

# CF Christmas Party – Sunday December 10

a struggle stopping a few times on the way up to catch my breath but I got there. Timmy and I then had another chance to catch our breath whilst Tim packed away the gear. We then made the trip back to the car and ate our Macca's Deli rolls.

All up the day was a lot of fun, Timmy and I were both exhausted, this showed as we both ended up in hospital! I really enjoyed the challenges and chatting to Tim from *Purple Soup* about life and Cystic Fibrosis, if I had the chance to do it again I would jump straight at it.

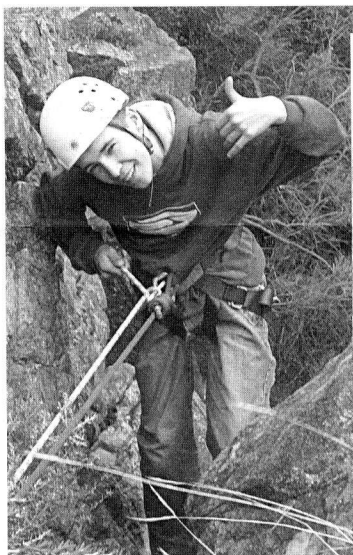
– Daniel Cox (CF)

## Jump off a cliff = A great way to do your physio!

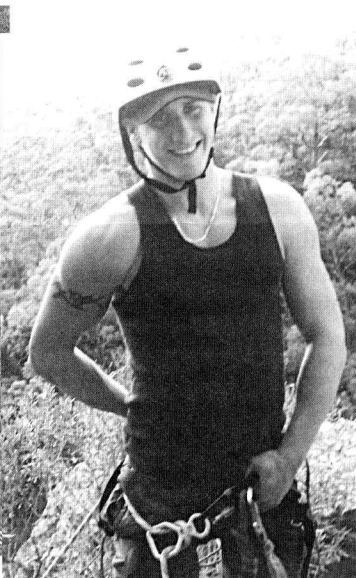
Jamie Craig (CF) and his partner in crime Josh, have just recently become experts in indoor climbing by attending an evening 'learn to climb' session at Vertical Reality Indoor Climbing Gym at Holden Hill. These guys were naturals and even overcame the giants ladder, where we added a blindfold. Looking for a greater challenge, the boys decided to meet *Purple Soupers* Tim and Jodie at Morialta for a spot of climbing. These guys were fearless and we had lots of laughs. Jamie now aims to use the indoor climbing as part of his keeping fit= keeping well plan.

## Purple Soup Sibling Camp

If you are between 6 years and 16 years, have a sibling with CF and are looking for some fun and adventure in a *Purple Soup* kind of way then register your interest now for the Sibling Camp to be held on Sat/Sun 4 & 5<sup>th</sup> November, 2006. Details are still a bit sketchy at this stage but **only those registered will be followed up with more information.**



Tim Doyle



Jamie Craig

## Particularly for Partners and Friends of Adults with CF

Looking at life and CF from the perspective of a partner – Alice (Jaan's partner) now has a blog so check it out <http://alicepotter.blogspot.com/>

## Lung Transplantation: When is it the right decision to make?

Making the monumental decision to have a lung transplant is probably one of the hardest decisions that a person with Cystic Fibrosis can face in their life time - even harder still is **when** to make that decision. Questions arise such as: is the time right now or is it too early? Doctors can give all the statistics and opinions in

the world regarding prognosis with current lung function and average length of wait time for a transplant, however they do not face the fear that lies ahead. The fear of numerous tests, of not being accepted to the transplant program, of being listed, of waiting for the transplant fearing that day may never come, of the false call, the real call and the fear of the operation itself. *It is the fear of the unknown.* No one can really understand the fear associated with the transplant journey unless you have been through it.

As a person with CF I went through this decision making process 11 years ago and was transplanted 9 years ago. After a bout of the flu doctors used their best medical guestimate to refer me for a lung transplant work-up. The journey began when my FEV<sub>1</sub> plummeted to less than 30% predicted and it was believed that I had a higher probability of not surviving beyond two years. The final decision to proceed

toward transplant took into account not only my medical decline but also psychosocial status (support of family and friends) and most of all quality of life. I waited on oxygen 24hrs a day for 2 years for my transplant whilst trying to complete my Psychology degree. My quality of life gradually diminished in those 2 years.

Deciding whether or not to get a lung transplant and when to be listed, is for most people a balancing act. Too soon and complications may develop post transplant - too late and you might die waiting. I've spoken to friends over the years who have felt like they have made a wrong decision and jumped too early but equally some have left it too late. For me I felt like the choice was taken out of my hands as I become so sick so quickly. The only choice I was given was yes or no, not **when**. I was very philosophical and realistic yet optimistic, and on occasion had

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