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# **Acknowledgments**

The Carer Perspective Supervision Framework has been a carer-led, co-produced project supported and funded through a partnership with the Department of Health, Victoria. The project team wish to acknowledge and thank the families, carers and supporters who came before us – their efforts have allowed us to continue to drive change to support the needs of a diverse range of families and carers across Australia.

The carer lived experience workforce proudly acknowledges Aboriginal and Torres Strait Islander people and pays respect to elders, past, present and emerging. We celebrate the diversity of Aboriginal people and those who are also carers. We acknowledge Aboriginal people as Australia's first people and as the Traditional Owners and Custodians of the land and water on which we live, work and play.

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### Special thank you

Carer Lived Experience Workforce Victoria (CLEW)
The many carer lived experience workers who participated in the focus groups
Helena Roennfeldt, National Mental Health Commission
Marianne Ryder, University of Queensland

# Language Statement

For the purpose of this document the terms carer lived experience workforce and carer lived experience worker have been used. These terms represent the workforce who have lived experience supporting someone with mental health concerns and whose work is informed by this perspective. We recognise that in different organisations/services other terminology may be used (for instance, family/carer worker, carer peer support worker, carer consultant). For a more detailed description of roles and responsibilities and other common terms please refer to the Glossary of Terms.

#### **Further information**

For ease of reading, full definitions and details may not be included in the body of the document. It is highly recommended that the Glossary of Terms and Resources are read for a comprehensive understanding of this framework.

This project was made possible by funding from the Department of Health













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# **Foreword**

# Peter McKenzie Carer Academic - Bouverie Centre

It is quite challenging to briefly express the contributions and significance of family/carer lived experience workers and their role in mental health services. We could begin to articulate this in terms of their committed support for carers/supporters and families supporting someone living with mental distress, and their challenging role and position in an emerging lived experience workforce. I think what we also need to talk about is their significant contributions in a mental health service setting that doesn't see families and carers as 'core' business; their insistence and persistence that services pay attention to the carer/supporter voice; and their significance in spotlighting the profound role of relationships and the 'relational' to good care and recovery.

Recognition of the impact of this work on family/carer workers themselves, up until recently, has at best been inconsistent or not even considered in terms of the workers' wellbeing and professional development needs. I see this supervision framework pointing the way to the importance and need for a professionally supported structure that effectively holds and cares for this work, acknowledging its complex and challenging nature and the significance of sharing experiences and challenges. I believe this framework, and the contributions that helped create it, are a genuine step forward in the recognition and professionalising of the family/carer lived experience workforce.

### Marie Piu CEO - Tandem

Tandem is proud to be the auspice for the Carer Lived Experience Workforce (CLEW) and the trusted voice of family and friends in mental health in Victoria. With a sole focus on the needs and interests of mental health carers, Tandem's role as the Victorian peak body is to provide leadership, coordination and knowledge for those who are working to improve outcomes for Victorian people living with mental health issues. Tandem is committed to ensuring that the importance of the contribution, expertise, experiences and needs of family, friends, the carer lived experience workforce and other carers is recognised and addressed, and that they are essential partners in treatment, service delivery, planning, research and evaluation. Tandem welcomes this long overdue supervision framework for the carer lived experience workforce. It is an invaluable tool that acknowledges the unique role of these amazing professionals. It is essential in the journey to officially recognise this dedicated and growing workforce and provide the tailored support to allow them to continue to learn and grow.

# Katrina Clarke CLEW Chair/CLEW Leadership Team

Carer Lived Experience Workforce Victoria (CLEW) is auspiced by Tandem and supported with workforce development and secretariat by the Centre for Mental Health Learning (CMHL). CLEW provides a safe space to connect with our emerging discipline, network, share practices, learn from others, co-reflect, get updates, be involved in the progression of the workforce and reduce feelings of isolation. In the past few years the CLEW workforce has grown considerably, with a current membership in excess of 125. What we know is that there is more growth needed to meet the needs of families and carers in Victoria. CLEW has been extremely passionate over these years about defining roles, building structures and support for the family/carer lived experience workforce, training and education, career pathways and promoting the growth or the peer workforce including workforce readiness. Many CLEW positions are isolated within organisations and have no access to other members of the family/carer workforce.

There is no question the Family/Carer Perspective Supervision Framework is integral to the future success of the family/carer workforce's growth and sustainability and will be an invaluable tool for services that are creating new positions and expanding their workforce. Hearing the voice of those past members of the family/carer workforce who have been great advocates for the support and supervision of this workforce, we know they would be as excited and proud as we are to see this come to fruition. Having access to supervision from the commencement of appointment to a family/carer position will mean these roles are recognised, valued and supported. Being able to engage in practice supervision will also help avoid re-traumatisation as a part of their work place experiences as well as peer drift, and create awareness and measures for workplace safety. It is envisaged that the tools and guidance from the Family/Carer Perspective Supervision Framework will provide the foundations for healthy supervision frameworks at the local and statewide level.



"Mental illness happens in loving families too" Wilding, H, (2013) Melbourne, VIC

# Co-designing this Framework

#### 2016

A Carer Workforce Development Group was set up in partnership with the Department of Health to provide direction and advice for policies and initiatives relating to the carer workforce. With the exception of two members, all members of the group were carer lived experience workers with experience across a range of carer lived experience roles.

#### 2017/2018

After the roll-out of the Expanded Post Discharge Support Initiative it became apparent that there was a shortage of carer lived experience staff who were qualified to provide discipline-specific supervision or co-reflection to other carer workers.

#### 2019

Strategy for the Family Carer Mental Health Workforce in Victoria was published. One aspect of the strategy was the creation of carer-led innovation grants. One of the grants was for 'Carer peer support worker supervision and training' which was awarded to the Royal Melbourne Hospital NorthWestern Mental Health (RMH NWMH).

A review of the limited literature pertaining to this area was undertaken and a focus group was facilitated with the Carer Lived Experience Workforce (CLEW) network to inform the project design.

'Consultations with carer lived experience workers cited experiences of receiving supervision from other disciplines which was experienced as unhelpful as "much of the time was being spent educating the supervisor about the carer lived experience role".'

(CLEW focus group participant, 2020)

#### 2020/2021

RMH NWMH commissioned a co-design group with membership from the RMH NWMH carer lived experience workforce, consumer lived experience workforce, family/carer lived experience line management, RMH NWMH Mental Health Training and Development Unit (MHTDU), Tandem, Carer Lived Experience Workforce (CLEW), Centre for Mental Health Learning (CMHL), multi-cultural family/carer representation and representation from family/carer workers from other clinical workplace settings. This group met monthly to develop and inform the content of this framework.

Once finalised, the framework was designed and illustrated by individuals with a lived experience.

# Introduction

There are in excess of 736,000 carers in Victoria who give their time, effort and love to care and support a family member or friend with a mental health concern. One of the most valuable ways the Victorian government has been supporting families and carers is through funding designated family/carer lived experience roles across the mental health service sector.

'Lived experience work will be a central pillar of the future mental health system: new lived experience roles will be established and supported, spanning service design and delivery, service system, leadership, research and evaluation, and system accountability and oversight.'

State of Victoria, Royal Commission into Victoria's Mental Health System, Final Report, Interim Report, 2019

As we write this, the Victorian mental health system is on the cusp of significant change as a result of recommendations made by the Royal Commission into Victoria's Mental Health System (Royal Commission). The interim and final reports outline these changes and, more specifically, recommend that implementation of these should be informed and driven by people with a lived experience, both consumers and carers.

The system reform will therefore see a substantial expansion of the carer lived experience workforce both at local and state levels and through the establishment of a family/carer/supporter-led centre in each region.

Importantly, to support this growing workforce, the Royal Commission has stipulated that the carer lived experience workforce is entitled to discipline-specific supervision in line with other disciplines working within mental health (Royal Commission Final Report, 2021).

'Integral to this vision is a future state where the consumer, family and carer lived experience workforces are recognised, understood and valued, with the support structures afforded to any other profession.'

State of Victoria, Royal Commission into Victoria's Mental Health System, Interim Report, 2019 p.508.

The development of this Carer Perspective Supervision Framework is an important step toward supporting this process and fulfilling these recommendations.

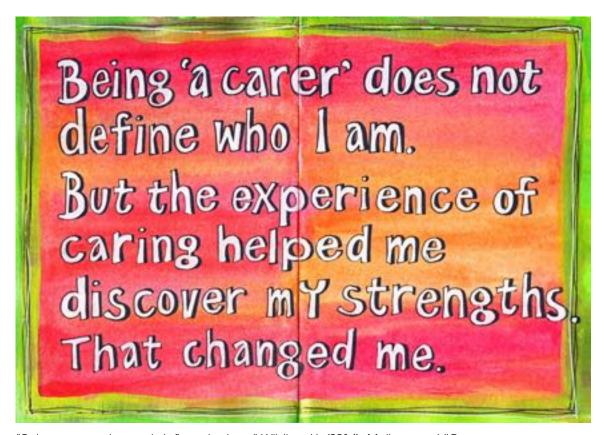
### **Carer lived experience workforce**

The carer lived experience workforce understands firsthand how traumatic and challenging years of supporting and witnessing a family member or friend struggle with mental health distress can be. It also understands the impact this can have on the relationships and dynamic of the whole family.

It is understood by this workforce that family, carers and supporters can:

- Struggle to understand the mental health system
- Be left with little support for their own mental health and wellbeing
- Feel unheard and lack information about how to understand the illness and support the unwell person
- Feel removed from the treatment and decision-making processes while still being expected to provide support

Carer lived experience workers are carers who, through both experience and training, have the skills to assist families and carers to navigate the mental health system. Their primary role is to provide support and to advocate for the needs of families, carers and supporters both directly and systemically within the service. Another key feature of the carer lived experience workforce is to increase the understanding of the family/carer experience in mental health service settings across other disciplines. In doing so, carer lived experience workers improve the culture and quality of mental health services and the delivery of care.



