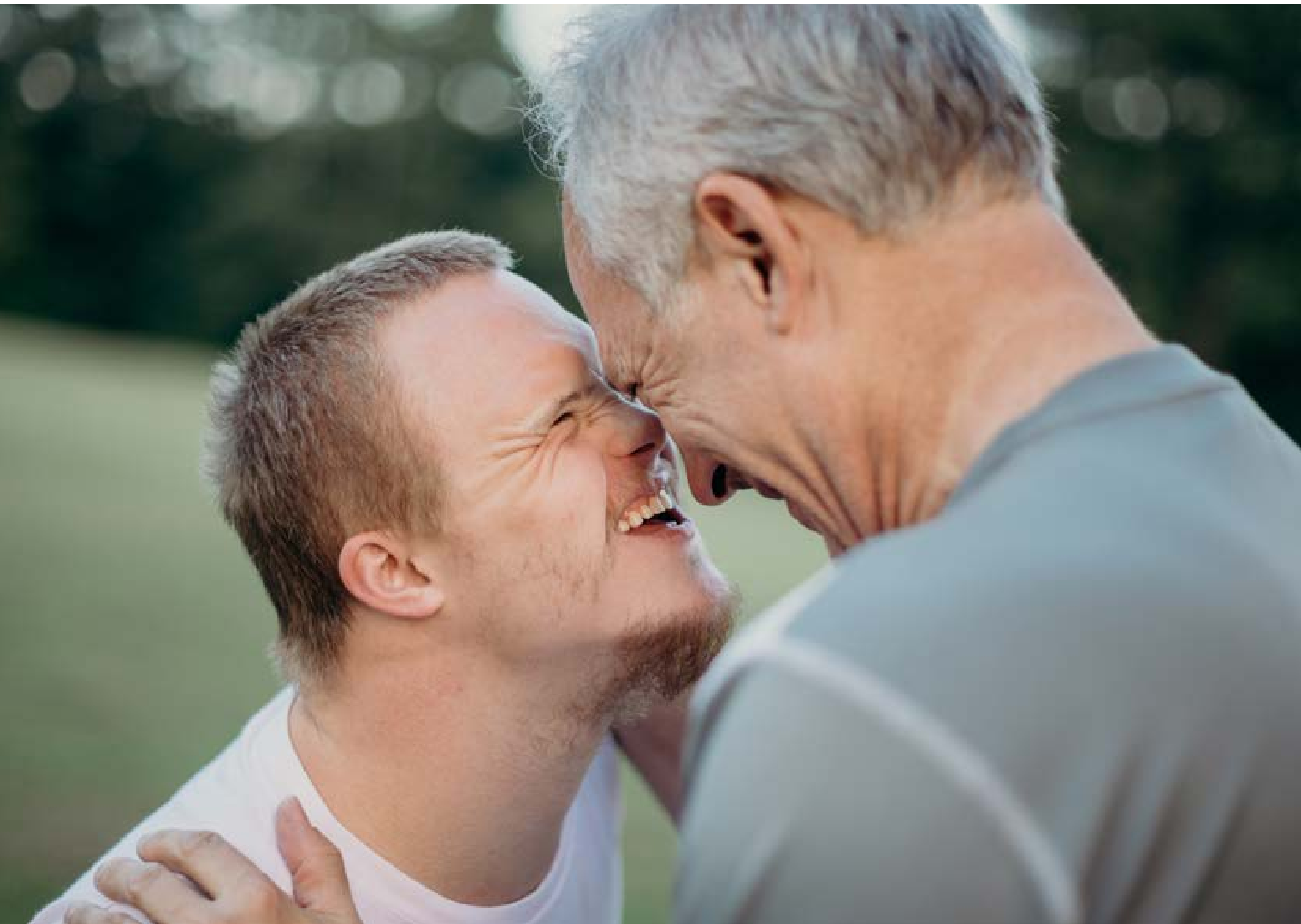
Australian Government | Carer Gateway

COACHING

Understanding the caring journey

Exploring how your role as a carer can change over time



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

Version 1, Published 28 June, 2019.

This resource was originally written in 2019 by Wellways Australia Services to support Regional Delivery Partners in the delivery of the Facilitated Carer Coaching services. Our gratitude goes to the members of the coproduction group and carers who generously provided insight and feedback during the development of the workbook.

