

A support kit for families and carers new to residential care.



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A checklist to help take care of yourself

#### Acknowledgement

'Sharing the Care – A support kit for families and carers new to residential care' was initiated by Uniting AgeWell's Tasmanian-based social worker Heidi Morton in response to the amount of carer stress she witnessed when the person they care for transitions into residential care.

Part of Uniting AgeWell's approach to mental health and wellbeing, the kit content was developed through consultation with family carers via focus groups held in Launceston and Hobart in early 2020, as well as with residents, staff and health professionals.

We are grateful to everyone who shared their experiences and advice to bring this support kit to fruition, with the aim of making it easier for family carers to access the information and supports they might need during this time of transition.

#### What is this kit for?

- > This kit is for YOU the family carer!
- > Family carer is the term used for the person in the new resident's life closest to them who acts as their point of contact. While usually a family member, they can also be a neighbour, friend or partner. Resident is the term used for the person you care for who has moved into residential aged care.
- > Everyone's focus, understandably, is on the wellbeing of the new resident.
- When a new resident moves into residential aged care this is a massive life change for them AND for their family. Family carers experience a lot of change too in role, in the ways they show love, in identity. Family carers experience new griefs and losses, fatigue, guilt, relief, concern for the person they care for, fear of the unknown, the confrontation of their own mortality as well as that of the person they care for, and dealing with existing family conflict that can flare up at this time. All of this can be difficult to recognise and cope with in the midst of this change.
- Family carers often feel they need to choose who to look after the resident or themselves and so they often will neglect themselves in order to focus on the wellbeing of the person they care for. It is important to know you can choose to look after both yourself and the person you care for and, in fact, neglecting yourself can have a negative effect on the person you care for.
- > Family carers often feel isolated and unaware that their experience is a normal and common one. They don't always realise that what they are going through is shared by many other family carers.

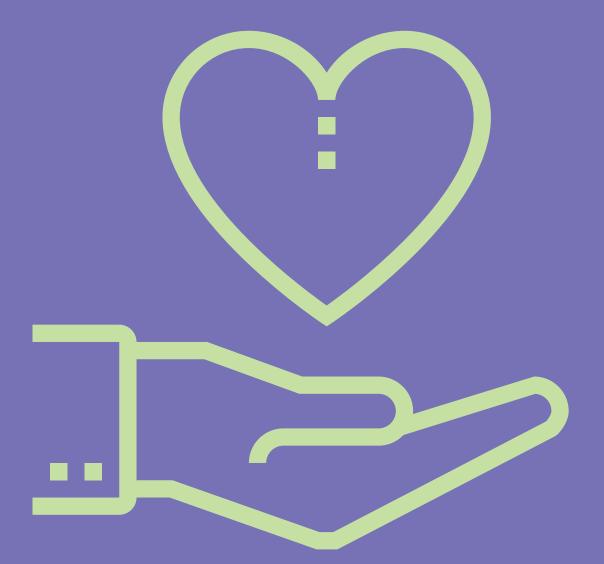
#### The purpose of this kit is to help family carers:

- > Acknowledge their own aged care experience, separate from but interdependent with the resident's experience.
- > Know that their family carer experience is normal and shared by many others.
- > Access information and resources that can help them cope with the common needs of family carers.



# My emotions are normal

How it can feel when you become a family carer for someone who moves into residential aged care



#### How am I supposed to feel when someone close moves into care?

Relief, anxiety, love, fear, grief, guilt, frustration, sadness, yearning, numbness...all these feelings are normal, legitimate, and allowed. All major change is disruptive, even positive change.

Family carers can sometimes experience what is called 'ambiguous loss' – the person they care for is physically absent (living in aged care) but psychologically present (you are thinking about them or missing them a lot); OR they can be physically present but psychologically absent (through dementia, depression, preoccupation, illness).

Having someone move into care can make us look at where we are in our own life, think about our own ageing process, our role in the family and family relationships, reconsider our own identities...and that can be confronting for a lot of people. We can feel a loss of control as all of this change happens to us and our family.

Sometimes family carers, especially those who live further away, can experience anger when the person they care for moves into care. Anger is a secondary emotion, there is usually something underneath it – guilt, fear, grief, sadness, loss, feeling out of control, unfinished business with family relationships, etc. Giving yourself permission and time to find out what is underneath the anger can help to loosen the hold it has on you and reduce the negative impacts it is having on your life and wellbeing.

You might experience a jumble of different emotions all at once. You might move between different emotions over time. You might have periods where you feel nothing.

### What do these emotions look like?

These emotions can show up in lots of different ways – tearfulness, exhaustion, headaches, muscle tension, difficulty sleeping, confusion, feeling a weight has been lifted, feeling heavy, trouble getting motivated to do anything, inability to sit still...

### Why are my emotions different to those of other people?

Different people will have different experiences and emotions at this time, depending on lots of things – their role in caring for the resident and their relationship with them; personality; history; gender; if they live local or live interstate/overseas; because of other things going on in their life. Other people may have a hard time understanding why you are feeling the way you are, especially if they have different emotional responses to you. No one is right, no one is wrong. Your feelings are your feelings and you can choose how you respond to them.

#### Family carer comments:

"Interstate family members don't understand the pressure and guilt experienced by local family carers, they say 'you don't have to visit every day, just don't do it' but they don't realise – they are able to not visit because they live far away, but I live right here so I would be making a deliberate decision not to visit; that is much harder."

"I feel guilty that I'm so relieved he has moved into care. It's not all on me anymore. I wasn't coping, but he doesn't see that."

### I don't want to have these emotions

Sometimes we try to ignore our emotions, we pretend they are not there, we keep ourselves so busy we don't have to feel them or to think about it. Sometimes we eat more or find we have no appetite at all. We might drink more than we usually do. We might work more, sleep more or have trouble sleeping, watch more tv or scroll on our phones to try and distract ourselves from the emotions that make us uncomfortable or upset. We worry that if we let ourselves have these feelings, we will fall apart.

Emotional avoidance can seem like a good coping strategy but too much of it leads to more suffering. Pretending the emotions are not there does not make them disappear, instead they get stuck and cause us more problems – we get stuck in worrying, we become depressed, our anxiety skyrockets, we become dependent on substances, we become exhausted, socially isolated, or sick.

#### Changing role and identity

If you have been providing direct care for a period of time, and that has changed now that your family member has moved into care, this is a big adjustment for you as the carer. While no longer providing the same kind of care as before, you are a vital part of the support team that is caring for your family member.

Your role has been changing as you have provided care at home and has changed again now they have moved into residential aged care:

#### Family carer comments:

"It's hard to know if others are going to judge you for putting your family member into residential aged care."

"Now I have to become 'the handyman' (or 'the gardener' or 'the cook' or 'the accountant') when I never used to do those things. My husband did all that, and now I have to."

"Even though I know it was the right thing to move dad into care, and I don't feel guilty, I do feel worn down by other family members getting upset at me about it."

"Sometimes professionals (like lawyers) don't seem to understand how much pressure and emotional strain you are under at this time and they can be irritable and judgemental that you're not on top of everything."

#### INITIAL ROLE

Husband & Wife Daughter & Father Grandmother & Grandchild

#### CARING ROLE AT HOME

Caregiver & Dependent Caregiver & Dependent Caregiver & Dependent

#### CARING ROLE IN AGED CARE

Family member of spouse in care Family member of parent in care Family member of grandparent in care

#### Family problems are normal

Family problems can be heightened and escalate at this time – conflict between siblings, sides taken, mistrust, hurt, old family issues flaring up, interstate or overseas family members and local family members experiencing the situation differently.

