



## Clinical Case of the Month

### Family situation and psychosocial issues including problems that impact on partnership or resettlement in the home and into society

M Kreuter<sup>\*1</sup>, L Butt<sup>2</sup>, M Carroll<sup>3</sup>, CA Glass<sup>4</sup>, S Oberg<sup>2</sup>, A Ohry<sup>5</sup>, JS Richards<sup>3</sup> and S Rutkowski<sup>6</sup>

<sup>1</sup>Spinal Injuries Unit, Sahlgrenska University Hospital, Göteborg, Sweden; <sup>2</sup>Psychology Department, Craig Hospital, Englewood, Colorado, USA; <sup>3</sup>UAB School of Medicine, Spain Rehabilitation Center, Birmingham, Alabama, USA; <sup>4</sup>Regional Spinal Injuries Centre, Southport, Merseyside, England; <sup>5</sup>Department of Neuro-Rehabilitation, Sheba Medical Center, Tel Hashomer, Israel; <sup>6</sup>Spinal Injuries Unit, Royal North Shore Hospital, Sydney, Australia

**Keywords:** spinal cord injury; family; psychosocial issues; care; physical complications

#### Case presentation

A 28-year-old man sustained a fracture of C4 and C5 in a motorcycle accident. Examination revealed a complete tetraplegia at C5 level, ASIA impairment scale A. The patient had been a professional sportsman since aged 18 years and motorcycles and motor races were his great and only interests besides his family. He was living with his wife and two small children in a flat on the third floor, with an elevator available. The family had been travelling a lot in connection with the patient's motor races.

The patient was well motivated and trained very hard during the rehabilitation phase, but he did not reach physical independence in any activities of daily living (ADL). The couple decided not to have any home health aid, although they were strongly advised that the wife should not act as a caregiver.

Three years after the accident. The patient needs help with his personal care and all daily activities, such as assistance with bowel and bladder care, dressing and transfers. His wife, his mother and another close relative assist him with personal care and daily activities. He is quite good in propelling and manoeuvring the lightweight wheelchair indoors but he is dependent on assistance outdoors. The patient is not working nor is he studying or making plans for the future, and he hasn't found any new interests or hobbies. He refuses to see people from the patient support organisation. He mostly stays indoors and feels rather depressed because of his current situation. He is frustrated, he has problems with bladder leakage despite the use of a condom device, his shoulders are painful, he has severe spasticity and he often feels very cold. The couple have stopped virtually all social activity because of the difficulties in getting out and loss of energy. The family has no car, so the patient is

reliant on a taxi service, which is provided for all that cannot use public transport. Furthermore, he has to be transported in a specialised handicap-adapted vehicle, as he is not able to transfer from wheelchair to car without help. The loss of spontaneity and feelings of being dependent on others even for mobility are a source of considerable frustration.

The wife is exhausted and explains that she feels like she has three children instead of two. The patient expresses concern about the strain imposed on his wife and says that this often gives rise to feelings of guilt and conflict. Furthermore, they are tired of having other persons in their home every day and think that the patient's mother is interfering in their lives. In spite of the negative impact of having the wife and the mother as personal assistants, the patient and his wife refuse to have anyone else helping him with his needs. Anxiety and stress are apparent in the family and they often argue about stupid things. They both feel trapped.

In spite of all these problems, they have a close relationship and are still sexually active, but less so than previously. The wife means that her sexual desire has decreased, partly because of tiredness and partly because of all the preparations needed before the sex act. The couple realise that the current situation is impossible in the long run and they have considered divorce.

What would your advice be?

#### First opinion

*Lester Butt, PhD, Head of the Psychology Department and Steven Oberg LCSW, Family Service Counsellor*

It would be the natural tendency of most professionals to render clinical assumptions in response to this vignette. Given the dearth of clinical 'facts' included herein, the tendency to 'fill in the blanks' with

\*Correspondence: M Kreuter, RPT PhD, Spinal Injuries Unit, Dept 12, Sahlgrenska University Hospital, SE-413 45 Göteborg, Sweden

projective constructs is high. It is felt that this approach is fraught with inherent liabilities, in that there is the inclination to utilize bias and prejudice in appreciating the origin and complexities of this couple's behaviour. All too frequently, clinicians react in pejorative manners while contending with individuals and family systems that do not comply with our internal definitions as to what constitutes a 'good patient and/or family.'

