

ECD Global Alliance Internet Chat Summary

28 Jan 2012

Attendees: 9

- A member left a message before the chat to tell us that she couldn't attend the chat session. She is on interferon, and her liver blood test values have risen, after her dose was increased. It looks like the dose will need reducing.
- One member has traveled from her home (38 degrees) to the "desert" (68 degrees), which is much nicer!
- A member had a review appointment early in the week, and is having another PET scan next week. Luckily, the PET scanner is not far away.
- A member, who has been having significant back pains, is starting pain killing injections next week. We hope that these prove effective.
- A member came onto the chat, who had just had a "long lunch" with her daughter. They had been out somewhere nice. There was a discussion about desserts. One person admitted to choosing the dessert off the menu first, and then choosing a first course that would leave enough room for the dessert!
- One member, particularly wanted to thank another, for the amusing e-mail messages that he sends.
- A member told how she is getting a loom ready for some weaving. She uses a variety of yarns, and makes a variety of things. Other members expressed a wish to see some of these products, and some would like to learn how to weave for themselves.
- There was also a discussion about wood-turning to make bowls. One member has a nice bowl, but is afraid to use it, in case it is damaged when being cleaned. Another member said that using a vegetable oil would be the best approach.

Questions were asked about sourcing suitable wood. Hardwoods are good, especially ones with a lot of colour. Sometimes neighbours have suitable pieces from trees that they are felling, or a lumber yard/saw mill might help.

- The member who has "escaped" the cold at home, has taken some things to get on with. One is getting photo-albums sorted out for the grand-kids.
- Our "nearly Just Married" couple, are having to sort out wordings for the wedding invitations. They have had a second "Engagement" photo shoot so that the pictures can be put into their guestbook. Our "Soon to be weds" have also been involved in a film that is

being made about rare diseases. The filming has been done, and there is too much "footage".. Now the film needs to be "cut-to-fit".

- Another member came on who has not been able to attend for a while. She has recently been diagnosed with diabetes, although diet and exercise are hopefully going to control this. She is also troubled with thyroid problems. She has been told that she has Hashimoto's thyroiditis. Her blood results have been variable and the doctors are struggling to get things in order. It seems perhaps a number of ECD patients have thyroid problems.

TSH is Thyroid Stimulating Hormone comes from the pituitary gland in the brain and is often monitored by doctors to check for thyroid issues. The pituitary gland "knows" how much thyroxine should be sloshing about in your blood. If there is not enough for its liking, it sends out TSH to "tell" the thyroid gland to "get it's act together, and make a bit more thyroxine!".