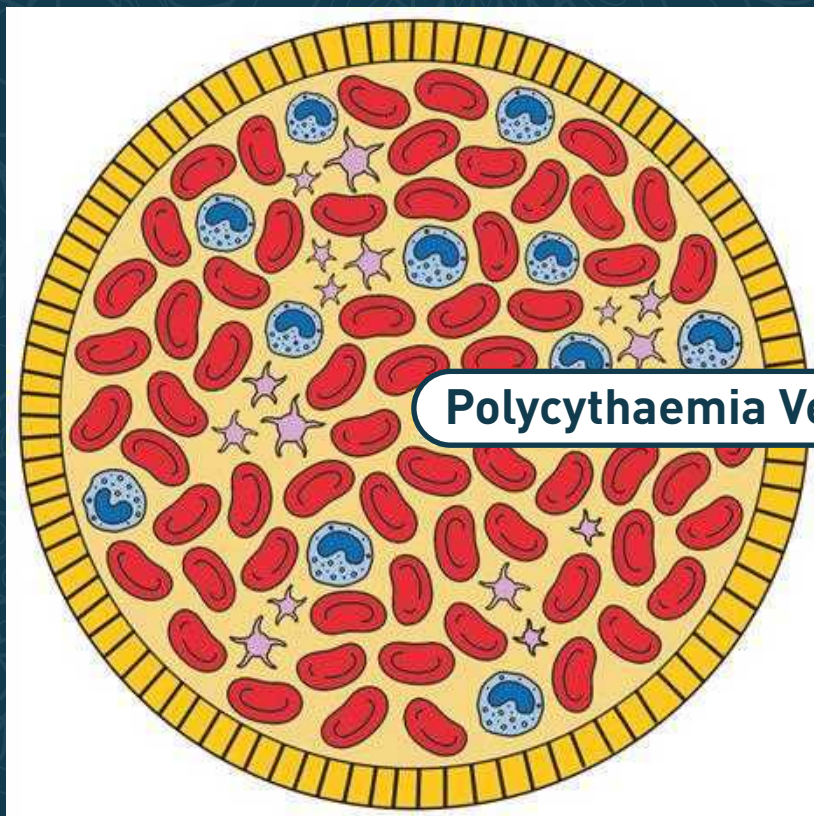


# SHARE YOUR COLOURS

## Silence Therapeutics Colouring Book



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This colouring book has been developed by Silence Therapeutics for people living with Polycythaemia Vera (PV) and their families. A special thank you for editorial support from the following Polycythaemia Vera patient advocacy organisations: MPN Advocacy Network, MPN Alliance Australia, MPN Research Foundation and MPN Voice.

# Introduction

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Polycythaemia Vera (PV) is a type of Myeloproliferative Neoplasm (MPN) – a group of blood cancers that cause the body to produce blood cells in an uncontrolled way. In PV, this leads to thicker than normal blood, which can result in a range of symptoms such as fatigue, dizziness, itching, red skin, and painful swelling or inflammation.

PV is a long-term rare blood cancer that has a major impact on quality of life. Cancer is a disease of abnormal cell

proliferation. There is an increasing focus on managing PV symptoms. Techniques such as mindfulness and meditation can be used to reduce mental stress and promote relaxation.

This booklet has been designed for those living with PV and their loved ones to tap into creativity as a means of finding some inner peace. This might be in a hospital waiting room, at a café, or at home. Keep it with you for wherever and whenever you might need it.

■ ■ **Silence is committed to supporting people living with PV and trying to improve their quality of life. We are grateful to partner with MPN patient organisations on this booklet. We hope it helps to relax people's minds and bodies – to reduce anxiety and tension a little if they are going through challenging times managing their symptoms** ■ ■

Dr Steven Romano, Head of R&D, Silence Therapeutics

**Colouring is a good way of engaging the mind, helping to reduce intrusive thoughts.**

Take time out to colour the illustrations and to relax with a calming activity, while learning about PV. The booklet also includes a series of mindfulness exercises that can help clear the mind and reduce stress.

# The different types of MPNs

Myeloproliferative Neoplasms (MPNs) are rare blood cancers that affect how blood cells are produced. The name comes from 'myelo', which relates to the bone marrow and 'proliferative', which means 'over-production'. Neoplasms are an abnormal growth of cells, in this case, blood cells.

The three most common types of MPNs are Essential Thrombocythemia (ET),

Myelofibrosis (MF) and Polycythaemia Vera (PV). These affect the blood in different ways.

MPNs are officially classified as rare blood cancers since the bone marrow is producing blood cells in an uncontrolled way. However, it is important to remember that PV usually develops slowly and with regular monitoring and treatment PV patients can live a normal or near-normal life.

