



## Dr Bruce Campbell's self-help course in Australia

### About the program

This program was created by Bruce Campbell, Ph. D, a Chronic Fatigue Syndrome patient who, before becoming ill, was a researcher who worked on self-help programs for arthritis and other chronic illnesses at Stanford University in the USA. The program began with in-person courses in the San Francisco Bay area but later was run as an online course. In the USA the program has been conducted via email discussion groups, with guidance from trained volunteer moderators and using Dr Campbell's book, *The Patient's Guide to Chronic Fatigue Syndrome and Fibromyalgia*, as the text.

The aim of the program is to help participants understand their illness better, reduce symptoms and create a more stable and predictable life. Topics covered include:

- pacing yourself to control the 'chronic illness roller coaster';
- setting realistic short-term goals;
- reducing stress and;
- managing emotions.

A small team of Australian ME/CFS and FMS advocates has pioneered an in-person course based on the program. This enterprise has the full cooperation and approval of Dr Bruce Campbell.

The new course consists of eight sessions, of two hours each, led by trained facilitators. The program is run at cost and includes Dr Bruce Campbell's book *The Patient's Guide to Chronic Fatigue Syndrome and Fibromyalgia* as well as all materials. Refreshments are included.

The course, run in Canberra by the ACT ME/Chronic Fatigue Syndrome Society, has also been held successfully in Sydney and Adelaide.

### More information, and personal experiences

#### 'A Life Regained' - Marian

I was quietly resting, with my feet raised and my eyes closed, when I overheard a conversation in the kitchen between our adult son and my husband.

"Is Mum alright?" he asked anxiously.

"Oh yes, mate; it's called pacing. It's all to do with this new course."

I have just taken part in the ME/CFS and FMS Self Help Course in Canberra, attending a two-hour session each week for the past two months. It has been the most wonderful experience. In our particular case, my participation has involved a considerable cost in travel and accommodation and a great deal of physical and emotional stress in making these journeys and a lot of help from our very generous neighbours. But the rewards have been overwhelming.

Chronic Fatigue Syndrome is a very silent disease; it is often referred to as the 'invisible disability' and I, like many others, have suffered for a number of years with a disease which effects almost every aspect of my lifestyle and by association, that of my husband and family. But the course in Canberra has been the start of a 'new life'. The group of course participants is intentionally small and together we have explored ways of living; living not waiting 'until I get better' or struggling to maintain the familiar lifestyle of the past or grieving over a life 'lost', but living within the confines imposed by CFS.

We have individually discovered the limits of our own 'energy envelope' and together have pooled our ideas on techniques to maximise this precious resource. The sufferer is now in control and not the disease. By using techniques such as pacing and target setting, we have, as a group, learnt that goals can be achieved. They may need to be modified but by using different coping strategies, I now know that there are some solutions. This energy reserve can be enhanced by using a more measured approach: balancing activities and taking pre-emptive rest, for example, and by using techniques of sleep management and changing patterns of exercise and nutrition. And all this new-found drive needs to be protected from the destructive effects of anxiety and stress and worry and self-defeating thoughts.

I am sure that I am speaking for many in the group when I say that I found tremendous value in learning how to identify these problems. I can now return home to start my 'new life', knowing now, that so much more can be done; it just has to be done in a different way.

In closing, I would like to convey my sincere thanks to the facilitators, Robyn and Drude. The success of the workshop has been largely due to their efforts in the preparation and conducting of the course. - Marian, March 2005

**"We were able to explore the tough stuff with love, laughter and a beautiful sharing of togetherness." - Robyn (Facilitator of the first course in Canberra) October 2004**

It was a chilly day, typical of a Canberra autumn, and I was feeling nervous. What person with ME/CFS or FMS would venture out on a day like this? But there was a surprise awaiting me - a greater than 100% turnout for the first session of the inaugural ACT ME/CFS and FMS Self Help Course. As the weeks rolled into winter and only one person left the course, our attendance never fell below 11 out of 14 - a near miracle! I could see some of our participants really had to make tough compromises in order to have enough energy to come. The motivation and commitment of everyone were incredible.