Our advice is directed toward the clinician, in service of a comprehensive, objective appreciation of the multi-faceted nature of non-compliance. This analysis provides the health care professional with the requisite vision into those potential factors that are catalysts for poor adherence. When conducting a non-compliance evaluation, the health care provider must look towards multiple factors. These include the following: patient, health care provider-patient relationship, regimen, staff-organizational, and family/socio-cultural variables. The following sections illustrating these factors are meant to be exemplary, not in any manner exhaustive.

*Patient* variables that lead to non-compliance include the following: a maladaptive personality style eg, negative attitudes towards authority, fear of dependency, etc; secondary gain emanating from the disability; the presence of irrational fears and beliefs; the need to present oneself in a unilateral positive image, eg shame regarding the SCI, fears of rejection, etc.; feedback may be seen as critique leading to resentful, oppositional behaviour; the need to defeat and render the staff professionally impotent; the presence of self-defeating ideation and anticipation of inevitable failure, eg internal dialogue of helplessness hopelessness, demoralization; the demands of the required treatments are not within the person's behavioural, cognitive, or affective repertoire due to mild head injury, anxiety, depression etc.

*Health care provider and patient relationship* variables leading to non-compliance can emanate from non-collaboration. An affective tone of non-caring, non-understanding, and non-empathy by staff can readily disenfranchise the patient from the process of rehabilitation. Additionally, divergent goals, expectations, and/or priorities can lead to a compromised relationship between the health care professional and the patient.

*Regimen* variables that can heighten compliance include, but are not limited to, full explanation of diagnosis and aetiology of symptoms; emphasis upon the beneficial impact of treatment compliance, the inherent risks of non-compliance; possible presentation of information in both written and verbal forms; heightening simplicity; and assistance in the integration of the prescribed regimen into the person's lifestyle.

*Staff-organizational* factors that can lead to non-compliance include both psychological issues on the part of certain staff members, as well as more direct systems related concerns. These include the need by certain staff to appear unconditionally knowledgeable

and correct, over-identification with the individual with SCI and/or the associated family, lack of staff continuity; and unrealistic clinic hours and scheduling times.

*Family-sociocultural* factors that can interfere with compliance involve competing family and work pressures, family reinforcement of negative patient behaviours, the presence of a family belief system contrary to compliance, and lack of information regarding the requested treatment regimens.

An additional concern is lack of reported prospective thinking on the part of the individual with the spinal cord injury. What is occurring on a subjective, internal level to create such an impasse in the accommodation to his injury? This needs a full exploration in the attempt to provide the clinician with heightened appreciation as to the nature of his crystallized stance *vis a vis* the spinal cord injury. An analysis of his thought processes could well prove invaluable in service of further delineating his possible distortions and biases regarding the disability and future. These may well involve the confusion as to his own identity, body image, and sense of disdainful dependence in light of his premorbid life style.

It is imperative for the clinician to use this assessment conceptualization, coupled with an appreciation of the world through the disabled individual's eyes, to more fully understand the nature of non-compliance. Included here is the forthright appreciation of any bias/prejudice carried into the relationship by the clinician. A trusting relationship must be formed, wherein the patient and/or wife feel that the health care professional is present in an understanding, non-critical stance. Only via this type of relationship can the clinician gain a window into the family's world that is the potential harbinger of constructive change.

## Second opinion

*J Scott Richards, PhD, ABPP, Professor and Director of Research and Michelle Carroll, PsyD*

This is a difficult but not unusual circumstance, particularly early post injury. At his level of injury, there are very few high risk options he can pursue as substitutes although there are some pursuits available if he is open to them: scuba diving, adapted shooting sports, etc. However, he may not be receptive to alternative activities; he still may be at a point of adaptation where if he cannot pursue activities he formerly enjoyed in the way he enjoyed them, he may be opting not to pursue anything. 'The problem' can be conceptualized as residing simultaneously in three places: the patient, the family and/or the environment. If the patient and wife are willing to engage in counselling, the most productive place to start is likely on physical/environmental interventions. These are best explored simultaneously with the attending physician. For example, it is apparent that independent mobility

