

Autumn 2020  
NEWSLETTER



**adss**

Asbestos Disease  
Support Society



WORKSAFE AUSTRALIA  
NATIONAL OCCUPATIONAL  
HEALTH & SAFETY  
COMMISSION

## Asbestos

Asbestos Disease Support Society  
16 Campbell Street, Bowen Hills, QLD 4006  
PO Box 280, Spring Hill, QLD 4004  
Phone: 1800 776 412

Code of Practice and Guidance Notes

# 2020 Date Claimers

# POSTPONED

*All ADSS Morning Tea Events and Social Support Groups have been postponed until further notice.*

*We apologise for any inconvenience.*

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In times like this, it's essential we support one another and show compassion to those who need it. This is a shared experience that's stressful for everyone and without a known timeframe. Fortunately, positive social support can improve our resilience for coping with stress, so staff at the Society/SSN (including our qualified social workers and registered nurse) are all here to provide support and other assistance throughout these uncertain times.

We are here to help through the provision of social support, information, occupational therapy, loaning of medical aids (such as portable oxygenators) and more.

Please contact the Society if assistance is required.  
1800 776 412

Cover photo is from the National Occupational Health and Safety Commission's 1988 booklet: "Asbestos: Code of Practice and Guidance Notes" which was provided by Margot Hoyte, a director of the Society.



# In Loving Memory

## *Tenderly*

May time heal your sorrow

## *Gently*

May friends ease your pain

## *Softly*

May peace replace heartaches

And may warmest memories remain

Kent Murton Taylor  
Robert Thomas Carey  
Allan Arthur Lowe  
Peter Coward  
Kenneth John Rake  
Graham John Lucas  
Myfanwy (Fay) Allanson Moss  
Bernard Gysbertus (Ben) Van Harskamp  
Arne Johannes Eriksen  
Michael Alfred Cassell  
Maxwell Fritz  
William (Bill) Donald McCulloch  
Ronald James Riggall  
Gary Patrick Walsh  
Keith (Ted) Lake  
Patricia Lynette Treloar  
Dennis John Silcock  
Geoff Cowan  
Keith Alfred George Thomson  
Hermann Schreiner  
Kerry John Smith





# General Managers Report

TREVOR TORRENS



## Welcome to the Society's first Newsletter for 2020 – the Autumn Edition.

Unfortunately, news is dominated by the COVID-19 (Coronavirus) pandemic which, at the time of writing, has continued to spread in Australia and globally. As the Society's members are in the top percentile of vulnerability, we have had to take the decision to suspend face-to-face contact, including our community morning teas and support group meetings. Due to the current uncertainty regarding the disease, I am not able to provide any timeframe when these events will recommence. But this does not mean we are closed for business – by any means.

The Government has introduced a number of necessary and important measures, including "social distancing" to combat the spread of the disease. Social distancing is a key measure being utilised to limit transmission of COVID-19. This reduces the burden of disease in the community and importantly, will ensure healthcare capacity is not overwhelmed at any given time. The health sector must continue to undertake its core functions, as well as maintain the capacity to support those with COVID-19 who require more intensive care. Unfortunately, "social distancing" for many of the Society's members potentially translates into a form of social isolation.

**Our Social Workers are in the process of contacting members to check on any welfare concerns and provide assistance as necessary.**

The Society has also become aware of nonfactual stories circulating in relation to the disease and this has caused distress to some of our members. Please contact the Society if you have any concerns in relation to the virus, require information or just want to check on something you have heard.

The Commonwealth Department of Health also has an excellent website on up-to-date information on the virus which can be accessed at [www.health.gov.au](http://www.health.gov.au). Included with the newsletter is a very comprehensive fact sheet for older Australians sourced from the website.

*As at 3:00pm on 25 March 2020, there have been 2,423 confirmed cases of COVID-19 in Australia. There have*

*been 287 new cases since 3:00pm yesterday. Of the 2,423 confirmed cases in Australia, 8 have died from COVID-19. More than 169,000 tests have been conducted across Australia.*

Location	Confirmed cases*
Australian Capital Territory	44
New South Wales	1,029
Northern Territory	5
Queensland	443
South Australia	197
Tasmania	34
Victoria	466
Western Australia	205
<b>TOTAL</b>	<b>2,423</b>

## Beta Sigma Phi – Epsilon Chapter

Beta Sigma Phi is a social, cultural and friendship organisation that incorporates service as part of its activities. Their motto is Life – Learning – Friendship. Service is done locally and internationally and is a tribute to the character of the members. Members are encouraged to grow personally, while at the same time participating in the growth of their sisters by broadening personal knowledge and understanding of self, friends, and the world.

The celebrated Manly community group, Beta Sigma Phi – Epsilon Chapter, has been a strong supporter of the Society for well over a decade through their generous donations and in-kind support. A number of their members have been touched and have lost loved ones to asbestos related diseases.

I was once again privileged to represent the Society at their annual change over breakfast on Sunday 16 February at the Manly Hotel and accepted a donation cheque for \$2,000.00. Not only was the Society supported but donations were also made to Young Care and Dementia Australia.

Thank you to the ladies of Beta Sigma Phi – Epsilon Chapter.



*Trevor and Valerie McLaughlin*

### Thanks Chris Heenan - CFMEU Delegate

Thanks to Chris Heenan, CFMEU delegate and the crew at John Holland's Everton Park job where more than \$1,600.00 has been raised for the Society - with John Holland and John Kelley also helping out. "We wanted a charity that is close to the industry, and with asbestos you either know someone who is suffering and needing support or know that you could be in that position yourself one day". Thanks Chris, the donation will go towards the Society's medical aides loan scheme which provides portable oxygenators, humidifiers and other equipment sufferers in need. A big man with a big heart.



*ADSS Officer Kay with Chris Heenan*

### Annual Board Planning Day

The Society is governed by a board of nine (9) directors elected by the membership from the membership. The board is responsible for the governance of the Society - ensuring it is effectively and properly run and is meeting its overall purposes as set out in the Constitution.

On Friday 14 February, the Board came together at the Society's office in Bowen Hills to review the current three (3) year strategic plan, consider new initiatives and get up-to-date information on asbestos and dust related issues.

