



An intimate story of a courageous family

# THE INHERITANCE

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[theinheritancedocumentary.com](http://theinheritancedocumentary.com)



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A **STUDY GUIDE** BY KATY MARRINER



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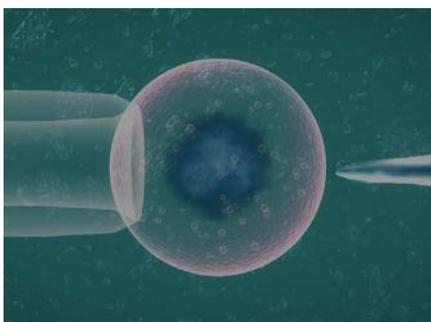
The Inheritance (2014) is a feature documentary by Bridget Lyon and Jeff McDonald.

## THE INHERITANCE

An intimate story of a courageous family.

The inheritance addressed in this personal and courageous film could hardly be more daunting. Huntington's Disease is a hereditary neurodegenerative condition that typically manifests in mid-adult life. When Australian-New Zealander Bridget Lyon was diagnosed in her thirties as carrying the Huntington's Disease gene, she knew she would one day deteriorate like her mother Judy Lyon. When Bridget's two older brothers were also diagnosed as carriers of the neurodegenerative gene, the worst was confirmed: that Huntington's Disease would impact an entire generation of their family.

Bridget and her partner Jeff McDonald decided to make a documentary about their experience, starting in Australia where they were living at the time and finishing in New Zealand, where they moved to be near Bridget's mother who was rapidly declining from the onset of Huntington's Disease. Struggling to face up to the crushing impact Huntington's Disease was having on her family and the harrowing possibility that her eldest son may have inherited it also, Bridget and Jeff take the audience of *The Inheritance* into the heart of a family whose love of life and devotion to each other is truly something to behold.



Before the onset of the disease, Bridget's mother Judy had been a staunch advocate for Huntington's Disease awareness – in marked contrast to previous generations who were forced to shroud its cruel heritage in shame. Historians have traced the passage of the gene back through generations, as Bridget has been able to do in her own family. Seeking hope for generations to follow, she meets leading medical scientists racing to find a cure and witnesses the everyday heroism of people living with the disease.

Judy died on March 27, 2015. Despite her ill health, she was able to attend the world premiere of *The Inheritance* on August 8, 2014 at the New Zealand International Film Festival.



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## CURRICULUM LINKS

This study guide to accompany *The Inheritance* has been written for students in Years 10 – 12. *The Inheritance* is a relevant resource to complete outcomes in Biology, English, Ethics, Health and Human Development, Media, Psychology and Science. Teachers should consult the Australian Curriculum online at <http://www.australiancurriculum.edu.au> and curriculum outlines relevant to these studies in their state or territory.

As a curriculum resource, *The Inheritance* expands and enriches students' knowledge of key life strategies, including:

- decision-making
- managing adversity
- building resilience
- dealing with family issues
- health management

Activities in this study guide provide opportunities for students to:

- o **acquire scientific knowledge** of how the transmission of heritable characteristics from one generation to the next involves DNA and genes;
- o access, **synthesise** and apply health information from credible sources to propose, **debate** and justify responses to health situations;
- o identify that **human health and development** is about expanding individuals' choices; enhancing individuals' capabilities and their freedoms; and enabling individuals to live full, productive and creative lives;



Running  
time:  
72 mins

- o **formulate** informed responses to the increasingly growing subject of genetics;
- o **respond** to a film both personally and in detached and critical ways;
- o **identify** the ways that texts communicate information, ideas, bodies of knowledge, attitudes and belief systems;
- o draw on appropriate metalanguage to **discuss** the structures and features of a film;
- o use their own written, spoken and multimodal texts to **explore** concepts and ideas and to clarify their own and others' understanding.

The study guide is structured as a series of discussions about the ideas explored in *The Inheritance*. Activities allow for individual and collaborative learning. Student responses may be written, spoken or multimodal in form. Teachers may select from the information and activities to support students' viewing and close analysis of the documentary.

Teachers are advised to preview *The Inheritance*. Students should be informed about the subject of the documentary prior to viewing. After viewing the documentary, allow students the opportunity

to share their thoughts and feelings about *The Inheritance* with the class.

For some students in the class, *The Inheritance* may be confronting viewing. Teachers need to provide students with a safe and supportive classroom environment given the sensitive nature of the subject, particularly those students who may be experiencing poor physical health or living with family members with poor physical health. Teachers need to respect the personal circumstances of these students and remain aware of their sensitivities.

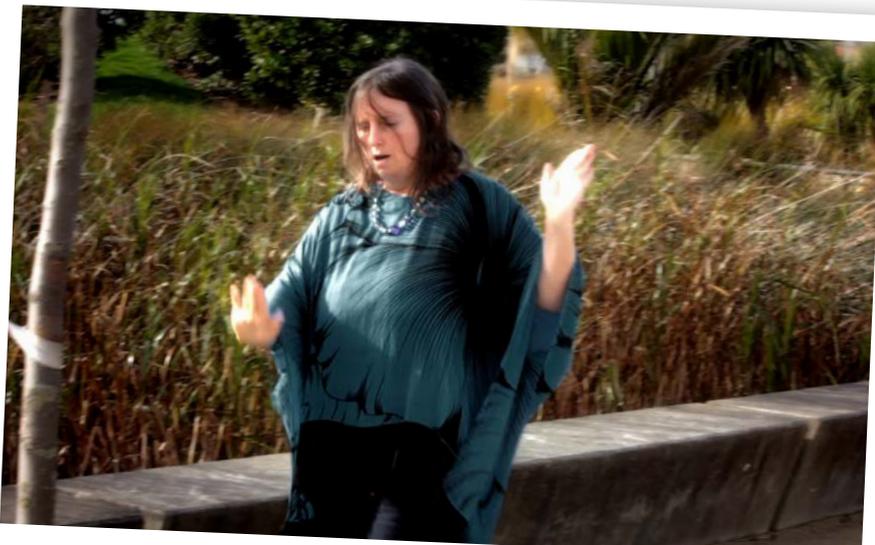
Other students may have questions that need to be answered before they can respond in an analytic way to the ideas and issues explored in *The Inheritance*. It is also important to recognise that some students may not want to share their responses to some tasks. In addition, students should be reminded that a classroom discussion is a public forum and that some information should not be disclosed in this context.

Watch the trailer at <https://youtu.be/PL0aXK9B8GM>.

## SCENE SELECTION

*The Inheritance* DVD allows teachers and students to revisit particular scenes from the film via the scene selection menu.

