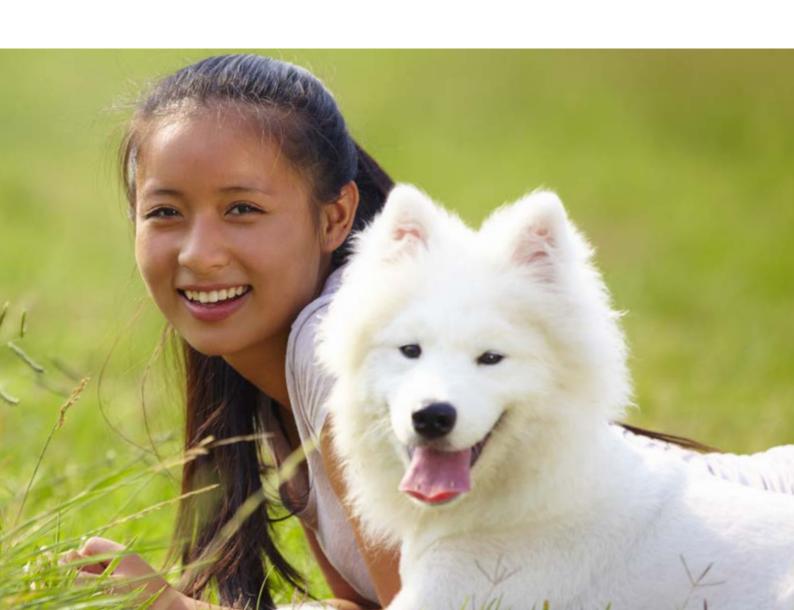




### How do you feel?

Exploring the emotions of caring



#### Do you need to call someone?

#### **Emergency**

In an emergency or if someone is in danger

Triple Zero 000

#### Need to talk?

If you are in crisis, anxious or depressed and want to talk with someone

Lifeline: 13 11 14 – for anyone

**Kids Helpline: 1800 55 1800** – for people aged 5 to 25

#### **Carer services**

Call the Carer Gateway Contact Centre for support and services:

**1800 422 737** – Monday to Friday, 8am to 6pm local time

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Except where otherwise indicated, the images in this publication show models and illustrative settings only, and do not necessarily depict actual services, facilities or recipients of services.

This publication may contain images of deceased Aboriginal and Torres Strait Islander peoples. Where the word 'Aboriginal' is used it refers to both Aboriginal and Torres Strait Islander peoples.





Name:
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## How to use this workbook

In this workbook you will find activities, information, resources and opportunities designed to support the facilitated and self-guided coaching experience. How you use this workbook is entirely up to you. We encourage you to make notes, draw or scribble ideas and thoughts throughout. It is your resource and can be something you refer back to in future.

You can work through this booklet at your own pace. You can choose to explore the content with a coach, with a peer or someone you trust, or by yourself.

#### Throughout this workbook you will see the following icons:

- indicates further information
- indicates an activity you can complete
- indicates an opportunity to pause for a reflection. You could discuss the idea with a friend or your coach, or you could write down your thoughts in your journal

# There's lots of feelings



Narelle, 36, N.T.

At the moment, I feel good! I'm proud of how we are all working together.

We are at a stage where we kind of know how it all works, and our routines are pretty sorted. It's great. I feel like there's space to be able to enjoy the little, ordinary happy moments.



Corey, 26, Tas.

To be honest, I feel a bit lost at the moment.

It's touch and go with Dad right now, and I'm all the family he's got. It's a big responsibility and I'm not sure if what I'm doing is even helping. I don't really know how this is all meant to work.



Amira, 47, Vic.

I used to feel guilty for taking time out for me.

I'd organise respite and then spend the whole time feeling bad for not being there with him, as if I'd abandoned him. Now I'm learning to see that time as essential to his development and my wellbeing. I'm letting go a bit.



Dina, 33, W.A.

I try to put on a brave face but it's hard. And it's quite lonely.

Caring for my husband has become my full-time job. I don't see my friends anymore and the only time I get out of the house is to race to the shops or go to his appointments. I love him dearly, but I miss the life I used to have



Steph, 35, Vic.

I'm angry. I feel like we both just keep getting knocked around.

It feels like we just keep struggling, keep hitting obstacles and road blocks and challenges. It's exhausting and I'm angry and frustrated. And I hate that I take it out on her. I feel like we can't catch a break.



Colleen, 54, N.S.W.

If I stop to think about how I feel, I'm worried I will fall apart.

