

# *No less a quality of life*

An evaluation of the Community Peer Support  
Service for people with Spinal Cord Injury



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The SIA Academy is the education, training and research arm of SIA. The Academy promotes training, education, social research, awareness of spinal cord injury (SCI) and best practice in living with injury, for both healthcare professionals and spinal cord injured people themselves.

At the heart of the Academy is the National Library on Spinal Cord Injury, a unique collection of books, journals and periodicals on spinal cord injury. The Library is open to students, researchers, medical professionals, doctors in training and spinal cord injured people themselves.

Training and education form a large part of the Academy's present work with currently over thirty training courses running both at SIA House and at Spinal Cord Injury Centres. These courses focus on a variety of topics from developing self advocacy skills, to specialist Master Classes, focusing on specific issues which affect the lives of disabled

people – for example, funding for care needs, housing and parenting. All courses are delivered by trainers with personal experience of the challenges disabled people face in living day to day with spinal cord injury.

The Academy is undertaking an increasing amount of social research. It has already published its findings on the issue of ageing with a spinal cord injury and on the benefits of specialist treatment in a Spinal Cord Injury Centre. This piece of work adds to the social research undertaken on the issue of support for newly injured people, and the value of early intervention from peers who are able to demonstrate that 'life needn't stop when you're paralysed'.

As the Academy grows, amongst our plans are those to establish links with overseas organisations such as the European Spinal Cord Injury Federation in order to share knowledge of spinal cord injury across Europe.

## **Executive Summary**

### **‘No less a quality of life’: An evaluation of the Community Peer Support Service for People with Spinal Cord Injury.**

#### **Background and Objectives**

This evaluation of the Spinal Injuries Association’s Community Peer Support Service (CPSS) was funded by the University of Plymouth Vice-Chancellor’s Community Research Fund and conducted by a team of researchers from the School of Health Professions in the Faculty of Health at the University of Plymouth. The aims of the evaluation were to explore the satisfaction of service-users with the service, to assess the perceived benefits and disadvantages of the service for healthcare professionals working with people with a spinal cord injury, and to explore participants’ views on how the service could be improved. Due to the nature of the funding, this evaluation focused primarily on the CPSS in the South West of England.

#### **The Evaluation Approach:**

Data were collected mainly by means of sixteen in-depth qualitative interviews with stakeholders in the service; people affected by spinal cord injury (SCI, both people with SCI and their spouses), healthcare professionals working in SCI rehabilitation, and Community Peer Support Officers (CPSO). The interviews were supplemented by informal discussions with staff at the Spinal Injuries Association (SIA) and a local Spinal Cord Injuries Centre (SCIC), a web-based discussion hosted by the SIA, observation of an education session delivered by a CPSO, and a review of published literature and other relevant documentary material. Close collaboration with the SIA was maintained by means of regular teleconferences. The evaluation, however, is independent.

#### **Summary of Main Findings**

##### *Perceived Benefits of the Service*

High levels of satisfaction with the service were reported by people affected by SCI and by therapists involved in their management. The benefit of the CPSS was clearly demonstrated by the data.

People with SCI valued the psychological and emotional support provided by a person who had themselves sustained a SCI. This direct experience of living with a SCI gave credibility to the practical advice and to the information and signposting provided by the CPSO, who was regarded as a 'role model'. The ongoing support and friendship provided by friendly and compassionate individuals beyond the initial contact in the DGH was highly valued.

Similar themes were identified by the relatives of people with a SCI who valued the re-assuring contact, support and "listening ear" provided by open access to the CPSO. Interestingly the CPSO also provided a role model for relatives, enabling them to begin to see what the possibilities of the future might be.

Health professionals considered the CPSO as a member of their team. They appreciated the support the CPSO provided for relatives as well as their role in supporting patients in coming to terms with their injury, preparing them for transition to a SCIC and providing a role model for a high quality of life with a SCI. They reported that the CPSO helped to drive up standards in their units by contributing to education and planning, keeping staff up to date with the latest research and resources, and providing a link with other units, particularly the SCIC.

#### *Factors influencing the success and challenges of CPSS provision*

Useful insights into key factors influencing the success of the service, as well as challenges faced by it, were gained from the interviews. It was emphasised that the positive interpersonal skills of the CPSO, which included the ability to communicate clearly and with empathy and sensitivity were crucial to the success of this post.

Judging the optimal timing for the initial visit made by the CPSO was identified as an important issue by people with SCI, the health professionals as well as the CPSOs themselves. Participants expressed that too early a visit, for example while the newly diagnosed person with SCI was receiving acute medical care or was in the early stages of grief or denial, could potentially be counterproductive. Sensitivity and intuition by the health professionals with regard to the timing of referral seem to be used successfully, but structured guidance, based (wherever possible) on evidence, may be helpful in enhancing service delivery.

Identifying people with SCI in the DGH in need of support was a challenge recognised by the CPSO, since no formal referral procedure had been developed. This necessitated building relationships with healthcare staff, respecting professional boundaries and dealing tactfully with occasional instances observed of less than optimal therapeutic practice. The rotating nature of the posts of health care staff required this to be an ongoing process.

### *Considerations for enhancing the service*

Based on the data gathered, suggestions for enhancing the service are outlined below:-

- Development of additional CPSO posts enabling national coverage of the service, and smaller catchment areas for the CPSO staff. Alongside this, when recruiting new staff, consideration should be made to the availability of a female CPSO to support women with SCI.
- Vigorous promotion of the CPSS, for example provision of information sheets to newly diagnosed SCI patients and relatives and healthcare staff to enhance awareness of the service.
- Extension of the service to include home visits for people newly discharged home could be considered.
- Development of a more efficient system of referral to reduce the considerable time spent by the CPSO in identifying people with SCI in the DGH in need of support. For example, inclusion of signposting to the CPSS within Integrated Care Pathways, or similar protocols, would help to formalise the referral process to the service, and would enhance awareness of the service. This mechanism may ensure fewer patients would be missed; and would facilitate audit of this service to be integrated within broader SCI service evaluations.
- It might be advisable to develop more structured guidelines on the timing of the first visit (wherever possible based on evidence); and a protocol for reporting instances when the CPSO perceives that poor clinical practice is being implemented.
- It may become necessary to develop more formal support systems for CPSOs as more come into post. One method may be a peer support mechanism provided through a designated Chatroom session for the peer supporters. This is of particular relevance given the recent expansion to the South West.

## Conclusions

This evaluation of the Spinal Injuries Association's Pilot Community Peer Support Service provides evidence of the wide ranging benefits this service offers both to those affected by SCI and the health professionals involved in their management. Consideration now needs to be made with regard to establishing more formalised guidance for CPSOs to optimise the effectiveness of this rapidly evolving service. Further research is indicated in determining important factors such as the optimal timing of referral, and in identifying who benefits most from this service, to allow more efficient targeting of this valuable but scarce resource.

The results of this evaluation were presented at the SIA Annual Conference in Peterborough, UK in October 2010. Both the Full Report and this Summary document will be made accessible via the SIA website. It is intended that a submission of a scientific report of the study will be made to the journal '*Spinal Cord*'.

## **Abbreviations:**

<b>CPS</b>	<b>Community Peer Support</b>
<b>CPSO</b>	<b>Community Peer Support Officer</b>
<b>CPSS</b>	<b>Community Peer Support Service</b>
<b>DGH</b>	<b>District General Hospital</b>
<b>HCP</b>	<b>Health Care Professional</b>
<b>SCI</b>	<b>Spinal Cord Injury</b>
<b>SIA</b>	<b>Spinal Injury Association</b>
<b>SCIC</b>	<b>Spinal Cord Injuries Centre</b>

## **Acknowledgements:**

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We are grateful for the involvement of all those who participated in this study and who gave freely and generously of their time during the interviews and chat room sessions.

We wish to thank the University of Plymouth who provided funding for this study through the Vice-Chancellor's Community Research Fund Award.



# **‘No less a quality of life’: An evaluation of the Community Peer Support Service for People with Spinal Cord Injury.**

## **Background**

SCI can occur at any age, the effects are usually permanent and currently there is no cure (Harrison 2000). It is estimated that there are approximately 40,000 people with SCI living in the UK; a prevalence of 0.07% (Nicholls et al 2005). Although the lack of a national database means that precise figures are not available, the estimated incidence ranges from 800 - 1200 new patients annually (Nicholls et al 2005; Aspire 2010; MASCIP 2010).

Learning to live with a SCI can require huge personal and psychological adjustment on the part of the person with the SCI and family members. This is in addition to the enormous physical challenges that are faced in order to learn how to optimise independence in daily living. There is evidence that a period of inpatient rehabilitation is necessary to achieve optimum quality of life after a SCI (SIA 1997). High quality scientific studies, however, have not yet been undertaken to investigate whether this rehabilitation is best placed within a non-specialist or specialist SCIC (Bagnall et al 2003, Jones and Bagnall 2008). Expert opinion in a number of countries including the UK, USA, Canada and Australia recommend that transfer to a specialist SCIC, where high quality rehabilitation and access to information and psychological and peer support is available, should be made as soon as possible after diagnosis of the spinal cord injury to optimise outcome (Aung 1997; Carvell 1989; Carvell 1994; SIA 1997). This stance is supported by both the UK Spinal Injuries Association (SIA) and the British Association of Spinal Cord Injury Specialists (BASCIS).

At present there are 12 specialist SCICs in the UK and Ireland, which provide comprehensive acute, rehabilitation and continuing care facilities and services. While it is desirable that all patients with a SCI should be referred to a SCIC, assessed, and admitted if suitable and this is the patient's wish, this does not always



happen. Currently, in the UK, it has been suggested that 10% of newly injured people are never admitted to a SCIC, 21% are not referred within a month and 41% are not admitted within one month (SIA 2009). For those who spend all or a long period of their rehabilitation in a DGH, not only is their access to specialist health professional input more likely to be limited, but they also may be the only SCI person in a unit, thus losing the benefits of sharing experiences with peers, and psychological support and practical advice about living with their injury. It was to support patients with a SCI who are spending time in a DGH rather than a specialist SCIC that the Spinal Injuries Association developed the role of the CPSO.

