Supporting long term health & wellbeing after spinal cord injury

Dr. Éimear Smith,

Consultant in Rehabilitation Medicine, National Rehabilitation &
Mater Misericordiae University Hospitals, Dublin

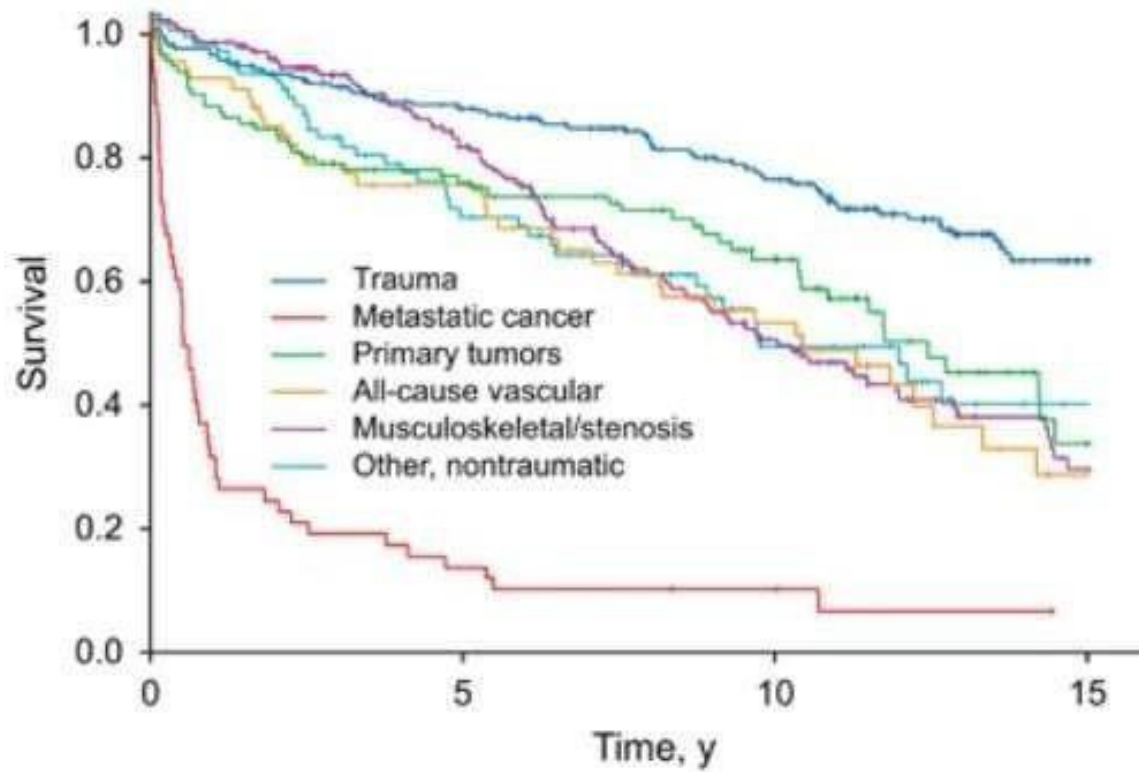Associate Clinical Professor UCD School of Medicine

- Patient's perspective
- Professionals' perspectives
- Systems challenges
- Changing delivery of healthcare

Life expectancy by attained age for people with traumatic SCI in comparison to the general population
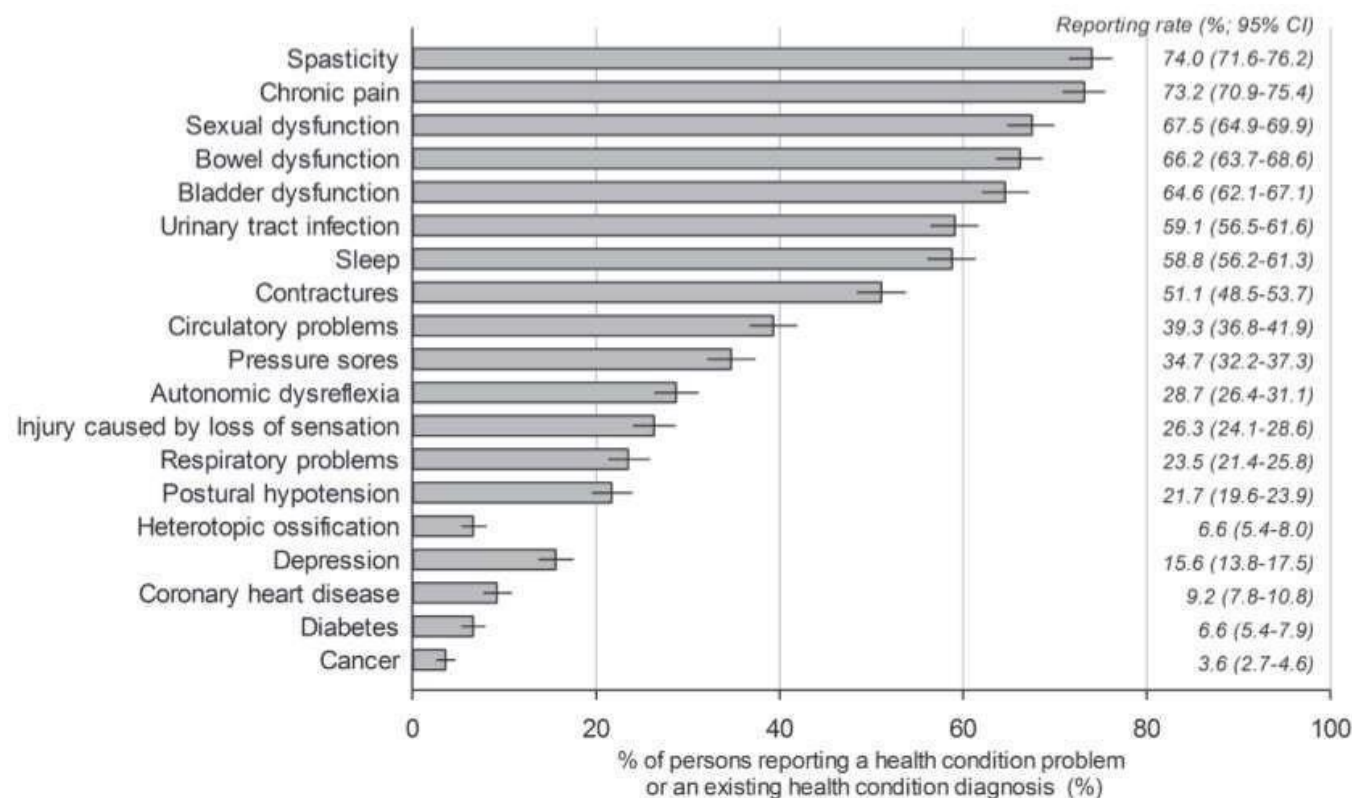
Age	C1–4 ABC (%)	C5–8 ABC (%)	T1–S5 ABC (%)	All D (%)
25	69	74	88	97
35	68	72	88	97
45	67	68	88	97
55	65	66	89	97
65	64	65	91	96

