

Living Well with Lymphedema

An occupational therapist's approach
to coping with psychosocial challenges
commonly seen with lymphedema

Lindsay Moore, OTS

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About the Author

I started working at the M.E.N.D clinic located in Maryville, Tennessee in October of 2014 as a therapy technician, which means I cleaned the treatment rooms, prepared clients for their treatment, and helped the therapists with anything they needed. At the time, we had physical therapists that treated lymphedema and some focused on wound care. We now have two nurse practitioners and a speech pathologist on our staff because our client's needs grew. I had never heard of lymphedema and I certainly didn't know how it was treated. But, the more time I spent talking with our clients, the more I learned about the challenges that everyone seemed to struggle with.

I started occupational therapy school in August of 2015 and brought with me to knowledge I gained while working at the M.E.N.D clinic. As an occupational therapy student, we are taught to not only focus on the physical impairment of the clients we help, but to also improve psychological and social well-being that is often affected by physical conditions. With the lymphedema population, I saw a place where occupational therapy could benefit the clients by providing interventions that address psychosocial challenges.

I created this workbook to empower individuals who have been affected by lymphedema by encouraging them to shift their thought process from "lymphedema is affecting me", and instead to think "I am affecting lymphedema". It is intended that the owner complete one activity per day in the order they are presented.

I would like to give a special thank you to Jil Smith for inspiring the activities included in this book. For similar activities, her book *A Perfect Fit* is available for purchase.

I hope you enjoy this workbook as much as I have enjoyed creating it for you. I wish you the best on your journey to recovery!

-Lindsay Moore, OTS

Doctor Directory

Name: _____ Name: _____
Phone: _____ Phone: _____
Specialty: _____ Specialty: _____
Address: _____ Address: _____

Name: _____ Name: _____
Phone: _____ Phone: _____
Specialty: _____ Specialty: _____
Address: _____ Address: _____

Name: _____ Name: _____
Phone: _____ Phone: _____
Specialty: _____ Specialty: _____
Address: _____ Address: _____

Name: _____ Name: _____
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Specialty: _____ Specialty: _____
Address: _____ Address: _____

Name: _____ Name: _____
Phone: _____ Phone: _____
Specialty: _____ Specialty: _____
Address: _____ Address: _____

Medication List

Medication: _____

Frequency: _____

Dose: _____

Medication: _____

Frequency: _____

Dose: _____

Medication: _____

Frequency: _____

Dose: _____

Medication: _____

Frequency: _____

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Medication: _____

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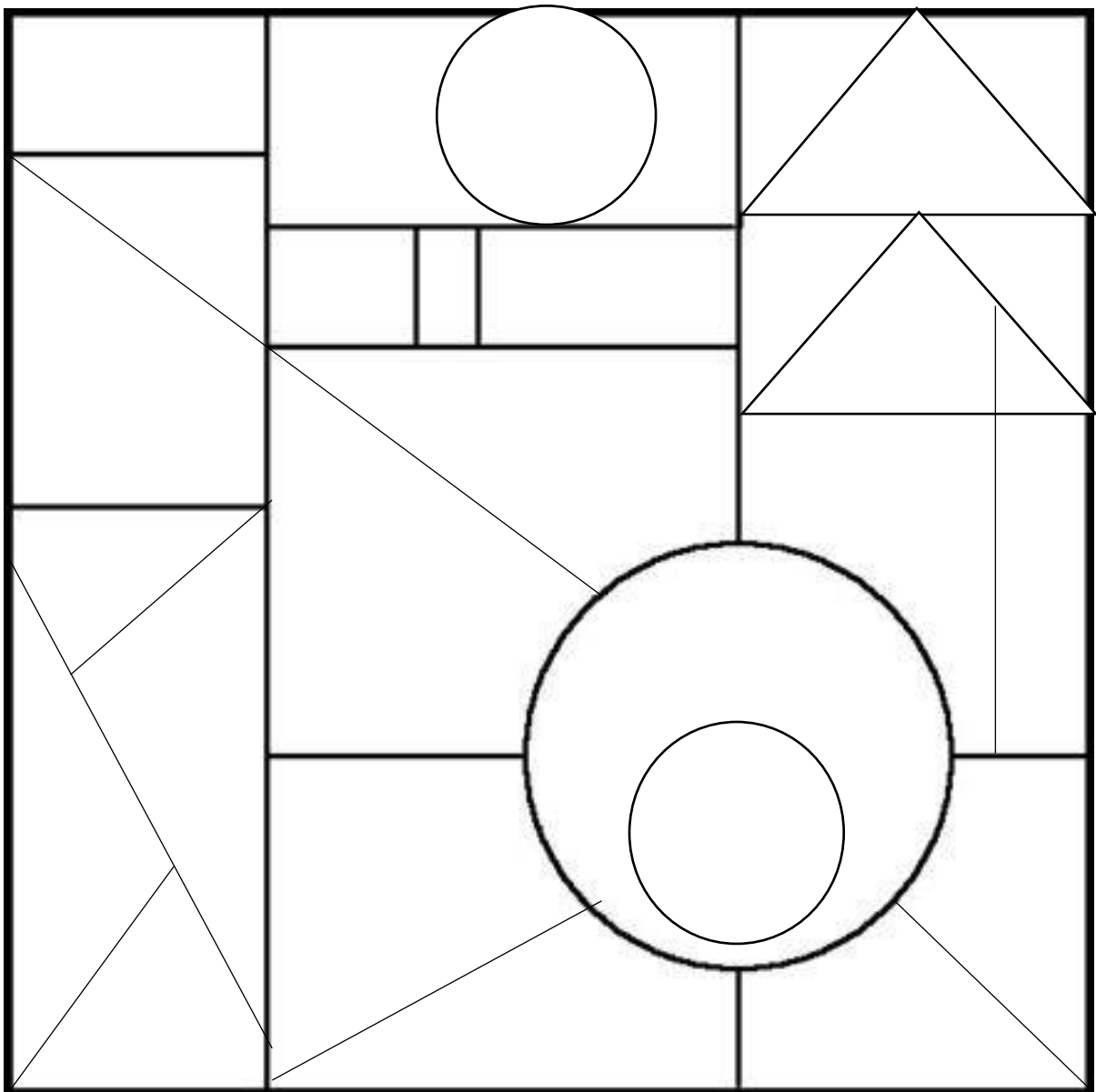
Medication: _____