This happens for a lot of families, friends and carers.

We might not be able to change the situation, or fix the problem, but there are things we can do to better cope with family problems at this time.

Mediation	Relationships Australia (Tasmania and Victoria) offers mediation and counselling for older people and families experiencing conflict or difficulties around age-related issues and decisions. Senior Services or Elder Relationship Services are free in Tasmania, with fees adjusted to income in Victoria. Call 1300 364 277 to enquire or see their website for your state and click on Services.
Counselling	A counsellor can help you to cope with the problem even if others involved do not wish to address it
Work out a communication plan	Staff can only communicate with the nominated Primary Contact/Next of Kin, not multiple family members, regardless of any family issues. If there is family conflict and you are the Primary Contact at the aged care facility for the resident, work out how information will be shared with the rest of the family in a way that reduces conflict. Maybe there is someone who can pass on messages, maybe you can create a visiting schedule that means the resident sees everyone but visitors do not have to see each other.
Other tips	Try to separate your needs and interests from the solution – sometimes we jump straight to a solution and won't budge from it, when there might actually be a few different solutions we could choose from that everyone can live with.

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Now that your family member is in residential care, it can feel like you have been forced to change the way you show love – instead of doing things for your family member your primary role now is to provide emotional support, which can be a much harder thing to do. We want to 'fix' things for our loved one, but we can't take away the changes that have required their move into aged care. What helps the resident the most is when you can let them know you care, you hear their thoughts and feelings and they are allowed to have them, and they are not alone as they go through this change.

This is often a more difficult transition than it was to become a family caregiver in the home.

Your transition to family member of someone in aged care is likely to involve three broad stages (we don't move through them in a straight line, we can go back and forth over time).

#### Stage 1 – Endings

It can involve sadness, fear, anger, shock, denial, uncertainty, frustration, stress.

It is important to make room for this stage rather than leaping to problem-solving.

Often what helps is others listening to you, being empathetic, providing open communication, being positive and supportive, providing education to reduce fear, help you figure out practical supports.

### Stage 2 – Neutral Zone (the old situation has ended but everything feels unfamiliar and 'in limbo')

It can involve confusion, uncertainty, anxiety, impatience, resentment, scepticism.

Often what helps is others providing empathy, listening, encouragement, frequent positive feedback, 'quick wins' (something small that goes right, that gives a glimmer of hope that things can improve and feel better).

#### Stage 3 – New Beginnings

It can involve acceptance, commitment, openness, hope, enthusiasm.

Often what helps is others listening and being empathetic, validating, normalising, supporting you to sustain a positive outlook, open communication, celebrating wins with you.

## How do I keep myself going?

Looking after yourself is not selfish, it means you can keep looking after the person you care for



#### The importance of taking time to care for yourself

Managing the change to your life when the person you care for moves into residential aged care is a big undertaking. While the change itself may be relatively quick, the adjustment for you can take quite some time – it is a marathon, not a sprint.

#### Get a full check-up with your GP

Carer fatigue can mean your own health has been neglected for some time.

You may not have had a check-up for a while, especially if you have been caring for the resident prior to their move into residential aged care. It is important to find out if there are any underlying problems that make it harder to cope with the big life change you are going through.

Your GP can run full blood tests and use screening tools to identify and treat high or low blood pressure; thyroid problems; depression; insomnia; etc

### Get a mental health plan referral from your GP

Counselling is not just for people who have a severe mental illness or are 'not coping'. Just like you need to put petrol in your car to keep it going – we all need support for managing a big life change in order to keep ourselves going.

A counsellor can help you with things like grief and loss, significant life changes, relationship difficulties, domestic violence, sexual abuse/assault, trauma, maintaining healthy lifestyles, career development, anxiety and depression.

The most important thing is to find a counsellor you 'click' with. If you don't feel comfortable that they are the right person for you, try someone else.

Your GP might be able to give you some names of counsellors to try. Or, you can look up counsellors or psychologists in your local area and give them a call to see when they have an available appointment. Think about what you are looking for in a counsellor – gender, location, specialisation (workplace issues, LGBTQI + friendly, family problems, substance use, financial issues, etc).

Psychologists and Accredited Mental Health Social Workers are covered under the Medicare Better Access plan to provide clients with a rebate, making counselling more affordable – ask your GP for a referral as part of this plan.

#### Identify the people in your life who can support and care for you

Do you have family, friends, neighbours, colleagues who can lend you a hand (or an ear) when it gets too much on your own? Talk to these people in your life and see how they may best be able to support you. One person may be good at listening without judgement on the phone every now and then. Another person may be great at encouraging you to get out walking with them on a regular basis and spend time where you don't have to think about it all. Someone else in your life might be really good at asking if you are looking after yourself and maintaining boundaries so that you are not overwhelmed with caring responsibilities.

### How to find the counsellor for you

#### Mental Health Social Workers

AASW (Australian Association of Social Workers) has a search function on their website https://www.aasw.asn.au/ find-a-social-worker/search/

#### Psychologists

APS (Australian Psychological Society) has a search function on their website https://www.psychology.org.au/Find-a-Psychologist

### What other things can I do to look after myself?

Looking after yourself is not about 'pampering'. It is not about selfishly looking after yourself and ignoring everyone else. It is not about being indulgent.

Looking after yourself, or self-care, is a necessary part of keeping healthy and functioning.

You can't pour from an empty cup – how can you care for others if you are running on empty?

There are a range of things you can do to keep yourself well, whether it is when life is going along pretty well or when you are coping with really big changes or hard experiences. You probably already do a number of things that count as self-care without realising how much they help you to keep well and keep going. Here are some examples:

Get enough sleep

Visit the GP for a regular check up

Eat well

Join a walking group

Go to the dentist

Spend time at the beach or bush

See a counsellor

Get some help with your finances

Join a Mens Shed

Spend time with a pet

Get creative with cooking, gardening, photography, carpentry, craft...

Have coffee with a friend

Do some things you really enjoy

Get your hair done

Watch a funny movie

Plan something to look forward to

Listening to music you love

Join a choir

### Where can I get some more ideas or help with self-care?

Included in this kit on page 45 is a self-care questionnaire that will help you to identify things you already do, and give you some ideas of what else might help you to stay well.

Places that offer great information, support groups, phone counselling, and opportunities for social contact include:

Beyond Blue T: 1300 22 4636 https://www.beyondblue.org.au/

Available 24 hours a day, 7 days a week for phone counselling and support. Good source of information and resources.

Lifeline T: 13 11 14 https://www.lifeline.org.au/

Available 24 hours a day, 7 days a week for phone counselling and support. Good source of information and resources.

Carers Tas (T: 03 6144 3700) or Carers Vic (T: 1800 514 845) https://www.carersaustralia.com.au/

Get support from others who know what you are going through as a family carer (you are still a carer now that your loved one is living in residential aged care). Scroll down on the website and select your state organisation. Anglicare Financial Counselling Tas (T: 1800 007 007) https://www.anglicare-tas.org.au/ financial-counselling

Vic (T: 1800 809 722) https://www.anglicarevic.org.au/our-services/ financial-counselling/

Get some help if you are experiencing financial stress and overwhelm.

School for Seniors Tas (T: 6165 5564) https://adulteducation.libraries.tas.gov.au/courses/ For+Seniors

Vic (T: 1300 797 210) https://www.seniorsonline.vic.gov.au/ Offers great opportunities to meet people, enjoy social contact and take up a new or old hobby,

#### Dementia Australia T: 1800 100 500

https://www.dementia.org.au/support/ family-and-carers

They offer a national dementia hotline, a free information kit, and more.