Abbreviation: SCI, spinal cord injury.

Middleton JW *et al.*, 2012

Survival for all SCI aetiologies

Hatch BB *et al.*, 2017

Prevalence of reported health conditions

Reporting rate (%; 95% CI)

Condition	Reporting rate (%; 95% CI)
Spasticity	74.0 (71.6-76.2)
Chronic pain	73.2 (70.9-75.4)
Sexual dysfunction	67.5 (64.9-69.9)
Bowel dysfunction	66.2 (63.7-68.6)
Bladder dysfunction	64.6 (62.1-67.1)
Urinary tract infection	59.1 (56.5-61.6)
Sleep	58.8 (56.2-61.3)
Contractures	51.1 (48.5-53.7)
Circulatory problems	39.3 (36.8-41.9)
Pressure sores	34.7 (32.2-37.3)
Autonomic dysreflexia	28.7 (26.4-31.1)
Injury caused by loss of sensation	26.3 (24.1-28.6)
Respiratory problems	23.5 (21.4-25.8)
Postural hypotension	21.7 (19.6-23.9)
Heterotopic ossification	6.6 (5.4-8.0)
Depression	15.6 (13.8-17.5)
Coronary heart disease	9.2 (7.8-10.8)
Diabetes	6.6 (5.4-7.9)
Cancer	3.6 (2.7-4.6)

% of persons reporting a health condition problem
or an existing health condition diagnosis (%)

Brinkhoff MWG *et al.*, 2016

Changes in secondary health conditions from rehabilitation to community settings

Glisic M *et al.*, 2024
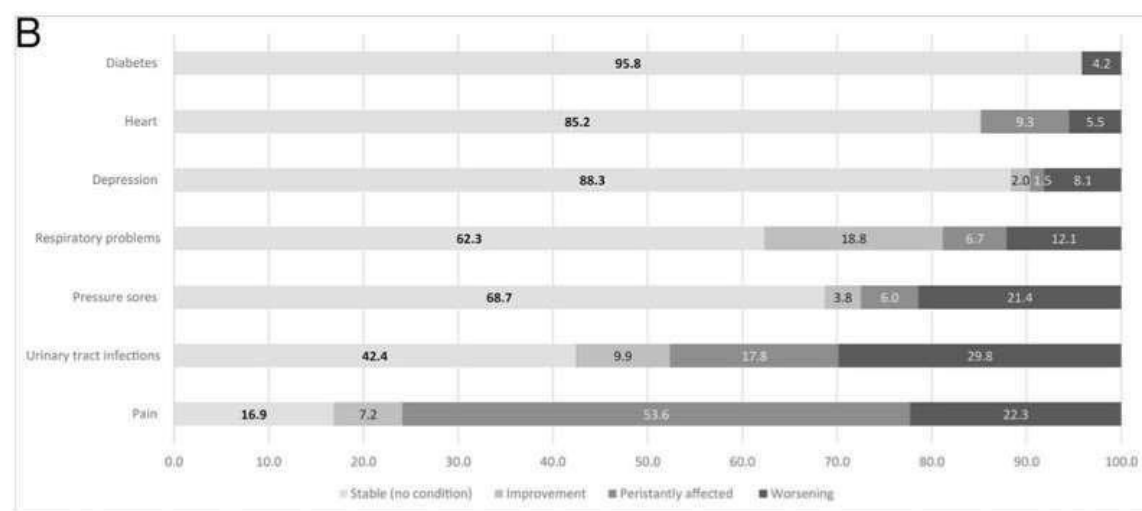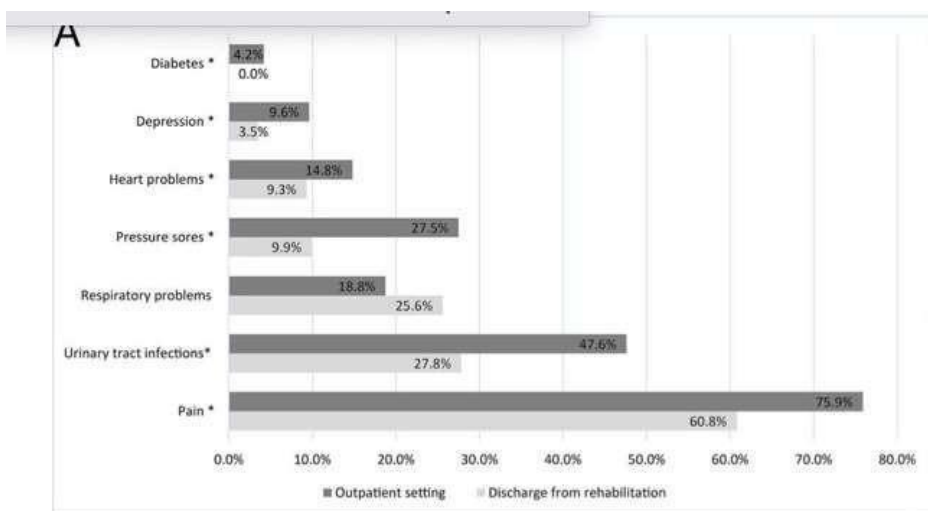
Causes of hospital readmissions

