



Early Onset Dementia – Three Different Journey's with Early Onset & Information on Early Onset Support Groups



Presenters:

- **Chris Nelson** – Person with Early Onset Frontal Temporal Dementia
- **Wayne Eaker** – Person with Early Onset Alzheimer's Disease
- **Bill & Sue Hobbins** – Sue was diagnosed with Early Onset Alzheimer's disease when she was 40 years old. She has familial dementia. Bill will talk about his journey as a care partner with his wife
- **Arlene Huhn** – Manager, Education and Support Services, Alzheimer Society of Alberta and NWT

Chris Nelson



Chris

- Diagnosed at 54 years of age
- Social Worker
- Full time caregiver to her mother who was diagnosed with Alzheimer disease









Chris

Help for myself and
others, for today and
Hope for our future

Wayne Eaker



Wayne

- Diagnosed at 62 years of age
- Unskilled carpenter
- Fairly good photographer
- A grandfather
- A husband



Wayne

A traveler, still on a
journey

Bill & Sue Hobbins



Sue & Bill

- Sue was diagnosed when she was 40 years old
- Sue was a physical therapist
- Sue & Bill are very “outdoorsy”
- Family History - father passed away in his 50's from dementia and uncle and aunt also had disease

Alzheimer Society of Alberta & NWT – Edmonton Regional Office

- Provides Early Stage Support Groups and an Early Onset Support Group
- Begin with 6 week group, 1x week for 1 hour (based on program by Robyn Yale)
- Move to monthly group 1x month for 1.5 hours



6 Week Early Stage Group Topics

- **Session 1 – Introductions**
- **Session 2 – The Brain and Memory Problems**
- **Session 3 – “Working Together” Video**
- **Session 4 – Changes and Feelings (loss & grief)**
- **Session 5 – Reminiscing**
- **Session 6 – Summary and Hope for the Future**



Early Onset Monthly Group

- Group is offered in the evening as some people with the disease and many of the care partners still work.
- We have two Early Onset Groups at same time, one being early stage the other a respite group.
- Occasionally we have speakers come in to the early onset group.



living and transforming with loss & grief

An inspirational guide for persons with
early-stage memory loss and their partners in care

A "By Us For Us" Guide



Loss & Grief

- Living and transforming with loss & grief (A “By Us For Us” Guide)
- Facilitator leads discussion on losses and grief in both the early stage and early onset group



Care Partner Group

- Care partner group is offered at the same time
- Care partners from both groups meet together
- Group is a closed group
- Care partners can attend without spouse



Transportation

- We have funding to provide transportation to the families who would not be able to attend due to driving issues.



History

- We have been offering Early Stage Support Groups for over 10 years
- In 2004 we started offering care partner groups at the same time
- In 2005 we started the ongoing groups instead of just the 6 week program



Current Statistics

- We offer four ongoing Early Stage Support Groups monthly
- We offer 4 - 5, six-week early stage programs per year

Need for Early Onset & Early Stage Groups

- More people are being diagnosed earlier
- Allows people with the disease to meet with others who have been diagnosed and share information
- Early Onset allows those who are younger a chance to meet people of similar age who have similar concerns



Gaps

- Need referrals from health professionals when people are in the early stages
- People in very early stages and their care partners may not see need for support

Questions