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.

Australian Government

Carer Gateway

Name: ....

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:

- ℹ 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

We each have our own caring journey

Richard, 63, Tas.

I don't really think of myself as a 'carer'. I'm a husband who supports his wife.

My wife has issues with her mental health, which means that she finds participating in life really challenging sometimes. Sometimes it's hard. We have been married for forty-two years and I can't imagine my life without her.

Trish, 46, W.A.

It's just go, go, go – no time to catch your breath sometimes.

We're in a pretty good routine now but it's taken a while to get to this stage and we often fall back into that 'just getting by, day by day' mode. I try to keep reminding myself that I'm doing the best I can.

Demi, 21, Vic.

I find it difficult to even think about what will happen when Grandad dies.

I just try to enjoy the time we have together now and be there to make sure he is treated with the respect he deserves. It is important for him to know he led a good life and to know his family are grateful for this.

Olivia, 11, A.C.T.

He's just my dad. We have fun together, we go bike riding and swimming lots.

I can't really remember Dad before he was in a wheelchair, it's just normal to me. I help him get things from shelves that he can't reach or carry things and stuff like that. He's just my dad. I know he'd help me if I was in a wheelchair.

Therese, 49, Qld.

It's taken us many years and lots of support, but I think we've 'found our groove' as a family.

We've all had to learn ways to communicate to make sure our own needs are met, not just Aaron's (my son). I used to feel overwhelmed; but learning how to step back has given me the confidence and the space to be able to return to work.

Jess, 32, N.S.W.

I started thinking about the things I'd always wanted to do but had been putting off.

Roller Derby is a bit of a chance for me to get away and de-stress. It's nice to have something to look forward to, something challenging but fun, something that's 'just for me'.

Lina, 51, N.S.W.

After his diagnosis, I was sad and angry, then guilty for feeling that way.

When I was noticing changes in Dad's behaviour – just little things like forgetting words mid-sentence – I was confused and a bit worried. I think my mind jumped to the worst-case scenario straight away.

Where are you in your caring journey?

In this coaching session we will be exploring common stages in a caring role, which we refer to as a caring journey. We will look at the impacts of your carer role on your life, your identity and your plans for the future.

Topics:

- What and who is a Carer?
- Life and the carer role,
- Phases in the caring journey,
- Planning a meaningful life.

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

- Recognise where you are in your caring journey,
- Identify what makes life meaningful for you,
- Make a plan for how you would like your future to be.

This workbook contains the following sections:

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

The Role of a Carer

Many people spend time caring for others. You might look after a family member living with disability or mental health problems; or a parent or spouse with dementia, a chronic condition or a terminal illness. Maybe someone you are close to has an alcohol or drug-related problem, or is frail aged, and needs your assistance to help manage their affairs or support them in their day to day life.

In each of these cases, the person providing this support is likely to be considered a carer. The level of support needed and the way we interact with the person we provide care for depends on our situation and it can change over time.

Being in the role of a carer can influence how we see ourselves and can alter the way we live our life. Being a carer may mean we have to reassess our plans for the future.

What is a Carer?

There are many names we call ourselves and ‘carer’ is usually not the first that springs to mind. We might think of ourselves as a dutiful daughter, a loving husband or a devoted parent. Maybe you are a tireless advocate, a neighbour, next of kin, big brother.

The title carer might actually fit our role and situation without us realising it.

A carer might provide assistance with daily activities like preparing meals, bathing, dressing, going to the toilet, moving around, attending appointments and taking medications. They might provide ongoing emotional support, encouragement, guidance and reassurance. Some provide care around the clock, while others do so only from time to time.

Every caring situation is different and as unique as the people it involves.

> A carer is an individual who provides unpaid personal care, support and assistance to a family member or friend who has a disability, a medical condition, a mental health issue or is frail aged.
>
> *Carer Recognition Act, 2010* [1]

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[1] legislation.gov.au/Details/C2010A00123

There are **2.7 million** unpaid carers in Australia

Around **856,000** Australians are primary carers — that is, the carer who provides the most assistance to a person with disability

The **average age** of a primary carer is **55 years** and more than two thirds of primary carers are female

272,000 carers are younger than **25 years** of age

Around **half** of primary carers provide care for at **least 20 hours** per week

56% of primary carers also participate in the **workforce**, compared with 80% of non-carers

Are the statistics accurate though?