Franceschini M *et al.*, 2023
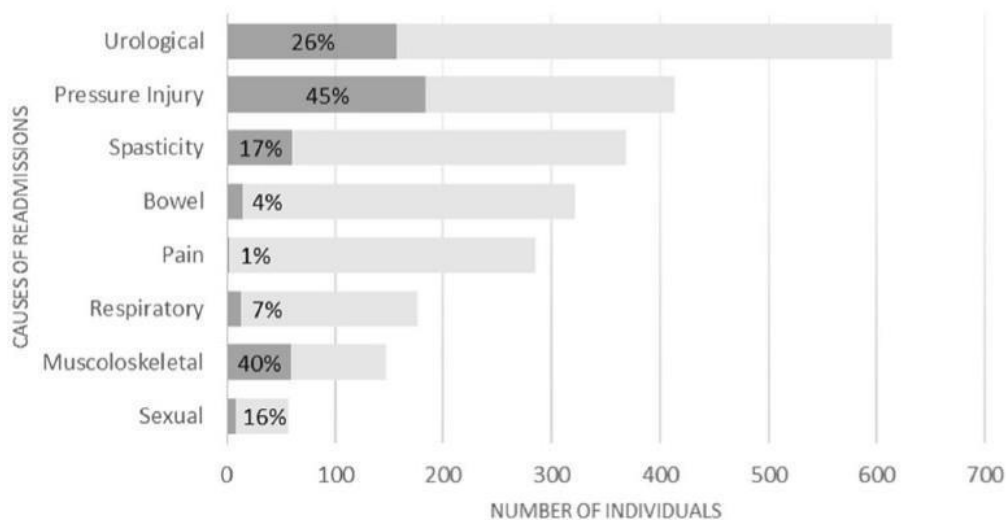
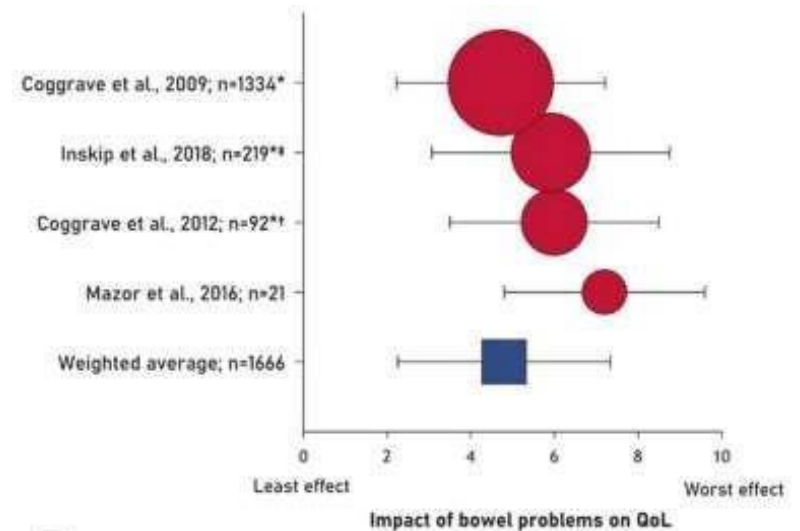| Cause of admission [2]	
Pressure ulcer	24 (13.3)
UTI	32 (17.7)
Respiratory infection	20 (11.1)
Fracture	22 (12.2)
Other urological causes	14 (7.7)
Autonomic dysregulation	4 (2.2)
Other infection	26 (14.4)
Unspecified health condition #	39 (21.6)

Jedrusik AM *et al.*, 2023

Neurogenic bowel problems

Sober-Williams EK *et al*., 2024

Neurogenic bowel & quality of life

- Faecal incontinence & time to do bowel care (constipation to a lesser extent) impacted negatively on quality of life

- Symptomatic AD negative impact on QoL

- Independence with bowel care: higher physical health related QoL (SF-12)

- Priorities: reduce time

    maximise independence
    reduce risk of faecal incontinence
    reduce risk of constipation
    reduce risk of AD

Sober-Williams EK *et al.*, 2024

Bowel management options

Transanal irrigation

What the evidence says:

Improvements in:

      incontinence

      constipation

      time spent on bowel care

      autonomic symptoms

      QoL

What we see:

Takes time

Getting it right early on is important

Still need aperients

A significant no. of users stop

Ethans K *et al.*, 2024

Colostomy

What the evidence says:

Improved QoL

  <time consuming

  <reliance on care giver C >independence

  less constipation

  reduced AD incidence

  reduced perianal complications

  easier PI management

What we see:

  The patient has to want it!

