

INNOVATIONS IN DEMENTIA CARER SUPPORT GROUPS

**A reframing of existing
concepts to address
specialized group needs**

The Need

A survey in 2002 established that the needs of carers were changing and they had specific issues they wanted addressed.

- **Loss & Grief**
- **Self Esteem/Guilt/Emotions**
- **The Practicalities of Entering Residential Care.**
- **Anxiety**

Loss & Grief

There is a very elongated process in dementia grief commencing before diagnosis and continuing long after death.

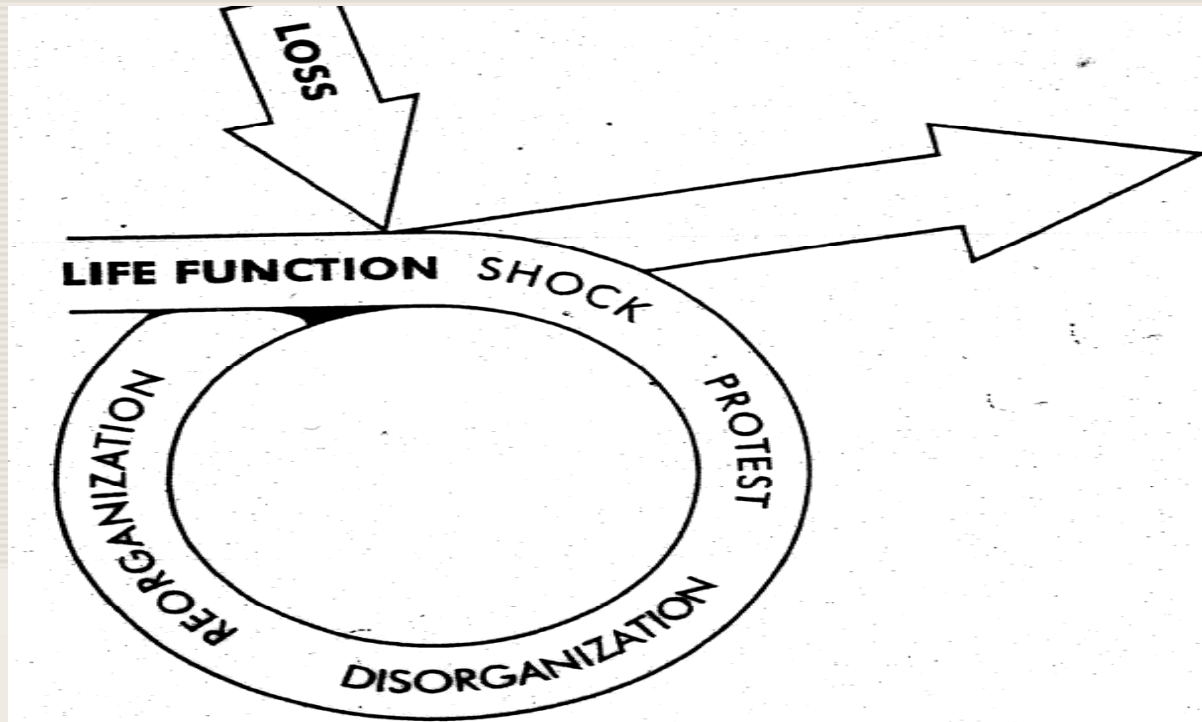
The unfolding issues of loss and the corresponding grief are a major concern for dementia carers.

What we set out to achieve

- Recognition that these are complex psychosocial issues
- Normalisation that grief is a normal process that people move through.
- Defining normal and abnormal grief that may become a pathological behaviour.
- Provision of a forum where carers can in a safe group setting unpack some of their grief concerns.

What we set out to achieve

- A simple structure “The Grief wheel” that allows where carers are to be put into a perspective.



The Emotional Melting Pot

- Carers speak of a spectrum of emotions that interplay in their daily lives. These include anger, guilt, fear, rage, sadness and compassion.

What Carers Say?

- “I thought that I couldn’t go on but discovered that with more understanding I could”.
- “I have learnt so much through this program.....thank you all.”
- “The combination of effective knowledge and an empathic approach has left me feeling that I have gained something worthwhile.”
- “Just having someone who understands has made all the difference.”

Entering Residential Care

This is a very difficult time for carers from both a financial and a psychosocial viewpoint.

We discuss:

- The path to residential care
- The right time
- Care options
- The behaviours of both the person with dementia and the family.

Entering Residential Care

Firstly the path to Entering Residential Care will differ from person to person and we acknowledge this difference.