- o Our inheritance
- o Onset
- o A gift from the heart
- o A hell of a legacy
- o Things haven't stopped
- o Happy Birthday Grandma



## PARTICIPANTS

### THE LYON FAMILY

- Bridget Lyon, Jeff McDonald, and Fynn and James
- Judy Lyon, David (Dave) Lyon, Nick Lyon and Warrick Lyon

### THE EXPERTS

- Charles Sabine, former NBC journalist and international spokesperson for people living with Huntington's Disease
- Jeanette Wiggins, Huntington's Disease Advisor, Wellington Huntington's Disease Association, New Zealand
- Dr Maria Björkqvist, Research Group Leader, Brain Disease Biomarker Unit, Lund University, Sweden
- Dist. Prof. Richard Faull, Director, Centre for Brain Research, The University of Auckland, New Zealand
- Prof. Anthony Hannan, Head, Neural Plasticity, The Florey Institute of Neuroscience and Mental Health, Melbourne, Australia
- Dr Danny Hatters, Head, Dept. of Biochemistry & Molecular Biology, University of Melbourne, Australia
- Dr Michael Hayden, President, Global R&D; Chief Scientific Officer, Teva Pharmaceuticals; Killam Professor, University of British Columbia, Canada
- Dr Clement Loy, Director & Neurologist, Huntington Disease Service, Westmead Hospital, Australia
- Prof. Paul Muchowski, formerly Uni. Of California, San Francisco, USA, now Teva Pharmaceuticals
- Dr Martha Nance MD, Clinical Professor of Neurology, University of Minnesota, USA
- Dr Ed Wild, Clinical Lecturer in Neurology, University College London (UCL) Institute of Neurology, UK

*The Inheritance* also features people who have tested positive to the Huntington's Disease gene and people caring for family members whose health has been compromised by Huntington's Disease.



## WHAT IS HUNTINGTON'S DISEASE?

Huntington's Disease is a hereditary degenerative neurological condition. The death of neurons, particularly in those parts of the brain known as the basal ganglia and the cerebral cortex results in gradual loss of cognitive, physical and emotional function. The condition is caused by an altered gene that can be passed from one generation to the next. A child born to a parent who carries the Huntington's Disease gene has a 50 per cent chance of inheriting the gene and developing the disease.

Symptoms usually, but not always, appear when the person is between the ages of the thirty-five and forty-five. The most common symptom is involuntary movement called chorea. A person with Huntington's Disease may also have difficulties with swallowing and speech. They will experience cognitive decline and there is a likelihood of loss of motivation, depression and psychiatric problems. Behavioural problems are thought to be caused by damage to the brain as the disease progresses and the understandable frustration and depression that is a consequence of chronic illness. A person with Huntington's Disease may live for 15 to 25 years after developing the first symptoms. The cause of death is not the disease itself but complications such as pneumonia, heart failure or infection developing from the body's weakened condition.

Diagnosis is based on a family history of Huntington's Disease, genetic testing and assessment of physical, neurological and emotional symptoms. People at risk can take a test to see whether they have inherited this gene. A person must be at least eighteen years old and want to know their gene status before they can have the test. Deciding whether to take the test is a personal choice. There is also a prenatal form of the predictive test for Huntington's Disease. The purpose of prenatal testing is to screen the foetus in order to avoid passing on the gene to the next generation. If the foetus is found to have a high risk of carrying the gene, termination of the pregnancy can be considered by the parents.

There is no cure for Huntington's Disease. The altered gene was isolated in 1993 and clinical trials continue to search for drugs and treatment that will delay the onset, slow the disease or control symptoms. It is hoped that medical researchers will find the answer to the puzzle of Huntington's Disease. Until then, support groups worldwide will continue to raise money for research, support services and to improve awareness and understanding of Huntington's Disease in the wider community.

Useful links:

Huntington's Disease Youth Organisation

<http://www.HDYO.org>

This is a volunteer organisation created by young people affected by Huntington's Disease

Huntington's South Australia & Northern Territory

<http://www.huntingtonssa.org>

Huntington's New South Wales

<http://www.huntingtonsnsw.org.au>

Huntington's Queensland

<http://www.huntingtonsqld.org.au>

Huntington's Tasmania

<http://www.huntingtonstasmania.asn.au>

Huntington's Victoria

<http://www.huntingtonsvic.org.au>

Huntington's Western Australia

<http://www.huntingtonswa.org.au>

<http://chdifoundation.org>

<https://www.enroll-hd.org>

## FIRST IMPRESSIONS

- Provide students with an opportunity to share their impressions of *The Inheritance*.
  - Or
  - 'Moving'
  - 'Inspirational'
  - 'Incredible'
  - 'Intimate'These are all adjectives that have been used by the media to describe *The Inheritance*. Ask students to discuss moments of the film via a series of adjectives. For example, students could be asked to name the moments that they found uplifting or inspiring, along with those moments that they found sad or upsetting. What moments struck them as hopeful? Were there any moments in the film that they found too confronting to watch?
  - OrAsk students to share their impressions of the individuals featured in the documentary.
- Prior to tackling the Discussions, ask students to respond to the question, 'What is the message of *The Inheritance*?'
- Post a comment about the documentary on the *The Inheritance* Facebook page at <https://www.facebook.com/TheInheritanceDocumentary>.



### DISCUSSION 1

## HUNTINGTON'S DISEASE

- What is Huntington's Disease?

Teachers may choose to provide students with the information about Huntington's Disease published in this study guide. Alternatively teachers may ask students to draw on the information provided about Huntington's Disease in *The Inheritance* and instruct students to utilise online resources to compile a class fact file.

- As you watch *The Inheritance*, compile a glossary of terms about Huntington's Disease.
- Create a tri-fold brochure for a medical surgery's waiting room. The brochure should provide patients with information about Huntington's Disease. The brochure should also be logically formatted and show some creativity in regard to the design aesthetic. The brochure should use text and images to convey accurate and up-to-date information.

It is estimated that for every 100,000 people worldwide, five to ten will have Huntington's Disease. Huntington's Disease can affect men and women of all ethnic backgrounds. The disease occurs throughout the world, however, there are geographic clusters where it is unusually common. There are no accurate estimates of the number of new cases each year.

- Can Huntington's Disease be eliminated? Can its frequency be reduced?

In *The Inheritance*, we learn that the disease has four definitive stages.

