

## Summary of ECD Global Alliance chat held on Saturday, 27th November 2010

9 Present:

- One patient has recently had an MRSA infection. An operation was needed to clean the affected area. The patient is improving.
- One patient mentioned that their family refuses to acknowledge their illness and asked if others on the chat had a similar experience. It is extremely difficult when the family pretends that everything is alright. Another patient responded that their spouse does not like to discuss the illness as they prefer not to think about how serious it could be.
- A patient commented that they feel bad that they rely on their loved one to transport them everywhere. Another patient on the chat said they felt the same. A caregiver commented that they thought it was very precious being able to help their loved one to get to the places they needed to go, although they could see that it was difficult from the patient's side.
- The difficulties experienced by caregivers were discussed. Tiredness and frustration with the illness can sometimes result in loss of temper with the patient, even when this is not meant to be directed at the patient themselves. One caregiver said that when they felt this way, they tried to imagine what it would be like to be in the patient's shoes. Several patients said how important it was to continually express appreciation to their loved ones for what they do. One patient tries to recognize when their caregiver needs a break and arranges for another family member to stay to look after them. One patient attends an Adult Day Care center five days a week where they have breakfast and lunch and cook, do crafts and play cards. This gives the patient some company and also provides a break for the caregiver.
- One patient is having their pacemaker changed this week.
- The next chat will be held on Saturday 4<sup>th</sup> December at 3pm EST.