The Board received updates from the Society's legal adviser, Thady Blundell of Turner Freeman Lawyers, Peter McGarry, Office of the Industrial Relations and Stacey Tomley of the federal government's Asbestos Safety and Eradication Agency. Presentations were also provided by the Society's social workers in relation to enhancing member care and support arrangements. Unfortunately, a number of new initiatives that are to be rolled out over the coming months have been delayed due to COVID-19 - but stay tuned for announcements. One initiative that has been completed is the engagement of a Society nurse, Karen Selmon who will provide clinical information and support to our members. Further information on Karen and her role is contained in the newsletter.

A big thank you to our directors for their invaluable input and stewardship of the Society.



## Thank you for your donation

The Society would like to thank all those that have made a donation since the last newsletter. Without your kind financial support, we would not be in a position to provide the services, advocate on your behalf or lobby Government for improvement in asbestos and silicosis related matters. In particular, we would like to recognise the following donations over \$500.00:

*Jan Carey (in memory of Rob)*  
*Beta Sigma Phi – Epsilon Chapter*  
*Precision Interior Walls and Ceilings*  
*Rosemary Cowtan*  
*CFMEU Members*  
*Turner Freeman*

## Member Services

The following free support services are available to members:

- Access to the ADSS social workers and nurse;
- Telephone and home visit support;
- Access to the medical aids loan scheme
- Free occupational therapy assessment;
- Dietetics and nutrition advice
- Consultation with ADSS lawyer;
- Morning teas in the local community;
- Up to date information on asbestos and silicosis related issues through the quarterly newsletter
- Invitation to the ADSS Symposium;
- Invitation to the annual Ecumenical Service

As I have indicated, member face-to-face contact has necessarily been suspended. However, we are working on a plan to keep members connected with the Society and each other. You will receive further correspondence

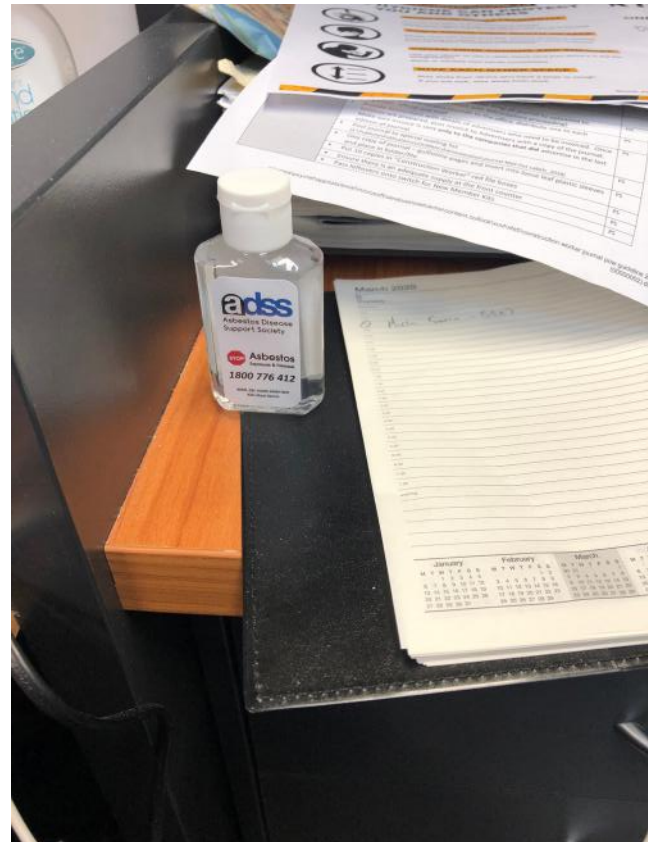
in the near future in relation to this plan.

In the meantime, please contact the Society if you require assistance or need just to talk to us.

Can I also take this opportunity to wish everyone a safe and happy Easter.

*Trevor Torrens*

General Manager





# Asbestos & Chest Infections



THADY BLUNDELL – SOCIETY LEGAL ADVISER

**Respiratory physicians, in providing reports on the effects of asbestosis and other occupational lung disease such as silicosis, have long mentioned that these types of conditions can exacerbate chest infections that a person might develop in the future.**

In the ordinary course of events, people develop chest infections. Those with healthy lungs find it easier to fight off these infections, those with underlying lung conditions, such as asbestosis and silicosis, can find it harder to do so and the effect of the chest infection can be exacerbated as a result.

**This is of significance now that there is the looming Coronavirus Pandemic and increasing incidence of this disease in Queensland and throughout Australia.**

There are various degrees of fibrotic lung disease, such as asbestosis and silicosis. Some are more severe than others. In addition, those with asbestosis

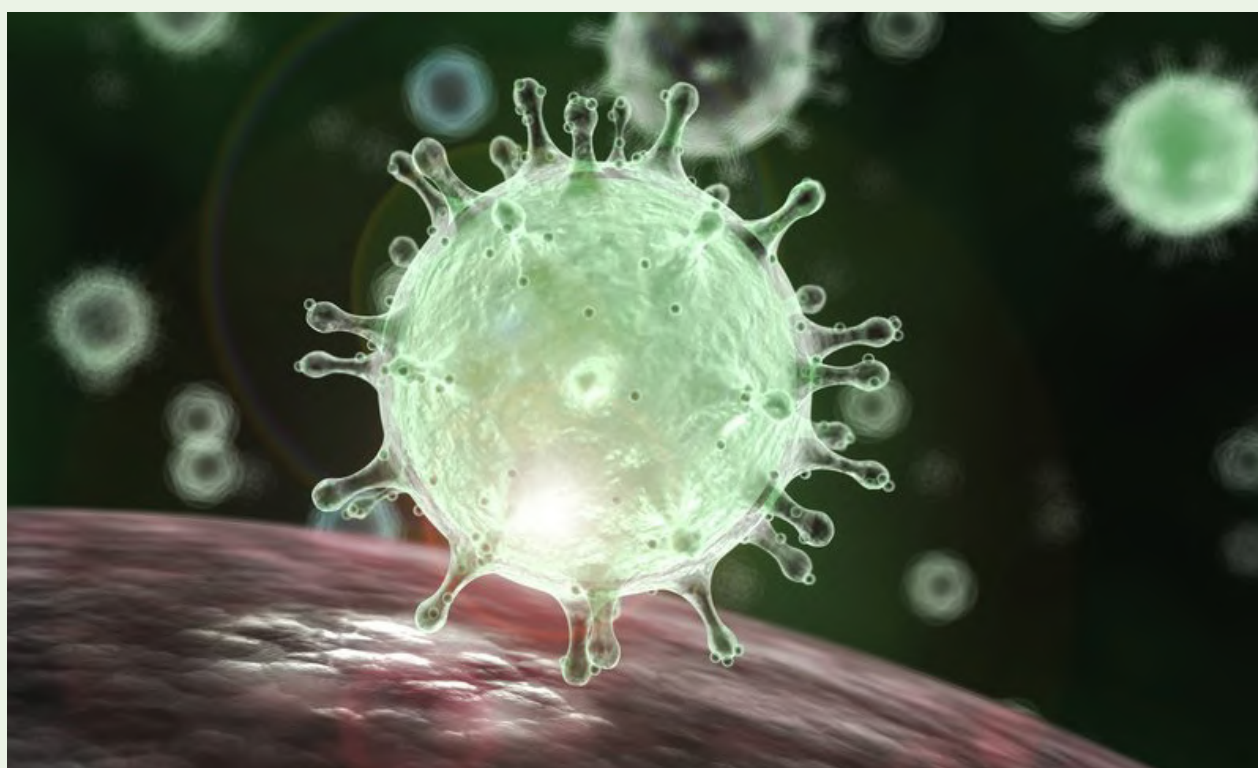
may also suffer from other health conditions.