  Aperients still necessary

  Occasionally no change in colonic transit

Neurogenic bladder problems

Neurogenic bladder research group registry

Neurogenic bladder symptom score C QoL

- Poorest in those who voided

- Then SICs

- Better for in-dwelling catheter/those who have had surgical procedure

Dilemma!

Myers JB *et al.*, 2019

Urinary Tract Infections

- Patient reported* UTI frequency in previous year

  0 UTI = 26%   1 - 3 UTI = 46%

  4 - 6 UTI = 15%   >6 UTI = 13%

- More patient reported UTI, greater impact on QoL based on 4 questions:
  UTI limited daily activities   Increase in spasms due to UTI

  UTI would not go away   Avoided going out due to UTI

  Theisen KM *et al.*, 2020

- Patients predict UTI with around 60% accuracy   Linsenmeyer TA *et al.*, 2003

- Definition of UTI: symptoms + WCC >10/hpf C >10^4 CFUs per ml Kennelly *et al.*, 2019

Spasticity – the problem

- Early onset spasticity within weeks (Modified Ashworth Score ≥ 3) predictive of spasticity @ 6/12   Yokota K *et al.*, 2024

- Problematic spasticity at discharge - more likely to require medication & have limitations to function at 1/2/5 yrs   Holtz KA *et al.*, 2017

Spasticity – the solution?

- No physiotherapy interventions have been proven effective de A Barbosa PHF *et al.*, 2021

- Oral baclofen
  - 1 point change in MAS
  - minimal change in penn spasm frequency scale
  - no improvement in walking (even when spasticity was reduced)
- Intrathecal baclofen
  - 2.1 point reduction in MAS
  - Improved ADLs C walking
- NB side effect profile: muscle weakness, fatigue   Dietz N *et al.*, 2023

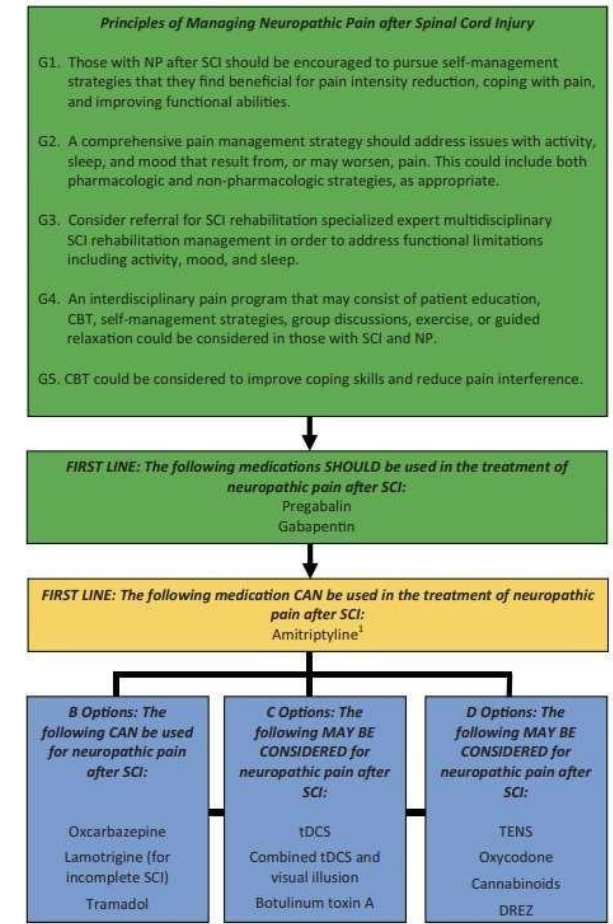- Few good quality studies on botulinum toxin in SCI

Neuropathic pain

- Point prevalence 53%
- Irish context: 36% reported neuropathic pain
                    total pain interference 3.8/6

Table 3. Comparison of Nociceptive Pain and Neuropathic Pain Presentations

Category Parametric Test	N	Nociceptive Pain Mean (SD)	N	Neuropathic pain Mean (SD)	*t* statistic	P-value
Numeric Rating Scale	201	5.57 (2.2)	232	6.91 (2.1)	6.538	<0.001
No. of pain presentations	183	2.29 (1.1)	204	3.16 (1.3)	6.924	0.002
Days with pain past week.	196	4.44 (2.4)	225	5.12 (2.1)	3.03	<0.001
No. of treatments used in the past 6 months.						
Medications	201	1.56 (1.5)	235	2.43 (1.9)	5.21	<0.001
Non-pharmacological Rxs	199	0.91 (1.2)	232	1.50 (1.7)	4.094	<0.001
Exercise therapies	203	1.51 (1.3)	234	2.15 (1.6)	4.524	0.003
No. of HCPs seen in past 6 months.	202	0.99 (1.1)	233	1.46 (1.4)	3.738	<0.001
Non-Parametric Test	N	Median (Range)	N	Median (Range)	*U* statistic	P-value
Pain Interference						
LSF Interference	197	2.33 (1–33)	234	3.67 (0–6)	15547,	<0.001
AMS Interference	234	3.00 (1–6)	232	4.00 (1–6)	15115,	<0.001
Total Interference	199	2.67 (1–19)	234	3.83 (0–21.2)	15451	<0.001

Burke D *et al.*, 2017, 2019

Neuropathic pain - interventions

Principles of Managing Neuropathic Pain after Spinal Cord Injury

G1. Those with NP after SCI should be encouraged to pursue self-management strategies that they find beneficial for pain intensity reduction, coping with pain, and improving functional abilities.