The SIA is a UK based charity whose aims are to offer support and assistance to people with a SCI from the time of their injury for the rest of their life. They provide support to individuals and their families and raise awareness of the causes and consequences of SCI. SIA's services promote the sharing of experiences and provision of information, support and training. This includes a Peer Advice Service within all Spinal Cord Injuries Centres in England, Wales and Northern Ireland, a Freephone Advice Line, an Employment Service set up to support spinal cord injured people back into work following injury, a range of training courses and Master Classes aimed at a variety of audiences, an interactive website and a wide range of publications. SIA is also a campaigning organisation, seeking to influence social policy and promote good practice in health and social care for spinal cord injured people, and it also undertakes or commissions research. Recognising the value of peer support in the early stages of a SCI the SIA supports a Peer Advice Service in all SCIC's in England, Wales and Northern Ireland, with peer support officers available to visit patients in the centres to talk, share concerns, reassure and answer questions on living with a SCI, as well as providing or sourcing information and practical advice. However, as a number of people will either not be offered or not desire rehabilitation in a SCIC, or will remain in a DGH for some time before a bed becomes available, the SIA secured funding in 2008 to provide a peer support service for such patients, known as the Community Peer Support Service. Piloted with one Community Peer Support Officer serving London and the South West, the service has recently expanded to four officers in post, with the longer-term aim of eventually providing national coverage.

***Peer support: the evidence to date***

Peer support is based on the philosophy that the person who can best understand is a person who has shared similar experiences (Patterson, 2005). It is an essential component of client-centred rehabilitation practice and is considered an important source of motivation, support, camaraderie, mentoring, information and practical advice for people with disabilities, enhancing the empowerment of the individual and contributing to an improved quality of life. Boschen and colleagues (2003) found that peer support, along with social support in general, was a key factor in accomplishing the adjustments necessary for living with a SCI. Jalovcic and Pentland's study of telephone peer support for women with a SCI living in rural and remote areas of Ontario found that participants experienced emotional, affirmational and informational support, resulting in reported positive change and transformation (Jalovcic and Pentland, 2009). The sessions were described as an important safe space for venting frustrations, alleviating feelings of isolation in injury, and learning strategies to live with disability.

In addition to this small number of studies which have studied the effectiveness of peer support for people with SCI, there is also a larger body of evidence to support the value of peer support in a range of other conditions, including traumatic brain injury (Hibbard et al., 2003), HIV (Funck-Brentano et al., 2005), mental health dual diagnosis (Klein et al., 1998), substance misuse in serious mental illness (Rowe et al., 2007), cancer (Hoey et al., 2008) and burns (Badger and Royse, 2010). Burns survivors share many of the characteristics of the health care experience of people who have a SCI. These include long hospital stays with separation from loved ones, altered appearance and attendant identity readjustment, possible stigma, psychological shock and trauma, chronic pain, physical and functional impairment and the need for a long period of physical and emotional healing (Badger and Royse, 2010). Supportive interaction with peers can make burns survivors feel 'normal' (Williams et al., 2004), which resonates with what has been called 'social comparison theory', which suggests people are drawn to others in a similar situation to themselves (Solomon, 2004), particularly so when experiencing a major challenge (Taylor et al., 2007). Hibbard et al concluded that community peer support of their

sample of people with Traumatic Brain Injury produced positive impacts in increasing knowledge of the injury, empowerment and improving quality of life, general outlook and ability to cope with depression. Both patients and their relatives reported a positive impact from peer support, the main benefit for relatives being enhanced knowledge of the condition (Hibbard *et al.*, 2003). In the qualitative phase of this study, shared experience with the peer mentor was reported to be the most beneficial aspect of peer support, reducing the feeling of being alone, with great value placed on the mentor's experiential knowledge of the injury. Advocacy and support in self-advocacy were also highly regarded aspects of the peer support. The value of peer support for people with newly diagnosed SCIs has also been demonstrated by feedback to the SIA from people undergoing rehabilitation in SCICs who have benefitted from the Peer Support Service provided by the SIA in these centres.

## **The Research Project**

The present evaluation of SIA's Community Peer Support Service was a result of the submission by the SIA of a research question – to evaluate the Community Peer Support Officer (CPSO) role - to the University of Plymouth Vice-Chancellor's Community Research Fund. This fund is designed to foster links between the university and local charitable organisations, and supports five small pieces of research each year. A proposal was developed by Jenny Freeman and Bernhard Haas of the School of Health Professions in collaboration with the SIA, and was successful in winning one of the available grants. The SIA was keen to evaluate the south west CPSO role, a recent addition to its repertoire of services, to gain systematic evidence of its value before rolling it out into the rest of the country, funding permitting.

## **Aims and Objectives**

There were three aims of the project.

The first aim was to explore and evaluate the service users' degree of satisfaction with the *Community Peer Support Service*, specifically in terms of whether it:-

- i. Enhances their understanding of "life after paralysis"
- ii. Provides a greater understanding of the support available to help them live independently
- iii. Helps to reduce the isolation faced by them after completing rehabilitation and returning to the community

- iv. Provides any other benefits or disadvantages / challenges to the service user

The second aim was to explore the potential benefits and disadvantages of this service from the perspective of the health care professional involved in the management of people with spinal cord injury.

The third aim was to explore, from the perspective of both these user groups suggestions for improvements to the service.

## **Methods**

The evaluation of the south west CPSO was designed as a small-scale qualitative study, that is, it was concerned to talk to stakeholders in depth about the advantages and challenges of the role. The Research Assistant, specifically employed for this project, talked at length to the CPSO on several occasions, including a more formal recorded interview, and accompanied him to a training session delivered to therapy staff at a DGH, and to the local SCIC which he was visiting to liaise with staff and people he had supported in DGHs. The research assistant also visited the SIA and spoke to staff there about the organisation as a whole, the support needs of people with SCI, and the CPSO role. The SIA hosted a designated web-based Chatroom Plus session to explore the opinions about the CPS by people who had and who had not experienced CPS in a DGH, therapists, CPSOs, SIA staff and Peer Support Officers from SCICs all were invited to contribute.

A qualitative research approach, using one to one semi-structured interviews was used. A fairly open framework, using a topic guide, was used which allowed for the interview to be focused, yet sufficiently flexible to permit both the interviewer and the person being interviewed to probe for details or discuss issues. This method is widely used to explore people's knowledge and experience of disease and health services. The aims of the study and the draft interview topics were developed based on detailed discussions with staff at the SIA; together with comments from participants in the web-based Chatroom Plus session. Fourteen in-depth interviews were conducted. These were digitally recorded, with the written consent of participants, transcribed and analysed thematically using QRS NVIVO software.

Research Governance Management approval from the relevant Trusts and approval from Trust Audit Departments was acquired. The Research Assistant acquired a certificate of approval from the Criminal Records Bureau before contacting participants. Ethical approval was gained from the Faculty of Health Research Ethics Committee, University of Plymouth on 15.12.2009.

The limitations to the sample were the small number of participants, their relatively old age, and the fact that they were all men, so that younger people and women were not interviewed. In fact recruitment to the study proved to be an unanticipated challenge, mainly because of the short time the CPSS had been in operation, meaning that many of those supported were still in hospital or NHS nursing homes and therefore not eligible to take part. Because the funding was limited and the time-frame quite short, the study was also quite circumscribed in capacity, meaning that follow-up could not be as vigorous as desired.

Participants were identified by the CPSO and approached by means of an initial letter from the SIA explaining the study, and requesting that they contact the university researcher if they might be interested in taking part. A stamped envelope addressed to the researcher and a response pro forma, as well as the Participant Information Sheet were provided. Of eight people with SCI identified, one had been recently bereaved and was not approached, and two did not respond. The remaining five were contacted by the researcher when they had consented to this, and were interviewed. Three of their wives also consented, and one mother was contacted by the researcher by email after she had given consent for this approach, following a conversation with the CPSO. Ten healthcare professionals who had had patients supported by the CPSO were identified and approached by an email with the Participant Information Sheet attached, asking if they would take part in the study. Of these, two did not respond, and one did not respond within the time-frame. Two people could not be interviewed because Research Governance Management consent had not been obtained for their hospitals because the CPSO's catchment area was wider than the research team had initially anticipated and consent had not been sought. Acquiring Trust Research Governance approval is a time-consuming process, and it would not have been possible to acquire management consent for

these additional Trusts in the time-frame. The remaining five health professionals agreed to take part and were interviewed.

## **Results**

### **Sample**

The sample comprised five people with a SCI, four close relatives of people with a SCI and five therapists working in DGH rehabilitation units, all of whom had been supported by the CPSO. The people with SCIs were all male, with an age range of 39-63, average age 52. Of the people with SCI supported, 34% had traumatic and 66% non-traumatic injuries, and 46% had paraplegia, 35% tetraplegia and 19% were walkers. The relatives were all women; three wives and one mother of people with a SCI. The therapists, four women and one man, were from three different hospitals and comprised three physiotherapists and two occupational therapists.

### **The Community Peer Support Officer Role**

The first Community Peer Support Officer, working in Greater London and the South West, was appointed in August 2008 and was in post for about 14 months before the second Officer, was appointed, taking over the Greater London area. Subsequently a third CPSO has been appointed for the North West, and a fourth for Wales. All are funded by charitable trusts, with one post part-funded by a corporate donor.

