

Think about your life

Practical tools for
people on the cancer
journey

Acknowledgements

HSA produced this guide, based on the Think About Your Life website founded by Amanda George, cancer survivor. The content for the website and workbook was developed by cancer survivors from the UK, Australia, Canada and the US.

Thank you to the cancer survivors who allowed us to use their examples for this workbook and contributed to the ideas that inspired this publication.

- Linda Rowley
- Amanda Petersen
- Eleanor Attrill
- Jane Bayley
- Debbie Madison

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The guide is based on the person centred thinking tools developed by The Learning Community for Person Centred Practices. You can learn about person centred thinking tools from www.learningcommunity.us and www.helensandersonassociates.co.uk

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Introduction



I was 30 years old when I started my journey with breast cancer. I remember hearing those words "you have cancer" and my life was forever changed - mostly for the better.

There is no guide, website, doctor or book that tells you 'how to do cancer' or what the future holds. Each person is on his or her own Cancer Journey. As I was struggling through surgeries, chemotherapy and radiation treatment I began using the tools in this workbook to process my feelings and just 'get a grip' on what was happening to me.

I thought about my life - a lot. Using the tools at the discovery stage and all the way through the Cancer Journey helps you feel more in control, find hope, and be able to handle what cancer brings to your life. The tools in this workbook help you find *your* way through cancer.

Why this workbook?

The website www.thinkaboutyourlife.org website was developed by cancer survivors. We developed this workbook in response to requests for a paper version of the website for patients and people to use in a small group setting.

The tools helped us navigate our journeys with cancer and we want to share them with more people. Each 'tool' provides a structured way of thinking to help you take action - even the smallest action of smiling when you don't feel like it can make a difference in how you feel and perceive your experience.

You can find more tools, stories and examples on the website: www.thinkaboutyourlife.org/cancerjourneyhome.cfm

Amanda George

Amanda George
Founder of www.thinkaboutyourlife.org

How to use this workbook

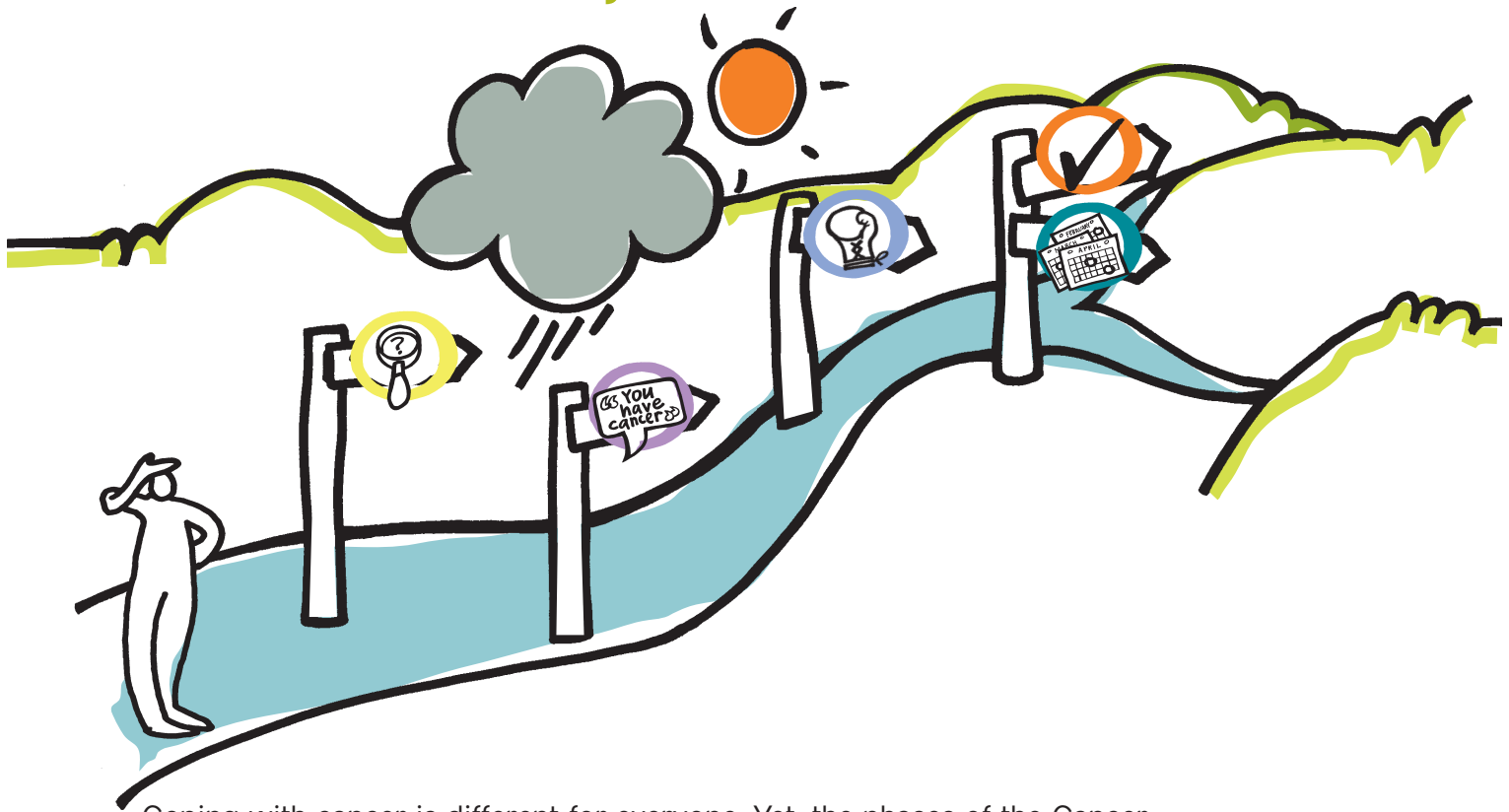
The Think About Your Life workbook can be used to help you think about and record your thoughts, feelings, needs, wants, hopes and fears, throughout the various stages of your Cancer Journey.

