



All Party Parliamentary Group on Spinal Cord Injury

To look at specific issues being faced by Spinal Cord Injury (SCI) people, particularly relating to medical treatment, care, support and developments in treatments as, well as social care and wider issues that affect the lives of SCI people.

All Party Parliamentary Group on Spinal Cord Injury AGM and Meeting – 23rd October 2018

Attendees

Ian Lucas MP (Chair)
Baroness Masham of Ilton
Lord Murphy of Torfaen
Graham Jones MP
Albert Owen MP

Owen Paterson MP
Mark Tami MP
Nick Thomas-Symonds MP

1. Apologies for Absence.

Apologies were noted for Baroness Wilkins and Dan Burden.

2. AGM and Election of Officers.

Ian Lucas welcomed everyone to the meeting and thanked them for attending before moving to the formal Election of Officers. Baroness Masham proposed that Ian Lucas remain as Chair and he was duly re-elected, there being no other nominations. All the existing officers previously in post had agreed to continue and they were reappointed. These appointments were collectively approved and the Election of Officers for the APPG was concluded.

3. Bed Closures and Winter Bed Pressures.

Dave Bracher, Campaigns Manager at the Spinal Injuries Association (SIA), gave an update on the current pressures experienced by Spinal Centres (SCICs). This update was not focused on any one Centre; the data collected by SIA via a Freedom of Information request and information also obtained from the National SCI Database clearly demonstrates that all the SCICs are under huge pressure and are losing a significant number of bed days to non-SCI people as a result of winter pressures.

Given the wealth of evidence about how much better a SCI person's long-term life opportunities are if they rehab in a SCIC, both from the perspective of interaction with specialist staff and also engagement with specialist charities like SIA and Back Up, this is a major concern for SIA. As a charity, SIA recognises that models of care may have to develop and change over time, but we will continue to advocate for all SCI people to have the opportunity to attend a specialist SCIC and benefit from the rehab opportunities they offer.

SIA are very concerned that a combination of a shortage of specialist staff in SCICs and losing beds due to wider winter bed pressures could amount to the 'thin end of the wedge'. These beds may not come back to SCIC use in the longer term. The Service Review carried out by NHS England identified that if the SCICs were all operating at the optimum level of capacity, an additional 54 beds would be needed in the system to cope with the demand from newly injured people and readmissions for existing injuries.

At a national level it has been recognised that more beds are needed, but at a local level beds are being lost. SCICs are under extreme pressure and longer-term thinking is required to support the fact that SCI people are living longer with their injury. Staffing is key to this, as is ensuring resources are used in the best way, for example by SCI people not always coming into the SCIC every time something goes wrong, but also utilising local services where possible. This more innovative approach will then free up the SCIC beds for those that need them most.

The pressure being experienced at SCICs and the gradual erosion of bed availability are causing grave concern to SIA, particularly against the backdrop of the acceptance that more beds are needed in the SCIC system. As winter bed pressures turn into year-round bed pressures in the NHS, SIA will continue to advocate for our members and push to ensure SCIC beds and service provision is protected. We would welcome any further ideas or suggestions around ways of ensuring our concerns are heard at the right level, whilst also being able to act as a 'critical friend' to the SCICs as they develop their service delivery for SCI people.

Ian Lucas then invited further comments or questions from the APPG observers. Concern was expressed about the lack of wider knowledge about bed losses in SCICs and the serious impact this has on all SCI people. It was agreed that commissioning beds is important, but that if there aren't the appropriate staff to support this, then the beds won't be filled. Delayed discharges were highlighted as a significant barrier, as was the lack of adequate social care and significantly reduced staffing numbers in the care sector. Many nursing homes simply don't have the specialist skills required to care for SCI people, and a nursing home isn't an appropriate environment for younger SCI people anyway. Finally, the use of step-down centres for rehabilitation was discussed and highlighted as a good idea.

Ian agreed that these were integrated, challenging and complex issues and consideration will need to be given about the best ways of exerting pressure and highlighting the issues. He thanked everyone for their input into the discussion and asked that any further comment or examples of good practice for wider circulation should be sent to Dave at SIA.

4. SCI Perspective from the National Spinal Injuries Centre (NSIC), Stoke Mandeville.

Ian then invited Dr Allison Graham, Consultant Physician in Spinal Cord Injury and Stuart Coalwood, General Manager at NSIC to provide their perspective.

Allison started by stating that it felt like everyone in the room was on the same page on many of the issues facing SCICs. She went on to say that now a days pressures are not just winter pressures – they are all year round. There was a need to discuss why the NSIC hasn't got all their beds open, what can be done and how APPG members can help.