"Being a carer does not define who I am" Wilding, H, (2014). Melbourne, VIC

# **Purpose**

- Explore the supervision needs of the current carer lived experience workforce
- Support the career development of the carer lived experience workforce
- Promote an understanding of carer lived experience supervision and how it supports and sustains the carer discipline
- Support Victorian services with discipline specific supervision for the carer lived experience workforce
- Support the Strategy for the Family Carer Mental Health Workforce in Victoria

# Scope

The framework is intended to support the unique functions of carer lived experience perspective supervision. It outlines:

- An understanding of the need for discipline specific supervision
- The importance of the supervisee and supervisor relationship
- Real-life carer workforce examples to illustrate practice experiences
- Foundational practice in developing carer perspective supervision

# **Aims**

The framework aims to:

- Define carer lived experience work and challenges
- Define discipline-specific supervision and how it can be helpful
- Provide understanding of the value and role of carer discipline specific supervision
- Define the role of the manager, the supervisor and the supervisee
- Provide useful tools to support carer discipline specific supervision for supervisors, supervisees and managers
- Outline the vision, values and principles that underpin the carer lived experience workforce and carer lived experience-specific supervision

# History of the Mental Health Carer Discipline

Historically the inclusion of carers and families in mental health service delivery has not been considered 'core business' for mental health services. In fact, carers, families and supporters have at times been excluded and treated as part of the problem and/or the cause of mental illness (Burdekin Report, 1993 and Richmond Report, 1983).

Deinstitutionalisation of the mental health system in Victoria had important outcomes for families, carers and supporters. Firstly, the onus of caring for consumers was increased for this group under the new community-based approach with little to no additional support. Secondly, there was an increase in activism to improve services and to increase the consumer and carer voice within the mental health sector as a response.

Consequently, a number of services emerged within Victoria that represented the carer voice to government and the mental health service. This included the development of Arafmi, Mental Illness Fellowship Victoria (now Wellways), the Victorian Mental Health Carers Network (now Tandem) and the Carer Consultant Network Victoria (now CLEW).

Government policy has come a long way and now supports the involvement of carers and family within the mental health service framework. Examples include Chief Psychiatrist Guidelines: Working together with families and carers and A guide to solution focused hearings in the Mental Health Tribunal. This has also since led to the introduction of carer lived experience workers across metropolitan and regional mental health services to support this important work.

# The Lived Experience Workforces

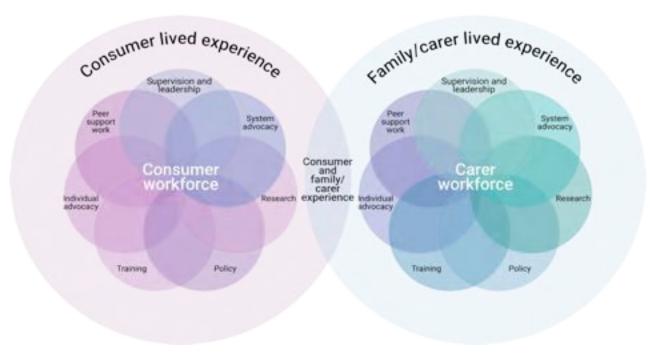


Figure 1 - Consumer and family/carer lived experience work (Downes & Edan, 2017)

An area of confusion is differentiating the work of consumer lived experience workers and carer lived experience workers – some services employ the one person to utilise both perspectives in their work. While acknowledging that there is a group of people that have both consumer and carer experiences, there are times when there are differences or tensions between consumer and carer experiences, needs and expectations. It is important to distinguish the roles to ensure that the focus of consumer workers is on consumer experiences and the focus of carer lived experience workers is on family/carer experiences. This is true whether the role is focused on the individual (such as individual advocacy or peer support work), or focused on broader systems (such as education and training roles, or policy advisor roles). Figure 1 illustrates where there is interconnectedness of lived experience and where there is still separation of the roles (Centre for Mental Health Learning – Peer Inside).

'For the majority of the carer workforce, they have shared that their title or roles are still often enshrined in confusion by the service that employs them into these roles, the colleagues they are working alongside and even within the community who still are not familiar to them.'

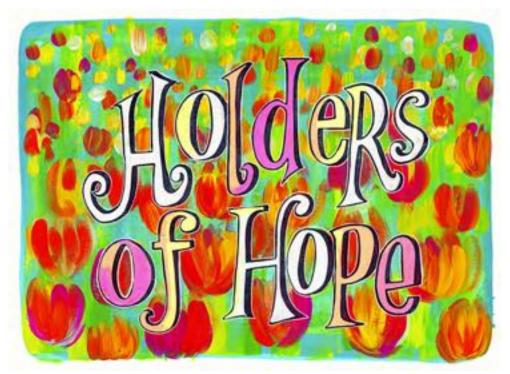
(CLEW Focus Group)

# Carer Lived Experience Workforce Values (CLEW)

The Carer Lived Experience Workforce (CLEW) operates as a statewide participation and advocacy network for the carer lived experience workforce. CLEW has articulated the carer lived experience workforce values as:

- Respect
- Accountability
- Advocacy
- Collaboration
- Relationship
- Connection
- Community
- Mutuality
- Compassion
- Diversity
- Flexibility
- Curiosity

These values which underpin the work of the carer lived experience workforce have been endorsed by the co-design group and used to inform this framework. The full description of the values and principles can be found in the Resources section.



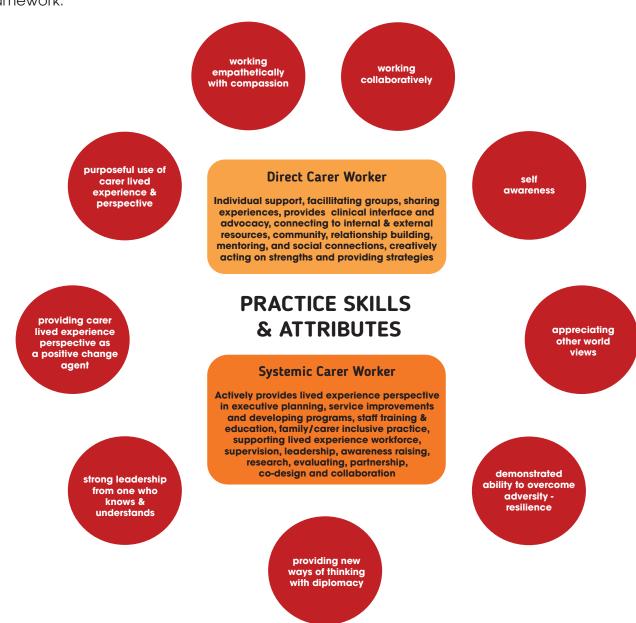
"Holders of Hope" Wilding, H, (2013) Melbourne, VIC

### **Carer lived experience workers**

The Australian Institute of Health and Welfare, 2018, describes mental health carer workers as: Persons employed (or engaged via contract) on a part-time or full-time paid basis, where the person is specifically employed for expertise developed from their experience as a mental health carer.

Carer lived experience roles and responsibilities within organisations inevitably vary, but the commonality of what they bring to their work is the carer perspective and how these real-life experiences are understood and applied to benefit other families, carers and supporters. There are many valuable attributes that they bring to these roles, often seeing themselves as change agents who can actively influence, advocate and contribute more broadly to effective mental health service delivery.

Some may work in direct care positions such as peer work, while others operate more at a systems level. A further breakdown of these roles can be found in the Resources section of this framework.



(This diagram speaks only to those in Carer Consultant or Peer Support Worker roles and does not encompass the broader carer lived experience landscape which will include educators, leadership, research roles etc)

# **Establishing Leadership Structures**

"The Commission has stated it understands that limited access to professional practice supports can have a negative impact on skill development and workforce wellbeing and while professional and clinical practice supervision can be cross-professional (conducted by a member of another discipline), the Commission has heard evidence from a range of professionals that intraprofessional supervision (conducted by a member of the same discipline) is optimal."

(Royal Commission Final Report, 2021 p.478)

As an emerging specialist discipline, there is a need for the carer lived experience workforce to continue to develop and grow effective leaders to support and strengthen the discipline group. This includes those who work in direct practice, policy and procedure writing, governance, research, service design and improvement, evaluation and more.

Discipline-specific supervision plays a key role in this. An experienced supervisor is able to share their own lived experience, their understanding of working with other carers and families and of navigating the service system. They provide the time and space to reflect on practice, effectively problem solve and, through this reflection, contribute to the development of new ideas and practices.

Where discipline-specific supervision is not available within the service, for example, where supervision is being offered by a clinical staff member, the expectation should always be that this is a temporary measure only. As the workforce expands, services will need to support the development of experienced carer lived experience workers into senior positions to meet the provision of carer lived experience supervision long term. Alternatively, where this is not possible, services should seek to engage external qualified carer lived experience supervisors to cover the gap.

# The Importance of Carer Lived Experience Discipline Specific Supervision

Despite a plethora of legislation, policies, family and carer practice guidelines and professional development programs, the benefits of working collaboratively with carers is still not widely understood or prioritised by many mental health clinicians. The expansion of the carer lived experience workforce is integral to assisting with further culture change in this area.

Further to this, carer lived experience workers can often be employed and expected to carry out their roles without organisations really understanding the tensions and challenges inherent in their work. What can at times be overlooked is that many carer workers enter the workforce while still in a caring role. This places them in a unique and challenging position as they can often be managing work responsibilities that are reflective of their experiences at home. This requires a significant level of resilience, energy, determination and support.