“Through my illness, I have found a deeper sense for the little things and have learned to appreciate the positive aspects of life more”

Werner, Germany, living with PV for 14 years

## Self-compassion

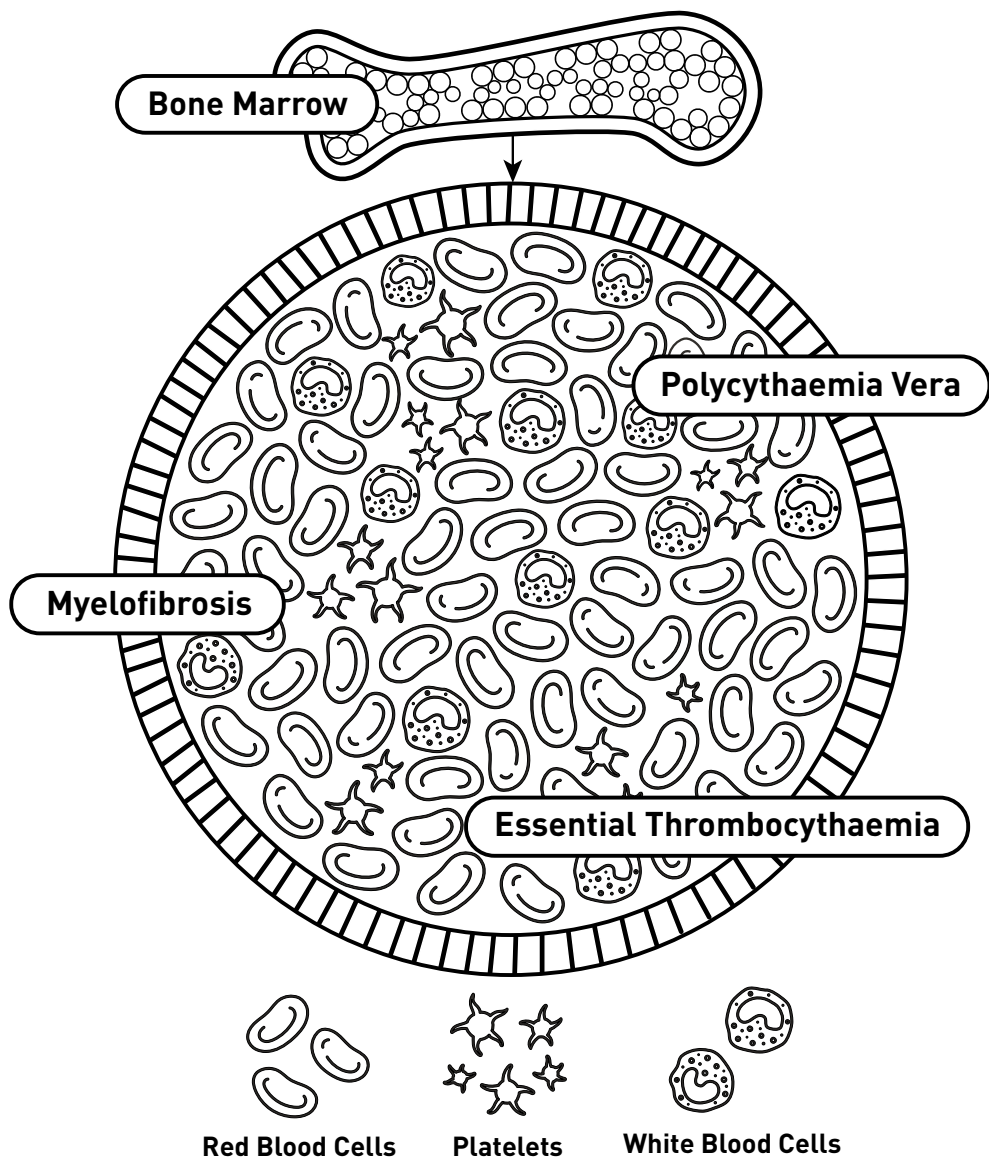
As you colour, repeat a kind phrase to yourself, such as: “I am doing my best,” or “I am worthy of love and care.”

Let the colouring help you to feel these words and accept them.

### Reflection:

*How does practicing self-compassion during this activity make you feel?*





# The cause of PV

PV is a rare blood cancer – the number of people diagnosed each year is 2 to 3 per 100,000 people.

PV is more common in men than women and is more likely to affect people over the age of 60, although it can occur in younger people.

PV is related to a genetic mutation (a change in one or more genes) that typically occurs in adulthood, although it can also affect younger people. Experts believe it is not a condition people are born with. Nearly 97% of people with PV have a change, or mutation, in JAK2V617F, a protein that is part of the process which regulates blood cell production in our bodies.

