

## Summary of ECD Global Alliance chat held on Saturday 11th April 2009

5Present

- Good wishes were sent to one member is in hospital with a chest infection
- Pain – two patients find that their pain is worse when they are overtired
- There was a short discussion on tiredness and ECD. Members commented that it is easy to become frustrated because you cannot do more. It is important to pace yourself and not worry about getting everything done today.
- The age of onset of the disease was discussed briefly. Dr. Haroche (an ECD ‘expert’ based in Paris) has stated that ECD is more common in later life but is known in all ages.
- Two patients have diabetes. It is unclear whether this is linked to ECD.
- Some drugs work well in some ECD patients but not others. This point has been mentioned in chats previously and seems to be a feature of ECD.