- What are the four stages of Huntington's Disease? What are the symptoms associated with each stage? How does *The Inheritance* shape the audience's knowledge and understanding of each stage?
- Dr Michael Hayden is an expert on Huntington's Disease. Explain Dr Hayden's claim that 'Huntington's Disease has been described as the worst disease known to man. Huntington's robs you of who you are.'

Dr Milton Wexler (August 24, 1908 – March 16, 2007) was a Los Angeles psychoanalyst who was responsible for the creation of the Hereditary Disease Foundation. Wexler and his daughter Nancy were pioneers in the discovery of the HD gene.

- Use online resources to research the contribution that Dr Wexler and his daughter Dr Nancy Wexler have made to society's knowledge and understanding of Huntington's Disease.

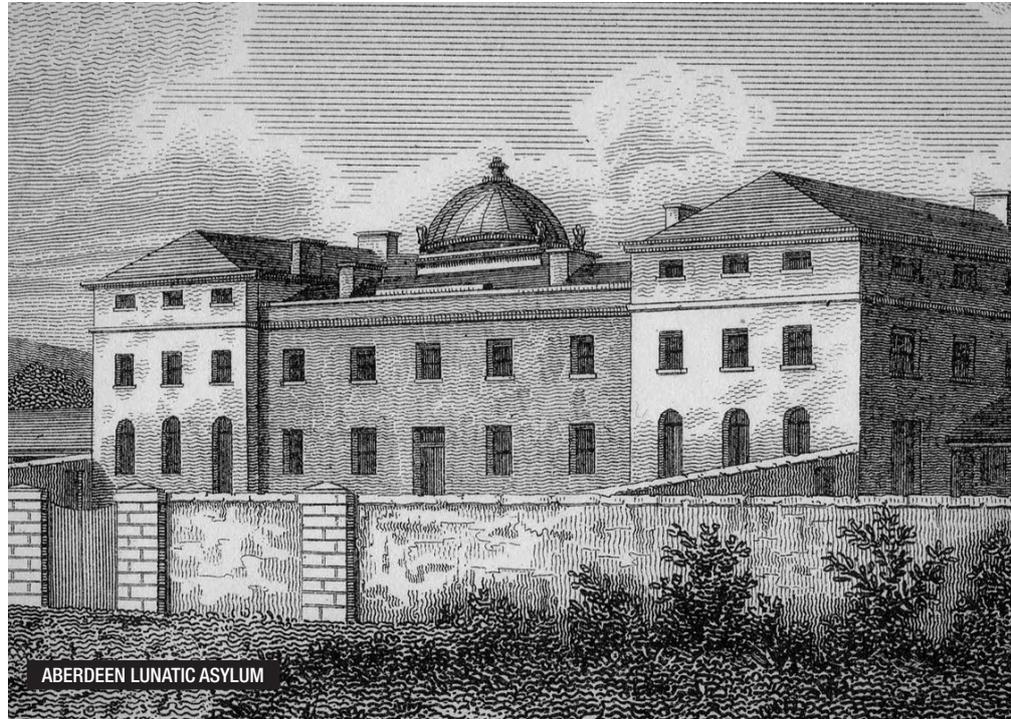
*The Inheritance*, through an interview with American historian Alice Wexler and a dramatised recreation, provides an account of how Huntington's Disease came by its name. Alice tells Bridget the story of a town in East Hampton in the United States of America where there were

many families with the disease,

'In 1806 there was in the newspaper, a little article about a woman who had disappeared one morning. Her husband had come home, she was working at home, she was ironing clothes and her husband had gone to bed leaving her there, working late at night. But when he got up in the morning she wasn't there.'

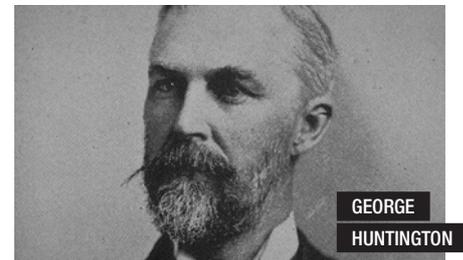
The woman was Phoebe Hedges, the wife of Captain David Hedges. Her doctor's journals indicate that she had called for the doctor to see her and that he had prescribed various calming medications. After a considerable search it was decided that Phoebe had drowned herself in the ocean surf. Phoebe was about forty years of age. Her very deliberate decision to end her life was attributed to her dread of the disorder Saint Vitus Dance.

Sixty years later in the same town the son of the doctor who had treated Phoebe Hedges, was visiting patients with his twelve-year-old son. The father and son encountered two women, a mother and daughter, making their way along the road on which the doctor and his son were travelling. The women were bowing, twisting and grimacing as they walked. The doctor's son was called George Huntington. At the age of twenty-one, George wrote a paper describing the hereditary pattern of a disease he and his father and grandfather, all physicians, had observed in East Hampton. Subsequently the disease was named after him.



ABERDEEN LUNATIC ASYLUM

- Use the Internet to research Saint Vitus Dance. What is Saint Vitus Dance? What are the symptoms of Saint Vitus Dance? How did it acquire its name? Why was it unlikely that Phoebe Hedges was suffering from Saint Vitus Dance?



GEORGE HUNTINGTON

Bridget has traced her family's history of Huntington's Disease. *The Inheritance* begins with an account of this history:

'In 1814 a baby girl was born in a tiny Scottish village. She was named Margaret after her mother. Her father worked long, hard days cutting trees in the forests of Aberdeenshire. When she grew up, she married her sweetheart in a dress that despite her tall figure, failed to obscure eight months of pregnancy. Over the next 18 years, Margaret gave birth to seven children. When her youngest, James, was two, she was admitted to the Aberdeen

Lunatic Asylum. When James was nine, his dear sister Jane set off in a sailing ship to a place they called New Zealand. She said it was on the other side of the world. As soon as James came of age he followed his big sister to that far away place. Was he running away from the spectre of his mother's madness? We'll never know. But he took with him an inheritance, deep within the fibre of his being. James passed the inheritance to his son William who passed it on to Mavis, my grandmother. My name is Bridget. For generations Huntington's Disease has decimated my family.'

The story of Bridget's great, great, great grandmother Margaret Pirie, a resident of a Lunatic Asylum in Aberdeen, Scotland in the 1850s highlights the devastating consequences of ignorance and misunderstanding that characterised treatment of Huntington's Disease patients prior to the work of George Huntington.

An entry in her doctor's journal reads:

'29th of April, 1856. Name: Margaret Pirie, 42 years. Those at present marking the disorder are: unnatural elevation of spirits, violent temper and a disposition much the reverse of that natural to



WILLIAM



JAMES PIRIE AND FAMILY

themselves in the larger community, who do not marginalise the person with the disease – amazing, beautiful, wonderful things happen.