◻◻ **When everything around you seems overwhelming, or you need time for yourself. Open the colouring book and enjoy the peace and mindfulness of filling the images with colours of your choice** ◻◻

Nona, UK, living with PV for 30+ years

## Body Scan Awareness

As you colour, take a moment to focus on your body. Where do you feel tension or discomfort? Breathe into that area, imagining the breath bringing ease and relaxation.

### Reflection:

*How does your body feel after colouring for a few minutes. Has anything shifted or changed?*





# PV symptoms and complications

PV causes the bone marrow to produce too many blood cells, including red, white and platelets. This makes the blood thicker than normal and, in some cases, can lead to potentially serious health problems such as blood clots, heart attacks and strokes. PV may remain stable for many years or only progress slowly.

Symptoms like itching or a burning sensation on the skin – especially after a hot shower – headaches, and

numbness or tingling in the fingers and toes tend to develop gradually, making diagnosis difficult. Some of the symptoms are shown in the illustration opposite.

About 15% of people with PV will develop Myelofibrosis, where scar tissue forms in the bone marrow, which affects the production of normal blood cells. Regular monitoring and appropriate management are essential to address potential progression in PV patients.

▀▀ **Your PV journey is uniquely yours—listen to your body, seek support, share your experiences, and never stop advocating for yourself** ▀▀

Sara Douglas, Registered Nurse / Oncology Certified Nurse.  
Director, Patient Engagement, MPN Research Foundation

## Gratitude Practice

While colouring, think about three things you're grateful for today, no matter how small. Write them down or simply hold them in your mind.

### Reflection:

*How does focusing on gratitude change your mood or perspective while colouring?*





**Fatigue**



**Inflammation**



**Itchy & red skin**



**Dizziness**



# Management of PV

There is currently no cure for PV but the focus of long-term management is to reduce blood cells and reduce the risk of clots, as well as treating symptoms. While current treatment options do not address the underlying cause of the disease, new treatment approaches are being actively explored in clinical trials.

PV is often an 'invisible' disease. Those living with it look well on

the outside but can feel unwell and fatigued. This can make it difficult for other people to recognise the impact of the disease.

Those living with PV can take steps to manage symptoms such as fatigue. Useful approaches include practising mindfulness, taking time out to relax and engaging in activities that focus and quieten the mind, such as colouring.

▀▀ **Use your colours to create a sense of calm, relaxation and a beautiful picture to enjoy** ▀▀

Maz, UK, living with an MPN for 22 years

## Mindful Breathing

With each stroke of colour, take a slow, deep breath in and out. Notice the rhythm of your breath as it comes in and out of your nose.

### Reflection:

*How does paying attention to your breath affect your colouring experience?*





**Reduce  
blood cells**

**Reduce  
clot risk**



**Manage  
Symptoms**



# Investigating potential new treatments for PV

Knowledge about PV is increasing all the time. The treatment of PV is evolving as new options are currently being investigated, which have the potential to improve the outlook for people with PV.

Gene silencing is a new approach to treating rare diseases. In simple terms, it makes use of the body's natural processes to control disease by suppressing ('silencing') specific genes that are associated with certain diseases. It is designed to precisely target and temporarily block

(or silence) specific genes without permanently altering DNA.

Some people living with PV may choose to take part in a clinical study to help researchers understand the effects of experimental medicines that could lead to breakthroughs and new treatments. Taking part in a clinical study typically involves regular visits to a hospital or clinic, where the individual is closely monitored through tests and check-ups to understand how well a treatment is working and ensure their safety.

“Colouring in brings your awareness back to the present moment, creating a sense of calmness and peace”