#### Friendline https://friendline.org.au

For anyone who needs to reconnect or just wants a chat. All conversations are anoynmous and casual. Register your phone number online and you'll receive a call a few times a week. Alternatively you can use the online chat service between the hours of:

- 5pm 8pm, Mondays
- 1pm 4pm, Wednesdays
- 10am 1pm, Fridays

## How to avoid compassion fatigue

Signs your emotional tank is running on empty and how to top it up



#### We need to refuel and regenerate to avoid compassion fatigue

Compassion fatigue is characterised by physical and emotional exhaustion and a profound decrease in the ability to empathise. It is a form of secondary traumatic stress, as the stress occurs as a result of helping or wanting to help those who are in need. It is often referred to as 'the cost of caring' for others who are in physical or emotional pain. If left untreated, it can affect mental and physical health.

### What are signs of compassion fatigue?

**Psychological** – low concentration, hard to separate work/personal life, social withdrawal.

**Emotional** – exhaustion, negative self-image, numbness, dread, guilt, anger, cynicism, anxiety, resentment, depression, sadness, helplessness, fear.

**Behavioural** – irritable, sleep disturbance, hypervigilance, avoidance, absenteeism, increased alcohol use, relationship problems.

**Physical** – pain, jaw clenching, dizzy, restless, lowered immune system.

**Spiritual** – question life's meaning, loss of hope or purpose, increased sense of personal vulnerability.

### What are some quick fixes on the run if my tank is empty?

- Notice five things you can see, hear, feel, or smell.
- > Step outside for 30 seconds, notice the sky and trees, feel the breeze or the sun.
- Touch base with someone who cares, who makes you smile, who you trust.
- Stop and take a slow breath in count to four as you inhale, hold for four, then breathe out for four. Do this four times.

### What can drain my emotional tank?

#### External stressors

- > More work than we can cope with
- > Financial stress
- > Relationship problems
- > Illness or injury
- > Death of a loved one
- > A needy person in our work or home life

#### Internal stressors

- Lifestyle choices (eg. not enough sleep, not enough healthy food and drink)
- > Negative self-talk (eg. I always mess things up)
- Negative interpretation of events (eg. this event means this person doesn't like me)
- > Belief systems (eg. people can't be trusted)
- > Personality type (eg. empathetic, anxious)

### How can I top up my emotional tank?

Awareness – of our needs, our limits of physical and emotional resources.

**Balance** – work, rest, play – if we are flooded by too much caring work to the exclusion of all else, we are at risk.

**Connection** – to yourself, to others, and to something larger.

- Socialising with family and friends can be central to supporting a sense of who you are and keeping a balanced perspective on things.
- > Physical exercise helps to activate and regulate your nervous system by elevating your heart rate.
- Creating transitions between activities helps to keep boundaries in place – eg. have a ritual for when you leave work (sing in the car, change out of work clothes when you get home, go for a walk after work).
- Make time for reflection and mindfulness make time to check in with yourself and ask "How am I going? Am I feeling stressed? Is my tank getting empty and do I need to top it up?"
- Make time for activities that make you feel refreshed, relaxed and energised – read a book, have a bath, plan something to look forward to, watch a funny movie, cooking, building, art, nature, pets, haircut, choir, swimming, catch up with people, have time alone.

## If life is feeling hard – for me or someone l know – what do l do?

Contact numbers to get some help for you or someone you know



#### Asking for help can make a real difference

If you or someone you know is not ok and needs some help, there are people you can call.

Remember you don't have to be a medical professional to ask someone if they are ok.

#### Is it an emergency?

If you or someone else is in danger call 000. Emergency Services will contact Mental Health Services if they are required to provide assistance.

### Is serious mental health advice needed?

Mental Health Helpline: 1800 332 388 – available 24/7 (Tasmania only)

In Victoria refer to: www3.health.vic.gov.au/mentalhealthservices/ for your local service

You may wish to seek serious mental health advice when you or someone you know is:

- > Showing obvious changes in mood
- > Behaving in an erratic way
- > Seeing things that aren't there or hearing voices
- > Expressing strange thoughts
- > Is very anxious and fearful
- > Expressing suicidal ideas or thoughts

### Who can I call immediately for support?

Telephone Helplines – available 24/7

Support for anxiety and depression:

- > Lifeline 13 11 14
- > Beyond Blue 1300 22 4636
- MensLine Australia 1300 789 978
- > Wellways (Tas) 1300 111 400

Support for suicide prevention and distress from suicide:

- Standby Response, Support After Suicide 0400 183 490
- > Suicide Call Back Service 1300 727 247

#### Support for complex mental health issues:

> SANE Australia – 1800 187 263

#### Can a GP help me?

Call your GP to make an appointment – or assist the person you care about to make a GP appointment – to get help when it's all too overwhelming to manage on your own.

The GP can also make a referral and through the Better Health Program, a Medicare rebate covers most of the cost for psychologist or mental health social worker appointments.

If you have a DVA card, funding covers psychologist appointments.

#### Is there information online?

Smiling Mind https://www.smilingmind.com.au/

Smiling Mind is modern meditation for young people. It is a unique web and app-based program, designed to help bring balance to young lives.

#### eheadspace

https://headspace.org.au/eheadspace/

eheadspace is a confidential and secure space where young people aged 12 to 25 or their family can chat, email or speak on the phone with a qualified youth mental health professional.

#### Man therapy

http://mantherapy.org

Start talking about your issues in a manly way. Man therapy is a campaign designed by beyondblue to challenge the 'Aussie bloke' to address mental health issues.

#### Black Dog Institute

https://www.blackdoginstitute.org.au/resourcessupport/depression/

The Black Dog Institute is a world leader in the diagnosis, treatment and prevention of mood disorders such as depression.

### How to ask someone "are you ok?"

If you notice someone seems not themselves, withdrawn, sad, more quiet or irritable than usual:

#### Where will I ask them how they are?

- > Over coffee?
- > In a quiet room?
- > While walking together?

#### What will I say?

- > How are you?
- > Are you alright, you don't seem yourself lately.
- > I've had a hard few days, how has your week been?
- > Is everything ok?

#### What will I say I've noticed?

- > You seem a bit flat.
- > You seem pretty tired.
- > You're not saying much lately.
- > You seem to be reacting strongly to things (it's not like you).

#### What can I do to help?

Say:

- > What could I do to help you?
- > Would you like me to let someone know you're not feeling good?
- Would you like a hug? I have no idea what to do, but let's figure it out together.

Do:

> Nothing, just be there for them.

#### Things to keep in mind...

#### If the person denies there's a problem:

You are there to offer support but it is up to the person to decide how they are going to get it. Be patient. Try not to pressure them. Say 'I don't know what you are going through at the moment but I'm here to talk if you ever need to'.

#### If I'm worried about them:

It is important to do something if the person is talking about self-harm, even if you promised not to. What's most important is your support right now. You can talk with them another time about why you had to get them help.

#### If I end up saying something stupid:

Don't beat yourself up. You can just admit you said the wrong thing and say that you'd still like to try supporting them if they need someone to talk to. The most important thing is to let the person know that you care.

#### If the person is struggling to explain their emotions and what's going on:

It might take time for the person to articulate what's going on, so be patient and don't push them too much by asking lots of questions. There is support out there to help them along. Together you could talk to someone on a telephone helpline, call a GP to make an appointment or plan something nice together.