G2. A comprehensive pain management strategy should address issues with activity, sleep, and mood that result from, or may worsen, pain. This could include both pharmacologic and non-pharmacologic strategies, as appropriate.

G3. Consider referral for SCI rehabilitation specialized expert multidisciplinary SCI rehabilitation management in order to address functional limitations including activity, mood, and sleep.

G4. An interdisciplinary pain program that may consist of patient education, CBT, self-management strategies, group discussions, exercise, or guided relaxation could be considered in those with SCI and NP.

G5. CBT could be considered to improve coping skills and reduce pain interference.

FIRST LINE: The following medications SHOULD be used in the treatment of neuropathic pain after SCI:
Pregabalin
Gabapentin

FIRST LINE: The following medication CAN be used in the treatment of neuropathic pain after SCI:
Amitriptyline[1]

B Options: The following CAN be used for neuropathic pain after SCI:	C Options: The following MAY BE CONSIDERED for neuropathic pain after SCI:	D Options: The following MAY BE CONSIDERED for neuropathic pain after SCI:
Oxcarbazepine	tDCS	TENS
Lamotrigine (for incomplete SCI)	Combined tDCS and visual illusion	Oxycodone
Tramadol	Botulinum toxin A	Cannabinoids
		DREZ

Loh E *et al.*, 2022

Table 4 Perceived effect of currently used non-pharmacological treatments.

| N (%)	Perceived effect*			
	−	+/−	+	++
Conventional treatments				
Massage (n = 27)	1 (3.7)	0	21 (77.8)	5 (18.5)
Physiotherapy (n = 107)	0	7 (6.7)	62 (59.6)	35 (33.7)
Physical exercise (n = 64)	4 (6.3)	3 (4.6)	34 (56.7)	19 (31.7)
TENS (n = 10)	0	1 (11.1)	7 (77.8)	1 (11.1)
CAM treatments				
Homeopathy (n = 5)	0	0	3 (60.0)	2 (40.0)
Medicinal cannabis (n = 8)	0	1 (12.5)	7 (87.5)	0
Non-medicinal cannabis (n = 9)	0	1 (11.1)	4 (44.4)	4 (44.4)
Supplements (n = 18)	0	8 (53.3)	7 (46.7)	0

Abbreviation: TENS, Transcutaneous Electrical Nerve Stimulation; CBP, Cognitive Behavioral Program.
* −: negative effect +/−: no effect, +: moderate effect, ++: good or excellent effect.

Crul TC *et al.*, 2025

Neuropathic pain - interventions

Internet delivered pain management programme: improvements in impact of pain on every day life, depression & anxiety, SWL Dear BF *et al.*, 2018
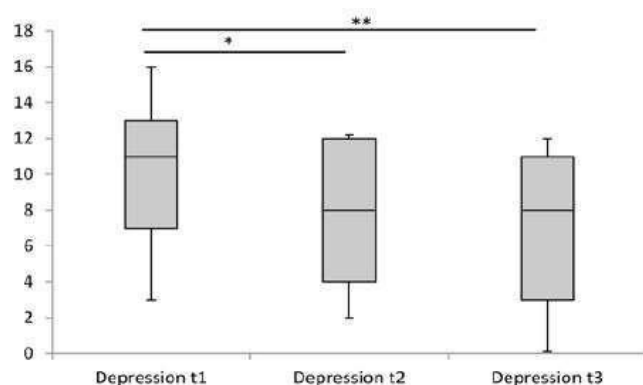
* Significant difference in HADS depression at t1 and t2 (Z=-2.555; p=0.01) and ** between t1 and t3 (Z=-2.533; p=0.01).
t1;baseline, t2; post-intervention, t3; six month follow up.

Figure 1: HADS Depression Scores at t1, t2 and t3.
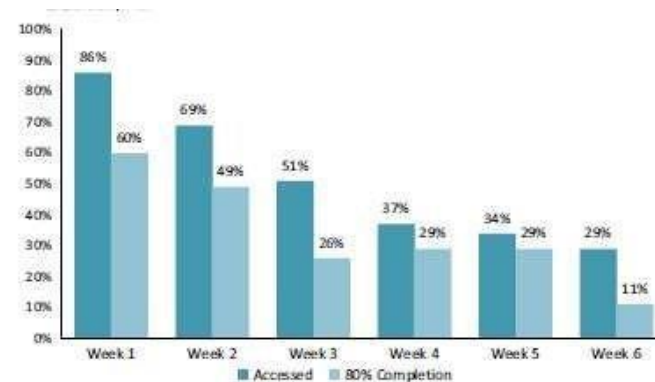
Access to SPIRE programme

Burke *et al.*, 2017, 2019

Shoulder pain

TABLE 2. Logistic regression analyses for the binary outcome "shoulder pain in the past week" (yes vs. no): univariable analysis (unadjusted model) and multivariable analysis adjusted for all variables (adjusted model)

