

Summary of ECD Global Alliance Internet Chat

22 Feb 2014

15 Attendees

- A new chatter left a message asking whether anyone had used any herbal medicines as well as conventional treatments (interferon). Her husband has been recently diagnosed with ECD. It was mentioned that one other member has tried several of these products.
- The member, who has been ordained, has just started work in a new parish, and told us that he was very busy - but pleasantly so. He finds the 'work' most fulfilling, and so getting tired is a "good thing" when kept within bounds.
- A member, who has been on vemurafenib for a few weeks has been "doing ok", but was tired. She had gotten everything ready for dinner guests tomorrow (vegetable peeling, meatball making) and she had walked 3 km on the treadmill (almost 1 hour of walking). She thinks that she may have been overdoing it a little, because she is now walking in zigzags! She had been feeling that she was "at a stand still", but recently met a physiotherapist who hadn't seen her in over 2 months, and the therapist said that she had gotten a lot better. "This was nice to hear". She has recently had a bit of a cold.
- A member is using the "Dragon Dictate" program which turns speech into text on your computer. No typing required! But it needs to learn your particular way of speaking, and this takes time. The computer needs training, and, at first, all sorts of strange things appear! He says it is still an improvement on his spelling! The member using the software wondered how it had been used for legal and medical terms. These were two of the first areas in which speech recognition was used. A member said that one of the docs, that he and his wife had seen, always dictated his letters into a Dictaphone. Then the staff typed them up to be signed. One day he dictated straight into the computer, and finished/printed it himself. This is a cheaper way (and therefore there are more profits for the doctor!) because the doctor doesn't need a secretary!!
- The benefits of Ctrl-Alt-Del were mentioned, and also the usefulness of having a Restart button!
- A member came on to tell us that he couldn't chat for long. He had to go and set-up for his wife's birthday party. A different member said that putting ALL those candles on the cake would take a heap of time! The husband told us that his wife wasn't looking forward to marking the passing of another decade but "She's just as beautiful as the day we met. So, who cares?!"
- A member has had a bad chest recently, and has been on antibiotics. This has stopped him from playing his trumpet, although, yesterday, his trumpet teacher came round to visit! The teacher must be missing his cash!
- A member told us that he may be visiting the doctor soon to have his arm looked at. He had a bad fall a few months ago, and his arm hasn't recovered as he expected. He also hurt one of his feet in a separate fall.
- A member, who has been stuck indoors, because of the weather, said that things were improving.

- A UK member came on, who has recently started vemurafenib, has been back to the hospital, that is treating him, three times, because of side-effects. He had abdominal pain on a full intake of breath, with shoulder pain as well. They said this was a pulmonary rub. He has had antibiotics for a sore throat, but he thinks that this is a side effect of the vemurafenib. The doctors said the rub could be caused by inflammation, caused by regression of disease! His breathing, which was badly affected by ECD, has improved a lot. He has recently had a PET-CT scan, and will be getting the results on the 3rd of March. He will be rung if there is anything that he needs to know about before then. He told us that he had asked the Prof how his treatment would affect his bones. The Prof said that he would expect the sclerosis to disappear as the skeleton regenerated itself. But obviously this will take time.
- A member, who has been having problems with dizzy spells, has had the results from the heart monitor test that she has had. It showed a wide range of heart rates, but there were no abnormal rhythms. The docs have suggested that she have a tilt table test. This examines how the balance organs are working in the inner ear, and how the blood pressure varies in different positions.
- A newly diagnosed UK member came on to say hello.