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CARE OF  
**STROKE**  
SURVIVORS



## Post-stroke rehabilitation

The aim of stroke rehabilitation is for the patient to regain the best level of health, activity and participation possible within the limits of any persisting stroke impairment.

Many stroke survivors are left with significant changes to physical, emotional, cognitive and social function and about half of patients who survive for six months will require some help with daily living (bathing, dressing, toileting, feeding and mobility). Stroke survivors are at risk of physical complications such as falls and long term psychological and emotional problems. Ongoing management of complex needs is often required after discharge from hospital.

Recovery of function following a stroke varies depending on the part of the body affected. Depending on the severity of the stroke, maximum functional improvement in paralysed limbs is seen within two to six months. In

contrast improvement of speech, domestic and working skills and unsteadiness can continue for two years or more. Early rehabilitation uses techniques that focus on neuroplastic change, and later rehabilitation encourages adaptive responses and coping strategies.<sup>1</sup>

The organisation of hospital services to provide specialised Stroke Units is the most important advance in stroke care. Best outcomes are associated with specialist multidisciplinary in-patient care in a stroke unit and with therapy that commences immediately or within days after a stroke. Patients who receive care in a stroke rehabilitation unit are more likely to be alive, independent and living at home (NNT = 33, 20, 20 respectively) than patients who receive non-specialist care or care within a general rehabilitation unit.<sup>2</sup> The benefits of stroke unit care are seen for all ages, genders and across the range of severity.<sup>3</sup>

### Key concepts


- Best outcomes after stroke are associated with prompt specialist multidisciplinary in-patient care in a stroke rehabilitation unit
- Stroke survivors require regular follow up in the community and should be referred for further therapy or specialist assessment depending on their problems
- It is useful to have a systematic way of checking for physical and practical problems with everyday living
- It is recommended to assess for hidden problems such as depression, anxiety, dementia or pain
- Together with stroke survivors, carers require information and long-term practical, emotional, social and financial support


## Stroke survivors require regular follow up after discharge

Leaving hospital after a stroke can be a frightening and difficult experience. This is often the time when stroke survivors suffer the greatest feeling of abandonment as well as facing a diversity of ongoing problems as they adapt to the longer term impact of the stroke.

General practice is ideally placed to undertake comprehensive reviews and coordinate best care in the community. Primary care follow up should be scheduled within the first few weeks following discharge from hospital, and then regularly at intervals appropriate to the clinical need.

Follow up should address:

- Information and education: enquire about information needs and access to voluntary organisations, peer support etc
- Secondary prevention: reinforce lifestyle changes and check medicine treatment for secondary prevention ( see BPJ 26, March 2010, “Secondary stroke prevention”)
- Physical needs: review the impact of the stroke on activities of daily living, and need for further referral, practical aids and rehabilitation
- Emotional and other hidden needs: screen for depression, pain, continence and sexual issues
- Social and carer needs: review the care plan and address the carer’s needs

 **Best practice tip:** On receiving a discharge letter, following a hospital admission for stroke, schedule a consultation with the patient and carer/whānau either in the surgery or at their home. A double appointment may be beneficial and consider whether a joint home assessment with the rehabilitation team is possible, especially in cases involving significant disability.

## Assess the need for advice, information and peer support

Receiving information after a stroke is one of the most important needs reported by stroke survivors and their carers, even years after the stroke. Face to face discussion is highly valued and can be backed up with written material.

The Stroke Foundation has a free public helpline and provides information through literature and videos and their website. Field officers are located nationwide and many areas have stroke support clubs. Meeting with other stroke survivors and carers provides invaluable social support, experiential knowledge and a social comparison.<sup>4</sup>


Stroke Foundation helpline:  
0800 STROKE (0800 78 76 53)  
Website: [www.stroke.org.nz](http://www.stroke.org.nz)

## Review physical needs

Physical and practical problems with everyday living are common following a stroke. Although the major part of physical recovery following a stroke occurs in the first six months, functional improvements in activities of daily living and fitness (lessening of disability or handicap) often continues long after specific neurological deficits have ceased to change. Most stroke survivors value opportunities for greater independence.

Because there is such a wide area of health and potential disability to assess, as well as responding to the main concerns of the stroke survivor and carer, it is helpful to have a structured way to check for any areas of difficulties. The following approach may be useful:

- Ask the stroke survivor and carer to fill out a simple checklist prior to the consultation to indicate any problem areas and help guide priorities.