Variable (*n* Missing)	Unadjusted Model			Adjusted Model		
	OR	95% CI	*P*	OR	95% CI	*P*
Sociodemographic/economic factors						
Gender (0)			<0.001			<0.001
Male	1					
Female	1.56	1.24–1.96		1.57	1.21–2.05	
Age category (0)			<0.01			0.103
16–30	1			1		
31–45	1.63	1.03–2.57		1.56	0.95–2.55	
46–60	2.21	1.41–3.47		1.83	1.11–3.02	
61–75	1.72	1.09–2.72		1.45	0.86–2.42	
SCI severity (156)			<0.0001			<0.01
Paraplegia/incomplete	1			1		a
Paraplegia/complete	2.2	1.69–2.88		1.36	0.96–1.92	
Tetraplegia/incomplete	1.97	1.49–2.62		1.81	1.32–2.48	
Tetraplegia/complete	2.12	1.43–3.14		1.51	0.95–2.41	
Time since injury (126)			<0.0001			0.033
0–5	1			1		b
6–15	1.33	1.02–1.74		1.33	0.98–1.81	
16–25	1.7	1.25–2.30		1.56	1.10–2.22	
26+	2.34	1.74–3.15		1.65	1.15–2.37	
Health conditions						
Spasticity (365)			<0.0001			<0.01
No	1			1		
Yes	2	1.57–2.55		1.49	1.14–1.95	
Contractures (402)			<0.0001			<0.0001
No	1			1		
Yes	2.85	2.32–3.49		2.77	2.21–3.48	
Depression (414)			<0.01			0.034
No	1			1		
Yes	1.54	1.16–2.04		1.39	1.02–1.88	

Bossuyt FM *et al.*, 2024

Shoulder pain

Mean-adjusted prevalence of shoulder pain (%)
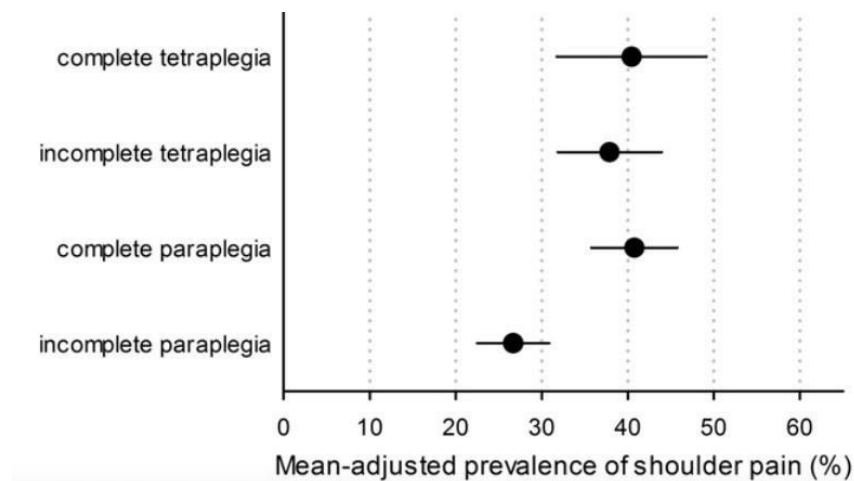
Independence in moving around 10–100 m (169)		<0.0001			<0.001
Walking with orthoses or without aids	1		1		c
Walking with aids and/or supervision	1.67	1.21–2.29	1.58	1.09–2.30	
Independent in manual whc	2.68	2.04–3.51	2.17	1.53–3.08	
Electrical/partial assistance in manual whc	3.37	2.39–4.76	2.16	1.41–3.31	
Total assistance	2.5	1.42–4.38	1.03	0.51–2.10	d

Bossuyt FM *et al.*, 2018, 2024

Psychosocial consequences of SCI

- Depression:16 – 38%, during rehab'n & after discharge
  left untreated compared with CBT, symptoms persisted
- Many factors influence depression e.g. personal relationships, finances, pre-existing psychological status, severity of 2° conditions
- Anxiety: 30-45% usually in first year, then decline
- Early coping strategies (3/12) predictive of clinical conditions 10 years later
- Level of injury not predictive of psychosocial outcomes

Budd MA *et al.*, 2022

Peer support

Patients with SCI

- First impression
- Able to talk about anything
- Finding solutions together
- Beyond the wheelchair
- Positive attitude towards life
- Open C honest →Trust

Peers

- Finding the right moment
- Meetings not planned ahead
- An informal environment
- Level of injury
- Setting goals
- Boundaries

Roth K *et al.*, 2019

Employment

Average 35 - 40% return to paid employment   Ferdiana A *et al.*, 2014

SII (2013): only 13% employed full time pre-injury returned to work full time

Switzerland: in 2017 – 61%; in 2022 – 64.6%

   Dynamic factors: education, pain, depression, independence

                                                    Schwegler U *et al.*, 2021, 2024

Multicentre study, 9494 people with SCI:

   QoL C self perceived health were related to employment status
   which interacted with GDP   Escorpizo R *et al.*, 2024

Exercise guidelines

FITNESS GUIDELINE

For cardiorespiratory fitness and muscle strength benefits, adults with a spinal cord injury should engage in at least:

20 minutes of moderate to vigorous intensity aerobic exercise 2 times per week

AND

3 sets of strength exercises for each major functioning muscle group, at a moderate to vigorous intensity, 2 times per week

CARDIOMETABOLIC HEALTH GUIDELINE

For cardiometabolic health benefits, adults with a spinal cord injury are suggested to engage in at least:

