

# *Spinning Out*

an Anne Deveson Production

**Information Handbook**

# *Spinning Out*

*a documentary special  
on schizophrenia*

*There has never been more than a miniscule amount of compassion shown to schizophrenia sufferers.*

*SPINNING OUT is a film that will help people to understand the human face of a uniquely human disease—schizophrenia.*

*It is a touching and important film. One which argues strongly for an activism amongst patients, carers and the psychiatric profession, which is sadly lacking at present.*

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# *Index*

|                                    |    |
|------------------------------------|----|
| Introduction                       | 4  |
| What is Schizophrenia?             | 5  |
| Symptoms                           | 6  |
| Causes                             | 7  |
| Frequency of Occurrence            | 8  |
| History of Schizophrenia           | 9  |
| Modern Treatments                  | 10 |
| Community Costs                    | 11 |
| Families and Support organisations | 12 |
| Stigma                             | 13 |
| About the film                     | 14 |
| Conclusions                        | 15 |
| For further information            | 16 |

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# *Introduction*

One in a hundred people will develop the mental illness schizophrenia at some time in their lives, forty million people worldwide. Schizophrenia has been a puzzle for centuries. There is no fixed pattern that allows us to predict the development of the illness in the individual. Schizophrenia can happen to anyone. That makes it pertinent to us all.

SPINNING OUT introduces us to a range of people with schizophrenia, beginning with a homeless man in one of the clinics in Sydney. He is displaying the most curious of all the symptoms of the illness—thought disorder, in which words often appear to make a different kind of sense.

1.55 mins

PATIENT: But if I'm not patient in this clinic can I walk out this door?

We also meet Simon and Susan in the coffee shop at the end of the film:

55.19 mins

SUSAN: There's a stereotyped image of the bum in the streets...but I find that's only a small amount of schizophrenics, most are just like normal people. You wouldn't even know.

Within the term 'schizophrenia' there is a whole range of manifestations and levels of severity at any given time. In fact there are probably many schizophrenias. In SPINNING OUT we have given a glimpse of this range and the difficulty of dealing with an illness for which:

- there is no known cause
- there is no known cure

This does not mean that schizophrenia is necessarily a dire and impossible illness. In fact the breakthroughs in treatments and knowledge in this century have offered more hope than ever before.

# *What is schizophrenia?*

Schizophrenia accounts for three quarters of all mental disorders. The name was coined in 1911 by the Swiss psychiatrist Eugene Bleuler and comes from the Greek words “schizos”—split and “phrenos”—the mind.

9.06 mins

ANNE DEVESON: Schizophrenia is a name given to a group of disorders. It isn't a split personality like Dr Jekyll and Mr Hyde. Instead it's a disorder in the brain which distorts the way a person thinks and experiences the world. This creates a loss of distinction between the inner and the outer world.

It is a biological disease of the brain. It affects the parts of the brain that allow us to make sense of reality, disrupting the ability to make rational decisions and often causing hallucinations and delusions. With schizophrenia, fundamental processes in the brain are disturbed. Messages are channelled to the wrong responses, like a computer chip making faulty connections. Information floods in and overwhelms the brain.

6.08 mins

DOCTOR: I think slowly we will find out the cause of schizophrenia. I can't say we know what it is yet, but in my view it's a medical illness of the brain. It's unrelated to the person knowing he is behaving badly...it's probably some chemical abnormality in the brain or some multiple centres in the brain that are impaired. It's unrelated to the way parents bring up the child.

# *Symptoms*

With schizophrenia there are active and inactive stages of the illness. Active symptoms include any one or a combination of the following symptoms to an extreme degree: delusions, hallucinations—visual or auditory (or both), paranoia, disturbance of thinking, extreme mood swings and sometimes apparently bizarre behaviour. Inactive symptoms include withdrawal, lethargy, loss of motivation. The state in which the most pronounced active symptoms occur is known as psychosis.

11.48 mins

JAY: First symptom is racing thoughts. I know I am going into a psychosis when my thoughts are tumultuous. Then afterwards there is anxiety and paranoia...I think the house is bugged.

A curious feature of the illness is that all over the world, symptoms are remarkably similar, which indicates that the breakdown is probably occurring within the same part of the brain—the limbic system. The limbic system acts like a filter, ordering and processing all the messages we receive, both internal and external. But people's explanations for their symptoms will depend upon their cultural background. A man in the rainforests of Nigeria hears the ghosts of his ancestors talking to him. A woman in New York thinks that the television is broadcasting her most secret thoughts.