was an extremely important value for this young man prior to injury but he currently has that independence only in his apartment. If a power wheelchair could be provided, he would have the independent means for leaving his apartment and getting outside, and this should provide very positive benefits. Given that he has chronic shoulder pain, this may prove to be the rationale necessary to justify that such a power chair is necessary. However, if bladder leakage remains a problem, even if this young man has the opportunity to leave his apartment, he may not do so for fear of bladder accidents. Again, working with the attending physician to remedy this problem will be important in terms of providing the security for this young man to begin venturing out again. Spasticity needs to be addressed so that he is not subject to being thrown from his chair. Even if the usual oral medications do not work in his case, other options are now available (for example, intrathecal medications) which should remedy this problem. If these problems can be remedied in a systematic fashion, these should provide motivation, encouragement and hope that in general at least some problems and obstacles can be overcome which negatively impact quality of life. Ideally, this patient should be taught, if possible, to drive and provided with transportation, since regaining the ability to drive for persons with spinal cord injury is inevitably an extremely liberating and uplifting event.

With the initial efforts of the couple, the psychologist and collaborating attending physician focused on the above physical problems, rapport and trust should build sufficiently that attention can be turned to patient and family issues. A major concern is the strain of caregiving for his wife who also has two young children for whom she provides care. It would be important to find out which member of this couple is so opposed to having external help provided. The patient expresses guilt over his wife's fatigue and they both feel invaded by other caregivers particularly his mother, yet are adamantly opposed to outside help. These are conflicting beliefs/feelings and may need to be separated out in individual counselling. With this kind of conflictual thinking about outside help, this couple understandably feels 'trapped' leading to feelings of hopelessness and despair particularly about coping with this situation in the long term. If such despair turns to a major depressive disorder, diminished energy and affect will further dampen their spirits and achievements, and limit their problem solving ability. If in fact a major depressive episode is present in either patient or wife, antidepressants are indicated with counselling. Such therapy could focus on prioritizing problems and, importantly, starting with the most probable in terms of being solved and working through those problems so that they experience some success with the counselling process. If he is receptive, a cognitive behavioural approach to reframing values and interests would be helpful; when more energy is available, assigning pleasurable outings for the two of them as a couple would be important so

that they can begin to stockpile pleasurable activities together and not simply SCI 'maintenance' activity. Ideally it would be helpful to gather personality data from this young man since treatment would be quite different if there is evidence of substantial personality disorder than if there is not.

### Third opinion

*Clive A Glass, PhD, FBPsS, Consultant Clinical Psychologist*

It is important in the first instance to find a way into the problem. Both partners, despite their initial refusal of external support have reached a point where they consider support is required and must be considered motivated to find a positive course of action.

