

Session 1

Looking Beyond the Mask: An exploration of loss and grief in Parkinson's



Parkinson's
Victoria
HELP TODAY
HOPE FOR TOMORROW

www.parkinsonsvic.org.au

Amanda Spillare
Client Services Coordinator

This session will cover

- ~ An introduction to Parkinson's
- ~ Current Treatment
- ~ Loss and Grief Responses
- ~ Loss and Grief Theory
- ~ What we can do to help



Parkinson's Victoria
www.parkinsonsvic.org.au
1800 644 189



Myths about Parkinson's

- Myth: Only old people get Parkinson's
- Myth: It's just the shakes
- Myth: People with Parkinson's also get dementia
- Myth: People with Parkinson's can control their symptoms
- Myth: Parkinson's is fatal

Incidence & Prevalence

- ~ PD is in all countries . globally 6.3 million
- ~ Second most common neurological after dementia
- ~ Approx 72,000 people in Australia
- ~ Approx 18,000 people in Victoria
- ~ \$1.4 billion to Victoria
- ~ \$88 million in unpaid care costs in Victoria
- ~ 15 % increase in the next 5 years
- ~ 25 per day or 1 person per hour
- ~ 1 in 5 of PWP are of working age
- ~ Parkinson's can affect adults of any age

Access Economics, 2007

What is Parkinson's?

- ~ Parkinson's (PD) first described in 1817 by James Parkinson is a progressive, degenerative, neurological condition involving a disturbance in the coordination of movement.
- ~ Loss of cells in the brain (Substantia Nigra) associated with lowering levels of dopamine.
- ~ Caused by genetic pre-disposition coupled with an environmental factor

What are the main symptoms?

- ~ Tremor (Shaking) . 70% of people
- ~ Rigidity (Stiffness)
- ~ Bradykinesia (slowness of movement)

Others include problems with:

walking, writing, swallowing, freezing, facial expression, balance, speech, fine movements, sexual functioning.

Non-Motor Symptoms

- ~ Depression
- ~ Sleep Disturbance
- ~ Slightly higher chance of dementia
- ~ Cognitive Slowing
- ~ Problems with generating strategies
- ~ Problems initiating responses
- ~ Attention problems
- ~ Rigid Thoughts

Treatment

- ~ Main type of medication is Levodopa (Also known as L-Dopa, Sinemet & Madopar)
- ~ Alleviates Symptoms
- ~ Does not alter progression
- ~ Becomes less predictable in effect / side effects
 - . Dyskinesia or Motor Fluctuations
 - . On/Off Problems
- ~ Physical Therapies
- ~ Surgery is also an option for some people

Life Expectancy

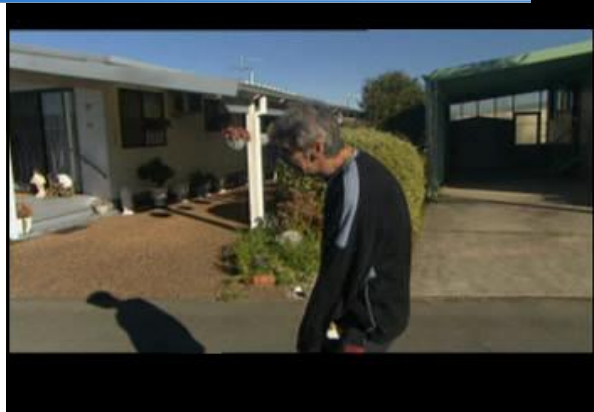
- ~ Disease is gradually and continually progressive
- ~ Usually progresses at quite a slow rate, but not always
- ~ Parkinson's is not fatal.

The person with PD may experience

- ~ Loss of independence
- ~ Loss of employment
- ~ Change in dreams for future
- ~ Loss of easy mobility . self esteem, authority, faith, privacy or dignity.
- ~ Changes to the relationship
- ~ Fear of becoming a burden
- ~ Fear of future progression
- ~ Depression
- ~ Prejudice from the community (that person is drunk, or assumption of dementia)

The Carer may experience

- ~ Shock and confusion
- ~ Neglect their own needs
- ~ Grief for loss of future goals, past life
- ~ Loss of identity, independence
- ~ Changes in relationship
- ~ Fear of future progression
- ~ Loss of faith
- ~ Stress or conflict



Loss and Grief

Plwp experience a range of losses that evoke a grief response. Grief is a person's response to loss.

The losses are ongoing and continual and do not have a linear structure, beginning from diagnosis.