The role of the CPSO as described in the job description for the post has a number of components. These include dealing with referrals from the SIA Advice Line, SCICs and hospitals, providing support and information by telephone or personal visit and working with individuals to establish a planned programme of support. The CPSO draws on the resources of the SIA by way of its Advice Line to offer a comprehensive range of information and support, as well as supporting individuals in dealing with statutory services such as health and social care services. The role involves introducing individuals to the range of SIA's services and the benefits of membership where appropriate, publicising the work of the SIA to relevant statutory and voluntary service providers and to identify training opportunities for non-SCI specialist staff dealing with people with SCI. Confidentiality and data protection must be safeguarded throughout. The CPSO maintains close liaison with the SIA's Peer Support Team and maintains

records for monitoring and evaluation purposes. At the time of writing (October 2010) in the two years the South West CPSO had been in post, over 150 episodes of support (including new injuries and follow up visits) had been provided for people with SCI, a similar number for relatives and 200 episodes for healthcare professionals.

The need for the CPSS was well demonstrated in the data. Evidence from the Chatroom session suggests that many people with SCI did not get any support while in DGHs, and would have found such support helpful:

***I don't remember getting any support. That's why I was keen to get involved. I think it would have been very useful to have met someone with SCI early on in my treatment.*** Chatroom Plus Participant, a Peer Support Worker in a SCIC

Living with a SCI is a not a static experience; a person's physical, psychological and emotional aspects needs are dynamic, and, will change and evolve over time. This is particularly the case in the early stages following the spinal injury, and then again later on with the aging process. In the continuous process of learning to live with a SCI, however good the healthcare professionals in their journey, for many it is peers, other people living with a SCI who provide the greatest support:

***I have 63 years of SCI and am still learning but most of my support has come from other SCI people.*** Chatroom Plus participant, female

For patients in DGHs therefore, who have perhaps never met or spoken to another wheelchair user in their lives and are being nursed or rehabilitated in units where they may be the only person with a SCI, the CPSO is their first, and possibly their only access to this very crucial peer support. This is the foundation on which the role is based; the CPSO provides the role model to demonstrate that a good, independent, high quality life is possible for people who are paralysed. This is a message which can only be transmitted by someone who is speaking from their own experiential knowledge of living with a SCI.

***And to me that completely summed up exactly what I want to do with people is just give them a little bit of hope. Once you've given them that it gives them thought process of asking, well hang on a minute he came in a car. Well why can't I, you know.*** CPSO1



Healthcare professionals also acknowledged the value of this aspect of the CPSO role: ***It's very easy for us to say things will get better but... for them to actually see...that there is a life outside. It might be a different type of life, but it's no less quality, you know, no less a quality of life. It's just a different type of life. And I think that's what they need to get their head around to start with.*** Sarah, Physiotherapist<sup>1</sup>

One CPSO remarked that the main reward of his role is believing that he is helping people towards a better quality of life than they might otherwise have had. Thus the role of CPSO is one of empowerment, an orientation could hardly be more explicit in his reflections on the role: ***My objective is to empower people.*** CPSO1

Part of this empowerment is to support people to take responsibility for their own rehabilitation by providing the necessary information. For the South West CPSO, the major issues are management of bladder and bowels and the protection of skin. It will be highlighted in a subsequent section on DGH issues that it is sometimes necessary to make the patient aware of best practice in these matters in order that they can insist on optimal clinical practice. Another aspect of the empowerment role is to provide information and to signpost people to the relevant organisations to enable them to access all the benefits and services necessary to optimise quality of life.

***So I will talk to people about benefits, I will talk to people about care packages, but not necessarily the nuts and bolts but where to go, what your entitlement may be. And we also could tap into solicitors as well, we know a number of solicitors that ...human rights issues if you feel you're being denied particular aspects of care, as an example. We do know some really good solicitors that will give you free advice, you know, so it's not we're touting for business for solicitors they will give you free advice.*** CPSO1

As part of the individually tailored support provided to patients and relatives, the CPSO role also involves promotion of the services offered by the SIA, and strong advocacy that patients are referred to SCICs. Should they be offered a bed in a SCIC then the CPSO would normally recommend the person to accept this if

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<sup>1</sup> Names have been changed.

possible. The CPSO may also be drawn into discussions on the person's prognosis, particularly for future 'walking'. It was acknowledged that this can be a challenging situation where they may feel under pressure to voice an opinion. The SIA are very clear that the CPSO should only offer peer support and are not medical experts.

### Themes related to the CPSO role

Analysis of the data collected for the evaluation revealed a number of themes relevant to understanding the role of CPSO. These are;

- the timing of the first visit from the CPSO
- DGH issues
- access to people with newly diagnosed SCI in DGHs
- the CPSO role in relation to relatives
- support for the support officer

### The timing of the first visit from the CPSO

The data from this study suggest that it is widely recognised that supporting people in DGHs can be a sensitive and delicate undertaking for a number of reasons. One of these relates to the timing of the first visit, in which a difficult judgement has to be made about the optimum moment to offer support. It was felt that it can be counterproductive if the CPSOs approach patients before they are ready. If the injury is traumatic, there will be a period during which the individual is receiving intensive and possibly life-saving medical care. After this acute period, readiness will depend on a multiplicity of factors, not least how the individual has adjusted to his or her injury. It is possible to theorise from the data collected that there is a range of adjustment styles from sanguine acceptance to rage and denial. It would appear that it is for people in the middle of this range, those who are slowly and perhaps painfully coming to terms with the reality of their disability, that CPS will be most helpful. For these individuals, when to offer support remains a crucial issue, and it was felt that 'going in too soon' could be counterproductive.

***Some people are just not ready to accept that they are “disabled” and don’t want to be involved with that.*** Chatroom Plus participant, male

***There are degrees of acceptance of SCI.*** Chatroom Plus participant, female.

***It can often be a little overpowering seeing someone in a wheelchair for the first time.*** Chatroom Plus participant, male

One CPSO participating in the Chatroom Plus session advocated working with healthcare professionals, who would have a good knowledge of when to approach. ***That's why I have chosen to work with the therapy teams. They get to know and understand their patient.*** Chatroom Plus participant, male, CPSO

However this raises other issues which will be discussed below in the section on access. Another felt that support intervention should be offered as soon as possible, but that it was necessary to assess in situ how much information was appropriate.

***Each SCI/family individual [is] ready at different stages, but I feel earlier the better and pitch your contact appropriately... Suss people out, they normally flag up help needed/go away!*** Chatroom Plus participant, male, CPSO

Currently deciding when to first approach people is a question of individual style and inclination; no guidance or criteria exist to help CPSOs in this decision-making process. Data from the Chatroom participants suggest that the formulation of guidance is likely to be very complex, and there may well be no single right approach, especially because, as people in the Chatroom vociferously pointed out, people with SCI are not all the same; there can be no universal rule. Clearly deciding when, how and to whom to offer support is part of the highly skilled nature of the peer support role.

***Everyone is different and it's just a gut feeling how you deal with it.*** Chatroom Plus participant, male, Peer Support Officer in a SCIC

***Becoming disabled doesn't discriminate. Everyone is a different character, and reacts in their own way.*** Chatroom Plus participant, male, CPSO

### DGH Issues

DGH's may be able to provide good quality rehabilitation, but they do not always have the specialist expertise or environment for patients with SCI. For the CPSO, a major part of the role is establishing and maintaining relationships of trust with DGH staff, for without this there will be no access to people with SCI. One of the most

difficult situations they reported is when they observe poor clinical practice which in their view may be poor practice and potentially adversely affect people's rehabilitation. Sadly they reported that this is not rare, and is a situation which requires the workers' last reserves of professionalism and diplomacy to negotiate the tension between giving the patient the best advice in the face of what they perceive as poor clinical practice and not alienating clinical staff. Both of the CPSOs interviewed described this as one of the most challenging aspects of their role.

***I think diplomacy is a big one. It's difficult to maintain a professional decorum when you see people that aren't being treated in a way that, you know, I would want to be treated. You know, I've seen somebody that that it borders on negligence, clinical negligence. ..So it's a balancing act, it really is, because you've got to, you know, first and foremost I'm there to support the patient, and like I say, it can be a difficult balancing act to get that right between the support and maintaining and establishing relationships with, with the health care professionals.*** CPSO2

Examples of perceived poor practice include failure to refer patients to a SCIC, failure to turn patients frequently so that they develop pressure sores which could delay their rehabilitation for several months, and failure to teach bladder and bowel management. The CPSOs are not healthcare professionals and are rigorous about respecting the boundary between peer support and clinical knowledge, particularly as some healthcare staff do appear to find their presence threatening. Instances such as these do challenge those boundaries however. The South West CPSO developed a two-prong strategy of on the one hand educating the patient and stressing the importance of good practice by drawing on his own experience, and on the other hand signposting healthcare staff to available resources for learning best practice for SCI patients (for example from the local SCIC, or from the SIA itself). He stressed that he sees it as part of his role to educate hospital staff as much as it is to inform patients.

***Because I am not a health care professional, I always stress I won't talk about health care professional issues. I would normally speak to the nurse in charge and say that you know you need to speak to somebody in the specialist spinal unit that can give you advice about skin toleration. Or, because it's happened to me I can actually talk about my own experiences of how I had a pressure sore in a similar environment. And the consequences of that pressure sore.*** CPSO1

Access to people with newly diagnosed SCI in DGHs

There is no central register or systematic record of people admitted to DGHs with a SCI. CPSOs must track them down themselves, and a significant aspect of their role is the painstaking process of getting to know healthcare staff, building up relationships of trust and promoting the benefits of the service they offer. Where this is successful, as we shall see below, the CPSO is regarded as an integral member of the team, and are likely to alert the Officer whenever a person is admitted with a SCI. In other units there is some suspicion of the role, and patients may miss out on peer support as a consequence. Another issue impacting on systematic referral to the CPSO is that a DGH rehabilitation unit may see a very small number of people with SCI. This can be made even more difficult by high staff turnover in some units and the use of bank staff, so that a painstakingly developed relationship can be lost and the CPSO must start relationship building, promotion of the role and developing trust all over again. Awareness-raising and relationship building then, are important, but time-consuming aspects of the CPSO role which are not always successful, requiring much repetition and reminding.