## Paperwork and sorting things out

The most important things you need to know



#### Doing what needs to be done can feel overwhelming

Centrelink, admissions paperwork, packing up the house, updating family members...all this comes at the same time as you are trying to cope with the emotional responses of the person you care for, those of other people, and your own feelings.

If you have been caring for the resident at home for some time prior to admission to aged care, you may also be experiencing carer fatigue and that alone can make it tough to cope with an overwhelming experience.

#### Here are some key things to know...

#### Centrelink

- Submitting a Nominee form enables you to act on behalf of the person you care for if you are not already their legally appointed Enduring Power of Attorney.
- Call Centrelink to update financial details and ask for a pre-admission assessment. If the person you care for has property you will be advised to complete a form (SA457 or SA485). If they have a DVA card, you will need to notify DVA. Until assessment is completed (takes up to six weeks), the resident will be paying the highest rate of fees.
- > Notify Centrelink when the lump sum has been paid (if the resident is paying one) so that fee rates they are charged can be adjusted down accordingly.
- Gifting. If the new resident has gifted assets to someone, Centrelink will count it as the resident's asset for five years from date of gifting. This means if the person you care for gifted you half their house or a lump sum of money and less than five years later they need to move into residential aged care, the government will calculate the residential aged care fees according to their full assets and that includes your half of the house or the lump sum. For financial advice and up to date financial information, it is recommended you

talk to a financial advisor with experience in aged care.

 Keep copies of everything! Sometimes things can go missing and you may be asked to resubmit to Centrelink.

#### Managing finances

You may want to talk with the person you care for about appointing an Enduring Power of Attorney (EPoA) early, when they are still capable and don't yet need anyone to assist with these things. Keep in mind that dealing with the bank, Centrelink and other institutions on behalf of the person you care for is much easier to do if you are the legally appointed EPoA rather than simply a Centrelink Nominee or Authority on their bank account.

If the resident can no longer undertake this responsibility themselves, and they do not have capacity to appoint their own EPoA, it may be necessary for you to submit an application for a Financial Administrator (FA) to be appointed.

Examples of when a legal appointment may be required to manage finances on behalf of the person you care for:

The resident can no longer physically go out to the bank or ATM to withdraw money and there is no suitable, available family member who can do it for them (residential aged care staff are not permitted to do this for residents).

- The resident no longer has the cognitive capacity to make decisions about financial transactions, cannot remember how much money they have withdrawn or where it is, and does not have a suitable, available family member to do this for them.
- > Concerns about vulnerability to financial abuse or misuse by others are raised.

#### For advice on appointing an EPoA

#### Tasmania

https://www.legalaid.tas.gov.au/factsheets/ enduring-power-of-attorney-fact-sheet

#### Victoria

https://www.legalaid.vic.gov.au/ find-legal-answers/powers-of-attorney

For advice on applying for a Financial Administrator

#### Office of the Public Guardian Tasmania

#### T: 1800 955 722

https://www.publicguardian.tas.gov.au/resources/ fact-sheets

#### Victorian Civil & Administrative Tribunal (VCAT)

#### T 1300 01 8228

https://www.vcat.vic.gov.au/case-types/ guardians-and-administrators/administrators

#### Non-Financial Decisions – about admission to aged care, medical treatment, restrictive practice and lifestyle choices

The person you care for may wish to appoint an Enduring Guardian while they have capacity, so that if at any time in the future they do not have capacity to advocate for themselves and make decisions, they have already appointed someone to act on their behalf. These decisions include things like restrictive practice (environmental or pharmaceutical measures to secure the safety and wellbeing of a person living with dementia), where to live, who to visit, what medical treatment is required, and dignity of risk decisions about activities to engage in.

If the resident can no longer make decisions for themselves, and they do not have capacity to appoint their own Enduring Guardian, it may be necessary for you to submit an application for a Guardian to be appointed.

Examples of when a legal appointment may be required to manage non-financial decisions on behalf of an individual:

- Doctors advise the person now requires the level of care available in residential aged care, they are unwilling to move into aged care, and they are medically assessed as no longer having capacity to make that decision.
- People who pose an identifiable risk to the physical or mental health of the resident wish to visit or take them out of the residential aged care facility they live in, there is no existing, registered Enduring Guardianship document, and there is family conflict.
- The person no longer has cognitive capacity to assess risk and make lifestyle choices – such as eating a favourite food that now poses a choking hazard – and requires someone to make those decisions on their behalf.
- > The person requires medical treatment that needs consent and is unconscious or unable to make this decision – this may be temporary as in the case of delirium, or permanent as in the case of dementia.
- The person has expressed end of life wishes that include not for resuscitation, no transfer to hospital or no active treatment and they are not in a position to advocate for themselves to have those wishes followed by medical personnel.

#### For advice on appointing an Enduring Guardian

#### Tasmania

https://www.legalaid.tas.gov.au/factsheets/ enduring-guardianship/

Victoria https://www.publicadvocate.vic.gov.au/ guardianship-and-administration

For advice on applying for a Guardianship order

#### Office of the Public Guardian Tasmania

#### T: 1800 955 722

https://www.publicguardian.tas.gov.au/resources/ fact-sheets

#### Victorian Civil & Administrative Tribunal (VCAT)

#### T 1300 01 8228

https://www.vcat.vic.gov.au/case-types/ guardians-and-administrators/administrators

### What if I have questions about all these forms?

If you need some help to identify what you need to do and which forms to use, contact the residential aged care facility where the person you care for has moved to and ask to speak with one of these people:

- > Admissions Officer or Client Liaison Officer
- > Residential Services Manager or Centre Manager

#### Packing up the house

Packing up house, if it is required, for the person you care for can be a daunting task.

Some immediate things that need to be done are relatively straightforward – eg. removals, re-painting, organising a real estate agent.

Other parts of this process can take a lot of time and emotional energy – sorting through belongings to identify what the resident wants to have in their room in residential aged care; what do they want to keep stored at your house or elsewhere; what do they want to pass on to particular family members; what is to be sold or sent to an op shop.

Some family carers have reported taking two years to complete this process entirely. It can bring up a range of emotional responses and experiences, it can inflame family conflict, and it can take a significant amount of your time.

Having some awareness of what this experience may be like helps you to put strategies in place to support you as you go through it.

- > Identify the tasks that are time-sensitive, what must be done by certain deadlines for financial reasons, and focus on those first.
- Identify tasks that you can complete over a longer period of time, such as removing personal items and clothes from the house and sorting through them at a different location where there is less time pressure.
- Identify the people who are supportive and who you can lean on when it all gets a bit overwhelming.
- Consider accessing counselling support, even if you do have friends and family you can talk to.
   Sometimes talking to someone who is completely independent from the rest of your life can help.
- Make time for activities that restore your mental, emotional and physical energy. It is not indulgent to do these things – these are the things that will help you to keep going.

## Help for me at home

Getting services at home (cleaning, gardening, shopping, etc)



#### Sometimes a little extra support can help you enjoy life more

There are a lot of changes for you when the person you have been caring for moves into residential aged care.

If you are over 65, you may find some extra help or services will make some of the changes in your life easier to manage.

The Commonwealth Home Support Programme or a Home Care Package could give you some useful support.

#### What is the Commonwealth Home Support Programme (CHSP) and how can it help me?

The Commonwealth Home Support Programme (CHSP) helps senior Australians access entry-level support services to live independently and safely at home. CHSP works with you to maintain your independence rather than doing things for you. The CHSP enables you to access services you need at a subsidised rate.