 An after stroke checklist is available for download from the bpac<sup>nz</sup> website: [www.bpac.org.nz](http://www.bpac.org.nz) keyword: strokecheck

- Talking through the activities of a normal day in a chronological sequence provides a simple systematic approach to identifying problem areas e.g. getting up in the morning, personal hygiene and toileting, dressing, breakfast and other meals, activities and leisure.

### Screen for silent problems such as depression and pain

Some problem areas may not be apparent during a routine consultation, unless already highlighted on a self-completed checklist. It is recommended to assess for depression, anxiety, dementia and pain, and discuss topics that may cause embarrassment such as incontinence, physical intimacy and sexual intercourse.

### Review the care plan and address the carer's needs

When consulting with stroke survivors it is important to consider the needs of the carer and whether the care plan is appropriate. Has the stroke survivor been discharged home to a distressed relative and too little help? The impact of the stroke on a partner or spouse can be devastating. Carer strain, anxiety and depression are very common after stroke.<sup>5</sup>

Together with stroke survivors, carers need information and long term practical, emotional, social and financial support. The carer can often need as much input as the stroke victim; ranging from counselling to cope with the changes in their life, to respite care to allow them a break. Closer medical supervision may also be required as often carers are elderly and have their own medical problems.

## Who to refer to for stroke related problems

When stroke related problems arise key specialists for referral for ongoing rehabilitation include:

- Continence advisors for incontinence assessment and treatment
- Dietitians for advice on healthy eating, especially if poor swallowing or artificially fed, under or overweight or diabetic
- Occupational therapists for help with independence in all daily activities including self-care (personal care), leisure and work, including driving assessment where appropriate
- Orthotics service to help correct abnormality or assist function of a disabled limb
- Physiotherapists for any movement difficulties, fitness, falls prevention and musculoskeletal complications such as shoulder pain
- Podiatrists for foot care especially if difficulty caused by paralysis or spasticity
- Psychiatric and neuropsychology support for depression, mood swings, personality changes, and dementia assessment and support
- Specialist clinics such as pain or spasticity clinics
- Speech and language therapists for difficulties with communication, cognition and swallowing



# Practical tips for problems associated with stroke

**Key references:** New Zealand Stroke Foundation “Life after stroke”<sup>6</sup> and Australian National Stroke Foundation “Guidelines for stroke rehabilitation and recovery”.<sup>7</sup>

## Continued exercise and therapy improves movement

Weakness on one side (hemiparesis) is often the single most disabling factor after stroke.<sup>8</sup> Reduced movement, weakness, clumsiness, impairment to balance and changes in tone all impact on the simple ability to move e.g. in bed, to roll, sit up, stand and walk.


Stroke survivors should be encouraged to be as physically active as possible, maintain walking and return to usual activities. Even after the initial recovery, further improvement may be seen with ongoing exercise, practice of activities of daily living and outpatient/community therapy.<sup>9</sup> National guidelines recommend that all stroke survivors with activity that has deteriorated since discharge (six months or later) should have access to further targeted therapy to recover any ground lost (e.g. physiotherapy, occupational therapy, speech therapy, psychologist).


## Stroke survivors are at much greater risk of falls and of serious injury

Falls are more common in people after stroke compared to age-matched controls. Over one-third of stroke survivors will fall in the first year.<sup>10</sup> Risk factors for falls are similar to those for older people in general. In stroke survivors there is a relationship between falling and depression but it not known whether the depression increases the risk of falling or if falling increases depression in this group.<sup>10</sup>

Stroke is strongly associated with secondary osteoporosis, similar to other neurologically incapacitating disorders.<sup>11</sup> Stroke survivors who do fall are at increased risk of injury compared with the general population (8% stroke survivors

compared to 3% general population),<sup>12</sup> particularly hip fractures (relative risk for hip fracture within two years of stroke is 1.4 [95%CI, 0.92 to 2.07]).<sup>13</sup>

 **Best practice tip:** screen for falls risk and osteoporosis risk (FRAX) in all patients after stroke. Consider treatment with calcium, vitamin D and bisphosphonates.

 For further information see:

- BPJ 26 (Mar, 2010) “Falls in older people: causes and prevention”
- Best Tests (Nov, 2008) “Osteoporotic fracture prevention: a new approach”
- BPJ 17 (Oct, 2008) “Prevention of osteoporosis”

## Spasticity in the arm or leg following stroke should not be routinely treated

Spasticity is not a major determinant of physical impairment therefore, spasticity that is not interfering with a stroke survivor’s activity or personal care, does not require treatment.

