function they may need to reach across a Client’s body in order to achieve a particular task. In doing so, they may rest an arm or hand on the Client’s bed directly above a Client’s body. While it may appear, to a Carer, that this is an innocent action, the Client may have very sensitive body areas and the action maybe causing the Client undue problems. This is especially true for Clients who have had a stroke, for example (Boivie2006; Akyuz & Kuru 2016; Nagasaka, Takashima et al2017). Stimulation of one sensitive part of their body can set up a chain reaction leading to painful spasms in another area. Furthermore, although it may not be realised, even a slight pressure can feel very weighty to a Client and be very uncomfortable. Avoid resting any part of your body on any part of the bed currently occupied by your Client.
25. Baby, it’s cold outside. Following the time I spent in hospital, I have had care, at first, for four times a day and later, I cut it to three times daily. That is, at least, one thousand care calls. Each visit, the Carers have to reposition me in the bed and that requires the use of a slide sheet. On almost every occasion, the Carers warn me, as they roll me off my side and onto my back on the slide sheet, “*it’s going to feel cold, sorry*.” My room is at a constant temperature, it never varies and the slide sheet stays near to my bed, in my room. After a thousand visits, I know how the slide sheet is going to feel, I do not need repeatedly to be informed of its temperature! It would drive me crazy if I did not find it amusing!
26. Remarkable. “*I left my children to come and help you and I am worried about them.*” This was said to me by a Carer (in an angry tone of voice). I had done nothing to provoke such an outburst and I thought the remark unprofessional.

*“Angry people are not always wise.”*

(Jane Austen, Pride and Prejudice, first published January 28th, 1813)

I was paying for the service and, thus, for her time. If that person did not want the job, she need not have taken it. I understand that she probably needed the income and, yet, had to leave her children sometimes when she had to work but her wrath was misplaced directed at me. Do not take out personal frustrations on a Client. Leave them at home. The remark was a little upsetting and did not help me at all. What is said is as important as what is

done!

1. Do not forget me. Elderly Clients and others experiencing learning difficulties may have problems with remembering names (Yoon, Ooi et al2018). If you are attending such a Client always begin the session by introducing yourself: “*Good morning John, it’s Helen, your Carer, come for your morning call. How are you today?*” It is a good idea to get into the habit of introducing yourself as you enter the Client’s room such that it becomes a habit and occurs without thinking.
2. Plots and plans. Each Client must have a Client-Centred Care-Plan (CCCP) (McLoughlin, Bayati-Bojakhi et al 2014) that is accessible for Carers to read prior to the provision of support. The plan should be amendable only via a specified route safeguarding the Client. The plan should include such things as Client condition, preferences, dislikes, potential areas of concern, specific practice to avoid, communication methodology, medical issues, advocates, family information, menu plans, hygiene practice, contact details, health and safety, and any other pertinent information that Carers might require to be able to provide the best professional person-centred service possible. No person providing care should attend a Client ‘blind’, that is, without knowing anything about the Client and her/his condition and needs. If staff absence (or other unforeseen events) mean that a novice must be utilised, always pair with a Carer that has experience with the Client and is familiar with the routine. One day, two Carers arrived who had never been on a morning visit with me. They admitted they did not have any experience and did not know what to do. I informed them that there should be a Care Plan. Their response? “*We haven’t read it. You don’t think that we have the time to read every person’s Care Plan, do you*?” During the 30-minute session, they made nine basic errors (points outlined in this document). After they left, I had my blood pressure taken; it was ten points higher than normal. It defeats the objective of ‘care’ if the very act of caring makes the Client ‘sicker’ than before the ‘caring session’. Health Warning: Poor quality care may be harmful to healthy living!
3. Location, location. In verbal and physical interactions with the Client try to ensure positioning such that the Client can see everyone clearly, and preferably make eye contact. To perform some form of physical manipulation of a Client when the Carer is located in a position, behind the person, out of sight and, without a verbal warning, could be construed as a form of physical abuse (Adigun, Mikhail et al 2020). Let the Client see and hear what you are going to do such that s/he can prepare for the forthcoming action. Never take hold of any part of a person’s body without forewarning the person of your intention. It is OK if the action itself necessarily involves repeated physical contact, just explaining what is about to happen without asking permission for every physical contact you will need to make. Although, the first couple of times that the Carers perform the action, it may be necessary to go into the details of each step involved seeking permission. When the Client has become accustomed to the process and knows what to expect, then it is enough to announce the particular action “*John, we are going to roll you onto your left side, OK*?” and wait for the Client to respond in the affirmative before proceeding.
4. Hand in hand. There may be times when it proves necessary to help a Client by gently taking their hand and moving it to assist in the performance of a specific action. The normal way this is undertaken is with a hand over hand approach. The Carer’s hand takes the Client’s hand and guides it to accomplish the task. Why is this the wrong approach? What does the Client see? Because the Carer’s hand is over the Client’s, they see the Carer performing the action! Better, if the Carer adopts a hand under hand approach such that Clients see their hand moving to achieve the task with the Carer’s hand underneath supporting and guiding the process. Hand under hand is the preferred method.