The Think About Your Life workbook can be used in different ways:

1. As a companion booklet to the website. The website has explanations of each Cancer Journey phase and a suggestion of which tools will help you depending on the issues you are facing. The website contains examples of tools and stories from cancer survivors and has tools we didn't include in this workbook.
2. At the various stages of the Cancer Journey. Use the tools to help you cope, find hope and resilience on your journey. You can fill this in yourself, with your family or friends.
3. Together with a small group of people with cancer - for instance at a cancer support group - to go through the tools.

Visit www.thinkaboutyourlife.org to find more tools, information, stories and examples. The website has the tools available online to complete. Register to use the website and save the tools you complete in your own confidential account.

The Cancer Journey



Coping with cancer is different for everyone. Yet, the phases of the Cancer Journey tend to be similar across all of our experiences. Each phase of your journey triggers changes in your life and perspective.

We believe there are several 'phases' or 'stops' along the Cancer Journey.



Discovery - Concern there is something wrong, waiting for results. Waiting can feel like torture.



Diagnosis - You hear the words "you have cancer." Stunned, angry, will I survive? Decisions about treatment. Telling other people you have cancer.



Treatment - Surgery, chemotherapy and/or radiation, medicine to fight cancer. Getting the help you need, managing treatment and work, family, slogging through cancer treatment.



New Normal - end of treatment - NOW WHAT? Will Cancer come back?



New Normal - living with cancer - Treatment is a way of life, quality of life and managing work and family responsibilities. Possibly planning for the end of your life.

The web links below provide more information about each stop on the Cancer Journey and suggest tools to use.

Discovery <http://www.thinkaboutyourlife.org/discovery.cfm>

Diagnosis <http://www.thinkaboutyourlife.org/diagnosis.cfm>

Treatment <http://www.thinkaboutyourlife.org/treatment.cfm>

New Normal – after treatment <http://www.thinkaboutyourlife.org/nn-free.cfm>

New Normal – living with cancer <http://www.thinkaboutyourlife.org/nn-cancer.cfm>

Survivorship Plan

If you have completed treatment for cancer, use the Think About Your Life Survivorship Plan. Simply click on the link to download from www.thinkaboutyourlife.org

Practical tools to use on the Cancer Journey

Listed below are the tools we (cancer survivors) have used to help us cope with the various stages of cancer.

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Good Days and Bad Days

Dealing with cancer is often described as a rollercoaster of experiences and emotions. Being down and feeling overwhelmed can change rapidly to appreciation when you receive a card from a friend that makes you laugh until you cry.

The focus of this tool is finding ways to cope to get through the bad days while trying to have more good days. Sharing this with friends and family can help them know how to support you through the ups and downs of the Cancer Journey.

The 'next steps', are where you think about what you have to do to achieve more good days and less bad days.

This is an example of using the tool when Amanda was going through chemo. She wanted to make the experience more manageable and less awful.

good days

No Chemo today!
No nausea today!
Go to work for half a day - feel productive and stay connected to friends.
Sit outside in the sun for an hour.
Do a little shopping.
Go out to eat - food tastes good!
Bed early after a hot shower.

bad days

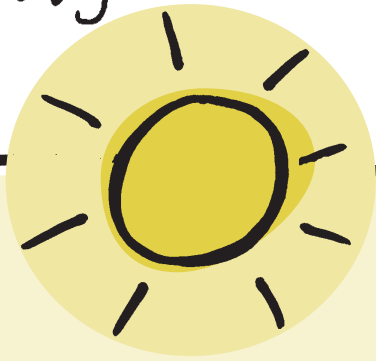
Chemo day...scared about nausea and how long it will last this time? will I have to go the hospital again?
Long wait at the cancer centre.
My favourite nurse isn't working.
Rainy cold day - depressing while at cancer centre all day.
My husband couldn't stay at home with me after chemo - I am alone at home and scared.

next steps...