***The problem I think, you know, it's quite obvious that we are a very, very small group of people. So if you've got a general hospital dealing with lots of different disciplines, spinal injuries is very, very small. And it's remembering that from my point of view that's it's not a priority for those therapists to suddenly pick up the phone and tell me they've got somebody with a spinal injury. Some will. Some are more passionate, some might see more spinal injuries than others so it's very much a hit and miss. And I'm not quite sure what else I can do.*** CPSO1

The newly appointed CPSO for the north west was realistic about this, recognising that for probably the first year he would be building up relationships with healthcare staff so that they would be likely to remember to refer people, rather than supporting many patients.

***I think the problem is with this job, the people that we are seeing, the vast majority of them will be the non traumatic spinal injuries and they tend to be scattered around all over the place. So it's not like you can go to a specific ward, you know, a spinal ward or, or a neuro ward. It's, you know very often the odd person on a stroke ward or an oncology ward or an orthopaedic ward, and although, each hospital might have, you know, four or five spinal injuries, there might be one on each ward and therefore it's just finding these people, and finding the right healthcare professionals to be able to signpost us to, to find them and refer them to us so that we can offer our support really.*** CPSO2

The vast majority of people supported by the South West CPSO were referred by a therapist. It was often one particular staff member who ensured SCI patients were referred to the CPSO. The other sources of referrals were family members, many of whom would have known about the service through contact with the SIA, other hospital staff, for example the consultant, the case manager, or nursing staff, the SCIC and SIA's Freephone Advice Line.

### The CPSO Role in relation to relatives

There is widespread agreement in the SCI population that in the early stages of an injury, it is relatives who need the support of the CPSO as much, if not more than the injured person. Support for relatives is therefore regarded as an equally important aspect of the role. Relatives were described as often feeling helpless, anxious, bewildered and guilty and in need of practical information and insight into the likely outcome and quality of life for their injured relative.

***In the early days often it's families that need all the support.*** CPSO1

***Relatives are confused and frightened often.*** Chatroom Plus participant, female

***Our experience is that, apart from everything else, family members often feel a lot of guilt for what's happened.*** Chatroom Plus participant, male.

Relatives have no idea what to expect, and the very fact of having the opportunity to observe the CPSO leading an independent high quality life, driving, working, staying in hotels, can give them hope for the future. While the SCI person has all the attention of the healthcare professionals, their relatives can be grappling alone with their anxieties and fears. For them the CPSO can be a lifeline.

***Sometimes the families want to talk about the negative things, like continence, sex, and needing to be looked after. I guess they just want to off load, while the injured person has all the attention of the professionals and is learning to live life a new way.*** Chatroom Plus participant, male.

***And then seeing me turn up very often gives them, you know inspires them to realise that all is not lost.*** CPSO1

### Support for the support officer

CPSOs are themselves wheelchair users with a SCI. The role is a demanding one. The South West CPSO covers an area of several hundred miles, from Wiltshire to Cornwall, involving long journey times and overnight stays. In addition, supporting people who may be traumatised and in distress, can take an emotional toll. This raises the question of where CPSOs get their own support. Both the CPSOs interviewed felt that the SIA provided excellent support, and that they could always 'offload' there, and to their manager at any time. In addition, of course, they could share experiences with each other, and offload to their family members.

***You know, the case that I've mentioned that was difficult, you know, it was really, it did impact on me quite, you know, quite strongly and it was something that I took away with me and I struggled. And then, just by being able to talk it through with my boss, and then talk it through with one of my peers and just to know that I'd done the right thing really and that, you know, that it wasn't an uncommon sort of occurrence really and that, you know, these things happen. I think that's the thing it was, we will come across, people that are in situations, that it's going to be rather harrowing and I think, that's just, that's part of the job, it comes with the, with the territory really.*** CPSO2

***Community colleagues are great at supporting each other, I find.*** Chatroom Plus participant, female.

***The team has a Manager who calls each CPSO each week to check they're OK and listen to any problems or issues. Same with the CPS Officers. And there's face to face meetings too.*** SIA manager.

One outcome of the Chatroom Plus session was the suggestion that Peer Support Officers could have their own, designated Chatroom session: peer support for the peer supporters.



## People with Spinal Cord Injuries' experience of CPS

For patients in hospital with a newly diagnosed SCI it is a traumatic and emotional time. The visit from the CPSO can seem like a lifeline for people who are bewildered by the turn their life has taken and are newly embarking in the journey of coming to terms with, and learning to live with a SCI. The main benefits of CPS described by participants in the evaluation were;

- psychological and emotional support
- the fact that the support was provided by a person with a SCI
- advice on living with a SCI
- practical advice and information
- ongoing support and friendship
- the personal qualities of the CPSO

### Psychological and emotional support

The CPSO himself recorded that the most common type of support he provided was a 'listening ear,' and the stories of the participants in this study reinforced the value of this type of non-specific psychological and emotional support. Just the fact that the CPSO came and visited and spent time with them at a vulnerable time was highly valued.

***But he came in. and of course you were lost at the time, you don't know anything what's happening to you or what's, why you, what has happened. And he was very good; he explained a lot of things to me. It's like things you didn't understand, and he came in, and he come beside the bed and he's there a long time, talking to me, and explaining what it was all about.*** 'Ronnie', 63 years old, traumatic injury, C8.  
***[CPSO name] was just very supportive.*** 'Charlie', 53 years, non-traumatic, T2-T8

One participant, in the context of being asked to reflect on the whether support had helped him come to terms with his injury felt that it had done so.

***I'm sure it did [help coming to terms with being a wheelchair user]. I didn't think about it at the time, but in retrospect. I'm sure it was, it was very useful.***  
'Sean', 49, traumatic injury, C5/6.

### The fact that the CPSO had a SCI; the 'peerness' of the peer support.

The fact that the 'listening ear' was provided by a person who was himself living with a SCI was a crucial aspect of the value attached to the support provided. The CPSO

provided a role model of the quality of life and independence which was attainable with a SCI, and exemplified the SIA's central tenet that 'life needn't stop when you're paralysed'. Almost all the participants expressed the belief that information provided by someone with a SCI somehow carried deeper relevance and was more meaningful than that provided by anyone else, even by healthcare professionals, because it was based in the personal experiences of someone 'further down the line'.

***And, the carers and the nurses are very good but, obviously they haven't experienced it, and it was nice that somebody came along to offer a bit of help, who knew all about it from the receiving end really. So from that point of view he was most welcome.*** 'Sean', 49, traumatic injury, C5/6.

***Because, anybody can come in and talk to you, but until you're in like this, you don't really know what you're talking about. You can only read it in books can't you, whereas it comes first hand from him what he could do.*** 'Ronnie', 63 years old, traumatic injury, C8.

#### Living with a SCI: the CPSO as role model

The CPSO could and did provide a plethora of advice and practical information on living with a SCI, but it was the fact that he was himself living with a SCI that was reassuring and often truly inspiring for the evaluation participants.

***But I remember him coming in and saying that, he'd got to a state where he could travel around and stay different places by himself, and he could get in and out of the car, and though I was just laid there things would happen where I would probably be able to get a little bit better. You don't know at the time how well you're going to get, but he gave me, like inspiration.*** Ronnie', 63 years old, traumatic injury, C8.

***He spoke about himself, how he's coped with it, and it was comforting to hear that, you know, someone who had been in for so long, had been able to function properly. Because for myself, as confident as I was at the time, you know, you're still early days and I didn't know, you know, after a protracted amount of time how, how things, would be for me.*** 'Matthew', 37 years, non-traumatic injury, T10.

***The main thing I got out of it was he was somebody who'd been there himself.***

***No, it's the fact, not that he was a wheelchair user, but the fact that he knew from a personal point of view, what it was like, if that makes sense. Not the fact that he was in a wheelchair, but the fact, that, unlike everyone else, he actually was speaking from experience.*** 'Sean', 49, traumatic injury, C5/6.

#### Practical advice and information

Participants mentioned asking about, and receiving advice on bowel and bladder management issues, and being advised on care of the skin, as well as information on housing, available sources of financial support and devices and appliances to support independent living with a SCI, and practical tips, for example negotiating showers and wet-rooms in hotels. All these factors could provide insights about what they could expect in the longer term in relation to living with their injury and what to expect when they got home. Those with a place in a SCIC were prepared with information about what to expect there.

***Because he did say about [the SCIC] to me, don't think that it's some kind of miracle. It's not like Lourdes, or anything like that. You know. No, you don't go there and just get a miracle cure, and walk out again.*** 'Dave', 59 years, non-traumatic injury, T10.

***And you're learning all the time when he come to visit, little things that would put your mind at rest. What's going to happen when I get out...It's when he come in you'd ask him about, when I go out will I be able to do this or, can I do that, he could tell you.*** . Ronnie', 63 years old, traumatic injury, C8.

***And he was saying about hotels that he stays in, because he drives a car and everything doesn't he? And he says not all hotels are what they're cracked up to be and you have to improvise and, all that. And, oh we were talking about skin care as well, because [CPSO name] is quite obsessed with skin care.***

'Dave', 59 years, non-traumatic injury, T10.

***He gave you any advice that you wanted and he told you different things then. And he'd give you little bits of specialist information if you know what I mean. Stuff that you couldn't even get from the nurses, because they weren't in this sort of thing.*** Ronnie', 63 years old, traumatic injury, C8.