5. Danger full! People that are fitted with a catheter generally require a night bag attaching in addition to their leg bag to allow extra capacity during the hours while the person is asleep. The leg bag alone would not have enough capacity to allow for the collection of urine during the period between the last call of one day and the first call of the next. A full catheter bag would not allow urine to flow from the bladder and could cause a Client significant distress. It is for this reason that it is very important to remember to check that the valve from the leg bag to the night bag is fully open such that urine is able to flow freely from one to the other. There are several different types of valve utilised by leg bags and, therefore, it is easy to make a mistake and not open the valve fully, especially with a valve that, previously, has not been encountered. A useful tip for this situation is to leave a small amount of urine in the leg bag from the previous call to test that the valve is properly opened after the night bag has been attached. Does the urine flow out of the leg bag? Does the leg bag empty? If the answer to these questions is yes, then the Carer can be assured that the valve is opened to the correct position and the Client is not likely to have trouble from it during the night. Remember to check that the night bag is properly attached and the valve is fully open.
6. The leg bag’s connected to… Catheters usually travel via the Client’s genitals to the bladder. It is not a good idea to pull on the tube therefore as this is likely to cause the Client a lot of pain. It is important, when changing a leg bag, or adding a night bag, to ensure that care is taken to avoid tugging on the catheter. This equally applies when doing anything that might involve movement of attachments to a catheter (for example, when rolling, hoisting, or repositioning).Be catheter aware!
7. Losing it. Occasionally, it will be necessary to work with a Client who is displaying behaviour that people may find challenging. (Kneebone & Lincoln2012; Alderman2013; Andrewes, Walker, & O’Neill 2014;) Challenging behaviour might occur any point during a call or the Client may exhibit such behaviour throughout. At times, being disabled can be frustrating and it is hardly surprising for POD to have the occasional outburst. Do not take it personally, probably the anger is directed more at the situation than at any one person. It is important to note that usually behaviour found to be challenging is not simply a part of the person’s character but usually has a specific trigger. The triggering event may not have been due to an issue with a particular Carer. It may be rooted in some previous experience with other Carers (even with Carers from long ago). The Client having generalised it to all Carers that come to call. If a person suddenly starts to exhibit behaviour that anyone would find challenging during your call, ensure a record is made of the events detailing *A B C. Where A* is for Antecedent; what was happening prior to the behaviour occurring? What were you doing? *B* is for Behaviour; what form did the behaviour take? Try to describe the behaviour factually without using pejorative or judgemental terminology such as ‘bad’, ‘terrible’, ‘unprovoked’. *C* is for Consequences; what happened because of the person’s behaviour? Did the behaviour stop suddenly? Did the response to the behaviour have an effect? At some later and calmer time, away from the Client, go through the ABC(s) and try to establish a possible triggering event. What did you do in response to the behaviour? Was it successful? Did it bring calm and restore peace or did it make no difference or make matters worse? Consider what might have been done differently, both before, so as not to trigger the behaviour, and after, to restore calm? For example, if it is discovered that the challenging behaviour has always occurred following rolling, it is reasonable to suspect that something occurring during this procedure is a trigger for the behaviour. I, regularly, am in pain when I am rolled onto my side because carers have a habit of pushing their fingertips into my flesh in order to gain a better hold to be able to move me or into the flesh of my inner thigh to pull my legs apart (particularly painful). The flesh on my legs and my sides is very sensitive and the action causes a lot of pain. I could elect to react with an outburst of anger but I choose to ignore it these days, as it only lasts briefly, and they release their grip as soon as they accomplish their task. I have shouted at Carers previously when their fingertips caused me pain but my reaction only elicited irate excuses, from the Carer, about having to hold me firmly in order to roll me. Responding to behaviour that people find challenging with anger can only serve to make a bad situation worse. Carers should do all that they can to prevent such an outcome. While I should not have shouted at my pain, the Carers should not have reacted as they did. They should have remained calm, listened to my complaint, apologised and changed their practice in future. On reflection, ask, if your response acted to calm or Inflame the situation? If the latter, consider an alternative course of action, one in which the situation remains calm and has a positive outcome. Do not be tempted to suggest that the Client should “*calm down*”, “*pull yourself together*” or some other such remark. Is there another person available whom might provide assistance? Do not allow the situation to escalate further. Are the Carers aware of a Client’s BEST? (**B**est **E**ver **S**timulating **T**hings). BEST is the particular thing (or things) the Client likes. For example, a specific song or style of music, a favourite event / period from the past, a preferred object, place to be, a treasured photograph or picture. Would the provision of any BEST restore some tranquillity? If so, ensure it is available and easily accessible to use in any future similar occurrence. Prevention is better than cure; try to avoid any triggering events in all future interactions. It may be the consequences of a particular behaviour prove to be rewarding for the Client. S/he might like the level of attention that results from a behaviour and the attention is reinforcing the behaviour. As such, the behaviour found to be challenging is more likely to occur in the future. In this instance, it will be necessary to refrain from providing the rewarding response and search for an alternative. It may not be the response to the challenging behaviour as such that the Client finds rewarding but, rather, the individual providing the response. Your Client may really like having that particular person’s attention. Changing the outcome perhaps changes the behaviour. Try using a different person to act in response to the behaviour. Challenging behaviour can be quite difficult to analyse and rectify. A team of people best addresses it with access to professional advice. However, there are some simple items for the TREATMENT of the Client which should be put into practice to help lessen the frequency with which behaviour that people might find challenging occurs:
* **T**reat the Client as an adult at all times,
* **R**emain calm and professional throughout the session,
* **E**nsure that the Client is in control,
* **A**sk for permission before making changes, leave the environment **A**lone,
* **T**alk with the Client, Don’t swear, Be polite,
* **M**aintain peace & calm, Keep opinions to yourself unless asked,
* **E**nter on time, consistently,
* **N**o use of fingertips; paws not claws,
* **T**alk to the Client using given first name.