For instance, carer workers may find themselves witnessing situations and practices in relation to carers and families that are not in line with their own values and that mirror their own experiences with mental health services. As a result, carer workers may re-experience negative feelings and emotions vicariously.

A carer worker may have had the experience of being 'judged' and accused of being overprotective of the consumer and being a part of the problem. Hearing and observing other carers being 'labeled' and their role not understood or respected can reconnect a carer worker with their own personal feelings of being in a similar situation.'

**CLEW Focus Group** 

While carer lived experience workers advocate for the support needs of carers they also have firsthand experience of the emotional, physical, psychological, relational and financial impact of the caring role. Many carer lived experience workers who may often prioritise the needs of others before their own will require support in identifying the parallels between their own caring practices and their work practices. Guiding carer lived experience workers to be conscious of their own self-care needs requires the specialised insight of someone who has 'been there and done that' – a carer lived experience supervisor.

Carer discipline-specific supervision is also important to ensure carer lived experience workers are not left feeling further disempowered, burdened and alone. Carer lived experience workers need to have a regular opportunity to reflect and share their experiences in a safe and mutually respectful space that honours their experiences and challenges. Discipline-specific supervision can provide the space to do this safely as well as create an opportunity to learn from shared experiences.

The carer lived experience workforce continues to drive cultural change in mental health by raising awareness of the importance of the caring role and service gaps for carers/families. Upholding this perspective can at times be challenging given the many competing demands and hierarchies within the mental health service system. Discipline-specific supervision can help the worker uphold the integrity and authenticity of the carer perspective in their work. This also helps to reduce the likelihood of 'peer drift' which can occur if the carer lived experience worker begins to adapt clinical practices and viewpoints in their work. Carer discipline-specific supervision helps workers remain true to lived experience values and principles in order to continue to influence broader cultural change.

### Internal and external carer perspective supervision

Carer lived experience workers should always be given the option of receiving supervision by a qualified carer perspective supervisor internally or externally to the service in which they work. While having local discipline specific supervision readily available to the workforce should be a priority for the organisation as there are benefits from being supervised by someone who understands local service policies, procedures and the teams they work alongside, it is also important that workers be given a choice to receive support independent to the service from which they work. This option may sometimes be preferred for privacy reasons where workers are seeking an independent / unbiased perspective and could also be in sought in addition to internal supervision.

### **Accessing Carer Perspective Supervision**

If you are currently unable to access internal discipline specific supervision, external carer perspective supervisors can be accessed through:

Centre for Mental Health Learning Victoria Telephone (03)83718218

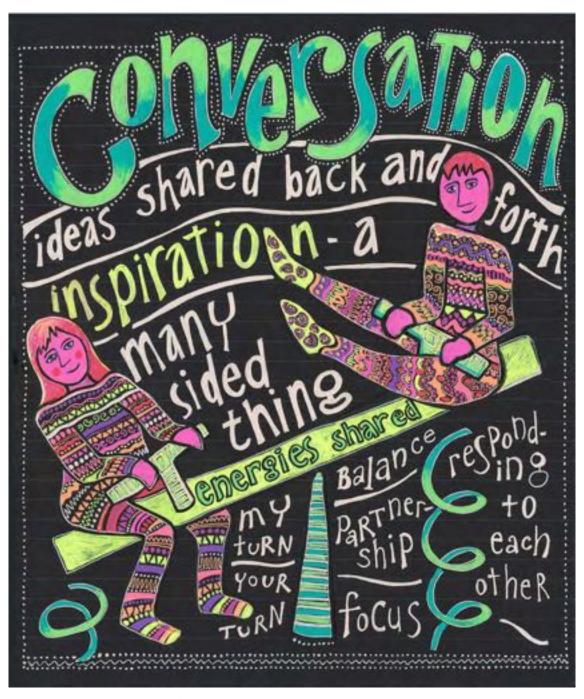
Email: contact@cmhl.org.au

# Understanding the difference between supervision and line management

The success of any workforce relies heavily on the type of support and leadership that is provided. In terms of supervision, the roles of discipline-specific supervision and line management can often be ill defined and confused.

Line management is generally responsible for the oversight and guidance of the direct operational activities of the staff member. This includes workloads, allocation of tasks, contracts, leave, human resource issues, performance development and the overseeing of compliance with policy and targets.

Discipline specific supervision on the other hand, focuses on reflective practice, the impact of the carer's work, debriefing, and the application of a worker's unique skills and lived experience in their working environment. It should be a safe space to explore strengths and strategies as well as problem solving issues, challenges, and tensions in the key areas of carer work. Lived experience discipline-specific supervision allows for the development of a relationship based on a shared understanding, where the safety, wellbeing and professional development of the carer's work is paramount.



"Conversation" Wilding, H, (2011) Melbourne, VIC

# What Informs Carer Lived Experience Work?

'A key principle of carer lived experience work is the understanding of the impact of mental ill health within a family network and supporting carers/families in their caring and recovery journey. The tasks in the carer/family recovery journey include: maintaining hope, reconnecting, overcoming secondary trauma and journeying from carer to family.'

(Wyder & Bland, 2014)

At its core, carer lived experience work is about advocating for better inclusion, support and outcomes for carers/families and consumers in mental health services. In order to apply this the work is informed by several models and frameworks of practice. Some of these are outlined below.

### **Carers Recognition Act (2012)**

The Carers Recognition Act recognises, promotes and values the role of carers. The Act formally acknowledges the unique knowledge that carers hold about the person they support and the contribution they make to the community.

# Mental Health Act (2014)

The Mental Health Act (2014) specifies that certain principles should guide the provision of mental health services.

Principles that speak specifically to working with carers and families include:

- Carers (including children) for persons receiving mental health services should have their role recognised, respected and supported.
- Carers (including children) for persons receiving mental health services should be involved in decisions about assessment, treatment and recovery, whenever this is possible.
- Children, young persons and other dependents of persons receiving mental health services should have their needs, wellbeing and safety recognised and protected.

### Intentional Peer Support (IPS) (Mead, 2014)

IPS informs the principles of engagement with carers and family members and identifies the tasks that underpin the work. These align with the principles and values of the Carer Lived Experience Workforce (CLEW).

The three IPS principles and four tasks from which all work is based are:

#### **Principles:**

- From Helping to Learning Together
- Individual to Relationship
- Fear to Hope & Possibility

#### Tasks:

- Connection
- World View
- Mutuality
- Moving Towards

# Carer Peer Support (Mercuri and Epifanio, 2019)

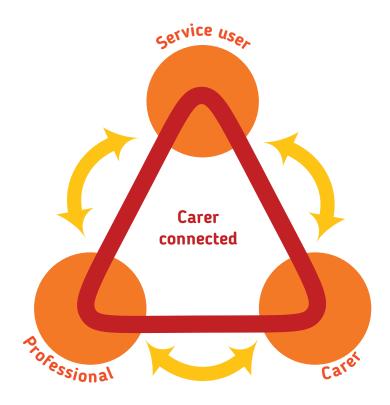
The development of this model of carer peer support was carer-led and implemented. It is useful to gain an understanding of the provision of carer peer support in both an inpatient and community setting.

#### Carer peer support can provide:

- General information on mental illness
- Assistance with navigating the mental health system
- General helpful strategies
- Emotional support and self-care
- · General carer information and information regarding care rights
- Information on confidentiality and information sharing
- Internal and external linkages
- An interface between the carer and the clinical team

### **Triangle of Care (Worthington & Rooney, 2010)**

The Triangle of Care promotes carer-inclusive practice and a three-way partnership of working collaboratively with consumers, carers and clinicians. Having carers as active partners in treatment will produce the best chance of recovery providing better outcomes for all.



### Single Session Peer Work (McKenzie, 2013)

This framework provides structure for direct peer work. It helps peer workers identify key issues pertinent to the carer while providing the carer with the opportunity to be heard, understood and emotionally and practically supported.

# **Carer Life Course Framework (Pagnini, 2005)**

This framework identifies the stages and cyclic nature of caring and the various support that might be useful for carers and families at these different stages.

Phase 1 - Suspicion that something is wrong

Phase 2 - Confirmation of mental illness

Phase 3 - Adjustment

Phase 4 - Management

Phase 5 - Purposeful coping

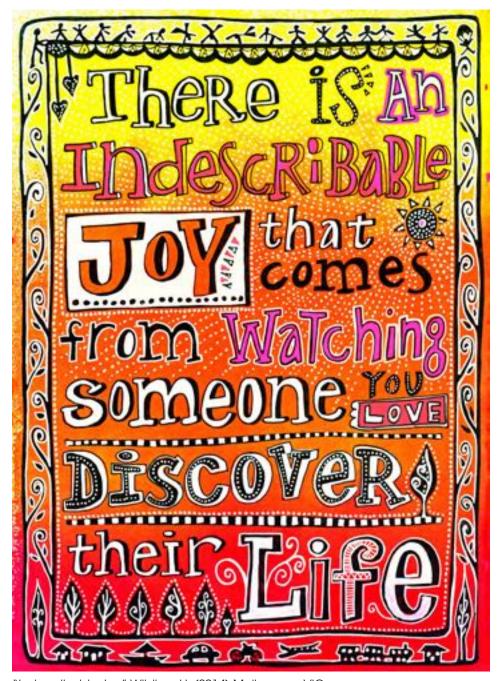
Phase 6 - End of active caring

### **Charter of Peer Support (2011)**

This charter provides an understanding of the rationale and benefits of peer support.

'Peer support is intrinsic to mental health and total wellbeing ... because it provides an unmatched, unlimited pathway to help, in a safe environment where people's shared lived experiences are heard, respected, honoured and understood.'