30 minutes of moderate to vigorous intensity aerobic exercise 3 times per week

Ginis KAM *et al.*, 2018

Cardiometabolic disease

- (Neurogenic) obesity most prevalent risk factor, underestimated using general population criteria
- BMI 22 − 25kg/m^2 overweight; >25kg/m^2 obese; 23% normal BMI de Groot *et al.,* 2024
- Other body composition changes below NLI   Mc Millan D *et al.,* 2021

- Prevalence of CMD: 31-72% depending on no. risk factors incl. in study
- Insulin resistance/diabetes: 16 − 33%
- Dyslipidemia: higher triglycerides C ratio of total:HDL cholesterol
- Hypertension: reports vary due to LoI, AIS, aetiology
- Physical deconditioning

Nash M *et al.,* 2018

Management of Cardiometabolic Disease[a]

CMD Risk	Goal	Primary Management: Lifestyle Intervention	
		Nutrition	**Exercise**
CMD Diagnosis	Reduce the number of risk components to < 3	Institute the following nutritional adjustments beginning as soon as possible after the SCI: 1. For all individuals, adopt a heart-healthy nutrition plan focusing on fruits, vegetables, whole grains, low-fat dairy, poultry, fish, legumes, non-tropical vegetable oils, and nuts, while limiting sweets and sugar-sweetened beverages, and red meats; 2. Adopt the DASH nutritional plan or Mediterranean nutritional plan if hypertension or additional cardiometabolic risk factors are present; 3. Limit saturated fat to 5-6% of total caloric intake; and 4. Limit daily sodium intake to ≤ 2400 mg for individuals with hypertension.	Encourage at least 150 minutes per week of moderate-intensity physical exercise beginning as soon as possible following acute spinal cord injury. The 150-minute-per-week guideline can be satisfied by sessions of 30-60 minutes performed three to five days per week, or by exercising for at least three, 10-minute sessions per day
Overweight or Obese	Reduce body fat mass to achieve a BMI ≤ 22 kg/m²		
Insulin Resistance, Pre-Diabetes, or Diabetes	Reduce FBG to ≤100 mg/dL and HbA1c < 7%		
Dyslipidemia	Reduce TG to ≤ 150 mg/dL and increase HDL-C to ≥ 40mg/ dL (male) and ≥ 50 mg/dL (female)		
Hypertension	Reduce BP-SYSTOLIC to < 130 mmHg and BP-DIASTOLIC to < 85 mmHg		

Risk	Goal	Secondary Management: Pharmacotherapy
CMD Diagnosis	As above	Treat specific CMD risk component
Overweight or Obese		None recommended
Insulin Resistance, Pre-Diabetes, or Diabetes		Metformin (Glucophage) as the first-line agent for treatment of HbA1c >7%, unless contraindicated or poorly tolerated. If the maximum tolerated dose of Metformin fails to achieve goals, add a second and possibly a third agent, according to ADA Standards of Medical Care (2017).
Dyslipidemia		Guide patient selection for pharmacotherapy by other factors commonly seen in SCI, such as low levels of HDL-C and high levels of C-reactive protein. Initiate statin monotherapy using at least a moderate-intensity statin (e.g., rosuvastatin 10 mg/day).
Hypertension		JNC 8 guidelines recommend initial antihypertensive treatment with a thiazide-type diuretic, calcium channel blocker (CCB), angiotensin-converting enzyme inhibitor (ACEI), or angiotensin receptor blocker (ARB) in the non-black population, and either a thiazide-type diuretic or CCB in the black population.

Nash M *et al.*, 2018

Long term respiratory issues

Respiratory function

- Dependent on level and completeness of SCI
- Decline – recover – decline
- Significant predictors: LoI, gender, weight
- PI $_{max}$ & PE $_{max}$ more accurate for prediction than FEV_1, FVC, PEF Raab AM *et al.,* 2019
- Evidence for benefits of respiratory muscle training Berlowitz C Tamplin, 2012

Sleep disordered breathing

- At least mild 83%, at least moderate 59%, severe 36% - tetraplegia
- Access to screening, testing, diagnosis, treatment is poor
- Adherence to treatment 20 – 40%*
- Non-sleep specialist models under consideration Graco M *et al.,* 2019, 2019, 2021, 2022, 2024

Paediatric spinal cord injury

- Scoliosis almost inevitable: 98% if SCI before puberty, 20% if after

- Spinal fusion: 67% if SCI before puberty, 5% if SCI after

- Leads to respiratory distress, affects bowel motility, spasticity, scapular stability, pressure injury risk

Vogel LC *et al.*, 2012; Mulcahey MJ *et al.*, 2013
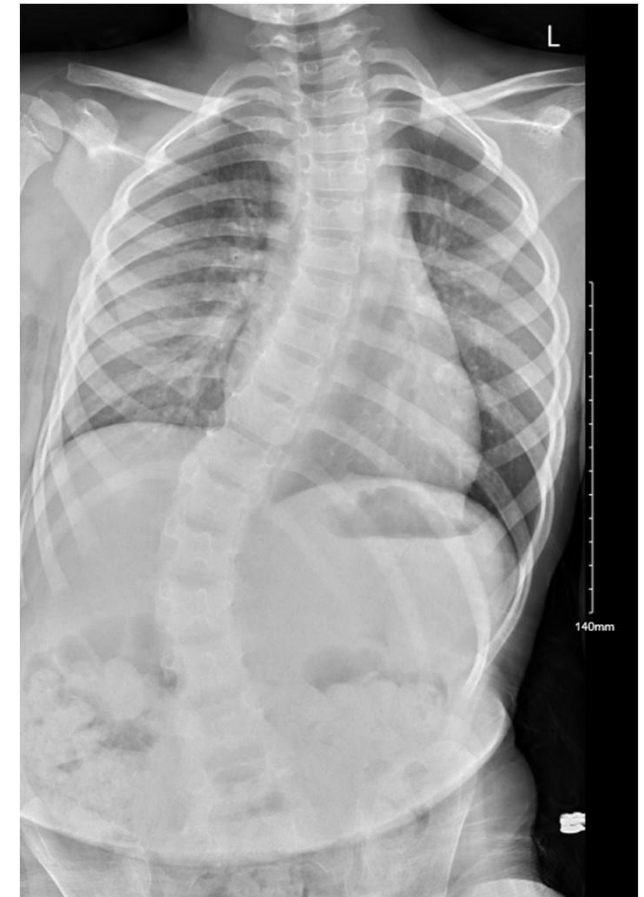
Paediatric spinal cord injury