1. Coughs and sneezes spread diseases (https://www.youtube.com/watch?v=W728NGYhmmQ). If a Carer has a cold, s/he should not be around vulnerable Clients. The Client already has enough problems with which to deal; s/he will not thank you for an additional one. If Carers are relatively healthy, and find having a cold troublesome, image what that cold would be like to a person with disabilities. Cold today? Stay away! Carers should keep germs to themselves. Ask for other duties if possible; do not put vulnerable Clients at risk. At the very least, wear a mask and ensure that your hands are clean. Attempt to keep physical interactions with your Client to a minimum.
2. Rocking and a rolling. (Vatwani 2017) It takes time for a Client to feel safe when being rolled. The Client ends up on his / her side on the edge of the bed and can feel insecure. Carers should reassure the Client of their safety and are very unlikely to fall. A further problem encountered when rolling Clients is dizziness. When rolled too quickly, I felt as though my room had begun spinning. It had made me feel somewhat sick for a while after the Carers had left until my vision has returned to normal. Roll slowly and carefully.
3. Bloody café. While in hospital, I had been moved into a room just off the main stroke ward. I grew to hate being in a room on my own because, once the door is shut, you really are on your own. As an IRON, being isolated in hospital is frightening. Sure, there is a nurse call button to summon assistance but it has to be in reach otherwise it may as well not be there. I got used to the nurse call button taking many minutes to summon a nurse (on one occasion, it took 45 minutes before my call was answered). It scared me somewhat to know that I was completely dependent on others and, yet, I had no means of calling for those ‘others’ in an emergency. I might be choking and press the nurse call button and be dead before anyone answered my call. Thankfully, that scenario never happened but it frightened me nevertheless. One night, around one in the morning, I really needed a drink. I pushed the nurse call button and waited. Nearly twenty minutes later two nurses came into my room. I asked for an orange juice from the fridge (my wife brought me cartons of juice, which she put in the fridge in the nurse’s office to keep them cool and fresh on the advice of day staff). One nurse looked sternly at me and said, “*Do you think this is a bloody café*”? However, I did get my juice but, such incidents, made me wary of calling for help during the night at all. I reported the incident to my wife when she came to visit. She informed the PET (Patient Experience Team) section of the hospital but, as far as I am aware, nothing much happened. The leader of the night staff did call my wife and said such behaviour was unacceptable. He said that he would talk to his team to ensure better practice but no nurse ever apologised and things did not improve. There were further incidents some of which, I have already reported at the beginning of this paper. Hospitals should not be frightening places. As an IRON, I dread having to go back there.
4. There’s nothing worse. Carers come for three calls a day. I often am in some form of distress. Carers ask “*what’s wrong*?” and I try to reply, if I am able to speak at all depending on the intensity of the pain at that time, to inform them of the issue. It might be bowels, catheter, earache, toothache, leg spasms, arm aching, headache, I’ve had them all over the months since my stroke. Whatever I state as the cause of my pain, the usual response is: “*There’s nothing worse.” “Headache? There’s nothing worse.” “Toothache? There’s nothing worse.” “Constipation? There’s nothing worse.” “Earache? There’s nothing worse.”* And so on. By definition, there can only ever be one solitary worst condition. Stating, as fact, “*There’s nothing worse*” to me, in bed, paralysed down the left hand side of my body, makes me want to shout out loud, “*being paralysed down the left hand side of my body, and confined to bed virtually 24/7, in pain a lot of the time.Guess what?* - *There’s nothing worse!!!”* You have to laugh (Don’t you?).
5. Keep informed. If there is an issue with anything to do with a Client, do not keep it to yourself, inform a significant other: a therapist, a spouse or other family member, call for medical assistance, talk to your team leader, involve social services… If uncertain as to what to do, ask a senior member of staff for advice, do not put it off, believing someone else is sure to deal with the problem. If someone has been told and the situation remains the same, inform another of your concerns. Do not allow a little problem to become an emergency (Health and Care Professions Council 2015).