Many of the more frightening symptoms of the illness may be a consequence of the mind trying to make sense of its inner turmoil. People may have auditory hallucinations and hear voices which tell them to behave in a certain way. Sometimes the voices are friendly. Often they are cruel and taunting.

13.59 mins

SUE: In my third year at uni I started to hear auditory hallucinations...as if someone was talking to me...often they said we want your heart...stupid...and a few insulting words...A couple of months ago I was in my room and I heard a baby scream.

Visual hallucinations may bring about flashing lights or inexplicable images (ACE 31.09 mins). Smells and tastes may change, and so may perceptions of time and space. A minute may seem like a hundred years and the face of a friend suddenly disintegrates or distorts into some horrifying form, (SUSAN 13.59 mins). Thoughts may become fragmented and all sense of personal boundaries disappear so that it may feel as if the world is invading body and mind, or that the person is spinning out into a black vortex from which there will be no return, (JAY 15.03 mins).

# *Causes*

The causes of schizophrenia are still not fully understood. Nobody is certain why this malfunctioning occurs, nor is there any test capable of providing undisputed diagnosis. A predisposition to the illness may be genetically linked or may be caused by damage to the brain cells before or during birth. Faults in the brain's functioning may then be triggered by any number of factors, ranging from environmental stress, to drug abuse and hormonal changes. These last factors are important when you remember that most people contract the illness initially in their teens.

Although social/environmental factors were given prominence in the past, it is now known that schizophrenia is not caused by childhood experiences or poverty, nor by poor parenting. Social and/or environmental factors may however affect recovery. Contrary to popular opinion there is no clear evidence that street drugs actually cause schizophrenia, but these drugs can trigger the illness in someone who is already predisposed to schizophrenia, or can exacerbate the illness in those who are sufferers.

Advances in medical technology in recent years have given us some of the keys to the mystery of schizophrenia, with a variety of intricate ways of imaging the brain and comparing the differences in functioning between those who have the illness and those who do not. It is still not known which comes first—the illness, which affects the brain physiology and functioning, or whether differences in physiology and functioning cause the illness.

9.29 mins

JOHN ANDERSON: What we see here is that in Simon's brain wave form there is only one trough in a time frame where we might expect to see two peaks and two troughs. This indicates that Simon's brain is being flooded with stimuli and it's making it very difficult for Simon to discriminate about what is important and what is not important.

9.52 mins

SIMON: I started to understand what these measurements were actually showing about the way my brain perceived and responded to stimuli...I realised that even over the simplest response my brain's really having to actually re-programme itself. It's like my...neuro-filing system is wrong and it's constantly having to be updated every second, to try to make sense of the world.

# *Frequency of occurrence*

Throughout the world there are some statistical constants:

- One in a hundred people will develop schizophrenia at some time in their life.
- Three quarters of those who develop schizophrenia will be young people between the ages of 16 and 25 years.
- Although an equal number of males and females develop schizophrenia, it occurs earlier and in a more severe form in males.
- Some people may have only one episode of the illness and recover (25%); the rest will continue to have the illness in an episodic form or may be chronically ill for the rest of their lives.
- Although frequency of occurrence of the illness is constant throughout the world, outcomes of the illness appear to be better in third world countries.
- Genetic disposition to the illness has been documented for a long time. In the general population there is a 1% chance of developing schizophrenia; if there is a distant relative with the illness the chance increases to 3%. If one parent or sibling has schizophrenia there is a 10% chance; if both parents 40%; an identical twin 35-50%.

But these are only figures on paper. In Jay's family, his father, sister, he and two of his four children have schizophrenia.

38.45mins

JAY: I was filled with remorse and anguish that such a thing could have happened to both him (my father) and me and other people in the family too. We were very unlucky to have two children with it. By rights we should have had one at the very most.

The exact nature of this genetic predisposition is still an unknown. Unfortunately this information may be wrongly used by the eugenicists to suggest enforced sterilisation, even though many bright and successful people are the offspring of a parent with schizophrenia and many sufferers make a significant contribution to our world despite their illness.

# *History*

Mentally ill people have been treated as social outcasts since earliest times. In the Middle Ages, mental illness was often seen to be the mark of the devil and people were burned as witches or cast out to wander the countryside.