The message is that it has been apparent to respiratory physicians and other medical practitioners for years that underlying lung conditions can exacerbate chest infections. The Coronavirus seems to be a much more serious form of “chest infection” and can cause serious symptoms. Those with asbestosis and other occupational lung disease also tend to be in the age group more at risk of the severer effects of Coronavirus.

Therefore, anyone with occupational lung disease, such as asbestosis and silicosis, should follow all appropriate guidelines as to proper hygiene, self-isolation, and any other steps necessary to avoid contact with, and possible infection with, the Coronavirus.

Hopefully the impact of Coronavirus on those with asbestosis will be minimal and avoided through safe practices, but only proper precautions can prevent the spread and incidences of this disease.

The Society has already fielded many enquiries regarding the Coronavirus Pandemic and the impact on its members, and is well placed to provide guidance and support.



# Society Social Worker

NATALIE BARBER



## **As humans, we yearn to huddle together in times of uncertainty.**

The warmth of our breath and bodies, of holding hands and hugging, of talking and listening, is a primary source of soothing. These connections are pivotal for responding to and maximizing our survival in times of stress. The Society acknowledges many members will take extra precautionary measures to self-isolate during these unprecedented times to protect themselves and their families from exposure to the coronavirus. Humans are innately social beings and social distancing may increase the risk of loneliness, anxiety or depression within the society family. In times like this, it's essential we support one another and show compassion to those who need it. This is a shared experience that's stressful for everyone – and we don't know how long it's going to go on for. Fortunately, positive social support can improve our resilience for coping with stress so staff here at the Society including myself, Trevor, Judith, Kerrie, Kay and Karen are all here to support you throughout these uncertain times and will be making regular contact with you. As a Society family, we feel it is important to look at new ways to stay connected. At present, we have cancelled our support groups and morning tea events however we will be offering alternative ways to stay connected and will be communicating this to you very soon.

In the meantime, I will be setting up a group email offering weekly newsletters to those members who would like to

be involved. Please send me any stories of what you have been up to during the week, this may include any good tv shows you have been watching, any ideas for a trip you are planning when the coronavirus crisis is over, or perhaps you might like to share a story of a trip you have just taken or reminiscing about or photographs of a puzzle you have finished, a new recipe you have made or a project you are doing, any funny jokes, a nice thing that someone has done for you or you have done for someone else, a positive story you have seen in the media or anything at all that you would like to share.

**Research suggests positive social interactions even remotely can help reduce feelings of isolation and loneliness.**

Showing genuine interest in others, sharing positive news, and bringing up old memories can enhance our relationships. Together we will get through this and we are here to help. My email address is natalieb@adss.org.au. If you don't have an email, please feel free to phone the Society and share any stories with me on 1800 776 412.

*Sending my warmest wishes and thinking of you all,*

*Natalie*





The information contained on the next few pages aims at providing you with information from credible sources on the coronavirus (COVID -19) virus and is designed to provide the latest information including symptom and emergency warning signs of when to seek immediate medical help, precautions to minimise your exposure, tips on how to stop the spread of the virus and developing an action plan.

## What is Coronavirus (COVID -19)?

Coronavirus (CoV) is a family of viruses that can cause respiratory infection. The illness caused by coronaviruses in humans can range from the mild common cold to more severe disease like Middle East respiratory syndrome (MERS), which can be fatal. Most recently, a new coronavirus has been linked to a SARS-like illness that started in Wuhan, Hubei Province, China, and efforts are being taken to try and limit its spread (American Lung Association, 2020).

## Who is at risk of contracting the Coronavirus?

The Lung Foundation (2020) has published research suggesting people living with a disease which affects the lungs and individuals diagnosed with lung cancer are at a higher risk of contracting viruses including influenza and pneumococcal along with the current COVID-19 (Coronavirus). The Centre for Disease Control and Prevention (2020) confirms older people who suffer from heart disease, high blood pressure, cancer and diabetes are at risk of experiencing a severe form of the virus if exposed to an infected person. Health Services Executive (HSE) (2019) note lung viruses can cause severe illness in people who have a weak immune system. This is likely to be the case for coronavirus and HSE have expressed particular concerns for individuals who may be immunosuppressed (have a weak immune system) as a result of cancer treatment, treatment for autoimmune diseases, such as rheumatoid arthritis, lupus, multiple sclerosis (MS), inflammatory bowel diseases, HIV or donors or recipients of organ and bone marrow transplants.

## Symptoms and emergency warning signs

If you develop emergency warning signs for COVID-19 get medical attention **immediately**. In adults, emergency warning signs\*

- Difficulty breathing or shortness of breath

- Persistent pain or pressure in the chest
- New confusion or inability to arouse
- Bluish lips or face

*\*This list is not all inclusive. Please consult your medical provider for any other symptoms that are severe or concerning.*

## Precautions to minimise your exposure

There are several precautions you can take to minimise your exposure (NSW Department of Health, 2020)

- Clean your hands with soap and water for 20 seconds, or an alcohol-based hand rub, particularly when visiting public areas.
- Cover your nose and mouth when coughing and sneezing with tissue or a flexed elbow
- Avoid close contact with anyone with cold or flu-like symptoms.
- Practice cough etiquette (keep away from other people, cover coughs and sneezes with disposable tissues or clothing, and clean your hands.
- Travellers to Asia should not visit live bird and animal markets, including 'wet' markets.
- Drink lots of water, eating a healthy diet and not being afraid to rest when you need to.