6. Check it. It is good practice to have a checklist for specific events during a visit (Wolff, Taylor, & McCabe 2004; Gawande 2009). For example; for use when rolling:
7. *Bone not flesh*
8. *Paws not claws*
9. *Glasses 👓?*
10. *Tell before do*
11. *Roll left is preferred*
12. *Cannot maintain right side position, requires assistance*
13. *…*

**Choice Is A Voice**

1. Choice is a voice. Always give the Client a choice (Dixon, Robertson et al 2010; Mulley, Trimble, & Elwyn 2012) but don’t constrain the Client to choices that Carers find acceptable: don’t ask, “*would you like tea or coffee*?” rather ask ”*would you like tea or coffee or something else*?”. In this way, the Client is permitted a freedom to choose any drink at all. While in hospital, I was asked what I would like for breakfast and had a good choice as many options for breakfast are, by coincidence, often vegan. However, institutional meal choice for vegans is typically very poor, something of a Hobson’s choice – take it or leave it. For example, while vegan Alpro yoghurt was an option on the menu, there was only one flavour; thus, no real choice. Hobson’s choice isn’t really a choice at all. It is, rather, a single option only. The phrase is said to have originated with Thomas Hobson (1544 – 1631), a livery stable owner in Cambridge, England, who offered customers the choice of either taking the horse in the stall nearest to the door or taking none at all. Providing real choice is another way of passing control of the situation to the Client. After days of no or poor choice, my wife had to bring in my main meal each day (at visiting time) which she cooked at home and kept, at least, vaguely warm by wrapping each Tupperware box, containing meal courses, in towels during the journey to my bedside. In this way, I was able to choose what I wanted to eat for my main meal on the next day and be assured it would be vegan. The goal is control. Choice is a voice.
2. Advocate an advocate. If Clients are unable to speak for themselves (or lack the cognitive capacity to communicate an understanding of the situation), an advocate (Davis, 2006) may speak on the Client’s behalf. Try to ensure that an advocate is present at least once a week to monitor practice and provide feedback on behalf of the Client. The Mental Capacity Act (2005) states that people can no longer make decisions on behalf of others without following a process. The process states that any act of substituted decision-making must be in the best interest of the individual. That is, if someone other than the Client makes a decision on his or her part, it must be in the Client’s best interest. Although, it fails to define ‘best interest’.
3. Night and Day. From my point of view, there is, no longer, a difference between the day and the night. I tell a lie, the Carers come during the day and I have meals during the day. Other than that, there is, for me, no difference. I am not saying that I am unable to tell the time of day: I have a clock, with an illuminated readout, by my bed that not only tells the time but the display shows morning or afternoon as well as the day, date and year. All in bright, white, large, capital letters as if it was shouting at me to ensure I am aware of every aspect of the time! No, I am aware of the time. What I mean is that there is very little discernible difference between me during the day and me during the night. I can be asleep in the day and awake throughout the night. I can be working or playing on my computer, watching Netflix, or Prime, or YouTube, or reading at any time of day. I can be working on this paper at three in the morning or three in the afternoon. Time has much less meaning since my stroke. My room changes very little from day to night. It is at a constant temperature of 21 degrees centigrade. The lighting is from a small table lamp 24/7, which I rarely turn off. The curtains are shut continuously (my room is directly on the Street and I value privacy) and therefore the light does not vary. Overall, the day and night, for me, are almost the same. That being the case, I may fall asleep at any time.Carers are unsure what to do if they arrive and I am asleep. What would I advise in this circumstance? Leave asleep or awaken? My advice is to ask a Significant Other, if one is available, a spouse or family member. If such a person is not available then wake the Client. Better still, allow the Client to decide! On a previous call, ask the Client (while awake) what s/he would want a Carer to do in that situation: leave asleep or wake the Client? The Client chooses. Client choice is a means of control. The Client is in control of the situation even when asleep!

**Eating and Drinking**

1. Food glorious food. If there is a requirement to assist a Client with eating and drinking (Corcoran 2005; Heaven, Bamford et al2013) there are a number of techniques that may prove useful.
* Dysphagia (problems with swallowing) (Foley, Teasell et al 2008; Cohen, Roffe et al 2016) is likely to be an issue with some Clients. Do not pretend to know how to cope in such a situation. Always seek professional advice. Speech and Language Therapists (SLT) usually have expertise in this area.
* Thicken drinks using a thickening agent, usually in the form of a powder added with a provided scoop. Adding more scoops of this powder and mixing into the drink will make it thicker. The Client Centred Care Plan should detail the Client mealtime regime. Typically, from one to four scoops per drink, four turning the drink into a sort of gelatinous substance somewhere between a liquid and a solid. Adding thickener also changes the drink’s flavour somewhat; the more scoops, the less flavour. However, it is a price worth paying if it helps prevent aspiration by making the drink more manageable and assists swallowing.
* Since my stroke, I have found it very difficult for my mouth to deal with extremes of temperature. I cannot cope with hot drinks or drinks straight from the fridge; those, I have to let stand until they reach room temperature. I do not know if this is an issue (with all who are in a similar condition to mine) but it is worthwhile asking the Client about drink temperature. The same is true of foods also. I have to wait until hot meals cool before attempting to eat them.
* As with drinks, select food carefully to aid the Client during the process of eating. Avoid some food completely if the client has difficulties in their management. Really dry and crumbly or flaky foods such as crisps (potato chips) and many biscuits may be out of bounds for quite some time. The SLT will be able to advise. Recommendations for foods to avoid should be contained in the Client’s Care Plan.
* Ensure the food is at the perfect temperature for the Client; the Goldilocks temperature, not too hot neither too cold. Allow the Client to perform a tongue test on the first spoonful to check the temperature. Hold a spoonful of food just in front of the Client’s mouth and encourage the person to test its temperature with the tip of their tongue. “*Is it OK*?” If the Client indicates ‘no’, ask closed questions to establish what is wrong. A closed question is one that can be answered with a ‘yes’ or a ‘no’. Do not ask, “*How is it*?” that is an open question which requires more than a simple yes/no response. Rather ask, “*Is it too hot*?” and await a response. The response need not be in the form of a spoken word, it may be a simple movement. If too hot or too cold, take the appropriate action to remedy the situation as quickly as possible.