- Bracing/TLSO: may prevent surgery in 50% patients with curves <20°, delays time to surgical correction in curves <20°.

  Little/no effect for curves >40°

- Once curve @50° rapid progression: pelvic obliquity, reduced UE function, increased PI risk, lung problems

- >curve at time of surgery >complications

- Hip dysplasia/instability: injury <5yrs 100% risk; 5 − 10 yrs 80%

Vogel LC *et al.,* 2012; Mulcahey MJ *et al.,* 2013
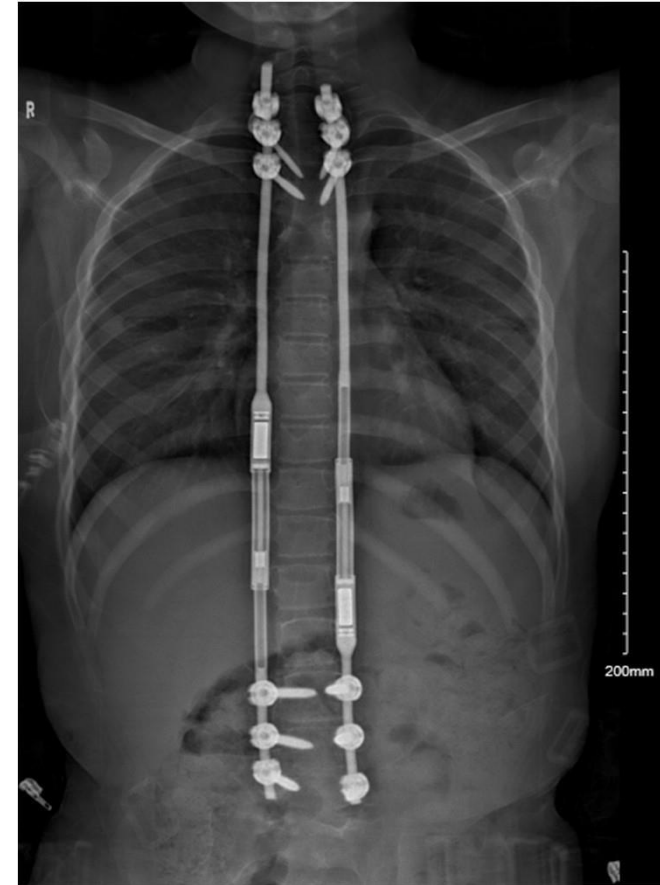
Risk of mortality when lost to clinic follow-up
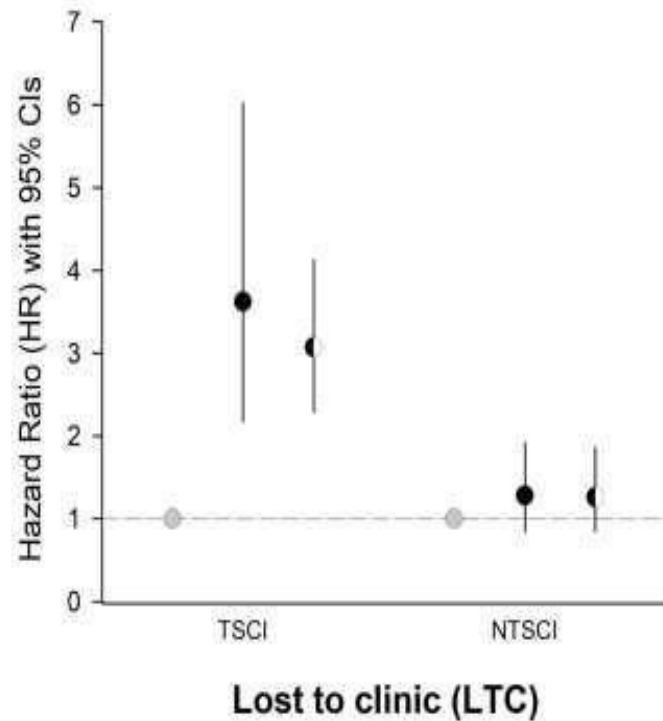
Chamberlain JD *et al.*, 2020

Useful resources

- **SCSC Programme - Patient Education and Resources - National Rehabilitation Hospital**

- **www.mascip.co.uk**

- www.bsprm.org.uk (SCI SIG)

- www.asia-spinalinjury.org

- www.iscos.org.uk

National Grand Rounds

Our next **National Grand Rounds** will be in September.

Clinical Rehabilitation Network

Presented by Ciara Lynch - Programme Manager, Neurorehabilitation Strategy and Managed Clinical Rehabilitation Network