Managing stroke survivors in the community

Your patient has survived a stroke and presents at your surgery a week after discharge.

Where do you start?

STEVEN FAUX
MB BS, BA, FRACGP, FAFRM(RACP), FFPMANZCA

Dr Faux is Director of Rehabilitation Medicine, St Vincent's Hospital, Sydney, NSW.

A stroke can transform a person's physical, psychological and social functioning. Stroke survivors are usually managed for the first seven or so days in an acute stroke unit, and rehabilitation promoting independent movement begins during this time. About one-third of these patients, depending on each individual's needs, then undergo further rehabilitation in specialised inpatient rehabilitation units. About 45% of stroke survivors die within five years of their initial stroke and 20 to 25% become significantly disabled.[1]

Stroke rehabilitation helps patients maximise their potential for recovery and provides practical ways of dealing with ongoing disability. Family members and other carers are also involved in rehabilitation in that they are trained how to care for stroke survivors. A stroke rehabilitation program involves a co-ordinated program of exercises (physiotherapy), the practice of daily activities such as dressing (occupational therapy), the optimising of speech and swallowing (speech therapy) and the mapping of memory and cognitive losses (neuropsychology). This is done within a framework of support for the patient and family (social work) and culminates in the stroke survivor's return to the community to live with a disability and draw out the best quality of life possible.

This article provides a practical guide to helping stroke survivors who have a persistent disability maintain and enhance the gains made in rehabilitation. The article is divided into three sections: what to do once the patient has been discharged from hospital, secondary prevention and how to approach general post-stroke deterioration.

Discharge summary: stroke

The initial post-stroke consultation probably occurs a week after discharge when the stroke survivor's supply of hospital medications is about to run out. This will be your first opportunity to assess your patient's condition and the presence and level of disabilities. Be aware that changes are not only physical but also psychological and

IN SUMMARY

- **To optimise a stroke survivor's quality of life it is important to become re-acquainted with the patient and to be aware of all aspects of his or her new care infrastructure.**
- **As stroke survivors have a 6 to 10% yearly risk of recurrence, secondary prevention is essential. Tight control of blood pressure and diabetes, the use of antiplatelet agents (or warfarin in those with atrial fibrillation), cholesterol level reduction, smoking cessation, a healthy diet and avoiding excessive alcohol intake are all important.**
- **Daily exercise is central to maintaining mobility and quality of life in stroke survivors.**
- **General deterioration in a stroke survivor is not always 'the final curtain' once acute causes have been excluded; quite often some simple rehabilitation is all that is required.**
- **Stroke rehabilitation helps patients maximise their potential for recovery and provides practical ways of dealing with ongoing disability. It involves an intense multidisciplinary program that can be undertaken in the community or as an inpatient.**

Trivia points

- Stroke was first likened to the 'stroke of God's hand' in 1599. The Greek word plesso means to 'stroke, hit or beat' and gives us the word plegia, as in hemiplegia.[2]
- Babinski didn't give his name to a reflex but described a loss of plantar response now known as the Babinski sign. There are over 20 different ways to elicit plantar/extensor responses.
- The League of Nations (the precursor to the United Nations) was formed following World War I essentially because US President Woodrow Wilson suffered post-stroke vascular dementia and world leaders felt sympathy for him. His wife hid him away from the press.

social, and that communication may be affected (for example, the patient may be aphasic).