Eligibility for this program is based on your support needs and age.

If you're having trouble with everyday tasks and feel that a little support could improve your health and wellbeing, CHSP could be right for you. You may be eligible for assistance with domestic tasks (like housework), personal care (like showering), meals, transport, allied health (eg. physio, podiatry), nursing, home maintenance, joining a social or exercise group, to name a few.

To be eligible for this program, you must be aged:

- 65 years or older (50 years or older for Aboriginal or Torres Strait Islander people),
- 50 years or older (45 years or older for Aboriginal and Torres Strait Islander people) and on a low income, homeless, or at risk of being homeless.

If your needs are more complex, a Home Care Package could be better suited to you.

### What is a Home Care Package and how can it help me?

A Home Care Package is funding to help you pay for services that keep you living independently at home. This package is for when you need a little more help than you did before, and provides for more services than a Commonwealth Home Support Programme (CHSP).

If there are things that are not so easy any more like showering and dressing, cleaning your house, cooking meals, getting out to appointments and social activities – a Home Care Package pays for help to keep doing those things and living well at home.

Home Care Packages can help with things like:

- > Personal care help with showering, dressing, mobility, meal preparation.
- Domestic and personal support help with household chores, gardening, home maintenance and modifications.
- Clinical care nursing, medication management and wound care.
- Assistive technology remote monitoring technology, mobility aids, personal safety alarms.
- > Transport for shopping, medical appointments, social outings.
- Other services in the community may include social support, allied health (like podiatry, physiotherapy, and other therapies) and other services to meet individual needs.

#### How do I get the Commonwealth Home Support Programme or a Home Care Package?

My Aged Care coordinates all assessments and referrals for community services programs across Australia. Contact My Aged Care on 1800 200 422 or through www.myagedcare.gov.au.

If you would like information or assistance with this process, Uniting AgeWell can help – call the Uniting AgeWell team on 1300 783 435.

Once you have been allocated a CHSP or Home Care Package, you need to find a service provider to turn that funding into services and activities that meet your particular needs.

You can access the full list of providers for anywhere in Australia from the My Aged Care website

https://www.myagedcare.gov.au/find-a-provider/

The website includes helpful information including the full list of Commonwealth Home Support Programme (CHSP) services and the value of each Home Care Package. On the website, enter your postcode and any key criteria to get a list come up. You will need to ask these providers if they service your area.

Uniting AgeWell is one of the largest and most trusted home care services providers, supporting clients with CHSP services and Home Care Packages across Victoria and Tasmania. If you would like help to access the Australian Government's My Aged Care gateway, advisory and assessment service (where you can organise an assessment for care), Uniting AgeWell can do that with you, simply call 1300 783 435.

Once you have contacted a service provider they will visit you at home to talk through your needs.

Some questions you might want to ask at the initial assessment visit at your home:

- 1. How much do you charge (for each service provided, ie. domestic assistance)?
- 2. What are your Care Management or Package Management fees?
- 3. How far do you travel to reach me and will this be charged?
- 4. Can you provide all the services I have approval for? If not, which ones can't you provide?
- 5. What type of experience and level of training do your carers have?
- 6. When can you start?

## When someone close to you has dementia

The basics of dementia and how to find out more



#### Understanding and support makes a big difference

Knowing the best way to support a person with dementia, as well as looking after your own emotions, is something everyone needs help with. Even if you have some knowledge about dementia, it is not always easy to cope with when it comes to someone close to you. It is not always easy to separate the dementia from the person who has it.

#### What is dementia

Dementia describes a collection of symptoms that are caused by disorders affecting the brain. It is a terminal disease of the brain. There are a number of types that all sit under the umbrella of 'dementia'; Alzheimer's is the most common. There is also dementia with Lewy bodies, Vascular Dementia, Korsakoff's Syndrome (alcohol-related), Younger-Onset Dementia, and more. Each type can present with different features.

### Why do some people get dementia and not others?

Researchers are still looking for answers, we don't know why some people get it and others don't. However, some things are believed to contribute to developing dementia or to lowering the risk of dementia:

- Genetics some types of dementia may occur in families.
- Heart health having a healthy heart reduces the risk of dementia. This includes doing physical activity, eating well, not smoking or drinking to excess.
- Social isolation and depression people who have little social support can have a higher risk of dementia.
- > Age as we get older the risk for developing dementia increases, though dementia is not a normal part of ageing.

### What does dementia look like in everyday life?

It depends on the type of dementia, but common signs include increasingly impaired short term memory; difficulty physically moving around; forgetting words; forgetting how to complete simple tasks like making a cup of tea or getting dressed; putting objects in 'odd places'; change in personality; disinhibition (doing things you wouldn't normally do); apathy and withdrawal. For each person living with dementia, it presents in unique ways. The uncertainty around how an individual's dementia is going to play out can make it hard for them and their loved ones to cope with.

#### What does dementia feel like for the person who is living with it?

Some people are aware that things are not right while others do not have that insight.

Whether aware of their dementia or not, people can often experience dementia as scary, confusing, frustrating, or isolating, and there can be a lot of grief. Early-life emotional experiences can surface, which can be confusing for the person and for their family.

## What helps family carers to cope with the dementia behaviour changes?

Changes can include increased aggression, anxiety, agitation, hallucinations and false ideas, wandering, repetitive questions, and disinhibition.

These changes can be made worse by fatigue, pain, sense of failure and embarrassment, confusion, need for attention or reassurance.

Coping strategies for family carers can include:

- > Distraction (sharing a cup of tea, looking at a magazine together, going for a walk).
- > Avoidance of something that you notice triggers the behaviour (such as a loud tv or bright lights).
- Validating the emotions and experience the person with dementia is having. Rather than argue or try to point out why they are wrong, instead enter their reality and 'go along'. A person with dementia cannot be in denial about reality because they do not have the ability to comprehend reality like they used to.
- Redirect the conversation to things you know they enjoy and feel good about, such as happy memories or hobbies.

#### Your feelings

Family carers can experience a range of feelings, sometimes all at once and sometimes none at all. Guilt, grief and loss, frustration are just some of the feelings that can come up for you.

It is important to know this is normal and shared by many family carers supporting someone who is living with dementia. It is important to look after yourself as well as the person you are caring for.

### Where can I get information and support from?

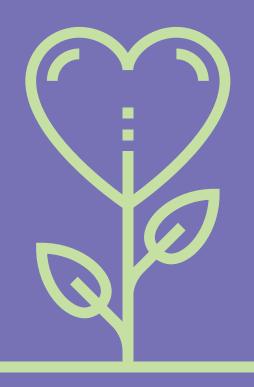
#### Dementia Australia

www.dementia.org.au T: 1800 100 500

Free and confidential, the National Dementia Helpline, 1800 100 500, provides expert information, advice and support, 24 hours a day, seven days a week.

## How can l help the person l care for settle in?

Making their room their own, validating their feelings and yours, focal points for visits



#### Adjusting to change can take a little time and positivity

When you can see that the new resident is feeling settled, safe and happy we know that helps you as the family carer too.

The transition into residential aged care happens over a period of time, and it is different for each individual. For some people it is relatively easy and doesn't take long. For others it involves a mix of intense emotions and can take quite a while.

The facility and staff will do all they can to promote a healthy adjustment at the pace the new resident needs to go to cope with this big life change.

There are also things that you, as a family carer, can do that no one else can. You know the resident in a way no one else does – their history, their likes and dislikes, what they value – and acknowledging and supporting them to have all those unique things about them continue in residential aged care will promote a sense of familiarity and comfort in their new home.