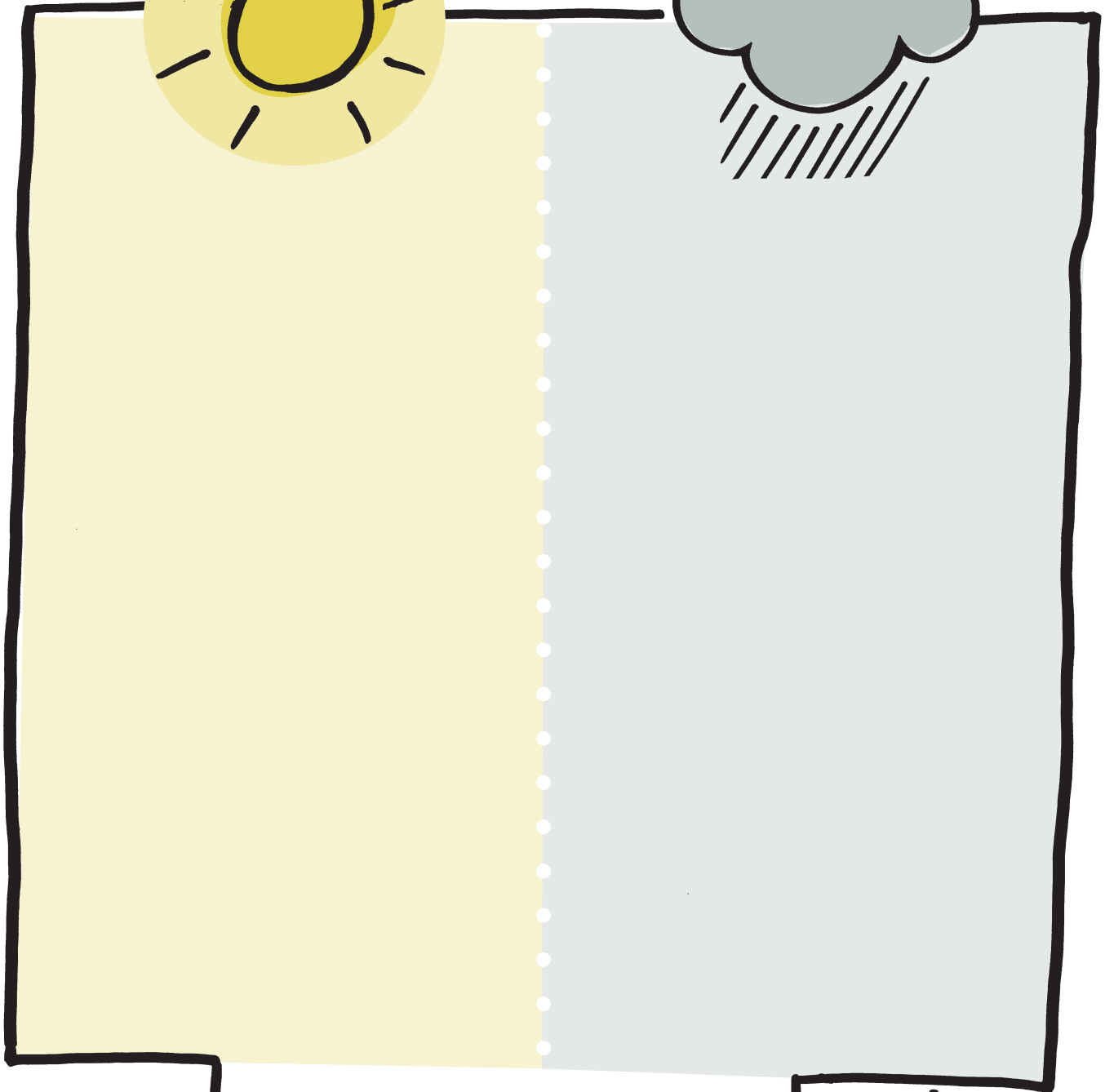
1. Schedule chemo according to my favorite nurse's schedule; request her each time.
2. Have friend hang out with me after chemo to keep my mind off things.

→

good days



bad days



next steps...



Working and Not Working

Frustration, fatigue and financial problems are all reasons to use the Working and Not Working tool. Using this tool helps you to stop and think. The Working and Not Working tool may not solve the entire issue or problem, but will give you something to try and provide clarity.

Below, Debbie identifies what's working and what's not working around her leg healing. For 'next steps' she determined she wanted to do resolve her concerns and keep healing.

working

Being unemployed is allowing me to pay attention to my ankle and leg and notice when it starts swelling and get it elevated.

Having the flexibility to move about and not sit 8 hours at a desk has been beneficial.

My Physical Therapist told me walking would help keep the swelling down but I haven't made it a habit yet.

not working

When I sit at a desk several hours, my ankle and leg swell and itch.

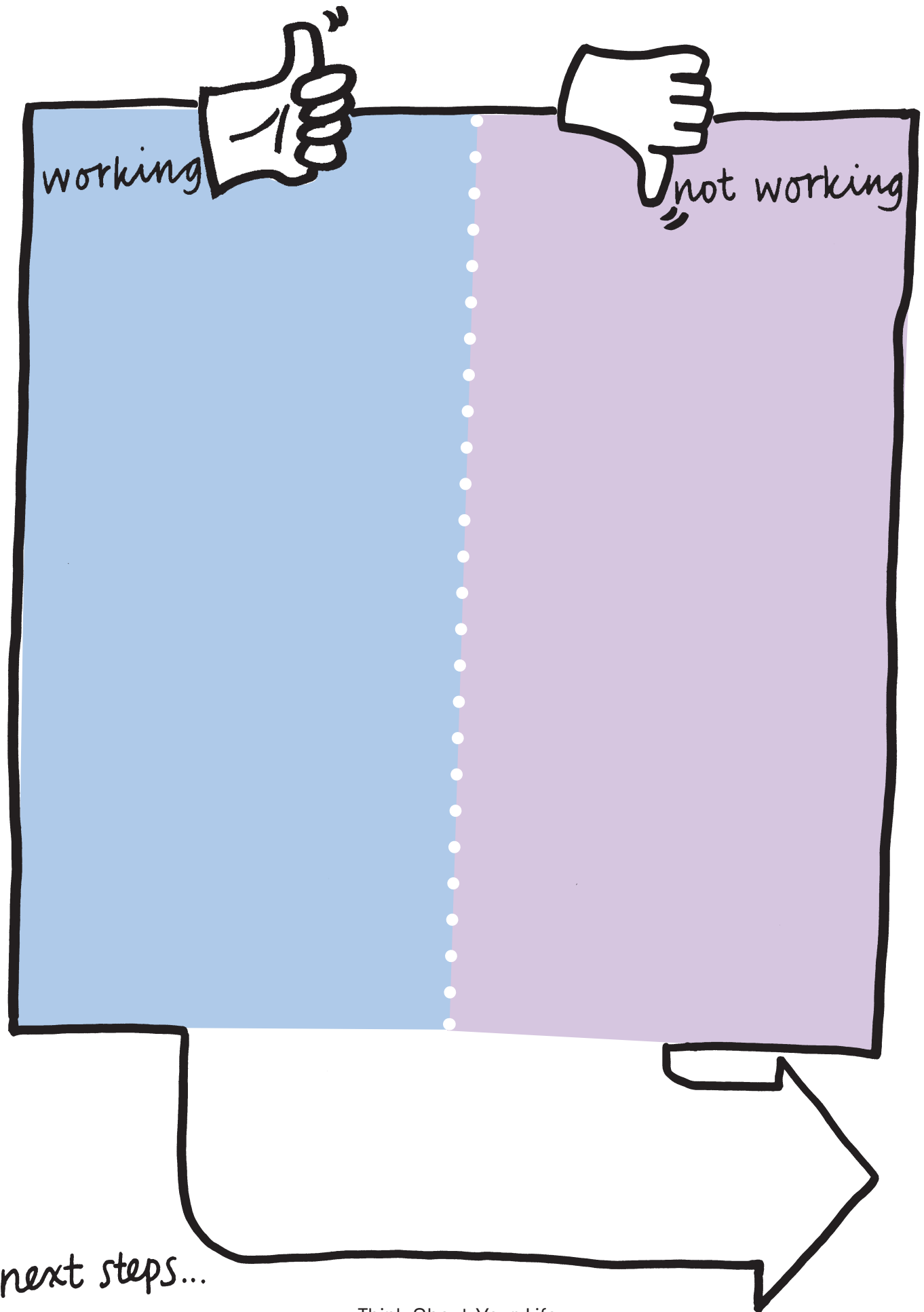
I need to exercise (walk) more. I have not yet made it a habit (but i will).