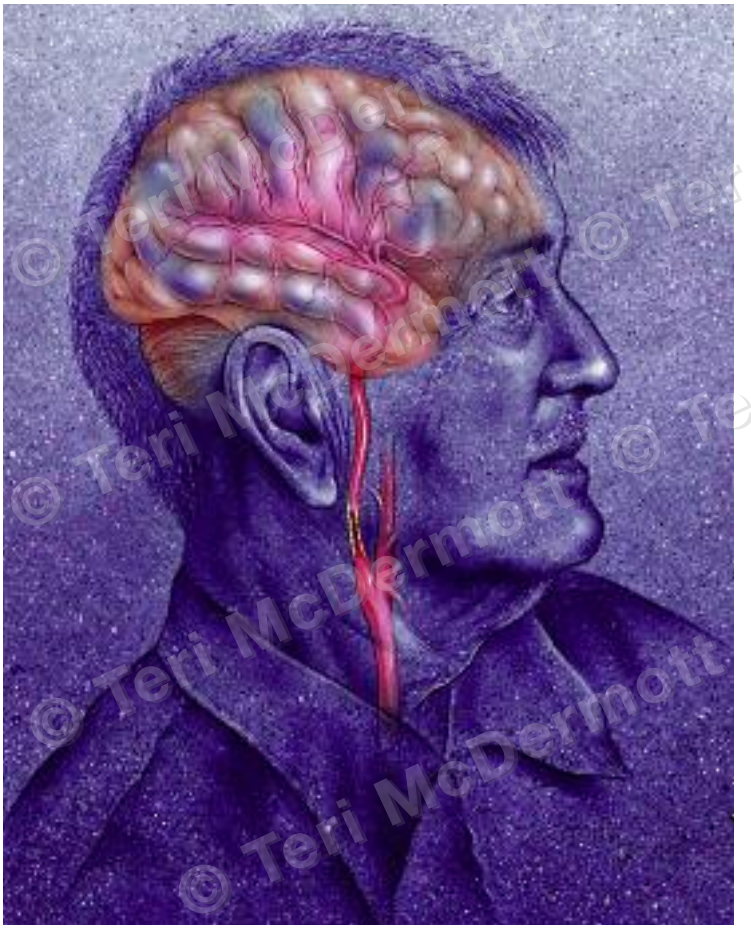
Ideally, GPs should be involved in the discharge case conference while the patient is in the inpatient rehabilitation unit so that the handover to community care can be streamlined. (Medicare Item Numbers 768, 771 and 773 of the Medicare Benefits Schedule, 1 November 2003, apply for the GP to attend these case conferences.)

The post-stroke follow up appointment

A comprehensive assessment of the patient is essential to establish a new baseline of physical and psychological function. If time does not permit this at the patient's first presentation after discharge, organise a follow up appointment. From the discharge summary determine whether the stroke was a hemisphere stroke (physical and cognitive effects) or a brainstem stroke (usually physical affects only), and the mechanism involved (thrombus 40%, embolus 30%, lacunar 20% or haemorrhage 10%). This differentiation will have determined the medical and/or surgical treatments used (such as warfarin, aspirin or statin, and carotid endarterectomy or carotid stenting, respectively).

A checklist for assessing a stroke survivor is given in Table 1. Your focus will necessarily start with ascertaining the patient's level of communication (Table 2) to determine if the history should be taken from the stroke survivor or the carer. You can then explore the patient's new functional baseline and document the level of dependence in self-care, home-care and work and leisure skills – i.e. the activities of daily living (ADLs; Table 3). Ensure that the patient undergoes a Mini Mental State Examination (MMSE)

Managing stroke survivors



The community care of stroke survivors includes promoting independent living, preventing further strokes and caring for the carers. These patients can benefit greatly from rehabilitation both in the first few weeks after their stroke and also later on when carers report that the patient has deteriorated but no acute cause can be found.

early in the assessment as post-stroke dementia occurs in 12 to 22% (and possibly more) of stroke survivors.[3]

The patient may still be in stroke rehabilitation, either as an outpatient or in the community. He or she should have a home-based exercise program prescribed as part of the rehabilitation, and compliance in minutes per day should be documented. If swallowing is a problem, the consistency of the food eaten (pureed food, normal food but thickened fluids or normal diet and thin fluids) can be recorded. Complaints of fatigue (which occur in 10 to 39% of patients) or pain can be documented using visual analogue scales (for example: 'If 0 is no pain [or fatigue] and 10 is the worst you can imagine, what level of pain [or fatigue] are you feeling right now?').[4] Ask also about mood, as up to 23% of stroke patients living in the community have reported significantly depressed mood.[5]

Examining a stroke survivor

Attention should be paid to blood pressure, which should be tightly controlled and as low as possible without there being symptoms of hypotension (at least below 135 mmHg systolic and 85 mmHg diastolic), and to heart rate.[6] Careful examination of respiratory status, cardiac status, visual loss, visuospatial neglect or inattention, and weakness are important. Testing muscle tone is helpful because a change in tone is often a harbinger of generalised illness or infection, or an indicator of a hidden site of pain.

