PLANNING-PEOPLE WITH TETRAPLEGIA
Planning for the future for people living with tetraplegia

Living with a spinal cord injury (SCI) creates a number of challenges, and as we get older the gap between independence and dependence narrows. Thinking about what may lie ahead will put you in a better position to deal with issues as they arise. To guide you through this planning process, SIA has produced this plan to list areas for you to consider. Some may seem obvious, others not, and some may even be uncomfortable issues that you have put off addressing.

How to use the plans

Areas for consideration are under relevant headings. Suggested time frames are shown in 2 columns, but these are merely for guidance and can be adjusted to suit your individual circumstances.

For example, evidence shows that physical wear and tear, especially of the upper limb joints, occurs on average 15-20 years post injury. You may wish to plan for the financing of a power wheelchair to help reduce pain and conserve your upper limb joints.

You may think of other issues that you wish to include in your individual plan.

<table>
<thead>
<tr>
<th>Equipment</th>
<th>Year 4</th>
<th>Year 2</th>
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</thead>
<tbody>
<tr>
<td>wheelchair – is it still fit for purpose?</td>
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<tr>
<td>transferring – additional equipment such as hoists to conserve upper limb joints and help prevent shearing injuries</td>
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<tr>
<td>additional equipment that will aid your carers / partner to facilitate transfers</td>
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<td>through floor lift</td>
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<tr>
<td>cushion</td>
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<tr>
<td>transfer board, for people with lower level tetraplegia</td>
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<td>hoist</td>
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<tr>
<td>profiling / height adjustable bed / mattress</td>
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Household equipment and assistance

- Cooker, washing machine and condensing tumble dryer
- Employ a cleaner for periodic dusting and vacuuming

**New Technologies:**
- Communication equipment
- Assistive technology devices

**Care**
Do you have the 'right' type and amount of care?
- Balance between relying on others and having the energy to focus on what is important.

Who is funding your care?
- 'Means tested' local authority.
- 'Non-means tested' NHS continuing Healthcare.
- Personal Injuries Compensation Package
- Private funding.
- Contingency planning?

Deciding who should be called in emergencies.
Is your care being delivered in the best place?
- In your own home
- Supported Living.

Residential/Nursing Home
Do you need?
- Increased level of care via your local authority
- Your care package transferred to NHS Continuing Healthcare
- To consider living in a Nursing Home.

**Health**
Support from appropriate professionals e.g. Spinal Consultant, Physiotherapist, Occupational Therapist, GP, Continence Specialist Nurse, Tissue Viability Nurse, District Nurse.

Reassessing your current lifestyle:
- Weight management, exercise regime
- Bladder and bowel management regimes
- Skin / pressure management
- Managing and controlling pain and fatigue
- Attention to posture – seating clinic
- Mental health / depression

- Annual medical check-ups at your Spinal Cord Injury Centre
- Health screening: bowel and bladder, diabetes, high blood pressure, breast, prostate.

**Finance**

Benefits:
- These may change when you reach 65 yrs of age
- Pension

Extra expenses:
- New or replacement equipment
- Medical / continence supplies
- Medications

Making a Will
- Living Wills

- Funeral costs and making necessary arrangements.

**Employment**

- Retraining
- Reducing hours
- Retiring
- Voluntary work.

**Housing**

- May be deciding to downsize
- Further adaptations e.g. ceiling hoist, wet room
- Garden.
<table>
<thead>
<tr>
<th><strong>Transport</strong></th>
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<tbody>
<tr>
<td>• Adapt vehicle e.g. tail lift</td>
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<tr>
<td>• Change to Wheelchair Accessible Vehicle (WAV).</td>
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<tr>
<td><strong>Leisure and Holidays</strong></td>
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<tr>
<td>• Take up new hobbies</td>
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<tr>
<td>• Respite care for partners</td>
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<tr>
<td>• Taking holidays - short breaks may be more manageable.</td>
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<tr>
<td><strong>Relationships</strong></td>
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<tr>
<td>• Staying in touch with friends and relatives</td>
<td></td>
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<tr>
<td>• Moving area to be near sons and daughters</td>
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<td>• Peer support – keeping in touch with old friends.</td>
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<td>• On-line Dating</td>
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<td><strong>Spiritual</strong></td>
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<tr>
<td>• Dealing with any unresolved emotions</td>
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<td>• Personal goals.</td>
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The Spinal Injuries Association (SIA) is the leading national user-led charity for spinal cord injured (SCI) people. Being user led, we are well placed to understand the everyday needs of living with spinal cord injury and are here to meet those needs by providing key services to share information and experiences, and to campaign for change ensuring each person can lead a full and active life. We are here to support you from the moment your spinal cord injury happens, and for the rest of your life.

For more information contact us via the following:

Spinal Injuries Association
SIA House
2 Trueman Place
Oldbrook
Milton Keynes
MK6 2HH

T: 01908 604 191 (Mon – Fri 9am – 5pm)
T: 0800 980 0501 (Freephone Advice Line, Mon – Fri, 11am – 1pm/2pm – 4.30pm)
W: www.spinal.co.uk
E: sia@spinal.co.uk

Charity No: 1054097
PLEASE SUPPORT SIA

SIA relies on fundraising, donations and gifts in wills to provide services that help spinal cord injured people rebuild their lives.

With your help, we can provide the right support to spinal cord injured people and their families and friends so they can enjoy a full and independent life after injury. Your donation today will go towards changing someone’s life.

I would like to give: £15  □ £20  □ £53  □ other amount £………….

Method of payment
□ I enclose a cheque/postal order/CAF voucher made payable to Spinal Injuries Association.

□ I would like to pay by Mastercard/Visa/Maestro/Switch (delete as appropriate)

Card number □□□□ □□□□ □□□□ □□□□ □□□□ □□□□
Start date □□□□ Expiry Date □□□□ Security Code □□□□

Signature __________  Date ……../……../…….

Name……………………………………………………………………………………………………

Address ……………………………………………………………………………………………

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Postcode ……………………… Tel no…………………………………………………………

Email address……………………………………………………………………………………

Please gift aid my donation  □

If you tick the box it means for every £1 you donate we can claim an extra 25p from the taxman, at no extra cost to you. You need to pay an amount of income tax or capital gains tax at least equal to the tax we reclaim from HM Revenue and Customs – currently 25p in every £1 you give.

Please send your donation to: FREEPOST SPINAL INJURIES ASSOCIATION or you can donate online at www.spinal.co.uk

Thank you for your support!