The scar tissue on the bottom of my foot is bothersome. It feels tough and dry and stretched. It is a constant reminder. I don't have insurance now and have not followed up with dermatologist.

next steps...

I resolve to walk 3 times weekly starting Monday 7/26/10.

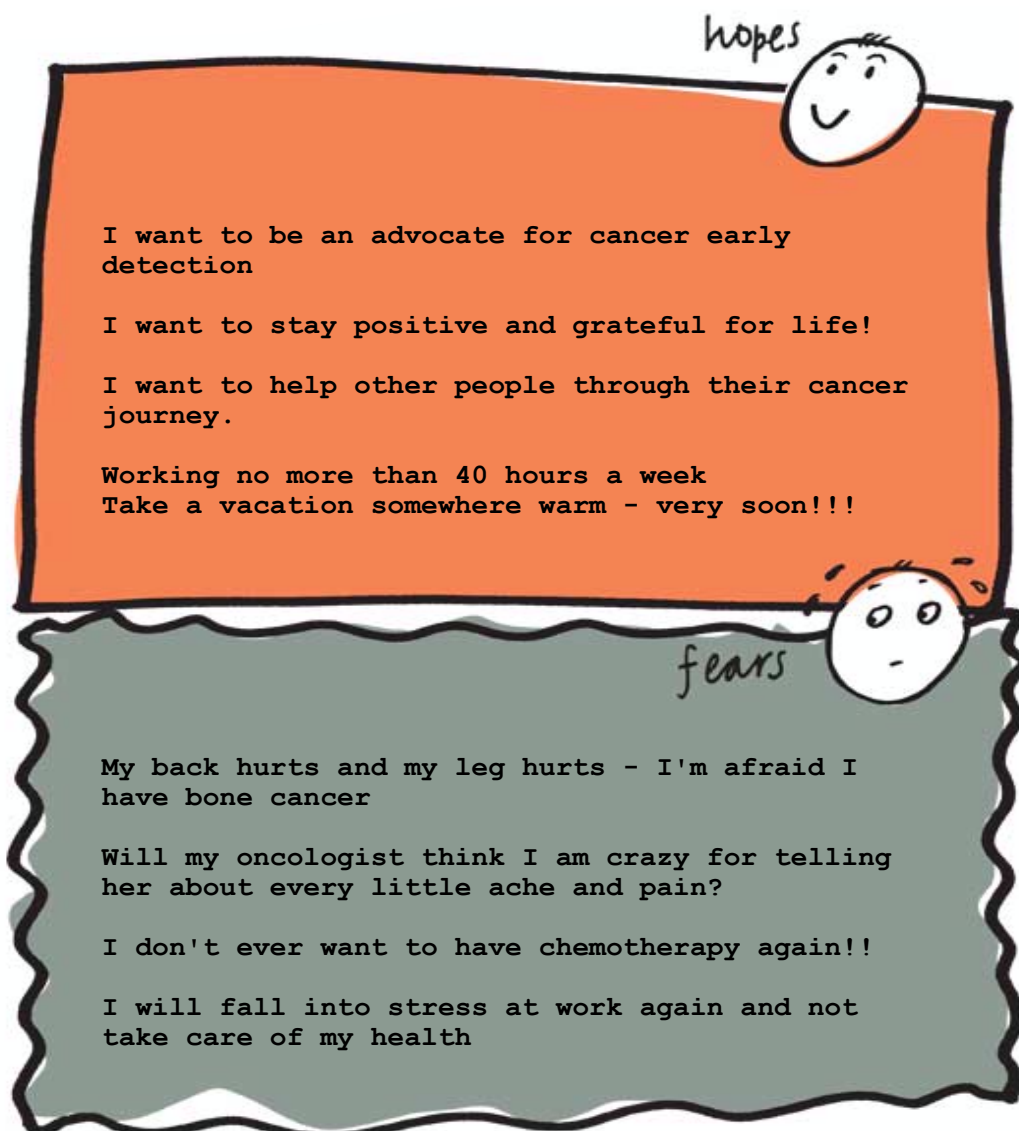
I need to make an appt at the free clinic & see if I can get a referral to a dermatologist.



What are my Hopes and Fears?

