



SHAKE RATTLE AND ROLL

A JOURNEY WITH PARKINSON'S

"Ross Collins is a man living with Parkinson's. He says he rides a Harley because it shakes and because he shakes it's the only time he feels normal."

Ric Holland, former CEO of Parkinson's Victoria



Synopsis

Shake Rattle and Roll is a sensitive documentary that tells the story of Ross Collins, a man in his mid-forties who at the time of filming had been diagnosed with Parkinson's disease for twelve years. The film explores his attempt to balance family life with a desperate search for a treatment to alleviate, maybe even cure, his condition.

Ross Collins' story

Before he was diagnosed, Ross was a detective sergeant in the Victorian Police force in the major fraud squad. As a result of his condition his wife Margaret went back to full time work as a nurse in an emergency ward and Ross took care of the house and two children, Madeleine and Jack.

Ross' father, a general practitioner, gave him a book about a healer in a small town in central Brazil. Accompanied by his father, and with Margaret's blessing, Ross made the trip. The film charts the journey taken by Ross over the next eighteen months. It reveals his desperate desire to tackle his Parkinson's and the massive strain that the condition, and his quest for a cure, have put on his family.

It also shows Ross' efforts to raise awareness of Parkinson's disease, powering along with his son on his beloved Harley Davidson, as he delivers a United Nations Charter on Parkinson's to prominent politicians.

This film is an intimate portrait of a family struggling with the enormous challenge of managing Parkinson's. It is also about one man's journey into an uncertain future.

Curriculum links

This film will have relevance and interest for secondary and tertiary level students of Health and Human Development, Personal Development, English and Media studies.



The start of the film

In a presentation to an audience which includes fellow people with PD /or 'Parkies' Ross says:

To those newly diagnosed here today, I welcome you to Club Parkinson's. You may have heard of Club Med – well it's nothing like that. I've been a club member now for the past eleven years ... I seem to be taking a lot of medication and starting to feel the side effects ... which in some ways, are worse than the symptoms of the illness. I used to joke that I needed to jump out of aero-





planes to get a challenge, but now it's a challenge to go out the front door and walk around the block with the dog.

That's what frightened me: the prospect of getting worse. I want to get well. I don't really like this new me. Time is running out. I want to be like the person that I was.

- Talk about what this extract tells you about Parkinson's, and about Ross?
- In what ways would seeing this film assist fellow sufferers?

What is Parkinson's disease?

Parkinson's disease is a progressively degenerative neurological condition that involves the motor part of the brain, and later other parts. Over time it becomes increasingly disabling. Individuals experiencing Parkinson's are unable to move spontaneously (without thought) and have to constantly think about balance, walking, speech and fine movement. People with Parkinson's disease develop rigidity in their muscles, difficulty initiating movements, and tremors (shaking). Parkinson's disease is *chronic*, meaning it is a life-long condition.

- What does the film reveal about how Ross is affected by the disease?
- What evidence do you see of changes in Ross's condition over time?
- How is Ross affected by medication, or the lack of it?

Health questions raised in the film

The film's director, Andrew Wiseman, raised these questions:

- To what extent should an individual accept an initial diagnosis or try to fight it?
- Is it foolish or wrong to try to cure an ailment



when mainstream medicine says that is not possible?

- How important is hope when people are confronted by life-altering conditions?
- How should a father balance the desire to get well with family responsibilities when they appear to be in conflict?
- Is duty to self greater than to others—how can these be balanced?
- How can we empathize with others when they are dealing with a condition we cannot relate to?





Impact on family life

Parkinson's disease can affect a person's role within a family, and therefore alter the roles and responsibilities of other family members. Leisure activities, household chores, driving, and the capacity to maintain current income can be disrupted or limited. The socially isolating effect of Parkinson's can limit the social activities of the whole family.

- What changes do you see in the family's ability to cope over the duration of the filming?

- In what ways have Margaret and Ross' roles changed as a result of Parkinson's?
- Why do you think their relationship broke down?

Ross Collins says:

I was a happily married man working a steady job. [Parkinson's] has grabbed my life, given it a good shake and sent me on a totally different course. It has changed the way I think about things. It has changed my relationship with my family. It's been extraordinary.

Think about these questions and prepare oral presentations of your ideas.

- In what ways has Parkinson's sent Ross on a different course?
- What evidence is there in the film of changes in his thinking?
- How has it changed his relationships?

Alternative treatments for Parkinson's disease

The term *alternative therapy*, in general, is used



to describe any medical treatment or intervention that has not been scientifically documented or identified as safe or effective for a specific condition. Alternative therapy encompasses a variety of disciplines including acupuncture, chiropractic, yoga, hypnosis, biofeedback, aromatherapy, relaxation, herbal remedies, massage and many others. Vitamin E is one alternative treatment that may help people with Parkinson's disease. Alternative therapy can be helpful in some cases, but some can be ineffective, costly, and even dangerous.