## How to stop the spread of the virus





If you become unwell there are a few steps which should be followed to prevent the spread of coronavirus:

- Stay at home and expect to get medical care **(individuals with a lung disease may require hospitalisation)**
- Separate yourself from other people and animals in your home (if you are hospitalised you will be placed in isolation)
- Call ahead before visiting your doctor
- Wear a facemask if you are sick
- Cover your coughs and sneezes
- Clean your hands often
- Avoid sharing personal household items
- Clean all “high touch” surfaces everyday
- Monitor your symptoms – seek medical help immediately if your illness is worsening (for example having difficulty breathing). **Contact Emergency Services on 000**



## Developing an Action Plan

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It is important to speak with your health care team and develop an action plan on what to do if you become unwell. An action plan may consider the following points;

- List of medications you take
- Phone numbers of your nearest doctor, specialist and hospital
- Give someone you trust a key to access your property if you become unwell and are unable to open the door. This could be a neighbour /friend or family member.
- Arrange for someone you trust to care for any pets if you become unwell and need to be hospitalised.
- Determine who can provide care for you if your carer becomes sick
- Monitor food and other medical supplies (oxygen, incontinence, dialysis, wound care) needed and create a back-up plan.
- Stock up on non-perishable food items to have on hand in your home to minimize trips to stores.
- If you care for a loved one living in a care facility, monitor the situation, ask about the health of the other residents frequently and know the protocol if there is an outbreak.



## Differences between the cold, flu, seasonal allergies and the coronavirus

Symptoms	Coronavirus* (COVID-19 CoV) Symptoms range from mild to severe	Cold Gradual onset of symptoms	Flu Abrupt onset of symptoms	Seasonal Allergies Abrupt onset of symptoms
 Length of symptoms	7-25 days	Less than 14 days	7-14 days	Several weeks
 Cough	Common (usually dry)	Common (mild)	Common (usually dry)	Rare (usually dry unless it triggers asthma)
 Shortness of breath	Sometimes	No**	No**	No**
 Sneezing	No	Common	No	Common
 Runny or stuffy nose	Rare	Common	Sometimes	Common
 Sore throat	Sometimes	Common	Sometimes	Sometimes (usually mild)
 Fever	Common	Short fever period	Common	No
 Feeling tired	Sometimes	Sometimes	Common	Sometimes
 Headaches	Sometimes	Rare	Common	Sometimes (related to sinus pain)
 Body aches and pains	Sometimes	Common	Common	No
 Diarrhea	Rare	No	Sometimes for children	No

\*Information is still evolving. \*\*Allergies, colds and flus can all trigger asthma, which can lead to shortness of breath. COVID-19 is the only one associated with shortness of breath on its own. Sources: Asthma and Allergy Foundation of America, World Health Organization, Centers for Disease Control and Prevention



# Suggestions of what to do whilst in self-isolation

## Keep Moving

The most common complaint about being stuck inside is that of course, you'd rather be outside. With the potential of lockdowns, many people may not be able to go out for afternoon walks or get adequate physical exercise. Movement is vital to optimal physical and mental health, so we recommend doing some at-home workouts. If you have a partner, neighbour or friend why don't you put on your favourite music and dance to your favourite tunes, it could be the waltz, or if you are feeling more energized you could try the tango!

- Meditation
- Stretches
- Exercises for self-isolation (See separate insert)



## Learn a new skill

- Use a book or on-line tools to learn a new language
- Learn how to play a musical instrument
- Learn how to use a computer or a computer program
- Learn how to cook
- Learn how to draw
- Complete a paint by numbers (You can get adult



ones online)

- Learn how to create a scrapbook
- Learn how to make a photobook
- Learn how to knit
- Learn how to build a DIY animal shelter (possum shelter)
- Learn about a new topic/country/religion/culture

## Other activities

- Do a jigsaw puzzle
- Play solo card games such as Patience
- Have a pamper session, paint your nails, do a face mask
- Play on your game console
- Read the book you have always wanted to read
- Listen to podcasts
- Binge watching Netflix
- Make a family recipe book
- Challenge your partner to a master chef cooking competition
- Play board games
- Create a playlist with happy songs and sing along!
- Build your own on-line fantasy baseball/football team and join an online competition
- Have a competition with a friend by setting up a fake share market portfolio and watch how much how much money you lose or make
- Have a movie marathon. You could pick an interesting theme like travel, or art history, or western.



- Have a go at Sudokus or cross word puzzles – watch Ted-Talks or listen to podcasts
- Keep a journal and list what you are grateful for each day
- Create a physical mood board. Collect inspiring images, magazine clippings, motivational quotes, or fabrics – anything that helps you visualize your dreams, decorating scheme or signature look.
- Find something that makes you laugh. A you-tube video, hilarious joke or a comedy show
- Grow a small herb garden in your window box
- Disconnect from the world for a little while. Light a few candles, listen to relaxing music, and enjoy the view from your window.
- Challenge your brain to a cross word or word finder puzzle

### Connect with others

- Think about how you can interact with others without putting your health (or theirs) at risk. Can you speak to your neighbours from over a fence (1.5 metres away) or across balconies? We've seen this in Italy
- If you have access to it, use technology to stay in touch. If you have a smartphone, use the video capabilities (seeing someone's facial expressions can help increase connection)
- Check in with your friends, family, and neighbours regularly. Wherever you can, assist people in your life who may be more vulnerable (for example, those with no access to the internet or who cannot easily use the internet to shop online)
- Spend the time connecting with the people you are

living with. If you are in a lockdown situation, use this time to improve your existing relationships.

- It's not just family and friends who require support, but others in your community. Showing kindness to others not only helps them but can also increase your sense of purpose and value, improving your own well-being.

If we all do one random act of kindness daily we just might set the world in the right direction.