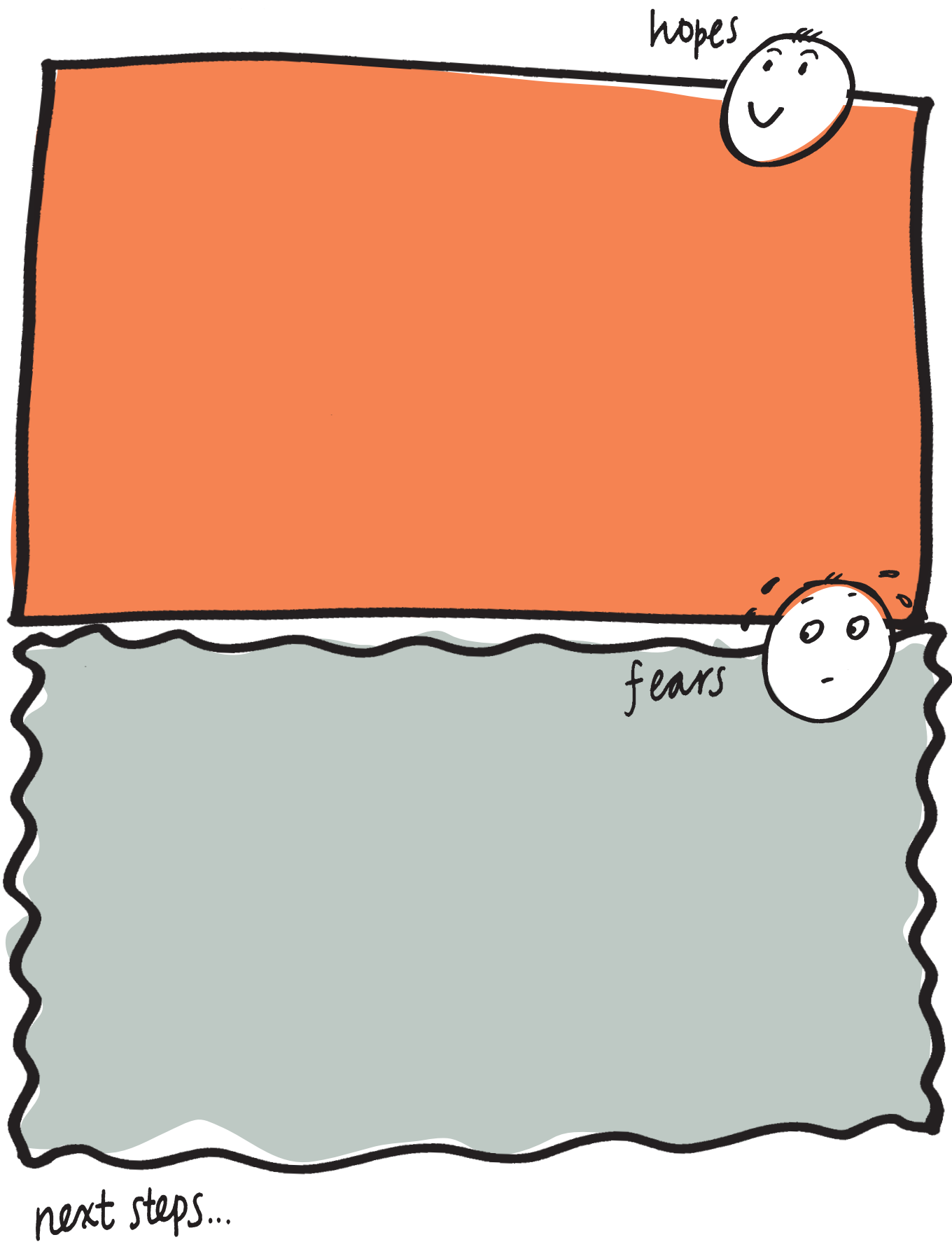
Often people experience uncertainty at each stage throughout the Cancer Journey. The lingering question of "what will happen to me?" brings up lots of hopes and fears. Although it may seem impossible, it will help if you are able to find things that bring a sense of hope for each day and the future. Once we face our fears in writing they may not seem so terrifying.

Amanda shares her hopes and fears after finishing treatment and entering the new normal phase of the Cancer Journey.



next steps

Call my oncologist and tell them about my pain - what is the worst that can happen?



Matching Support

Figuring out what you need from the people who want to help you is part of gaining control over your cancer experience. This tool helps you sort out what you need and who would be the best match.

Relationship List: List the people in all areas of your life; friends, family, co-workers and paid professionals, who have the capacity to support you. This is your list of people to call or email when you need help (grocery shopping, babysitting, lawn mowing etc.).

Use the space on the next page to list the help you need. Match specific people on your relationship list with something they would enjoy. Then, think about who can you call or email right now to get the help you would like.

Debbie used this tool after having surgery to remove lymph nodes in her leg to treat melanoma.

Skills needed

- Monitor pain meds
- Monitor drain tube and bandage
- Help positioning me
- Help moving about
- Help bathing
- Preparing meals
- Follow up visits to doctor

Support needed + wanted

- Family - wanted them there
- Mobility
- Meals
- Bathing
- Household chores
- Improvement, I wanted to do for myself

personality characteristics needed

Someone understanding, willing to do for me but assist when I want to do for myself. Someone who will leave me alone to rest, do for me when needed, assist me when desired

shared common interests

My helpers were family and girlfriends so we had common interests from the start.

THINK ABOUT YOUR LIFE



Communication Chart

A lot of how we talk and communicate with each other happens below the surface of our words, and sometimes the words we use do not really tell the entire story. The Communication Chart can help take some of the guesswork out of your actions and moods to let your family, friends and co-workers know how best to support you.

Eleanor used the Communication Chart whilst going through chemotherapy. It helped her family and friends know how to support her during this difficult time.

