

## **FACES NEWSLETTER**

#### Editorial - February 2020 Issue

Can you feel the freshness in the air? Perhaps it is the New Year, with all the new opportunities I am sensing? Or maybe, like lots of carers, I am just wishful and hoping the next wind will miraculously change my circumstances.



I made the decision at the end of 2019, that I wasn't going to bring forward any of the baggage from 2019 into 2020. I think that was a good decision. Although, sometimes these decisions get challenged! But I am still determined that I am moving forward with a fresh slate and the opportunity to create a better life for myself and my loved ones.

And as I was considering how I want to show up in 2020, it was actually a picture, a fleeting image in my mind, which I saw of myself that helped me to become grounded and focused.

I don't know about you, but I love it when you get a picture in your head and it just has this creative power about it. It resonates with your spirit. It points you in a direction, kind of like when you line up the greyhounds and put the rabbit on the runner in front of them. There is this something that is drawing you forward towards what you hope will be a better future.

If you don't have a 'rabbit' in your life, it tends to be the 'same old, same old', I find. I would encourage you to take some time out early in the year to find your 'rabbit', that something that excites you just a little that you can chase after this year.

I talk about 'Carer's Fatigue' in this issue and I think one aspect of this is losing yourself in your caring role and no longer having your own plans and projects. Lisa will be talking about living with uncertainty, as well. Both of these subjects are critical factors in not only surviving but thriving as a carer. Sadly, if you are not central to your story, then it is not a story about you.

Some food for thought as we step into this New Year.

Hayley | A/Peer Work Coordinator



- Living with Uncertainty
- Creative Expressions Poetry
- Find a Word
- Managing the Rescuer in Me
- What's in a Name?
- Recovery Rocks Community Inc
- I Didn't Realise I Needed Support
- A Guide to Supporting Recovery
- Carer Fatigue

# MHPHDS CARER SUPPORT SERVICES

**Older Adult Carer Support Group** 

Lower West meets monthly at 6 Lemnos St, Shenton Park. For carers of a person with mental illness or behavioural difficulties related to dementia, who reside in the Lower West. To attend, contact Lower West OAMHS Social Work Department or Carer Liaison and Education Service on 9328 0800.

Mirrabooka Carer Support Group meets on the **3rd Tuesday** of every month.

Osborne Park Carer Support Group meets10am-12pm, 2nd Monday of every month, (starting 8 Oct, 2019)

Sir Charles Gairdner Hospital Inpatient Unit Carer Support Group for carers of inpatients only.

Osborne Park Hospital Community
Clinic, Mirrabooka Community
Clinic Carer, Joondalup
Community Clinic Carer Peer
Support Workers - available upon
request, ask the case manager.

Youth Hospital in the Home (HiTH)
Carer Support Available upon
request, ask the social worker.



### February 2020

#### **Self-Care Tips**

Living with Uncertainty
by Lisa | Carer | Lower West Community Clinic

The human mind enables us to make plans, invent things, coordinate actions and analyse problems, so it is not surprising that we have high expectations of control in other arenas as well.

Personally, I have always tried to control situations for the one I care for so they can feel safe, calm and are not triggered by anything.

In a way, my worry helped me to try and predict life and be prepared, when in reality worrying had not made anything more certain or predictable. So, it was of no surprise that this resulted in me becoming extremely anxious and my own health suffering.

Our primary motivation in trying to control our uncertainty is to avoid unpleasant situations. However, this only causes us intense anxiety which creates more problems.

Let's face it, if these things were that easy to control, wouldn't we all just live in perpetual bliss?

Life is full of uncertainties but we have to learn to tolerate uncertainty and 'cross that bridge' when or if it comes.

Three strategies that helped me learn to live and accept uncertainty were:

#### Being aware

Acknowledge the presence of worries about being uncertain. What are you trying to control? Can you do anything about it today? If not, then let it go.

#### Let go

Do not engage with your worries or try to control everything. Let your worries float by like clouds in the sky rather than pushing them away. The feelings of uncertainty are unpleasant, unhelpful and a drain on your energy. With our uncertainty switched off we do not waste time and energy fighting or trying to avoid certain situations.

