



**Lynch  
Syndrome**  
Australia

**Many families. Many cancers.**  
**One common cause.**



**Missing out:  
uninsured, uninformed and  
discriminated against.**

**Missing out: uninsured, uninformed and discriminated against.**

**A report by Lynch Syndrome Australia - 2018**



**Lynch  
Syndrome**  
Australia

## Introduction

Lynch Syndrome Australia (LSA) recently surveyed 101 Australians who have Lynch syndrome, which means they have inherited a gene fault that leads to an increased risk of developing up to 12 different types of cancer.

The survey showed that many healthy Australians with Lynch syndrome are unable to obtain affordable life, disability or income protection insurance, or any life insurance at all, despite engaging in regular screening which significantly reduces the risk of developing cancer, and in many cases, undergoing radical, preventative surgery.

One sixth of our respondents were unable to obtain life insurance cover **although they had not had cancer or pre-cancerous polyps or lesions**, they actively pursued rigorous and timely cancer surveillance and, in many cases, had undergone radical, preventative surgery.

- 104 Australians participated in the study and almost all had been diagnosed with Lynch syndrome, an inherited cancer predisposition.
- 33 of the 104 Australians with Lynch syndrome **had not been diagnosed with any cancer or pre-cancer**.
- Yet more than half of these respondents with no personal cancer history (16% of all respondents) had no life insurance cover.

*"[They] wouldn't cover me for any types of cancer at all with income protection and trauma insurance. Tried to apply through multiple companies"*

- 100% of those diagnosed with Lynch syndrome, but who had not experienced any cancer, undertake timely surveillance for the most common Lynch syndrome cancer risk.

*"I have applied for more life and income protection insurance since my diagnosis but have been refused this on medical grounds. Even though I have surveillance – apparently, the insurance companies don't take surveillance into consideration."*

- Nearly 50% of these respondents had been **specifically refused due to their Lynch syndrome** condition.

*"[I was told] I did not qualify due to genetic 'disease' "*

*"They just said [Lynch syndrome] was classified as a cancer and I was ineligible"*

- Fewer than 5% of all respondents appealed decisions to deny cover or increase premiums

*"I didn't know that I could appeal - and I didn't think I would be successful anyway. I just thought I could never have insurance again even though I had beaten [cancer] and was better monitored than most 'well' people"*

## Case Studies



*Finding out that you have inherited a pre-disposition to cancer is stressful. All alone, you have to come to terms with your diagnosis and understand what it means for you and your family. You must devise a plan to reduce your cancer risk decide whether to share your distressing news with family and friends. You then discover that you are not even able to protect yourself against financial risk.*

*Yes, the risks of developing cancer for someone with a Lynch syndrome gene mutation can be high: the average number of cancers in a lifetime is two and the can be up to eight different cancer diagnoses for an individual . Nevertheless, carefully-planned surveillance regimes and risk-reducing surgery can improve your odds and prevent further cancers.*

***Indeed, thousands of people who test positive for Lynch syndrome will never develop cancer. The better the steps they take to reduce their risk, the less likely it is that they will have a Lynch syndrome-related cancer. Yet the insurance industry takes a one-size-fits-all approach to assessing risk. Many people living with Lynch syndrome find themselves financially vulnerable and without adequate insurance. This situation must be improved for the estimated 80-100,000 Australians living with Lynch syndrome.***

## Sally's Story

Sally\* is a 46-year old Australian woman who has a Lynch syndrome gene mutation.

She has not had any cancer or pre-cancer and has undergone risk-reducing radical hysterectomy and oophorectomy. Every year, Sally has a colonoscopy and endoscopy, has bi-annual breast screening and skin checks every few months.

Yet Sally has no life insurance. The insurance products she *does* have (income protection and related to her superannuation) were taken out before her Lynch syndrome risk was confirmed by genetic testing, and all premiums related to these existing products have increased since her positive test for Lynch syndrome.

She has applied more than once with different companies and has been denied life insurance cover.

*"[I was denied cover] just because I had Lynch [syndrome]. But I have never had cancer!"*



## Andrea's Story

Andrea\* is 38 and was diagnosed with Lynch syndrome earlier this year. Andrea has not suffered from cancer but has not been able to obtain life insurance.

Like many people faced with genetic testing, Andrea did think about taking out cover before getting tested but, at the time, she was focused on her health not her finances. Now it's too late and the insurance company has denied her insurance because of her Lynch syndrome risk.

Since her diagnosis, Andrea has undergone risk-reducing surgery and a series of tests including colonoscopy, endoscopy, breast screening, blood tests and skin checks which she will repeat each year. Andrea did not appeal the decision because she had no idea that she could.

