

Paediatric patients with myalgic encephalomyelitis/chronic fatigue syndrome value understanding and help to move on with their lives

Katherine Rowe 

Royal Children's Hospital, Murdoch Children's Research Institute, Melbourne, Vic., Australia

Correspondence

Katherine Rowe, Department of General Medicine, Royal Children's Hospital, Hon Research Fellow, Murdoch Children's Research Institute, Flemington Road Parkville, Vic., Australia 3052.
Email: kathy@rowereresearch.com

Abstract

Aim: The aim of this study was to document qualitative questionnaire feedback regarding management from a cohort observational study of young people with myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS).

Methods: Between 1991 and 2009, 784 paediatric patients, age 6-18 years, were diagnosed with ME/CFS following referral to a specialised clinic at the Royal Children's Hospital, Melbourne. Over a 14-year period, feedback was requested on up to seven occasions.

Management included the following: symptom management and a self-management lifestyle plan that included social, educational, physical and a pleasurable activity outside of home. They adjusted it by severity of illness, stage of education, family circumstances and life interests.

Results: Questionnaires were returned from 626 (80%) with 44% providing feedback more than once. They reported that their management plan allowed them to regain control over their lives. They cited early diagnosis, empathetic, informed physicians, self-management strategies and educational liaison as helping them to function and remain socially engaged. Ongoing support, particularly assistance to navigate the education system, was essential for general well-being and ability to cope.

Conclusion: Young people valued regaining the control over their lives that was lost through illness, support to maintain social contacts and assistance to achieve educational and/or life goals.

KEYWORDS

adolescent, chronic fatigue syndrome, feedback, management strategies, myalgic encephalomyelitis

Abbreviations: ME/CFS, Myalgic encephalomyelitis / chronic fatigue syndrome.

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1 | BACKGROUND

Myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) is a condition of unknown aetiology that commonly follows an infective process in young people. There is a new onset of fatigue for at least 3-6 months that is not relieved by rest and not explained by other medical conditions. Post-exertional malaise, cognitive difficulties and unrefreshing sleep are present. In addition, a variety of somatic symptoms is commonly present such as headache, abdominal or muscle pain, as well as flu-like symptoms without fever, and symptoms associated with orthostatic intolerance.¹⁻⁵ Although case definitions have become more refined,^{6,7} the key features and symptom patterns in young people have remained consistent.^{5,6,8,9} Anxiety and depression may also be presented but when compared with population levels were only mildly increased in prevalence and generally did not precede the illness. They were understandably associated with diagnosis delay, not being believed or social isolation.^{9,10}

A follow-up study published in 2019 of young people indicated that of those that reported recovery, the mean duration of illness was 5 years with a range from 1 to 16 years.¹⁰ This was consistent with Bell's findings¹¹ and the follow-up of the placebo group from the immunoglobulin trial.¹² In each, there was a residual group of affected young people that did not report recovery,^{10,11} but there were no clear predictors for improvement.¹⁰

This is a frustrating illness for which there is no defined treatment, as the underlying pathology is not well understood.¹³ In addition, chronic illness occurring at a time of significant changes in young people, disrupting their educational, social and physical activities, creates significant challenges both for the young people and their families.^{14,15} It is the commonest cause of reduced time at school^{16,17} and has a significant impact on educational functioning.¹⁸

Although there are other chronic illnesses during childhood that have physical, emotional, cognitive and educational impacts,^{19-22,24} this illness does affect all these areas. Therefore, in addition to managing symptoms, strategies for coping with this chronic illness and its impact on the young person and the family have been central to its management in this clinic.¹⁰ If social interactions are neglected, there is a risk of social withdrawal and anxiety. If educational opportunities are not available, there is a loss not only of aspirations, but also of ability to have satisfying work that can be less physically demanding and may be better paid. Neglecting to attempt to perform some form of physical activity, even if bed-bound, can result in the young person not being sure whether they cannot perform tasks because they are unwell or they are de-conditioned. Finally, by committing to attend regularly something enjoyable and worthwhile outside of home, they reduce the risk of using the illness as an easy excuse to avoid effort. They consider the effort worth the recovery time. Each plan was individually devised by the young person where some of these activities might be combined. Neglecting these aspects can compound the effect of the illness and impact on the developmental tasks of adolescence or the transition to or from adolescence.