#### Practise mindfulness

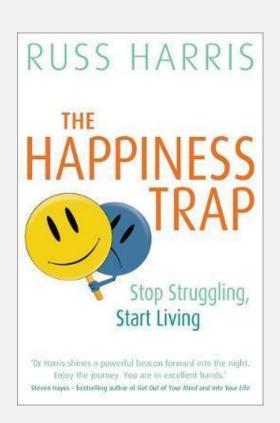
Mindfulness is a type of meditation that helps people to focus on the present moment. People just notice whatever they are experiencing, including good or bad thoughts, without trying to change them. Mindfulness helps people to change their state of mind so that they can experience what is happening right now.

People who are intolerant to uncertainty often worry about future events, so by focusing on the present this stops their minds wandering off into thoughts about the future or past. It may also help to prevent people from behaving in unhelpful ways as they try to avoid unpleasant thoughts, feelings and situations. Focus on the present and do what you can today.

Remember, you may not be in control of what the final outcome can be, but you are in control of your actions and the directions you take today.

#### Reference:

Book: *The Happiness Trap* by Dr Russ Harris www.cci.health.wa.gov.au



#### **Creative Expressions**

## The Sad Saga of Arbuthnot's Tongue by Norm | Consumer

When Arbuthnot was very young, He had a palpitating tongue; It wiggled to, it waggled fro Wherever he was wont to go.

"Tis clearly quilsy", was the word From doctor one.
"But that's absurd!"
Cried doctor two when he had heard.

"Why, nothing like it has occurred.
This tongue is wracked with auto-motion,
To be relieved with static potions
Which, painted on three times a day,
Will make it work the normal way".

Doctor one was most upset:
"Don't heed this popinjay as yet;
The laddie needs an operation —
His ping-pong motor's gone berserk;
It must be spliced t make it work."

"Spliced, indeed!" quoth doctor three, "You'd better leave it up to me.
Just listen how his speech is slurred.
Hs roto-rolo groove is burred;
He needs a new and rustless ping,
More than any other thing.

The quarrel raged for hours long, With none admitting he was wrong; Until at last, they did insist In calling in a specialist.

There came a man, not old, not young, Who specialized in only tongue; He pushed, he pulled, he probed, he pawed, He measured it with bits of cord.

He x-rayed it in stereo (In glowing colour, too, you know). He hemmed, he hawed, he coughed, he frowned, He made a little clicking sound.

At last he wiped his weary brow.
"I've found the trouble, anyhow.
You've heard of folks whose tongues get tied;
This lad is on the other side.

His waffle baffle pin is stuck, Which makes his tongue run quite amok. It's not at 'stop', it's not at 'rest' (Which really is the place that's best).

To keep it at its constant toil Requires a large amount of oil. His spigot sprocket's leaked a lot Which makes his motor run so hot. The oil supply is nearly gone, Which causes him to waffle on.

Now, Arbuthnot's a normal lad, Sometimes good, more often bad; Yet, sad but true, it must be sung – He has an oil slick on his tongue.

## Find the Word – Physical Activities

jog	knit
surf	crochet
bike ride	gardening
ski	Skate
run	fly
jump	paraglide
dance	rollerblade
float	bungy
punch	kayak
box	karate
trampoline	bowl
snowboard	bounce

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#### Let's Talk About It

#### Managing the 'Rescuer' in Me Hayley Solich | A/Peer Work Coordinator

I don't know if I am speaking for other carers, but certainly in my own life I have been plagued by the behaviours of a 'Rescuer'. You know, you see a situation and you want to be helpful, so you do whatever is required to make the situation resolve.

Enabling is what the Rescuer does. The definition of enabling here is the unconscious encouragement of another's disability. 1

For me, that has meant giving ground on important issues, sometimes compromising my personal values, because I wanted that resolution so badly. And I think if I am really honest, at the time, I unconsciously needed to be needed just as much as the person I was caring for needed me.

It has also meant trying to do more than was probably helpful for the person that I loved and was providing with care. It has meant that I stepped forward when I should have stepped back; that I controlled or assisted in good faith, when I should have facilitated independence.

The problem is that often my 'Rescuer' behaviours resulted in negative consequences for myself and interfered with the development of independence or autonomy for the person I was providing with care

So, when do we step back and when do we step forward as carers? What is helpful support and what is unhelpful support?