There is good reason to believe that the real number of carers in Australia is much higher than the statistics show.

For example, researchers believe there are about 75,000 more young carers in Australia than reported. They also think there are many more Aboriginal and Torres Strait Islander carers.

One possible reason for the inaccurate statistics is that many people just don’t see themselves as a ‘carer’. They see themselves as children, parents, partners or friends of someone who requires extra support. They care for someone close to them because that is what is expected; they are doing what needs to be done.

For example, you might care for a sibling who has a disability because you see it as a commitment that is expected of you as a family member. In fact, in this situation, you would be defined as ‘a carer’ and you may therefore be entitled to government assistance and support services.

People who don’t call themselves carers are often referred to as ‘hidden carers’.

Why do we provide care?

Whether we identify with the title of carer or not, our caring role is often central to our identity. What we do becomes who we are. So, why is it that we do what we do? Put simply, we care because we care!

People become carers in many different ways. Sometimes it starts with helping someone out bit by bit. Sometimes it happens suddenly, because of an accident or illness.

Providing necessary and unpaid physical, emotional, administrative or social support for someone else is usually not something we would actively choose; most likely we wish it didn’t have to be this way. Most likely the person we provide care for wishes things were different too.

Our caring role is usually something we didn’t actively choose. We often ‘step up’ because we feel we have to and because, if we don’t, who will?

What led to you being in your caring role?

Care taking

The level of support that we provide varies greatly depending on the level of independence available to the person we care for.

When the person we support is *unwell* or *highly dependent*, the kind of support we provide can be classified as **care taking**.

Care-taking is when we take the responsibility for the wellbeing of someone else. This might include giving medications, making meals, assisting with movement and/or hygiene requirements or even making decisions about their medical care.

In a care taking scenario, we are ‘doing *for*’ or ‘doing *to*’


FARM

Care giving

In some circumstances, the person we support doesn’t require us to do things for them; what is needed is support to be able to do things for themselves.

It’s also possible that their level of independence can change. Sometimes illness can be episodic or independence can develop over time. In these instances, it is vital that **care-taking shifts to cooperative caring**.

Providing this kind of support can be referred to as **care giving**.

When we are in a care giving situation, we are working with the person we support and acting more like a safety net or a coach. We provide guidance, encouragement and reminders as needed.

In a care giving scenario,
we are ‘doing ***with***’

Your life and the carer role

Every carer is unique. The way we become a carer, who we care for, how we care for them and the impact this has on our life is different for each of us. How we feel about being a carer is individual to us too and it changes over time.

Finding your own independence and self-determination can appear problematic or even impossible when you are caring for someone else. The caring role can sometimes limit our ability to make choices and decisions about how we want to live our lives.

Caring for someone can place restrictions on the life we are able to live, on the things we can do and the decisions we are able to even contemplate.

The impact of the caring role on our ability to live in the way we choose varies depending on so many factors. How long we have been in the role, who we are caring for, the degree of their needs and the availability of additional supports will all influence our capacity for independence and control over our own life.

What makes life meaningful for you?

Our main priority in life is usually getting the best outcomes for the person we support. We know what is helpful for them, we understand what brings them joy, what maintains their dignity and ultimately, what creates meaning in their lives.

But what about you? What brings you joy and fulfilment? Are there people, places or activities that nourish you?

Carers commonly find that providing care and support has become the main, or only, source of meaning in their lives.

It's very common for us to be so intent on ensuring that the person we care for has a meaningful life, that we forget we are allowed to have a meaningful life too. Or, perhaps even more commonly, we find that providing care and support has become the main, or only, source of meaning in our life.

Caring for someone we love does provide us with fulfilment and meaning. However, if our happiness is reliant on being needed or feeling satisfaction only from being able to look after someone else, it's unlikely to be a sustainable approach to living a fulfilling life.

What gets in the way?

Being able to name or visualise what makes life meaningful for us doesn’t necessarily mean that our life looks that way day in, day out. There are good days and bad days; days where we feel we are doing well and moving forward, others where we feel stuck or frustrated by our inability to live the life we want to, because of our responsibilities.