### Helping to make their room their own

Include personal effects such as photos, favourite paintings or posters, quilts, cushions, lamps, a favourite chair. Items from the resident's home can come with them into this new stage in their life, helping to bridge the gap between what they have left behind and where they are now.

Bring personal items such as preferred soap, toothpaste, aftershave, perfume. Smells trigger memory and related emotions. Familiar smells from home will promote comfort, calm and a sense of belonging. Support the resident to communicate to staff their preferred ways of doing things. For example:

- > Hanging tops on wooden coat hangers rather than folding and storing in drawers.
- Sleeping in until 8am and then having a cup of tea in bed.
- > Having a glass of whisky from a special whisky glass in the evening.
- Having photos of family, travel, pets and places they have lived on display so that staff can engage in conversations with them.

### What can I do when they are upset or distressed?

It can be upsetting and stressful for family carers when the person they care for is distressed about moving into aged care. They may not understand where they are, they might express fear about unfamiliar surroundings and people, they could become angry or tearful when they speak with you or other family members. They might blame a family member for 'putting them in aged care', or continually phone family members to say they want to go home.

These types of responses can leave family carers feeling a range of things – overwhelmed, guilty, frustrated, grieving, stressed, numb or defeated.

It can help as a start to know that:

- Their emotions, fears, or longings are all normal for someone going through such a big change, especially if it was not their choice or they are living with dementia.
- > Your emotions (whatever they are) in response, are also normal.
- > While the reasons for the move cannot be changed (their care needs are such that they now require residential aged care), there are things you can do that will help.

#### Validate feelings

Respond to the emotion behind the words. "I want to go home" is not just about a place, it is also about feelings. There can also be more than one 'home' that a person is missing, from different times in a person's life. When someone says I want to go home, they are also saying:

- > I want to feel safe and secure
- > I want to feel comfort
- > I want to feel in control
- > I want to feel like myself
- > I want to feel relaxed and have privacy from the world

Home gives all of us these things. It is the place we relax; feel nurtured by ourselves or others; where we keep our belongings and treasured possessions; a place we associate with memories and experiences from our life; a place that holds our identity and reflects who we are.

Moving into residential aged care means leaving behind the home that provided all of these things. For a person living with dementia, wanting to go home can also be about wanting to return to a time in childhood when they felt safe in the care of their parents or grandparents.

### When responding to the person saying"I want to go home"

- Try to understand and acknowledge the feelings behind the wish to go home. Most of us would feel the same. Our difficult or uncomfortable feelings are allowed.
- The person needs the support provided by residential aged care AND they are entitled to have feelings of sadness and grief about having to make this move. Both things can be true at the same time.
- Reassure the person that they will be safe. Touching and holding can be reassuring.
- Reminisce by looking at photographs, by talking about childhood and family, about happy times and experiences in their life, about loved hobbies or work they enjoyed, about things they are proud of – whatever brings them the most comfort and pleasure.
- Try to redirect them with a cup of tea, a snack, updating them on news from family or friends, or engage in activities such as a walk, listening to music, playing cards, etc.
- If the person is living with dementia, personcentred care suggests that rather than disagreeing or trying to reason with them about why they cannot go home, a supportive and ethical response is to:
  - agree that how they are feeling is normal and ok ("I understand, you want to go home, I would feel that way too");
  - let them know you care about them (with your words, body language, and tone of voice); and
  - re-direct them to happy memories, activities or a cup of tea.
- If the person you care for is living with dementia, it can be helpful to seek advice, strategies and counselling from Dementia Australia – Helpline 1800 100 500.

# Notice and acknowledge your own feelings

When the person you care for becomes upset, it can be useful to notice how your body, thoughts and emotions respond. That way you have an opportunity to reduce your own anxiety or distress and respond to the person in a considered way.

Sometimes we are not able to notice these things until afterwards, but that's ok. It is useful to reflect on how you felt at the time. It can help you to make plans for how you might handle things next time, and what you might find helpful in the meantime.

#### Notice any body sensations

Shallow breathing or holding your breath, tightened chest, faster heart rate, knotted stomach, sweating, tension in your jaw, muscle weakness or heaviness, etc. Just noticing, and reminding yourself to take slow breaths in and out, can help to calm things down.

#### Notice your thoughts

"I shouldn't have come today"...."I knew he'd do this"...."I'm a terrible daughter".... "I hate seeing her unhappy" ... "someone should fix this!"

When you are able to notice the thoughts you have, as though they are words you are reading on a screen, this allows you an opportunity to question whether they are true, if they indicate something you need to do, or if they are indicative of difficult feelings you can make space for. You might want to talk these thoughts through with a trusted friend or counsellor.

Having a response planned ahead of time can help make unhelpful thoughts not so loud next time. For example 'next time if they say this, I will say and do this'. Let them know you hear what they're saying and understand their feelings, that you love or care for them, and redirect if necessary.

#### Notice your emotions

Guilt, anger, fear, worry, no emotions at all. Being aware of what you are feeling allows you to dig down to what you need. Do you need understanding and reassurance from a close friend? Information from the staff or doctor? Rest and recuperation after having been a family carer for an extended period of time? A walk on the beach to clear some of the tension in your body? Permission to have challenging feelings?

#### Establish boundaries

Family carers, like everyone, have only so much time, mental and emotional energy. You are not a robot. If your energy runs out, you will have nothing left to give the resident or anyone else in your life. It is much harder to be compassionate and cope with the resident's difficult emotions if you are running on an empty tank yourself.

Make deliberate decisions about which day to visit, how often you visit, how long you stay for, whether you will visit at the facility or take them out, when to have phone calls and when to call back at a later time when you are not so depleted.

If you find visits can be draining, plan ahead of time to do something enjoyable for yourself after the visit – call a good friend, go for a coffee, work in the garden, have a sleep, listen to music you love, walk the dog, etc.

Communicate with staff about what you need help with. You are now part of a support team around the resident and do not have to carry all the responsibility yourself.

#### Create a focus point for your visits

There is no right number of times to visit or amount of time to stay. The important thing is to aim for making the visit as good as it can be, whatever that looks like for you and the person you care for. Visiting can sometimes be difficult, especially as the abilities of the person with dementia decline or if you have a challenging relationship.

What to try:

- > Bring newspapers and magazines to look at together
- > Reading mail together
- Play games that have been enjoyed in the past (eg cards, chess)
- > Listen to music together
- > Watch a well-loved video
- > Look at photo albums together
- > Help decorate and tidy the room
- > Help with personal grooming brushing hair, painting nails
- > Assist with writing to friends and relatives

In the later stages of dementia you can try activities that include the senses – sight, taste, smell, hearing and touch:

- > A gentle kiss or hand holding may be reassuring.
- Massaging legs, hands and feet with scented creams or oils may be enjoyable for some people.
- > The scent of perfumes and flowers may also be enjoyed.
- > A smile, a comforting gaze or a look of affection may often provide reassurance.

- Music may provide comfort and familiarity. Or listening to a favourite book or poem.
- > Visits from friends and relatives, even though they may not be recognised or remembered, can still provide stimulation and comfort.
- > A stroll around the grounds, even if in a wheelchair, may be enjoyable for both the resident and visitor.
- > Just sitting with the resident while you read the paper. You don't have to talk to make the visit worthwhile.

# How do I know the person I care for is safe?

Supports on-site, relationship and communication with you, and the national safeguards to support wellbeing and safety



#### Safe high quality care is the norm not the exception

The aged care system, quality standards, accreditation processes and ongoing monitoring, actively support services to provide safe, high quality care.