I had a wonderful conversation with **Kerry James, Senior Occupational Therapist** at Osborne Park Community Mental Health Clinic, who provided me with a balanced perspective on this subject.

Here are some questions you may want to consider in deciding if you would like to make the switch from 'Rescuer or do-it-for-them' to 'facilitator'.

- 1. What are the outcomes or risks associated with not helping? Is there a threat to life or limb? Would there be any negative long-term consequences? E.g. the person doesn't want to go to an appointment. Do you call and reschedule for them or do you let them do it themselves? If they don't call, how will that impact on future service access or health? If you call for them, does this cause them to respect or disrespect the service opportunity?
- 2. What is the perception or view of the consumer? What would they like to be able to do for themselves now, or work towards into the future? What do they want from you? What don't they want from you? E.g. you think that the consumer needs you to monitor their medications to make sure that they are taking them on time. The consumer is committed to taking their medications on time and feels that you are interfering and nagging them by reminding them. They feel you don't trust them. They would prefer that you leave them to get on with it, as you already organised a Webster pack so they know when to take it.
- What is the relationship with the Guardianship consumer? ls it а arrangement or informal caring relationship? I.e. a Guardianship is in place because there are limitations for the individual to effectively carry out these tasks and it is important that responsibilities vou fulfil the of the arrangement as a Guardian or carer. An depends informal agreement the relationship between the carer and consumer. How does your role in assisting the person impact on your personal relationship?

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https://www.psychologytoday.com/au/blog/traversing-the-inner-terrain/201104/the-rescuer-identity

- 4. **Do they have capacity?** I.e. some consumers may lack insight into their own abilities and so may not be able to see or understand their circumstance.
- 5. Is the level of care necessary? Have they recovered sufficiently for you to wind back your level of care and hand over responsibilities in a measured way? And is now a good time for a review? I.e. People change and do recover over time to the level of their own ability. It is good to reflect and review regularly to ensure you are not over caring and hindering the person's recovery.

Kerry reminded me that recovery and growth is very different for every person, so there are no hard and fast rules. It is personalised. The time taken and the level of progress can vary significantly, so be mindful of expectations on yourself, the person you care for and where the person is in their recovery or life.

It is also important to remember that roles do change over time and the level of need may reduce, especially with young people as they mature and develop life skills.

If the consumer in your life desires more independence, I suggest that after considering these questions, and if appropriate to your circumstance, start the journey to independence.

As you are facilitating independence, remember that some people may interpret your supervision of tasks as interference. The person's recovery, their individual needs and aspirations, level of risk and your relationship should guide the level of support required.

And finally, remember that you also matter in this equation. If you are able to wind back your level of care through facilitating greater independence or identifying other ways for the person to obtain support (i.e. external community organisations or voluntary groups etc.), you create space for yourself. What could you do with that time and energy?

I recently returned to work after an extended period of caring. It had become really tough mentally, as we were both frustrated by the situation due to physical health complications.

What I realised was that work afforded me time away and time away is as important as time together in any relationship. It just reminded me that as carers we often have a hard gig and it can be difficult to maintain our own identity. It is important to remember that there is life after caring and it is valuable to retain yourself in this process and not give everything to others.



#### **Carers Sharing Stories**

What's in a name?
by Lisa | Carer | Lower West Community Clinic



I had never thought of myself as a carer. I was Mum and just doing what mothers do when they have someone in their family who is not well. I was taking care of them!

So, it came as a shock when a clinician mentioned to me that I was eligible for the <u>Carers Allowance</u><sup>1</sup> since I was a full-time carer. Somehow being labelled a carer didn't feel right.

My understanding of a carer was someone who is trained and gets paid for looking after a person with a disability, when in fact these are 'carer support workers' or 'personal support workers'. Not me struggling to cope in this very hard role that at times I felt ill-equipped to do. However, the more I thought about it I soon realised that I was in a unique position that went beyond normal mothering. I began to understand my new role better. It made sense and helped me to separate my two roles.

According to Carers Australia, a carer is someone who 'provides unpaid care and support for a family member and/or friend who has a disability, mental illness, chronic condition, terminal illness, an alcohol or drug issue, or the frail and aged. These are what is known as 'informal carers' There are 2.7 million of us in Australia that provide this unpaid care and support for a loved one.