(Charter of Peer Support, 2011 p.5)



"Indescribable Joy" Wilding, H, (2014) Melbourne, VIC

# From Carer Lived Experience to a Carer Lived Experience Worker

In this section examples of the work are provided, including common challenges the workforce face and how carer perspective supervision can be applied. These examples were highlighted through focus group sessions with the CLEW Group.

### The complexity of the work

The carer lived experience workforce functions from a perspective informed by their own personal lived experience of supporting someone living with mental illness or psychological distress.

The discipline defines workers' expertise by the many – often traumatic and challenging – years of supporting and witnessing a family member and/or friend struggle with mental health distress. This encompasses the experience of attempting to access support and the impact this can have on relationships, family dynamics and their own personal health and wellbeing.

Becoming a mental health carer is often not an active choice. Most carers are suddenly thrust into their caring role as a matter of necessity, whether it is motivated by love or duty. This often results in a major life change for the family and carer.

Carers often choose to step into these workforce roles because of their desire and passion to improve the mental health system for others. They wish to influence service providers and government to change practice and policy, making it more inclusive of family, carers and supporters with the aim of better outcomes for all consumers, families and their carers.

The reality of holding and balancing one's work and personal life may impact carers in their work. Key aspects of their lived experience and knowledge are integrated to inform systemic change across a mental health system. This mental health system, however, often does not recognise the value of carers and the impact of mental health issues on the entire family.

# Trauma - The carer experience

Trauma: An event that is (a) sudden, unexpected, or non-normative; (b) exceeds the individual's perceived ability to meet its demands: and (c) disrupts the individual's frame of reference and other central psychological needs and related schemes.

(McCann & Pearlman, 1990 p.131)

Witnessing a mental health crisis is very often a traumatic and terrifying experience (Albert & Simpson, 2015) and can be categorised as primary trauma (McCann & Pearlman, 1990).

Carers look to mental health professionals for assistance in understanding the illness and practical support strategies on how to provide support to the unwell person (Pirkis, 2010). Instead of help, they often experience 'double deprivation' – lack of support from mental health professionals while trying to manage the situation and minimise its impact on family and themselves (Albert & Simpson, 2015). The challenges involved in persuading mental health professionals of the seriousness of the situation as well as witnessing the involuntary admission and enforced treatment of their family member adds to this emotional trauma.

#### Examples of a carer's experience

'My son had a very unusual presentation. He had gone into a catatonic state and I called the crisis team, who responded promptly and admitted him into intensive care for three days. The second time I called them for help the same two people who had admitted him the first time and told them that my son was becoming sick again and needed admission, they said that they would not admit him unless he had hit "rock bottom". I was phoning them every day and was begging them to admit him as I could see that his condition was deteriorating. He had been roaming the streets for three days, had no food, hadn't slept, and had only a tee-shirt on. If this is not "rock bottom" then what is? ... In the end he was picked up by the police.'

Shankar & Muthuswamy, 2007, p.302

My son experienced his first psychotic episode 2014... Since Harold has been suffering from mental illness, it has been nine long torturous years struggling to get help. I have been forced to watch my beautiful boy's life deteriorate in front of my eyes. I have felt so disempowered and exhausted from constantly battling to get my son the support and care he needs. I have been pushed aside because staff are busy. Mental health workers have said to me "I can't talk now" or "I'll let you go now". I've felt like saying "I don't want to be let go".

There have been thousands of phone calls, between 20 to 50 calls on some days, yet I have been unable to get my son the help he needs. Sometimes the situation has to be really drastic before you are taken seriously, and help is provided. I've had to talk to the Mental Health Complaints Commissioner, the Office of the Chief Psychiatrist and, at times, I have had to threaten legal action because otherwise you just don't get listened to. It shouldn't have to be like this.'

Anna Wilson (Carer)
(RCVMHS, Final Report pg.26)

Carer workers may have experienced trauma as part of their caring role and, as a result, can be faced with unique and specific challenges in the work environment when witnessing parallel situations experienced by other families/carers. While the caring experience increases empathy as the carer worker can easily relate to situations that families/carers may find themselves in, hearing the details of other carers traumatic experiences can also increase the chances of retraumatisation, secondary trauma and compassion fatigue (Ellis & Knight, 2021). This can impact the carer worker's own health and well-being as well as the quality of the support they provide.

#### Vicarious trauma / Secondary trauma

The carer workforce can also at times find themselves working in service settings that expose them to traumatic events. For example, staff assault within an inpatient unit or the application of restrictive interventions such as seclusion or restraint. Additionally, like their clinical colleagues, carer lived experience workers can often be exposed to distressing stories (e.g., physical, sexual abuse). If not addressed appropriately this can impact on the carer worker's own health and wellbeing. This experience is known as vicarious trauma or, secondary trauma.

Secondary trauma is the emotional and psychological effect experienced through exposure to the details of the traumatic experiences of others and can change a person's perception of themselves

(Ellis & Knight, 2021).

Carer discipline supervision is key to raising awareness of the impact of the work and understanding the feelings associated with these experiences. This is achieved through connection, mutuality and learning. Discipline-specific supervision provides opportunities to reflect upon and make connections between personal caring experiences and work situations, as well as addressing the impact this may have on the worker through appropriate linkages to organisational or community support. Carer discipline-specific supervision can have a 'normative, formative and restorative function' (Proctor 2011).

# The Carer Perspective Supervision Relationship

The carer perspective supervision relationship is a dynamic partnership between two carer workers who share their professional and personal expertise through mutual understanding. This relationship can support, educate and strengthen both workers. This relationship thrives on trust, openness, honesty and good will.

The carer discipline-specific supervisor can provide opportunities to explore the use of carer lived experience to advocate for improving the health and human service systems, positively changing the culture and, in turn, helping carers thrive in their workplace. The carer perspective supervision relationship is underpinned by the shared foundational values of the carer perspective. The workers learn together and discuss ways to identify and purposefully use carer lived experience in the work. It is through this shared lens and mutuality that ideas can be explored and developed.

The developing relationship between the supervisor and supervisee is built on trust and feeling safe to explore and grow. The relationship is essential to supporting needs, developing and meeting goals, enhancing career development and building on achievements.

Carer discipline-specific supervisors have a range of skills, expertise, experience and understanding.

It is important to begin the carer perspective supervision relationship with clear discussions and negotiations regarding the needs and expectations of the supervisee.

Supervisors need to be familiar with carer lived experience practice frameworks and the associated challenges in clinical settings, which helps them appreciate the contribution this valued workforce brings. The supervisor can provide support, guidance, feedback and advice while giving the supervisee independence and autonomy to grow and develop.

This relationship needs to be constructive, respectful and encouraging to develop professional and personal strengths whilst maintaining professional and ethical standards. Both the supervisor and supervisee need to act in good faith and have a mutual responsibility to listen, learn and grow. A respectful relationship is key, as is clarity around confidentiality (that is, when information will be shared and why, as well as to whom and how this will be done). Both the supervisor and the supervisee have a responsibility to uphold confidentiality of the session, unless there is a specific decision between them about the need and reasons to share certain information.

Good connection between the supervisor and supervisee are essential for an effective supervisory relationship and needs to be maintained to be effective.

# Carer Perspective Supervision - A place to reflect and be supported

Having a quiet moment to sit, think and be supported to reflect on your work with someone who has experience in the same field is an important component of supervision.

#### A supervisor that supports a reflective space should:

- Provide encouragement to describe what is going on
- Support, not judge
- Allow time for you to digest and resolve things in a way that is helpful
- Validate your experiences
- Support and reassure if new to the role
- Encourage and affirm good reflective practice
- Enquire with curiosity about your work
- Learn from another person's experiences
- Reflect on common challenges and brainstorm strategies and ideas on how to address them
- Empower through sharing own lived experience to enhance knowledge
- Build on your strengths to gain a sense of self confidence
- Explore work experiences and share knowledge with others
- Create opportunities to review and reflect on the work, role and outlined position description
- Be open to diverse perspectives to spark new ideas
- Support self-care in the work
- Reflect on boundaries in the work



"Pay it forward (cropped words at base)", Wilding, H, (2012). Melbourne, VIC

# Supervision Practices and Approaches

Reflective practice, as the name suggests, employs a process of reflection on personal and work situations, awareness of thoughts and feelings, as well as identification of the relevance and the impact these thoughts and feelings have on the worker to create a new understanding. In carer lived experience supervision it might include discussion of particular situations either in direct practice or systemic work that are deemed by the worker to warrant further exploration. These include but are not limited to: the complexity of the situation, the feelings evoked, similarity to their own experiences or clarification of practice.

Carer lived experience supervision is about sharing individual experiences and making sense of those experiences in the context of the individual and their world and how those experiences may have affected them. It's about learning from each other and expanding our understanding of our own and each other's worldviews in a safe, non-judgmental and non-hierarchical environment.

'Reflection can be defined as thinking and feeling activities in which individuals engage to explore their experiences in order to lead to new understanding and appreciations'.

(Boud, Keogh & Walker, 1985)

#### Supervision may include:

- Raising self-awareness
- Exploring uncomfortable thoughts and feelings
- Finding meaning and work parallels with carer lived experience
- Incorporating co-reflection (intentional peer support) or reflective practice
- Identifying and exploring better work and more effective work practices
- Working within boundaries
- Actively choosing to use your lived experience and selecting where, when and how much is needed to share

Carer lived experience is a partnership between the carer worker and the supervisor – both have a responsibility in their roles in the practice and approaches to supervision.