Key Notes

- A cohort observational study of 784 young people with myalgic encephalomyelitis/chronic fatigue syndrome provided feedback across a 14-year period regarding helpful strategies and ways to improve management.
- Early diagnosis, empathetic informed physicians, assistance with symptom control, self-management strategies, educational liaison and advocacy enabled them to regain control, remain socially engaged and function optimally.
- Doctors and teachers awareness of helpful strategies could significantly reduce distress with this illness.

Parents have a role in helping navigate these tasks, as well as trying to manage an unwell child.^{19,20}

The aim of this study was to document feedback obtained from the open-ended questions in follow-up questionnaires from a cohort observational study of 788 young people with ME/CFS. Their opinions were sought regarding ways to improve their management, and what information and strategies they found helpful.

2 | METHOD

A specialist ME/CFS clinic in a tertiary referral paediatric hospital that services both urban and rural areas in the state of Victoria, Australia, has been functioning for over 20 years. ME/CFS was initially diagnosed using Holmes criteria.² However, as the illness was not well documented in young people, data regarding symptoms were collected⁸ and contributed to the paediatric case definition.⁵ The characteristics were noted to be consistent over time.¹⁰ As part of a cohort observational study to assess recovery rates, feedback had been formally requested from 788 children and young people diagnosed over a 14-year period between 1994 and 2008. Of these, 409 had provided questionnaire-based symptom¹⁰ and depression (Beck et al²⁴) data and the majority of the regular follow-up questionnaires. There was a maximum of seven occasions when a questionnaire was distributed. This feedback questionnaire (Appendix 1)¹⁰ not only indicated the progress of the illness but what information, recommendations or aspects of management had been helpful or otherwise. The management strategies and illness outcomes have been reported previously,¹⁰ and this report focuses on the details of the feedback regarding management. Responses from questionnaires returned during the early years (1996-2000) of the clinic were compared with later years (2002-2010) coinciding with increasing recognition of the illness. Data were entered in spreadsheets and categories of responses identified and quotes selected. Responses from individuals provided on several occasions were compared for consistency or change. Descriptive data, chi-square and t tests were analysed using Statistica 13 (Statsoft-TIBCO).

Formal ethics approval was not required for the feedback questionnaires obtained during the clinic, as it was considered part of

routine clinical care; however, informed assent was obtained from the young person and a parent, if applicable. For the follow-up study that also included these questions, institutional ethics approval was obtained to contact the last known address to obtain consent to forward a questionnaire. Informed consent was again obtained.

3 | RESULTS

3.1 | Participants

A total of 1150 formal feedback responses were provided by 626 of 784 (79.9%) young people (25.5% males) on up to seven occasions over a 14-year period. Follow-up occurred a mean of 8 years (1-21) after the onset of illness. The mean number of occasions was 2.2 (range 1-5), and 43.8% provided feedback on more than one occasion. Table 1 provides details of the total cohort as well as the groups providing either clinical data alone or supplementary formal questionnaire baseline data. During 1996-2000, 264 questionnaires were returned from those who completed baseline information and the remainder of the returns occurred between 2002 and 2010 over

TABLE 1 Characteristics of the groups providing clinical data or additional baseline data