### Friendship and ongoing support

As well as the initial visit or visits while participants were in the first phase of recovering from and coming to terms with their injury, the CPSO kept in touch with the people he had supported, both in the SCIC, where he would make a point of catching up with their progress, or at home by telephone or email. It is not part of his remit to make home visits. This aspect of the support, which was more like a normal friendship, was appreciated by the participants.

***Yes, oh yes. I've seen him a few times. He's very good, he follows up.***

***..Whenever he came up [to the SCIC] he used to always come in and see me.***

***Because he had everybody, so many to see didn't he like, you know. But he used to come in, have a talk, and just build, used to build me confidence up.***

'Ronnie', 63 years old, traumatic injury, C8.

***In fact he rung me the other day, four or five days ago I think now. I was picking his brains then about something, so.*** 'Dave', 59 years, non-traumatic injury, T10.

***And, I remember thinking that it was nice, it was a nice thing that it existed. I mean I remember when he came down, I think, I think we more or less just spoke, I mean there was nothing, there was nothing specific which sticks out, it was more like just having a, a conversation with an old friend or something. So I mean that was, that was pleasant.*** 'Matthew', 37 years, non-traumatic injury, T10.

### Personal qualities of the CPSO

It takes a particular sort of character to offer peer support to people with a SCI. As well as the skills of tact and professionalism required to address the problem of the less than optimal care sometimes provided in DGHs, the commitment and energy necessary to travel long distances and the resolve required to support people who may be in distress, the personality of the CPSO is likely to have a big impact on the quality of the supportive relationship. This relies on friendliness, compassion and trust. The up-beat personality of the CPSO was something mentioned by several of the participants.

***Because I remember him, he used to come in so quick, with his wheelchair and pop beside the bed. He was always jovial, always trying to bring you up like, you know?*** Ronnie', 63 years old, traumatic injury, C8.

***He's a very affable person, isn't he. And I tell you what, he tells it as it is as well.*** 'Dave', 59 years, non-traumatic injury, T10.

#### Timing of the first visit

Because this had been raised as an issue of concern by the CPSO, participants were asked about the best time following injury for the CPSO to visit. In relation to the timing of the first visit it is perhaps worth noting here that some participants had only the haziest recollection of the early visits from the CPSO, being, as one put it, 'away with the fairies' recovering from an accident or operation.

***And you're fairly well drugged up to be honest. Like the first month I can't remember much at all except for nightmares, big dragons and that flying over the sky.*** 'Ronnie', 63 years old, traumatic injury, C8.

Despite very positive recollections of the first visit of the CPSO, there was some consensus that this should not take place while the individual was still in the initial period of recovery following their injury.

***No time, to start with is the right time. Because you can't remember, realize what has happened. It's only after the time, after many months that you begin to realize, what is, what it's all about... To start with I wouldn't have been able to take anything in at all.*** 'Ronnie', 63 years old, traumatic injury, C8.

***But you only take on things the further you get. Because after my operation I was still on the effects of the drugs I think they give you, things like that, so, even when I thought I was ok I don't think I was, totally.*** 'Sean', 49, traumatic injury, C5/6.

***I don't think you want to be going to see people when they're not feeling particularly well.*** 'Dave', 59 years, non-traumatic injury, T10.

The optimal time to visit (and indeed, whether CPS is indicated at all) will be contingent on a number of factors, such as whether the injury is traumatic or not, the extent of other injuries and traumas following an accident, and the degree of acceptance of a SCI and its implications. It was notable that reaction to a SCI varied

from horror and despair to almost instant acceptance, even in this very small sample of people. Two of the participants, 'Matthew' and 'Dave' regarded their SCI as something to take in their stride, and as a consequence, although they enjoyed their relationship with the CPSO, and took advantage of his support to address practical issues, did not wish for the sort of psychological support that was valued by others such as Ronnie.

***I mean it was, it was funny with me, because I never, I never at any point found the experience traumatising. I never really found it hard to come to terms with. I kind of just got on with it straight away... And, you know, I've always liked challenges. You know, I've always been one to, to confront challenges positively and for me it was a challenge, you know. There was nothing, you know, that I wanted to do that somebody was going to tell me, well you can't actually do that anymore. I wanted to put it, look I can do this. So I had that kind of attitude towards it. And I know that I've been very fortunate in my life, and I think it would have been very ungrateful for me to all of a sudden say, start complaining about, you know, not being able to do this, not being able to do that, because I knew that, and I know that, my life is still probably a lot better than a lot of people that can walk.***

'Matthew', 37 years, non-traumatic injury, T10.

Matthew accepted that his own positive attitude was different to that of others who may have more of a struggle to come to terms with their injury, but was unusual in feeling that even for them CPS might be counterproductive.

***Well I think if, you know if you're battling to, to come to terms with that and you see somebody who's, you know, in the same situation as yourself and they're able to do it I can see why some people may find that even more disheartening, and they might, they may even, close up a bit more... I think everybody in their own time and their own manner will come to terms with their predicament.***

Matthew's reflections on the usefulness of CPS are not borne out by the evidence from this evaluation, nor from the evidence which identified the need to develop the role in the first place. However, his view that 'I don't know if this would be for everybody' would indicate that further investigation into who does and who does not benefit from CPS would be useful and could be helpful in targeting this resource appropriately. The CPSO himself reported a failed intervention with a patient who

was in extreme denial about her injury and for whom the visit of the CPSO in a wheelchair was experienced as extremely threatening. The latter instance however may have been a matter of inopportune timing of the support visit.

For Ronnie, by contrast, for whom coming to terms with his injury was an existential struggle, early CPS by a person in a wheelchair with a SCI represented a turning-point which he felt pointed in the direction of recovery and away from despair.

***You've got to have somebody like him, who can bound in, pull up beside your bed, and you're laid there like a lump of meat. Because I was there with a catheter on the front, I had the same on the back end; going into a bag, both ends was connected up. I had a pipe in here, and then I'm being fed up through the nose so you just lay there, and they're turning you, and somebody like him comes in and says look, I was like that after me operation, I've now got to this... if there hadn't been somebody like him, you would have got through, but you wouldn't have knowed what to do. It would have been a lot harder, because you wouldn't have had anyone to give any information. Nurses and that can give you information, but no one can tell you, hands on information like he can, or someone like him, you know.*** 'Ronnie', 63 years old, traumatic injury, C8.

Even those who were less positive about their own need for peer support acknowledged the value of knowing where help is available if needed.

***I guess it's always good to have the peace of mind that the help is there if you do need it.*** 'Matthew', 37 years, non-traumatic injury, T10.

## **Relatives' experience of CPS**

As discussed above in the section on the CPSO role, relatives of people with SCIs are important beneficiaries of CPS; perhaps in the early stages more so than the injured person. Bewildered and traumatised, it is often relatives who actively seek this support. Health professionals too are likely to recommend CPS for relatives. The main themes in relation to CPS emerging from interviews with relatives are;

- psychological support,
- understanding and empathy
- a role model of recovery and living with a SCI and explanations as to what to expect in the longer term;



- information and signposting;
- knowing someone is there if you need them.

Psychological support, understanding and empathy: a listening ear

Just as people with a SCI need a listening ear, so too do their relatives, particularly during a period of adjustment which is bewildering and frightening.

***But, it was just generally talking about the injury and that, and that sort of thing, he talked to us about his injuries, we told him about Ronnie's. 'Sally', wife of 'Ronnie', 63 years old, traumatic injury, C8.***

In the early days following a SCI, the injured person may be fighting for their life and extremely unwell, and relatives found CPS during this ambiguous period particularly helpful. The CPSO accepts this as part of his remit, and if he does not meet with relatives at the bedside, makes a point of phoning them.

***Because at that time, I mean Ronnie was quite, quite ill and we didn't know which way it was going to go. So he was quite a support we found. 'Sally', wife of 'Ronnie', 63 years old, traumatic injury, C8.***

***The support he gave me was very good... Because those early days are such a, are scary, type of thing. 'Maggie', mother of 'Wayne', not a participant in the study.***

As we have discussed in a previous section, patients with a SCI do not always receive optimal care in a DGH, and two of the participants in the study had been involved in litigation or complaints procedures with (different) Healthcare Trusts. To observe their relative enduring poor clinical care at a time of utmost trauma and stress was almost unbearable for relatives. While the CPSO emphasises that he is no more a lawyer than he is a healthcare professional, he is able to signpost relatives to the appropriate complaints procedures and to provide a safety valve by enabling them to 'offload' to him as an independent mentor.

***And I left a message for [CPSO name] and he actually phoned me back and we had a quite a long discussion about my concerns. And he was helpful in a very positive way. But it was just to offload, for me. It was great. I mean thank goodness there was someone out there who'd been through it. And I just said, I need somebody to talk to and that's for me, that was...Somebody that wasn't***

***to do with hospital or anything else or Charlie or whatever, just somebody, you know.*** 'Pauline', wife of 'Charlie', 53 years, non-traumatic injury, T2-T8.

A role-model of recovery and living with a SCI and explanations as to what to expect in the longer term

For relatives, as for the injured person, it was the fact that the CPSO had himself been through the experience of having a SCI that was particularly helpful. Most people had never met a wheelchair-user or someone with a SCI, and had no idea what to expect for the future.

***I mean I mean he sort of, he talked us through how it was for him, and explained lots of things about being in a wheelchair. I can't remember, sort of like getting in and out, we watched, we actually watched him get in and out of his car, and things like that, you know. We felt it was just because, because you've never been through it before, it was somebody, to talk to that had been through it. Which you know, as I say, it all helps because it's someone who's in the same position you are, but is that, so much further ahead and they can tell you a lot of things to look out for really..*** 'Sally', wife of 'Ronnie', 63 years old, traumatic injury, C8.