# The stories in the media frighten me

The Royal Commission into Aged Care Quality and Safety and the resulting media coverage, have been instrumental in shining a light on issues causing distress and harm for those in residential aged care. However, these stories have tended to convey to the public that the negative events depicted are common and the only story to be told.

For members of the public who don't go into an aged care facility to visit someone they know, or to work or to live, the only picture they have is one that creates great anxiety and concern.

We know family carers worry about the safety and physical, emotional and spiritual wellbeing of the person they care for, particularly when they move into residential care. There are a range of ways we support you and provide the assurance of wellbeing that everyone wants for people living in residential aged care.

#### General safety

The safety of residents is a key priority for everyone. Uniting AgeWell's organisational culture and systems are designed to facilitate the pursuit and delivery of safe, person-centred care, which encourages and embraces diversity, is inclusive of all people and respects differences.

Staff are qualified for the roles they hold and provided with ongoing training and professional development to ensure they can deliver their best. A range of measures are in place to ensure the security of the residence, including locked doors after hours; keypad access to some areas; electronic surveillance cameras at entrances, access points and some public areas; night duty staff, including an RN, and security patrols as required.

An active Health and Safety Program and systems are in place to identify and eliminate or control hazards and staff are trained to manage emergencies.

Additionally, Uniting AgeWell has a thorough infection management and control program and COVID-Safe protocols, including mandatory vaccination for all staff, volunteers and contractors.

#### Clinical governance

A strong focus on clinical governance is a priority of the Board and all leaders at Uniting AgeWell. Our reporting systems and structures ensure clear line of sight, accountability, escalation procedures and rigorous monitoring of a range of health and risk indicators. All incidents are reported and analysed and help drive continuous improvement and ensure high quality, safe services.

We strive to build relationships through open and transparent communication, respectful relationships and informed decision making where residents and/or their family carers are fully engaged in decisions relating to their care. Uniting AgeWell has an Open Disclosure policy, so any incident will always be reported. Feedback is also regularly sought and acted on as appropriate.

#### Clinical care

Most GPs with patients in Uniting AgeWell facilities are contactable or use the after-hours GP Assist service when they are not.

Uniting AgeWell has a registered nurse (RN) on-site 24 hours a day, seven days a week.

Our RNs and ENs (enrolled nurses) are approachable, empathetic and communicative and want to get to know you and the resident. The nursing team have a positive impact on standards of care – ensuring better health outcomes and fewer hospital admissions. They will advocate for residents to support quality of life and general wellbeing.

The Care Manager or Senior Care Manager on-site oversees the nursing staff and makes it a priority to connect with family carers and act as the point of contact for any queries or concerns. You will meet with them (by phone or in person) at the postadmission case conference to check on how the person you care for is settling in and address any questions or concerns.

## Goal directed care plans

Under the Aged Care Standards, all residents are required to have a Goal Directed Care Plan in place. This provides a plan for each resident based on their individual needs, goals and preferences and is developed in collaboration with the resident or their family or representative. These plans are reviewed and updated every three months or as required, to ensure staff know the individual choices, needs and wishes of each resident. The resident and or their representative is offered a copy of their care plan.

# Resident and family meetings

Monthly resident meetings are held at each facility, giving residents the opportunity to provide feedback, ask questions, receive updates on news and developments around the facility, and to have their voices and priorities heard. A variety of staff attend the meetings and make themselves available to engage with residents on issues that matter to them. Minutes are taken and action items responded to by relevant staff. Family carers are welcome to attend resident meetings.

A post-admission case conference is held four to six weeks after a new resident moves in – over the phone, via video, or in person. The purpose of this meeting is to focus on the resident's needs, priorities and experiences; identify any issues that require action; to ensure family carers can contribute to the care and support of the resident; and make sure there is a shared understanding amongst all concerned, of what matters most to the resident. Family carer meetings can be requested at any time and aim to address any issues of concern with a collaborative approach. These meetings will be attended by whomever is most relevant to the discussion, for example the resident, family carers, nursing staff, lifestyle staff, allied health, hotel services, etc.

# Mental health and emotional wellbeing Leisure and Lifestyle

The Leisure and Lifestyle teams focus on getting to know the resident from the day they arrive. Spending time getting to know who someone is helps us to identify what brings them joy and meaning, what they find soothing and comforting, and what their values are. This enables us to link them in with like-minded fellow residents and tailor activities and supports suited to their needs. When staff have a strong understanding of the resident, it makes it easier for us to notice if they seem not quite themselves and perhaps are in need of some additional support.

We offer activities for large groups, small groups, one on one, outings, community visits onsite, entertainment visits onsite, special events at the facility and culturally-supportive resources and activities. This ensures everyone is catered to in terms of their personal needs for social engagement and emotional support.

You are an important part of this circle of support. Our relationship-based approach includes you as family carer along with nursing, care and allied health staff, kitchen and cleaning staff, the lifestyle and chaplaincy teams, and administration and maintenance staff.

# Chaplaincy, spiritual care and respect

We all know that stress and anxiety can impact emotional, spiritual and physical wellbeing. Our chaplains, pastoral volunteers and faith leaders from the community are an important source of support and guidance for residents and their families during every-day and more significant times of need.

Chaplains, with your help, enable residents to transition from living in their own home to settling into a new home. They understand the grief and loss associated with such moves, and the questions that arise, such as 'will people respect who I am, value the things that are important to me, and take time to get to know me and what gives me strength and hope, even amidst life challenges?'

The provision of spiritual and religious care at Uniting AgeWell is to nurture the inner world or the spirit of each resident in accordance with their religious, spiritual, or secular beliefs. Individuals have the choice to guide whether they wish that care to be through religious tradition and ritual, or through spiritual and secular practices. Uniting AgeWell seeks to provide a spiritually safe environment, in which every resident knows their religious or spiritual beliefs and needs can be expressed and will be respected.

Chaplains meet residents individually and in small group discussions that connect residents to each other. They ensure different religious church services are provided as required, and are companions through quiet reflection and conversations, and when residents are facing physical, social, emotional, and spiritual life changes.

### Social work support

Uniting AgeWell social workers provide support to residents and family carers across Uniting AgeWell facilities. The social workers can assist with a variety of issues affecting residents and family carers, including the transition to care experience, dementia support, anxiety and depression, family conflict, financial and guardianship issues, Centrelink requests and more. The social workers contribute to suicide intervention assessment and planning, short-term counselling, case management collaboration, and liaison with and referral to external services for a variety of supports (eg. mental health, LGBTQI+, culturally-sensitive resources).

Social workers can facilitate resident peer support groups and engage in advocacy in an empowering and person-centred way for residents.

## Aged Care Quality Standards

Organisations providing Australian-Government funded aged care services are required to comply with the Aged Care Quality Standards (Quality Standards) to ensure the care and services they deliver are safe, high quality and meet the needs and preferences of the people under their care.

Providers are assessed and must be able to provide evidence of their compliance with and performance against the Quality Standards in order to achieve and maintain accreditation.

Each of the Quality Standards is expressed in three ways:

- > a statement of outcome for the consumer
- > a statement of expectation for the organisation
- > organisational requirements to demonstrate that the standard has been met.

The Quality Standards focus on outcomes for consumers and reflect the level of care and services the community can expect from the aged care provider.

From 1 July 2025, strengthened Quality Standards will be introduced that cover the person; the organisation; care and services; environment; clinical care; food and nutrition; and the residential community.