* Eating and drinking, while lying in bed, are problematic and potentially dangerous. The Client should be sitting as upright as possible to reduce the risk of aspiration.
* Establish a simple method for the Client to indicate that s/he is ready for the next spoonful. Remember, the goal is control, so put the person in control over the rate of food delivery. This equally applies to giving any form of medication.
* Ensure the spoon goes into the mouth. Make it as easy as possible for the Client to manage this process.
* To minimise the possibility of choking, do not overload the spoon. Rather too little than too much. After assisting with one or two meals, establish the correct amount per mouthful.
* Ensure the Client clears his / her mouth of all food before presenting the next portion for the Client to take.
* We all have foods that we do not like. The Client will not like some foods also. Keep a record of disliked items and add these to the Client’s Care Plan for future reference.
* Allow plenty of time for the Client to chew and swallow.
* A Client may have difficulty with chewing. Present the meal in easily managed pieces. The Client may also find it difficult to keep every bit of food in his / her mouth, not having sufficient lip control to avoid drooling. Have wipes ready for this purpose. Always ask if it is all right to wipe / clean the Client. Obtain permission before performing this action.
* The Client may have a dietitian or a speech and language therapist who has assessed and provided guidance on suitable foods, consistency, and foods to avoid. This information should be in the Client’s Care Plan. Ensure that it is studied.
* If a person shows any signs of choking or discomfort of any kind whilst eating or drinking, stop and seek further clarification from a superior or professional attached to the Client. Their contact details should be in the Client’s Care Plan. Aspiration can be dangerous and therefore proceeding, when the person is clearly having difficulties, is foolhardy. Aspiration occurs if something enters a person’s airway or lungs by accident. It may be food, liquid, or some other material. This can cause serious health problems, such as pneumonia. Aspiration can happen if the Client has trouble swallowing normally. Trouble swallowing is known technically as dysphagia.
* The Client should decide when s/he is replete and has finished eating. Do not encourage the person just to ‘have a few more mouthfuls’ to clear the plate. The Client is in control. Avoid mentioning any uneaten food unless asking if the person wants it saving for a later time.
* Use a menu plan where possible. It should provide for a variety of suitable and nutritious meals.
* Control implies choice. Allow for Client choice whenever possible.
* A Client may choose an unhealthy option for every meal. Chips with everything! Presenting the Client with a choice of healthy options at the start should help avoid this. The goal is control.
* A Client may require some form of clothes protection whilst eating. Do not refer to this item as a ‘bib’. Protect the Client’s dignity as well as clothes by using an age appropriate term (dining apron, clothes protector, surcoat, tabard) for this item at all times.
* There is a significant chance of aspiration when assisting a Client who requires a drink. Ensure that the Care Plan is read and understood. Is there therapist guidance? Body position, drink thickness (thickeners may need to be added), drink temperature, drink presentation, and drink container may all require special attention. If you do not know what you are doing. Stop! Seek advice. This action may require further training. Always seek professional guidance. A Speech and Language Therapist will be able to provide support to ensure mealtimes are safe, enjoyable and provide sufficient nutrition.
* It is important not to force a Client to eat or drink. This will only make the process more difficult. Try to make all mealtimes as enjoyable an experience as you can. Take your time; never rush a drink or a meal.
* Pretend not to mind the Client not eating or drinking, even if it is annoying or frustrating. Never show signs of anger or frustration. Remember, the Client is in control. Empathy and patience are virtues worth cultivating.
* If a person consistently refuses food or drink, ensure you notify someone who can act on the situation. Do not attempt to address the issue yourself; always seek professional advice.
1. Out of date. I heard from one of my Carers that, she had witnessed another Carer going through a Client’s refrigerator and throwing away any out of date items, even if the produce was only out of date by a day or so. She had done this without any permission from the Client. Even if a product is two years out of date, it is not your decision as to whether it should be discarded. The Client is in control. It is the Client who decides whether an item is to be kept or discarded. The Client’s alone, although as a responsible Carer, you should provide advice to the Client to help the Client reach a decision. If the Client decides to keep the product and asks for it to be prepared, you are within your rights to politely inform the Client that you cannot do anything that would put her / him in danger, even if the danger is small or uncertain. If the Client’s choice is DUBIOUS (se earlier this paper) you have the right to overrule it.