	Formal baseline data n = 409	Clinical data only n = 375
Total cohort n = 784 (M:F 1:3) Mean age 22.5 y (range 7-35.7 y) Follow-up (FU) data from 626 (79.9%) Mean length FU 8 (1-21) y Proportion reporting recovery 43% Mean duration illness 5 y (1-15) (n = 298)		
N providing FU data (%)	349 (85.3%)	277 (73.9%)
No of returns	832	318
N providing multiple occasions	220 (63.0%)	54 (19.5%)
Age at FU (range) years	23.2 (14.6-33)	21.9 (7-35.7) ^b
Mean length FU years	8.3 (1-19)	7.6 (1-21.6) ^a
Mean duration illness (months) until help/diagnosis	13.4 (3-72)	13.8 (3-84) (ns)
Proportion reporting recovery	46% (n = 156)	40% (n = 110) ^c
Mean duration illness (years)	4.9 (1-14)	5.1 (1-15) (ns)
Proportion scoring as depressed (Beck) ²⁴	75/368 (20.4%)	
Most pronounced ill-health score (Bell) ²⁵	1.9 (0-5)	2.2 (0-6)

^at test $P < .05$.

^bt test $P < .005$.

^cChi-square 6.8 $P < .01$.

four occasions. Between 2008 and 2010, the whole cohort was followed up.

3.2 | What was found to be helpful?

The responses to this question fell into five broad categories: relationship with the clinician; provision of self-management strategies; symptom and medical management; school liaison and advocacy and emotional support. The responses from individuals were consistent across each of the survey occasions.

As questions were open-ended, not all provided additional information. Twenty per cent of all the returns cited the importance of the clinician taking them seriously, being understanding, kind, caring and patient. Similarly, providing emotional support, being supportive and helping and supporting the family as well, was reported with comparable frequency. Providing follow-up was implied in many of the responses and also specifically stated in many responses. Follow-up, however, was regular but not necessarily frequent, generally 3-4 times per year after the initial consultations.

A quarter of the responses included management strategies or sensible, practical advice as being helpful. Some expanded on these statements to indicate that they now felt more in control of their lives and could make decisions about what they could manage, and were supported in those decisions. They had a framework within which to deal with the illness. In addition, comments about the importance of being provided with a diagnosis, an explanation and current information was commonly combined with the comments about practical advice and support. Some stated that a diagnosis was reassuring as it excluded more serious concerns such as malignancy.

Symptom management including general medical care, and specific comments about headache, muscle pain or menstrual pain were identified in 18% of responses. A similar proportion cited liaison and advocacy with schools and teachers as crucial, providing advice and assistance with educational planning. Thus, educational assistance was rated with similar importance to medical care.

Finally, the remaining comments tended to deal with emotional support but were quite specific about help with dealing with depression as well as giving hope again. Feedback to their family doctor to provide guidance and validation was also in some comments.

3.3 | What could have been handled better?

The 264 returns from 156 respondents from the earlier years (1996-2000) indicated that 62% considered their management could have been improved.

These responses covered three main areas: knowledge, recognition, understanding and attitudes by doctors and teachers, family and general community; earlier diagnosis; and improved self-management and emotional well-being (Table 2).

From the 24% of respondents who provided two returns and the 13% who provided three returns, the suggestions were very consistent. The only variations over time related to family understanding and self-management. This included management of emotional

TABLE 2 Percentage of all responses with suggestions for improved management over the three survey periods in the early years of the clinic

	1996 returns % (n = 53)	1998 returns % (n = 75)	2000 returns % (n = 136)	Total % (n = 264)
Percentage who thought management could be improved	68	71	54	62
Areas for improvement				
1 Medical, school, family, community understanding				
Arrogance/ignorance medical profession	28	13	18	19
More understanding and help at school	17	12	12	13
Family/community understanding	4	7	13	9
2 Earlier diagnosis				
Earlier diagnosis	9	13	12	12
3 Emotional, self-management issues				
Emotional issues, depression	6	5	2	4
Improved self-management	11	12	8	9

issues, the need for moral support as well as managing themselves better by learning to pace their activities, manage sleep and maintain social contact. Comments regarding understanding, ignorance or perceived arrogance of the medical profession or lack of support from school staff were consistent from individuals over time. However, the proportion of respondents who reported this did reduce. To place this in context, ME/CFS was very rarely recognised or accepted as a diagnosis at that time, even amongst paediatricians, and the mean duration of illness before diagnosis was 18 months (range 1-6 years). Considering their level of disability and loss of time from school, this amount of time without knowing what was wrong, understandably caused significant distress.