Advocacy has mostly been led by families affected by the disease. When the American singer Woody Guthrie died of Huntington Disease in 1967, his wife Marjorie campaigned to raise awareness of the condition. The story of the Lyon family is also evidence of this being the case. Bridget recalls,

‘When I was a child, my mother became a founding member of the local Huntington’s Disease Association and did her part to raise awareness of the disease. In the eighties she got a book about living with Huntington’s Disease from Dr Edmond Chiu. For me it was the first time I had seen the words Huntington’s Disease associated with the word living rather than the word death.’

- How can *The Inheritance* improve the quality of life for those living with Huntington’s Disease? How can *The Inheritance* encourage greater understanding and empathy towards those living with Huntington’s Disease?

Huntington’s Disease continues to carry a significant amount of fear and stigma from both the public and from health

her. She has been violent towards her husband at times. She has also several delusions of witchcraft and others such as that people are doing her harm, casting ill upon her. But latterly her talk has been about money making.’

On February 12, 1857, the doctor noted, ‘This case has remained stationery since admission. She is noisy, excited and incoherent when addressed.’ Five months later, having suffered an acute attack of bronchitis, Margaret died.

- Spend time as a class discussing the stories of Bridget’s ancestors. Why are these stories significant to the story told in *The Inheritance*? What do these stories suggest about the importance of medical research? What do these stories reveal about the importance of awareness-raising around Huntington’s Disease? Consider the comments made by some of the documentary participants to help you shape your responses:

**Charles Sabine:** So people who did have it were just diagnosed as being lunatics and just stuck in an asylum or even more recently, diagnosed as having Schizophrenia.

**Dr Michael Hayden:** When I tried to learn about Huntington’s Disease in South Africa or Africa in the late 70s, there was almost nothing written. In fact, most of my mentors told me it didn’t exist. We then went on to visit every single mental hospital in the country and identified hundreds of patients with Huntington’s Disease.

**Charles Sabine:** Up until this point, people have been ashamed about having this disease.

**Dr Michael Hayden:** In some parts



of the world, even today, just as there is discrimination with people with mental illness, Huntington’s Disease is hidden.

**Dr Martha Nance:** Many families still don’t talk about it and if they do talk about it, it doesn’t go well.

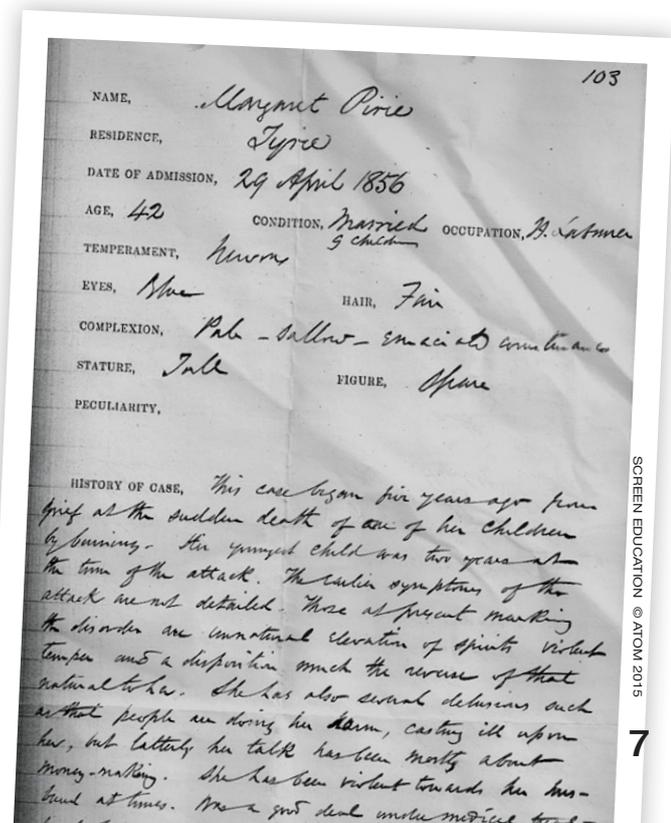
**Charles Sabine:** My family, like including my mother and my brother and his family, do not say the H word.

**Dave Lyon:** I remember Jude was very open. When she tested positive, she put a notice on the staff notice board telling everybody she tested positive for Huntington’s Disease. Brilliant.

**Dr Michael Hayden:** These diseases are just like diabetes and cancer. These are unfortunate, but they don’t carry any other value judgement. They don’t say who you are as a person. They say you are just unfortunate.

**Charles Sabine:** Communication brings awareness and that process dissolves fear.

**Dr Martha Nance:** The patients, the families who are open about it, who engage





professionals due to lack of knowledge and understanding of the illness.

- Has your understanding of Huntington's Disease and people who have Huntington's Disease changed after watching *The Inheritance*? Explain why.

## DISCUSSION 2

### LIVING WITH HUNTINGTON'S DISEASE

*The Inheritance* tells the story of individuals and families who are living with Huntington's Disease. The experiences of these people illustrate the extraordinary challenges facing families affected by Huntington's Disease, as well as their remarkable courage and resilience.

Spend time as a class discussing all that the individuals, those with Huntington's Disease and those caring for someone with Huntington's Disease, featured in *The Inheritance* must face and accept.

- What do we learn about the needs of people who have been diagnosed with Huntington's Disease in *The Inheritance*?  
Working in small groups, use the Internet to further identify the physical, social, emotional and medical needs of people who have been diagnosed with Huntington's Disease. Compile your findings into a table. What conclusions can you make about the needs of people who have been diagnosed with Huntington's Disease?

Add another column to your table. In this column compile information about the physical, social and emotional needs of those who care for people who have been diagnosed with Huntington's Disease. Use *The Inheritance* and other online resources to facilitate your completion of this task. What conclusions can you make about the needs of those who care for people who have been diagnosed with Huntington's Disease?

- Why do you think the Lyon family made the decision to share their experience of living with Huntington's Disease with the documentary's audience?

Would you describe *The Inheritance* as a positive account of life with a hereditary illness? Explain your reasoning.

Children with a parent affected by Huntington's Disease have a 50 per cent chance of inheriting the defective gene. Dr Michael Hayden states: 'But even worse than that, is that at the time that you might be dying of your illness is the recognition that your children might also follow the same course.'

Bridget Lyon was twenty-one when she learnt that her mother had the gene for Huntington's Disease. At age thirty-three, she decided to be tested for the condition.