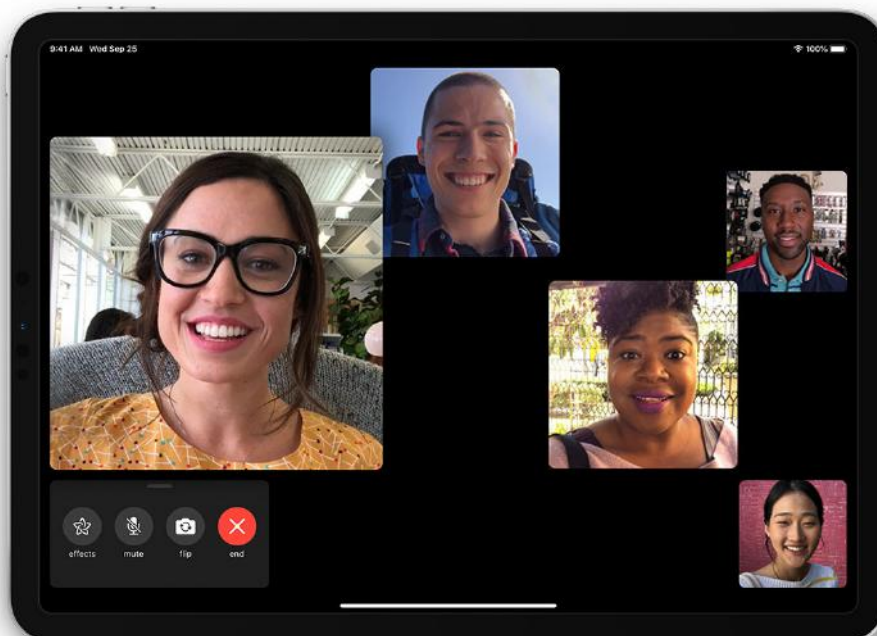


**World Health Organization**

### Look after your mental health

Source: [www.beyondblue.org.au](http://www.beyondblue.org.au)

- Try to maintain perspective
- While it is reasonable for people to be concerned about the outbreak of coronavirus, try to remember that medical, scientific and public health experts around the world are working hard to contain the virus, treat those affected and develop a vaccine as quickly as possible.
- Find a healthy balance in relation to media coverage



- Being exposed to large volumes of negative information can heighten feelings of anxiety. While it's important to stay informed, you may find it useful to limit your media intake if it is upsetting you or your family.
- Access good quality information

It's important to get accurate information from credible sources such as those listed below. This will also help you maintain perspective and feel more in control.

- » Australian Government coronavirus (COVID-19) health alert
- » Health Direct – Coronavirus (COVID-19)
- » smartraveller.gov.au – travel information for Australian citizens
- » World Health Organization – coronavirus disease (COVID-19) outbreak

- Try to maintain a practical and calm approach
- Widespread panic can complicate efforts to manage the outbreak effectively. Do your best to stay calm and follow official advice, particularly around observing good hygiene habits.
- The Australian Psychological Society has advice about maintaining positive mental health during the outbreak.
- Try not to make assumptions
- To contribute to a sense of community wellbeing, try to remember that the coronavirus can affect anyone regardless of their nationality or ethnicity and remember that those with the disease have not done anything wrong.

- Managing your mental health while in self-isolation or quarantine

### There are a number of ways to support your mental health during periods of self-isolation or quarantine.

- Remind yourself that this is a temporary period of isolation to slow the spread of the virus.
- Remember that your effort is helping others in the community avoid contracting the virus.
- Stay connected with friends, family and colleagues via email, social media, video conferencing or telephone.
- Connect with others via the Beyond Blue forums thread: Coping during the coronavirus outbreak.
- Engage in healthy activities that you enjoy and find relaxing.
- Keep regular sleep routines and eat healthy foods.
- Try to maintain physical activity.
- Establish routines as best possible and try to view this period as a new experience that can bring health benefits.
- For those working from home, try to maintain a healthy balance by allocating specific work hours, taking regular breaks and, if possible, establishing a dedicated work-space.
- Avoid news and social media if you find it distressing.





# Society Social Worker

JUDITH THOMSON



## **A very uncertain future... Living with silicosis, a matter of life and death.**

What a joy it was to meet some of our wonderful members at the morning teas and the memorial service during the run up to Christmas. I was so touched by the warm welcome that I received and the encouragement and interest of our members in how we are responding to the tragic re-emergence of silicosis. What sits with me is the connection, caring and concern that you hold for each other while courageously meeting the daily challenges of living with an asbestos related disease (ARDS). I look forward to joining Natalie and Trevor at more of the upcoming events to meet other members and of course to offer support where I can.

For the purpose of this newsletter, let's wind back the clock to the 1960's... Asbestos was known to be a killer causing asbestosis, asbestosis-related lung cancer and mesothelioma. I don't have to tell you, our members that these asbestos related diseases were tragically killing workers and by default their loved ones. Yet industry denials continued, and global production of Asbestos products escalated. After a hard-fought struggle by the asbestos victims' action movements, staffed by passionate volunteers worldwide, including Australia, the campaign gained traction and the world eventually sat up and took notice. The agonising struggle for compensation, recognition of multiple loss's and your ongoing suffering was finally acknowledged.

**“Asbestos victims have been disabled by a material that they were told was safe...that same material is now killing them” (Kavanagh (1995), London Hazard Centre).**

Now let's fast forward to the present day, 2020 and I find myself face to face with equally innocent workers amid

a silicosis epidemic, who while working with a product like engineered stone are in danger of losing their lives. These young workers share their hopes, dreams and their ultimate fears for both themselves and their young families with me, while trying to come to terms with the fact that they too are at risk of premature death for 'simply doing their job'.

**“My boy, he was my apprentice, he's only 19 years old and I was terrified that I was responsible for him getting it (silicosis) but he got tested and he's okay” (John 48, accelerated silicosis sufferer).**

Silicosis is generally a younger person's occupational lung disease. The youngest person diagnosed at the moment in Queensland is only eighteen years old with the oldest being just fifty-one years old, the average age of a silicosis sufferer is approximately 35 years old. The stonemasonry industry is presently the most impacted with 95% silica in engineered stone, a product that graces most of our kitchens, bathrooms and laundries. Now, when I wipe down my smooth and glossy waterfall kitchen benchtop, I cannot help but reflect on the people who are paying the most terrifying price for its existence. We recognise that other industries are also impacted by silica exposure.