Everyone faces limitations on living the life they dream of. The realities of time, money and responsibilities are faced by us all. Instead of fantasising about what we wish life was like, focusing on how we can make the best of what we have can help us to take practical steps towards a more meaningful life.

Knowing what we want life to look like and being able to name what makes life meaningful and fulfilling is our first step. Acknowledging the things that get in the way is the next step.

Other than your caring responsibilities, what gets in the way of you being able to create a meaningful life?

The caring journey

If we are to create a life for ourselves that is meaningful, where we can work towards achieving our goals and dreams, it is helpful to take stock of where our life is now.

How we see ourselves and how we relate to our caring role changes as we change – and as the person we care for changes. Over time, our understanding of the person we support grows, as does our understanding of their condition, the health care system and additional supports available to us.

Our relationship with the person we support, and with other family members and friends, develops and changes too.

To be a carer is to be on a journey – an emotional, challenging, tiring and rewarding process of moving forward with our life while supporting another to move forward with theirs.

Even though every carer has their own unique life journey, research shows that there are some distinct phases of caring; there are commonalities of experiences in all carer journeys.

Phases of the caring journey

The course of a caring journey is far from simple; it is usually complex and complicated and rarely follows a straight line from start to finish.

The diagram opposite attempts to represent a step-by-step progression through six distinct phases of the caring journey – from first noticing changes in the person you care for, to making adjustments and managing a new way of living (with various levels of success), through to a time when the active caring role is no longer needed.

It is really important to note that the length of time spent in each phase and the order in which a carer experiences the phases will vary. Not all carers will begin their caring journey by noticing changes. Some may never experience the confirmation stage.

It is very common to move backwards and forwards between stages, to skip in and out of 'life after caring' or to cycle between phases.

No two caring journeys are the same.

Phases of the caring journey

Diagram adapted from Pagnini et al. 2005

Where are you in your caring journey?

When we can identify where we are in our own caring journey, we can begin to make sense of our experiences and start to look at ways to move towards a place of stability and confidence; towards a place where we can thrive.

The next section of this workbook explores each of the six phases of the caring journey. There is a description of each phase, including some of the common feelings you might experience at this stage in a caring journey and some of the resources you might find useful. There are also some suggestions that might be useful if you want to move forward from this phase in your caring journey.

On the page opposite are brief descriptions of each of the six stages. Think about where you might be at in your own caring journey. For more information about each stage, read through the information on the pages indicated.

Noticing changes

You can see that something has changed in a loved one; ‘something isn’t right’.

Page 36

Confirmation

A health professional confirms that ‘something isn’t right’ and you learn the extent of the condition.

Page 40

Surviving

Adjusting and readjusting to meet the demands of the caring role.

Page 44

Managing

Learning to live with the person’s condition on a day to day level.

Page 48

Thriving

Living with balance between the caring role and life outside of caring.

Page 52

Life after caring

Being in a non-active caring role.

Page 56

Noticing changes

This stage often represents the first stage of a caring journey and is characterised by noticing that something is different or has changed in a loved one; that ‘something isn’t right’. It may be that you notice changes in the behaviour of someone close, or the person themselves may notice they are feeling different.

The duration of this phase varies greatly depending on the visibility of symptoms and the degree of interaction you have with the person experiencing the changes.

This phase can be drawn out over years as symptoms or indicators gradually become more apparent, as in the case of cognitive disorders, mental health issues, addictions or degenerative diseases. This phase can also happen very quickly and be relatively short, as in the aftermath of an accident or trauma, or with the sudden onset of illness.

Carers might feel...

shocked confused scared worried

Carers might need...

- Someone to talk to who will listen to their concerns
- Appropriate referrals
- Information on ‘who does what’ in the relevant health care system

Is this, or has this been, your experience of the *Noticing changes* stage in your caring journey?

Noticing Changes and moving forward

If we have been noticing changes in someone we support, we can be stuck in a very confusing place. It is important to find a way to move forward to a place where we can find certainty.

Accessing reliable information and speaking with health professionals you trust is vital. It is also important to try to stay connected with friends and family where possible, as they can often provide emotional support in times of uncertainty.

You might like to consider:

- Speaking with a friend or family member about what's going on,
- Spending some time socialising with friends or family,
- Starting a journal where you can make note of the symptoms you are seeing and how you are feeling,
- Approaching your GP to talk about some of the changes you are noticing.