In Victorian times, treatment was based on the belief that mental illness was due to weakness of character. Vast numbers of mentally ill people were locked away in asylums and, although treatment was sometimes humane, many endured cruelty, filth and starvation, (18.33 mins).

Hospitals remained the primary care centre for many sufferers until the 1950's. Various therapies included insulin and shock treatments, the use of straightjackets and even lobotomies. These methods had varying success in the treatment of individuals with schizophrenia.

In the 1920's and 1930's psychoanalysts questioned the physical basis of schizophrenia and proposed that it was caused by bad parenting or traumatic childhood experiences. These theories were given further attention in the 50's and 60's, when the anti-psychiatry movement saw schizophrenia as a label for scape-goating people who were eccentric or difficult to live with.

None of these theories were substantiated by valid research and have since been discredited, but for a long while they led to cruel attacks on families, (46.3 mins).

The discovery of the anti-psychotic drugs in the 1950's at last led people to have some control over their illness. Since the advent of the anti-psychotic drugs most people are able to live back in the community. Previously two thirds of people with schizophrenia were confined to hospital care for life.

16.15mins

Paul and Bill are both in their late 50's and have spent most of their lives in hospital care. Paul can play every hymn in the Oxford collection. Bill was an articled lawyer before he had his first attack. Both have had insulin and shock treatment and now respond well to anti-psychotic medications, allowing a return to community living.

# *Modern treatments*

For each individual the course of the illness and the outcome will be different. Modern management requires an integrated approach which involves the use of the anti-psychotic medication, together with information about the illness, and how to live with it. It is important that family members are kept informed and included in patient care, (44.09 mins).

Anti psychotic drugs relieve the symptoms of the illness but they do not cure the disease. Often these drugs have side effects such as restlessness, stiffness, muscle spasms, dry mouth or weight gain. Secondary medications are used to balance this.

53.28 mins

ANNE: It must be awful being ill again Simon.

SIMON: Yeah, its horrible...The physical movements, the aches, trying to figure out what's the drug and what's the you know...because some of the drugs help your memories come back, others actually suppress your whole brain, you know knock out everything...

Hospital respite is still valuable for many people to monitor medication, to give protection in extreme psychosis and to give the family a break. Mental Health laws vary considerably and some make it difficult to get hospitalisation unless the person with the mental illness is considered a danger to themselves and others. In SPINNING OUT, after an emotional visit to a locked ward in a city hospital (18.33mins), Simon, who has also spent time in a locked ward mulls over the role of asylum.

22.15mins

SIMON: For me asylum is still one of the most beautiful words in the English language...I mean I think there are ways of locking people up, if you like, with feeling...we often forget that the things that work for most people will work for people with schizophrenia.

For many people with schizophrenia, basic life skills have never been learnt due to the early onset of the illness. Health teams not only monitor medications but also ensure people have food, money and shelter and teach them how to look after themselves. In SPINNING OUT we see an inner city health team with Ace, a homeless street kid who has schizophrenia, (24.57 mins). A few years ago help of this kind would not have been available.

One of the most optimistic breakthroughs has been the emergence of self-help groups and the encouragement given to self-monitoring of the illness. In SPINNING OUT the Glebe Group, which has been running for a decade is a good example of this new approach, (32.33 mins).

# *Community costs*

Since schizophrenia mostly affects people in their youth, ongoing care of people in a chronic or intermittent condition makes it one of the most costly of all illnesses. Schizophrenia costs Australia \$1.5 billion a year in direct and indirect costs. It takes up more hospital beds than any other single illness. Despite these costs little is spent on research—\$7.50 for each patient with schizophrenia, compared with \$70 and \$400 for heart and cancer patients.

Almost half the homeless in our big cities are mentally ill, and in some night refuges this can be as high as 75% of the residents. For some people the development of schizophrenia can lead to a downward economic spiral. Poverty and homelessness are a real consequence of loss of health and livelihood.

31.33 mins

ACE: I've been on a pension now for four years...money doesn't really interest me.

DOCTOR: Well that's a bit lucky if you're on the pension.

The loss of sense of self, feelings of being stigmatised, combined with loss of income, study years and even loss of social life can lead to feelings of depression for schizophrenia sufferers. Suicide becomes a real risk.