In *The Inheritance*, Bridget acknowledges how her parents' knowledge of Judy's future health situation shaped their family life:

'I always knew about the risk of Huntington's Disease because of my parents' attitude that they shouldn't hide anything from their three children. And we grew up in a frenzy of adventure with a family motto of trying to fit in as much as we could into every day.'



- Compare Bridget's experience of growing up in a family affected by Huntington's Disease with the experiences of previous generations of her mother's family.
- Why do you think Bridget refers to Huntington's Disease as an 'invisible enemy'?

Previous generations of Bridget's family went undiagnosed and were sent to psychiatric wards as their health declined.

Prior to the onset of the debilitating stages of Huntington's Disease, Bridget interviewed Judy about her memories of her mother's, Bridget's grandmother's, ill health. Judy recalls,

'She would take herself to town and go in by bus and she would fall over in the street and people thought she was an alcoholic. There was a chemist shop there that she went to a lot and he was very good, he would take her in if she got into strife and look after her and put her in a taxi and get her home. So she ended up in hospital and I'll never ever, ever forget going in and then finding her in this ward, and there she was, she must have been on Valium ... all the traces of the personality had gone and she was just doped up to her eyeballs just sitting there. In retrospect, we should have done more for her. We didn't really realise at that stage what it was. I



thought she may have had Parkinson's and a nervous breakdown. And it wasn't until you were born that we found out it was Huntington's.'

Mavis died after fifteen years of mental and physical deterioration at the age of sixty-two. Judy remembers saying goodbye to her mother:

'I was at Massey at a seminar. Dad had managed to get a message to me that Mum was not expected to last the evening so I drove from Palmerston North to Wanganui and she waited for me. It breaks my heart to think of what we didn't do for her. That I didn't stop and listen and talk to her and just talked too much and didn't think. Just that she missed out on us finding out what it was and being able to help her.'

- How does Judy respond to the limitations imposed by her illness?

**Judy:** I'm beating it, I'm beating it. I'm making the most of it.

**Bridget:** I am inspired by her, by the way she's fought to try to keep the symptoms at bay.

Living with an illness involves facing challenges and accepting limitations. Having watched her own mother become debilitated by Huntington's Disease, what choices does Judy make about living with Huntington's Disease?

The average age of adult onset of Huntington's Disease is between the ages of thirty-five and forty-five. In general, the earlier the onset, the faster the illness progresses. Judy did not start to develop symptoms until her mid-fifties. *The Inheritance* documents the four stages of Judy's experience of Huntington's Disease.

- **Bridget:** Once mum's brain deteriorated further she would visit us and do crazy things like wander around naked, seeing things that weren't there and I would watch her horrified, walking about like a living nightmare. Spend time as a class discussing Judy's experience of the four stages of Huntington's Disease.
- Use the following quotations to facilitate a discussion about the way Judy's illness impacts on her relationship with her husband, children and grandchildren.



**Dave:** You constantly do what you can, to keep her in the best of health. To keep her from pain. I don't know where it goes from here.

**Warrick:** I can't really have a conversation with Mum. The responses are quite simple but sometimes she can be so lucid, so, you know all of a sudden you can have a conversation about something. You live for those moments.

**Dr Clement Loy:** It continues to amaze me how courageous and resilient families are with Huntington's Disease.

**Dist. Prof. Richard Faul:** For some people this will bring out the best in the family. In other families, the gene tears families apart.

**Dr Martha Nance:** You cannot go through the course of Huntington's Disease alone and in fact, I don't think that a couple can really go through the course of Huntington's Disease alone, just the two of them. In fact, I feel as a physician, I can't really care for a patient or a couple with Huntington's Disease by myself. I think it is done best by a team, by a community, by a family.

**Bridget:** Since coming to live in New Zealand, I've felt a bit confronted by Mum's situation and really, really, honestly been thinking, she would be better off not living, really. And I just kept anticipating that she would be kind of dying at some point from the cancer or from the Huntington's. But having spoken to Jeanette it seems that people can go on for years and years in the state that Mum's in.



Maybe Mum being able to see her grandchildren play on the lawn is the equivalent of doing something incredibly marvellous. In a way, what she's doing is kind of what Buddhist Monk's achieve: thoughtlessness. Think they call it mindfulness though, don't they? It's a bit different.

**Bridget:** I can see that Dad doesn't want to let Mum go, he wants to keep her here. He's not religious, so here is the only place there is. So he wants to keep her with him, as long as he can.

**Bridget:** The idea of imagining your future with Huntington's is that you think 'Oh no, I'm going to be an idiot. I'm going to lose everything that I've worked so hard to be', you know. But as you're losing all those things that are important to you, you're conscious of it and I don't know how you deal with that.

**Nick:** We've got to think about what we want to put ourselves and those that will be caring for us through.



There's the big question about how much of the HD experience you want to have too. You know, I'm not interested in these middle or late stages. I've got no plans to go there. It sounds macabre, doesn't it?

**Bridget:** It's hard. I'm a bit attached to life, to be honest. I'm really attached to it, so attached to it. Spend time as a class discussing sibling relationships and the significance of these relationships. What do we learn about the relationships of the siblings in *The Inheritance*? How does each of the Lyon siblings respond to testing positive for the HD gene?

**Brenda:** You can only do so much to help. You know, you're kind of powerless, really. As a mother you think 'I can always look after my child or protect them', but you can't. But you just can't give in and you've got to keep doing what you can do.

**Robyn:** I try and cope with a bit of humour ... I've always said I want to die young and good looking. What is gained from learning of the experiences of Brenda and her son Darren and the experiences of Bev, Karen and Robyn?





**Jeanette Wiggins:** You're lucky; you are from a strong family. Some people have got nobody else and if I don't help them, there is nobody. Either their family is dead or they've disowned them because they've created mayhem or they've got no money or, they've drunk themselves into oblivion.

Explain the significance of Jeanette's comment.

In June 2011, Judy was diagnosed with rectal cancer. Her health deteriorated all the more. She received treatment for the cancer and the level of care that Judy needed increased. Bridget explains,

'The cancer grew and blocked Mum's bowel, so if she didn't have a colostomy operation she would die. As a family we had previously discussed that we would let the cancer take her but when it came to the moment of truth, we couldn't let her go.'

Bridget asks her father is he ever feels like giving up. He replies,

'No. We've been married 50 years in a couple of months time. Sure, I've threatened her at times and I say – if she won't open her mouth for her medicine or something – 'Well, you're off to the rest home.' But I don't mean it. I don't mean it.'

- **Bridget:** One night I was saying good night to Mum. I stared in her eyes and she stared back at me with



eyes full of love. I soaked it up; we had connected. She blinked and told me she hated me.