<i>At this time</i>	<i>When I say or do</i>	<i>It means</i>	<i>And I want you to</i>
<i>Anytime – just before my treatment or afterwards on the phone or in person.</i>	<i>When my answers are short or I seem a bit abrupt.</i>	<i>I don't want to talk about something or I am finding it difficult.</i>	<i>Acknowledge that I don't want to talk about it and/or end the call! Texts are good or I will ring you.</i>
<i>Anytime – during three week cycle (particularly at the first weekend).</i>	<i>I am complaining, banging about, ranting or shouting at kids.</i>	<i>I am tired and fed up.</i>	<i>Acknowledge it and ask what you can do. Going for a walk on my own really helps so if you can be here for the kids that's great.</i>
<i>Anytime during three week cycle (particularly before the treatment i.e. Sunday).</i>	<i>I go quiet and don't want to talk.</i>	<i>I am thinking about something or am worried, anxious or sad.</i>	<i>Ask if I want to talk, or what you can do. Going for a walk on my own is good or I may want to talk.</i>
<i>Anytime.</i>	<i>I cry.</i>	<i>I must be feeling really bad and overwhelmed.</i>	<i>Don't try and fix it, let me be and, if I know you well, a hug may help.</i>
<i>Anytime.</i>	<i>You ask to visit and I hesitate.</i>	<i>It probably means I want to say no because I'm tired.</i>	<i>Acknowledge this and make another time (I struggle to say no).</i>
<i>Anytime.</i>	<i>You ask to visit and I say 'Yes!'</i>	<i>It means I want to see you (I can be very decisive).</i>	<i>Come and see me!!</i>

At this time...	When I do this...	It means...	I need you to...

next steps...

4+1 Questions

The 4+1 Questions tool is a helpful way to process your efforts and develop new ideas for potential solutions. It is especially helpful if you are struggling to find a next step to resolve an issue with cancer treatment or survivorship.

The first thing you want to do is select an area or issue for focus. Then list your responses to the four questions outlined in the template on the next page. By processing through writing, it is easier to figure out the next steps to resolve the issue. Amanda shares her 4+1 below. She is in the survivorship phase of her journey and wants to be healthier to make it more likely she stays cancer free.

tried?

- Working only 8 hours and taking a lunch.
- Packing healthy lunch and avoiding fastfood.
- Walking after work every day.
- Joined Curves.
- Yoga.
- Taking vitamins.

learned?

Neck injury put all exercise on hold except physical therapy. Physical therapy didn't provide "cardio" workout.

If I walk after work, I don't get to be with family until 6:30. Miss dinner and family time before Steve goes to bed.

Healthy lunch works and helps me avoid fastfood!

Vitamins - most upset my stomach - except gummies.

pleased about?

- One thing has worked! Spend less money on lunch and eat healthier.
- Found a vitamin I can take that doesn't hurt my stomach.

concerned about?

EXERCISE!
Finding something I can do regularly that doesn't cut into family time.

do next?

- I could do a quick exercise video in the mornings.
- I want to add meditation to my morning routine

tried?

learned?

pleased about?

concerned about?

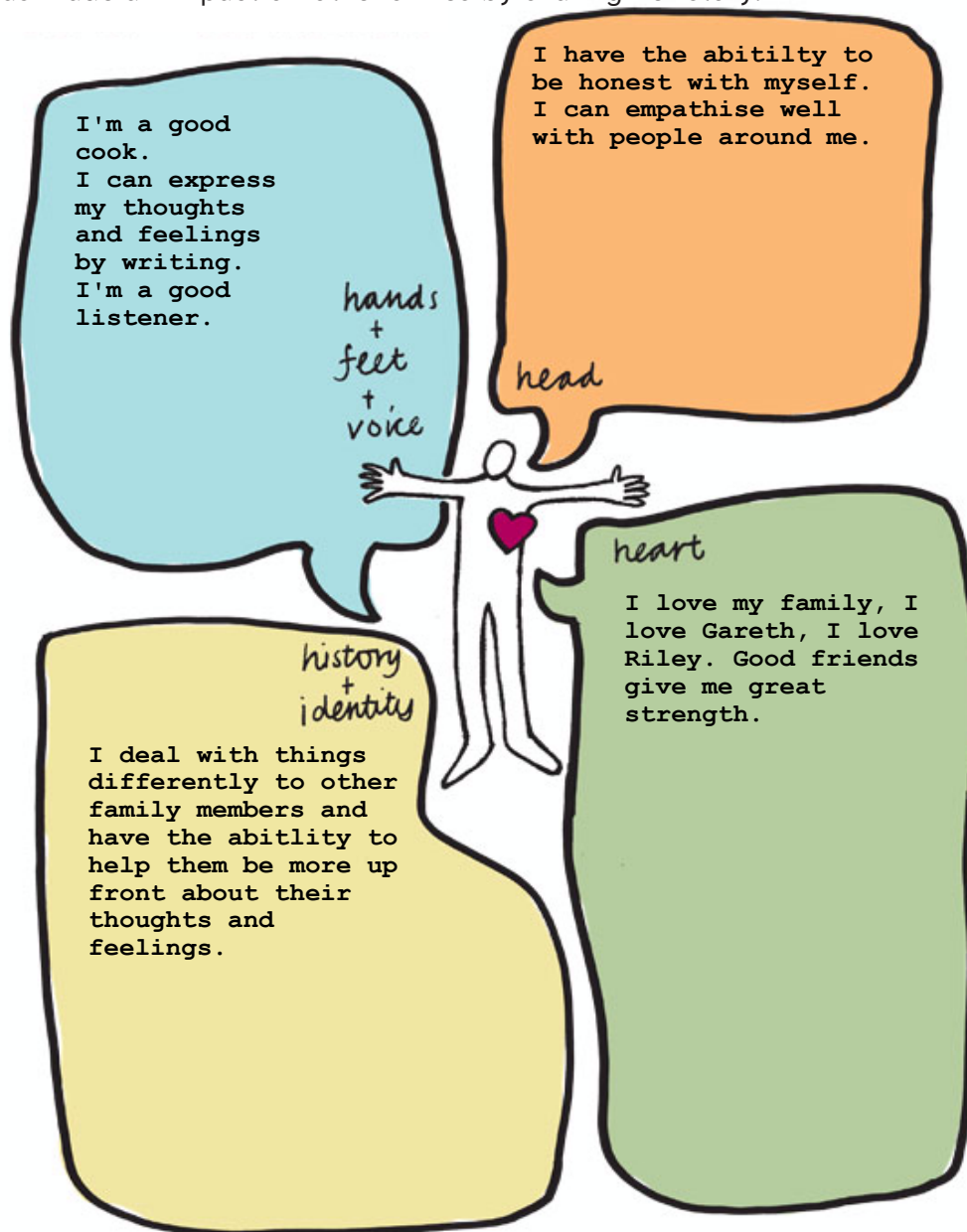
do next?