***Well, I can say my experience, I mean, was, thank goodness there was someone, out there who'd been through it.*** 'Pauline', wife of 'Charlie', 53 years, non-traumatic injury, T2-T8

***Yeah it was someone that was in that, situation, wheelchair that understood. I think, because he'd been through, a certain amount he had a lot of empathy with what was going on.*** 'Maggie', mother of 'Wayne', not a participant in the study.

***I think anyone who's, been in a wheelchair for a long time is useful to, um, it, it's just nice to know other people's experiences as well.*** 'Penny', wife of 'Dave', 59 years, non-traumatic injury, T10.

Relatives described their sense of reassurance when the CPSO explained what to expect at the SCIC.

Knowing someone is there if you need them.

As well as actual support provided by the CPSO, the very fact that he is available and approachable can create a climate of virtual or hypothetical support which can be just as tangible and helpful for relatives. Feeling they are not alone, that there is someone at the end of a phone even if they never need to call is an added value to the CPSO role which will not appear in any records or audit data, but needs emphasising here. The very existence of an approachable and accessible CPSO creates the 'peace of mind' for relatives described by 'Matthew' in the previous section as being a valuable aspect of the role for individuals with a SCI themselves.

***But at least you know somebody's there, don't you? That's the, I think that's the most important thing of all, to know that somebody's on the end of the phone.*** 'Penny', wife of 'Dave', 59 years, non-traumatic injury, T10.

***[CPSO name] went and spent a lot of time talking to Wayne. And he's been, I mean he's there at the end of the phone now if I need him. He's brilliant for that.*** 'Maggie', mother of 'Wayne', not a participant in the study.

### **Health Professionals' views on the CPS service**

The CPSOs had reported a small minority of healthcare units who appeared to be threatened by their presence and one of the therapists participating in the study confirmed that this had also been his experience in the past, though not in his current work-place.

***I think there's always a worry that an outside agency or somebody that's not medically trained will overstep the mark . But never, obviously, never from [CPSO name].*** 'Martin', Senior Physiotherapist, DGH1

By contrast, the healthcare professionals (HCPs) interviewed for this study were without exception overwhelmingly positive about the CPS service, perhaps largely because of that very professional diplomacy reported as an important part of the role by the CPSOs themselves , and confirmed in HCPs' own reports. Healthcare professionals reported a number of benefits of the CPS service;

- psychological support for patients and help with coming to terms with their injury and a role-model of living well with a SCI;
- support for relatives;

- a useful addition to the therapeutic team, providing a holistic, humanistic element to care;
- links, liaison, feedback and continuity with other healthcare units, for example between the SCIC and the DGH

### The timing of the visit

Health professionals also added insight to the timing issue; when is the best time for the CPSO to approach patients. The South West CPSO's approach to the problem of knowing about the existence of patients and of obtaining access to them was by painstakingly building up relationships with therapists. That this was successful and enabled patients to be approached at the optimal moment was fully supported by the accounts of the healthcare professionals. For the therapist quoted below, it is apparent that calling in the CPSO is now a routinely embedded practice, and that the therapist himself makes the judgement on the best time to call in the CPSO. It is a good example of the CPSO and healthcare professionals working cooperatively as a team.

***He would probably come when we've got the patient stable, settled, understanding the system and started to engage and the assessments are completed, so we know what we're looking at in relation to the underlying levels of spinal injury. Timing is critical because the bereavement process that quite often goes with, spinal injury, we have brought [CPSO] in, in all levels of the bereavement process if you like with injury, even into people that were in total denial in a way, blaming themselves, or others, for their injury. So, that again has been, we've gauged it and we've, explained it to [CPSO] on the phone, the situation and it's never done blind, we always have a discussion about what the situation is and, then he can also make an evaluation of whether it would be, a good time to come.*** 'Martin', Senior Physiotherapist, DGH1

The therapists in DGH2 expressed a commitment to making the decision about whether and when to call in the CPSO in consultation with the patient, and using their own judgement about whether the patient is ready for peer support and likely to benefit from it.

***But the way the system works really well for us, when we get a spinal cord injury patient in, when they become medically stable enough to be able to consent to actually talk to someone about that, then we will sometimes call [CPSO name] then, just to make him aware that there is a patient that is potentially, would like***

***to talk to him. But we would get the consent of the patient first before we make that call. And, generally that response has been very positive and, we have gauged it, based on the therapist as to when we call [CPSO name]. So depending on the sort of questions they're asking, and how, how they seem to be coping in terms of with their spinal injury at the time, depending on how receptive they are into, into that kind of approach.*** 'Emily', Physiotherapist, DGH2

The decision about whether to call in the CPSO was mediated by therapists' perceptions of how acceptable this would be. As discussed above, people's response to a spinal injury is highly variable, and some people never come to terms with it. If people are in denial about their SCI then a visit from a CPSO could potentially be adding insult to injury. The CPSO himself reported such an adverse experience, and the therapists in DGH2 were sensitive to this issue.

***You get a flavour from the patient of how far you can push things and how accepting they are at the time. The patients who do not want to even consider it, as I say, would be about one or two in ten I would say wouldn't consider it. ...Sometimes people don't accept that they have a spinal cord injury, so why would they want to see somebody from the Spinal Injuries Association? That would be the only reason I think?*** 'Sarah', Senior Therapist, DGH2

The therapists in the other unit on the other hand regarded the visit from the CPSO as an important resource for starting patients on the road to acceptance of their SCI, and while acknowledging that individual patients will differ in their response to injury, their practice was to call in the CPSO as soon as possible. In this unit patients were mainly from overseas, and tended to spend many months in the unit.

***Well we want to get them in as soon as possible. Because we try and start the acceptance process straight away. So as soon as these patients came in all the therapists get together and say look let's get the support worker in and see how it goes.*** 'Lianne', Occupational Therapist, Other Unit.

This strategy was not always successful, and as with the therapists in DGH2, staff on this unit had experienced patients who refused CPS as a result of not accepting that they would never be able to walk.

***I think that's why this particular patient wouldn't go and chat to him. Because***

***it was just too confronting.*** 'Lianne', Occupational Therapist, Other Unit.

The therapists in DGH 2 reported some difficulties with calling the CPSO in at the optimal time, because patients spent very little time on their units, remaining only for the period when they were being stabilised before moving on to a SCIC or rehabilitation in another unit.

***It's hard to get [CPSO] in at the right time because we're so rapid.***

'Sarah', Therapist, DGH2

Patients here could be on the unit for as little as 48 hours and would not be at a stage of acceptance of their injury to benefit greatly from a CPSO visit. Given this, for therapists in this unit it was support for relatives, liaison with the SCIC and their input into the education and informational development of staff which were the most highly valued aspects of the CPSO role. A further issue was that SCI admissions were extremely sporadic; sometimes there would be no SCI patients for a month, sometimes there would be four at once. This made any sort of regular visiting slot unfeasible. There was also an issue of high staff turnover and the use of bank nurses, creating a situation where the policy of calling in the CPSO was less robust, and patients could miss out, although this was more likely to happen when patients were admitted to other parts of the hospital rather than the rehabilitation unit.

Sarah described her own approach to when to call in the CPSO, a decision that was made very much in consultation with the patient.

***I let them usually read the information that there is , rather than introduce [CPSO name] straight away, in that there's somebody that could come and talk to them. And we sort of say you know, he's got much more experience, given that he's already a wheelchair user. He's had the experience of being in hospital. He's had the experience of being in [SCIC]. He can bring in a lot of that, expertise, particularly with this particular patient, the, the non traumatic type patient... but it's getting the right time to get him involved really. We don't force him on them. We couldn't because of the way that it works... And so it's very much a choice and people will say no I don't want to speak to anybody.*** 'Sarah', Senior Therapist, DGH2

The CPSO provides psychological support for patients and help with coming to terms with their injury and is a role model and example for living well with a SCI. He prepares people for transition to the SCIC.

The psychological support provided to patients at the appropriate stage of coming to terms with their injury was an element of the CPSO role which was highly regarded by HCPs. HCPs particularly noted the responsiveness and flexibility of the CPSOs, the tailored support they provided according to individuals' needs and stage of acceptance, their skill at establishing rapport, their ability to set patients on a forward path towards rehabilitation and their cultural sensitivity. HCPs also remarked upon the respect for boundaries which CPSOs showed in relation to the peer support/healthcare division.

***And then there also is the psychological support and advice side of things that he does for the patient, again which is important. He's seen someone last week for me and it, it very much gives them, not just psychological support, but also an idea of where they are where they're going and because [CPSO name] also has been through that himself, there's no better person really to explain it.*** 'Martin', Senior Physiotherapist, DGH1

***I think [CPSOs] have shown very good skill in developing rapport and meeting the patient where they're at. So they're flexible enough in order to know where that patient is at, to know the amount of information that is needed in order to allow that patient not to be too overwhelmed but also to be empowered. And it's that balance that I've never seen the boundaries crossed with either of them. At all.*** 'Barbara', Occupational Therapist, Other Unit

***I've never had a negative experience with [CPSO name] coming. It's always been a very positive one from all parties involved, and that input has been variable. Sometimes it's been only just a, here's my card, I'm here if you need to speak to somebody, or you want some information or just here is the number and the card, how you get hold of me. When you feel ready come and, I'm there. And sometimes it's been more of a lengthy chat.*** 'Emily', Physiotherapist, DGH2

***Oh it's been brilliant, absolutely brilliant. They've been so approachable and flexible and really um, been accommodating for our service. Our population***



***here is mainly Arabic patients so they've been very accommodating to the cultural needs of the client as well and coped very well with interpreters and all of those kind of things to [provide] best support for the patients. And they've given great advice they've given personal experiences which has really helped the patients and really opened them up and yeah, it's just been a fantastic service.*** 'Lianne', Occupational Therapist, Other Unit

A significant aspect of the psychological support provided by the CPSOs resided in the fact that they themselves had a SCI, were wheelchair users and were living high quality lives travelling the country and supporting others. This could provide patients with a direction of travel at a time when their life as they knew it could seem to be over. HCPs were well aware of the importance of this 'role-model' aspect of support, which they themselves could not provide.