**Consultation and Coordination (Post-Stroke Provision)**

1. Pain management. While the stroke itself did not really cause me much pain (it was over in seconds), the aftermath, the days, weeks, and months post –stroke, were filled with frequent episodes of intense pain. Pain in my left arm and leg, pain when my leg began to spasm (which it did several times each day), pain from my catheter, pain from bypassing, pain from constipation, pain from continual pressure on my bottom as a result of my stationary position, pain from my mouth, the left side of which felt ‘alien’ following the stroke. One form of pain would set off another and that would cause my leg to spasm and my foot to tense painfully, in a cruel chain of increasingly painful events. It is essential, therefore, that there is good post-stroke pain management. (Bowsher1995; Hansson2004; Henon2006; Widar, Ek, & Ahlström2007; Kim2014; Mulla, Wang et al2015; Choi‐Kwon, Choi et al2017). No doctor has ever been to see me to assess my needs and formulate a Post-Stroke Management Protocol (PSMP). Each time I have been in serious pain, it has been up to my wife to ring the doctor and book a ‘telephone consultation’. A few times, we have had to tell the doctor the name of the medication I needed prescribing. Ringing the doctor and booking a call back is not an example of good practice. I would wait for hours, still in pain, until the end of surgery for a doctor to call and, on each occasion, my wife had to explain my condition to the doctor. It is not a very helpful system for a person in my position. A lot of time and effort could have been saved by a PSMP initiated on my discharge from hospital. Ongoing pain affects the quality of life of the individual and can result in post-stroke depression (Kong, Woon, & Yang2004; Jensen, Chodroff, & Dworkin2007; Şahin-Onat, Ünsal-Delialioğlu et al 2016; Kwon 2017; Payton & Soundy 2020). Hospitals should have a continuing duty of care, to the acute stroke Patients whom they discharge, at least, in the first six months.
2. Quality control. Is there adequate monitoring of care services? (de Waal 2008) Each day, I have three care calls involving two Carers per call. The same two people generally do not staff the calls; it can be different combinations every time. Sometimes a complete stranger arrives! The quality of service provided by individual Carers varies enormously. One Carer rarely speaks and never says ‘hello’ whilst others are the complete opposite. Standards vary a lot from Carer to Carer and nobody seems to be monitoring my provision. Consistency is important. Quality is important. Care provision should aim to deliver both. Schools are inspected regularly, the quality of provision being important. There is even regular, ‘in house’ quality checks to ensure standards are maintained. I suspect this happens as standard in other professions also. The Care Quality Commission (CQC) appears to be the regulatory body ensuring standards in home care provision. I just looked at their website to see what they say about my Care Company. I found it and it states that, “We have not inspected this service yet.” I hope my service is inspected soon and the customer gets to give an opinion. The Client, who has to pay for the service, cannot simply stop and move to another care provider company because it is quite difficult to get any provision. I have experienced two different care companies and virtually all the same issues occurred with both. I have no reason to believe that similar issues would not occur with any other company that I chose to employ. I have real concerns for aged non-verbal Clients under a provision financed by other than the Client (local council?) whom no one monitors for quality and the standard of service in place. Not every call is bad, far from it – some Carers provide excellent care and most are adequate. However, even the Carers that I would rate as outstanding, make a few of the ‘mistakes’ reported in this paper. I suspect that their training was not thorough and, after initial training, there were no subsequent training sessions. While, learning on-the-job is one form of training provision, if it is not supported with regular in-house training to review what has been learned, bad habits can easily become standard working practice. Quality of life is dependent on quality of provision. What is your employer doing about it? The CQC appears to monitor across five areas: safe, effective, caring, responsive, and well led. Each area is given one of five ratings after the inspection: outstanding, good, requires improvement, inadequate, and no rating given / rating under appeal / rating suspended. An overall rating is finally provided based on an analysis of the former results. As far as I can tell, the majority of local care providers have a ‘good’ rating (148) following inspection, with 29 that ‘require improvement’ and, only four (out of 279 in total) receiving the ‘inadequate’ result (at the time of writing). I am surprised that so many were rated as ‘good’ when the two with which I have experience, I would rate as ‘requiring improvement’. I wonder what experience the inspectors have and if any are IRONs in the role? I have been asking my Carers if their practice had ever been inspected. One excellent Carer had been working for my Care Company for 22 years and said that she had never been inspected or even had her practice observed by the Company (although other Carers reported that they have had a senior Company member doing inspections). She reported that, as far as she was aware, the CQC only ever go into the office and look at the books. Each of my Care team I asked said that their practice had not been observed (by the CQC). If what they told me is factual, I think that standards in the quality of care provision have little chance of improving. They did report that they have had training on various topics; moving and handling, medication, etc. However, someone like me, an actual recipient of care, had never provided the training. I find that it all ‘requires Improvement’! It is poor if quality of care is measured only as a standard of recording in documents (that have been generated by the Companies and their care teams themselves). They are hardly likely to put in print anything negative about their practice, with even problematic events receiving a bias and positive gloss. Obviously, the focus should be on the care provided itself, anything less falls short of the mark. It is hardly surprising that there are so many ‘good’ ratings if the actual practice in the homes of Clients is not observed. At the very least, Clients should be asked if they would be willing to provide the Care Company a report on their view of the quality of their provision four times annually. The Company should keep Client reports such that they may be scrutinised by the inspectorate. IRONs should have a voice. Otherwise, they become ‘Clients in the IRON mask’. Personally, I would be more than willing to be interviewed by an inspector or even have inspectors view the quality of my care provision. So many people have seen me naked since my stroke, what are a few more going to matter to me? When my Care Company finally are inspected, I would not be surprised if they get a ‘good’ grading under the current system. If I were to grade them, presently, I would say that the Care Company ‘requires improvement’. Indeed, the whole post-stroke provision in my area requires improving! My hospital proudly displays a plaque in the entrance which states that it has been awarded an Outstanding rating by the CQC. Outstanding, really?