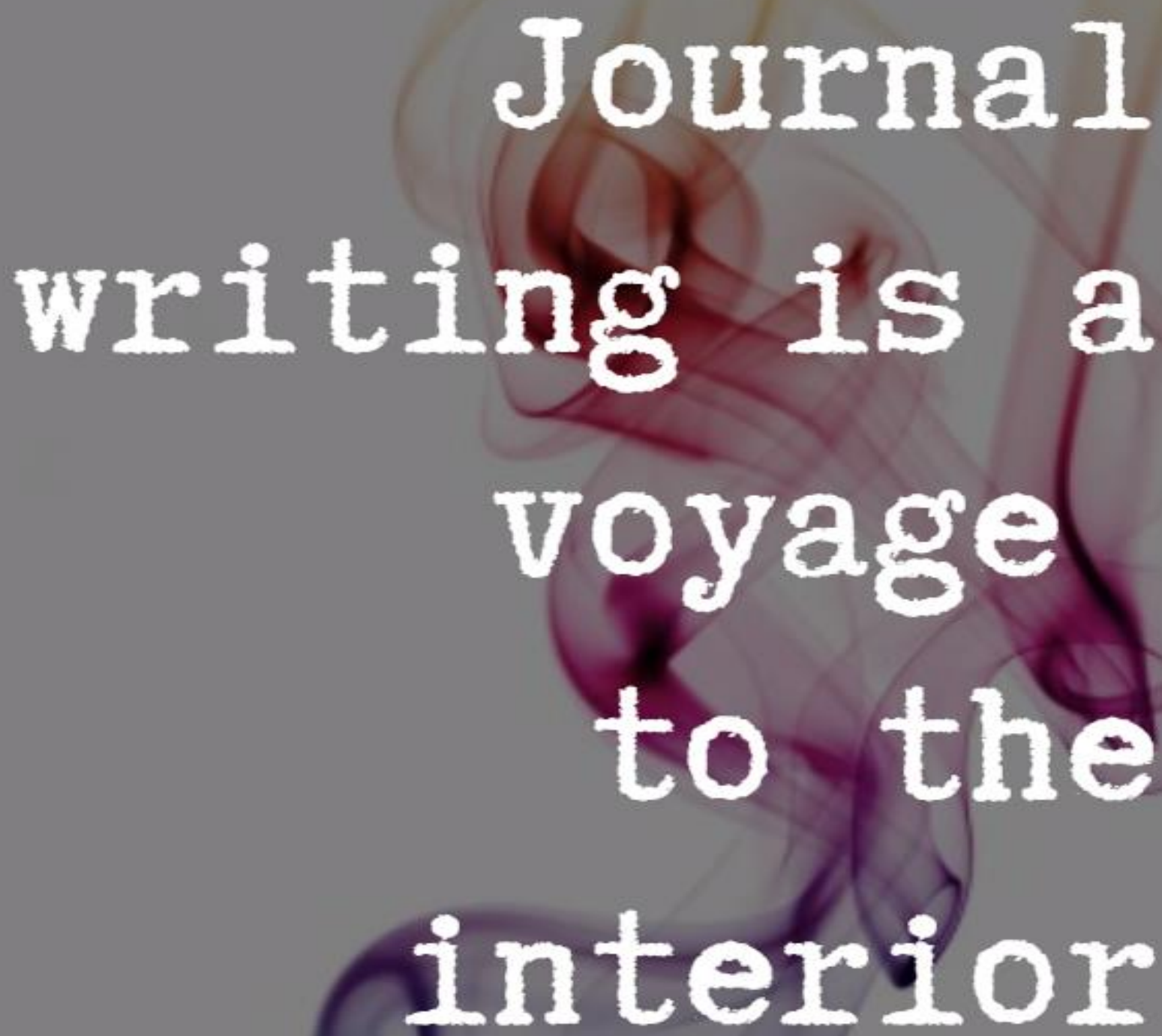
Frequency: _____

Dose: _____

Motivation Tracker

This is a creative way to keep track of the way you feel during lymphedema therapy. After each day, you will color in one piece of the design with a color that represents how you felt that day. There are 30 pieces in this design, each piece represents one day for a month. You will need marker, crayons, colored pencils, or hi-lighters. Another options would be to use patterns instead of colors (stripes, squiggles, polka-dots, checkerboard, etc.) Label each color or pattern with an emotion, for example, 'feeling great', 'could be better', 'a little discouraged, 'tomorrow will be better'. At the end of the month, you will have a visual representation of your emotional journey.