In the survey period between 2002 and 2010, 57% of the 570 respondents who provided 740 returns, indicated that there could have been improvements in their management (Table 3). This involved the following: earlier diagnosis and access to management strategies;

more understanding by doctors, community and teachers; improved assistance at school; self-management concerns; emotional support including for depression; and medical liaison and advocacy.

The most common response (mean 14%) cited the need for an earlier diagnosis and access to management strategies. This was frequently linked to helping prevent depression. There were comments regarding the need for more understanding of the illness both by the medical profession and also by teachers at school. Concerns about school related to not being believed or the teachers assuming that they were being lazy. There was reported lack of knowledge by schools of acceptable ways that students could be assisted as well as the help that might be available such as a visiting teacher service, distance education or special provision for assessments. A reduced subject load, or other ways to enable them to navigate the education system, to ensure they could pursue their original aspirations was not often offered. These concerns were associated with comments

TABLE 3 Percentage of all responses with suggestions for improved management over the four survey periods in the later years of the clinic

	2002 returns % (n = 240)	2006 returns % (n = 57)	2008 returns % (n = 270)	2010 returns % (n = 183)	2002-10 Total % (n = 740)
Percentage where management could be improved	65	47	58	36	57
Areas for improvement					
Earlier diagnosis/management					
Community/medical/family understanding	9	19	9	6	9
More understanding and help at school	7	13	10	4	8
Emotional support, depression	6	5	2	4	5
Improved self-management	6	12	7	3	6
Arrogance/ignorance medical profession	3	4	5	5	4
Medical liaison and advocacy	3	3	5	4	4

about a general lack of understanding of the illness by the community and often within their extended families. Sometimes, this was perceived as arrogance, disbelief or providing unhelpful comments including: the illness being all in the mind or that it has to be depression.

Compared with the early years of the clinic, there were fewer complaints about the arrogance and ignorance of the medical profession and more acknowledgement of the role that young people had in managing their illness. Those who reported that they struggled with self-management also reported difficulty learning how to pace themselves. They reported that they struggled with being more positive and being more adventurous occasionally. Within these comments were statements about difficulties managing sleep, healthy diets and appropriate amounts of activity,

There were suggestions for improved medical liaison such as improved education for family doctors so that they could be more constructive in their assistance, if help was needed between hospital outpatient visits. For the transition from paediatric to adult care to be smooth, an awareness of tertiary education provisions and requirements for students was required. This was rarely available. There was insufficient awareness of the impact of postural orthostatic tachycardia syndrome, its symptoms and management amongst paediatricians. In addition, there were comments about the need for regular follow-up particularly after an inpatient rehabilitation programme. The young people felt there was an assumption that the strategies provided should be sufficient for them to manage without further assistance.

Regarding emotional support, 5% indicated that they needed assistance in addition to the clinic care, for stress management, depression, pain management or family support. This included assistance with a parent not understanding the impact of the illness. They reported needing encouragement to remain engaged socially and to access the help of others with the illness, such as a support group. However, several also commented that they recognised that they were not really ready to accept this help when they needed it so it may not have been welcome anyway. They indicated that they should have been more willing to accept help especially for their emotional issues. Others made it clear that practical strategies to regain some control over their life were more helpful than being given medications.

Finally, there were reported challenges with understanding requirements for accessing social security support, or University special provisions or/and conveying information to employers. All of which required medical documentation. However, even if this was provided, it did not ensure that it was well received or produced the desired effect.