3. Time Critical (Kiley2014). I am paying for three care calls a day; one early morning, one midday, and one in the afternoon at three thirty. The cost of care is expensive but the service I receive mostly falls far short of excellent (some is very good). The time of the afternoon call can vary by as much as an hour. I have had Carers arrive at before three o’clock and, on different days, as late as four. I realise that there may be staffing issues, staff can become ill and then not turn up for work, or a delay can occur for a myriad of understandable reasons. However, there is no excuse for not calling to let me know. Today, the Carers arrived thirty minutes later than normal. When I queried the late time, the Carers replied that the Care Company schedule informed them to arrive at that time. The Care Company had made no effort to contact me and let me know of the time change. Each month I receive an invoice for the service and, somewhere in the listing, it always reads, “Time critical call” but the times listed are not the same. Thus, a ‘time critical’ call can be at a specific time one day but at a quite different time on others. The Company is lacking in professionalism, if there was an inspectorate worthy of the name, they would almost certainly be placed in ‘special measures’. The trouble is, there are so many people in need of care services and only a few companies serving the market. It is not easy to find and set up a care package. When my wife was trying to sort out my provision, she tried several companies. Some were fully booked and could only guarantee provision of care if an existing Client was to ‘cease use of their service’. Some were charging over a thousand pounds a week and we just could not afford that level of payment; our retirement savings would not last much more than a year or two before we would be penniless. Some companies charged double for Sundays and for all holiday periods and (to add insult to injury), if the customer did not need the service for a few days, payment was still required! As a result of financial constraints, and other issues, our choice of Care Company was restricted. We had little time to ‘shop around’ because the hospital kept calling demanding to know when we were going to start with our own care plan such that they could terminate their provisional post-hospital package which they were financing. Our world had changed drastically yet, at a time of great stress, we were coerced into making a quick decision with little help or counselling. A post-stroke counselling service would have been a great help in the early days when we had very little idea what assistance was available. If such a body exists, we were not aware of it and my wife struggled through the early days mostly on her own. I was of little help as I was fighting pain for much of the time. Just a person who had some level of expertise who came every day for a few days to provide advice and support would have helped enormously. Someone who might guide us in the selection of a Care Company and recommend one with a good standard of service. There is little incentive for Care Companies to improve standards. My wife has complained, in writing, a number of times and the Care Company suggested a review but weeks have passed and nothing has happened. Care Companies should face penalties for not meeting basic standards of practice. Mine is but a lone voice shouting (if I could shout) in darkness but, if enough people read this and act, perhaps something will change. I cannot be the only person receiving care who has issues with the quality of provision. I sometimes have a male Carer. While the female Carer arrives at one time, the male arrives up to ten minutes later. My care requires two Carers working together. When only one is present, she has clocked in on arrival. My half hour slot then begins. If the second Carer arrives late, both Carers leave together after the half hour. Thus, I have lost care time for which I still am charged. The late Carer shows no concern over the issue. Indeed, one Carer simply walked out while I was explaining the problem knowing that I could do nothing about it.
4. To bed, to bed, sleepy head. When I left hospital, I was provided with a hospital style bed complete with mattress. I was (and still am) very grateful for this provision. At the time, I was unaware of my continuing needs. However, as days turned into weeks and weeks into months, I began to comprehend just how the bed provided was failing to meet my needs. Soon, after hospital, I realised that, while my bed has a function to lower the bottom (such that my feet are lower than my head), it did not have a function to lower the top (my head in respect to my feet). I was slipping down the bed as I used its various features throughout the day and required others to reposition me several times a day. This involved rolling me to position a slip-sheet underneath my body (which is used to aid movement of a body by reducing friction). The process required two Carers working together. When the Carers were not present to assist with this matter (which was the majority of the day), it fell to my poor wife to try to drag me up the bed on her own. I am not overweight but, even so, it was a strenuous task for my wife on her own. If she hurt her back, who would be around to help? I learned that the head lower than the feet position is known as the Trendelenburg function. The position is named after the German surgeon Friedrich Trendelenburg (1844–1924). A reverse Trendelenburg position has the feet lower than the head. For an IRON, a Trendelenburg function is a necessary requirement for a suitable bed. The requirement is as much for the person’s spouse as it is for the Client. It significantly eases the aforementioned repositioning task and reduces likelihood of Carer injury. My condition means that I am incapable of rolling onto either side of my body unaided. The Care Company insists this procedure requires two Carers to prevent injury to those assisting. Carers are able to wash specific areas of my anatomy whilst I am on my side and are only able to deal with certain other bodily functions while I am in this position. When two Carers are not in attendance, it (once again) falls to my wife to attempt to roll me and hold me on my side (I have a tendency to topple back onto my back, when on my right, if not held in place by some means). This requires one hand to hold me and the other to try to perform whatever task is necessary. It is very difficult for my wife acting on her own. Again, this task raises the chance of injury. A bed can have a function to tilt a Patient laterally to either side to ease this process considerably in the instance where only a single Carer is available. The luxury of having two Carers in attendance, in my household, happens for one hour fifteen minutes each day. For the remaining twenty-two hours and forty-five minutes, my wife is my sole Carer. When I began to develop pressure sores, I involved the local nursing service. They ensured that I had a change