When friends ask I just say I'm fine, we're managing. I suppose I am afraid of what I will find if I take the time to step back and think about how I am really feeling.

I just don't want to feel that pain that I know is there.



John, 69, Qld.

I'm trying to just enjoy the time we have but I know it's going to be hard when she dies.

I am trying so hard to stay focused on the here and now, but the thought is always in the back of my mind, I can't escape it. I'm scared of how I will react when she passes.



## How do you feel today?

Emotions can be complicated. Noticing what you're experiencing and being honest about your feelings can be challenging.

In this coaching session you're invited to think about how you might look at and listen to your emotions, and how you might be able make meaning from them.

#### **Topics:**

- What are the possible emotional impacts of the caring role?
- 'The River.'
- · Looking at unpleasant emotions.

#### By the end of this coaching session, you will be able to;

- Acknowledge some of the emotions you experience,
- · Recognise some of your responses to your emotions,
- · Have an idea about how you would like to feel.

This workbook contains the following sections:	Page
Introduction to the emotional impacts of a caring role	8
Exploration of caring experiences	20
Looking ahead	38

## What's important to you?

As you work your way through this course, it can be helpful to keep in mind the things in life that are of the most importance to you. As you explore the topics, questions and activities, consider how your responses are shaped by the values you hold.

On the right is a list of values. The list is by no means complete, and the values included will mean different things to different people.

As you read through the next few sections and reflect on your own experiences, think about how these values might influence your choices and actions.



#### Read through the list and circle five values that are very important to you.

Hint: Try not to over think it; your first response is enough.

Acceptance	Family	Justice
Accuracy	Flexibility	Knowledge
Belonging	Friendship	Love
Challenge	Fun	Order
Comfort	Growth	Passion
Compassion	Honesty	Respect
Cooperation	Норе	Responsibility
Creativity	Humility	Stability
Dignity	Humour	Tradition
Excitement	Independence	Wealth



# The emotional impacts of the caring role

What ever the feeling you are having, it's OK to have it.

There are emotions that we might deem as acceptable to have, depending on the expectations of our family, friends, community or the way we have been brought up, or we might judge our feelings as shameful or inappropriate. We might hide these feelings from others; or maybe even from ourselves.

Being a carer means you experience a huge array of emotions, sometimes all in one day. There are highs and lows and complicated, or hard to identify feelings, somewhere in the middle. Sometimes you might experience a sort of emotional numbness or a disconnection from your feelings.

How we navigate and respond to the feelings we have comes down to understanding where they come from and accepting that we are feeling them. Unfortunately, we can't avoid the hard to hold emotions and we can't manufacture the pleasant ones.

Noticing, acknowledging and allowing ourselves to safely experience the emotions is key. Learning to be gentle with ourselves and to experience our emotions without judgement takes practice.

### The river

To identify and describe our feelings can be challenging; it's sometimes hard to put them into words. One approach that can make talking about our feelings a little less confronting is to use symbols and ideas to tell a story that explains our situation.

#### The following exercise asks you to think about your life as a river.

The experience of being on this river feels different depending on where you are. There are calm sections on this river, as well as chaotic or turbulent sections with obstacles or hazards. There are places on the river where the water moves slowly, maybe even getting stopped and stagnant, and other places where the water rushes. There are ways in and out of the river; tree branches you might be able to grab or places you can easily wade in or climb out. There are dangerous parts of the river, especially if you don't see them coming. There are quiet parts and noisy parts, safe parts and dangerous parts.

We can use the places on the river, the ways the water is moving, the strength of the current and the things surrounding the river to help describe what our life feels like for us.

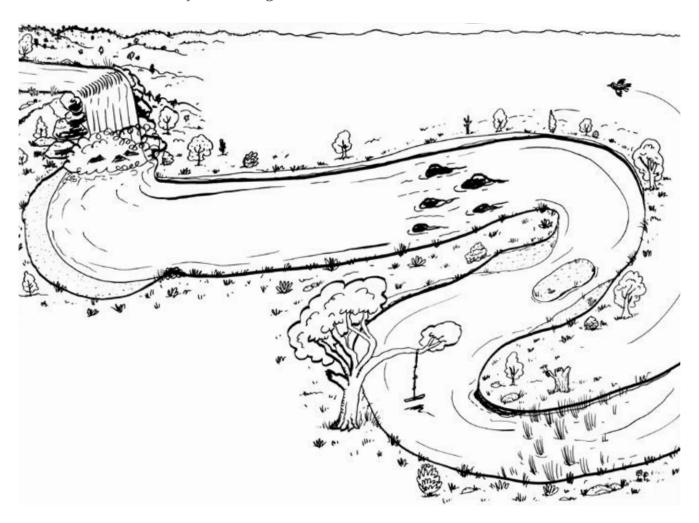
Different people will see and describe the river differently. What one person considers exciting, another may view as scary and yet another may see as mundane. Some might see challenges where others see comfort.