NSIC has internal pressures within the centre which are not unique, but are magnified in a small specialty in an expensive area of the country. There is difficulty in recruiting appropriate trained nursing staff and medical staff; knowing that there will be a career for you if you commit to a specialty is important, but sadly is less certain in SCI than it is in others. NSIC has looked to nurse practitioners from Europe and physician associates to provide dedicated staff, as they want to grow their own specialty team and need to get it right first time. It needs to be a speciality to attract and retain personnel, including what could be called the 'super specialties' e.g. paediatrics and care for those with domiciliary ventilation and specialist pressure ulcer care.

Improved staffing must come with more efficient bed usage, which would increase available beds no matter how many are funded at any given time. Allowing earlier admission and improved readmissions with better outcomes is vital – NSIC wants every bed day to count, which is why NSIC are looking at how other specialities interact with SCI people to best effect.

Health is not the only factor that influences length of stay. It is also housing, social care and Continuing Healthcare. Without a fully integrated service enabling the person with a SCI to move in the right direction towards home and their community with the correct level of support and opportunity to implement the learned rehabilitation skills, NSIC and the other SCI Centres will remain inefficient and be forever hungry for resources. Allison finished by stating that NSIC feels very strongly that they can be bold and influence many internal factors, but also need assistance and support for the whole picture of living with a SCI after discharge from the Spinal Centre.

Ian asked a question about staff shortages, and Allison confirmed that the issue was about a shortage of appropriately skilled people. Ian expressed his great frustration that, as a politician, he regularly hears about skilled jobs available that can't be filled. Allison highlighted that it is also about looking at what can be done differently and using different models of care, including from abroad. It was also questioned if staff have the same pride as they may have had in the past in

being a spinal specialist nurse now that SCI is categorised as a 'general rehab' role, and about ways of helping to develop this, for example via staff recognition schemes.

Allison reinforced the issue that it is very difficult to recruit nursing staff at the correctly graded job and that it is very difficult to get UK staff to come and work in spinal cord injury. For the right people, there's excellent progress available, but getting people in initially and then retaining them remains difficult – SCI is physically and mentally a difficult area to work in. NSIC has recruited from all over the world, but retention remains difficult, especially given the proximity of NSIC to London and the wider opportunities available there.

Stuart Coalwood noted that part of the reason why NSIC has had to try and recruit from abroad is because people in the UK wanting to work in spinal cord injury simply don't exist. He went on to say that for the generations coming through now, a career for life is a thing of the past and not how they think. He concluded by pointing out that the financial challenges facing Trusts will get increasingly difficult, and so we need to focus on what can be influenced and fixed.

Ian observed that as someone outside the system, he felt staff working in Spinal Centres did an incredible and often unheralded job, which Owen Paterson echoed. He thanked Allison and Stuart for their contribution to the meeting.

5. Update on NHS Continuing Healthcare (CHC).

Dave Bracher explained that the Equality and Human Rights Commission (EHRC) had sent 'Letters Before Action' to 13 Clinical Commissioning Groups (CCGs), threatening Judicial Review over concerns about their blanket CHC policies which placed arbitrary caps on funding and failed to consider the specific needs of individual patients. The EHRC felt this amounted to a serious breach of the Human Rights Act, the Public Sector Equality Duty and the Department of Health and Social Care's own CHC framework.

The CCG's have all since demonstrated that they are in the process of revising their policies, meaning further legal action is not necessary at this time. The EHRC has asked to see the revised policies to ensure they are lawful. Dave asked that if anyone becomes aware of a CCG that may not be playing 'by the rules', then they contact SIA so they can investigate.

The revised and updated National Framework for CHC has now come into force. There have been some positive developments with the revised Framework, but sadly what hasn't been reviewed are the Assessment Tools. These remain a concern for SIA in the way they are used and interpreted, and an area which SIA will continue to push for changes in, especially as they are used against the backdrop of the acute funding pressures that the CCG's are under.

Finally, it was noted at the last APPG meeting that it would be helpful to invite Caroline Dinenage MP, Minister of State for Care, to a future APPG meeting to discuss the issues with CHC. Sadly, and very disappointingly, her office has declined a direct request from Ian and also from SIA to attend the APPG, but SIA are continuing to push for a face-to-face meeting.

6. AOB

There was no further business; Ian thanked everyone for attending and for their contribution to a very informative meeting.

7. Date of Next Meeting

The next meeting will be held in 2019 and the date will be confirmed in due course.