



WRITING THROUGH ILLNESS

INTRODUCTION VOL. 1

Writing Through Illness is a collection of worksheets that guide you through writing activities designed to support wellbeing and quality of life for people living with Parkinson's and other chronic illnesses. Each worksheet was developed by Tara during the *Placing Unheard Voices* study – initially as poetry and journaling prompts to help her process emotions related to researching Parkinson's while also living with the condition, and eventually as poetic inquiry and therapeutic writing techniques. Volume one in the series offers five therapeutic writing prompts to affirm resilience and wellbeing.

A NOTE ON HANDWRITING AND COMPUTER WORK

Micrographia (small writing) and difficulties producing legible handwriting can be a part of Parkinson's. If you struggle with handwriting, you might like to consider using the exercises in the *Writing Through Illness* series to practice your handwriting. Here are some tips if you'd like to give this a try:

TIPS FOR HANDWRITING
Write during "on" times when medication is working well.
Make sure you are seated comfortably. Stop and rearrange your desk/table if you need to.
For micrographia, try writing 'big' and experiment with using lined paper (see your GP to discuss your unique situation).
Take regular breaks – use a timer and make rest breaks part of your writing routine.
If you are struggling, rest and reapproach. Talk to your GP or physio about assisted technologies, devices, and physical exercises that may help you.

If you are like me, when your hands turn rouge and won't obey you, nothing but rest will help. In this situation rest is sensible, though I confess I am not good at resting. I usually turn to the Voice Memos app on my phone when I am inspired to write and my hands aren't cooperating. Voice recording is not perfect, especially with a kiwi accent! But if you speak clearly and not too fast, it gets words on the page and can help to satisfy the urge to write.

If you are typing on a computer, make sure you are practicing correct posture and take regular stretch and rest breaks. You could also consider adaptive technologies like ergonomical keyboards or screen reading and dictation software.

It is worthwhile seeking the advice of a GP and/or physiotherapist as there may be assisted technologies and physical exercises that could help you be more comfortable.

WORKSHEETS IN WRITING THROUGH ILLNESS VOL. 1

VOLUME ONE	Title
Worksheet 1	Poetic Affirmations
Worksheet 2	Word Play
Worksheet 3	Fragments of Change
Worksheet 4	Different Selves
Worksheet 5	Re-Storying

Visit www.placingunheardvoices.org to access individual worksheets

WORKSHEET #1

POETIC AFFIRMATIONS

What are poetic Affirmations? The use of poetry to make positive statements and reciting these to cultivate a positive mindset.

Why use poetic affirmations? They are a fun and relaxing way to engage with affirmations that can boost self-esteem, motivation, and overall wellbeing. You can use them any time, not just when you feel low. For example, try reading affirmations aloud, perhaps performing them to family and friends, or even start a social group that meets in person to read and discuss them (a group of people with Parkinson's did just that during the research and reported increased optimism).

Affirmations and Parkinson's: Life with Parkinson's can be a bit rocky at times. Dealing with change and readjustment can be demanding, even draining. Sometimes life becomes all about Parkinson's and we forget to affirm other parts of ourselves. Poetic affirmations are a gentle and enjoyable way to balance things out and remember we are much more than illness.

Exercise 1: Poetic affirmations

Step one: Spend 5 minutes or so reflecting on how long you have lived with Parkinson's. What have you learned in that time – note down anything that comes to mind that you have learned.

Step two: Looking over your notes, circle all the words that stand out as affirmations of you strength, courage, and resilience.

Step three: Move these words onto another page and use them to write a poem affirming your knowledge and wisdom.

WORKSHEET #2

WORD PLAY

Playing with words: Sometimes living with Parkinson's means struggling to find the words you want to say. Other times your voice may suddenly become small and faint despite effort to project and animate. Slurring words can also occur, leading to accusations of moodiness or even drunkenness. Communication can become a source of uncertainty, stress, and pressure. Finding fun ways to enjoy communication can help boost your confidence and keep you motivated to keep participating in conversation. Playing with words is also good brain gym and is an activity you can do on your own or with others, like a crossword puzzle.

Double entendre word play: A double entendre is a phrase of multiple meanings that can be taken in different ways. An example is the phrase 'totally sick', which could describe a day literally feeling very unwell or an outstanding and very cool day.