Think about how you are feeling at the moment. Where are you on the river?



#### How you interpret different points on the river is totally up to you.

If you think about how you're going at the moment, how life feels to you, where are you on the river? Circle the place on the river that fits most closely with where you're at, right now.





Chat with your coach about how it feels to be in this spot on the river. You might also like to write a few notes in your journal about why you are choosing this location.

### Feeling good

Feeling good... feels good! It may seem obvious, but experiencing pleasant emotions is essential to our overall wellbeing. There are suggestions that experiences of connection and pleasant emotions can even increase our life expectancy.

It's important to recognise that there are times when we feel good even if they are brief, noticing when we have pleasant emotions, or remembering how it feels to experience them, is something we might need to be reminded to do.



#### Below are some emotions that might be pleasant to experience.

Circle the feelings you have experienced in the last week. You can also add your own in the space below.

Energised	Joyful
Proud	Relaxed
Motivated	Нарру
Relieved	Grateful
Calm	Satisfied
Optimistic	Enthusiastic
Capable	Loved
Confident	Triumphant



What was happening when you were feeling these emotions?

### Feeling not so good

No emotion is in and of itself 'bad'. The emotions are what they are; it's how we experience them and how we respond to them that give them their negative and positive characteristics.

When the experience of an emotion is unpleasant, painful or uncomfortable, we tend to respond in ways that can be unhelpful for others and for ourselves. We might lash out, or shut down. We might deny or ignore the emotions, or dwell in them. Our responses might make it difficult to continue doing the things we need to do. This could be one reason why many carers report feeling numb; we might subconsciously deny our emotions because we feel like we don't have time for them.

Noticing how we are behaving can often be the key to identifying our emotions. Acknowledging the emotion and being able to see the experience, without judgement or expectation, can help us to minimise our unhelpful responses to unpleasant emotions.



#### Below are some emotions that might be difficult to experience.

Circle the feelings you have experienced in the last week

Helpless	Empty
Angry	Frustrated
Ashamed	Unwelcome
Overwhelmed	Critical
Nervous	Defeated
Pessimistic	Hopeless
Bitter	Grumpy
Disconnected	Guilty



What was happening when you were feeling these emotions?



## **Emotional connections**

Our emotions are not experienced in a vacuum; they are intricately connected to the behaviours, actions and ambitions of other people.

Our emotions arise in a response to what others do or say, or what they don't do or say.

We might also empathise with another person's situation and feel their emotions as if they were our own. We might imagine what we'd do or how we'd feel if we were them.

As carers, our emotions can become entwined with the emotions of the person we care for. If they feel happy, we feel happy. If they are angry, we are too.

We can also experience emotions on behalf of the person we support. We might encounter a situation where the person we support is treated badly and doesn't realise it. Our emotional response might be to feel and express the emotions for them.

Working out how to distinguish between their emotions and our own can be challenging.

## Looking at the unpleasant feelings

It's human to avoid or run away from experiences that don't make us feel good. In fact, it's a protective mechanism that's designed to keep us safe and works very well when the experience involves danger.

Many of us become quite good at denying unpleasant emotions too, because, of course, they don't make us feel good. On the surface, this might look like a good strategy. But pretending the emotions aren't there doesn't make them go away. In fact, avoiding or ignoring unpleasant emotions can allow them to fester and grow stronger.

Investigating the unpleasant feelings, without having to feel them at the same time, helps us find out more about them. The more we know about these emotions and our responses to them, the less dangerous they feel.

There are four broad but distinct categories of feelings that most people classify as unpleasant: worry and anxiety; anger and resentment; guilt; sadness, loss and grief.

The next section explores how carers may experience these unpleasant emotions.









Worry and anxiety

Anger and resentment

Guilt

Sadness, loss and grief

Page 22

Page 26

Page 30

Page 34



### **Worry and anxiety**

Feeling worried or anxious is an indication that you want something to be different.

Most anxiety comes from feeling powerless to bring about the changes you want to see. And when things can't be the way you would like them to be, or you can't control the outcome, you can worry endlessly.

