



A FOOT IN BOTH CAMPS

SIA member **Peter Henry** has lived with a high-level SCI for nearly 30 years. With experience of being a client and a care provider, Peter offers advice to help other SCI people when recruiting a PA, whether it be from an agency or other means.

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I started needing live-in care following my accident in the late 1980s, which left me with a C5/6-level injury. At the time, specialist live-in care was extremely limited.

Generally, if you needed live-in care you had to hire privately, scratch around various au pair, nanny or generalist agencies, or rely on friends and family. It was a scary time. You were desperate and often ended up with a patchwork of some very odd and unreliable people helping you – along with the rare gem. No commercially available SCI training of any kind existed, so you had to do it all yourself.

Realising that others were struggling with the same dilemma led me to providing specialist live-in SCI care services, using PAs specially trained in the care of SCI people.

My circumstances are, therefore, very unusual as I truly do live and understand both sides – client and agency.

I completely share the wishes of every other person who needs specialist SCI care. I want my PAs to be well trained, reliable, experienced, around for a good length of time, good drivers, have decent domestic standards, be reasonable company – basically just to be ‘normal’. Many will think: “Surely, it can’t be THAT hard to get these people?”

Having been a director of live-in SCI agencies providing exactly these kind of people for more than 25 years, I assure you it can be extremely difficult to recruit, train and retain such individuals. Those who have tried to recruit their own PAs will appreciate this, and it is only getting more difficult and expensive.

Yes, this is exactly why and what you pay an agency for, but let me share some of the challenges facing agency recruiters. There is a greater variety of jobs/options now open to good candidates, and live-in care is not a job for everyone as it can be challenging, stressful and isolating.

Increasing regulation and inadequate care funding do not help and of course, issues relating to the exchange rate and Brexit are contributing challenges. Even generational and social aspects such as changes in individuals’ own choices and their views on work/life balance come into play in recruiting the good PAs we all want and need. All that said, recruiting good people is helped by the growth of the internet, social media and French language films like *The Intouchables*, which promote a positive view of SCI life and care.

Change isn’t all one sided and thankfully there have also been changes in the expectations of those with SCI, who now embrace the belief that life doesn’t stop when you have an SCI. More disabled people now have full-time and demanding jobs, travel opportunities and social and sporting aspirations that can mean, for many, the requirements of today’s PAs have expanded. These expectations have both negative and positive effects on the role of PAs, and subsequently the recruitment dilemma.

The bottom-line though is that you still need a good PA and for everyone the place to start is considering what kind of care you want and need – family and friends, live-in, live-out, via agencies or directly employed by you. Also needed is a good job description that clarifies, in detail, what your PAs will be doing and how you want them to work with you. This document should cover everything from personal care, moving and handling, domestic and cleaning, food and cooking, and less tangible things like how you will live with PAs regarding time together and apart, social expectations when you and your family and friends are together, etc. Once you have clarified these issues, you will be in a good position to explain to others, whether agencies, funders or whomever, exactly what kind of care you are looking for.

As a C5/6 client just like any other, it is frustrating but the reality is that we all have to accept that there is a limit as to what agencies can offer clients regarding choice, experience, PA commitment and level of training. In order to avoid annoying and disappointing clients, agencies do need to

be honest with clients before starting work and manage clients’ expectations as to what their PAs and services can, and more importantly, cannot, be and do.

Ultimately, live-in agency care does mean that clients get warranted and professionally supported care and this can form a major part of a reliable care package. Pleasingly, other models do now exist such as live-out care, volunteers, directly employing your live-in PAs, friends and family, etc. However, these all have their own complex issues. You can also combine these models. As a client and assuming funding is in place, you do now have a variety of SCI care options and I really do hope you find the best solution for your own, unique situation.

Help your SCI agency to help you

When working with an agency, be prepared to provide and do the following:

- Job description
- Details of your individual routines
- Cleaning plan
- House rules
- Talk to the agency about what’s going right/wrong
- Be prepared for ups and downs
- Work through issues constructively
- Be patient.