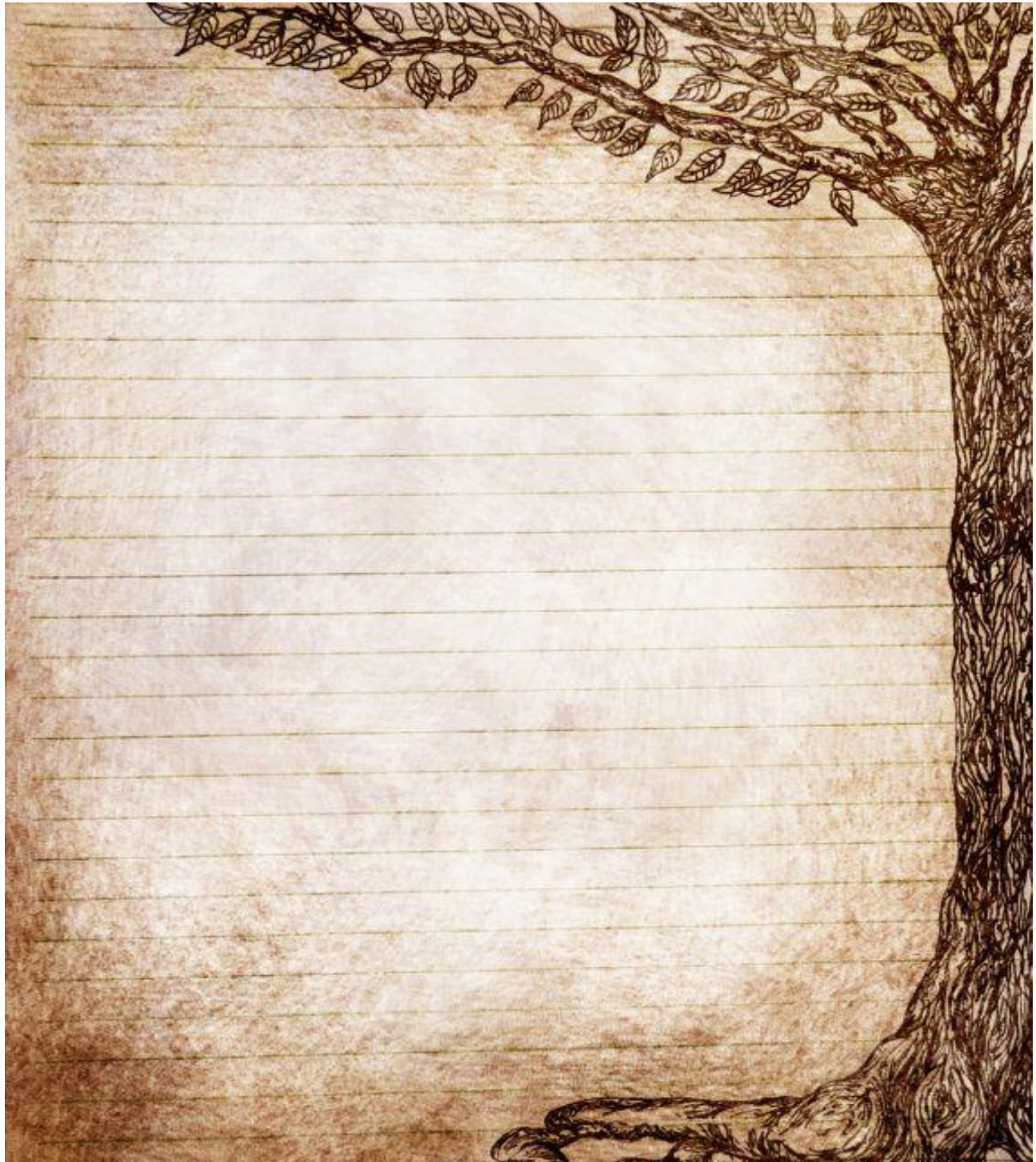


Journal
writing is a
voyage
to the
interior

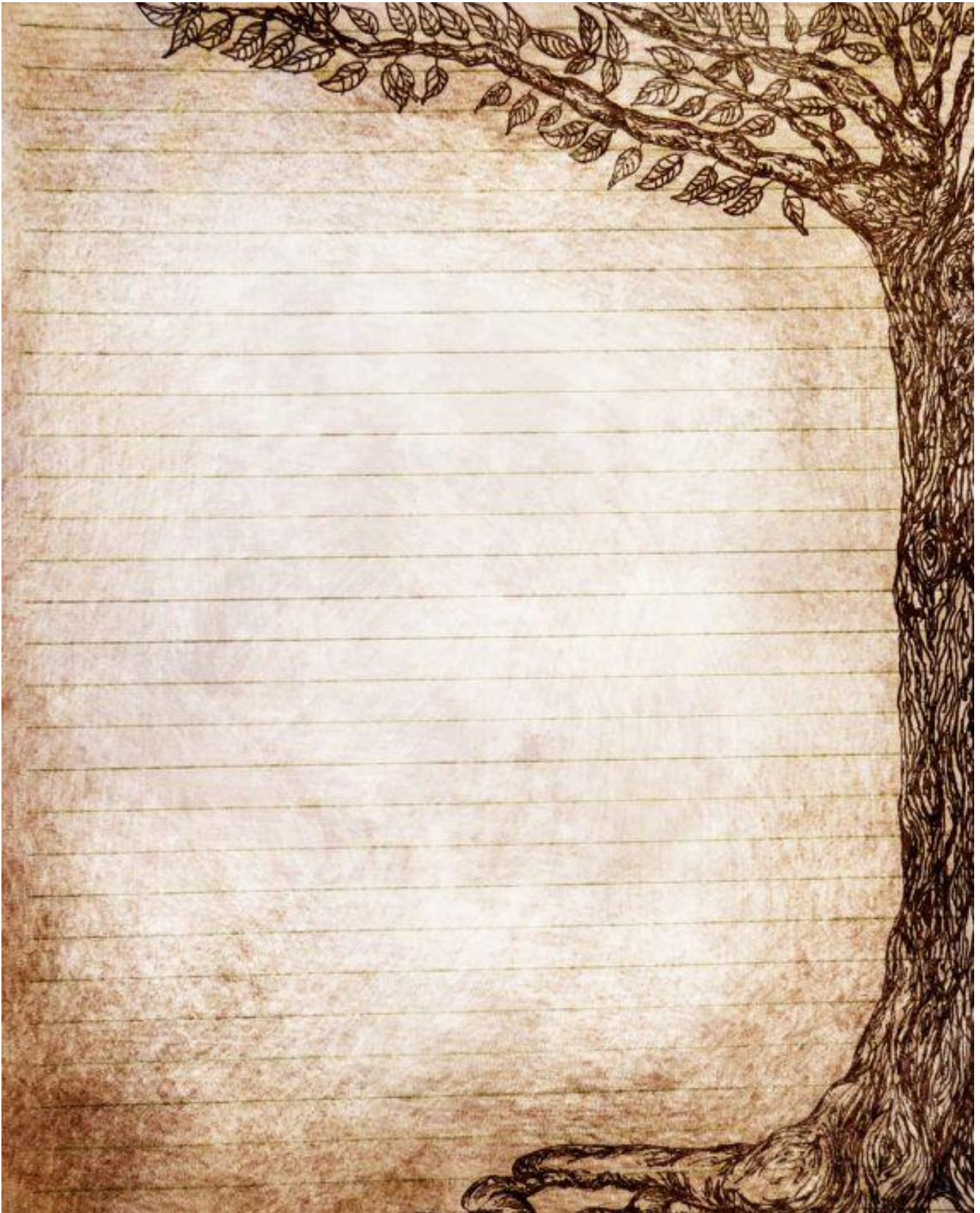
Christina Baldwin

Free Writing

For this activity, just start writing about whatever comes to mind, and do not stop for 10 minutes. Don't worry about spelling, grammar, punctuation, etc. Just write down what you are thinking. You can even start with something like 'I don't know why I'm doing this' or "I'm not sure what to say." It doesn't matter what you write about, just keep writing. You will be surprised where your mind goes.



Continued...



Consider These Things...

1. How did you feel when you first started writing?

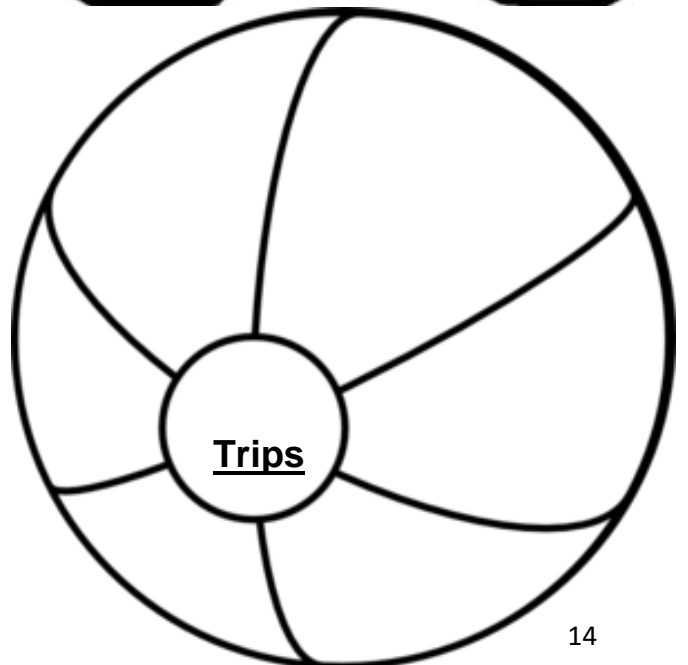
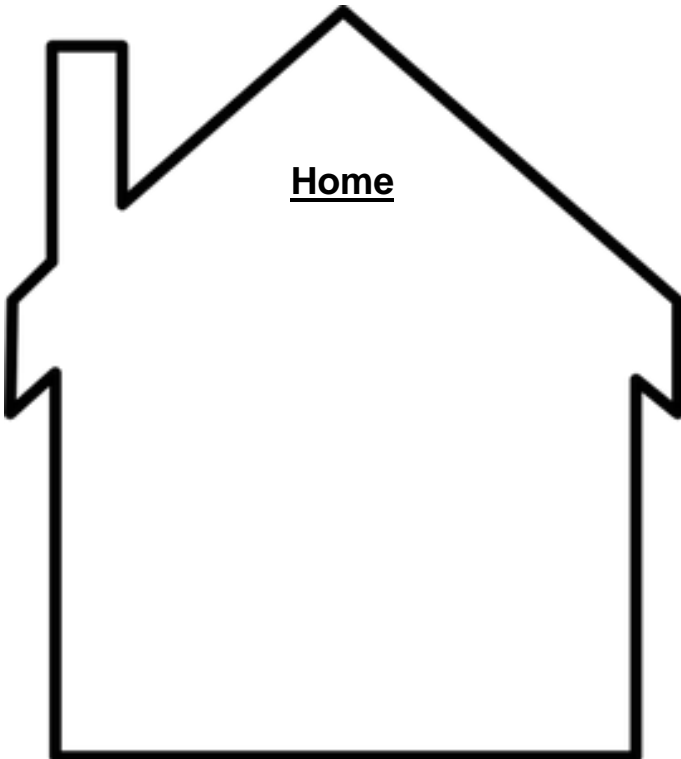
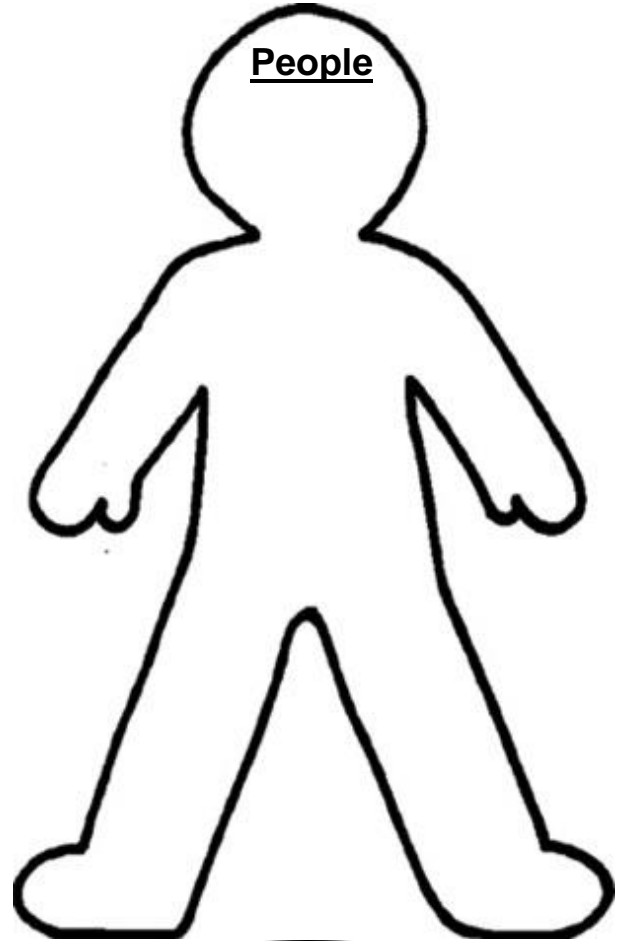
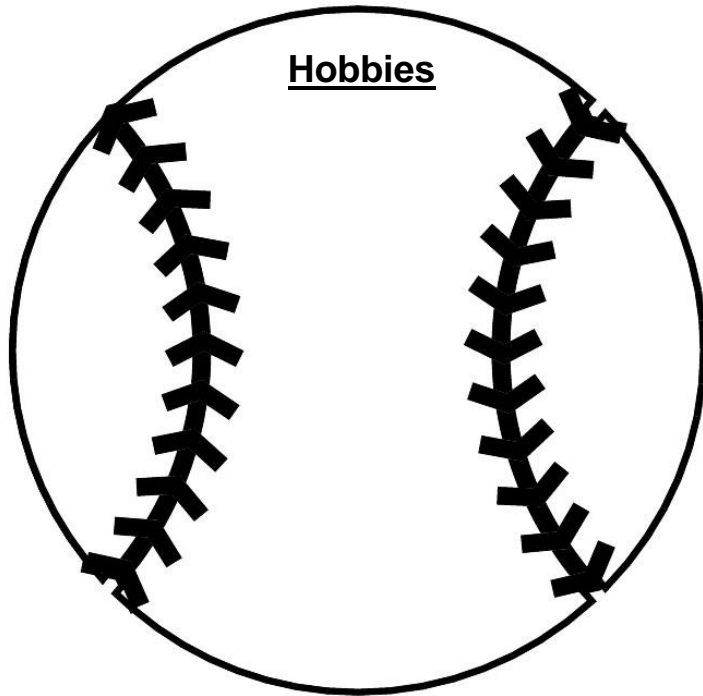
2. Were you surprised at what you started thinking about?