of mattress to one designed specifically to better cope with the issue. Surely, it was possible to foresee the probability of development of pressure sores, for a person with my level of disability, while I was in hospital and the correct mattress for use by an IRON provided initially. The lack of functional capability of my bed became more of an issue over time. I was not able to sit upright whilst in bed to eat or drink. To get me out of bed and into a chair of any description continues to involve a number of actions that take time and effort. Initially, I could not sit on any chair for longer than a few minutes without becoming increasingly uncomfortable and with growing pain. This was realised while I was in hospital because therapists worked to improve my tolerance to being sat in a chair. There are beds that are able to adopt a chair like position safely at the touch of a button. Whilst my current bed is able to approximate a chair function, it is not at the touch of a button and I find it uncomfortable. As I became increasingly frustrated with the lack of functionality of my bed, I started searching on-line for something more suited to my requirements. I discovered a whole host of amazing beds with much more functionality. I began emailing companies to enquire about the purchase of this item. I realised that such a bed would likely cost me thousands of pounds but, as I would likely spend a considerable amount of time in bed in the future, and comfort and health are extremely important to me, the money was not the first thing on my mind. My wife and I have saved all our lives and planned for our retirement (although we had not considered that I would be spending it as a POD. Although the money would considerably eat into our savings, we both agreed it was worth the expense. However, I received a phone call from one company to inform me that it was against their policy to sell a bed into a residential household. They went on to explain that if I were to employ a full-time nurse there was no problem. I found the refusal to allow me to purchase a bed that I wanted very troubling. Informed that it could, however, be supplied if I was to employ a nurse full-time really made me angry. It implied that my wife and I did not have the intelligence or the ability to master the bed control and my care safely. I have a Master's degree and my wife is also educated to degree level. Furthermore, I have had a hospital-style bed for eleven months and not a single hospital nurse has set foot anywhere near my home. My wife and I have to manage my care without any hospital help whatsoever (except for a thirty-minute visit from a brilliant physiotherapist once a fortnight and some basic follow-up information in the first couple of weeks).  We have not had one incident with my bed in eleven months and my care is totally in our hands. I was further informed that the Trendelenburg function is a safety issue not permissible in a residential setting. However, other companies were willing to provide a bed with this function, so there was some issue with that claim. I emailed the company concerned following the call to complain and raise issues of discrimination against individuals of disability residing at home. I pointed out that they had just lost a customer and several thousands of pounds for the purchase. I noted that, although the company may view itself as applying the highest standard to the sale of its merchandise, it was discriminating against POD (such as myself. I am an IRON POD!) who would be perfectly good customers. I also wrote to my MP, several media outlets and a few other people to highlight the issue because I genuinely believed it to be discrimination and, if it is law, then the law requires changing. My grievance is with any form of discrimination against POD, no matter the rationale. To cite health and safety as a reason, when clearly my health and safety issues are being adequately managed already without any nursing assistance post-stroke via a local provision (there isn't any; it feels like we have just been abandoned), is somewhat ironic.
5. Air on a bed spring. Above, I noted that I have a Royal System alternating pressure relieving mattress system. It is an air mattress specifically designed to reduce the possible development of pressure sores. It comprises a number of sausage shaped segments that run from side to side. A pump situated at the bottom of the bed alternately inflates, first, the odd segments and then, the even. Thus, the mattress is continually changing the surface contour and its pressure. A ingenious idea except I slept on it for two days and nights (or, to be precise, didn’t sleep) and found it to be both uncomfortable and to hurt my bottom. I had to use two memory foam mattress toppers and a soft fleece under blanket on top of the air mattress just to make it comfortable. I also used two memory foam cushions;one under each buttock, to relieve pressure off my bottom. These cushions work for an hour or two but then, they become so compressed under my weight, it feels as if I am sitting on a solid floor. Usually, by the time I am beginning to feel uncomfortable with my cushions, the next pair of Carers arrive and can sort me out. I think a pressure relieving mattress is overkill for my particular problem. It attempts to relieve pressure over its entire surface, top to bottom. I only have an issue with my behind and the remainder of the mattress is just serving to make me uncomfortable. What I believe I need are two inflatable cushions joined together down one side. The inflation of the cushions would be controlled via a simple four button Client control pendant. The Client is able to both adjust the inflation (up or down) of the right cushion and to adjust the inflation (up or down) of the left cushion. The Client would be in control. If the Client’s bottom began to feel uncomfortable, the Client could then make the necessary adjustments to rectify the situation. The Client would not be able to over inflate either cushion because the system would have a maximum inflation setting. My present air pump hangs off the bottom of my bed. It is in operation constantly 24/7. It is noisy and the noise affects my sleep. Furthermore, it vibrates the board at the foot of my bed. If my bad left foot comes into contact with the vibrating board, it triggers a spasm which is painful. As I have no control over my left leg, I cannot move it off the footboard and the vibrations and the spasms continue. In this situation, I raise the knee break on the bed which takes my foot off the board. I have the knee break raised until the Carers arrive and can pull me further up the bed and my feet away from touching the footboard. The air mattress system is expensive. It is also, in my opinion, badly designed. The pump is noisy and vibrates and the mattress itself is uncomfortable. Pressure sores are quite literally a pain in the bum but the system, used to alleviate the problem, comes with additional issues.

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