## The role of the supervisee

#### The supervisee is responsible for:

- Preparing the supervision session
- Identifying what is wanted out of the supervision relationship that is, bringing specific issues to discuss
- Identifying frequency of supervision
- Actively developing a trusting working relationship with the supervisor

- Understanding the limitation of supervision in its power to be supportive but non-directive
- Being open to reflect upon and explore their own strengths and limitations
- Being open to growth and development

### The role of the supervisor

#### The supervisor is responsible for:

- Scheduling mutually convenient ongoing supervision sessions
- Arranging the location of sessions face-to-face or online
- Providing initial orientation of what supervision entails
- Discussing a supervision agreement if mutually agreed
- Taking informal supervision notes that identify key issues and that could be shared with the supervisee and others with mutual agreement
- Confidentiality and privacy of supervision notes and record keeping they are not to be saved in any organisational shared drive, but kept in a safe place
- Providing a mutually safe, non-judgemental sharing experience
- Keeping the conversation confidential except in cases of duty of care

### Joint responsibilities to be considered

#### Both parties are responsible for:

- Flexibility in cancelling and rescheduling sessions as required
- Session location and times
- Following up on relevant tasks or issues

# What level of experience should a supervisor have?

The supervisor is expected to have been working within the mental health sector, preferably in a variety of carer lived experience roles, for a number of years. They need extensive experience in understanding not only the broader experiences of families and carers but the systemic challenges within organisations when advocating for inclusive practice for carer rights.

#### A supervisor is expected to:

- Have broad carer lived workforce experience and be a in a role senior to the supervisee
- Be responsible for their own learning around carer rights, responsibilities, and the carer movement
- Keep up to date with changes in the sector, so that they are able to provide accurate information to their supervisees
- Have expertise in carer perspective supervision

- Have a good understanding of the practice models and underpinning frameworks of carer lived experience work
- Be familiar with the supervisee's organisational structure and context
- Have a thorough understanding of historical and contemporary workings of carer workforces
- Have thorough understanding and knowledge of the Mental Health Act and other relevant policies and legislation as it pertains to carers
- Work in line with the values and principles that underpin The Carer Perspective Supervision
   Framework
- Be familiar with the practice requirements around confidentiality and documentation
- Have experience/knowledge of advocating for carer rights, e.g., the right for family carers to access support for themselves irrespective of consumer consent, or the right for family/carers to be provided with information necessary to carry out their caring role
- Have strong knowledge of ethical behaviour and delivery of supervision and its expectations
- Have a strong ability to recognise the benefits and importance of self-care and wellbeing
- Have good communication skills and an ability to provide constructive feedback in a mutually empathic and respectful way

#### **Qualities and attributes of a supervisor**

#### A supervisor needs the following to be in a successful partnership with a supervisee:

- Empathy
- A focus on collaborative and mutually respectful communication
- The ability to communicate and provide feedback effectively
- A mature and curious outlook
- The ability to minimise any perceived power differentials
- To care about the wellbeing of others
- To model the principles and values of the carer lived experience workforce
- To be flexible and understanding

# Organisational Responsibilities

The Carer Perspective Supervision Framework has highlighted the importance of discipline-specific supervision and the value it brings to the carer lived experience workforce. It also acts as a resource for organisations to draw from.

Organisations are responsible to ensure that the carer lived experience workforce receive supervision and, more specifically, supervision within their discipline.

Organisations should also be committed to discipline-specific supervision and have policies and procedures that support it. This includes:

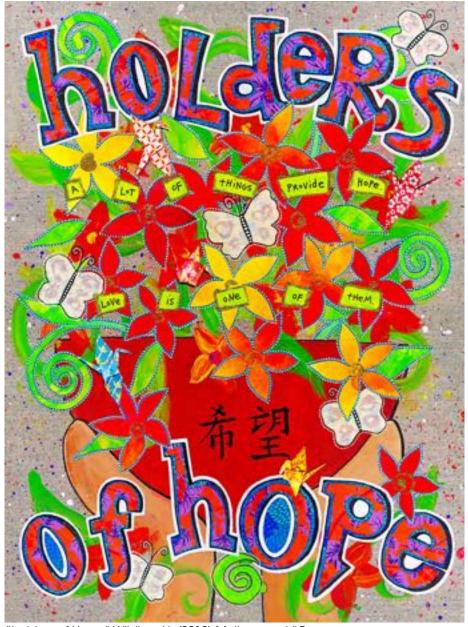
- The arrangement by managers of how supervision will be offered and by whom
- Whether the discipline supervision is to be provided internally or by an external carer discipline supervisor
- Discussions with the carer lived experience worker to negotiate the discipline-specific supervision requirements and preferences
- Ensuring the frequency and duration of supervision is based on the supervisee's needs and assessment of the supervisor
- Ensuring the minimum supervision provided is monthly
- Providing more frequent supervision in the supervisee's first year of work
- Ensuring the supervisor is receiving their own discipline-specific supervision
- Allowing supervision to be held within working hours
- Ensuring supervision is paid for by the service
- Providing a quiet, private room to conduct supervision
- Ensuring discipline-specific supervisors have a higher level of practice experience then the supervisee
- Ensuring discipline-specific supervisors are different to the person providing line management supervision, even if that person is a carer lived experience employee
- Support for all supervisors to be trained in carer perspective supervision training

Another consideration for organisations is commitment to the development and training of potential carer lived experience supervisors within the service. Staff with interest and experience should be provided with support and resources to complete training in this framework.

### Issues relating to the organisation and the supervisor

Clarity of arrangements between the organisation and supervisor is vital. Clarity of roles and responsibilities can be achieved through the negotiation of a contract and it should cover issues included in the organisational responsibilities as well as:

- The minimum frequency of supervision meetings (monthly)
- The escalation principles and processes
- The reporting of systemic issues that are impacting the ability for staff to do their work effectively
- The provision of internal family/carer discipline-specific supervision for internal family/carer discipline-specific supervisors



"holders of Hope" Wilding, H, (2012) Melbourne, VIC

# Carer Workforce Supervision Examples

Below are some supervision case examples that pick up on common issues that carer workers might be faced with.

### **Advocacy within clinical settings**

A carer lived experience worker is expected to work alongside other mental health professionals and provide the carer lived experience perspective in a clinical space that is often made up of significant power differentials. Conversations in these spaces can typically be concerned with consumer recovery needs only. As such, it can be challenging for the carer worker to advocate for families/carers or to be included as part of the consumer's recovery discussion.

### **Example 1**

'A new carer peer support worker is supporting an older woman whose husband was admitted to hospital. She described his behaviour as controlling and sometimes violent, but states that he is always remorseful afterward. When the carer worker raises this with the treating team their response is, "Yeah, but she always takes him back and the discharge of the patient is the priority". They proceed with discharge planning without taking this information into account.'

#### Ideas for supervision:

Create a safe space - In the carer perspective supervision the carer worker should be supported to feel safe to explore the challenges of advocacy and the impact on their self-confidence when they feel like their opinion or that of families and carers have not been heard.

Validate the experience – The carer perspective supervisor can use their own lived experience to validate the worker's feelings of being pushed aside and might provide an opportunity to explore the worker's doubts about their effectiveness. The supervisor and supervisee might discuss ways to strengthen the worker's confidence in advocacy.

Encourage speaking up and identify clear escalation pathways – The importance and value of speaking up in certain situations should be discussed. Escalation processes could form part of the conversation to ensure the worker has a clear pathway to follow, particularly when they feel like someone's safety is at risk.

Assist with understanding varying perspectives and skillsets - The varying perspectives of people within the treating team might be discussed as a way to better understand the challenges that each group faces and the priorities driving the work.

#### **Peer drift**

The pressure to adhere to a particular way of thinking or adopt a more 'clinicalised' standpoint can be referred to as 'peer drift'. Though carer workers have many unique skills that enrich the entire team they work alongside. Over time the carer worker may begin to adopt the language and practices associated with a clinical world view. In other words, over time the work of a carer worker might begin to resemble the work of other clinicians within the team. This can happen by way of adoption and use of clinical language and concepts to expedite communication or by workers applying a clinical perspective in order to try to fit in with a team. Peer drift means that the purpose of the work that carers do becomes compromised.

In addition to this, peer driff might include being asked or expected to undertake work that is not within the scope of the carer worker role, e.g., a carer worker being asked to find housing for someone who is ready to be discharged from an inpatient unit. While a carer worker may feel that they have additional skills to work outside of the carer lived experience role, doing this work can muddy peoples understanding of the carer workforce, compromise the importance of its focus on families and carers and potentially reduce the impact of potential culture change toward carer workers.

# **Example 2**

A carer peer support worker has just completed her studies in social work and has shared this with her team. The carer peer support worker is working with a mother who is currently experiencing challenges in supporting her daughter who is currently in an inpatient unit. The carer worker identifies that it would be useful to identify alternate accommodation for the consumer as the mother is about to undergo chemotherapy and does not feel she is able to have her daughter live with her during this time. The mother has also asked whether her daughter's diagnosis can be explained to her, as she has not fully understood why her daughter is behaving so aggressively. The carer peer support worker is asked by the treating team if she could assist them in finding accommodation for the consumer and to provide the mother with psycho education. The carer peer support worker knows this is not part of their role but wants to feel valued and respected within the team.

#### **Ideas for supervision:**

Validate the experience - The carer perspective supervisor can use their own lived experience to validate the workers feelings of wanting to help both the carer and the team that she is working within.

Assist in understanding the pros and cons of undertaking these tasks – Discuss the importance of boundary setting and of not working outside the scope of their role. Discuss the potential repercussions of complying with requests outside of their roles for other carer workers. Look at the uniqueness and value of their work and explore ways to gain respect and understanding from the team. This can only occur when their work aligns with the values and principles of carer lived experience work.

Talk about how to increase the team's understanding of the carer worker role – This might include running professional development sessions for the team, thinking about what information is already available via orientation or online.

Consider role playing – Provide a space to practice responses and having conversations with the treating team. This might include conversations on appropriate boundary setting and how this can best be articulated in a way that everyone understands.