Observe whether the patient is able to stand from a seated position, walk independently and get on and off the examination couch without assistance. Examine the hemiplegic shoulder with care because there is a high incidence of hemiplegic shoulder pain (from a combination of rotator cuff tears, adhesive capsulitis and complex regional pain syndrome).

Secondary prevention

You are likely to see a stroke survivor about every six months for repeat prescriptions and this provides an opportunity to review secondary prevention measures. This population has a risk of recurrent stroke per year of 6 to 10%, which can be reduced by up to 13% with antiplatelet therapy and by up to 60% with the use of warfarin (Coumadin, Marevan) in those with atrial fibrillation.[7,8]

Studies have shown hypertension to be the strongest modifiable risk factor for stroke and the lower the blood pressure is kept then the better the prevention. Tight asymptomatic lowering of the blood pressure by as little as 3 to 6 mmHg has been shown to decrease the risk of recurrent stroke by up to 32%.[9] While reducing the blood pressure seems more important than the type of agent chosen, ACE inhibitors such as perindopril and ramipril have been shown to

Table 1. Assessing a stroke survivor: baseline history and examination

First step

- Assess communication (see Table 2)
- Perform a Mini Mental State Examination

History

Ask about:

- problems since discharge from hospital
- activities of daily living (ADLs; see Table 3)
- mobility and falls
- continence
- pain – shoulder, hemisensory, arthritic
- mood – sleep disorders, social withdrawal, appetite, interests and hobbies, suicidal thoughts
- devices and equipment used – gastrostomy feeding tube, suprapubic catheter, walking stick, wheelchair, commode, dressing stick, personal medical monitoring system (e.g. VitalCall)
- food consistency and diet – pureed food, normal food but thickened fluids or normal diet and thin fluids
- medications and side effects
- carer stress – ask carers how they are managing and whether they have any health problems of their own

Examination

Assess:

- blood pressure – should be as low as possible without symptoms of hypotension (at least <135/85 mmHg)[6]
- cardiovascular status – atrial fibrillation, cardiac failure or murmurs, carotid bruits
- respiratory status – swallow deficit poses risk of aspiration
- transfers – chair to standing, standing to examination couch
- mobility – stick use, hemiplegic gait, stumbling, hemiplegic foot clearance (foot drop), arm swing (abnormal posturing during walking)
- vision – hemianopic, diplopia, eye movement abnormalities
- speech and swallow – dysarthria, dysphonia
- muscle tone – hypertonicity, clonus, spasticity; plus any associated pain
- muscle weakness in face, arms, legs – test reflexes
- hemiplegic shoulder – pain, contracture, poor axillary hygiene
- sensory loss – visuospatial neglect or inattention, hemisensory loss of pain and temperature (risk of burns), loss of proprioception in leg (risk of falls)

Table 2. Assessing a stroke survivor: communication skills

- Check the patient's ability to hear and see
- Establish how many steps the patient can comprehend by asking him or her to:
  – close your eyes (one-step command)
  – close your eyes and open your mouth (two steps)
  – close your eyes, open your mouth and poke out your tongue (three steps)
- Establish naming ability by asking the patient to name three items of increasing complexity. For example:
  – show a watch
  – show the band of the watch
  – show the clasp of the watch
- Establish repetition ability by asking the patient to repeat a number sequence such as 1,2,3,4 and the phrase 'No ifs, ands or buts'
- Establish alexia and agraphia by asking the patient to read and write

reduce recurrent stroke even in normo - tensive patients.

Tight diabetic control is extremely important, and needs to be reviewed regularly. Also, a healthy diet, smoking cessation and avoiding excessive alcohol should all be encouraged.