What is gained from the honesty in which *The Inheritance* documents Judy's decline?

- **Bridget:** I live with the knowledge that my beautiful brothers will most likely lose their minds and die slowly, trapped in unresponsive bodies, unless they choose another way out. And Jeff and my sons will most likely have to watch me do the same. But despite all this, somehow on this journey I've discovered that I'm stronger than I thought. I've looked the enemy directly in its yellow eyes and told it to beware. If it wants to take us all on, then fine, good luck to it. I know for sure, it still hasn't seen the full strength of my family. What does Bridget learn from living through her mother's experience of Huntington's Disease?

### DISCUSSION 3

## GENETIC INHERITANCE

Our bodies are made up of millions of cells. In each of these cells, we have 46 chromosomes arranged in 23 pairs. One of each of these pairs is passed down from our mother and the other from our father. 22 of these pairs, called autosomes, are numbered from 1 to 22, and the last pair is made up of our sex chromosomes (XX for females and XY for males).

Huntington's Disease is a monogenic autosomal dominant disease.

Monogenic diseases result from modifications in a single gene occurring in all cells of the body. Though relatively rare, they affect millions of people worldwide. The nature of the disease depends on the functions performed by the modified gene. Monogenic diseases can be classified into three main categories:

- o Dominant
- o Recessive
- o X-linked

Autosomal dominant inheritance means that the gene causing a condition is located on one of the numbered chromosomes and a person only needs one copy of the gene to be faulty in order to develop symptoms of the condition. Recessive diseases are monogenic disorders that occur due to damages





what the genetic test tells you. How many CAG repeats you have. Mum has 43.'

The Huntington's Disease gene contains a three-nucleotide sequence – CAG – that is repeated several times in a row. Geneticists refer to it as a trinucleotide repeat because it is a three-nucleotide sequence that is repeated several times back-to-back. It is also sometimes referred to more specifically as a CAG repeat.

- How can the number of the CAG repeats predict whether or not a person will develop Huntington's Disease?

**Dr Ed Wild**, a British Clinical Lecturer in Neurology, remarks,

'Anyone who has an expanded gene has a 50% chance of passing on that gene any time they have a kid. So it's exactly like tossing a coin.'

In 1994, medical technology allowed Judy to undertake genetic testing. Dave recalls,

'When Jude was tested positive for the disease I was just crying my eyes out. It was a tragedy to know that this disease could be passed on to you children.'

Huntington's Disease does not skip a generation. If Judy had tested negative for the Huntington's Disease gene, then her children would not have had the chance of inheriting the gene.

In 2003, Bridget found herself in love and unexpectedly pregnant. While Bridget

in both copies. X linked diseases are monogenic disorders that are linked to defective genes on the X chromosome which is the sex chromosome.

Given Huntington's Disease is autosomal, it affects males and females equally, and because Huntington's disease is a dominant condition, each child of an affected person has a 50% chance of inheriting the gene and eventually developing Huntington's Disease.

The gene name for the causative gene is huntingtin, and it encodes a protein with the same name. The protein coded by a Huntington's disease allele codes for a protein that slowly damages brain cells. The exact mechanism by which the disease form of the huntingtin protein damages cells is unknown.

In *The Inheritance*, the medical experts provide accessible explanations of the impact of the causative gene:

**Prof. Paul Muchowski:** It's a bad gene which makes a bad protein and it does a lot of bad things. And that's the scary thing. You know in some diseases you're lucky and it might be one bad protein maybe like kills a blood cell. The really difficult thing with Huntington's Disease and the Huntington protein, it does a lot of bad things.

**Dr Danny Hatters:** The proteins cluster together so they become kind of sticky like glue, so they form these very small balls inside the nerve cells inside the brain.

**Dist. Prof. Richard Faul:** It's a bit like pouring cement inside a brain cell, which cause the brain cells to die.

**Dr Maria Björkqvist:** This gene is expressed everywhere, in all the cells in the body and we might get effects in all the cells in the body. So it's more than a disease of the brain, I would say.

In 1993 the gene for Huntington's Disease was located. It had taken ten years of medical research for scientists to find the HD gene near the top of Chromosome 4. Bridget explains,

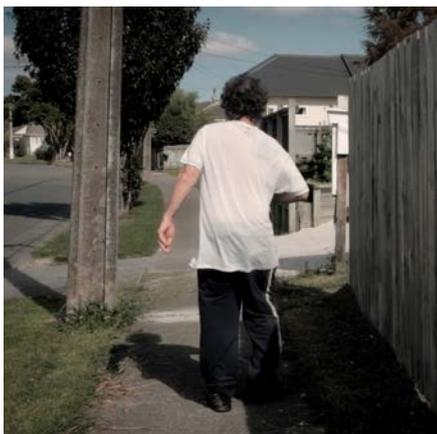
'Genes are made up of four chemicals that are represented by the letters A, C, G and T. What the scientists had found was remarkably simple. On the top of Chromosome 4 the parts are spelled CAG. Everyone has this gene, but people who have Huntington's Disease have too many repeats of CAG in theirs. That's



had always thought that she would find out her gene status before starting a family, both Bridget and her partner Jeff did not regard termination as an option. Bridget took the predictive test after the birth of her first child. Bridget and Jeff's second child was conceived by IVF technology using Pre-implantation Genetic Diagnosis (PGD). Bridget provides an insight into how the process works:

'We had twenty-two eggs collected. Five days later, only four had grown to the size they needed to be for testing. It turned out three of the four had the Huntington's gene so we had one embryo without HD. One chance. We were extremely lucky and the embryo resulted in a pregnancy and a gorgeous baby boy was born who has zero percent chance of having Huntington's Disease.'

- **Dave:** We didn't have available the technology that Bridget and Jeff have used to conceive young James. If PGD had been available, and had we known at the time we were conceiving our children, would we have done that? Absolutely. What is Pre-implantation Genetic Diagnosis? What are the advantages



of this medical technology? How has the use of this medical technology benefited the McDonald family? Who should have access to Pre-implantation Genetic Diagnosis?

In New Zealand the government rebates Pre-implantation Genetic Diagnosis IVF. This is not the case in Australia. Discuss the political, ethical and social implications of this.

**Female Radio DJ:** And your first son, you don't know? Have you discussed with your partner about when he should know?

**Bridget:** The genetic counsellors strongly advise that children aren't tested for Huntington's and so it's after he's eighteen he can decide for himself whether or not he wants to be tested. So I don't think it's something he needs to know before he's an adult.