Nathalie, Australia, living with PV for 18 years

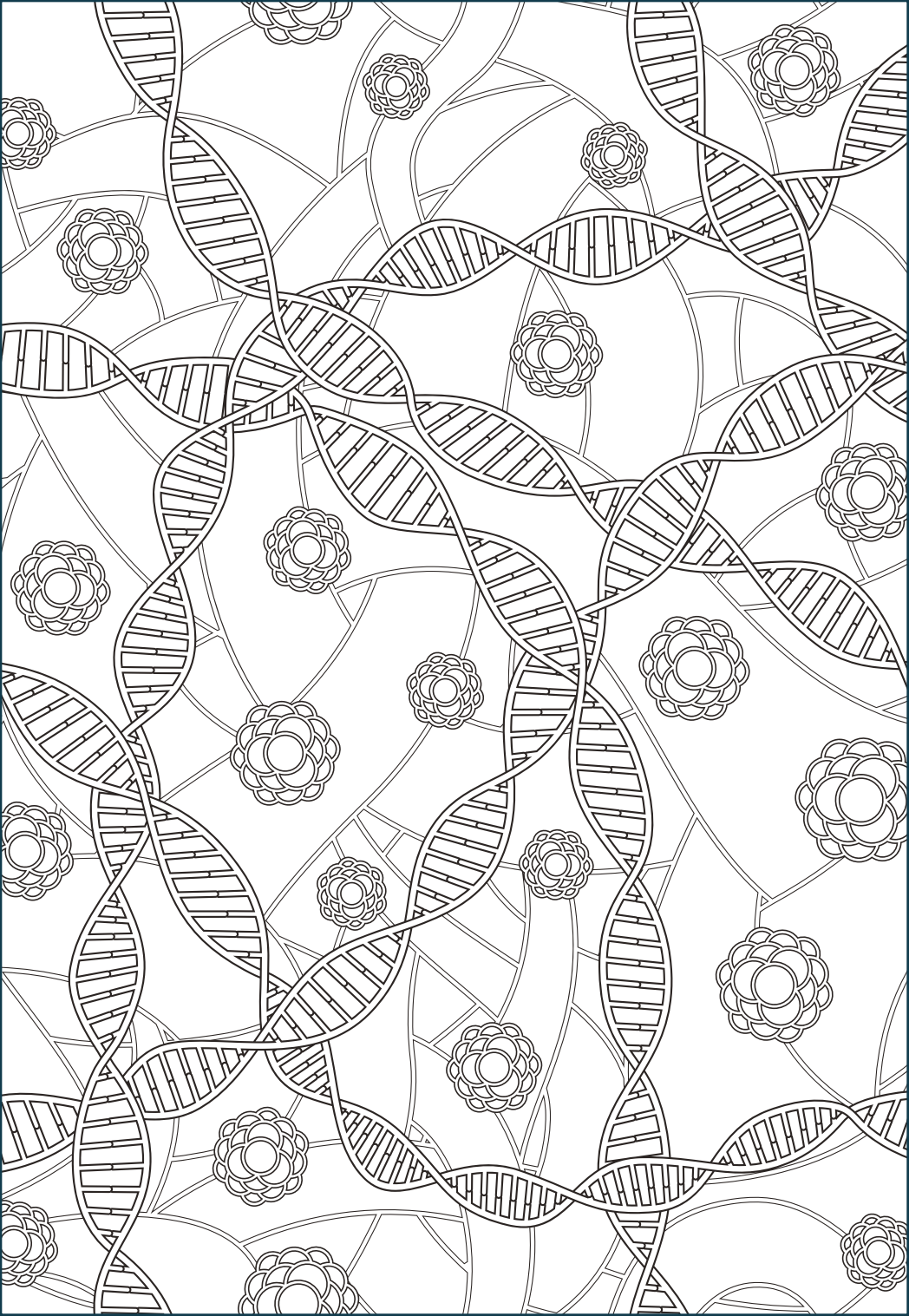
## Emotion Check-In

Before you start colouring, pause and ask yourself: “What am I feeling right now?” Name your emotions without judgment. As you colour, imagine each emotion flowing into the page.

### Reflection:

*Did any feelings change as you coloured? What colours did you gravitate toward, and why?*





# Explaining PV to family and friends

PV is a rare blood cancer and few people will have heard of it. Family and friends are bound to have questions. Don't overwhelm them with information – keep things simple and stick to some key facts:

- I have a condition called PV that causes my blood to be thicker than normal
- If untreated, it can be very serious, but when well-managed I'll still be able to live a long, happy life
- I might need your help more from day to day than I used to, as PV is linked to fatigue, which is an invisible symptom and means I need to rest more
- Even though there is currently no cure, treatments are available to keep me well and new treatment options are being researched

People living with PV, along with their family and friends, may find it helpful to connect with other PV patients and caregivers for mutual support.

◀◀ **Colouring helps calm my worry and confusion about my parent's diagnosis. It gives me time to think and understand what's happening better** ▶▶

Libby, Australia, daughter of a parent with an MPN

## Visualisation and Positive Imagery

Imagine each colour you use represents a quality you want more of in your life, such as peace, strength, or joy. Let these colours fill your page and your mind.

### Reflection:

*Which colours and qualities resonate with you most today?  
How can you carry this energy with you after colouring?*







For more information on PV, as well as support, resources, and the latest research advancements, please visit the websites of your local MPN patient organisations and healthcare providers. You can also visit MPN Advocacy Network, MPN Alliance Australia, MPN Research Foundation and MPN Voice for additional assistance.

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Special Thanks to:



[mpnvoice.org.uk](http://mpnvoice.org.uk)



Silence Therapeutics is a biotechnology company, seeking to transform peoples' lives around the world by silencing diseases through its precision engineered medicines. We are committed to driving positive change for the communities around us, including for people living with or affected by Polycythaemia Vera.

Visit our website: [www.silence-therapeutics.com](http://www.silence-therapeutics.com)