“EDGE ON”

Experience of running Experiential Support Groups for People with Dementia in Care Homes

Elizabeth Bartlett
Dementia Trainer & Consultant

In conjunction with Wessex Care Ltd.
What is one of your earliest memories?

How did it make you feel?
Experience shows that our most enduring memories frequently have high emotional content.
“Even if I forget my facts, I can remember my feelings.”

These may include traumatic memories from early life and childhood.
One lady said,

“*I try to box my painful memories away in the cupboard,*

*but something from the box falls on my head.*”
In a care home the first concern is usually for residents’ physical needs.

- Food and drink
- Keeping safe
- Washing, dressing and personal care
- Sleeping at night; mobility during the day
A Resident’s Experience

- Loss of personal identity and possessions
- Surrounded by people they do not know – staff and residents
- Have feelings they are unable to express
Concept of an “Edge On” Group

◆ It gives residents an opportunity to discuss their feelings in an accepting experiential memory support group.

◆ It is based on the residents’ own experiences of living with dementia.

◆ Lessons learned from these experiences
  – Help members support each other
  – Enable staff to promote sensitive care.
Concept of an “Edge On” Group

◆ The name is derived from a comment by a 92-year-old resident who said,

“*We have just edged each other on*”.
Structure of an “Edge On” Group

▲ A small group of residents with dementia meeting at a designated time (approximately 8 people).
▲ A group led by a trained facilitator.
▲ It is co-facilitated by a care home manager.
Objectives of an “Edge On” Group

To help residents with dementia
- realise they are not alone
- understand the reasons for their dementia
- increase their self-esteem
- share painful experiences in an accepting group
- support one another.
Experience with Wessex Care

Milford Manor, Salisbury
Some members of the group with the group leader
Achieving our Objectives
Helping members realise they are not alone and the reasons for memory loss

◆ We bring residents together as a group.
◆ They are often relieved to be able to talk about their memory loss
  “I used to able to do so much! Now I have a passion for forgetting.”
◆ We talk about the reasons for memory loss.
◆ We emphasise that it is NOT ‘their fault’.
  “Don’t blame yourself.”
  “Blame your neurotransmitters!”
The group in action
Achieving our Objectives
Helping members understand their need for residential care

◆ One lady was distressed that she was in a home with locked doors
  – She referred to it as “her prison”.
◆ Another member of the group said, “I remember walking out of the front door and not being able to remember where I was.”
  She added, “I feel much safer being in here.”
◆ The first lady rather reluctantly agreed.
◆ The facilitators and other group members encouraged her but acknowledged her frustration and pain she felt over needing this level of protection.
Achieving our Objectives
Increasing members self-esteem by recalling life achievements

◆ We regularly encourage residents to recall things they have achieved during their lives.
Recalling achievements in life
Achieving our Objectives
Increasing members self-esteem by recalling life achievements

◆ We regularly encourage residents to recall things they have achieved during their lives.
  – A psychiatric nurse expressed her joy over her work with mentally ill patients and the pleasure of dancing with some of them at the ‘Asylum Ball’!
  – One man often recalls his deep admiration for Lord Louise Mountbatten when he worked for him during his service career.

◆ We are happy to share the same sense of achievement on a number of occasions.
Achieving our Objectives
Sharing painful experiences

- We give members an opportunity to talk about painful experiences that remain with them.
Achieving our Objectives
Sharing painful experiences

◆ We give members an opportunity to talk about painful experiences that remain with them.
  – One member said, “*It is when I am on my own [in the home] that I feel the ‘twang’.*”

◆ Examples of topics discussed
  – Bereavement
  – Difficult relationships with parents
  – War experiences
  – Divorce
  – Gender issues
Achieving our Objectives
Building relationships

◆ Between members of the group
“*You think you are on your own … it’s the isolation. Now I have someone to share with.*”
“It is nice to know that we have achieved something. With all our losses, this works wonders.”

◆ Between residents and staff
The co-facilitator said, “*I feel privileged to take the journey with our residents. It filters through to the staff team. I find I can bring the lessons learnt in the group into care practice in the home.*”

◆ With relatives
“*Mother seemed a bit down this morning … but Jenny told me you'd all met on Monday and how successful it was. Thanks a million.*”

Elizabeth Bartlett
Running an “Edge On” Group
Facilities required

◆ A room free from interruptions
  – Large enough for everyone to sit in a circle
  – Available for about 90 minutes each week
◆ Name badges for everyone
  – Recommend using first names only
◆ Tea and biscuits for the whole Group
Running an “Edge On” Group
Abilities required in a co-facilitator

◆ Good knowledge of the members
  – Ability to use this knowledge to draw members into the Group
◆ Ability to listen to, and analyse, what members are saying
  – Willing to share own experiences when relevant
  – Able to create a relaxed atmosphere with humour
  – Record discussion and feedback at end of session
◆ Ability to feed back key points to other staff
◆ Understanding of the need for confidentiality
Who can be a member of an “Edge On” group?

◆ Any resident who
  – Has some awareness of their own memory problems.
  – The ability to speak and understand most of what is being said in the group.

**Note:** Individuals who appear to be withdrawn often blossom in a supportive group.
“Edge On” Group members experience

◆ Affirmation of their personal identity.
◆ Acceptance of their current situation.
◆ Ability to develop deeper relationships.
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