***It's very easy for us to say things will get better but we're doing it with two legs and they wouldn't, don't necessarily have those legs, and sometimes no arms as well, and for them to actually see...that there is a life outside. It might be a different type of life, but it's no less quality, you know, no less a quality of life. It's just a different type of life. And I think that's what they need to get their head around to start with.*** 'Sarah', Senior Therapist, DGH2

***The service is very valuable. Not having it would have negatively affected therapy because of what they [the CPSOs] bring. It empowers patients to actually know someone in a wheelchair...It changes the mind-set.*** 'Barbara', Occupational Therapist, Other Unit.

***It's nice for the patient to have someone to talk to, who has been there. Even though it's different, through a different causative factor potentially, but it's still just as for them to ask questions, it's been really, really, really, really useful.*** 'Emily', Physiotherapist, DGH2

***Just to have that support of someone that had gone through a similar thing. And seeing, I think the most important thing, is seeing someone, you know, two or three years post or, ten, fifteen years post, and how well they can cope and how they can live a normal life, that, I think that's key. I know [CPSO name] recently demonstrated to one of our guys how to get in and out of a car and his injuries were quite high up and just incredible strength and ability to***

***manage with such a high spinal cord injury. So, yes, we, we found that very useful here.*** Lianne'. Occupational therapist, Other Unit.

There is no doubt that waking up to a new life with a SCI can be a terrifying experience. Effective management of what one of the SCIC staff called 'the fear factor of SCI' is an essential first step towards rehabilitation, and HCPs were keen to acknowledge the invaluable role CPS played in this. People's response to a SCI will be enormously variable, as was demonstrated in the report from the interviews with patients. HCPs acknowledged this as a factor affecting their patients' need for CPS. In one practitioner's experience people whose lifestyle had been fairly sedentary prior to the injury could be less traumatised than those who had lead a more physically active life, a hypothesis which might benefit from research. In contrast, those patients who were still grieving, who were angry or in denial about their injury were also unlikely to benefit from peer support at that time, although this was considered likely to change as the patient adjusted.

The member of the SCIC team pointed out that there is no other role that does what the CPSO does, which is to explain from experience what life is like after a spinal injury, a point of view also eloquently expressed by the therapists from non-specialist hospitals. Peer support can turn patients around and empower them to actively engage in their rehabilitation.

***That feeling of being helpless, that feeling of just being useless is pretty apparent sometimes, like 'I can't, what's the point, what's the point, I might as well give up because I can't use my arms, I can't use my legs, so I'm just going to, be a lump, just sat here, not doing anything'. And it's just like, well, there is hope. It's difficult because you don't want to say, you know, things are going to improve, but there is a life after spinal cord injury and I think that's what is difficult at that early, early stage to know quite what level they'll get to functionally. But certainly to give, just to remind them that there is, you know, there are people who are functioning and, it may not be what they're used to, but there actually is a life after that and obviously I'm not the person necessarily to be able to tell them, you know. I can't, I'm not in their position so I can't say well, you know, it's going to be a great life, because you speak to people with spinal cord injury and they have a hugely varying attitude to life as we all do in the normal population.*** 'Emily', Physiotherapist, DGH2

***But his role of supporting the patient and empowering them with knowledge and psychological support is, is one that he carries out the most, you know, to a... often when, patients see [CPSO name], they suddenly get an extra second wind in, and they're more, even more enthusiastic to engage with therapy.***

'Martin', Senior Physiotherapist, DGH1

***What I've found is that when you have somebody who's in a wheelchair living independently, that kind of takes their barriers down in accepting that person with, quote, their disability, allowing them to accept themselves with, quote, their disability.*** Barbara', Occupational Therapist, Other Unit.

The CPSO complements this sort of general psychological support by example with information about what to expect at the SCIC where they will continue their rehabilitation, and healthcare professionals regarded this aspect of the role highly because it was another aspect of having a SCI of which they had no experience themselves.

***I suppose the questions that I can't answer, certainly in terms of what it'll be like when you're, when I get, when they get up there [to the SCIC].*** 'Emily', Physiotherapist, DGH2

***And all of us would have his details. So if one of us gets referred a patient, or gets to hear about a patient, and we speak with them, then quite often we would refer to [CPSO name] for that patient if they had issues that we felt they needed to speak to them. In terms of sort of, you know, dealing with, just the, the whole dealing with being a, you know, a spinal cord injury patient, what they might expect when they go to [the SCIC].*** 'Sarah', Senior Therapist, DGH2

There are many misconceptions about the SCIC among SCI patients, which can put them off agreeing to referral, which will be detrimental to the quality of their rehabilitation.

According to a member of the SCIC staff team, there is evidence that patients have actually been advised not to go to a SCIC, despite the better outcomes such specialist units provide. It is therefore an important aspect of the CPSO's role to prepare people realistically for this important transition, and to address patients' more practical concerns as well.

#### The Community Peer Support Officer provides support for relatives

At the early stages of a SCI, when the patient is being stabilised and may be confused

by the after-effects of an operation or an accident, and by medications, it was relatives, also likely to be frightened and confused, who often benefited most from CPS. This was especially the case in DGH 2, where patients stayed a very short time, and less the case in the other unit in which a typical stay was likely to last months. Relatives will have a great many questions of both a practical and a personal nature, and there may not be the opportunity, or the inclination, to discuss these with busy clinical staff.

***Certainly, the other thing I've also done, in the past is contacted [CPSO name] regarding the parents of the injured person, because they equally, sometimes have a lot of questions that they want answered, or at least beginning to answer and he's been more than willing to try, and come and speak with the family. He's done that numerous times for us... So, in that respect even when the patient wasn't even aware of it just from the family's point of view, it was like, well, they obviously, would like to speak to somebody. And it's just having that link*** 'Emily', Physiotherapist, DGH2

As with patients, the opportunity to meet with, or just observe, a person with a SCI leading a full and active life, could itself provide reassurance that 'life goes on'. As a counterpoint to this, however, the CPSO could be a useful means of managing relatives' expectations in relation to the likelihood that the patient would regain the ability to walk.

***But [CPSO name] met with the family which was just as useful, because their expectations needed to be managed. Because they thought that he would walk. Just the level of understanding about spinal cord injury for some of the patients is just so obscure. So just starting with the basics and educating and managing, managing expectations is most important. He spent a lot of time with them. This particular guy that was in denial, he spent a lot of time with their family, and they had streams of questions and he answered them all, you know, and really managed their expectations, which was really helpful for us.*** 'Lianne', Occupational Therapist, Other Unit.

Relatives also had questions about the SCIC which the CPSOs could address.

**But for the family often, you know, accommodation, what's it like in terms of the families being up there [at the SCIC]; will I be able to stay up there. And they do ask.** 'Emily', Physiotherapist, DGH2

The Community Peer Support Worker is a useful addition to the multi-disciplinary team, providing a holistic, humanistic element to care

It was notable that HCPs in both the DGHs and the SCIC regarded the CPSO as an invaluable member of the therapeutic team, providing a dimension to care that health professionals cannot offer, by being able to focus on patients' emotional and psychological needs rather than clinical imperatives, and by being willing to share his own experiences. In a busy unit with a clinical focus and high patient turnover such as DGH2 the CPSO added an element of compassion to the care provided which might have otherwise not been possible. The members of staff at the SCIC, particularly the Acute Outreach Worker emphasised that the CPSO's role and their own were mutually beneficial and complementary, with mutual referral between them. The participant from DGH1 was quite explicit that he felt the service his unit provided would be impoverished without the input of the CPSO.

***I'd just like to say that if the service was actually disengaged, or not there, it would be a tremendous loss for us as well.*** 'Martin', Senior Physiotherapist, DGH1

***He's part, we feel he's an integral part of our team.*** 'Sarah', Senior Therapist, DGH2

***They're a valuable part of the team because I can teach somebody how to live in a wheelchair but I've never experienced it.*** 'Barbara', Occupational Therapist, Other Unit

***We see [CPSO name] as part of our team. It's invaluable to have someone who's been through a spinal system and come out positively.*** Member of staff at the SCIC

***So it's a holistic approach really and it also adds a human side into a quite often, what seems to be an overwhelming medical side, really.*** 'Martin', Senior Physiotherapist, DGH1

The Community Peer Support Worker facilitates links, liaison, feedback and continuity with other healthcare units and with the SIA

The CPSO is a channel of communication between different healthcare units which benefits patients, relatives and healthcare professionals and which would otherwise

not exist. For patients and relatives, he can prepare people for the SCIC and what to expect when they get there, as well as offering the reassurance that there will be a familiar face when they get there. The SW CPSO works closely with the SCIC, where he is regarded as an integral part of their team, and he makes frequent visits there. This ensures he can follow up people at the SCIC whom he has supported in the community, providing continuity and coherence to their rehabilitation experience. Healthcare professionals reported on the value of this for their patients.

***And I think a lot of the time it's having that face. It's not necessarily the information he can provide so much as, this is me, you can speak to me, I'm here, and, I will follow you up to [SCIC], and I think that's been quite nice in terms of having that continuity between here and there, so they know that there's a face that's going up there.*** 'Emily', Physiotherapist, DGH2

They also felt it was valuable for themselves as professionals and for the units.

***In relation to spinal injury care, [CPSO name] is often the link, between [the SCIC] and us.*** 'Martin', Senior Physiotherapist, DGH1

***Another useful aspect of [CPSO name's] work is that he provides a link with other units. We don't always get to hear about spinal cord injury patients in the community. That's an important part of [CPSO name's] role'*** Member of staff at the SCIC

***I think it has improved communication between the centres.*** 'Emily', Physiotherapist, DGH2

The two-way flow of communication between centres, and the link with the SIA was therefore an additional value reported by the healthcare professionals, ensuring they are up to date with information and news relevant to their role.