- Qualifications to enter residential care in Western Australia include:
- Diagnosis by qualified medical specialist.
- Aged Care Assessment
- Completion of application forms

Entering Residential Care

- The right time is when the principle carer feels it is right this is often driven by circumstances such as incontinence, falls etc.
- The wishes of the person with dementia are to be considered in a person centred approach.
- What is best for the individuals welfare and safety can override their expressed wishes due to the effects of the dementia.

Entering Residential Care

- Care options
 - Low impact care is the entry level of residential care in Western Australia. This can be dementia or non dementia specific.
 - High impact care is a level where a person has been reassessed as high care or fails to meet criteria within the low care facility that requires a re-evaluation.

Entering Residential Care

- The residential care facilities can be purpose built eg low care only, two tier (low and high care) or three tier (Ageing in place, low and high care).

Entering Residential Care

- Capacity to cope varies significantly from carer to carer and this can be a factor for entry into residential care.
- Some individuals with dementia fight vehemently against entering care facilities. Others are more accepting of the inevitability of the process.

What Carers Say?

- *Very empathic and helpful and addressed issues we had very well.*
- *The program has addressed things and helped my understanding of the condition.*
- *The sharing and friendly openness of the group didn't feel threatened or fearful about opening up.*
- *The experience of meeting other carers and realising your not alone.*

LIVING POSITIVELY

- **Self Esteem/Guilt/Emotions were raised as issues of concern by carers. These concerns were written into a course “Living Positively” to assist carers in their caring role.**
- **This course of six sessions is interactive and helps to evaluate the caring role in a positive framework.**

LIVING POSITIVELY

- The rocky road of emotions.
- Feelings & Emotions
- Taking time for self.
- Understanding guilt

LIVING POSITIVELY

- Living Positively touches on a cross section of deep psychosocial issues that can greatly affect carers including *The rocky road of emotions* and *Feelings & Emotions*. This leads to *Understanding guilt* and the process of the feelings of guilt within self.

What Carers Say?

- *I feel it helped me deal with the situation where before I had no one who really understood what I am going through.*
- *The ideas that were put forward by everyone that we could use in our own situation.*
- *Sharing experiences and hearing thoughts and strategies for dealing with some problems. The chance to share humour and compassion.*
- *Information given, sharing stories and having my feelings validated.*

Understanding Carer Stress

- Anxiety is a significant factor in carer stress.
- We developed a six session program that specifically looked at Understanding Carer Stress.
- The criteria was to explore the psychosocial behaviours that create stress and develop positive frameworks to assist carers.

Understanding Carer Stress

What causes stress?

- May occur when people are faced with events they think they can't handle
- Can be a traumatic event
- Or can be an every day habit that wears you down

Understanding Carer Stress

The effects of stress

- Anxiety can make tension headaches worse by:
- Increasing muscle tension
- Flooding the body with stress chemicals, such as adrenaline
- Reducing the amount of 'relaxation' chemicals in the body, such as endorphins

10 Signs of Carer Stress

- 1. Denial
- 2. Anger
- 3. Social Withdrawal
- 4. Anxiety
- 5. Depression
- 6. Exhaustion
- 7. Sleeplessness
- 8. Irritability
- 9. Lack of concentration
- 10. Health problems

10 Commandments for Reducing Stress

1. Thou shalt **not** be perfect or even **try** to be
2. Thou shalt **not try** to be all things to all people
3. Thou shalt leave things **undone** that ought to **be done**
4. Thou shalt **not** spread thyself too thin
5. Thou shalt learn to say '**No**'

10 Commandments for Reducing Stress

6. Thou **shalt** schedule time for thyself
7. Thou **shalt** switch off and do nothing regularly
8. Thou **shalt be** boring, untidy, inelegant, and unattractive at times
9. Thou shalt **not** feel guilty
10. Especially, thou shalt **not** be thine own worst enemy, but be thine own best friend

The path of managed risk

- Learning about anxiety
- Relaxation techniques
- Correct breathing techniques
- Cognitive therapy
- Behaviour therapy
- Dietary adjustments
- Exercise
- Learning to be assertive
- Building self-esteem
- Structured problem solving

CONCLUSIONS

- This presentation is a snapshot into the world of dementia carers and the often extreme pressures they face.
- We believe that there is a great need for programs that target specific issues such as those outlined today.
- Alzheimer's Australia believe that with the continuing increase in information and technology the needs of carers will also change over time. We seek to be a provider of this specialised information to carers of those with dementia.