Minutes of the APPG for Spinal Injuries

Spinal Injuries APPG – Inquiry Session 1: Why Do We Need a National Strategy for Spinal Injuries?

Date: 3 June 2025
Location: Portcullis House

Chair: Andy McDonald MP, Chair of the APPG for Spinal Cord Injuries

1. Opening Remarks

- Andy McDonald MP welcomed attendees and outlined the inquiry's purpose: to build a National Strategy for Spinal Injuries through a series of six evidence-gathering sessions.
- The inquiry aims to identify systemic gaps in spinal cord injury (SCI) care, including rehabilitation, workforce, patient experience, community reintegration, and research coordination.
- This first session focused on establishing the rationale for a national strategy, highlighting fragmentation in care, missed prevention, and regional inequalities.

2. Evidence from Witnesses

2.1 Mark Ridler – Spinal Injuries Association (SIA)

- Identified fragmentation across the SCI care pathway: inconsistent rehabilitation influenced by geography and socio-economic status, fear and lack of training in non-specialist settings, and poor transition from specialist to community care.
- Highlighted stark regional disparities in access to specialist care, employment, and wheelchair provision.
- A national strategy is critical to:
    - Provide a clear vision and system-wide planning.
    - Improve patient safety, reduce health inequalities, and enhance research.
    - Embed the patient voice and formalise third-sector roles.
- Noted the "cliff edge" effect at discharge, with key blocks being housing, wheelchair provision, work, and care.
- Emphasised lack of mandatory frameworks leads to postcode lotteries; only 2 of 42 Integrated Care Boards have SCI-specific policies.

- Raised the absence of a national SCI registry and gaps in preventative care and psychological support.

2.2 Dr. Simon Shaw – Clinical Director, National Spinal Injuries Centre

- Stressed SCI care is under-resourced and fragmented, particularly in primary care and community services.
- Pointed to delayed admissions, bed shortages, and inadequate discharge processes due to social care funding gaps.
- Highlighted major clinical gaps: pressure sore treatment, specialist surgeries, basic nursing care, and psychological services.
- Identified workforce shortages and lack of a national strategy or registry stalling progress and research.
- Noted significant regional inequities in outreach and bed capacity, plus poor collaboration across specialties (respiratory, urology, etc.).
- Called for modernisation of service specifications, investment in outreach and research infrastructure, and international benchmarking.

2.3 Brian Carlin – CEO, Aspire

- Shared findings on serious gaps in patient education and coordination.
- Aspire introduced patient admin roles, national conferences, and longitudinal patient follow-ups to address education deficits.
- Found that 1 in 5 patients are discharged to care homes unsuitable for rehabilitation; only 10% go to accessible housing.
- Linked poor housing outcomes to high mental health issues and secondary complications requiring readmission.
- Aspire provides 57 accessible transitional properties enabling independent living and return to work.
- Identified lack of accessible housing as the main discharge delay and barrier for 27 years, with no NHS or local authority ownership, shifting burden onto charities.

3. Chair’s Closing Remarks (Andy McDonald MP)

- Expressed being staggered by the scale of unmet need, lack of data, and inconsistent discharge pathways.
- Highlighted urgent need for government attention amid wider disability employment initiatives.
- Noted inefficiencies lead to higher public costs elsewhere.
- Confirmed this session’s evidence would be written up and form a foundation for a ministerial briefing and future Westminster Hall debate.
- Acknowledged shocking reports such as people being denied essential bowel care.
- Thanked all witnesses and participants for a strong and impactful session.

4. Additional Notes

- Dharshana Sridhar (SIA) requested copies of the Aspire study and details of the GIRFT programme examples mentioned, to inform further inquiry questions and evidence sessions.

5. Outcomes and Recommendations

Outcomes

- Clear consensus that a National Strategy for Spinal Injuries is urgently needed to address fragmentation, inequity, and resource shortfalls.
- Evidence demonstrated substantial regional disparities in care quality and outcomes.
- Identified critical gaps in education, discharge planning, housing, workforce, and clinical service provision.
- Confirmed that without national coordination, patients experience preventable complications, delays, and reduced independence.

Recommendations

1. **Develop a National SCI Patient Registry** to accurately capture prevalence, demand, and outcomes.
2. **Create a coherent National Strategy** with clear goals, national standards, and accountability mechanisms across the care pathway.
3. **Modernise NHS Service Specifications** to include lifelong care, specialist surgeries, psychological services, and outreach models.
4. **Invest in Workforce Training and Capacity** at specialist centres, community services, and primary care to reduce knowledge gaps.
5. **Ensure Integrated Discharge Planning and Accessible Housing**, with clear responsibility for NHS and local authorities to prevent bed blocking and promote independence.
6. **Formalise and Fund Third-Sector Roles** (e.g., Aspire and SIA) within the strategy to provide patient education and community support.
7. **Address Regional Inequities** by mandating national frameworks and ensuring equitable resource distribution.
8. **Enhance Cross-Specialty Collaboration** among respiratory, urology, mental health, and other relevant services.
9. **Benchmark UK Services Against International Best Practice** to improve innovation and research capacity.
10. **Prepare for a Westminster Hall Debate** to raise awareness and garner wider parliamentary support.

Next Session: Focus on Rehabilitation, chaired by Gill Furniss MP, with NHS specialists providing evidence.

Minutes prepared by the APPG Secretariat