Disenfranchised Grief

Doka (1989) proposed the notion of Disenfranchised grief

Grief that a person experiences when they incur a loss that is not or cannot be openly acknowledged, publicly mourned, or socially supported+

It is important to be aware of the impact of Disenfranchised grief on Plwp

Theories on Grief

- ~ Freud (1957) withdraw and reinvest. Normal vs pathological grief
- ~ Kubler-Ross (1970) describes stages: (Denial and isolation, Anger, Bargaining, Depression, Acceptance, Hope)
- ~ Worden (1991) Task Theory (accepting reality of loss, work through pain of the grief, adjusting, emotionally relocate)

Theories on Grief

- ~ Constructivist Theory (Koka 1989; Klass & Silverman 1996; Neimeyer 1999) (challenge traditional theory)
- Focus on the unique meaning that each person attributes, both in their internal and external worlds, to the grief and loss they are experiencing.

Grief Theory Continued

- All individuals are unique and so to is their experience of loss and grief (constructing meaning according to social, historical, cultural and spiritual influences)

Therefore it is important to realise that all people respond differently to grief and there is no %normal+way to grieve. The process in ongoing throughout life.

How can I help as a DSW?

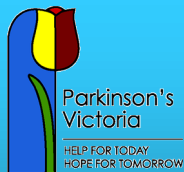
1. Contact Parkinson's Victoria
2. Refer to a counsellor or support group
3. Be aware that the grieving process is complex and feelings can be extreme.
4. Use empathy and understanding in your interactions.
5. Adopt a strengths approach. When have they been faced with similar life challenges . what helped?
6. Give them time . give is not linear.
7. Take care of you own needs as well as the person you are caring for.

. . . And remember

Ignoring grief wont help to go away.
Find someone you can talk to.
At the very least, acknowledge you are grieving

Hope is Important

- ~ With hope, there is a future.
- ~ Whilst acknowledging difficulties, it is also important to have something to hope f or small or large.
- ~ This may even be an event, or a time together.



Questions and comments??

Parkinson's Victoria
www.parkinsonsvic.org.au

1800 644 189
or 9551 1122

amanda@parkinsons-vic.org.au

Session 2

How Support Groups Help



Outline for today

- ~ Profile of Parkinson's Vic Support Groups
- ~ Frameworks
- ~ How to start a support group
- ~ Case Study
- ~ Scenarios

How do support groups help?

Support groups help by offering a forum for:

- Friendship . new friends
- Support . both emotionally & practically
- Compassion
- Idea Sharing
- Political lobbying
- Awareness raising
- Being able to speak to people who have been there+
- Fun!
- Fundraising for programs

Example

- ~ Personal story from Richard . Eltham Support Group

PV Support Group Profile

- ~ 46 Groups operate statewide (metro and rural)
- ~ Our longest running group is 21 years old, the newest has been running for 6 months
- ~ All groups are coordinated by volunteers
- ~ Volunteers vary in background (age, sex, professional, plwp, carers)
- ~ Every group is different and have from 10 . 150 members.

Frameworks for PV sg's

- ~ We use an anti-oppressive, anti-discriminatory framework when establishing groups, and all groups are run using community development principles
- ~ We give people the tools they need to make decisions, access funding, and facilitate groups in the community
- ~ We use a grassroots approach . responding to needs identified by the community and bring people together

Case Study - Mildura

- ~ Experience high number of people diagnosed with pd
- ~ Plwp had nowhere to access support for living with the Parkinson's
- ~ Generic health services had low level of awareness (no PD neurologist)
- ~ PV were receiving a high level of phone calls through helpline from distressed plwp

Responding – starting a group

- ~ Clear from the community that they needed a forum for regular support and information.
- ~ Began the process of collecting information, and thinking about possible professional and community partners
- ~ We also had to think about how to access plwp.

Responding – starting a group

- ~ I began the process of contacting everyone on the wish list.
- ~ Spoke with the local hospital and was able to secure a venue for a town meeting and morning tea on Parkinsons+
- ~ We utilised media (newspapers, interviews on ABC radio, signpost, internet, and mailouts) to publicise the meeting and bring people together, and put the issue on the local agenda.
- ~ The meeting had 2 purposes:
 - . To give information on Parkinsons
 - . To bring people together, and help facilitate the process of starting up a local group.

Outcomes

- ~ 50 people attended the meeting
- ~ Everyone enjoyed coming together and wanted to do it more regularly
- ~ Identified a host for the first meeting who I briefed . Cheryl was then approached
- ~ Regular group formed (2 years strong)
- ~ Influenced SCHC to participate
- ~ Dance classes for Parkinsons
- ~ Visiting Neurologist
- ~ Group meets monthly and has over 50 members and growing!

Take home messages

- ~ Be organised
- ~ Ensure you have the support of key community members (local champions) to mobilise the issue
- ~ Involve your audience in the process from the very beginning and during planning
- ~ Be transparent in your process and keep people in the loop (news updates were a good way to do this)
- ~ Don't be disheartened if you hit a couple of speed humps!
- ~ Amazing things can be achieved with minimal \$\$

Question Time

Thank you for listening!

Questions??