The Mind Report 2015 indicated that Informal mental health caring (unpaid hours of support provided by carers to people with mental illness), "...would cost \$13.2 billion to replace informal mental health care with formal support services".

It is easy to see that our informal caring work adds great value to the community.

Our journey is a difficult one. Having the term carers and consumers turns natural supports into one-way roles and often the one you support may not relate to the term carer and find it detrimental.

It is a continuous balancing act, I find. Showing care but not being over involved. Giving your time and having time for yourself and others in your family. Helping them but making sure they are as independent as possible. Helping them, but enabling not them. Accepting that you can only do your best and you are not perfect.

#### So does it matter what term we use to describe this role we play?

For me it validates the unique situation we find ourselves in. It acknowledges and recognises our efforts to support a person who struggles with mental health issues.

I will always be mum but one day I hope not to be a carer.

1

https://www.servicesaustralia.gov.au/individuals/services/centrelink/carerallowancehttps://www.servicesaustralia.gov.au/individuals/services/centrelink/carerallowance%20

### **Showcasing Carer Support Services**

Recovery Rocks
by Hayley | A/Peer Work Coordinator
Mental Health Matters 2

Looking for a community of people with experience of mental health challenges to connect with and support the recovery journey of the consumer in your life?

**Recovery Rocks Community Inc.** is a community of people who have experienced mental health challenges and are choosing to live a life of Recovery and Wellbeing.

The vision for this group is to 'foster a Peer Led and Peer Run Mental Health Recovery Community.' (Recovery Rocks Community Inc., 2020)

The purpose of this community is to 'strengthen their diverse community through peer support and lived experience of mental health recovery.'

Recovery Rocks Community Inc. offers the following:

- Informal peer support
- Monthly social gatherings
- Members forums
- Recovery education
- Monthly newsletters
- Opportunities to volunteer



Recovery Rocks Community Inc. relies heavily upon their volunteers to run their programs, as it operates 100% on volunteer power.

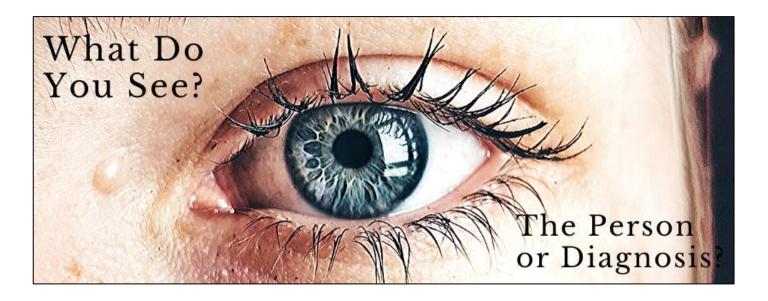
If you have time to spare and would like to get involved, there is a commitment to ensure that all volunteers are valued and appreciated by providing resources, induction, training and support.

To discuss your interest in finding out more about volunteering with Recovery Rocks Community Inc., please call 0447 641 122 or email <a href="mailto:our.recovery.rocks@gmail.com">our.recovery.rocks@gmail.com</a>

More information:

Website: <a href="https://www.recoveryrockscommunity.org">www.recoveryrockscommunity.org</a>

Facebook: RecoveryRocksCommunityInc



#### **Carers Sharing Stories**

#### I Didn't Realise I Needed Support Anonymous Carer Story

I was caring for family members with mental illness and addictions. I was really starting to feel the pain and the pressure. The cracks were starting to show. There were times when I cried myself to sleep. I was so stressed and irritable. I felt helpless to change the situation. All my mind could focus on was what my family members were doing. It was causing us all so much distress, as I felt compelled to confront them all the time.

I was having trouble sleeping. I would lie awake and my head just went round in circles. There were so many questions looping in my mind like... "If only I had..." or "I should have..." etc. I was continuously beating myself up and I couldn't separate my family member from their issues. We were constantly bickering and fighting because of my expectations and their reaction to them.

There was also this domino effect on other family members and I was carrying their reactions and pain as well as my own.