The proportion of returns that believed that the management could be improved changed from 68% in 1996 to 65% in 2002 to 36% in 2010.

There was no difference in the proportion suggesting improvements between those that reported recovery (66%) and those that did not (64%). Of those rated as clinically depressed at baseline, 85% provided follow-up data and there was no difference in rates

of suggested improvements in management compared with those who were not depressed (chi-square 1.87, $P = .17$). As reported previously, depression at baseline was not predictive of nonrecovery, but later depression was associated with poorer functional score.

3.4 | What information was useful?

For the young person, the most useful information was having a diagnosis and an explanation of current knowledge. The self-management strategies were cited frequently with comments regarding the relief at being able to make some decisions about their life and feel that they had some control over the illness. They could choose what they could manage. They could pace themselves, and they had some support to pursue their aspirations.

4 | DISCUSSION

The concerns about lack of understanding and recognition of the illness by doctors and teachers were commonly and strongly expressed by nearly a third of the respondents. This was comparable to issues raised by Friedman in his review.¹³ Respondents rated flexibility and support for education as highly as medical treatment in the management of their illness. Different education systems clearly have different requirements,²³ but advocacy by the clinician and co-operation with teachers by providing appropriate documentation to support the young person was highly valued but often not seen as part of the medical role.

Early in the illness, most were unable to attend school but some educational input was generally possible. It may have been via distance education or much reduced school attendance mainly for social reasons. Doctors need to be cognisant of how the schools function that their patients attend, and what is feasible within the daily schedules of students and staff when suggesting assistance. In secondary schools, where students attend between year levels seven and twelve (age 12-18 years), there are multiple teachers teaching individual subjects. These are irregularly timetabled through the day, and it was generally not sustainable to recommend attending school for a specific time each day. This would mean encountering multiple different subjects, and teachers, and having to catch up with work all the time. It was considered better to reduce subjects to a manageable load. For example, they selected teachers they liked, subjects they enjoyed and what they needed as a minimum to progress through the school or for what they needed for their chosen career path. They also needed to consider what was feasible with the timetable. This was reported as much less stressful. Even though the timing of attendance may vary, it was predictable for the family and the school. Every teacher did not have the added burden of forwarding work after most of the classes. The student's peers also knew when to expect them. The young people reported that they were provided with more support from their peers and less criticism or envy because they were missing classes.

In some educational systems, visiting teachers are provided to assist young people with chronic illness and reduced school attendance. Visiting teachers assist the student to integrate back into school, serving as school liaison, assisting with timetabling and balancing school attendance and distance education, if appropriate. They also provide strategies to complete tasks. They have been invaluable in providing support and taking the pressure off parents and students. They provide information to schools, while advocating for students in the schools.²⁶ If there were problems with gaining acceptance or flexibility at school, there was significant distress, often social withdrawal and students reported loss of heart and hope.

Navigating the developmental tasks of childhood and adolescence in the context of chronic illness is challenging for parents.²⁷ For younger patients, there were concerns regarding persistent dependence on parents and anxiety regarding the illness, such as concerns about what was actually wrong and whether there would be recovery. They worried about managing at school, as well as social anxiety when they had been absent from their social network for some time. There could also be depression and a sense of helplessness and powerlessness, especially if some family members, the medical profession or teachers do not understand.²⁸ They reported it would be much easier if they had their arm in a sling rather than constantly feeling exhausted and unwell which is not as obvious. In addition, the transition into adolescence and secondary school was exacerbated when they were not able to attend frequently enough to engage socially.

The developmental tasks¹⁹ of adolescence may fail to progress during the illness and may need to be addressed during management or time allowed for some catch up when the young person is well enough. Such tasks can be difficult for any parent to navigate but even more difficult when the young person is clearly unwell and not able to manage some simple activities of daily living. These tasks include increasing sense of independence and responsibility for their actions, peer relationships, sexual identity and development, assessment of risk, sense of self worth and hope for the future. Persistent dependence, uncertainty about what is required, social anxiety and withdrawal, extreme caution in making decisions, poor self esteem and depression regarding the future can be the consequence of the limitations imposed by chronic illness.