Being worried is a sign that's telling us we need to pay attention to something. It tells us there is a need that isn't being met. The focus of our worry isn't usually the actual cause of the anxiety; it's an outward symptom of something within us that isn't feeling safe, satisfied or comfortable with the situation.



It was life changing for our family to realise there are things we can control and things we can't.

We can't change the fact Caitlyn has a spinal condition that limits her mobility; worrying won't make a difference there. We can influence her wheelchair situation though.

We can put our energy into worrying about that and advocating for her right to live independently.

Karen



I used to stay awake at night worrying about what will happen to my son in the future after I die. I eventually realised I was avoiding talking about this with my family because I was worried they wouldn't want to be involved in looking out for him. I was even more scared my son would be hurt if he thought that I thought he wouldn't be able to cope on his own. All up it took us a couple of hours to get a plan together. I feel relieved knowing there is something in place for the future.

Nicky



I used to worry that my brother wasn't eating healthy meals. I would cook for him every night and drive over to deliver it, on top of all my other work. I was convinced this was the best thing for him and I had to do it.

When I joined a peer group someone said to me "But he's a young guy in his 20's! They all eat rubbish!" I realised my concern was more about my need to protect him than being about his need to eat properly.

Tom

## **Experiences of worry and anxiety**

Whether the focus of the anxiety is seemingly small or huge, it can help to investigate it a bit by asking:

- What is it that I need from this situation that I am not getting?
- · Whose need is not being met?
- Is it up to me to fix this?



- What do you worry about most?
- Are some of your worries about things you can't control?
- What might your worries be telling you about needs that aren't being met?



## Anger and resentment

Feelings of anger let us know when something isn't OK. Anger arises when things don't happen the way we want, or when we experience unfairness. Anger tells us that a boundary has been crossed, or our values have been dismissed or ignored. It can also be a response to being hurt.

We are often taught that showing or even experiencing anger is wrong. Feeling anger is not wrong; it is how we act to express the feeling that matters. Anger can actually be a source of energy and motivation. Finding a way to increase the time between feeling the anger and acting on it is key.

If you can't take action or you are unable to communicate what isn't right for you, anger can grow and become difficult to express in a constructive way. If anger is left unresolved, resentment can develop.



I was so angry about how they treated my son when he was in hospital. Later on, I was able to speak up about it and put in a complaint. They ended up contacting me and asked me to help them create a care plan for use with patients on the autism spectrum.

I'm actually proud that I used my anger to make a change for the better. Maybe it will help others avoid going through what we went through.

Carlos



I couldn't let go of my anger that he was going to die and that we were losing our dream of growing old together. At times I was angry with him, even though I know it wasn't his fault. Sometimes I would get angry with doctors and make a big scene.

One thing that helped was realising I held a position of trust; I had the chance to support him in planning the end of his life. He trusted me to do that.

Alex



If I'm honest, I'd say yes, I do feel resentment. I didn't get as much attention when we were younger and I feel like the focus is still always on my sister. People say things like "Oh she's so lucky to have such a wonderful sister!" and I honestly have to bite my tongue sometimes. I wish they could walk a mile in my shoes.

For me, talking with other carers helps. They just get it and I don't have to hide my resentment. I can just vent.

Cara

### **Experiences of anger** and resentment

Whether the cause of your anger is something minor or something big, it can help to investigate it a bit by asking:

- What is it about this situation that is not OK for me?
- · Whose values and beliefs are being overlooked? How?
- Is it up to me to act on this?



- What makes you angry?
- Are you able to use your anger in a constructive way, to bring about changes?

Could your anger be telling you something about a need that isn't being met?



### Guilt

Feeling guilty can be a useful sign that we are on the wrong track. It can be a helpful feeling because it tells us that maybe our actions are not in line with our values.

But feeling guilty can also mean we've taken on blame that doesn't belong to us. Maybe we feel bad about having something that others don't, or having something we think we don't deserve.

Either way, guilt is not a very useful emotion to dwell in. It doesn't tend to energise or motivate us. If we feel guilty without feeling able to alter our actions, our self worth can start to erode.

We can also run into problems if we are feeling guilty about something that isn't actually wrong or doesn't need to, or can't change. Sometimes guilt arises from judging our actions or situation against impossible standards or against other people's unfair expectations.



I felt so guilty about putting Mum in an aged care facility. I knew the rest of my family expected her to stay living at home with me and I know that both Mum and I wanted that too.