Many stroke survivors (up to 35%) have concurrent coronary and carotid artery disease, and cholesterol reduction is important in these patients. Although the relation of statin use to stroke prevention is much looser than to ischaemic heart disease prevention, it is likely that more than 22% of stroke survivors will die from a cardiovascular event.[10]

Exercise is required on a daily basis to minimise muscle contractures, assist in blood pressure control and improve endurance and spasticity. Stroke survivors might need to attend outpatient rehabilitation centres where specialised home exercise programs can be developed. Carers are often trained to help supervise these exercise programs and physiotherapists may monitor an individual's program once or twice over a six-month period.

A medication review is needed, including of antiplatelet therapy (or warfarin use in those with atrial fibrillation). If a patient is on an antiepileptic medication that is metabolised by the liver (such as phenytoin [Dilantin, Phenytoin Injection], carbamazepine [Carbamazepine-Sandoz, Carbamazepine-BC, Tegretol, Teril] or sodium valproate [Epilim, Valpro]), it may be wise to check liver function tests every six months. If levels are elevated, increasing or associated with symptoms, referral to a neurologist or a rehabilitation physician should be considered. A six-month period free of fits should encourage the gradual withdrawal of the medication, particularly in stroke survivors with cognitive deficits that might be worsened by the sedative side effects of the antiepileptic agent.

Carer stress cannot be overemphasised. The carer should be seen separately or spoken to directly during the patient's consultation. Enquiring about his or her health, cardiovascular risk factors and the number of hours per week he or she has for recreation time, as well as discussing respite services in the community, is vital for preserving the care infrastructure needed by the stroke survivor.[11] In extreme situations, such as family breakdown or acute illness in the carer, inpatient respite care (in a hostel or nursing home) may need to be organised for the stroke survivor.

Table 3. Assessing a stroke survivor: activities of daily living (ADLs)

ADL functioning levels

- Independent – no help needed
- Supervision required – someone standing by just in case
- Assistance required (i.e. dependent) – hands-on help needed

Types of ADLs*

Personal ADLs (PADLs or 'paddles')

- Feeding
- Grooming
- Dressing
- Showering
- Toileting
- Transfers

Domestic (DADLs or 'daddles')

- Cooking
- Cleaning
- Laundry

Community (CADLs or 'caddles')

- Driving
- Shopping
- Gardening
- Telephone use
- Money management
- Medication management

*Domestic and community ADLs also fall in the category of instrumental ADLs (i.e. activities enabling community living).

Post-stroke deterioration

Deterioration after a stroke – 'He or she is just not him or herself' – can be difficult to diagnose and manage. An approach is presented in the flowchart on page 16.

It is essential to determine whether there are focal or general symptoms (such as an overall increase in tone), and acute causes of deterioration should be excluded (Table 4). Acute focal neurological symptoms or signs should be treated as an emergency. The most common infections in people who have had a stroke are chest infections