The strength of this study was the high participation rate of a large cohort consistently followed over time, and the frank responses obtained when the participants were given the opportunity to offer their views. This feedback has informed and modified management in a poorly understood illness, especially the importance of continuing social engagement for social learning and the importance of maintaining engagement in education. Minor modifications to the overall plan have occurred but the central importance of providing a self-management framework has been affirmed over time, including for the severely affected patients who provided feedback. This has now evolved into the provision of an intensive self-management programme over 4 weeks for those where outpatient support has not been sufficient.

The limitation of this study was that it was one service in a single state in Australia, and although Victoria is a highly multicultural and multiethnic society with universal healthcare available, the findings of this cohort may not be transferable to another setting. Similarly, education systems may not be as flexible or cooperative in other settings.

5 | CONCLUSION

Young people with ME/CFS identified the importance to their well-being of both clinicians and teachers being aware of their condition, but also feeling understood and believed regarding an illness that few understood and was only recently acknowledged. They also appreciated being able to feel more in control of their lives by having a framework for self-management and the ability to adjust the details of that plan according to their interests, capacity and family circumstances. Long-term follow-up confirmed the importance of remaining engaged in education as well as continuing social contact as central to their ability to function well and cope with their illness.

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CONFLICT OF INTEREST

The author has no conflicts of interest to declare.

ORCID

Katherine Rowe  <https://orcid.org/0000-0002-2165-5028>

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APPENDIX 1

Follow up Questionnaire

Date: / /

Date of birth / /

Name: _____

ID _____

Please tick () the appropriate response.

- 1 Are you attending school/tertiary education/work full time,
 more than half time,
 less than half time?

- 2 Did you, or are you, completing a tertiary course? yes no
 If so, which course/s

- 3 If you are working – what is the nature of your work?

- 4 If you are not at school full time, have you used the Visiting Teacher Services since you were sick? yes no

- 5 Are you still using them? yes no

- 6 Are you enrolled with Distance Education? yes no

- 7 Do you receive the Disability Support Pension? yes no

- 8 Do you feel you are no longer suffering from CFS? yes no

- 9 How would you rate yourself out of 10? /10

(1=bedridden, 10=well)

- 10 When was the onset of CFS? / Month / Year

- 11 How long had you suffered from CFS before it was diagnosed? months

- 12 How long had you suffered from CFS before receiving help? months

- 13 If you have recovered, how long did the illness last? months

- 14 Have you had significant infection/s in the last twelve months?
 yes no

If so, how many?

How long were you unwell on average? weeks

- Did any symptoms of CFS recur? yes no

15 Have you had any prolonged recurrence of symptoms? yes no

If yes - How long did the symptoms last? weeks

Was there any particular or obvious trigger? yes no

If so – what was it?

16 Have you had any other serious illness? yes no

If so – what was / is it?

17 Have you found any professionals helpful? yes no

If so - which ones? _____

In what way? _____

18 Has any information been particularly helpful/useful? yes no

If so - which? _____

19 Is there anything during your illness which could have been handled better or differently?

yes no

If so - What? _____

20 Have you sought alternative treatments in the management of your illness?

yes no

If so - What were they? _____

Do you feel they have worked? yes no

21 Do you have any other members of your family who have (or still have CFS)

yes no

If so, what relationship? eg., sibling (brother or sister), mother, father, mother’s brother, or cousin (on father’s side etc)

22 Any other comments? _____

Thank you so much!