# **Boundary setting**

Carer workers can often be placed in situations that lead them to extend their work boundaries. The level of their empathy for the challenges that families and carers experience can make the carer worker want to do more to support them, especially if they are not able to access immediate support elsewhere in the community.

# **Example 3**

A carer lived experience worker gives their private home or mobile number to a carer who is really struggling and offers for the carer to call any time, including outside of working hours.

#### Ideas for supervision:

Validate the experience - The carer perspective supervisor can use their own lived experience to validate the workers feelings of wanting to go over and above to help the carer.

Help to highlight any risks/issues – For example, if the carer was to call out of hours and a situation needed to be escalated what support does the carer have? If a serious event/incident happened after hours how might the work of the carer worker be implicated in that process? How might duty of care be understood in this context?

Help to find additional resources/support – An experienced supervisor might be privy to internal and external resources that help the carer worker in these situations. Supervision is an opportunity to share such learning and resources.

Help to promote the importance of self-care – This might include how workers separate the personal and professional so they can sustain the work that they do.



"This is the moment right now "Wilding, H, (2012) Melbourne, VIC

#### **Authentic vs tokenistic involvement**

Carer lived experience workers are increasingly being asked to participate in both service development and service delivery projects in mental health services. Effective engagement in these processes relies on understanding the role of the carer worker and the value of the perspective that they bring. At times, however, carer workers might be invited to participate in processes but not truly be given a voice.

Discipline-specific supervision can provide a space to reflect on personal practice and opportunities to improve genuine participation, advocacy and a more authentic approach within systemic roles. This can include building an understanding of the continuum of lived experience engagement/participation: inform, consult, involve, codesign (collaboration), co-produce (empower).

(Roper, Grey & Cadogan, 2018)

# **Example 4**

A carer consultant is asked to provide a carer perspective on a number of brochure documents designed for families and carers at the end of the brochures' development period. The carer worker wants to help however they feel that they are not providing genuine input to the development of these documents or reflecting true insight into the needs of families, carers and supporters. This has happened before and they are feeling frustrated and exhausted with the lack of true collaboration and co-design. They feel that their time could have better been spent by being involved in the project at its inception.

#### **Ideas for supervision:**

Validate the experience - The carer perspective supervisor can use their own lived experience to validate the workers feelings of feeling misunderstood and frustrated. .

Tokenism vs co-design - The carer worker could be helped to explore feelings associated with tokenistic, tick-the-box engagement. This includes exploring what a true co-design process might look like. The supervisor and supervisee might discuss ways these issues could be brought to the attention of other staff, such as the supervisee's line manager, carer participation portfolio holder or even more senior carer lived experience roles, to see how they can find solutions together to help address these issues.

Role model conversations – Provide a safe space to practice having conversations around what authentic involvement means to the carer worker.

# **Consultation fatigue**

Although there is a significant increase in the consultation of carer lived experience perspectives, outcomes for families and carers may not be commensurate with the level of input being provided by carers. For example, carer lived experience workers who sit in systemic roles can find themselves sitting on numerous committees, however, they might feel like their input goes unheard. It is important that organisations are clear about their commitment to processes such as co-design and also clear about their commitment to hearing the voices of people with lived experience. This should also include articulating reasons as to why the carer perspective views have not been taken on board when this occurs. If carer workers are routinely placed in situations where they feel unheard, disempowered or disregarded, consultation fatigue and resentment can easily set in.

# **Example 5**

A carer consultant is asked to sit on a number of committees to provide a carer perspective. Each time the carer worker speaks they feel like their opinion is dismissed or overridden by clinical staff. This happens so frequently that the carer worker expresses that they have now lost the energy to participate. They are either not attending meetings or are reluctant to contribute to meetings when they do attend.

#### **Ideas for supervision:**

Validate the experience - the carer perspective supervisor can use their own lived experience to validate the workers feelings of feeling ignored and powerless.

Explore how this makes the carer worker feel and how this might be impacting their work.

Talk through the meetings/committees the carer worker is currently sitting on and workshop opportunities for better engagement – This might include having conversations with the meeting chair outside of the meeting to come to an agreement about the role and participation of representatives within the group. Such conversations might also help inform the carer worker's continued representation on certain committees if they feel there is little real value in doing so. Are there areas that the carer worker has a particular interest they would like to pursue that they might feel more empowered in?

Discuss support mechanisms at a system level - Are there clear processes to support effective lived experience engagement to committees across the organisation?

# Safety and duty of care

Much like supervision, conversations between a carer and a carer worker should be held in a safe space. Workers and supervisors alike want to create spaces where the people they are supporting feel safe to talk about their situation and experiences. Safety is also paramount and where the safety of any party is understood to be compromised, or where there is a significant risk of harm to self or to others, workers and supervisors must prioritise this. Carer lived experience workers should never be left 'holding' information or responsibility for situations that are outside of the scope of the carer worker role and must always be supported with what is often very complex situations and work.

# **Example 6**

A carer discloses to their carer peer support worker that their situation at home has become untenable and that they have had recurring suicidal thoughts.

#### **Ideas for supervision:**

Understand the situation and level of risk for the carer.

Explore if the carer worker has escalated these concerns to the treating team and if not why?

Help the worker understand that addressing suicidality is not the responsibility of the carer lived experience worker to hold alone and that it requires clinical support.

Discuss duty of care and how it applies to the role of a carer lived experience worker. Carer lived experience workers are employed by an organsiation and have a duty to escalate concerns when there is a perceived risk to the person they are working with or, a risk to others. These risks must be both verbally handed over and documented in the client record. Carer peer workers can often feel conflicted with sharing this type of information with clinical staff as they can hold concerns that doing so may compromise their relationship / rapport with the carer. Things that can help include; supporting carer workers to be transparent about the necessity to share this type of information from the outset of a work relationship and providing opportunities to practice having these conversations (for example, role playing how the carer worker might talk to the carer about needing to raise their concerns with others, including supporting the carer to raise issues directly with clinical staff themselves perhaps with the support of the carer worker).

Understand appropriate escalation pathways and what this might look like while maintaining the confidence and rapport of the carer.

Reflect on feelings and emotions that this might bring up for the carer worker, does their own lived experience have any parallels with the situation? Consider any additional organisational support systems that the carer worker might be able to tap into (e.g. EAP program, staff wellbeing service).

#### **Self-care**

A common challenge for any carer worker is managing their own self-care while balancing their workload and personal caring role. The need for continual self-care is obvious but critically important. Discipline-specific supervision is an avenue for self-monitoring wellbeing and discussing self-care strategies. Self-care strategies might include things like reaching out and talking with peers, having time off, exercise, relaxation activities (mindfulness, yoga) and/or maintaining social connections. A useful self-care assessment tool (including stress assessment) is located in the Resources section. It can be helpful to use prior to a supervision session to help focus the supervisee's thoughts in preparation for the session.

# **Example 7**

A carer peer support worker working at an inpatient unit has a daughter who is experiencing mental health distress and has just had her first admission to an acute mental health facility. The carer peer support worker is feeling extremely fearful for her daughter and feels like her fear and anxiety is affecting her work with other families in the unit.

#### Ideas for supervision:

Validate the experience - The carer perspective supervisor can use their own lived experience to validate the workers feelings of feeling stressed and overwhelmed.

Provide a space to reflect on the carer worker's own self-care needs - This might include discussing opportunities to reduce the carer worker's case load or to take some time off. Discuss what has worked for the supervisor and the supervisee in the past, and what helps them when they are feeling depleted. Consider writing down a self-care plan to draw on when things feel overwhelming.

Address any feelings of guilt associated with self-care – this should be discussed so that the carer doesn't feel alone in these feelings and to highlight the importance of looking after oneself so that quality care can be provided to others.

# **Conclusion**

With a growing carer lived experience workforce across Victoria it is hoped that this framework will continue to evolve and to support the provision of carer discipline-specific supervision. The project team has worked tirelessly to try to include the views, experiences, underpinning values and principles of the carer lived experience workforce, however, it acknowledges the diversity of experiences and perspectives that necessarily make up this discipline group.

The Carer Perspective Supervision Framework's co-design team is now working on accompanying training in Carer Perspective Supervision in line with this framework.



"Entanglement" Wilding, H. (2010), Melbourne, VIC.

# Glossary of terms

The co-design group has drawn from and adapted the recently released Royal Commission into Victoria's Mental Health System for the following definitions and discussion. In line with the Commission, the co-design group has considered the many valued perspectives on terminology. Although it has at all times tried to use inclusive and respectful language, the co-design group is aware that not everyone will agree with the terminology used.

Below is a list of important terms utilised throughout the framework.

#### Carer

A person, including those under the age of 18 years, who provides care to another person with whom they are in a relationship of care.

# **Family**

May refer to family of origin and/or family of choice. The co-design group acknowledges that the terms 'family' and 'carer' do not reflect the full range of relationships, social connections and support that many people have in their lives, and the important role these relationships play as part of a support network. For example, in its Interim Report, the Commission noted that LGBTQI+ communities in particular may draw on support from relationships beyond biological family.

Family includes the consumer and those with a significant personal relationship with the consumer. This includes biological relatives and non-biological relatives, intimate partners, expartners, people in co-habitation, friends, those with kinship responsibilities, and others who play a significant role in the consumer's life. Others will identify more with the characteristic of their relationship (for example: parent, child, partner, sibling).

# Family/carer/supporters

This term is used in the Royal Commission into Victoria's Mental Health System's Final Report (2021) to describe the range of relationships between the consumers and those who support them. 'The terms "family" and "carer" are not interchangeable, and people may not identify with a particular term. Not all carers are family members, and family members do not always take on a caring role. Family members may, however, be valued supporters of a person experiencing mental illness or psychological distress, along with other people in that person's broader social and support network.' The co-design group decided to use this term when referring to the family/carer/supporters that the family/carer workforce supports.