Confirmation

This phase in the caring journey begins when a health professional confirms that ‘something isn’t right’ and you learn the extent of the illness or condition. There may or may not be a diagnosis provided at this stage.

The impact of confirmation can be shattering. Denial is a common reaction, as is refusing to believe in the seriousness of the illness or condition.

The *Confirmation* phase involves making a lot of decisions, sometimes quite quickly. Carers are faced with decisions about treatment for their loved one, how or if to inform family and friends, where the person receiving support will live and whether work and financial arrangements need to be altered. This is a high pressure, emotional and stressful part of the caring journey.

Carers might feel...

sad
confused
angry
afraid

Carers might need...

- Information about the condition of their loved one
- Information on how to navigate confidentiality issues
- Information on support systems and services

Is this, or has this been, your experience of the *Confirmation* stage in your caring journey?

Moving forward from the Confirmation phase

When your concerns about the health of your loved one are confirmed, you can feel many emotions. It can be a time of shock, denial, anger and anxiety.

You may also have feelings of relief, guilt or maybe even enthusiasm that now you can get on with treatment or try to address the problem. It's important to look for reliable information in this phase, and establish clear channels of communication with treating professionals and with your loved one.

You might like to consider:

- Asking to be included in treatment planning,
- Approaching a trusted health professional for information about your loved one's condition,
- Reading information about other people who have been in similar caring roles,
- Talking things through with a trusted friend or family member who might help provide perspective,
- Checking in with a counsellor who can help you to implement some coping skills and offer some emotional support.

Surviving

The third phase in the caring journey marks a period of change. When the initial shock of confirmation wears off, we find ourselves needing to adjust and readjust our lifestyle to meet the new demands of caring. This is a time marked by the realisation that life will not be the same as it once was.

The focus in this phase is very much on the person who is being supported: getting them into a routine with treatment, trying to stabilise their health, making adjustments at home or work to support their wellbeing, learning how to talk to people about their needs and becoming familiar with the relevant health care system.

For many carers, the *Surviving* phase is about getting through each day, hour or moment however they can, with whatever works.

Carers might feel...

sad lonely angry worried

Carers might need...

- Peer support
- Explanations about warning signs of a crisis and what to do, and who to call for assistance
- Support with family communications and working together

Is this, or has this been, your experience of the *Surviving* stage in your caring journey?

Moving forward from the Surviving phase

The challenge of surviving in a caring role can be incredibly draining and wear us out if it continues day in, day out, for an extended period of time.

If you are to move on from just getting by – to a place where you are managing, it's essential to begin to connect with outside supports and build a team of people who can support both the person you care for, and you.

Moving forward from the Surviving phase means that we accept we can't do it all by ourselves and it's OK to ask for help.

You might like to consider:

- Joining a peer support group,
- Checking in with a counsellor to talk about how to cope with the stress, feelings of loss and changes you are encountering,
- Looking into community support organisations for tailored information, advice and assistance,
- Reaching out to a financial counsellor or planner to help organise your finances,
- Discussing treatment and crisis prevention strategies with your loved one's treatment team.

Managing

The fourth phase comes as carers move from an adjustment/ readjustment period to a stage where immediate crisis has abated and the health of their loved one is more stable. Carers learn to live with the person's condition on a day to day level. They have more effective coping strategies like routines and regular additional support.

Some carers may be able to step back somewhat into care giving, rather than care taking, however there is always an emphasis on 'helping' or 'checking in' with the person they support.

While this phase is seemingly more stable, there is often a constant underlying fear of another crisis being just around the corner. It is very common for carers to cycle between *Managing* and *Surviving*.

Carers might feel...

Shocked tired depressed anxious

Carers might need...

- Family relationship support
- Strategies to help cope with crisis
- Regular respite opportunities

Is this, or has this been, your experience of the *Managing* stage in your caring journey?

Moving forward from the Managing phase

It is very common to cycle between the *Surviving* and *Managing* phases in a caring journey. Often it feels like being stuck in a washing machine or being on a merry-go-round that we just can't seem to escape. Sometimes we will be managing quite well, only to encounter a new crisis that sends us right back into survival mode.

If we are to move forward from the managing phase, or the spin cycle of managing and surviving, it's important that we start to strengthen our own agency and establish some boundaries within our caring role. Re-establishing our identity outside of our caring role is vital.