3. What did you expect to think about?

4. How did your feelings change throughout the activity?

Count Your Blessings

For each space provided, fill it with all the things you are thankful for that fall within that category. This is a great activity to do at the beginning or end of each day, it helps to keep in mind all the blessings you have in your life.



Reflection...

1. Was this activity easier or harder than you expected it to be? Why do you think that?

2. Do you think you will tell the people on the list that you are thankful for them? Why or why not?

3. How would it make you feel if someone told you that they are thankful for you?

4. What are some different ways that you could show someone that you care about them?

Time to Talk About Yourself

Answer the following questions about yourself from the point of view of your best friend.

This is my best friend _____ (your name)

1. He or she is the kind of person who enjoys doing:

a. _____

b. _____

c. _____

d. _____

2. Some of my favorite memories of my best friend are:

a. _____

b. _____

c. _____

d. _____

3. I admire my best friend because:

a. _____

b. _____

c. _____

d. _____

Let's Reflect...

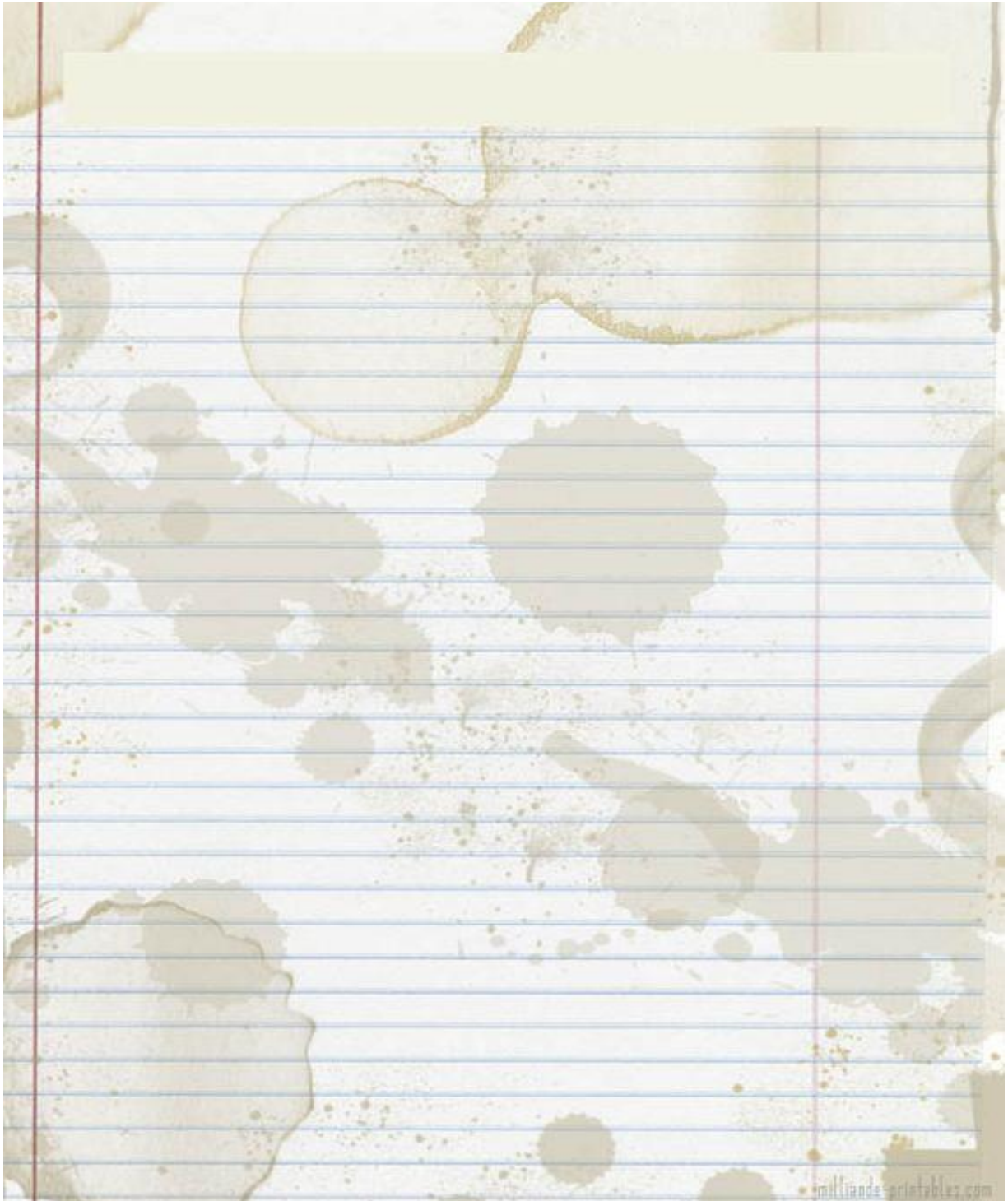
1. Was this activity easy or difficult for you to complete? Why?

2. Did changing the point of view have an effect on the way you see yourself?

3. How has your perception of yourself changed since developing lymphedema? Why do you think it has changed in this way?

Unsent Letters

Using the pages provided, write a letter to your lymphedema (or to cancer or a specific body part). Explain how it is affecting your emotions, why it is giving you trouble, or tell it how your life has changed. This is a very personal letter, so feel free to express how you truly feel.



Continued...