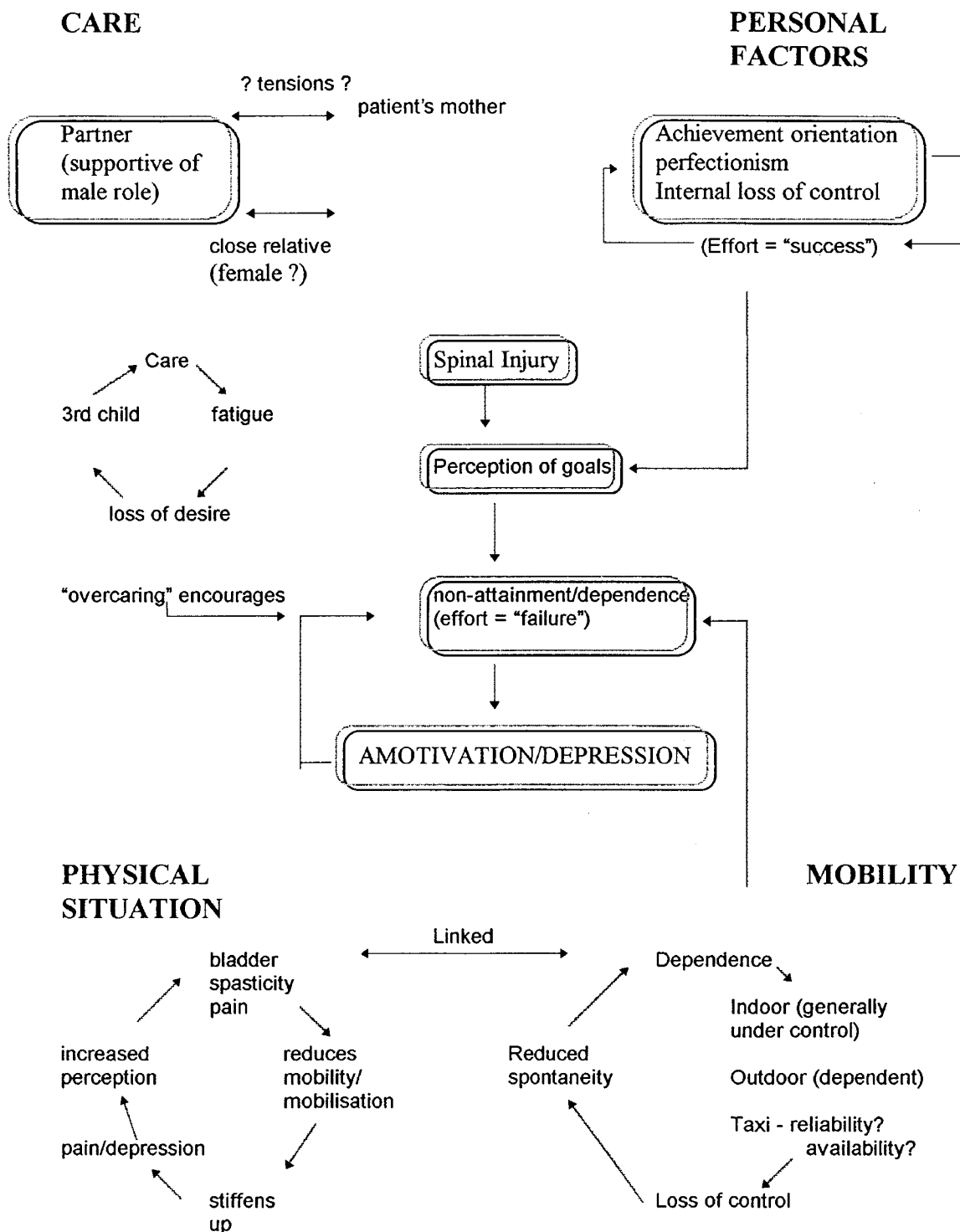
It will be important to establish cognitive and behavioural goals which are attainable and which have meaning for the patient. The role of his wife is crucial in both developing these goals and providing support in their attainment and I would recommend an initial consultation with both partners in the home environment; attendance at a hospital or clinic may only serve to reinforce the development of external elements of control and if the intervention is to have any lasting effect it must be seen as the responsibility and under the control of the patient and his wife (I am presuming his sporting background is associated with a clearly established internal locus of control). His wife (or indeed a close carer in other cases) is of crucial importance in this initial planning stage as, despite her emotional involvement, she is able to provide a more realistic interpretation of his behaviour. I purposefully use the word realistic, as his depression is likely to make him view all his behaviour as negative, whilst his wife, who remains close, is more likely to recall some positive events.

Whatever goals are set they must be attainable and meaningful to the patient. There are clearly a number of physical problems which must be addressed before the patient and his wife are likely to feel comfortable enough to give all their attention to addressing his psychological needs. All behaviour occurs as a function of the individual's prior learning history and their personal and environmental circumstances; physical comfort is fundamental to these issues. By reducing the avoidable physical complications the mood of both partners is likely to be optimised. This would be a good point to commence psychological intervention.

I would spend time whilst these matters were being addressed developing a functional analysis of the dynamics of the patient's situation. If we accept that the central behaviour requiring modification is the depression/loss of direction or amotivation then a number of factors are likely to be maintaining this position. I have developed this further below (Figure 1). For the sake of clarity I have separated the important variables into four areas;

*Personal factors* There may be an element of competitiveness and perfectionism regarding his pre-trauma behaviour, which essentially met with success whilst his attempts at rehabilitation have not resulted in independence. His perception of 'failure' to attain

independence may be considered a reflection of this aspect of his personality. His situation depresses him. He therefore retains some insight into the effects of his situation and his behaviours on himself and other family members. He may be considered to be depressed



**Figure 1** Factors associated with the development and maintenance of amotivation/depression following spinal cord injury

about being depressed; retaining such a concern is often a positive variable associated with eventual resolution of the problem.