You might like to consider:

- Talking with a counsellor about strategies for developing or strengthening your sense of self,
- Implementing regular access to respite,
- Accessing financial planning resources – for yourself and for the person you support,
- Joining a peer support group or a carer's support program,
- Making some space to connect (or re-connect) with friends and other family members.

Thriving

This phase represents a time where carers are able to take a pro-active, rather than reactive, approach to the caring role. It is a stage of ‘purposeful coping’ where carers are able to establish balance between their caring role and their life outside of caring. They are able to step back from over-involvement with the person they support, allowing space for each person’s independence to grow. In this phase, carers have developed the knowledge and skills to be able to handle difficult situations and experiences of crisis effectively.

If a carer reaches the *Thriving* phase it is important to note that this is not a fixed state. It can be challenging to maintain a pro-active approach and to have the space for reflection and learning. Carers commonly switch back and forth between the *Thriving*, *Managing* and *Surviving* phases.

Carers might feel...

hopeful
confident
calm
proud

Carers might need...

- Access or assistance to return to work or study
- Relationship counselling
- Social or community engagement opportunities
- A Wellness Action Plan

Is this, or has this been, your experience of the *Thriving* stage in your caring journey?

Sustaining in the Thriving phase

Many carers will reach a place of confidence and stability in their caring role, where they are able to step back from 'care taking' and see their caring role as just one aspect of their life. It is very common for carers to reach a place of 'thriving' only to be thrown back into the cycle of managing and surviving when a crisis occurs or a new obstacle emerges.

To maintain our ability to thrive in a caring role, find a way to shift your mindset towards acceptance – and to be able to create meaning from your experiences. This might come via advocacy, education, self-reflection or sharing your own learning and growth with others.

You might like to consider:

- Seeking opportunities for advocacy (working on behalf of others,)
- Finding a way to use the skills you have gained in your caring role to take you in a new life direction,
- Re-engaging with parts of yourself you may have forgotten. For example, is there a hobby you'd like to do again or a talent you'd like to develop?
- Sharing your story with other carers,
- Spending quality time with family and friends.

Life after Caring

This phase represents the end of the active caring role. Stepping out of the caring role may come about due to decisions made by the carer, decisions made by the person being supported, improvements in the health of the person being supported or the death of the person being supported.

There are many reasons why our caring role may end. Some we have control over and others are out of our hands. No matter when or why the period of active caring ends, carers will usually experience an intense and complex range of emotions.

Some carers are always in an active caring role, others move in an out of active caring and will experience the *Life After Caring* phase many times. It can be a difficult to cope with stepping in and out of active caring.

Carers might feel…

guilt frustration loss fear

Carers might need…

- Grief counselling
- Peer support
- Community connections
- Life Coaching

Is this, or has this been, your experience of the *Life after caring* stage in your caring journey?

Your life after caring

There are many reasons why a caring role may come to an end. Regardless of why we stop caring, whether it is by choice or by circumstance, there is usually immense grief associated with moving out of the caring role. Shifting our focus from looking after someone else to looking after ourselves is often difficult.

It is important to note that it's very common for the caring role to be episodic in nature – we can step in and out of caring roles. It may be that we care for different people at different times, or the same person from time to time. Adjusting from being an 'active' carer to an 'inactive' carer involves understanding the supports available to you, and being aware of your changing needs.

You might like to consider:

- Speaking with a counsellor about the end of your caring role,
- Spending quality time with family and friends,
- Connecting with peer support services,
- Reflecting on your experience as a carer,
- Sharing your story with other carers.

Action plan

After reading through the information and ideas in this workbook, you might like to choose one specific step you would like to take in relation to moving forward in your caring journey.

You can use the questions below to help plan how you will turn your ideas into an achievable action.

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.

Action: Write one thing you'd like to try

Why do I want to do this? What is your reason? What do you want to achieve?

Who will I do this with? Who might help you with this? Who might be involved?

When will I do this? Be precise as possible. Can you name a day and time?

