

Summary of ECD Global Alliance Internet Chat

27 Apr 2013

7 Attendees

- A member is currently staying in a nursing home for a few days, and trying out “respite care”, for the first time. One of the members of a local Carer's group, had recommended it. Her son, who has cerebral palsy and is in his 20s, had been there. The Carer's group has been very helpful, both for getting hold of practical info, and also for mutual support. And the home had a 4 nights for the price of 3 offer on the go. Too good to refuse!
- Some members mentioned that it was difficult to find places for such care. In the UK, the Care Quality Commission inspects all homes, and publishes the findings on their website. This is a good place to start a search for somewhere suitable.
- A member told us that pain was a big problem.

This has meant that medications needed upping, and the member is very dizzy. If the increase in medication doesn't work, then chemotherapy will probably be the next step. A doctor's appointment is scheduled for this week.

- A member has just had a physical exam, and a TB test.
- A member told us that he had been celebrating his wife's 40th birthday for the last week. He will get to be a “toyboy” for the next 6 months!
- A letter has arrived, for a UK member, from the Social Services Dept. about Care Assessment. All Brits on benefits are going to be re-assessed in the next couple of years. A US member asked whether anyone had gone through the medical exam for social security. The member didn't know what to expect.

(Editor's note: The organization has had several patients apply for social security disability in the US. In general, it seems that it normally takes an appeal to be approved. However, in December of 2012, ECD (DI 23022.947) was included on the SSA Compassionate Allowance List. It is hoped this might help streamline the process. See: <http://www.ssa.gov/compassionateallowances/conditions.htm>)

- A member is going to a “double christening” tomorrow, and wishes to be able to speak a little. Last time the member was out with the parents and friends, they had thought that it was drink that was affecting his speech!
- The member, who has been troubled with leg pain, told us that things seemed to be getting better. A massage is scheduled for this week.