*Care* The family were well advised not to become primary carers. The dynamics which operate between the wife and mother would need to be addressed and any tensions resolved. In assuming the third care provider is also female, the patient is faced with an entirely female source of interaction whereas his life around motorcycles would most likely have been male dominated. Consideration must be given to involving external carers and I would want to clarify the reasons for the reluctance of the patient and family not to accept this (see Figure 1). This must change if any meaningful improvement in their relationship is to be effected. There are considerable difficulties shifting between the role of carer and lover. His wife clearly sees his dependence on her as equivalent to having a third child and until this perception is altered, as his independence is enabled, I would suggest the couple place their sexual activity on hold. It will be important to stress to both partners the rationale behind this and to encourage open, honest communication to address their initial concerns.

*Physical complications* His bladder management requires reassessment and should be relatively simple to overcome. His shoulder pain may be postural or neuropathic. If the former is the case a programme of gradual mobilisation and increased activity is likely to significantly reduce the problem. If it is neuropathic some pharmacological intervention in conjunction with increased activity and psychological support should be of benefit. His increased spasticity may be a consequence of bladder difficulties and once this is resolved the spasticity may improve. If not, pharmacological management must be reassessed. Reference is also made to the patient experiencing the cold and despite the assertion that the patient worked hard at his rehabilitation he has not developed good insight into the implications of his trauma. Loss of thermoregulation is common in tetraplegia and part of his rehabilitation would have involved developing an awareness of environmental effects of his body temperature. If he feels cold, either he is not managing temperature homeostasis or he does not understand that feeling cold is not necessarily indicative that his body is cold.

The first step should be to identify the extent of these physical problems and enable the patient to take responsibility for organising the clinic appointment to begin to address these matters; the clinical psychologist could suggest the patient arrange with the community liaison nurse at the spinal injuries centre to visit him prior to this to clarify the problems in more detail. Either way, the contact remains the patient's responsibility.

*Mobility* His outdoor capabilities are restricted and it will be important to establish why he has not accepted an electric chair. Patients are more often concerned about the perceptions of others of their appearance in

a wheelchair. Given his personal factors he may well consider such a chair reinforces his disability. Addressing the distinctions between impairment and disability may be of benefit; struggling to push a chair outside is commendable but pointless if after arriving at the destination further activity is impossible through fatigue.

Developing interests/sources of reinforcement outside the home may also encourage acceptance of mobility aids. Assuming he retains his interest in motor sport, attending a local race meet, trade fair or dealership may be of benefit. Patients in similar situations commonly state that because they cannot take part as they did before their accident why bother? In such circumstances, altering the emphasis from physical involvement to training others, becoming involved in racing development, administration, or CAD/CAM (Computer Aided Design/Computer Aided Monitoring) issues begins the process of shifting emphasis; in this case his aspirations or concerns for his children's involvement in sport might be used to enable him to think such issues through.

As each individual involved in the home interacts so too do each of these four areas. The resultant cycle of poor physical circumstances, isolation and amotivation are mutually reinforcing. Breaking the cycles that operate in any of the four areas is important but in isolation likely to be of only limited benefit. I have provided a framework within which the psychological problems might be addressed but the specifics of intervention would depend on the professional appointed to the case. I would use a cognitive approach to examine how the patient's thoughts influence his feelings; I would ask him to try to remember the thoughts he has during times of feeling particularly low, whether these thoughts produced the unhappiness and whether the recollection produces similar effects. I would then ask the patient to contrast these thoughts with thoughts associated with a time when he felt happier. Once he became able to distinguish between his thoughts and feelings, it would be appropriate to address the intensity of these feelings and begin a process of enabling him to challenge these feelings and thoughts. Success in resolving less crucial issues would reinforce attempts at exploration of increasingly disruptive thoughts and feelings, and re-establish positive coping strategies. Such intervention usually takes between 10–20 sessions.

Reading through the above paragraph the process sounds ponderous. The actual process is more fluid; it revolves around the patient's use of his own experiences by his own use of language and the skill of the therapist is essentially to respond in a way the patient can understand. Through this the patient will accept and develop his own answers to his problems in a supportive environment. The involvement of his wife in this process either from the outset, or as both partners become comfortable with the ideas, would be of considerable benefit.