Consider treatment if spasticity is causing abnormal posturing or involuntary spasms that interfere with activity, discomfort/pain, or difficulties in personal care, e.g. hand hygiene in a flexed hand.<sup>14</sup>

- First line treatment is physical therapies such as stretching and dynamic splinting<sup>15</sup> (physiotherapy referral).
- Intramuscular injection with botulinum toxin may be effective<sup>16</sup> and is available via specialist stroke and rehabilitation services where other specialist therapies can also be considered.
- Oral anti-spasmodics, e.g. baclofen are not recommended for routine treatment. They provide marginal benefit, if any, for this indication and are associated with high levels of adverse reactions.<sup>17</sup>

## Improving independence in personal care, around the home and getting out


At six months post stroke, about half of patients are partially or totally independent in their activities of daily living such as bathing, dressing, toileting, feeding and mobility. By one year this has increased to about two-thirds and further recovery in function is often seen long after neurological deficits have ceased to change.<sup>18</sup>

Being able to complete everyday activities as independently as possible is important for most stroke survivors. Stroke survivors who have limitations on any aspect of activities of daily living can be referred to occupational therapy, for advice on coping with the disabilities and information on available aids, equipment, and home or work adaptations as required.

### No driving within one month after a stroke

After a person has had a stroke, they should not drive for at least one month.<sup>19</sup>

After this time if there is doubt about driving fitness due to residual disability, a driving assessment by an occupational therapist trained to provide off road and/or on road assessments should be undertaken.

 For more information see: "Medical aspects of fitness to drive", available from [www.nzta.govt.nz](http://www.nzta.govt.nz) and BPJ 26 (Mar, 2010) "Driving rules and assessment in older people".


Driver licences are generally not granted on Class 2, 3, 4 or 5 licences (heavy transport/passenger endorsement) following a stroke. However, if the stroke survivor has made a complete recovery and has a supporting report from a specialist neurologist or physician, then the possibility of a return to driving can be considered by the Licensing Agency.

## Ask stroke survivors if they are experiencing pain


Pain after stroke is common and is seen in up to 50% of survivors.<sup>20</sup> All patients should be asked if they are experiencing pain.

There are numerous possible causes of the pain. Two main types to consider are:

- **Musculoskeletal pain** from immobility and abnormal posture is particularly common in people with arthritis, spasticity and contractures. A subtype of musculoskeletal pain is shoulder pain. This is seen in up to 80% of stroke survivors with upper limb weakness in the first year after stroke.<sup>21</sup> Musculoskeletal pain may improve with physiotherapist advice and improved handling techniques, posture and movement. Treat with simple analgesics and increase, as necessary, up the World Health Organisation (WHO) analgesic ladder. Musculoskeletal pain that is not controlled may require referral for specialist treatment.

 For further information see BPJ 16 (Sep, 2008) "Pharmacological management of chronic pain"

- Up to 8% of stroke survivors experience **central post stroke pain (CPSP)**.<sup>22</sup> This is felt as a superficial, unpleasant burning, lancinating or pricking sensation. It is often made worse with touch, water or movement. If there are no contraindications the first line neuropathic analgesic for CPSP is a tricyclic antidepressant such as nortriptyline.<sup>23</sup> Other options are anticonvulsants and opioids. CPSP that is poorly controlled within a few weeks should be referred to a specialist in pain management.


 For further information see BPJ 16 (Sep, 2008) "Pharmacological management of neuropathic pain"

## Fatigue may improve with treatment of disrupted sleep, depression, anxiety and pain

Many stroke survivors report substantial fatigue and describe it as the most difficult symptom they have to cope with.<sup>24</sup> Fatigue may affect mood, cognition and communication, worsen physical symptoms and the ability to participate in activities and increase risk of falls. It is multifactorial in origin.<sup>25</sup>


Management consists of:

- Providing reassurance that fatigue is usual after stroke
- Planning daily activities to allow for regular rest periods
- Treating associated conditions such as disrupted sleep, depression, anxiety and pain
- Screening for other medical causes of fatigue e.g. anaemia, hypothyroidism, sleep apnoea

 Stroke Foundation “Fatigue after stroke” information sheet, available from: [www.stroke.org.nz/pdfs/resources/SF2116FatigueLR.pdf](http://www.stroke.org.nz/pdfs/resources/SF2116FatigueLR.pdf)

## Nutritional problems are common in people who have had a stroke

To identify adults who are at risk of malnourishment or are malnourished, the Malnutrition Universal Screening Tool (MUST) is recommended. Referral to a dietitian or to a speech and language therapist, for swallowing problems, may be required.

 For further information see BPJ 15 (Aug, 2008) “Strategies to improve nutrition in elderly people”.