Exercise 2: Playing a double entendre

Step one: Write a few lines describing yourself as a sick person (literally someone experiencing illness). Then construct a few lines describing yourself as 'sick' – as in, amazing and cool!

Step two: Write a brief description of yourself as a poet (e.g., are you new to poetry, a seasoned or reluctant poet).

Step three: Find a metaphor to tie together these different identities. For example, a river changing course, shifting weather patterns, or a garden in different seasons. Use this metaphor to share different sides to who you are, be playful with your words. As you read your poem, notice how you are so much more than literally sick.

WORKSHEET #3

FRAGMENTS OF CHANGE

When explaining *Placing Unheard Voices* to others, I often find myself talking about the significant demands of ever-evolving changes in the lives of people with Parkinson's. We are well-practiced at coping with small and large alterations to daily life, whether associated with medication regimes, physical symptoms, or emotions in response to change. This exercise explores change as something you can respond to rather than something that happens to you.

Exercise 3: Befriending change

Step one: Make rough notes about recent or long-term changes you have experienced— these could be a physical, emotional, relational, or practical changes. Describe what changed? How did you react?

Step two: From your notes, choose 1 to 5 changes you have experienced and write one or two sentences explaining the importance of each one. (e.g., "This change felt...")

Step three: Arrange these sentences in a way that feels right to you (e.g., a way that tells your story of change). Let poetic form take shape without too much effort from you by adding details to the emotions of the changes you describe. Keep your poem loose and don't worry about rhyme or full sentences.

Step four: Edit your poem to minimise description and emphasise emotions.

Step five: Add a final line or stanza that expresses what the change you have written about has taught you.

WORKSHEET #4

DIFFERENT SELVES

With all the change Parkinson's brings, it is challenging at times not to feel a significant sense of loss day to day. Following feelings of loss, there is often grief and a sense of changing identity. On top of that, because Parkinson's symptoms fluctuate during the day, self-image can radically shift, sometimes moment to moment, and you may feel as if you're living on a merry-go-round. We live in a culture that provides only limited windows of time to express loss and grief. The loss of sense of self, or self-image, is only rarely acknowledged by health and social care providers. This exercise is about noticing when you feel your sense of self shift and processing feelings of loss and grief that may ensue.

Exercise 4: Different selves, loss and grief

Step one: Create space for responding to changing self-image and associated feelings of loss and grief, by answering these questions:

How do you see yourself today and why?

Do you see yourself differently at different times – if so, describe this in detail

Are there versions of you that you miss?

Can you think of an image that is symbolic of your sense of self?

If you could say two things to a past self, what would they be?

Step two: Circle any words that seem important or rouse your emotions. Arrange these words to form a poem. Remember to play around with telling your story of loss in different ways – perhaps, mixing up the order of things, looking back or writing from the future. You might like to arrange your poem around the image you have chosen as a symbol of your sense of self. For example, when I did this exercise, I chose the symbol of an autumn tree and the poem I wrote initially appeared to be a simple poem about a tree until on closer inspection the theme of loss became clear.

WORKSHEET #5

RE-STORYING

Re-storying is one of my favourite writing activities. It involves taking the story of something that is not sitting well with you, and re-telling it in a way that brings you peace and comfort. It can be a powerful writing process. During *Placing Unheard Voices*, I met many people who were traumatised by their experiences of being diagnosed. Typically they had been diagnosed in a hurried or cold way, and were not offered adequate information or care at the time. The following exercise is based on re-storying a diagnosis experience, but you can apply it to any experience you'd like to re-story..

Exercise 5: Re-storying diagnosis and other experiences

Step one: To begin this exercise, write a brief description of how your diagnosis unfolded and why it was traumatic for you.

Step two: Write your diagnosis again, this time writing as if your diagnosis was everything you needed and wanted it to be, and left you feeling well cared for.

Step three: Write your diagnosis again, this time write as if you are reporting on someone else's diagnosis.

Step four: The three stories you have now written represent three different voices commenting on the experience of diagnosis. Cut and paste statements made by each voice into one poem by selecting sentences from each story. Don't think too much about the sentences you choose, follow your instinct and choose sentences quickly.

Step five: Read the new collaged story of diagnosis you have written. What is the message in this alternative story – add this message to the beginning or end of your poem.