

## Summary of ECD Global Alliance chat held on Saturday 18<sup>th</sup> September 2010

7 Present:

- It was mentioned in last weeks chat that a patient had a tendency to lean to one side when sitting. This week the patient has worked on sitting up straight, without resting their back against the chair and has managed to sit fairly straight.
- Anyone who has yet to send in updates for the Case Log, please do so fairly soon if possible. It is hoped to send out a document for review shortly.
- The question for discussion this week was:
  - “Think back one year and share with the group the changes that have taken place in 12 months, Perhaps you are doing well due to finding the right doctor. Perhaps you are on new medication. Things may have gotten worse both physically and in regards to your emotional state. Can you do more or less now? This question applies to the caregivers also. Are you satisfied with your life?”
  - One patient mentioned that they had been in the hospital at Christmas and in Jan/Feb, but had been doing better since they started taking methotrexate. They had gained weight whilst taking steroids!
  - One patient is in remission and has not had any drugs for the treatment of ECD for over a year.
  - One patient mentioned they felt more tired than last year and had less drive and ambition.
- The next chat will be held on Saturday 25<sup>th</sup> September 2010 at 3pm EST.