While there are some similarities between asbestos and silicosis there are noticeable differences too. As we know it may only take one exposure to asbestos for it to be deadly however silicosis is developed over a more sustained and intense period of consistent exposure to silica dust. Additionally, it has a much shorter latency period of approximately 7 years or less which is why we are seeing such a young group of people affected. There is no certainty or clear timelines with a silicosis diagnosis, there are lots of questions and very few answers. I hear about struggles with depression, anxiety and feelings of sadness and anger. And yet, these young men consistently demonstrate tremendous courage, comradeship... and continue to hold hope despite the enormity of this battle.



“We hope for changes in the industry, a ban of engineered stone. We hope to prevent others from getting this news, we hope to live a little bit longer than seems possible right now” (anonymous, Silicosis support group, 2020).



It no surprise that I feel privileged and humbled when I sit with someone like Daniel (32) who is struggling to understand ‘why me’? When he describes how hard it is to catch his breath after playing with his two young daughters in the back garden or the devastation, he feels at losing his job, his purpose. How for the first time in his adult life he has nowhere to be in the morning.

**“Being a stonemason, that was my life”, being with the boys, working hard but having a laugh too, that was my world, my identity (Daniel Lewis).**

Or what about Paul (36) a loving dad to six children, this 6ft 4’, gentle giant reduced to tears after his recent diagnosis of PMF and silicosis, “What about my kids, what do I tell them, this just isn’t right”.

As a social worker for the Silicosis Support Network , I am

humbled by their trust in me and I am determined to offer exceptional support and services to Paul, John and Daniel and all of the people impacted by silicosis including their partners, families and workmates. While reflecting on the momentous struggle of all asbestos sufferers worldwide in their drive for justice, I realise that we too can be ‘stronger together’ in the face of this silicosis epidemic. My hope is that this is not the beginning of a very long story...

Warmest regards

*Judith*

*Some names have been changed to ensure confidentiality.*

## Introducing Karen Selmon

SOCIETY NURSE



Please welcome to the Society the newest member of the support care team, Karen Selmon. Karen is a registered nurse who has had many years’ experience caring for patients diagnosed with cancer and currently volunteers as a personal carer at Katie Rose Cottage Hospice on the Sunshine Coast and facilitates the Society’s Sunshine Coast support group. Karen brings a wealth of knowledge to the Society having previously supported individuals and their carers who have been impacted by an asbestos related disease through her previous role as a clinical nurse with the Asbestos Disease Research Institute in Sydney. Karen has a deep understanding of how an asbestos related disease can impact individuals, their partners and families, having cared for her partner for four years after a diagnosis of Mesothelioma. During this time Karen supported her partner as he underwent several treatments including chemotherapy, radiotherapy, immunotherapy and participation in clinical trials. This experience gave Karen both an insider knowledge on what it is like to be a carer supporting a loved one through an asbestos related illness as well as developing further medical knowledge in her clinical nursing capacity.

Karen can provide unique support for members diagnosed with Mesothelioma, their carers, families and friends and assist them to navigate their illness pathway with current clinical information on managing symptoms, expectations and palliative care measures.

Karen believes everyone should feel supported and well connected to services. A member who has recently been supported by Karen commented “I felt so relieved after talking with Karen, I knew from the first call I could talk to her about all my fears and she would understand. She answered the questions my doctors would not, it eased my anxiety knowing how to plan for the future and what services I needed to consider”.

Karen’s end of life clinical knowledge and experience as a nurse working with patients, carers, families, and health professionals as well as her personal experience in caring for a loved one with Mesothelioma, make her a wonderful addition to the Society and we are privileged to welcome her to the team.

If you would like to receive telephone support from Karen, please contact the Society’s social worker Natalie on 1800 776 412 or [natalieb@adss.org.au](mailto:natalieb@adss.org.au) who will be able to refer you.

# Around the World

## MESOTHELIOMA CLINICAL TRIAL INVOLVES IMMUNOTHERAPY BEFORE SURGERY

*By Tim Povtak  
Research & Clinical Trials  
Feb 24, 2020*

### **Three of the country's leading cancer centers have opened a collaborative clinical trial that potentially could change surgical treatment of mesothelioma.**

Researchers will measure the safety and efficacy of using two different immunotherapy drug regimens — Opdivo (nivolumab) and Yervoy (ipilimumab) — beginning 42 days before surgery.

The hope is that at least one will make surgical resection more effective.

Sidney Kimmel Cancer Center at Johns Hopkins University, MD Anderson Cancer Center at the University of Texas and Greenebaum Cancer Center at the University of Maryland are working together to enroll at least 30 patients for the study.

Principal investigator Dr. Patrick Forde Forde, a thoracic oncologist at Johns Hopkins, spoke about the study to several patients and patient advocates in a conference call orchestrated by the Mesothelioma Applied Research Foundation in Washington, D.C.

“The study is building on work already done for other cancers,” Forde said. “Initial results in other cancers, such as breast and lung cancer, have been promising with this approach.”

### **Yervoy Delivered Just Once in Clinical Trial**

The study wants 15 patients receiving Opdivo before surgery and another 15 taking Opdivo and Yervoy.

Opdivo will be given 42, 28 and 14 days before surgery. Yervoy will be administered just once, on day 42.

The study also allows for patients to continue receiving regular immunotherapy treatments after surgery for up to one year or until disease progression.

“We know from other cancers that giving immunotherapy prior to surgery has been shown to lead to regression of the tumor and infiltration of the immune system attacking the cancer,” Forde said. “We know from other cancers that it can be effective.”

Both drugs are known as immune checkpoint inhibitors.

The two drugs target different surface proteins, but they

work in similar ways, negating their effectiveness that restricts a patient's immune system from stopping the tumors.

### **Two Surgeries Eligible for Immunotherapy Trial**

The eligibility of the clinical trial will include patients undergoing either a pleurectomy and decortication or an extrapleural pneumonectomy surgery.

It also will include patients with either the epithelioid or biphasic cell type of mesothelioma, but not those with sarcomatoid.

Although neither Opdivo and Yervoy have been approved by the U.S. Food and Drug Administration for use with mesothelioma, the drugs already have shown effectiveness without surgery for a small percentage of patients.