49.04 mins

ANNE H: When we'd say "Look, he's terribly depressed", all you'd get put forward to you "Now look Mrs Hems, the statistics are 10-15% of all schizophrenics commit suicide." OK, we live with that on a day-to-day basis. But if you see a statistic coming, you don't stand back and say "Come on in statistic." You're talking about a person—a human being, not a statistic.

43.19 mins

ANNE DEVESON: Susan, since we started making this film, you've overdosed twice, why do you do it?

SUSAN: Oh, just being fed up, fed up with the illness, can't live with it any longer...The continual thinking...your mind's just going full bore...I don't ever get peace ever, never, unless I'm asleep.

7.15 mins

SIMON: You hear things like the only good schizo is a dead schizo...which really hurts...especially if you've lost mates because they couldn't take it any more.

# *Families and support organisations*

Throughout Australia there is a growing number of consumer support organisations and these are listed in the back of this booklet. Such organisations provide counselling, education and support groups for people with schizophrenia and their families. Some organisations have also developed services such as accommodation, holiday care and rehabilitation programmes. However, there are limits on funds and human resources and groups struggle to meet the enormous needs in areas not covered by the health care system. In SPINNING OUT we meet Dr Margaret Leggatt of Schizophrenia Australia, (46.22 mins).

46.34 mins

DR MARGARET LEGGATT: I'd carried out a piece of research looking at what happens in families when a son or daughter was diagnosed as suffering from schizophrenia and I have to say I found that research a very shattering experience...they were coping in the most extraordinary circumstances...these families were not getting the help they needed.

51.26 mins

I think it won't change much until we have everyone accepting that schizophrenia is very much a treatable illness. I'm sure until that happens parents are still going to be blamed, which I think must be one of the most subtle forms of cruelty I can think of.

# *Stigma*

The stigma against people with mental illness is age-old. Schizophrenia is sensationalised, (15.20 mins). In any video shop there are rows of “madness” titles. Most feelings of mistrust and fear are due to ignorance.

What do you do if you are on the receiving end of this? If you are always told you are no good or dangerous? If you are treated like a 20th century leper? In SPINNING OUT Simon attempts to put a positive view of schizophrenia.

7.15 mins

SIMON: I started to think people with schizophrenia were special. I have a highly biased view obviously...what it comes to mean for me now, if you look at the letters...

*Special*

*Creatively*

*Heightened*

*Individual*

*Zanily*

*Overly*

*Perceptive*

*Humorous*

*Really*

*Emotional*

*Needing*

*Insight and*

*Care*

# *About the film*

We decided to focus SPINNING OUT on the people who live with schizophrenia rather than concentrating on medical details of the illness. By showing the daily courage of those who battle with a baffling and often frightening illness we hope this will help overcome some of the stigma which has kept schizophrenia locked away.

This film was not an easy one to make because of the vulnerability to stress of the people who participated—and filmmaking is a stressful process. In addition one of the paranoid delusions of schizophrenia is that people are spying on you, so the very process of filming created its own problems.

2.54 mins

SIMON: With schizophrenia one of the delusions you often have is that people are bugging you, you know, that you've got a wire on you, listening to everything you say. Or that people are making movies about you...and all of a sudden it's like whoo...they're here.

The unpredictability of schizophrenia made it difficult to be rigid about schedules. We lost Ace (the street kid), found him and then had to cancel the final sequence with him because he had shaved off all his hair including his beard. We also had to postpone part of the shoot with Simon when he became ill halfway through our filming. We waited until he was better and then he made the decision to resume. Throughout the entire film we had on-going briefing sessions and involved participants in all discussion and decisions.

# *Conclusions*

We applaud the courage and honesty of everybody who agreed to appear in the film. They were willing to confront the risk of stigma because they felt passionately about the need to overcome community ignorance and fear. We are also grateful to the generous help given to us by health professionals throughout the whole process of making the film.

In spite of improvements in medical care for schizophrenia, and in spite of our knowledge that schizophrenia can have a better outcome than previously imagined, many people with schizophrenia are unable to obtain the treatment and rehabilitation they need. Families are still often left to flounder unaided. This is partly because people were “de-institutionalised” before the necessary support facilities were available in the community, and partly because schizophrenia still carries stigma, blame and fear.

It is time that we established the legitimacy of schizophrenia as an illness that can be assessed and treated. It is time that we stopped rejecting and ignoring people whose lives are journeys of courage and endurance.

*Anne Deveson and Chris Pip*

*\*For further information please contact the organisation in your state*

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