- Which of these treatments did Ross try?
- What did his treatment in Brazil involve?
- What evidence was there of success in the treatment?
- What risks do you think Ross was taking?
- What did the treatment cost?
- Margaret was trained in western medicine. What do you think her attitude was at first to the alternative medicine Ross tried—and later?
- Suggest reasons why Ross was prepared to travel to Brazil, and ultimately choose that course of treatment over his family life?
- What processes was Ross involved in with the faith healing?
- Why do you think Margaret's attitude changed when Ross wished to return to Brazil?
- Do some further research to explore other forms of faith healing people use.

Looking in more detail at Parkinson's disease

Physiology and symptoms of the disease

Symptoms result from the progressive degeneration of neuronal cells located in the part of the brain called the *substantia nigra*. This causes a deficiency in the availability of *dopamine*, a chemical *neurotransmitter* (messenger) necessary for the production of smooth, controlled movements. The symptoms of Parkinson's disease



appear when about 70 per cent of dopamine-producing cells stop functioning normally. The symptoms develop slowly in the patient and gradually progress over years. These days, most patients are greatly helped by drug treatment. The presentation of symptoms varies greatly between individuals and no two people will be affected in the same way. The three symptoms used for diagnostic purposes are:

- 1 Tremor (shaking, trembling) is the best known symptom of Parkinson's disease, but it is absent in a third of people who are first diagnosed. Tremor usually begins in one hand



and then spreads to the leg on the same side before crossing to the other side of the body. It may also be felt internally. Typically tremor is most noticeable when the person is at rest and when stressed or tired; it disappears during movement and when asleep.

- 2 Rigidity or stiffness of the muscles is a very common early sign of Parkinson's disease in which the muscles seem unable to relax and are tight, even at rest. The person might feel that the muscles will not do what he or she wants them to do. Rigidity may be experienced through the entire range of movement of a joint (called *lead pipe rigidity*) or just in parts (called *cog-wheel rigidity*).
- 3 Bradykinesia (slowness of movement) occurs because the brain is not able to control smooth and delicate movements. This leads to a lack of spontaneous activity (for instance, arm swing diminishes) and fine motor coordination is reduced (for instance, hand writing becomes smaller). There may also be freezing or periods of immobility.

Other symptoms. In some patients symptoms include pain and discomfort in an arm or leg, anxiety and depression, slowness of thinking,

memory problems, and tiredness and disturbed sleep. Constipation is common and bladder problems, especially a tendency to pass water more frequently and with more urgency, may occur. Sexual difficulties may trouble some people. Speech and swallowing problems tend to be more of a problem later in the illness.

- Which of these symptoms do you see Ross experiencing in the film?
- How does Ross cope with these symptoms?

The cause of Parkinson's disease

At present there is no known cause and therefore the illness is termed *idiopathic*. It is not considered to be genetic, though ten per cent of cases occur when other members of the family are already affected.

- What is meant by the term *genetic*?

Who is affected by Parkinson's disease?

Predominantly people in the middle to later years, that is, 50 to 75, are affected, though less commonly it affects adults between 30 and 50. There are difficulties in diagnosing Parkinson's disease but its prevalence is estimated at 1–2:1000 of the population in Australia. One in seven sufferers is diagnosed before the age of 50 years. Approxi-

mately 30,000 people are diagnosed with Parkinson's disease in Victoria per annum.

Incidence. Approximately 500 new cases are diagnosed in Victoria each year.

Understanding Parkinson's disease

The following information from the World Health Organisation Press Office (Fact Sheet No. 152, April 1997) will help you to understand Ross's condition and story.

Impact of Parkinson's disease on the individual

Physical. Functional mobility and the ability to perform all activities of daily living independently become more difficult. Unpredictable fluctuations in motor movement and "freezing" (inability to initiate movement) can occur. Tremor or other physical abnormality of movement causes embarrassment and can socially isolate the individual.

Body functions. General slowing of muscle activity can lead to problems with temperature regulation, ingestion and digestion of food/fluids, elimination, sleep and sexual relationships.

Emotional. Every person with Parkinson's experiences an increased level of anxiety related to the unpredictable nature of motor fluctuations and an uncertain future. It is estimated that approximately 90 per cent of people with Parkinson's also suffer from depression.

Social. Difficulties with communication, for instance having a mask-like face, soft voice, diminished non-verbal gestures, and indiscernible hand-writing, limit the person's ability to socialize. Increased physical incapacitation, a growing dependence on others, and feeling that there is a stigma about the illness in the community – all contribute to social isolation.

Cognitive. During the advanced stages of the illness, some people

are affected by dementia associated with the degenerative processes of Parkinson's disease, although most retain intellectual functioning. Difficulty with tasks involving sequential steps, or activities which require use of short term memory are reported.

- In a small-group discussion, look at this list and suggest its possible impacts on individual sufferers. Compare their experience of Parkinson's disease with Ross'.

Treatment

At present Parkinson's disease is incurable, though drug therapy can alleviate its symptoms. The main treatment is medication, and its main objective is restoring the deficiency of dopamine. Two kinds of drugs are used: those able to cross the blood-brain barrier and be converted into dopamine by the brain; and those able to effectively stimulate the dopamine receptors of the brain.