MUST is available from: [www.bapen.org.uk](http://www.bapen.org.uk)

## Control of bladder and bowel often improves over time

In the acute post-stroke period faecal and urinary incontinence is very common. A proportion of stroke

survivors continue to have problems (20% have urinary incontinence six months post stroke) and incontinence is one of the key reasons for referral to long term care.<sup>26</sup>

The causes of incontinence are multifactorial. Faecal incontinence is often associated with constipation and overflow.<sup>27</sup> The three most common reasons for urinary incontinence are urge incontinence, urinary retention and functional incontinence.


Diagnosis of incontinence is based on the history, examination (including rectal examination), and possible further investigations. Treatment depends on the cause (Table 1). In the community setting patients may be referred to a continence adviser. Where continence is not achieved, containment aids, e.g. pads, can be used.

## Take the initiative to talk about sex

Sexual dissatisfaction is very common after stroke but rarely discussed unless prompted by a health professional.

Psychological and interpersonal factors may include lack of communication, diminished self esteem and sense of attractiveness, depression, fatigue, fear of sexual failure or fear of causing a stroke.<sup>29</sup> These factors have a significant influence on sexual intimacy and compound the physical problems after stroke such as difficulty with positioning, anorgasmia and erectile or lubrication difficulties.

Sildenafil (a PDE5 inhibitor) may be used with caution to treat erectile dysfunction post stroke. Contraindications are very recent stroke (less than two weeks), unstable cardiovascular conditions and concomitant use of nitrates.

 For further information see BPJ 12 (Apr, 2008) “Erectile dysfunction”

Information on intimacy after stroke is available from the Stroke Foundation: [www.stroke.org.nz/pdfs/resources/Sexuality-Booklet.pdf](http://www.stroke.org.nz/pdfs/resources/Sexuality-Booklet.pdf)

**Table 1:** Summary of treatment strategies for incontinence<sup>28</sup>

Type of incontinence	Management strategies
Faecal (often associated with constipation)	<ul style="list-style-type: none"> <li>▪ Rectal examination</li> <li>▪ Minimise use of medicine with anticholinergic properties e.g. antipsychotics, TCAs, oxybutinin, antiemetics</li> <li>▪ Review hydration and dietary fibre</li> <li>▪ Laxatives</li> <li>▪ Bowel training e.g. daily routine to promote defaecation</li> </ul>
Urge incontinence	<ul style="list-style-type: none"> <li>▪ Bladder retraining e.g. scheduled voiding regimen</li> <li>▪ Anticholinergic medicines e.g oxybutinin</li> </ul>
Urinary retention with overflow	May be aggravated with constipation and anticholinergic medicines. If severe, consider urinary catheterisation (intermittent if practical)
Functional incontinence (unable to toilet successfully because of problems with cognition, communication, mobility, undressing, etc)	Usually requires a multidisciplinary approach

## Mood and emotions


Psychological and emotional issues may be significant after stroke even when there has been good physical recovery. Key issues are recognising and coping with the limitations caused by the stroke, grief for what has been lost, fear of another stroke, generalised anxiety, frustration and depression and coping with stigma and social isolation.<sup>30</sup>

### One-third of stroke survivors develop depression or an anxiety disorder

Regularly screen for depression and anxiety in stroke survivors. Depression is very common in people who have had a stroke. At six months post-stroke approximately one-third to one-half of stroke survivors will be depressed<sup>31</sup> and 3 to 9% will have major depression.<sup>32</sup> Similar figures occur for anxiety.<sup>33</sup>

Treatment strategies for stroke related mood disorders are similar to those for the general population. Stroke

survivors with depression or anxiety that does not respond to standard measures, is causing distress and is interfering with recovery, should be assessed by an expert e.g. clinical psychologist, psychiatrist.<sup>34</sup>

 For more information see:

- BPJ (Special edition, 2009) “Adult depression”
- BPJ 11 (Feb, 2008) “Depression in elderly people”
- BPJ 25 (Dec, 2009) “Generalised anxiety disorder in adults”

### Emotional lability may be treated with antidepressants

Stroke survivors who have exaggerated changes in mood such as uncontrollable laughing or crying, or heightened irritability or anger, may be experiencing emotional lability.<sup>35</sup> Antidepressants, such as SSRIs, are first-line treatment to lessen the frequency and severity of outbursts and reduce anger.<sup>36</sup>

## Dementia is very common after stroke

Around 10% of people will be diagnosed with incident dementia soon after a new stroke. More than one-third of stroke survivors will have a diagnosis of dementia after recurrent stroke. Dementia and cognitive impairment post-stroke usually requires detailed cognitive assessment and a full multidisciplinary re-assessment such as referral to stroke team or psychogeriatrician.

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