For more information on the Quality Standards go to www.agedcarequality.gov.au

### Star Ratings

The Star Ratings system applies to residential aged care homes across Australia.

The ratings provide information about the quality of care an aged care home delivers and how they compare to others. They are designed to help you make informed choices about your aged care.

The Aged Care Quality and Safety Commission is responsible for the Compliance Rating and the Department of Health and Aged Care handles the ratings which cover quality measures; residents' experience and staffing minutes.

Compliance ratings are updated daily, immediately impacting a provider's Star Rating.

For more information on the Star Ratings go to http://www.agedcarequality.gov.au

### Serious Incident Response Scheme (SIRS)

The Australian Government introduced a new scheme from 1 April 2021. Called the Serious Incident Response Scheme (SIRS), it is an initiative designed to enhance transparency in the aged care sector, which in turn will help reduce the risk of abuse and neglect of people receiving aged care services.

The scheme requires aged care providers to identify, record, manage, resolve and report (via a government web form) all serious incidents that occur, or are alleged or suspected to have occurred, in a residential aged care service.

If you become aware of, or suspect a serious incident has occurred, please speak with the RN, Care Manager, Senior Care Manager, or Residential Services Manager at your facility so that appropriate action can be undertaken. Serious incidents include things such as unreasonable use of force, unlawful sexual contact/conduct, psychological or emotional abuse, unexpected death, stealing or financial coercion, neglect, inappropriate physical or chemical restraint, and unexplained absence from care.

For more information, please see this website: https://www.agedcarequality.gov.au/sirs

## National Aged Care Mandatory Quality Indicator Program

It is a requirement of the Australian Government that residential aged care facilities report on a number of key clinical indicators. Quality indicators measure important aspects of quality of care that can affect a resident's health and wellbeing.

These include: pressure injuries; physical restraint; significant unplanned weight loss and ongoing unplanned weight loss; falls and major injuries; those prescribed nine or more medications (polypharmacy); and those prescribed antipsychotic medication.

This means a resident's clinical status is consistently and regularly reviewed. Any changes are identified, reported to the government, communicated to the resident/family, and response plans developed, implemented and evaluated. For more information, please see this website:

https://www.health.gov.au/initiatives-andprograms/national-aged-care-mandatory-qualityindicator-program

# Family & carer self-care assessment

A checklist to help take care of yourself



This worksheet for assessing self-care offers ideas rather than a list of 'must do' activities. Feel free to add areas of self-care that are relevant for you and rate yourself on how often and how well you are taking care of yourself.

When you are finished, look for patterns in your responses.

Are you more active in some areas of self-care but ignore others? Are there items on the list that make you think, "I would never do that"? Listen to your inner responses about self-care and making yourself a priority. Take particular note of anything you would like to include more of in your life.

Rate the following areas according to how well you think you are doing:	Psychological self-care
3 = I do this well, frequently 2 = I do this ok, every now and then 1 = I never do this ? = this never occurred to me	<ul> <li>Take day trips or weekends away</li> <li>Make time away from phones, email and the internet</li> <li>Make time for self-reflection</li> <li>Notice my inner experience – listen to my</li> </ul>
Physical self-care	thoughts, beliefs, attitudes, feelings See a counsellor
<ul> <li>Eat regularly (eg breakfast, lunch and dinner)</li> <li>Eat healthily</li> <li>Exercise</li> <li>Get regular medical care for prevention</li> <li>Get medical care when needed</li> <li>Take time off when sick</li> <li>Get massages</li> <li>Dance, swim, walk, run, play sports, sing, or do some other fun physical activity</li> <li>Take time to be sexual</li> <li>Get enough sleep</li> </ul>	<ul> <li>See a counsellor</li> <li>Write in a journal</li> <li>Read books or magazines that are unrelated to caring for my loved one or to my work</li> <li>Do something at which I am not expert or in charge</li> <li>Attend to minimising stress in my life</li> <li>Engage my intelligence in new areas, eg. go to an art show, sports event, theatre</li> <li>Be curious</li> <li>Say no to extra responsibilities sometimes</li> <li>Other:</li> </ul>
Wear clothes I like Have holidays Other:	

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Emotional self-care	Relationship self-care
Spend time with others whose company I	Schedule regular dates with an important
enjoy	person in my life
Stay in contact with important people in my	Schedule regular activities with my children
life	(if relevant)
Give myself affirmations, praise myself, feel	Make time to see friends
proud of myself	Call, check on, or see my relatives
Love myself	Spend time with animals or pets (if relevant)
Re-read favourite books or re-watch favourite	Stay in contact with faraway friends
movies	Make time to reply to personal emails and
Identify comforting activities, objects, people,	letters; send holiday cards
places and seek them out	Allow others to do things for me
Allow myself to cry	Enlarge my social circle
Find things that make me laugh	Ask for help when I need it
Express my outrage in social action, letters,	Share a fear, hope or secret with someone
donations, marches, protests	l trust
Other:	Other:
Spiritual self-care	Workplace or professional self-care (if relevant)
Make time for reflection	Take a break during the workday (eg lunch)
Spend time in nature	Take time to chat with co-workers
Find a spiritual connection or community	Make quiet time to complete tasks
Be open to inspiration	Identify projects or tasks that are exciting and
Cherish my optimism and hope	rewarding
Be aware of non-material aspects of life	Set limits with clients and colleagues
Try at times not to be in charge or the expert	Balance my workload so that no one day or
	balance my workload so that no one day of
Be open to not knowing	part of a day is 'too much'
Be open to not knowing Identify what is meaningful to me and notice	
	part of a day is 'too much'
Identify what is meaningful to me and notice	part of a day is 'too much' Arrange work space so it is comfortable
Identify what is meaningful to me and notice its place in my life	part of a day is 'too much' Arrange work space so it is comfortable Have someone I can talk to
Identify what is meaningful to me and notice its place in my life Meditate	part of a day is 'too much' Arrange work space so it is comfortable Have someone I can talk to Negotiate my needs
Identify what is meaningful to me and notice its place in my life Meditate Pray	part of a day is 'too much' Arrange work space so it is comfortable Have someone I can talk to Negotiate my needs
Identify what is meaningful to me and notice its place in my life Meditate Pray Sing	part of a day is 'too much' Arrange work space so it is comfortable Have someone I can talk to Negotiate my needs Other:
<ul> <li>Identify what is meaningful to me and notice its place in my life</li> <li>Meditate</li> <li>Pray</li> <li>Sing</li> <li>Have experiences of awe</li> </ul>	part of a day is 'too much' Arrange work space so it is comfortable Have someone I can talk to Negotiate my needs Other:
Identify what is meaningful to me and notice its place in my life Meditate Pray Sing Have experiences of awe Contribute to causes in which I believe	part of a day is 'too much' Arrange work space so it is comfortable Have someone I can talk to Negotiate my needs Other: <b>Overall balance</b>
Identify what is meaningful to me and notice its place in my life Meditate Pray Sing Have experiences of awe Contribute to causes in which I believe Read inspirational literature or listen to	<ul> <li>part of a day is 'too much'</li> <li>Arrange work space so it is comfortable</li> <li>Have someone I can talk to</li> <li>Negotiate my needs</li> <li>Other:</li> </ul> Overall balance Strive for balance within my work-life and

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Other areas of self-care that are relevant to you:				

Adapted from Saakvitne, Pearlman & staff of TSI/CAAP (1996). Transforming the pain: a workbook on vicarious traumatization

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Uniting AgeWell is an organisation of the Uniting Church in Australia