## Fourth opinion

Avi Ohry, MD, Associate Professor

Based on our own centre's experience and on existing statistics concerning complete tetraplegics, the prognosis for this couple's survival as a partnership is problematic, even pessimistic. However, because of their loving relationship there is reason for hope. I would urge the patient and his wife to accept intensive multi-disciplinary counselling by the rehabilitation team, for each of them individually and as a couple. They are faced with two possibilities: the first, to move the patient to an institution for chronic patients. This is the easiest solution, but it means the couple's break-up and the end of their family life. In the long run there might be no other alternative, but it is certainly worth trying something else before this. The second possibility, based on the couple's strong relationship and desire to raise their children together, would call for the following changes;

- 1 The patient's nursing needs should be taken over by paid help from outside the family. His wife and mother should only act as caregivers to relieve the helper during his or her time off. In Israel, 24-h local and foreign help for the chronically disabled is legally available at a reasonable price.
- 2 The patient should receive vocational counselling. With his vast experience in motor racing, some professional tutoring and acquisition of computer skills he could become a sports journalist or work for a sports organization. In Israel he could also participate in accident prevention programmes for schools, in which the disabled from such accidents play an important role. A work-related activity is essential to revive the patient's self-esteem and social status.
- 3 The patient and his wife should be encouraged to go out for short, then longer outings. Trips are also possible and can be organized. The wife should also be encouraged to take separate vacations occasionally.
- 4 The wife should be strongly advised and helped to work part-time outside the home.

The conclusion to be drawn from such cases indicate that during the rehabilitation process strong emphasis should be put on vocational counselling before the patient leaves hospital and also in the importance of employing outside help. During hospitalisation patients often do not realise the future impact of these questions. The rehabilitation team must make every effort so that the patient and his family understand these principles.

## Fifth opinion

Sue Rutkowski, MBBS, Director, Spinal Injuries Unit

This case as presented poses a significant problem to address in that the patient and his family have

established a set pattern of living making any change difficult. I assume the couple approached the treating Spinal Cord Specialist for advice, otherwise as an observer of the psychosocial situation it would be more difficult to proffer advice.

Ideally I would involve a multidisciplinary team approach. An appropriate team member with counselling skills should interview the patient and his wife both separately and together. When assessments of physical, functional and psychological status have been undertaken there should be a meeting held with all the parties involved. I would think some advice could be offered and agreed goals could be established at this stage.

The assessments are likely to provide the team with some suggestions for the couple in the following areas:  
*Medical* The bladder leakage should be investigated by renal and bladder imaging (possibly using ultrasound) to establish normal upper tracts and exclude urinary tract calcification. Alternate urinary collecting methods could be explored and consideration given to suprapubic cystostomy with the use of anticholinergics. Spasticity may well be addressed by improving bladder management and other sources of increased afferent input should be excluded.

Methods to manage poor temperature control should be explained to the couple as they may not have been totally aware of this at initial discharge.

Painful shoulders would of course be aggravated at this stage by overuse of imbalanced musculature due to the C5 neurological level. Use of a motorised wheelchair outdoors or even indoors should be advised along with review of transfers in regard to use of a hoist. This may also address the loss of energy that the couple describe.

*Physical/Mobility* The use of a motorised wheelchair outdoors should be strongly advised and other methods of exercising advised such as rowing type activities. As mentioned above, the use of a hoist, at least in part may assist the carers as well as the patient's shoulders.

*Psychological* Both patient and his wife should be assessed for depression and if possible the patient should also have a neuropsychological assessment for possible cognitive impairment due to brain injury associated with the initial motorcycle accident. These assessments will provide information as to whether treatments such as cognitive behavioural therapy may be of some benefit.

This man, with a background of motor racing, will have a strong drive to remain 'in control' and any change may be strongly resisted. This process may require repeated counselling sessions both individually and together.

*ADLs* Use of outside carers should be strongly advised and perhaps introduced gradually to allow his wife to undertake some activities outside of the home such as shopping or taking the children to activities etc. It should be suggested that the carers will be trained to perform the assistance in regard to his

bladder, bowel, bathing, dressing, grooming etc to his direction so that he can maintain control. This should remove one daily cause of stress which possibly occurs when his family act as carers.

*Vocational/leisure* Availability of courses or leisure outside the home should be explored; if necessary through peer support assistance. Encouragement to leave the house independently in a motorised wheel-

chair would help 'normalise' the relationship by allowing each partner have their own time.

This advice and any intervention for the couple would need to be given in a non-confronting manner – to avoid resistance and rejection of the proposed change. The couple may manage to find enough 'life' within the relationship if even only some of the issues are addressed.