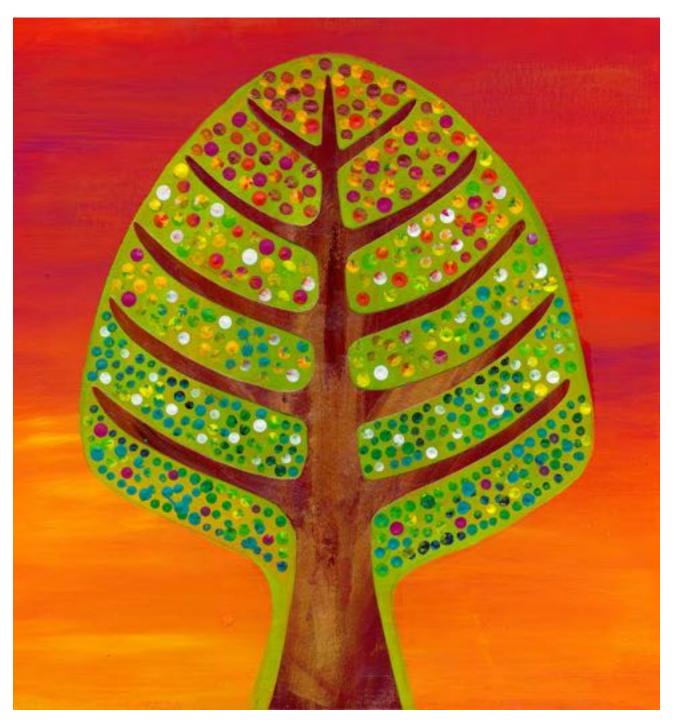
# **Lived experiences**

Refers to people with lived experience who identify either as someone who is living with (or has lived with) mental illness or psychological distress, or someone who is caring for or otherwise supporting (or has cared for or otherwise supported) a person who is living with (or has lived with) mental illness or psychological distress. People with lived experience are sometimes referred to as 'consumers', 'carers' or 'family/carers'

## **Carer lived experience workforce**

Refers to people with the lived experience of caring for, being a family member or supporter of someone with mental health distress that are employed in a specific lived experience role and use their lived experience as their primary expertise.

Definitions adapted from State of Victoria, Royal Commission into Victoria's Mental Health System, Final Report, Summary and recommendations, Parl Paper No. 202, Session 2018–21.



"Tree of Life" Wilding, H, (2012) Melbourne, VIC

# Resources

# Carer Lived Experience Workforce (CLEW) values and principles

RESPECT	We model respect for ourselves and others, including people from different disciplines and lived experience perspectives.
ACCOUNTABILITY	We are clear about and promote family/carer lived experience roles. We develop and maintain the skills and knowledge we need to do our job and we drive the creation of structures and evidence necessary for our discipline.
ADVOCACY	We are informed about services and issues impacting family and support networks. We use our knowledge and expertise to understand, educate and advocate for families within the mental health sector and the community.
COLLABORATION	We promote collaborative practices that are inclusive of all perspectives.
RELATIONSHIP, CONNECTION, COMMUNITY, MUTUALITY	We explore our lived experiences together for stronger relationships to cultivate/foster belonging and hope, and build connections between individuals/colleagues, teams and communities.
COMPASSION	Our work is founded on meaningful, empathetic and mutual connections that are supportive, safe and accessible and nurtured by wisdom gained by sharing experiences.
DIVERSITY	We acknowledge, value and respond to the unique needs of people from all backgrounds and perspectives.

#### **FLEXIBILITY**

We aim to include a consistent framework to guide our practice. We remain open to new ideas, experiences and new ways of doing things.

#### **CURIOUSITY**

We embrace a culture of curiosity and mutual learning for the wellbeing of all and to create opportunities for all.



"Thank you for caring" Wilding, H, (2012) Melbourne, VIC

# **Carer lived experience workforce roles**

Some organsiations will interchange the term 'carer' with 'family' to describe this workforce (e.g. family peer support worker instead of carer peer support worker). For ease of reading we have used the term carer in the table below.

#### **Carer worker**

A carer worker is someone who works in mental health services, or who works independently from formal services, and declares their lived experience and uses this intentionally in their work. They are employed to bring their perspective and represent the experiences shared by carers, families and supporters. They may be employed in systemic work or, direct service provision. The Australian Institute of Health and Welfare, 2018, describes mental health carer workers as: Persons employed (or engaged via contract) on a part-time or full-time paid basis, where the person is specifically employed for expertise developed from their experience as a mental health carer.

#### Carer peer support worker

Peer support work focuses on building mutual and reciprocal relationships with carers to support recovery. These workers use their experience of supporting a family member or friend who has experienced 'mental distress' to directly support family members and friends of consumers. This includes working directly with individuals, or groups.

#### **Carer consultants**

This role focuses on system works such as service improvement with particular attention to access and equity for family/carers. Consultants are employed to bring the carer perspective to the processes of policy development, service design, planning, delivery and implementation system leadership, research and evaluation, accountability and oversight to support continuous improvement of the service and its responsiveness to family/carer needs and to communicate the broad views of family/carers to the mental health service and other relevant services.

Family carer consultants may also collate information and feedback from families and carers about their views and experiences of services.

#### Carer managers, co-ordinators or team leaders

These experienced carer workers are responsible for the support and development of other carer lived experience workers. There are some unique challenges for workers who choose to work from a lived experience perspective. It is important that management recognises this and provides appropriate management structures. Depending on the organisational needs,

structures and the number of workers from each perspective employed, these leadership roles should ideally support workers from within their discipline, that is, a family/carer team leader for family/carer workers.

#### **Carer educators**

Lived experience educators make a significant difference to education and training outcomes for mental health professionals. Carer educators ensure family/carer perspectives, and participation and involvement are included in all aspects of the education and training

provided in services. Carer educators also develop and facilitate, or co-facilitate, education and training for staff, consumers, families and other carers, as well as the general community.

#### **Carer advocates**

Advocates support an individual or group to speak on their own behalf and in their own interests, or they may speak for and/or on behalf of an individual or group under instruction. In disability work, the first approach should always be one of self-advocacy with paid advocates supporting individuals to advocate for themselves. Advocates often assist with resolving issues at an individual level, e.g., helping someone ask about medication issues or to access social housing, or assisting a family member to obtain the Carer Payment.

The carer advocate helps family and carers be heard in relation to the issues that affect them.

'Advocacy usually occurs under potentially difficult conditions when the individual is trying to achieve an outcome which may be at odds with the stated and unstated outcomes desired by the organisation and or its staff' (Southern Health, 2010). For this reason, advocates are usually employed by consumer or carer peaks or by advocacy organisations.

#### **Carer policy advisors**

Carer policy advisors draw on the views and the body of collective family/carers knowledge and research to inform changes to those aspects of the mental health system that impact on families and carers and to promote family/carer sensitive/inclusive practice.

#### **Carer researchers**

There is a growing understanding of the importance of utilising lived experience expertise in research.

Family/carer researchers draw on their lived experience to promote and enable the engagement of families and carers at all stages of research. Family carer researchers may be involved as advisors in others' research, as partners in collaborative research, or as leaders – initiating, directing and driving research.

#### **Practice supervision**

A growing need in lived experience work is for practice supervision from those with experience working in a designated lived experience role. Given the challenges often encountered by lived experience workers it is important that provision of discipline-specific supervision from experienced workers is available. Practice supervisors with experience in family carer work can provide coaching, mentoring or supervision to other family/carer workers respectively as well as to others working in mental health services. This might be provided internally or sourced from external agencies or private providers.

Adapted from lived experience workforce positions in Victorian public mental health services and the Centre for Mental Health Learning's Peer Inside.

Note: These roles are current as of April 2021, but as the workforce develops in line with Royal Commission recommendations they may change names and others may develop.

# Questions to consider at the initial supervision session

The following questions should be considered by both the supervisee and supervisor when negotiating supervision or at the initial supervision session to identify and clarify responsibilities:

#### **Supervisee**

- 1. Do I want group or individual supervision?
- 2. What do I think I need from supervision?
- 3. What is the purpose of supervision?
- 4. What can I learn from discipline-specific supervision?
- 5. What sort of topics can I bring to supervision?
- 6. What worries me about supervision?
- 7. What are the parameters around confidentiality and information sharing in these sessions?
- 8. What's my expectation of my supervisor?
- 9. How often can I receive supervision?
- 10. How long should each supervision session go for?
- 11. Is external or internal supervision best for me?
- 12. Who will pay for my external supervision?

#### **Supervisor**

- 1. How frequent will the supervision be?
- 2. How long will each session go for?
- 3. Will the supervision be conducted face-to-face or online?
- 4. How much will I charge for external supervision?
- 5. What style of supervision would you find to be most useful to you?
- 6. How do you feel about receiving feedback?
- 7. Consider what is and is not in the scope of the supervisor in these sessions.
- 8. What do I expect of participants?
- 9. How do I maintain confidentiality and safety within the session?
- 10. How do I ensure confidentiality with regard to record/note keeping?