Reflection

1. How did your feelings change throughout writing the letter?

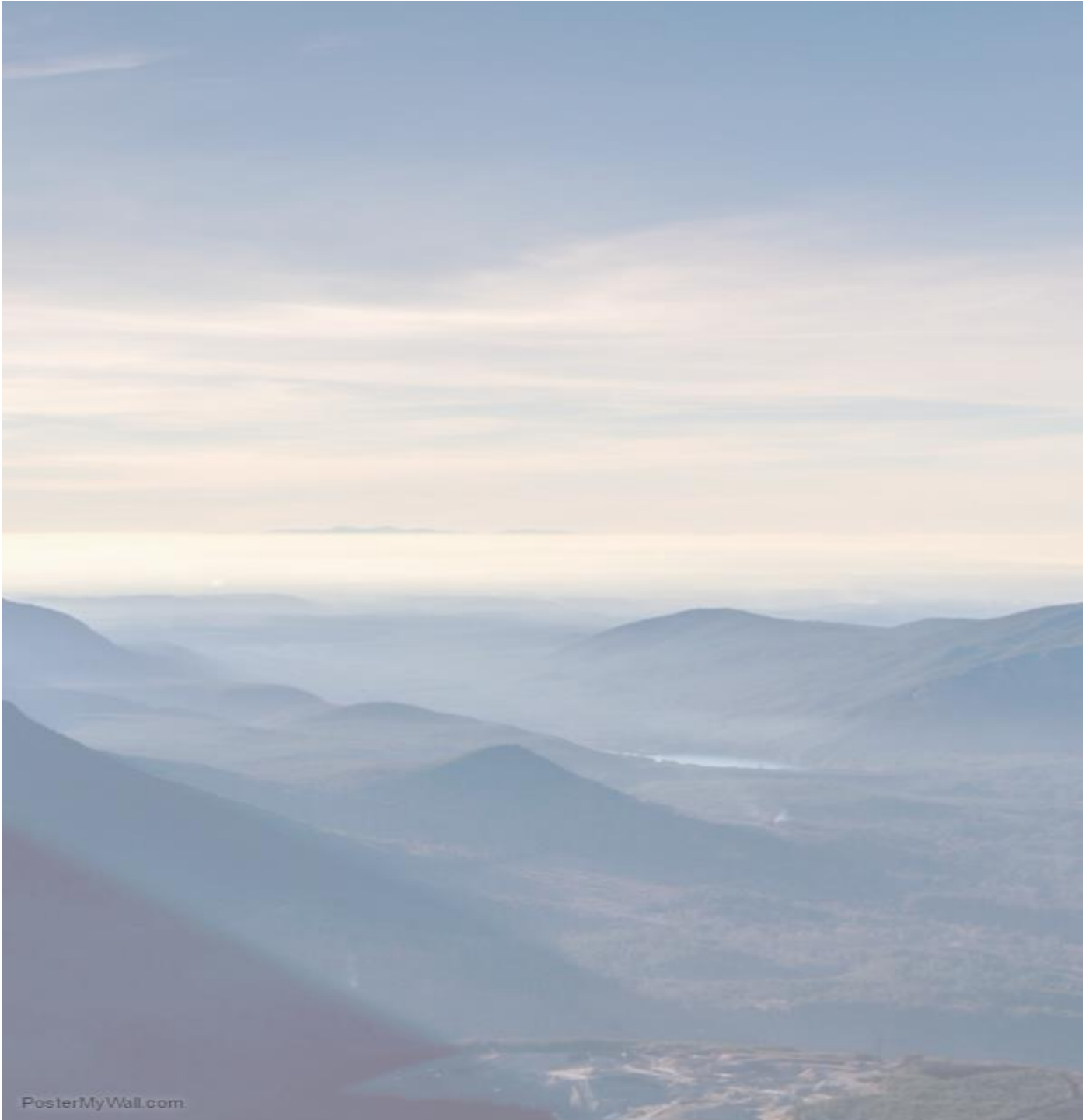
2. Were you surprised by any feelings that surfaced during this activity?

3. How did you feel after your letter was complete?

4. Why is it important to stay aware of your emotional state?

Ideal Place

Think of a place that you would like to visit. It can be a real or imaginary place. For example; a beach you have never been to, a cabin in the mountains, maybe a location from your favorite book or movie. Write a detailed description of that place using all of your senses (vision, smell, sound, taste and touch).



PosterMyWall.com

Consider This

1. How did it feel to use different senses (other than sight) to describe a location?

2. Why do you think it is important to be aware of all of your senses?

3. How would your life change if you lost one of your senses?

4. Which sense do you think is the most important to have while going through treatment for lymphedema? Why?

Finish the Sentence

Finish the sentence provided and be as descriptive as you can. Try not to duplicate answers.

1. I would describe myself as _____

2. Some of my hopes are _____

3. Some things that are important in my life now are _____

4. Some things that may become important to me are _____

5. Three things I am trying to achieve are _____

6. I feel confident when _____

7. I am proud of _____

Let's Reflect

1. Were you surprised by some of your answers? Why?

2. How has lymphedema affected the way you view yourself?

3. Which of the sentences was the most difficult to finish? Why?

4. .If you finished these sentences before you developed lymphedema, how would your answers be different?

CREATIVE WRITING

*The idea is to write so
people hear it and it slides
through the brain and goes
straight to the heart
- Maya Angelou*

*I can shake off
everything as I write; my
sorrows disappear, my
courage is reborn.
- Anne Frank*

Feelings Poem

Think of an emotion that you feel strongly that is related to lymphedema or the treatment for it. It can be a positive or negative emotion. Think for a few minutes about that emotion. There is one more outline so you can write more than just one poem if you choose to do so.