***It's more our links between each other which is, which is really important, than necessarily what he can necessarily offer me as such but it's certainly useful for, it's been a good link to have between [the SCIC] and ourselves about up and coming things that the Spinal Injury Association's doing as well, so just bringing forward research and things that they're doing at the moment.*** 'Emily', Physiotherapist, DGH2

A further benefit is that the CPSO's close links with the SCIC enable healthcare professionals to know how past patients are doing.

***It's been very nice to find out because he is still often in contact with some of our past patients because then he can, he often will feed back to us about, you know, with their consent obviously, how the patient's getting along, and that's been really nice . 'Emily', Physiotherapist, DGH2***

The Community Peer Support Worker contributes to raising standards through educational input, feeding back patients' experiences and sharing knowledge of research and resources

As well as being the main, or even the only channel of communication between SCIC servicing patients at different phases of their recovery and rehabilitation, and a channel to the resources of the SIA, HCPs felt that the CPSO made a major contribution to raising or maintaining standards in their individual units, providing a unique viewpoint in CPD and in-service training for and offering advice on the latest research and developments in relation to people with a SCI.

***His support for us is also good as well because he has an idea of what's going on, he's very knowledgeable of what's going on in around the country, so that's great for us as well. 'Martin', Senior Physiotherapist, DGH1***

***We have a, it's probably two monthly roughly at the moment, spinal cord injury focus group which meets to try and progress the service and try to streamline the service as much as possible, and he, and when possible he'll attend those. He does attend most of them. 'Emily', Physiotherapist, DGH2***

***So [CPSO name] worked well with that education programme. And then we also had [CPSO name] giving a couple of in-services to the OT department and the whole multi disciplinary team. 'Lianne', Occupational Therapist, Other Unit.***

***It's just been quite, it's just increased the knowledge that we have in terms of what's going on in the community, which has been quite good. It makes us more aware as I said about the research that's going on, and about current practice. 'Emily', Physiotherapist, DGH2***



**Sometimes he would point out there's new information or new books or literature around that might be useful for us to have a look at. 'Martin', Senior Physiotherapist, DGH1**

The participant in DGH1 had inherited a unit with a history of less than optimal care provision for people with SCIs, and was working hard to drive up standards. In this case the contribution of the CPSO, (who had himself had an unfortunate experience there well in the past) was particularly appreciated.

***In the past, you know there have been difficulties. And feedback from patients that he had met, and including his own stay here, we're not Odstock, we're not Stoke Mandeville, but the idea was to bring it up to an acceptable standard the best we could. And [CPSO name] has been part of that process. I've seen [CPSO name] as a key worker that would be greatly utilised in trying to achieve these standards and also a marker, about, you know, we're doing this and we're doing that and just talking things over with him. And I think he's very willing to feed back really objective information. It's very difficult to also to feed back, I guess, negative information to a unit, from [CPSO name's] point of view, but we were aware that our standards could be better. We had the problem with the unit at one time it didn't actually follow the...for most, many patients wouldn't be on this strict kind of systematic approach taken by the spinal injury units. And it's still very difficult because staff education for us is important. And the feedback of patients, of their treatment here, via [CPSO name] back to us is often a good indication, a mark of how well we're getting our spinal injury care.*** 'Martin', Senior Physiotherapist, DGH1

#### How could the CPS service be improved?

Participants in the evaluation were asked, as part of the in-depth interview, for suggestions as to how the service could be improved. The absence of large numbers of suggestions almost certainly bespeaks high levels of satisfaction with the service as it is. The following suggestions were received:

- There should be universal national coverage of the service
- CPSOs should have smaller catchment areas
- The service should be more vigorously promoted. An information sheet which could be provided for each newly diagnosed SCI patient was one suggestion.

- Nursing staff (as well as therapists) need to be more aware of the service
- There could be even more information, education and courses provided
- The service could be extended to include home visits for people newly discharged
- There needs to be a more effective and efficient system of referral
- Advocacy, or representation could be provided where there are issues of litigation
- Female CPSOs should be available to support women patients.

## **Discussion and Considerations for the Future**

This evaluation of the Community Peer Support Service has demonstrated that this is an invaluable service highly regarded by all its stakeholders; people with SCI, their relatives and healthcare professionals involved in their care and rehabilitation. For patients, support provided by an individual who has shared their experience of sustaining and living with a SCI can be an empowering experience and may be the first step in their journey towards coming to terms with their injury, rehabilitation and a new way of living. The emotional and psychological support and practical advice provided by the CPSO, and the model of successful living and a high quality of life he provides could potentially accelerate the rehabilitation process and was thought to mitigate some of the negative effects of this traumatic event. For their relatives, especially in the early days following injury, the CPSO may be the only person who can talk them through their anxieties and explain from personal experience what to expect, as well as providing practical advice and signposting to services, agencies and sources of funding which will enable successful rehabilitation. Healthcare professionals value the role for the liaison it provides between different sorts of healthcare units and for the contribution the CPSO makes to service improvement through his participation in education and planning.

The evaluation has a number of implications for the service as it expands towards increased national coverage. The difficult issue of the timing of the first visit is one which is addressed at present through a combination of the empathy, sensitivity and judgement of both CPSOs and HCPs. There are however considerable implications for both CPSOs and patients where this goes wrong and the visit is either too soon or not soon enough. As the service expands, it would seem advisable to give some consideration to the possibility of producing some sort of guidance to both support

officers and healthcare professionals which could inform the decision on when to visit. The possibility that there is an optimal time to visit a newly injured patient should be considered and explored. However this raises further areas of difficulty relating to whether, given the large geographical areas covered by the CPSOs and the problematic situation regarding identification of patients, visits could be planned to coincide with this.

Referral and access to people in DGHs was an area of some difficulty for the CPSOs. At present simply knowing there is a patient in need of support in a DGH depends on quite a fragile system based on personal relationships and trust between individual CPSOs and individual HCPs. Inevitably patients will be missed and lose out on the opportunity for peer support where these relationships have not been successfully formed, and where there are changes of staff. There is a need for a more formalised system of referral, ideally involving written protocols and pathways for the management of people with SCI in DGHs. This would suggest liaison with Acute Trusts at a higher level to ensure contacting the SIA is built into integrated care pathways and thus rendered accessible to clinical audit to identify ruptures and gaps in the referral process. In addition, the suggestion from participants that a written information sheet be provided for all newly diagnosed SCI patients and their relatives would provide a further means by which people could be prevented from falling through the net. Such a leaflet could advise families to request that staff contact the SIA to inform them when the patient has been admitted, as well as providing SIA contact information to enable relatives to do this if necessary.

The evaluation suggested that not everyone with a SCI will benefit from CPS, and that need for such support is likely to relate to an individual's acceptance of and attitude to their injury. Further research into the factors which affect this need is indicated. This additional knowledge would allow more efficient targeting of this valuable but scarce resource.

Another need likely to change as the service expands is support for the CPSOs. At present this works well but relies heavily on personal support from the manager and informal support from peers. However it is worth considering the possibility of providing a more structured system of support when there are more officers in post. The suggestion from Chatroom Plus participants of a designated Chatroom forum or

regular Chatroom Plus session would seem worth considering, with perhaps some regular face-to-face 'offloading' sessions structured into the job description. There are existing models of peer supervision which are available to guide this process.

The issue of managing the sometimes ambiguous boundaries between peer support and clinical management is another area which may benefit from clearer guidelines as the service expands. Both the CPSOs who participated in this evaluation had observed instances of what they perceived to be poor clinical practice which they felt were likely to impede rehabilitation and compromise patients' ability to achieve a good quality of life. This is a difficult area which is likely to become more so as additional officers are recruited, and one which would benefit from more formal guidelines as to how this might be managed. Another aspect of the CPSO role which relates to clinical/lay boundaries is that aspect of the role which is concerned with managing patients' hopes and expectations of regaining the ability to walk. It is not unusual for the CPSO to be drawn into discussions of this nature. The SIA policy, however, is that the CPS service should not offer medical advice, recognising that determining a prognosis is ultimately the responsibility of the medical staff.

## **Conclusions**

This evaluation of the Spinal Injuries Association's Pilot Community Peer Support Service provides evidence of the wide ranging benefits this service offers both to those affected by SCI and the health professionals involved in their management. Consideration now needs to be made with regard to establishing more formalised guidance for CPSO's to optimise the effectiveness of this rapidly evolving service. Further research is indicated in determining important factors such as the optimal timing of referral, and in identifying who benefits most from this service, to allow more efficient targeting of this valuable but scarce resource.

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## NOTES

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# About **sia**<sup>///</sup>

spinal injuries  
association

The Spinal Injuries Association (SIA) is the national user-led organisation for spinal cord injured people, which provides support and assistance to the estimated 40,000 people in the UK who experience this devastating injury which can result in partial or total paralysis.

The Association provides a range of services to support the injured person and his or her family. Through the sharing of information and campaigning for change, SIA provides lifelong support to anyone affected by spinal cord injury from the moment of injury and beyond. The Association plays a pivotal role in assisting paralysed people to rebuild full and active lives in line with their ethos that life needn't stop when you're paralysed.

Our current activities include:

- Freephone Advice Line providing lifelong support on all topics related to living with paralysis
- Workwise Service supporting spinal cord injured people into work, education or volunteering
- SIA Academy which provides a range of training courses for spinal cord injured people on topics such as parenthood, care funding and self advocacy
- Peer Advice Service and Community Peer Support Service which provides peer support to spinal cord injured people being treated in Spinal Injury Centres and District General Hospitals
- Interactive website including a chatroom and message board where spinal cord injured people can share experiences
- The production of high quality information resources including a bi-monthly magazine and online news bulletin



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