It just became too much for me. I didn't actually have the skills required to care for her. I felt really bad, like I'd failed, like I should just be able to do it all. I think Mum being in care is what's best for her and for me.

Angela



I felt so bad about going out and having fun because I knew my wife couldn't really do those things much anymore. I think I thought it would help if I didn't do the things that she could no longer do. Like it would show solidarity or something.

Sarah was the one who realised what was going on. She said she hated how I'd stopped surfing and being active and seeing my mates. It hurt her to see that, it made her feel guilty. We talked a lot about guilt and it really opened up our ability to talk about what we could and couldn't change.

Mark



I used to wonder sometimes if it would be better for my daughter to die. Maybe then she would be free from the pain and we could grieve for her and move on. I would let myself think this for a second before feeling crushed by such huge guilt that I'd wanted that even for a second.

I remember the first time I went to a support group and heard someone else share this same thought. The relief I felt was incredible.

Trudy

### **Experiences of guilt**

It's useful to investigate feelings of guilt by asking:

- Have I acted in a way that reflects my values?
- Who is responsible for this situation? Is anyone at fault?
- How do my thoughts change if I replace 'should' with 'could'?



Where does your guilt come from?

Whose values are you acting in line with?

- Is there anything that you can change that would remove your guilt?



## Sadness, loss and grief

Feeling sad is usually a sign that you are grieving for something you have lost.

Everyone experiences loss at some time in their life. Losses such as the death of a family member or the break up of a relationship may be obvious to other people. Some personal or private losses may be less obvious to others, yet still very painful.

Sometimes what we have lost is not visible. We can grieve for what we once had or how things used to be. We can also grieve for things we don't, won't or can't have, for possibilities and hopes and dreams we are forced to let go. These kinds of losses might affect your self esteem and confidence, they can have a big impact on how you see the future.

Grief can also be experienced before a loss occurs. This may happen when someone you care for has a terminal illness and you know you will have to face the loss in the future. You might also have ongoing grief.



I know he's going to die. And I'm grieving before he's even gone. It's horrible, I want to be able to enjoy the time we have left together. I was trying to hide it from him but he sees it. How could he not?

The hospice organised a grief counsellor for us and it's helped. It's been bloody hard but it is helping. We're talking about death and being honest. I'm proud of us for that, for kind of leaning in to it.

Lauren



It saddens me when I think about what our relationship used to be like. I miss how he used to be, how we used to talk and debate ideas and laugh and argue and fight and make up. I miss all of that.

Some people don't really get it. They say I should be grateful that he survived. I am so grateful he survived but I also miss the man he used to be. I feel strange saying that. My close friends get it though. I have a bit of a cry with them every now and again.

Anne



It dawned on me the other day that I won't ever get to walk my daughter down the isle. I know it sounds silly. I mean, had she been able, she might have chosen not to get married or eloped or not invited me! Who knows?!

I just know that on the day she was born I saw that picture in my mind of me walking her down the aisle and giving her away. I think knowing that will never even be an option is where the sadness comes from.

Darren

# **Experiences of sadness, loss, grief**

It's useful to investigate feelings of sadness by sharing them with people you trust.

- Have you been able to share or express sadness?
- · Could grief underline other emotions you experience?
- How would you describe how loss feels?



- What do you worry about most?
- Are some of your worries about things you can't control?
- What might your worries be telling you about needs that aren't being met?

# Revisiting the river

At the start of this session, you identified where you are on 'the river' at the moment. Do you still feel that's accurate?

After reading some carers' experiences in this session and investigating some of the unpleasant emotions, take some time to reflect in more detail about how you are feeling at the moment.

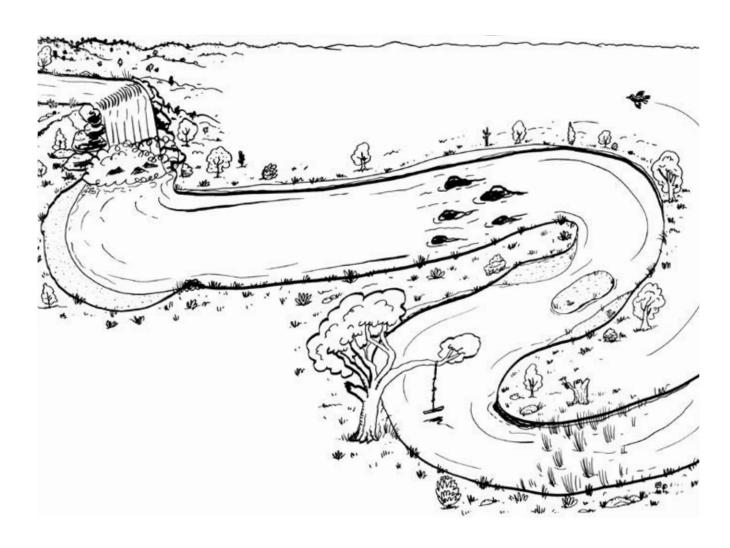
You don't have to figure out how to travel along the river on your own. You might like to talk it through with a carer coach or you could speak with a counsellor, online or in person.