Bridget's first pregnancy was unplanned. Their eldest son may have inherited the HD gene. What are the reasons why children are not tested for Huntington's Disease?



Why is it recommended that individuals wait until they are eighteen before they decide to take the test?

Bridget was the first of the Lyon siblings to be tested for Huntington's Disease. In 2005 Bridget's eldest brother Nick took the predictive test and the result was positive. Four years later, Bridget's other brother Warrick took the test. His result was also positive. Despite the 50/50 odds, the three siblings had all inherited the Huntington's Disease gene.

- Not everybody who could possibly be a carrier of the Huntington's Disease gene wants to know. Dr Martha Nance, a Clinical Professor of Neurology at the University of Minnesota in the United States of America comments: 'By far the majority of people are not having predictive testing but those who want the predictive gene test really want it.'
- Why do you think the majority of people who could potentially test positive for the Huntington's Disease gene choose to delay or avoid testing? What are the potential advantages of predictive testing? What are the disadvantages?
- In answering the question consider the following perspectives:
- Charles Sabine:** When I was working for NBC in the last days of the war in Bosnia, I was taken captive by some Mujahideen Guerrillas who had executed some people the day before. So we were by the wall where they had executed these people and one of them held

a grenade to my head at one point, which is about a scary moment as you could imagine. But that was not as scary as taking that test for HD. For someone who already knows about what Huntington's Disease is, to go through that test which is going to be so completely and utterly determining.

**Bridget:** So this is *Mapping Fate*, a book written by Alice Wexler about her family. There's something at the front of it – 'Everyone, real or imagined, deserves the open destiny of life.' The open destiny of life, that's what got me. And that's what I feel like has been taken away because I did the predictive test.

- What is genetic counselling? Why is genetic counselling an important aspect of the diagnosis and treatment of genetic illnesses?

#### DISCUSSION 4

## TREATING HUNTINGTON'S DISEASE

**Alice Wexler:** We don't have many treatments for Huntington's Disease and there's no cure for Huntington's Disease at the present time.

In *The Inheritance*, Bridget acknowledges her family's association with those medical experts at the forefront of research into Huntington's Disease,



'... we had been inextricably linked to scientists studying the disease. My mum had been friends with the visionary neuroscientist Professor Faull for many years.'

Professor Richard Faull is the Director of the Centre For Brain Research in Auckland, New Zealand. In *The Inheritance*, he explains how a 'normal' brain differs from a brain affected by Huntington's Disease:

'So what is really interesting about Huntington's Disease is that it causes cells to die in their millions in the area

called the Basal Ganglia. It's right in the center of the brain. In the normal brain you can see the Basal Ganglia there. This is the normal brain. Whereas in the Huntington's brain, they're shrunken down. As a result, the ventricle becomes massive.'

**Professor Anthony Hannan**, the Head of Neural Plasticity at The Florey Institute of Neuroscience and Mental Health in Melbourne, Australia informs the audience of *The Inheritance*,

'The cerebral cortex, that enormous sheet of tissue around the surface of the brain, which actually separates humans from other primates – this is one of the most evolved parts of the human brain – also becomes dysfunctional.'

In conversation with Bridget, Professor Hannan reflects, '... the more we look, the more we find.'

Professors Faull and Hannan are just two of the many medical scientists around the world researching Huntington's Disease.

- **Dist .Prof. Richard Faull:** I was always told as a medical student you don't make new brain cells. Well, in the Huntington's brain we found that this layer of stem cells was in fact not only there, but we saw it multiply. The more advanced the disease, the more new brain cells the brain was trying to make from these stem cells. In other words, it was trying to repair itself. By studies that we then do on the normal brain we found that every person can make new brain cells. That was revolutionary.





**Prof. Anthony Hannan:** We made this discovery that if we took the mice and increased their mental and physical activity, we found that lead to a dramatic delay in onset of the symptoms of Huntington's Disease in the mice. The idea that you can stay more mentally and physically active and build in a brain reserve, but together with a good diet and other things that are healthy for the body and therefore healthy for the brain. Huntington's Disease is unique because the condition can be genetically predicted before people show any symptoms. This is why Huntington's Disease is positioned to offer the testing ground for therapies that could influence the treatment of any number of diseases.

Use these comments to initiate a discussion of the importance of medical research in determining the future treatment of Huntington's Disease. How can medical research improve the quality of life of those living with Huntington's Disease?

- What is gene therapy? Use the Internet to research how gene therapy could be used to treat Huntington's Disease.
- **Dr Martha Nance:** There should never be nothing you can do for someone with Huntington's Disease. It bothers me to think around the world, patients and families are still left with that impression. They go to the doctor's office and they're told, 'Well, that's a fatal disease. There's nothing I can really do for you.'

**Bridget:** Mum exercised, took supplements, used brain training and alternative therapies.

**Prof. Richard Faull:** She would read and know everything that was going on about the disease. She would see all the challenges and the ways you could overcome the disease.

**Dave:** We're taking a different attitude to it in that we're trying all sorts of things. If there's a possibility this will work we will give it a go. We believe that cumulatively they have been able to slow down the progression of the disease.

**Warrick:** She really led the way with finding ways to beat Huntington's Disease.

**Bridget:** Great. Couldn't it have been that lying around like a slob was the thing they found would help? Did it have to be exercise? I had avoided it reasonably well for twenty years and now it was my lifeline. What does *The Inheritance* suggest about the treatment of Huntington's Disease?

- **Dr Clement Loy:** We now realise that people could develop thinking difficulties up to 15 years before they develop movement problems. So we've tested your thinking ability and your movement today and both of them are clear, so that's good news. How are Bridget and her brothers endeavouring to delay the onset of Huntington's Disease?
- **Dr Ed Wild:** I've always said that HD is the most curable incurable brain disease.  
**Dr Martha Nance:** I would say that if there was ever a time to be hopeful for the future, this is it.  
**Jeanette Wiggins:** I think there is a great deal of hope. There is a lot of work being done, but it is unlikely to be fast. Science takes a long time. I think people with Huntington's are coping really well and I think we do really well here with the sort of support and the sort of things that we can offer them.

**Dr Michael Hayden:** There was a time that Polio was a fatal illness, or that AIDs – all these diseases have been overcome. Huntington's is different but we're making massive in-roads and the community is working in ways that are incredible. So I'm quite hopeful. I'm hopeful not that we will cure this disease, but that we will have a way to change the course of this illness in your lifetime.

Based on the information provided in *The Inheritance* and online resources, is there every reason to be hopeful about the future treatment of and possible cure for Huntington's Disease? Will life be different for Bridget and other Huntington's Disease positive individuals in their lifetime?