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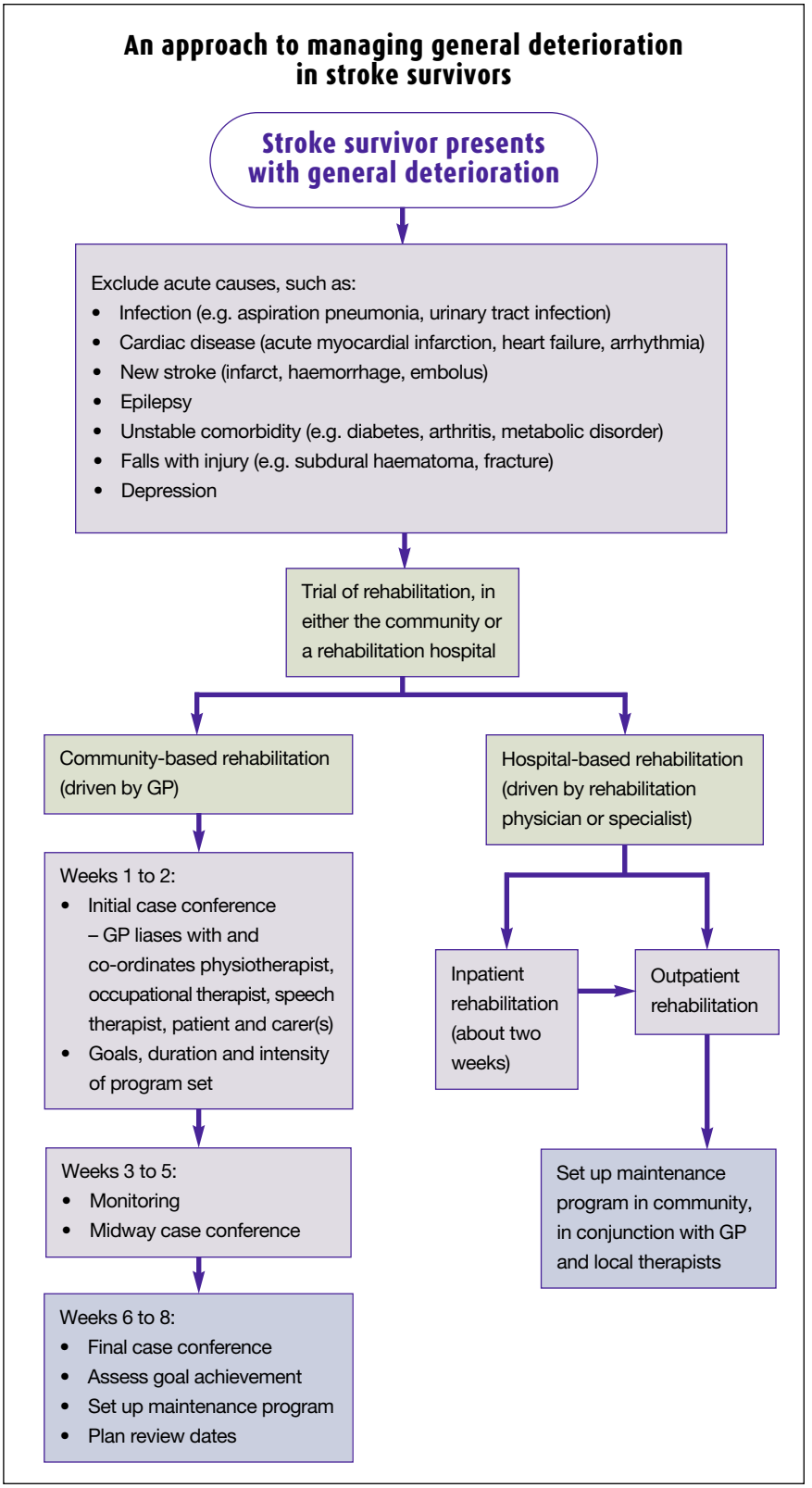

(particularly in those with dysphagia), urinary tract infections and cellulitis. Motor or psychomotor seizures are reported by carers in 5 to 10% of patients, and a work up (including EEG, blood tests [sodium and antiepileptic medication levels] and a brain scan) is necessary in these patients to exclude causes of seizures. Stroke extension, haemorrhage, or fitting despite good antiepileptic cover usually requires referral to a neurologist, physician or rehabilitation physician.

Cardiac disease is common in stroke survivors and they may develop arrhythmias (up to 50% of patients), myocardial infarcts or heart failure. These patients need to be treated urgently because cardiac reserve, related to endurance, is often reduced in patients who have motor deficits.

Falls need attention as sensation can be abnormal and pain may not be reported. Finally, continence changes can be due to infection, constipation or outflow obstruction (for example, prostate disease), as well as failing mobility.

Post-stroke depression

Post-stroke depression can occur as late as two years after the stroke and is often difficult to diagnose. Lack of participation in usual activities and decreasing levels of functioning in ADLs are good indicators, as are suicidal thoughts, sleep disorder and social withdrawal. Personality change, blunted affect, crying, cognitive decline, changes in appetite and weight, and anhedonia can often be confused with the neurological manifestations of stroke (such as cognitive impairment, emotional liability, facial paralysis, dysphagia and immobility).

It is reasonable to give the stroke survivor with symptoms of depression a trial of a selective serotonin reuptake inhibitor (SSRI), choosing one likely to have the least adverse effects in that patient. Citalopram (Celepram, Cipramil, GenRx Citalopram, Talam, Talohexal) or sertraline (Zoloft) are often appropriate.