*"I was verbally denied because of Lynch [syndrome]"*



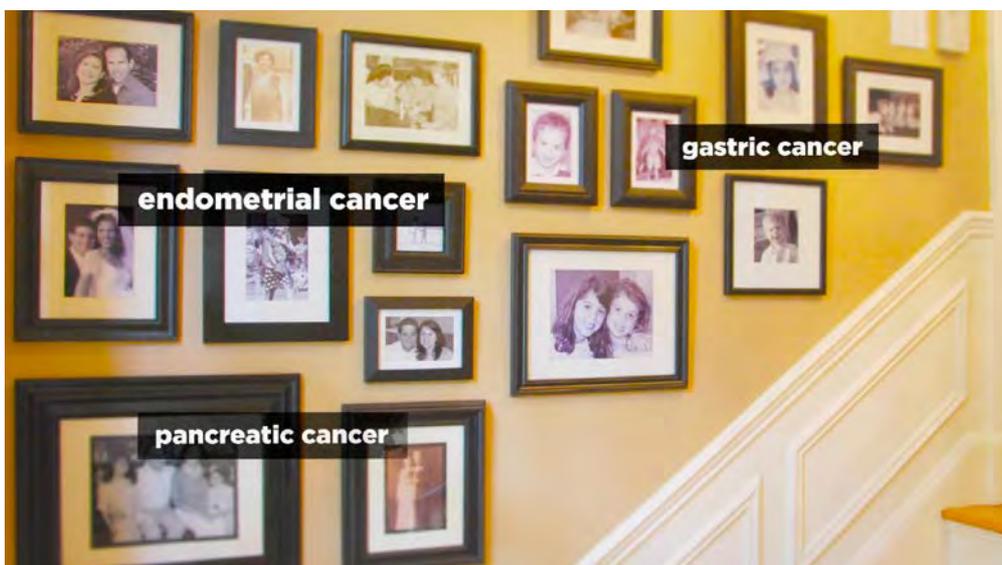
## Lilly's Story

Lilly\* found out that she had a Lynch syndrome-related cancer risk in 2013. Now 42 years of age, Lilly has never been diagnosed with cancer or pre-cancer and yet has been denied life insurance cover more than five times by different insurance companies.

Lilly follows a detailed cancer prevention plan, based on general Lynch syndrome risks and her family's own cancer history, but this has made no difference to the way she has been treated by the insurance industry. In the past, she has a pelvic ultrasound every few months, colonoscopy investigation, blood tests and abdominal ultrasound each year, endoscopies every other year and has recently had risk-reducing hysterectomy and oophorectomy.

Lilly has minimal life insurance related products via her pre-existing superannuation fund and income protection but has been denied the opportunity to increase or upgrade these products. She has been unable to obtain either life insurance or mortgage or disability related protection since finding out that she has Lynch syndrome.

*"When trying to obtain life insurance or switch current [related] insurances, advice was give that] due to Lynch syndrome [they] will not cover [me]"*



\* Pseudonyms used to preserve privacy

# The Survey

## Background

Lynch Syndrome Australia (LSA), established in 2013, is a registered charity and an all-volunteer, survivor-led organisation that supports the many thousands of Australian families that carry the Lynch syndrome genetic mutation.

In 2015, LSA conducted a global survey of 461 people from Lynch syndrome-affected families. The survey's 50 qualitative and quantitative questions covered topics such as: demographics; the experience of diagnosis; cancer risk management; individual experiences with cancer and treatment; family cancer history; navigating the health system and the psycho-social impact of living with Lynch syndrome.<sup>1</sup> **Responses to a short question about life insurance indicated that a Lynch syndrome diagnosis could adversely impact an individual's ability to obtain appropriate risk-related insurances.**

To explore further whether access to life insurance and related products was impaired due to a person's Lynch syndrome diagnosis, LSA designed an additional study, the aim of which was to provide evidence for the Parliamentary enquiry into the life insurance industry.

The 26-question survey opened on 16 September 2017 for a period of one month. The survey was promoted through the LSA Facebook support page for families with Lynch syndrome and targeted to health consumers on the LSA database who have been diagnosed with Lynch syndrome.

There were 127 responses from Australia and overseas.

---

<sup>1</sup> Morris, S., Rice, T., O'Neill, S., Raets, E. and Fairbank, B. (2017) *Misdiagnosed, misunderstood and missing out: Lynch syndrome, Australia's untold health story*. Lynch Syndrome Australia, Brisbane.