Line one: Name the feeling _____

Line two: What does it smell like? _____

Line three: What does it look like? _____

Line four: What color is it? _____

Line five: What does it feel like to touch? _____

Line six: What does it sound like? _____

Line seven: What does it taste like? _____

Line eight: Name the feeling again _____

Think About These Things

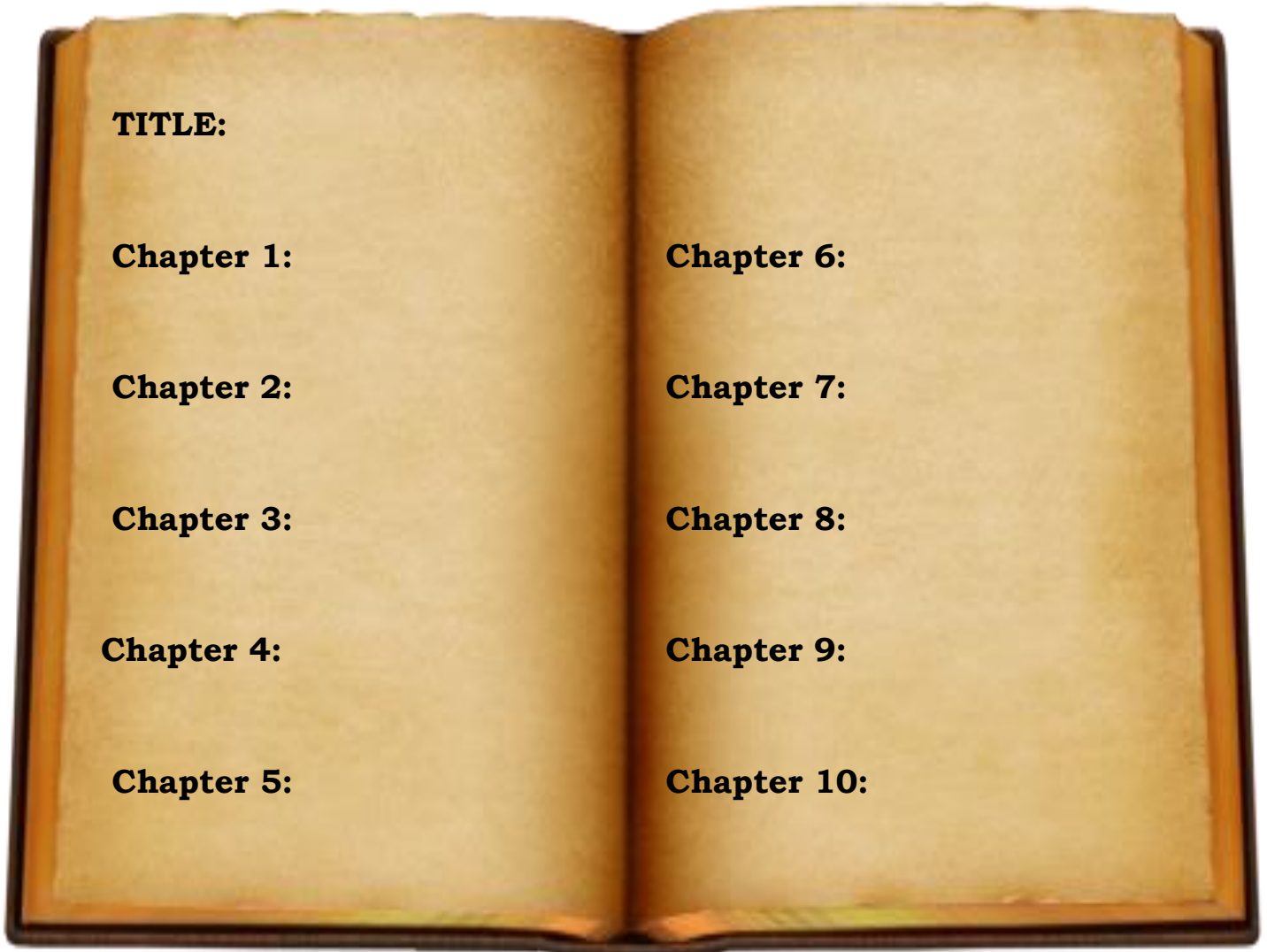
1. When are other times in your life that you have felt these emotions? How did you handle it then? Would you change anything about the way you reacted?

2. Has lymphedema treatment changed your normal emotional state? For example, has it made you angrier, more self-conscious, or depressed?

3. What has been the most challenging part of living with lymphedema? How are you handling the challenge?

Novel of My Life

How many types of books can you think of off the top of your head? There are so many different kinds; action, mystery, romance, adventure, fantasy and many more. Take a moment think about what kind of book your life would be and decide on a title. Then take a minute to think about how you want to divide your life story into sections. It can be by different ages, places you have lived, or by any other kind of experiences you have had. These sections will be the chapters in the novel of your life. In the spaces provided, write the title of your novel and the chapters you have decided on.



TITLE:

Chapter 1:

Chapter 2:

Chapter 3:

Chapter 4:

Chapter 5:

Chapter 6:

Chapter 7:

Chapter 8:

Chapter 9:

Chapter 10:

Consider the Following Questions

1. What type of novel did you decide best represented your life story? Why did you choose this type? What were some memories that surfaced during this activity?

2. What were some memories that surfaced during this activity?

3. Who would be some main characters in the novel of your life? How do they contribute to your unique story?

Life is Like a Box of Chocolates

Like the famous line from the movie *Forrest Gump*, Forrest uses an object to explain that you never know what you are going to get in this life. On the opposite page, there are comics, cartoons, pictures, and other various and random images. This activity involves using images to represent different emotions and experiences. Take a minute to look over all the images to see what is available, then come back to this page and use the images to fill in the following sentences.

1. For me, life is like _____ because _____
_____.

2. When I'm having a good day, I feel like _____ because _____
_____.

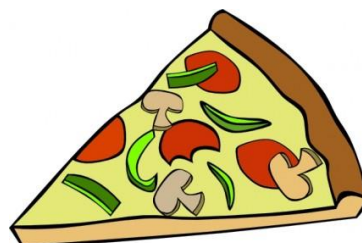
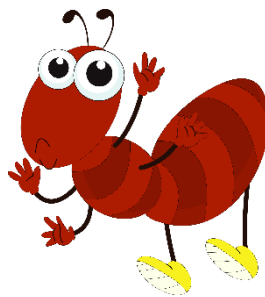
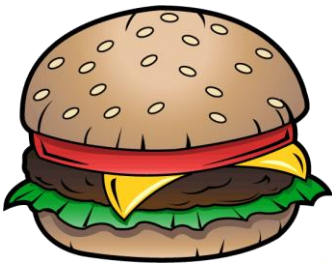
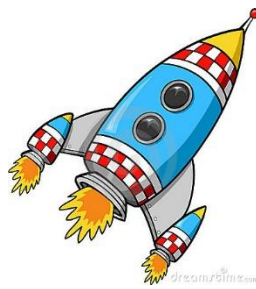
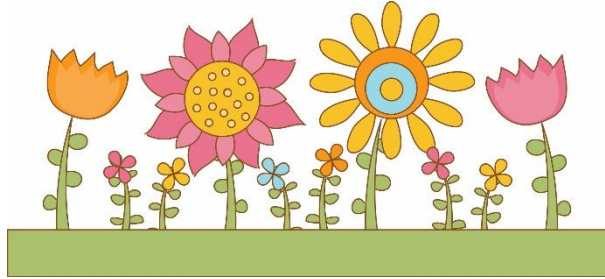
3. I see my challenges as _____ because _____
_____.

4. To me, my family and support system is like _____ because _____
_____.

5. Negative emotions are like _____ because they _____
_____.

6. When I found out I had lymphedema, it felt like _____ because _____
_____.

Life is Like a Box of Chocolates



Elevator Speech

Have you ever had an encounter where someone asked a question about your garment? Or a family member asks what lymphedema is? What was your answer?

Imagine you are in an elevator with someone you don't know. You only have about 30 seconds to explain what lymphedema is to someone who has never heard of it. By having a clearer understanding of the condition, it can help you take ownership over lymphedema and to feel like you are in control again.

If you don't have a clear understanding of what lymphedema is, you should ask your therapist to explain why the swelling occurs and the reasons for wearing your garment. When you have an understanding of lymphedema and the treatment for it, use the space below to write out how you would explain it to someone who has never experienced lymphedema.



Think About These Things

1. Did this exercise help you have a better understanding of what lymphedema is?

2. Did this activity answer any questions you may have had about lymphedema?

3. Do you think this will help you better explain to others what lymphedema is?

Sometimes expressive
arts is an ugly mess at

the end.
Full of carefully
articulated
emotions.



Mandalas

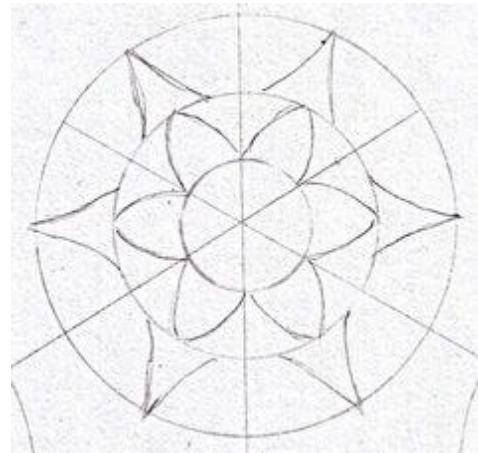
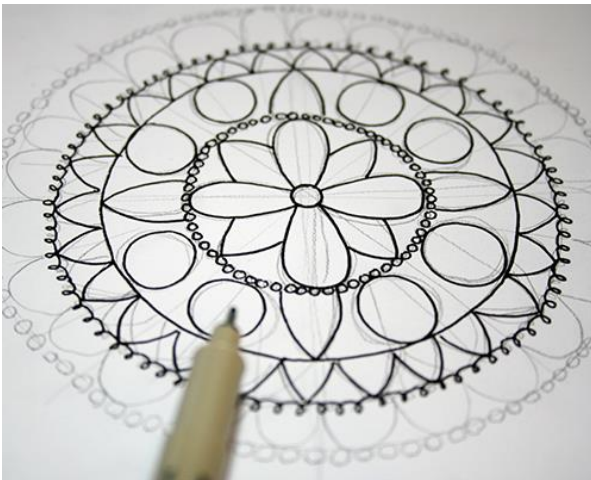
Mandalas (pronounced mon-dah-las) are circles that are filled with mirrored designs in each 'slice of the pie'. This activity is used to promote relaxation and meditation by repeating the same design over and over. While you are completing your mandala, think of a phrase or word and repeat it over and over, such as a meaningful bible verse or an encouraging phrase. Here are some example phrases to encourage you to think of your own.