- Write and publish a feature article about medical research into Huntington's Disease beginning with the discovery made by George Huntington and the work of the Wexler family. Draw on your close analysis of the documentary. Draw on the information that you have gained from completing some of the discussion and research tasks that are part of this study guide. Before you begin writing, decide on the publication that will feature your article. Are you writing for a newspaper or magazine? When you have made your decision, think about your likely audience and the format of your article. Use vocabulary and adopt a tone that best suits the publication that you have chosen. Download appropriate images from the Internet to include in your article.



## DISCUSSION 5

# DOCUMENTARY FILMMAKING

*The Inheritance* is a documentary. A documentary is a non-fiction text that represents events and people from real life. The purpose of a documentary film could be to provoke thought, to educate or to persuade. To be successful a documentary film also needs to engage its audience.

Having been informed that she had not escaped the family inheritance, filmmaker Bridget Lyon decided to document her story and the stories of others with Huntington's Disease. Reflecting on *The Inheritance*, Bridget has said:

'I discover a profound tale of unconditional love as I visit my Mum who fights silently everyday with my Dad by her side. I struggle to face up to the reality of such an inevitable demise for so many of my family and the harrowing possibility that my son might have inherited it. But as my family strains under this impossible pressure we find that we are even stronger than we thought.'

Her husband and director of *The Inheritance* has acknowledged the importance of making a documentary about Huntington's Disease,

'We all want to know what cancer is and what we can do...When it's Huntington's people say, "What's that?" and are less likely to be supportive. Tragedies are unfolding behind doors no one knows about. People haven't shared stories because they're too busy falling apart.'

*The Inheritance* was filmed in both Australia and New Zealand from 2009 to 2014.

- Have you watched other documentary films? Share your experiences of this genre with the class. What are the conventions of a documentary? How does *The Inheritance* use the conventions of a documentary to tell its story?
- Watch the trailer for *The Inheritance*. How does it position a potential audience?



Teachers may choose to provide students with a viewing chart to facilitate note taking. The chart on the following two pages requires students to consider how *The Inheritance* draws on story and production elements to construct a personal narrative about Huntington's Disease.

### Jump to chart.

- Having watched *The Inheritance*, what comments would you make about the purpose of this documentary?
  - How does *The Inheritance* begin? What expectations does the opening sequence create? How are you positioned as a viewer? How does *The Inheritance* end? Why do you think the filmmakers end the documentary in this way?
  - *The Inheritance* is narrated by Bridget Lyon. Do you think having Bridget tell her own story of living with Huntington's Disease is to the documentary's advantage?
  - Write a brief description of the filmmakers' portrayal of the participants. Make sure your description comments on both the filmmakers' view of the participants and how the filmmakers position the audience to view the participants. Make reference to specific moments from *The Inheritance* to endorse your responses.
  - List the settings used by the filmmakers. What do these settings reveal about the concerns of *The Inheritance*? How are these settings used to create meaning and draw an emotional response?
  - What symbols and imagery are used throughout the documentary? What do they suggest about the filmmakers' purpose? How do they add to an audience's understanding?
- 'The Gift' is an original song by New Zealand singer-songwriter Ryan Edwards. It is featured in *The Inheritance*. How is this song and other music used to shape the audience's responses to the events portrayed in *The Inheritance*?
  - Working as a class, make a list of the challenges of making a documentary like *The Inheritance* for the filmmakers and for the participants.
  - Complete a detailed analysis of a key sequence to explain how *The Inheritance* represents a subject and constructs a narrative. What is seen and heard? How does the sequence contribute to the overall narrative? Describe the intended and unintended representations – that is, how do the filmmakers intend the audience to view their subject and how might an audience respond to their representations? Shape your notes into a 350–500 word response.
  - Understanding *The Inheritance* involves an investigation of film making techniques employed in telling the story. Working with a partner, describe the way the filmmakers have used one of the following techniques:
    - o Re-creations
    - o Home videos and family photographs
    - o Archival footage
    - o Interviews
    - o Observational footageUse PowerPoint to present your description to the class. Limit your presentation to four slides.

STORY ELEMENTS	DESCRIPTION	EXAMPLE(S)
Opening, development and resolution of narrative		
Cause and effect		
Establishment and development of relationships between characters		
Point/s of view		
Function of setting		
Relationship between multiple storylines		
Structuring of time		

STORY ELEMENTS	DESCRIPTION	EXAMPLE(S)
Production Elements		
Camera techniques		
Lighting		
Mise-en-scene		
Acting		
Sound		
Editing		

## ONLINE RESOURCES

Official website

<http://theinheritedocumentary.com/>

Official Facebook page

<https://www.facebook.com/TheInheritanceDocumentary>

Official Twitter

[https://twitter.com/Inheritance\\_Doc](https://twitter.com/Inheritance_Doc)

## KEY CREATIVES

### Jeff McDonald Director, Producer & Co-writer

A Director and Producer with over 21 years experience in the film and media industries, Jeff McDonald established Leapfrog Productions in 1994, creating several films including the features *Son Of A Lion* (2007); *Beneath the Flame* (2009); and several short films and webseries, as well as working on the production of

independent thriller feature *Bunyip* (2013). McDonald was involved with the founding and management of several market leader film and media companies.

### Bridget Lyon Editor, Co-writer & Narrator

With an editing career that has taken her to the UK, Ireland, India and France, Bridget Lyon has worked on major blockbusters, independent features and short films, including *Holy Smoke* (1999), *Mission Impossible II* (2000), *The Visitor* (2007), *Blessed* (2009) and *Maya* (2001). Documentary projects have included *First Australians* (2008), *Beneath the Flame* (2009), *Cup of Dreams* (2011) and the SBS series *My Family Feast*. Lyon worked as in-house editor for STUDIO, SBS's subscription TV arts channel and on the New Zealand TV series *Street Hospital*, *The Trouble with Murder* (2014) and *Bullies* (2015).

### Michelle Hanna Post Production Supervisor & Impact Producer

A producer of arts and special event television and online broadcasts, Michelle Hanna worked closely with Bridget Lyon at the arts channel STUDIO and previously as a producer and presenter at the Ovation arts channel. Committed to helping people communicate their personal and creative stories, Michelle also worked as an Arts Reporter for SBS World News Australia and, previous to her career in television, as an arts publicist.

### LEAPFROG PRODUCTIONS

Leapfrog Productions are dedicated to telling great stories that inform and entertain, affecting the way we see and feel about the world.

<https://leapfrogproductions.wordpress.com>

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