## Key results

The survey data was analysed for duplicate and incomplete responses resulting in 109 complete responses. The following key results are based on the 104 Australian responses.

### Demographics

- 83% of respondents were aged between 30-60
- 97% of respondents have a confirmed diagnosis of Lynch syndrome

### Lynch syndrome status and cancer history

- 22% of respondents were unsure of their gene variant. This was an improvement from the 2015 survey when almost 30% of respondents weren't sure of their exact mutation.
- 63% were diagnosed with Lynch syndrome between two and 10 years ago with 20% diagnosed over 10 years ago
- 34 individuals indicated that they have not had cancer diagnosis/precancerous cells.
- The top four cancers diagnosed were bowel, endometrial, skin and ovarian cancer
- 35% of individuals reported having bowel polyps
- All respondents followed a surveillance regime, that differed between individuals
- Almost half of the women who responded had undergone preventative gynaecological surgery
- Almost a third of respondents took chemoprevention in the form of daily Aspirin

### Insurance

- 61% of individuals do not have **life insurance**
- Of the 41 individuals who had **life insurance** only 4 took out insurance after a diagnosis of Lynch Syndrome
- 63% of individuals do not have **income protection insurance**
- Of the 37 individuals who indicated they had **income protection insurance** only 6 took out insurance after a diagnosis of Lynch Syndrome
- 72% of individuals do not have **disability insurance**
- Of the 28 individuals who indicated they had **disability insurance** only 4 took out insurance after a diagnosis of Lynch Syndrome

### Barriers to obtaining insurance

- 46% of respondent's experience difficulty obtaining insurance or were charged an increased premium related their or their family's Lynch syndrome diagnosis
- Only 8% of individuals who had difficulty obtaining insurance appealed the decision. Most respondents were not aware that they could appeal the decision
- Alarming 15% of individuals had applied for and been denied insurance between three and more than five times.
- 22 individuals had applied to different insurance companies

# Lynch syndrome fast facts

## The basics

- Lynch syndrome is a mistake (mutation) in a gene that should be repairing new cells
- Each child has a 50/50 chance of inheriting the mistake from a parent who has it
- The gene mistake results in a high risk of getting cancer, starting at a younger age than normal
- Someone with Lynch syndrome often has a strong family history of cancer; often different types of cancers that don't seem to be connected
- The average lifetime risk of having a Lynch syndrome cancer is around 70%, although not everyone who inherits the gene mistake will develop a related cancer

## The science

- Lynch syndrome (formerly known as HNPCC) is characterised by a mutation in one of four genes that repair mistakes in cells when they divide (i.e., mismatch repair (MMR) genes)
- Everyone has two copies of each gene, one inherited from their mother, the other from their father
- If one of these copies is faulty, as in Lynch syndrome, the person carrying the gene mutation has a higher risk of developing one or more of up to 12 different cancers
- The average age that people with Lynch syndrome develop their first cancer is 40 years of age but cases of childhood and teenage cancer are also seen
- Cancers that are considered to be associated with Lynch syndrome are located in the following organ/ systems:
  - Colon/rectum (also known as bowel cancer)
  - Endometrium (sometimes described as womb cancer)
  - Ovaries/fallopian tubes, stomach/duodenum
  - Biliary tract/gallbladder, pancreas
  - Urinary tract, kidney/ureter
  - Skin, brain, breast, prostate

## About Lynch Syndrome Australia

Lynch Syndrome Australia (LSA) established in 2013, is a registered charity and an all-volunteer survivor-led organisation that supports the many thousands of Australian families that carry the Lynch syndrome gene mutation.

Whilst other cancer organisations and charities concentrate on specific cancers, LSA concentrates on a genetic condition where people affected have a lifetime risk of many different cancers and sometimes more than one primary cancer at once.

LSA does this by:

- raising awareness of Lynch syndrome amongst health professionals and the public
- hosting Living with Lynch syndrome events, seminars and conferences
- developing tools and resources for families and health professionals to help those affected to manage their medical care and to reduce their cancer risks and
- actively engaging in and contributing to the health care reform process, both as a peak body and in collaboration with other consumer organisations to ensure the unique needs and concerns of families with Lynch syndrome are recognised, understood and given due consideration.

LSA is governed by a Board of Directors and supported by a Scientific Advisory Committee.



**Lynch  
Syndrome**  
Australia

**Many families. Many cancers.**

**One common cause.**

**Mailing Address**

PO Box 292  
The Summit, QLD, 4377

[info@lynchsyntax.org.au](mailto:info@lynchsyntax.org.au)