-Breathe in the good, breathe out the bad

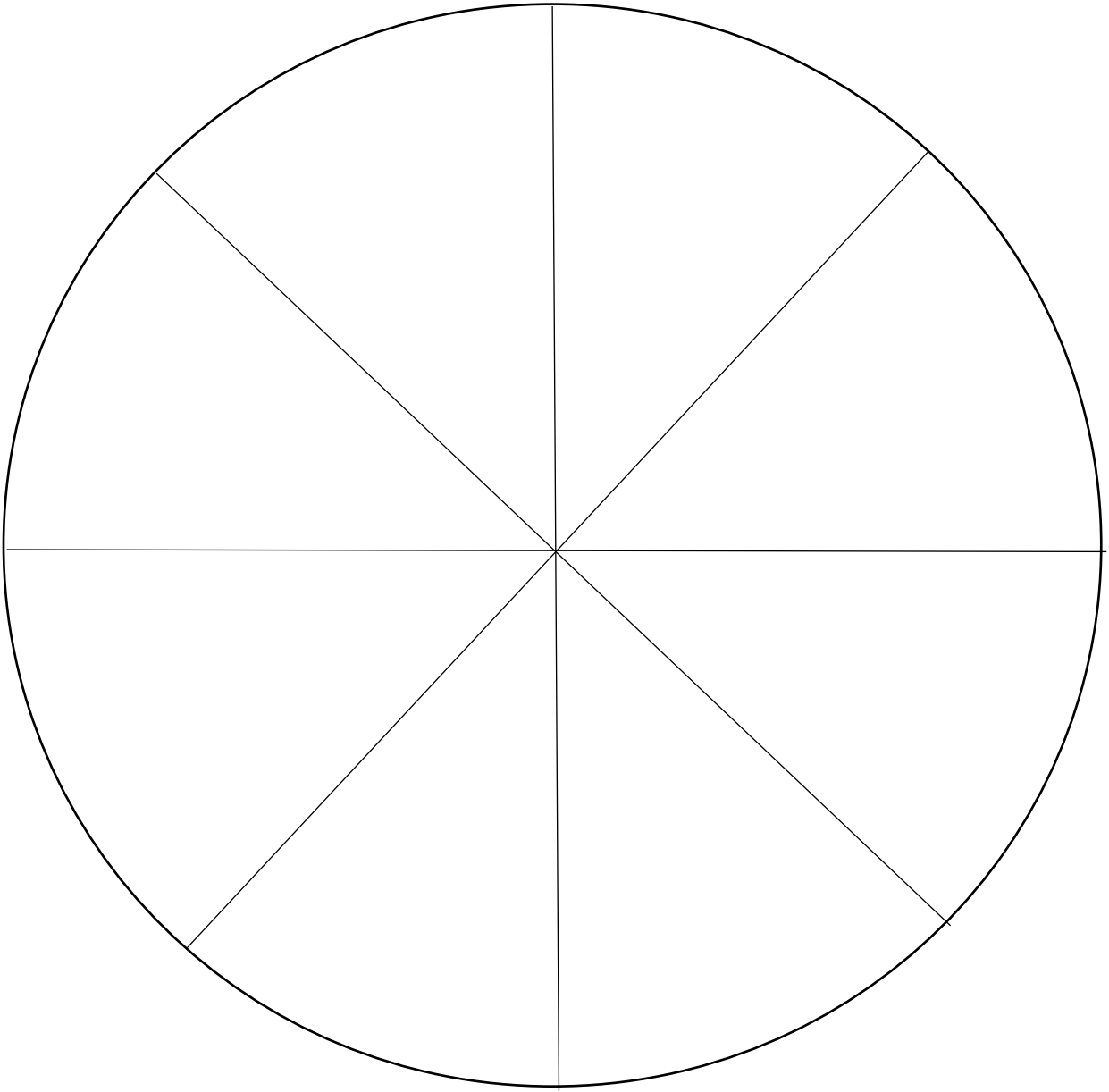
- Relax, enjoy, unwind

-Clear eyes and a full heart

The next page contains a simple outline for your mandala. For this activity, you will need a pencil, a ruler (or something with a straight edge such as a book). Feel free to color your mandala once you are finished.



Mandala Outline



Reflection

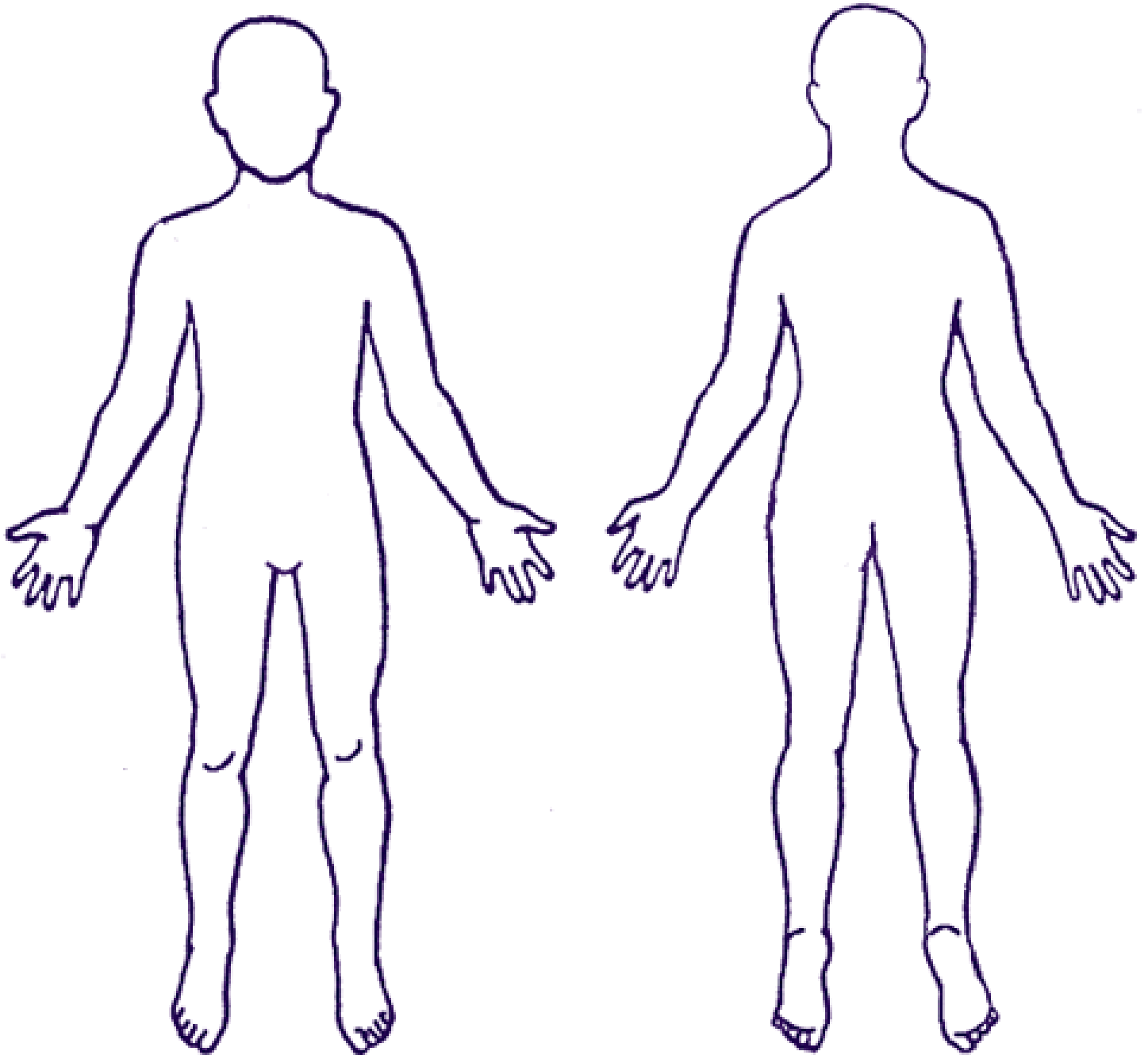
1. What are some things that cause you stress?