Strengths, Gifts and Capacities

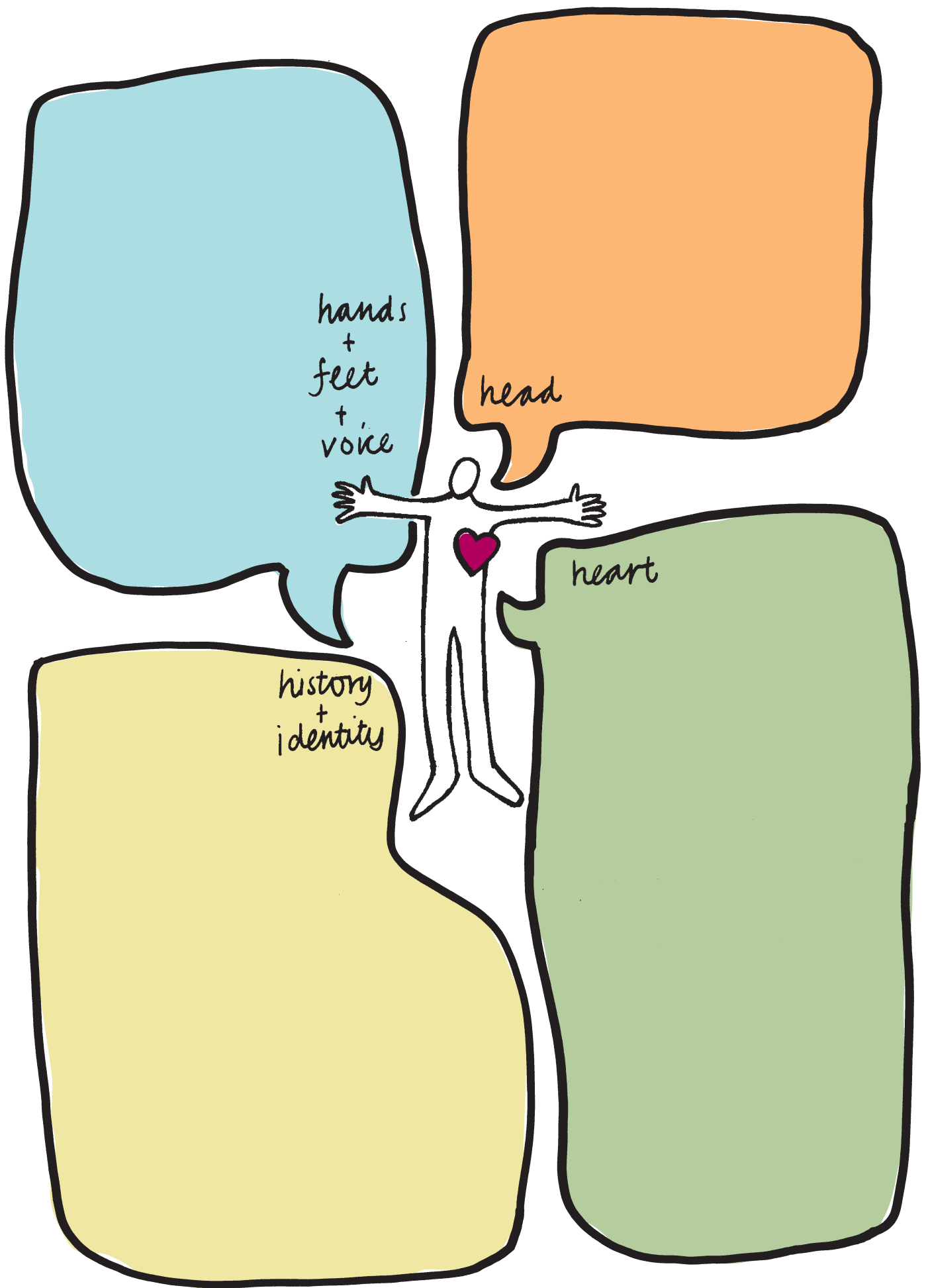
During and after a cancer experience, it is not unusual for people to lose confidence and faith in their ability to do the things they did prior to their diagnosis. The Strengths, Gifts and Capacities tool can help you discover, or rediscover, your unique qualities now that you have experienced cancer.

Think about a time you made a positive difference in someone else's life that made you feel good about yourself and your place in the world. Think back to the situations and activities which made you feel invigorated, energised and buzzing. What are those? List by gifts of the mind, hands, feet, heart and identity.

Jane shares her example below. She reflects on her cancer experience and realises she has made an impact on other's lives by sharing her story.



Learned:
I have an inner strength I never thought I could have.
I can effectively communicate my needs to those around me.
My writing has helped at least 2 people that I know of to go and have a smear.



Think About Your Life

Dreams

When you are diagnosed with cancer, dreams you have for yourself may shift dramatically. This is not necessarily a bad thing! A cancer diagnosis can be the jump start to making changes in your life. For some people, it opens up opportunities to reassess and re-focus their life.