Which level on the CFIDS Disability Scale (Bell) describes _____

- (a) Present level of health _____
- (b) Most pronounced ill health _____

CFIDS DISABILITY SCALE

- 10 No symptoms at rest. No symptoms with exercise. Normal overall activity level. Able to work full time without difficulty
- 9 No symptoms at rest. Mild symptoms with activity. Normal overall activity level. Able to work full time without difficulty.
- 8 Mild symptoms at rest. Symptoms worsened by exertion. Minimal activity restriction noted for activities requiring exertion only. Able to work full time but with difficulty in jobs requiring exertion.
- 7 Mild symptoms at rest. Some daily activity limitation clearly noted. Overall functioning close to 90% of expected except for activities requiring exertion. Able to work full time with difficulty.
- 6 Mild to moderate symptoms at rest. Daily activity limitation clearly noted. Overall functioning 70% to 90% of expected except for activities requiring exertion. Able to work full time with difficulty.
- 5 Moderate symptoms at rest. Moderate to severe symptoms with exercise or activity; overall activity level reduced to 70% of expected. Unable to perform strenuous duties, but able to perform light duty or desk work 4-5 hours a day, but requires rest periods.

- 4 Moderate symptoms at rest. Moderate to severe symptoms with exercise or activity, overall activity level reduced to 50% to 70% of expected. Not confined to house. Unable to perform strenuous duties; but able to perform light duty or desk work 2-3 hours a day, but requires rest periods.
- 3 Moderate to severe symptoms at rest. Severe symptoms with any exercise. Overall activity level reduced to 50% of expected. Usually confined to house. Unable to perform any strenuous duties. Able to perform desk work 2-3 hours a day, but requires rest periods.
- 2 Moderate to severe symptoms at rest. Unable to perform strenuous activity. Overall activity level reduced to 30% to 50% of expected. Unable to leave the house except rarely. Confined to bed most of the day; Unable to concentrate for more than an hour a day.
- 1 Severe symptoms at rest. Bed ridden the majority of the time. No travel outside of the house. Marked cognitive symptoms preventing concentration.
- 0 Severe symptoms at rest. Bed ridden constantly. Unable to care for self.

(See Reference: ²⁵)

Young people's global functional scale for ME/CFS

Score	School/work	Stamina	Recovery	Social	Symptoms
10	Full time If study—often part time job as well	“normal”	Recovers well	Active social life	No residual symptoms. Feels “back to normal” and comparable to peers.
9	Full time—often with part time job as well	Gets more tired than would expect	Can participate in active sport	Good social life	Manages well but needs to “pace”
8	Full time—either work or study not both especially if playing some sport as well	Needs occasional day to “recover”	Needs some time to recover after vigorous activity	Good social life	Has periods with some symptoms and rarely feels “refreshed”
7	Full time either work or study	Reduced load	Some regular sport but usually not vigorous	Some social contact	Continuous symptoms but not severe. Rarely feels “well” but not prolonged recovery time
6	Part time	Reduced load	Infrequent active, regular mild activity eg walking	Reduced social contact and needs to intentionally keep in touch.	Has to carefully plan activity and rest. Symptoms present continuously with fluctuating severity
5	Less than half time	Reduced subject load if studying	Regulates activity—no vigorous activity	Regulated in timing and quantity	Occasionally can attend activity with recovery period—persistent symptoms

Score	School/work	Stamina	Recovery	Social	Symptoms
4	Few hours per week concentrating	Significantly reduced load if studying—both subject and content	Minimal regular activity	Major impact on life	Intrusive symptoms that worsen markedly after activity
3	Minimal participation	Only for short periods across the week	Struggles with activities of daily living	Reduced	Persistent and intrusive
2	Attempting to read but difficulty with recall	Very limited stamina	Limited outside of home. Modified activities of daily living	Markedly Reduced	Persistent and intrusive
1	Not participating	Very limited stamina	Rarely leaving home. Needing assistance with daily activities	Very limited	Constant, moderate to severe symptoms

See Reference¹⁰.