By the time I asked for help, I was ready to walk away. I was tired, tense and miserable. I'd put my whole life on hold and it felt like there was no appreciation for me or the impact the situation was having on me. I was almost done with everything. My body was starting to break down too, as I kept getting sick because of the stress. I just felt trapped.

Fortunately, it was around this time that I was introduced to a carer support group.

I vividly remember the first time I attended. I remember thinking to myself on the way there, "I don't belong in this group. I'll just go this once to get them off my back." I was in denial and self-sabotaging because I was clueless about what I really needed and not wanting to own my situation.

At that first meeting the lady sitting next to me was new to the group. She talked about how her partner had an injury and the impact it had on her because of his incapacitation.

The support group leader called what she was experiencing *ambiguous loss*. It was the first time I could put a name to what I was feeling and I realised I was grieving the loss of our former life with my family member.

I could relate to everything the lady next to me shared. And when it came my turn to speak, I broke down for the first time publicly and let others know how deeply I was struggling.

Immediately, I felt the empathy of the whole group who held space for me to work through my emotions. Suddenly, I was not alone on this journey. There were others who were experiencing the same or similar frustrations and pain. I cried my first real tears of understanding of the reality of my situation.

I realised then that I was a carer and that a carer support group was actually really worth my time investment. As much as I didn't want to face it because of the stigma associated, I realised I belonged to this group of courageous women and a few occasional men.

After the group, I was also referred to a carers' community organisation (MIFWA), who host carer retreats and carer wellbeing programs regularly. Before I knew it I was booked into a weekend retreat for carers of people with a dual diagnosis of mental health and drug or alcohol use issues. At that weekend I learned how to separate my family member from their behaviours and condition. I saw my family member again, not just the frustration of their behaviours. It was life changing.

If you are caring for someone and starting to fell burnt out, I would encourage you to talk to someone about it. I am glad that I did.

#### Let's Talk About It

#### A Guide to Supporting Recovery

**Excerpt from Australian Health Ministers' Advisory Council flyer,** Consumer & Carer Guide to Recovery Principles that Support Recovery-Oriented Mental Health Practice

As carers we often try to manage our lives as best we can with limited knowledge or understanding of how we can help or hinder our loved ones recovery process.

The National framework for recovery-oriented mental health services defines personal recovery as 'the consumer is able to create and live a meaningful and contributing life in a community of choice, with or without the presence of mental health issues.'

Here are some reflective questions to help you work out if your loved one is receiving recovery-oriented care.

These reflective questions provide carers with a recovery principles approach to ensure that mental health services facilitate the recovery journey.

# 1. Uniqueness of the individual

- Am I supporting my consumer to build on their unique strengths and promote selfresponsibility?
- Am I supporting my consumer to ensure their physical health needs and overall wellbeing are being supported?

- Am I experiencing staff sensitivity to cultural, religious and social needs of my consumer? - Am I being given the opportunity to discuss the consumer's experience of trauma?

#### 2. Real Choices

- Am I ensuring my consumer is provided with sufficient information to make informed choices about care and treatment and future planning?
- Am I engaged in discussions about difficult choices with the service provider?
- Does the service try to understand difficult choices from my consumer's perspective?

#### 3. Attitudes and rights

- Am I ensuring my consumers legal and human rights are advised, respected and promoted?
- Does the service provider convey an attitude of respect and a desire for an equal partnership?

#### 4. Dignity and Respect

- Do I feel welcomed to the service, and continue to feel welcomed?
- Does the service make the environment physically and emotionally safe for me?
- Does the service listen to and support my

consumer with their recovery goals?

## 5. Partnership and communication

- Does the service proactively involve my consumer and I in all aspects of care planning and treatment with a recovery focus?
- Am I proactively linked with other services and supports to help me achieve my recovery goals?

#### 6. Evaluating recovery

- Am I involved in the review of my consumer's recovery goals?
- Does the service evaluate their recovery outcomes and use them to drive service quality improvement?

Excerpt from Australian Health Ministers' Advisory Council flyer, consumer & Carer Guide to recovery principles that support recovery-oriented mental health practice.

# Other Carer Support Services

Helping Minds (08) 9427 7100 Carers WA 1300 227 377 MIFWA 9237 8900 HTTPS://WWW.SANE.ORG/INFORMATION-STORIES/THE-SANE BLOG/CARING-FOR-OTHERS/AVOIDING-CARER-BURNOUT

# Six Common Symptoms of Carers Fatique

DO YOU RELATE TO THESE IN YOUR CARER JOURNEY?