Both drugs are manufactured by pharmaceutical giant Bristol-Myers Squibb, which is helping fund this latest study.

In two separate studies published in 2019, researchers from France and the Netherlands showed the combination of Opdivo and Yervoy created a synergy that helped stop or slow pleural mesothelioma tumors in a second-line setting.

### **Earlier Opdivo/Yervoy Studies Show Promise**

The study in France involved 125 inoperable patients, all of whom entered after chemotherapy failed.

Results included a 44% disease control rate for patients taking Opdivo and 50% for those with the Opdivo and Yervoy combination.

The median overall survival was nearly one year for Opdivo and 15.9 months for the combination.

Forde also was involved in another study using Opdivo before aggressive surgery for patients with lung cancer.

He published results in 2017 that included a 90% tumor regression in nine of the 21 patients.

Bristol-Myers Squibb is sponsoring another



mesothelioma clinical trial that began in 2017 at cancer centers across the U.S.

The trial is measuring the effectiveness of Opdivo and Yervoy compared with standard chemotherapy for inoperable patients.

In this latest trial, patients and their medical providers will have the option of doing standard chemotherapy before and/or after surgery, along with the immunotherapy drugs.

They also may have the option of radiation therapy after the surgery.

Surgical resection after immunotherapy will allow for a more in-depth assessment of immune and pathologic response rates.

"In general, these drugs are well tolerated," Forde said. "We've also learned that a lot of times, these different forms of treatment can synergize in a positive way."

## FDA MOVES CLOSER TO STANDARDIZED TESTING FOR ASBESTOS IN TALC

*By Tim Povtak  
Asbestos Exposure & Bans  
Feb 5, 2020*

### **The U.S. Food and Drug Administration moved closer on Tuesday to formulating standardized testing of talc-based products for the presence of toxic asbestos fibers.**

Experts from eight different federal agencies explained earlier recommendations at a day-long hearing. The session also featured input from 25 members of the public, which included industry representatives, consumer advocates and testing experts.

"Standards are needed," said Dr. Paul Howard, FDA Office of Regulatory Science, during his presentation. "They just don't exist at this time."

Dr. Linda Katz, director of the FDA Office of Cosmetics and Color, said the next step will be producing a white paper after reviewing all recommendations as an authoritative guide on the issue.

"There are challenges in establishing the most suitable approach to testing for asbestos in cosmetic products," Katz said. "We know there is confusing terminology. Data from different labs suffers from a lack of procedural standardization. There is a need for standardization."

### **FDA Pushed by Recent Findings of Asbestos**

This was the first official FDA hearing on asbestos in talc in almost 50 years.

The FDA has intensified its oversight efforts after finding traces of asbestos mixed with talc in several different cosmetics and powders in the last two years.

In October 2019, the agency found asbestos fibers in one bottle of Johnson's Baby Powder, leading to a voluntary recall of the product.

Johnson & Johnson, though, hired an outside laboratory

for further testing of the product — using the same bottle of powder — and found no asbestos.

The discrepancy of findings is not uncommon, stemming from a variety of factors, including the testing methods of the product. The recent recommendations, some of which reject long-held industry procedures, are designed to end those differences.

Johnson & Johnson, in a recent statement before Tuesday's hearing, said it was encouraged by the FDA's "thorough review of the most effective and reliable ways to test for asbestos in cosmetic talc."

### **FDA Has Limited Authority**

One of the problems is that the FDA currently has only limited authority over the cosmetics market.

Products do not have to be approved or undergo review before they go to market. They only have to be considered safe by company standards. Companies can use any number of testing methods.

The problem originates from the mining of talc, which often is found and mixed with asbestos deposits near the earth's surface.

While talc is known as one of the world's softest minerals — and used in myriad of consumer products — asbestos is toxic. Exposure to asbestos can cause serious health problems.

Johnson & Johnson currently is facing more than 15,000 lawsuits stemming from consumers who believe its talc products have caused their cancers, including ovarian cancer, lung cancer and mesothelioma.

### **Standardizing Testing and Protocols**

The Scientific Analytical Institute in Greensboro, North Carolina, last month uncovered asbestos-tainted talc in a children's makeup kit marketed by IQ Toys. The

company quickly recalled the product, and the FDA is still investigating those findings.

Testing of the makeup product was commissioned by the Environmental Working Group, an advocacy group in Washington, D.C.

“It’s time to end the honor system that has failed us for so long,” Scott Farber, vice president of the Environmental Working Group, said during Tuesday’s hearing. “We’re calling to require companies to use the most state-of-the-art testing.”

The three most commonly used testing methods involve X-ray diffraction, polarized light microscopy or transmission electron microscopy. Experts discussed strengths and weaknesses of each method during the hearing.

Another topic discussed was the issue of identifying and quantifying elongate mineral particles, which have the

same composition and structure as asbestos fibers.

The Interagency Working Group on Asbestos in Consumer Products, a task force of the multiple federal agencies, has recommended all be viewed as potentially harmful and banned alongside asbestos.

Some testing methods identify all elongate mineral particles as asbestos, while others do not, leading to the conflicting test results. Some have proven to be harmful, but others have not.

Other challenges include changing the size and consistency of what determines the presence of asbestos, the handling of samples, the chain of custody, management of documentation, and the expertise of those conducting the testing.

“Not everyone interprets fibers the same way,” Katz said. “How fibers are characterized, counted and expressed in statistical terms is not standardized now.”

## On the National Front

### CASES OF MINE-DUST LUNG DISEASE AND SILICOSIS INCREASINGLY FOUND IN QUEENSLAND COAL MINE WORKERS

*ABC Capricornia by Jemima Burt and Rachel McGhee  
Updates 27 Feb 2020, 3.23pm*

#### Key points:

- There have been 56 new cases of mine-dust lung disease reported to the Queensland Government since the start of the 2019 financial year
- The rise could be due to improved diagnostic and reporting strategies, or increased dust levels in mines
- The Queensland Government has established a hotline for mine workers, doctors and family members, a move praised by the union

**The total number of diagnoses of mine-dust lung disease (MDLD) in Queensland has now reached 133 cases since 1984 – up from 102 in February last year.**

State Government data includes all cases of coal workers’ pneumoconiosis (CWP), mixed dust pneumoconiosis (MDP), silicosis – a form of pneumoconiosis from silica dust – as well as chronic obstructive pulmonary disease (COPD) and asbestosis, reported since 1984.