Drug therapy is complicated by side effects which often occur as a result of long-term use of anti-Parkinsonian medication (medication usually has a maximum benefit of ten years). These side effects can be as disabling as the condition itself. One of the most distressing side effects is the 'on-off' syndrome, or disabling fluctuations in ability. This side effect is often misunderstood by health professionals, who may label such a person when 'off' as difficult or uncooperative.

Neurosurgical management of Parkinson's disease using *steriotactic* surgical techniques has been used since the 1940s, though surgery's popularity waned with the introduction of the medication called *levodopa* in 1967. Improved imaging techniques and the need to arrest disabling long-term-medication effects have seen renewed interest in the surgical form of treatment. It is still somewhat experimental.

- What impact do you see of drug treatment on Ross's life?

Management. Because of the indi-

vidual complex nature of Parkinson's disease, management requires a holistic approach which takes account of the whole of the affected person's life.

- What lifestyle changes does Ross make to cope with the disease?

Diagnosis. The diagnosis of Parkinson's disease is often a shattering experience for both those diagnosed and their families. It needs to be given in a sensitive way so as to allow people time and space to come to terms with it, and to encourage them to seek further information and advice as they need it.

Individual approach. There is no optimum drug treatment for Parkinson's disease. Each person must be prescribed a specific regimen in terms of both timing and dose to suit his or her particular needs. This regimen will often involve a cocktail of different drugs to ensure the best possible result for the patient. It is important to note again that drug treatment does not cure Parkinson's and so the disease continues to progress even when it is under treatment. As it progresses, the individual treatment regimen needs to be reviewed and modified when necessary.

Multidisciplinary support. Early access to a multidisciplinary team is essential. Multidisciplinary assessment can be made of the person's abilities. Potential difficulties can be identified and coping mechanisms put into place before problems start. The team may include physicians, dietitians, chiropodists, counsellors, psychologists, specialist nurses, physiotherapists, Occupational therapists and volunteers. Continuity of care, particularly with the involvement of so many different professionals, is very important.

Carers. Carers can be partners, parents, brothers, sisters, friends or children of any age who provide care for someone with a disability. Many carers receive no training, guidance or instructions on how to cope with someone who has Parkinson's disease. Carers may experience a whole

range of feelings: guilt, anger, resentment, fear and bereavement. They need general information and practical advice, and most importantly they need emotional support.

What are the medications for Parkinson's disease and what do they do?

Information provided by Parkinson's Victoria

Nowadays levodopa is the first line of treatment for Parkinson's and usually it remains so for the duration. Other medications may be introduced, but they are all extra to levodopa and help it to deliver maximum benefit. Levodopa is like petrol in a car: without it Parkinson's sufferers don't go – well, not too well anyway. It is important to take the medication absolutely correctly, particularly as the disease progresses, to avoid

- running out of petrol between doses
- taking more than necessary to treat symptoms
- side-effects
- under treating symptoms.
- What happened to Ross when he did not take all his medication in Brazil?

What other health professionals do Parkinson's disease patients use?

Information from Mary Jones of the Movement Disorders Clinic at the Peter James Centre, Burwood, Victoria

A **physiotherapist** can help with mobility and safety. The physiotherapist's role is to offer assistance in improving gait, balance and bed mobility.

An **occupational therapist** is responsible for looking at all the functional activities of daily living and teaching strategies or introducing equipment to facilitate ability to remain independent. Writing, hygiene, dressing, food preparation, cutlery, work and play are all the domains of the occupational therapist.

A **speech pathologist** looks at communication and swallowing and helps to ensure good volume and speech as well as attending to any swallowing difficulties that may develop. There are an enormous number of muscles involved in swallowing and if the dopamine isn't getting the message to these muscles, choking may be an issue.

A **dietician** may work with the speech pathologist if food modification becomes an issue in relation to swallowing, and will also see people with weight loss issues. Dieticians may also be able to assist with interventions that enable medications to be more effective. They may also be able to help with constipation.

A **social worker** can assist with issues involved in managing life generally and can assist in accessing community services.

Further research on Parkinson's disease

Consult the following websites to find out more about the disease:

www.parkinsons-vic.org.au/

www.michaeljfox.org/pdf/newsletter_sprwin2005.pdf

my.webmd.com/content/article/46/1833_50763.htm

www.holistic-online.com/Remedies/Parkinson/pd_home.htm

or call 1800 644 189 across Australia for help and support

Media studies

Andrew Wiseman, who followed Ross's life for a year and a half, wanted to tell the story of someone dealing with Parkinson's, because he saw his father battle with a similar disease (progressive supra-nuclear palsy). He wanted to show the truth of the disease but also to give viewers hope.

- What elements of this documentary cover these two aspects?

Andrew commented:

In Ross, I saw someone refusing to be intimidated by a life-altering condition – and I think that is inspiring ... He impressed me as an open, eloquent and candid man.

Andrew gave Ross a video camera to record his daily family life.

- How would you describe the genre of this film?
- Whose voices are heard in this story? What are the advantages of hearing these different points of view?

Shake Rattle & Roll: a journey with Parkinson's

A one hour documentary for television
Producer/director, Andrew Wiseman
Editor, Uri Mizrahi

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