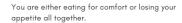




#### 1.) PHYSICAL EXHAUSTION

You feel tired most of the time and may even feel as though you are not able to complete tasks to the same standard you once did.

#### 2.) CHANGES IN APPETITE







## 3.) CHANGES IN SLEEPING PATTERNS

You can't sleep or you don't want to get up.

#### 4.) LOWERED IMMUNITY

You don't understand why you keep getting sick.





#### 5.) FREQUENT HEADACHES AND TENSION | INCREASED CYNICISM & NEGATIVE VIEW OF THE SITUATION

You feel wound up like a coil and you are experiencing headaches more than usual.

## 6.) LOSS OF MOTIVATION | FEELING HELPLESS

You feel like you have lost your mojo and are helpless to change the situation.



#### Self-Care

# Carers Fatigue by Hayley | A/Peer Work Coordinator

It is very common for carers to experience something that is called 'carers fatigue' or 'carers burnout'. What this means is that the carer becomes 'burnt out' because of their caring responsibilities and unrealistic expectations on themselves or by others.

# So, how does this happen and what can be done to prevent it?

It happens when the carer's circumstances and their choices place more stress on the carer than their body and mind is able to manage. The situation becomes overwhelming and what was an empathetic motivation to support their loved one now becomes a drudgery and overwhelming task.

Essentially, the high level of energy required to be able to care with an open and caring attitude in a demanding situation is replaced with low energy and this causes the carer to want to retreat and shut off. Where they previously were positive and concerned for their loved one, they now feel negative and unconcerned.

According to <u>Sane Australia</u>, symptoms of 'Carers Fatigue' may be:

- Physical exhaustion, where you feel tired most of the time and may even feel as though you are not able to complete tasks to the same standard you once did
- Changes in appetite, either eating for comfort or losing your appetite all together
- Changes in sleeping patterns
- Frequent headaches and tension
- Lowered immunity resulting in frequent sickness
- Loss of motivation
- Feeling helpless
- Increased cynicism and negative view of current situation
- Decreased satisfaction or sense of accomplishment

- Feeling a sense of guilt or shame, or doubting your skills and ability to assist the person you care for
- Social withdrawal
- Procrastination
- Using alcohol or drugs to cope.

If you are experiencing these symptoms, it is time to put yourself first and seek medical attention. Talk to your GP and see what services there are available to provide you with the support that you need to re-vitalise yourself.

Sometimes we don't know what we don't know until we ask the question. There may be services that can give you respite or more support. If you are working and have access to the Employee Assistance Program, utilise the opportunity to speak to a counsellor or psychologist.

I vividly recall a conversation I had with a friend who had a child living with a disability in the school parking lot.

She was working full-time, plus caring for her daughter, and I asked her one day, "How do you manage it all?"

At the time I was struggling to raise four children and work parttime. I couldn't even imagine working full-time.

She responded, "I go to the gym first thing every day and I make sure I get my hair done and take time out for me. If I am not well, I am no good to my family."

That wisdom has stuck with me all these years. When I start to feel the pressure mounting in my caring role, I take time out for myself.

Like they say in the Qantas safety sessions, make sure you put the oxygen mask on yourself first.

Remember, life is a balancing act. For every negative you need a positive counter measure to keep you afloat. Look back through our newsletters at the Self-Care Tips for some ideas.

If you are struggling with your caring responsibilities and not coping, talk to your GP or the Case Manager about accessing carer support services or respite. You are not alone and support is available if you ask.



#### **Important Numbers**

# Mental Health Emergency Response Line (MEHRL)

1300 555 788

#### **Rural Line**

1800 552 022

For help with mental health emergencies

#### **Crisis Care Help Line**

1800 199 008

Help with temporary accommodation, protection for children, financial aid, counselling and other support services

#### **Police**

131 444

For police assistance or attendance: when any person feels in danger, under threat or at risk.

# Triple 000 Emergency (Police, Fire, Ambulance)

For urgent help in a lifethreatening emergencies

### LifeLine

131 114

24/7 crisis support telephone counselling service