Coal workers’ pneumoconiosis accounts for 40 of the total 133.

Twenty new cases of MDLD have been reported to the Queensland Government since July last year on top of 36 new cases reported during the 2019 financial year.

The potentially fatal diseases are caused by long-term exposure to high concentrations of dust generated during mining and quarrying activities.

Experts have said the rise could be due to improved diagnostic and reporting strategies, but that modernisation of coal mining methods may have also contributed to increased dust levels.

The State Government said it has been doing all it can to support victims and today announced a new hotline for workers, family members, or doctors with questions about dust diseases.

‘I’m on oxygen  
6 hours a day’

Allan Whyte worked in Queensland’s coal mines for 46 years and was diagnosed with coal workers’ pneumoconiosis (CWP), or black lung disease, in March 2019 after more than 10 years of misdiagnosed lung issues.

“I’m on oxygen 6 hours a day – minimum – and it’s only going to get worse from here,” he said.

“One day they switch the oxygen off and you’re finished.

## “I’m old now but I did play bowls – I can’t even play bowls now.”

Mr Whyte said his CWP has continued to worsen over time and there is no cure.

“It’s a matter of sitting at home and waiting for it to happen and you just gradually get worse,” he said.

“It’s not as easy as what anyone thinks: ‘Oh, he’s got black lung, he’ll get a big payout’.

## “I’m finished ... now all I’ve got to do is sit back and wait, wait, wait.”

Mr Whyte is part of a Mine Dust Victims Group made up of affected coal miners who meet regularly to lobby for change and support each other.

“I’ve got lots of friends who have already died prior to this being a big deal, and they would have died from that [CWP],” he said.

Mr Whyte said he was not surprised by the growing number of diagnoses and said he expects more to come.

## “There are a lot of people out there that are still in denial, they won’t go out and get the X-ray in case they’ve got it,” he said.

“That’s only the tip of the iceberg – us silly buggers here we’ve just been down the right track and gotten onto the right bloke [for a diagnosis].”

## Union commends state response

The mining union said it is pleased with the State Government’s response to the diagnoses of a disease which is thought to have re-emerged after 30 years.

Queensland President of the CFMEU Mining and Energy, Stephen Smyth, said most of the recent cases came from current mine workers, meaning new detection systems are working.

## “We’ll continue to see the rise in mine-dust lung disease,” he said.

“We have a lot of miners out there that haven’t even participated, particularly the retired miners and even the current miners.

“We’ve got to commend the State Government on the response they’ve taken to certain black lung reforms and the other reforms they’re implementing through the legislation.

“We’d like to congratulate them on the work they’ve done.”

### What is black lung disease?

- A potentially fatal disease with no known cure
- Caused by long exposure to coal dust that turns the lungs black
- There are two types of black lung: simple and complicated
- There are relatively few symptoms associated with simple black lung, coal workers’ pneumoconiosis (CWP), and the prognosis is usually good
- CWP can progress into the more complicated progressive massive fibrosis (PMF)
- PMF symptoms can include a long-term cough and shortness of breath

Source: University of Kentucky, US National Library of Medicine and The Lancet

### Black lung victim says mine-appointed doctors didn’t know how to read X-rays properly

A former coal miner says he would’ve left the industry had he known he had silicosis, but the doctors hired by his employer failed to diagnose his condition.





## Why have MDLD diagnoses increased?

Robert Cohen is a clinical professor of environmental and occupational health sciences at the University of Illinois in the United States.

He is the internationally renowned expert on black lung disease who diagnosed Mr Whyte.

Dr Cohen said there are two possible reasons for the recent resurgence of the disease.

“One [reason] is that it was rediscovered rather than re-emerging,” he said.

“I don’t believe the disease was ever eradicated — I think we stopped looking for it.

“If you stop looking for it then people were diagnosed with other diseases, where in reality they probably had coal mine dust diseases.”

Dr Cohen said advances in mining technologies could also explain the increase in diagnoses.

“As technology has improved we have these massive machines that generate these huge amounts of coal production but they also generate huge amounts of dust,” he said.

“It’s possible that our dust controls didn’t keep pace with modern technology’s production of coal and production of dust.”

Dr Cohen praised the way the Queensland Government has handled the resurgence, describing the diagnosis process as “worldclass”.

### ‘I can’t stand it anymore’

Retired coal miner Percy Verrall spent most of his working life in Queensland’s Ipswich coalfields and is now paying the price.



“We now have a wonderful coal mine workers’ health scheme that’s actually looking at X-rays and carefully evaluating miners in a way that they hadn’t been for decades,” he said.

“So we’re identifying a disease that’s been out there, that needed to be found, and these folks need to be treated and have preventative measures taken.

“I think this is what we would have expected, [but] what was unexpected is that there would have been no cases and that was the thing that we had fixed.

“We’re now looking for them and we are finding some.”

## ASBESTOS: DEALING WITH PROHIBITED ASBESTOS

*Tuesday 10 March 2020*  
*Safe Worker Australia: News*

**Three of the country’s leading cancer centers have opened a collaborative clinical trial that potentially could change surgical treatment of mesothelioma.**

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The hope is that at least one will make surgical resection more effective.

Sidney Kimmel Cancer Center at Johns Hopkins University, MD Anderson Cancer Center at the University of Texas and Greenebaum Cancer Center at the University of Maryland are working together to enroll at least 30 patients for the study.

Principal investigator Dr. Patrick Forde Forde, a thoracic oncologist at Johns Hopkins, spoke about the study to several



# The Society at Work

4.12.19 Bundaberg Support Group - Xmas Lunch



9.12.19 Donations for the CFMEU Toy Drive for RizeUp for Domestic and Family Violence



20.12.19 John Shenfield (BERT) Presenting a donation Cheque from the BERT Charity Golf Day in October



16.1.20 Rockhampton Support Group



20.2.20 Rockhampton Support Group



21.2.20 Trevor (Gilly) Gilmeister - GM for the Day





10.12.19 Andrew Ramsay being presented with ADSS Life Member



11.12.19 Hervey Bay Support Group - Christmas Lunch



5.2.20 Bundaberg Support Group



14.2.20 ADSS Strategy Day



24.2.20 Toowoomba Morning Tea



10.3.20 Maroochy Morning Tea





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