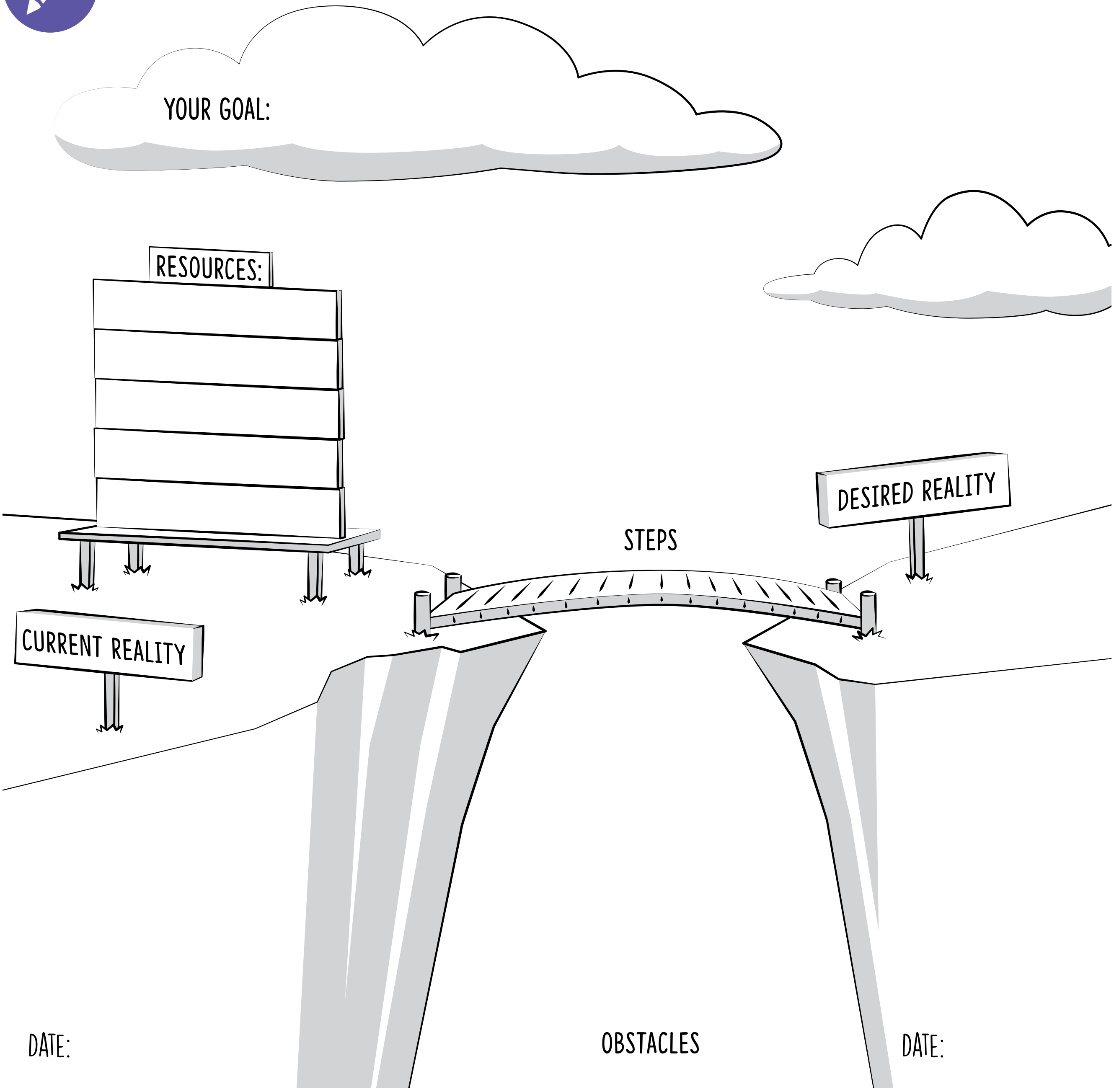
Visualising your meaningful life

Throughout this course you have been encouraged to consider many aspects of the life you currently have and the life you want for the future.

We hope to help you find practical ways to live the life you want – one that is fulfilling for you and the people you love and care for.

Another way of visualising the process towards the life you want is to use a goal planning poster.

This is great to print out, write on and stick on the fridge as a little reminder of the things you can do to create the life you want.



YOUR GOAL:
RESOURCES:
CURRENT REALITY
STEPS
DESIRED REALITY
DATE:
OBSTACLES
DATE:

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:

- The values that matter to you, such as family, hope and growth,
- How you now feel about the current phase of your caring journey.

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.

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