Following the successful introduction of Bruce Campbell's Self Help Course in Sydney, the ACT ME/CFS Society decided to run its own version in Canberra. While we used Bruce's course notes, we changed the format, using two facilitators with a larger group. This allowed us to mix pair work and group discussions with 'brainstorms' (where people call out ideas/solutions on a topic), and to scribe so we could supply everyone with typed notes of the group interactions. These notes were a major success. People could concentrate on the discussion, knowing that the notes would help them to remember what had happened. (The joys of being with a group that understands brain fog!) It also meant we had a good depth of experience and views on any topic (although we will reduce group size to 10-12 in the future).

Using the course notes, we gradually worked through the major issues of living the fullest life possible with ME/CFS and fibromyalgia. Several people had major shifts in attitude, moving their focus from always trying to get better and have more energy to making the most of what they have. One participant commented that her family had noticed she was making better decisions. Others felt the course really reinforced things they already knew, and gave them encouragement to 'continue the good fight'. Sharing with others and validation were considered major benefits by everyone. The variety in topics and format encouraged us to discuss what is often left unsaid. It was "a major relief for most of us to discover we all had difficulty in making decisions, particularly when our energy was low - and how many of us had judged ourselves as being indecisive(?) rather than realising it was part of our condition. We all liked the suggestion of wrapping a bandage around our head, to let everyone know there was a reason for our condition".

Group interactions often worked on many levels. Input on handling the thought "I'm never going to get better" ranged from giving hope and getting this moment in perspective to accepting that our old way of life was gone and that it wasn't necessarily worth returning to - that perhaps we could forge a more enriching life. Many discussions also suggested that working towards fully accepting

yourself without needing a prerequisite role in our society was fundamental. This illness is in some ways a privilege - as it pulls away the illusion that our achievements and roles in life define us (a fundamental belief in our society) and gives us a chance to look deeper. As a community we were able to explore the tough stuff with love, laughter and a beautiful sharing of togetherness.

The 'Chat and Nap' group was established by the participants after the course and has since held its inaugural meeting. Bruce Campbell has also generously allowed all people who complete his face-to-face program access to his graduate online alumni groups and target setting courses to help you to stay motivated within a community environment.

When comparing the face-to-face version of Bruce Campbell's program with his online version (you can subscribe to this at [www.cfidselfhelp.org](http://www.cfidselfhelp.org)), more material is discussed in the face-to-face version and there is also the chance to build up a good relationship with others in your local community with a similar illness. The main disadvantage is that you do need to travel to a particular location at a particular time on a particular day. The advantage of the online course is that it can be completed from home at any time. The difficulties I found with the online course included getting tired reading everyone's online responses and the longer time it took to get a feel for each person from their emails alone - I had to keep going back to their introductory email, or look back through their responses to 'remember' who each person was.

Both courses explain the advantages of self-management and give you the tools to do it. Being people might think - they involve skills of awareness, prioritising, logging and gentle discipline. Both courses also give you a chance to throw off the isolation of managing these complex skills alone and allow you to take your place in a community of people with the same goal - to live a rewarding and satisfying life. If you've never explored how to improve your own illness management, I'm sure you won't be disappointed with either course or the communities you join as a result of them.

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### **'A very worthwhile experience' - Vicki in South Australia**

I am a person who has had CFS since glandular fever and viral hepatitis in July 2000. I'm pretty good at finding information (books & internet). I'd been in touch with the ME/CFS Society and read all their stuff, read lots of books, connected with other PWCs (people with CFS) at the ME/CFS Society and on OZME. The message of pacing yourself and resting had been a great help. I considered myself pretty good at self-managing.

I read the Bruce Campbell stuff on the net. It is what I would wish for every newly affected person to read! It explains in simple terms how the symptoms interact to make things worse. It lets you understand that this is a complex illness and there is a lot going on with the symptoms, let alone the grieving process. I decided to do the course anyway, even though I'd already started doing the things I'd read about. For me pre-emptive resting has been a great help.

The course was a very worthwhile experience! A whole group of people who understand and can relate to what you are experiencing. It is a very validating experience. You can somehow be more 'yourself' with these people, no judgements. Now I have a great network of local PWCs. We meet regularly and encourage and support each other and have now set up a Café Club to reach out to others with CFS/FMS.

[Click here](#) to read Dr Bruce Campbell's own story of recovery.