2. What did you meditate on during this activity?

3. How do you feel after you are finished designing your mandala?

Draw Your Pain

It can sometimes be difficult to explain what physical and emotional pain feels like to others who have never experienced it. Using the diagram below, illustrate how lymphedema feels to you and how it makes you feel. Is it red and burning? Does it make you feel a little yellow and uneasy? There is no right or wrong way to complete this exercise, it is only for you.



Reflect on This Activity

1. Which emotion was the most challenging to illustrate? Could you explain it better with words?

2. Did this activity make you aware of any sensations or emotions that you were unaware of?

3. Does the pain make it difficult to participate in any activities? Like grocery shopping, cleaning your house, or cooking?

Self Portrait

Use the space below to illustrate yourself before and after you developed lymphedema. But instead of drawing typical body parts, use objects to represent them. For example, a sun instead of a head to represent a bright outlook or a tree for an arm and its branches for fingers to represent the goals you want to reach. Be creative! You will need a pen or pencil to draw and feel free to use color if you wish!

<u>Before</u>	<u>After</u>

Consider the Following Questions

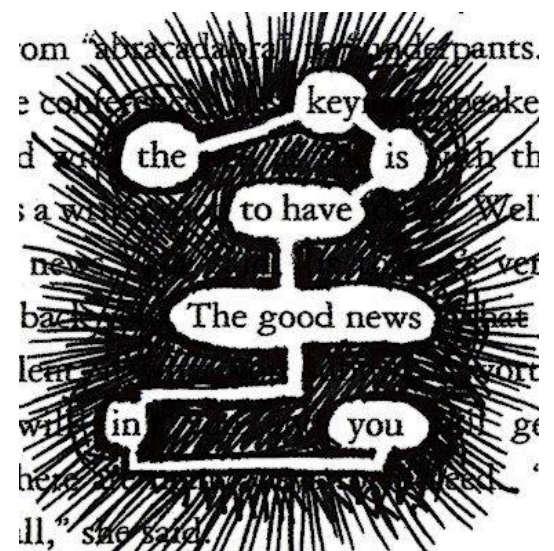
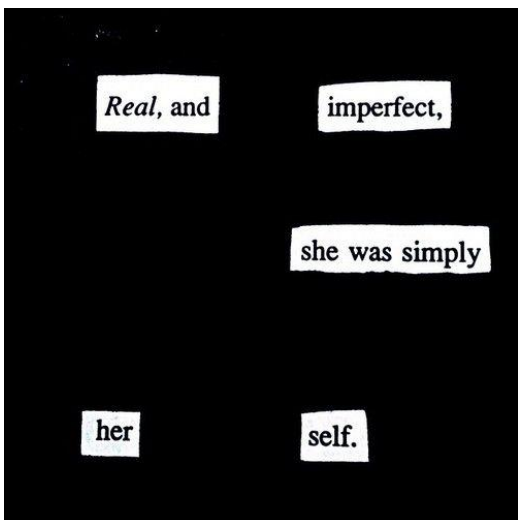
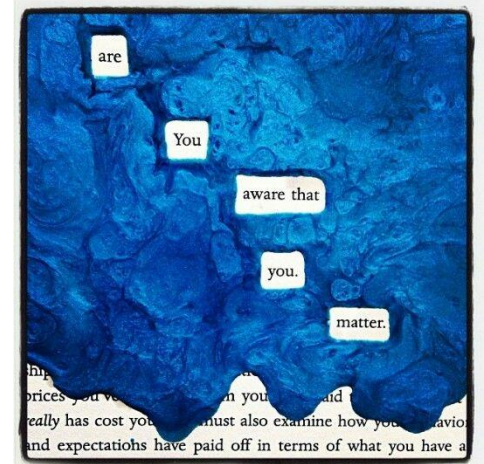
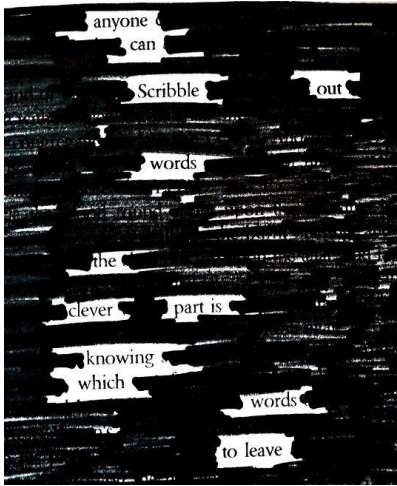
1. What are some main differences between the two drawings?

2. Which one your two 'selves' are you more proud of? The before or after? Why?

3. How has lymphedema affected the way you view yourself?

Blackout Poetry

For this activity, you will need a novel that you no longer have any use for. A great place to find used paperback books is a local secondhand shop, like a thrift store. Tear out a few pages and think about what kind of poem you want to “write.” Look through the page and find a few words or phrases you would like to keep and underline them. Then search the page for any smaller words (such as ‘the’, ‘and’, ‘they’, etc) you need to create your poem, and underline them. Using a marker, cover all of the words you do not want to keep and you will be left with your unique work of art.



Use this page to keep all of your poems by using glue, tape, or paper clips.

Consider This

1. What were some similarities in your poems?

2. Did this activity provide any new information about your feelings towards lymphedema?

3. Why do you think it is important to have a way of expressing difficult emotions?

Redesign Your Garment

When you have lymphedema, your garment becomes a part of you and can change the way you see yourself. Since you are wearing your garment during so much of your life, it should be something that you love. For this activity you will need a separate sheet of paper, a pencil, and possibly markers, crayons, or colored pencils. First, draw a rough outline of your garment. Then using a pencil, design your garment to look the way you want it to look. Use your imagination and creativity to design a garment just for you. After your design is complete, answer questions on the next page.

If you would like your design to be made into a one-of-a-kind garment just for you, please go to the Lymphedivas website at www.lymphedivas.com.



Images used with permission from Lymphedivas

Reflect on Your Design

1. How do you feel about your one of a kind garment?

2. How would you explain to another person what it's like to wear a garment every day?

3. How does your design represent you?

Lymphedema Treatment Act

Currently, Medicare and other private insurance providers do not cover the cost of the most important components of lymphedema treatment, the medically necessary compression garments that are used daily by individuals who live with lymphedema. As a result, many of these individuals cannot afford the compression supplies which can lead to infections, continued worsening of the condition, and eventual disability. Medicare cannot make this change, only congress can. The Lymphedema Treatment Act was first introduced to congress in 2010, and has continued to gain more and more support.

You can help by going to www.LymphedemaTreatmentAct.org and following the step-by-step directions located on the left hand side of the page.



Act Now to Pass
The Lymphedema Treatment Act