Tricyclic antidepressants can worsen swallow, cognition and urinary outflow and diminish ADL functioning; these drugs should probably be avoided.[12]

Deterioration in the absence of obvious cause

If there is no obvious cause of a stroke survivor's deterioration, it might be that deconditioning is involved. After the patient's return from rehabilitation he or she may have been allowed to rest excessively and have everything done for them because of circumstances such as environmental change, lack of a support framework, poor motivation or inadequate carer education. Such a 'killing with kindness' scenario may lead to muscle weakness and poor mobility, followed by the development of contractures (usually at the knee and hip but also at the hemiparetic shoulder), falls or even urge incontinence (because it takes too long to walk to the toilet).

In these circumstances a burst of multidisciplinary rehabilitation can be undertaken, either in the community with GPs co-ordinating the treatment or as an inpatient or outpatient of a rehabilitation medicine unit. (The website of the NSW branch of the Australasian Faculty of Rehabilitation Medicine, www.afrmnsw.org.au, has a search engine that allows an entered postcode to bring up all the local rehabilitation facilities and information on outpatient and inpatient programs.) A two-week burst of inpatient rehabilitation has the added benefit of giving the carer a break.

If the rehabilitation is to be done in the community, Australian Physiotherapy Association accredited physiotherapy practices should be able to put you in touch with local private occupational therapists and speech therapists if needed. Therapists can also be found through OT Australia and Speech Pathology Australia, respectively (www.ausot.com.au and www.speechpathologyaustralia.org.au). The initial case conference, a phone hook-up or brief meeting with the therapists, carers and possibly the patient, can set the goals. Possible goals could be the improving of:

- mobility and transfers
- education and carer training
- upper limb strength
- intelligibility of communication
- independence in ADLs.

The physiotherapist, occupational therapist and/or speech therapist will need to see the patient two to three times a week for six to eight weeks to achieve the set goals. Quite often this is a trial by fire, and lack of progress can point to a more serious or complex organic process such as the progression of vascular dementia. For this reason, a case conference needs to be held with therapists, patient and carers about halfway through the process. Another case conference is needed at the end of the process to determine whether goals have been achieved. Medicare Item Numbers 740, 742 and 744 (Medicare Benefits Schedule Book, 1 November 2003) apply for these case conferences. A monitoring stage then follows, during which the GP reviews the patient every few months to ensure the goals are maintained.

It should be noted that rehabilitation in the community can be a costly process (private physiotherapy costs from $40 to $90 per session) and can involve significant transport issues for the patient and carer. It also relies greatly on excellent communication between the various team members.

The rural setting

In rural settings, access to allied health personnel and transport are major issues. It may be necessary to admit the patient to the local district hospital for investigation of deterioration and for physiotherapy and occupational therapy services. Patients unable to return to work such as farming or driving because of deterioration qualify for therapy services provided by the Commonwealth Rehabilitation Service (a government agency with a charter to assist disabled people to return to the workplace).

Telemedicine facilities exist in some rural hospitals and can be used to contact hospitals in large cities for advice from rehabilitation physicians and allied health staff on approaches to post-stroke rehabilitation.

Trainers at local swimming pools, instructors at local gyms and even carers can be educated by physiotherapists to oversee the performing of specific exercise programs.

Table 4. Post-stroke deterioration: acute causes

- Infection – e.g. aspiration pneumonia, urinary tract infection
- Cardiac disease – acute myocardial infarction, heart failure, arrhythmia
- New stroke – infarct, haemorrhage, embolus
- Epilepsy
- Unstable comorbidity – e.g. diabetes, arthritis, metabolic disorder
- Fall – injury to subdural haematoma, fracture
- Depression

Conclusion

Stroke survivors with substantial disabilities are often put in the too hard basket and may be thought of as complex cases with poor outcomes. On the contrary, assisting a stroke survivor in maintaining his or her best quality of life is a great achievement and well appreciated. In the words of one of my patients, a retired doctor: 'I summit Mt Everest every day; thank God for the sherpas!' MT

A list of references is available on request to the editorial office.

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STEVEN FAUX
MB BS, BA, FRACGP, FAFRM(RACP), FFPMANZCA

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