- Do you still feel that the place you identified earlier reflects your life at the moment?
- On the river where would you like to be? Why? How will it feel to be there?
- What do you need in order to move along your river?



If you think about how you want to feel in the future, where would you be on the river?

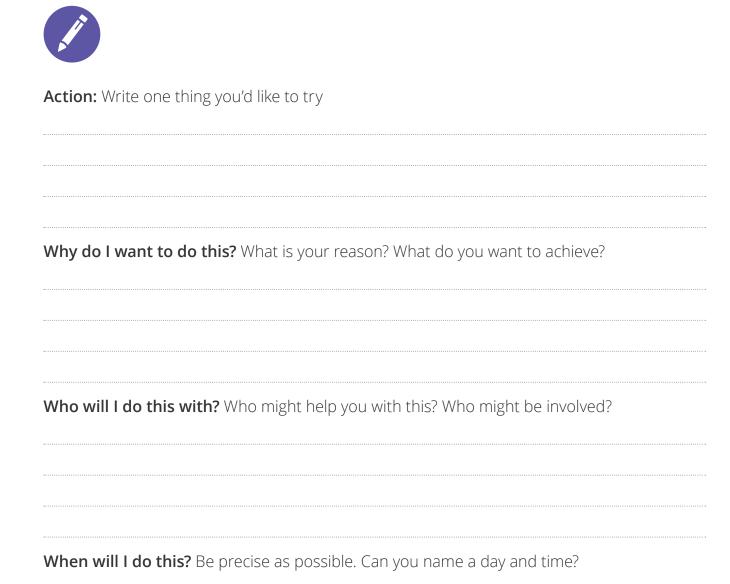


# **Action plan**

After reading through the case studies and information in this session, choose one specific, realistic and achievable thing you would like to do with regard to how you are feeling.

Refer back to the page earlier in this workbook where you identified the values that are important to you. Write them in the space provided below.					

When you create your plan, think about how the action you want to take will express, support or align with your values.



## LOOKING AHEAD



Now that you have finished this coaching session, we encourage you to spend a few minutes putting down some of your thoughts or talking through some ideas with your coach or someone you trust. You can write your ideas on this page or in your coaching journal.

#### You could write or chat with someone about:

- · Where you are on your river, or where you'd like to be,
- Some of the pleasant emotions you experience,
- Some of the unpleasant emotions you experience.

This workbook represents a significant amount of time and energy that you have dedicated to your own wellbeing. It is an important part of your journey and worth hanging on to. Keep it somewhere that allows you to revisit it whenever you need to.

You can also come back to look over, check in on, revise or change your action plan. You can even re-do the activities or share some of the information or resources with friends.



### REFERENCES

- Cancer Council Australia (2019)
   Emotions and Cancer: A guide for people with cancer, their families and friends
   Available at: cancercouncil.com.au/cancer-information/when-you-are-first-diagnosed/emotions-and-cancer/ [Accessed 12 Jan 2019]
- Carers ACT, Carers Feelings Fact Sheet
   Available at: carersact.org.au/fact-sheets/ [Accessed 12 Jan 2019]
- Carers ACT, Loss and Grief Fact Sheet
   Available at: carersact.org.au/fact-sheets/
   [Accessed 12 Jan 2019]
- Dementia Australia, Looking after Families and carers: Feelings Fact Sheet (2015)
   Available at: dementia.org.au
   [Accessed 12 Jan 2019]
- Dementia Australia, Looking after Families and carers: Coping after the death of someone with dementia – Fact Sheet (2015)
   Available at: dementia.org.au
   [Accessed 12 Jan 2019]
- Kezelman C., Stavropoulos P. (2017)
   Talking about Trauma: Guide to Everyday Conversations for the General Public:
   Blue Knot Foundation
- Wellways: Building a Future, edition 7, (2016), Wellways Australia, Melbourne

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