The Hopes and Dreams tool can be for the next week, the next month, the next year, or the next five years. When you identify your dreams and describe them to people around you, your way forward will become clear, and it will be easier to make the decisions to come.

Jane shares her hopes and dreams for the future as she finishes treatment.



Think About Your Life

What are my resources?

Who do I need to involve?

What are my next steps?

What are your hopes and dreams?

Where do my dreams make sense?

What have I learned?

One Page Profile

Use the One Page Profile to share what is most important about who you are right now and the support you need.

Think if you could give tips to the chemo nurses who need to know about how to best help you! "Don't show me the needle" or "realise I am terrified - make me laugh, and this will go better for both of us!"

The One Page Profile used at the end of treatment can help you create a "new normal" by capturing what's important to you right now as you return to work or get transition to the new normal phase of the Cancer Journey.

The One Page Profile pulls together a lot of information that is really helpful for family, friends, nurses, doctors, and possibly co-workers. It may also help to have copies of this to email out, post on your blog or hand to people as an update of your life, without you having to retell your story over and over.

On the next page complete each section:

Me

This is a place to upload a picture if you use the on-line version.

History

Write a little bit about where you come from and who you are. Also include diagnosis information if you wish.

What other people like and admire about me

This can be a hard one. What do people tell you when they compliment you? Are you brave? Funny? Smart? Good with your hands? A good cook? A problem solver?

Hopes and dreams

What are your hopes and dreams for the next few months? How do you want the next few months to look? How will you live your life? What needs to be in place for you to 'thrive' - during treatment or after treatment is over?

Important to me

What are the things that you hold dear and make you who you are? What are your favourite activities? How do you like to spend your free time? Who are the people who know and love you the best? What are things that you absolutely do not want to happen in your life? What are the qualities of the people you like to have around you?

How to support me

In an ideal world how would the people around you help you through this time? What would family and friends do; watch the children? Laundry? Grocery shopping? Phone calls? Letters? What would nurses and doctors do; talk with you about your care? Be timely in calling you back? How would they answer your questions; write them down? How would they greet you? How would they keep you informed?

one page profile

Me



What people like and admire about me...

Knows where to find information about breast cancer.

Passionate about supporting people with disabilities and other breast cancer survivors.

Good friend.

History

Was diagnosed on Oct. 17, 2001 with invasive ductal carcinoma. Stage IIB - 4 treatments of AC; 36 radiation treatments. Tamoxifen - 4 years, Zometa - 20 monthly treatments, Zolodex 4 years of monthly treatments. Had baby in June 2006-Ben. Started Tamoxifen and Zoladex in 2007 and finished in 2008.

Hope and dreams for the next few months

I want to develop my meditation practice to help improve my health.

Start making time for exercise.

Share the thinkaboutyourlife.org website with more people.

What's Important to Me...

Quality family time - having family dinners, hugging my son and husband.

Continuing to survive breastcancer! I crave new information that will help me be proactive and knowledgeable about my future health.

Reducing stress is really important to me and do worry stress could contribute to poor health.

My work - helping people find hope, achieve their dreams and have a good life.

Being with friends and having "girlfriend" time to talk, have wine and laugh.

Doing the cancer walks with friends is a really good time! I try to do one every year.

In October, I present to younger women on facts/risks of breast cancer.

How best to support me...

I am experiencing side effects from having 5 years of treatment.

At times I feel frustrated (and complain) about having to deal with health issues women much older than I am typically experience. I appreciate people listening to me rant.

Realise, I know exercise is healthy and beneficial to my life. Suggesting PRACTICAL ideas for me to get exercise is very helpful.

I want to know about the latest treatments.

one page profile

Me

What people like and admire about me...



History

Hope and dreams for the next few months

What's Important to Me...

How best to support me...

Co-survivors

Co-survivors are family, friends, health care providers or colleagues who support people on their journey with cancer from discovery of cancer through treatment and on to finding a new normal. Co-survivors can use the tools to support the person in their life with cancer. Below is a story from Jo, Jane's sister-in-law who shares how she felt as a supporter for Jane.

"My sister-in-law, Jane, or maybe that should say sister, because that is how close I feel to her, was diagnosed with cervical cancer in January 2011. I went with Jane to Stepping Hill Hospital the day she was diagnosed and to be honest I didn't quite know how to react. My first thoughts were "Oh no, not Jane; not cancer". I was devastated that she should have to go through this. It was that word and it frightened the hell out of me. I wanted to cry and shout - it's not fair, but at the same time other thoughts were going around in my head - this isn't happening to you, stop being selfish and thinking about how you feel - you need to be strong now to help support Jane through what was going to be a horrendous journey. One with many potential twists and turns, and an uncertain outcome, with the treatment that she was going to endure.

We cried together and the nurse at the hospital held both of our hands. On the way out of the hospital I tried to cheer Jane up which obviously wasn't going to happen, whilst my head was buzzing with all sorts of thoughts and emotions - "How could I help? What could I do?". How do you help someone so close to you who is going through this terrible ordeal? I decided that I just had to act normally and not smother her and to give her some space. Even though I just wanted to put my arms around her all the time and hug her. I told her that I was there for her whenever she needed me; I would go to whatever hospital appointments she wanted me to go to. I just wanted to be there for whatever she needed me for - no matter how useless that actually made me feel.

To be honest with you I don't know how she coped with what was happening to her. I thought she was amazing and her strength inspired me. I don't really feel that anything I did was out of the ordinary, I just got on with my day to day family life and when I was needed by Jane, I was there for her. It just seemed the natural thing to do."

Below is Jo's Good Day and Bad Day tool. She used this to help sort out how to provide good support for Jane and find the balance with being available for her husband and daughters and work. Often, co-survivors have to navigate difficult decisions about 'being there' for the person with cancer and not overdoing it to point of exhaustion or damaging relationships.



Notes