# **Example: Carer lived experience discipline specific supervision agreement**

Betw	een (supervisor)			
And	(supervisee)			
Date	To be reviewed			
The s	structure we have agreed upon is:			
1.	Frequency:			
2.	Length of supervision sessions:			
3.	Location:			
4.	The way we will set up the agenda for sessions will be:			
5.	This arrangement will cease when:			
The c	content of sessions may include:			
1.	Reviews of your work through discussion and direct observation/recording of your work especially in relation to aspects of your work you would like feedback on			
2.	Reflections on the values inherent in your work			
3.	Reflections on the impact of the work on you			
4.	The development of your skills repertoire and knowledge base			
5.	Consideration of your development needs and professional goals			
6.	Mutual constructive feedback and periodic review			
Goal	s of supervision:			
1.	In six months, what would I see that told me I was getting what I want from supervision?			
2.	If I wasn't getting what I wanted how would I deal with this?			
3.	What learning objectives would I like to bring?			
4.	What worries me about supervision?			
5.	What interests me most about supervision?			
6.	What is important from my point of view to be included in any 'contract' or understanding with my supervisor?			
Expe	ectations of supervision:			
Α.	What I want from you as a supervisor:			
B.	What I want from you as a supervisee:			
C.	Supervisee responsibilities:			
D.	Supervisor responsibilities:			
Signe	ed:(supervisee)			

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Signed: \_\_\_\_\_\_ (supervisor)

# **Example: A supervision session**

The following can be used as a guide for the structure of a supervision session:

#### 1. Context setting

- Outline the process, agree on details of regularity, location, etc., and document accordingly.
- Discuss confidentiality, responsibilities and duty of care considerations.
- Understand each other's context, values and worldview.
- Discuss a good outcome for overall supervision aims and for each session as they arise.

#### 2. Find a focus for the session

- The Self-Care Check Sheet is useful for a focused discussion about wellbeing.
- The supervisee can tell a story about the work/issue they have chosen to focus on for the session.
- Establish a particular aspect to focus on.
- Discuss how to proceed.

#### 3. Stay on track

 The supervisor checks in to see if they are discussing the right issue. 'Are they hearing the story correctly?' 'Can I just check that we are focusing on what is needed?' 'Is there anything I am missing?'

#### 4. Discuss the issue

- On reflection is there anything you'd do differently, the same or would use again?
- What do you know about yourself that is helpful here?
- The supervisee shares what they have tried and what has been successful or what has not worked so well.
- The supervisor listens for issues that they recognise from their own experience as a family/carer lived experience worker and shares this constructively.

#### 5. Check in/review

• The supervisor checks that they have enough information, 'Before I tell you what I am thinking, is there anything further I need to know? Have I understood the issues so far do you think? Is there anything I haven't asked you but should have?'

#### 6. Reflection

- The supervisor offers their opinions and experience as openly as possible reflecting on the specific issues experienced by this workforce and making structural and political observations where appropriate.
- The supervisor checks in to see if there is anything that has been said that doesn't sit well with the supervisee.

#### 7. Check in and closure

- The supervisor and supervisee agree on the path from here. 'What have we learnt today?', 'What things will you do differently?', 'Is there anyone else we need to include in this conversation?', 'How will we action this if it needs to be escalated?'
- The supervisor checks in to see if the supervisee's expectations have been met/concerns have been addressed. 'How far have we come in meeting what you have come for?'
- The supervisor makes sure that there are no final questions or concerns that the supervisee has before they end the session. 'Any last questions/concerns?'

#### Other areas to consider:

- Time frames Once a month for 6 months
- Duration One hour
- Price To be negotiated
- Sessions conducted During work time

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# Registering for an Australian Business Number (ABN)

If you are providing supervision independent of an organisation, you will need to register for an ABN. This is a free process and you will also need to provide a tax file number to do this. Information is available on the Australian Tax office website:

https://www.abr.gov.au/business-super-funds-charities/applying-abn

# Creating a tax invoice

If you are providing supervision independent of the organisation you are working for, you will also need to provide an invoice to the person you are offering supervision to and the organisation for whom you are providing the service to.

#### The information is required by the ATO:

- A. Supplier name
- B. Supplier address
- C. Supplier ABN
- D. Not registered for GST

#### Information you will need:

- Bank account details
- Bank name
- Account name
- BSB / Account number

#### **Example Tax Invoice**

Your Details
Sarah Marshal
Date: 01/01/01
45 Hillside Ave

Melbourne, Vic 3002 Australia

**Invoice Number: 000\*\*\*** 

**Bill To:** 

Royal London Hospital White Chapel Rd, Moonee Ponds, Vic 3039 Australia

DESCRIPTION	DATE	HOURLY RATE (INC. GST)	HOURS	TOTAL AMOUNT

### **Self-care tools**

#### Compassion satisfaction and fatigue

(PROQOL) Version 5 (2009)

In the information below the term 'help' may be replaced with another term that people find more appropriate depending on their area of work (e.g. support, advocate)

When you (help) people you have direct contact with their lives. As you may have found, your compassion for those you (help can affect you in positive and negative ways. Below are some questions about your experiences, both positive and negative, as a (helper). Consider each of the following questions about you and your current work situation. Select the number that honestly reflects how frequently you experienced these things in the last 30 days.

1 = Never	2 = Rarely	3 = Sometimes	4 = Often	5 = Very Often
1.	I am happy			
2.	,	upied with more the	an one persoi	n I (help)
3.	·	tion from being abl	•	
4.	I feel connec	cted to others	, , ,	•
5.	l jump or am	startled by unexpe	cted sounds	
6.	I feel invigor	ated after working v	with those I (h	elp)
7.	I find it difficu	ılt to separate my p	ersonal life fro	om my life as a (helper)
8.	-			n losing sleep over traumatic
_	*	of a person I (help)		
9.		-	· ·	e traumatic stress of those I (help)
10.		d by my job as a (h	. ,	
11.		, , , , , , , , , , , , , , , , , , , ,	felt "on edge	e" about various things
12.	•	cas a (helper)		
13.	•			periences of people I (help)
14.			ng the traumo	a of someone I have (helped)
15.		s that sustain me		
16.	I am pleased protocols	d with how I am abl	e to keep up	with (helping) techniques and
17.	I am the per	son I always wanted	d to be	
18.	My work ma	kes me feel satisfied	ł	
19.	I feel worn o	ut because of my w	vork as a (help	per)
20.	I have happ them	y thoughts and feel	ings about th	ose I (help) and how I could help
21.	I feel overwh	elmed because m	y number (wo	ork) load seems endless
22.	I believe I co	ın make a differenc	e through my	v work
23.		in activities or situa of the people I (he		e they remind me of frightening
24.	I am proud c	of what I can do to	(help)	
25.	As a result of	my (helping) I have	e intrusive, friç	ghtening thoughts
26.	I feel "bogge	ed down" by the sy	stem	
27.	I have thoug	hts that I am a "suc	cess" as a (h	elper)
28.	l can't recall	important parts of	my work with	trauma victims
29.	I am a very o	caring person		
30.	I am happy t	hat I chose to do th	nis work	

#### What is my score and what does it mean?

In this section, you will score your test so you understand the interpretation for you. To find your score on each section, total the questions listed on the left and then find your score in the table on the right of the section.

#### **Compassion Satisfaction Scale**

Copy your rating on each of these questions on to this table and add them up. When you have added them up you can find your score on the table to the right.

Q. 3	
Q. 6	
Q. 12	
Q. 16	
Q. 18	
Q. 20	
Q. 22	
Q. 24	
Q. 27	
Q. 30	·
TOTAL	

The sum of my Compassion Satisfaction questions is:	So my score equals:	And my Compassion Satisfaction level is:
22 or less	43 or less	Low
Between 23 and 41	Around 50	Average
42 or more	57 or more	High

#### **Burnout Scale**

On the burnout scale you will need to take an extra step. Starred (\*) items are 'reverse scored'. If you scored the item 1, write a 5 beside it. The reason we ask you to reverse the scores is because scientifically the measure works better when these questions are asked in a positive way though they can tell us more about their negative form. \*

*Q. 1	=	
*Q. 4	Ш	
Q. 8		
Q. 10		
*Q. 15	Ш	
*Q. 17	=	
Q. 19		
Q. 21		
Q. 26		
*Q. 29	=	
TOTAL		

The sum of my Burnout questions is:	So my score equals:	And my Burnout level is:
22 or less	43 or less	Low
Between 23 and 41	Around 50	Average
42 or more	57 or more	High

You wrote	Change to
1	5
2	4
3	3
4	2
5	1

<sup>\*</sup> For example, question 1. "I am happy" tells us more about the effects of helping when you are Not happy so you reverse the score.

#### Secondary Traumatic Stress Scale

Just like you did on Compassion Satisfaction, copy your rating on each of these questions on to this table and add them up. When you have added them up you can find your score on the table to the right.

Q. 2	
Q. 5	
Q. 7	0
Q. 9	0
Q. 11	0
Q. 13	0
Q. 14	0
Q. 23	0
Q. 25	0
Q. 28	0
TOTAL	0

The sum of my Secondary Trauma questions is:	So my score equals:	And my Secondary Trauma level is:
22 or less	43 or less	Low
Between 23 and 41	Around 50	Average
42 or more	57 or more	High

#### YOUR SCORES ON THE PROQOL: PROFESSIONAL QUALITY OF LIFE SCREENING

Based on your responses, your personal scores are below. If you have any concerns, you should discuss them with a physical or mental health care professional.

#### Compassion Satisfaction

Compassion satisfaction is about the pleasure you derive from being able to do your work well. For example, you may feel like it is a pleasure to help others through your work. You may feel positively about your colleagues or your ability to contribute to the work setting or even the greater good of society. Higher scores on this scale represent a greater satisfaction related to your ability to be an effective caregiver in your job.

The average score is 50 (SD 10; alpha scale reliability .88). About 25% of people score higher than 57 and about 25% of people score below 43. If you are in the higher range, you probably derive a good deal of professional satisfaction from your position. If your scores are below 40, you may either find problems with your job, or there may be some other reason, e.g., you might derive your satisfaction from activities other than your job.

#### **Burnout**

Most people have an intuitive idea of what burnout is. From the research perspective, burnout is one of the elements of compassion fatigue. It is associated with feelings of hopelessness and difficulties in dealing with work or in doing your job effectively. These negative feelings usually have a gradual onset. They can reflect the feeling that your efforts make no difference, or they can be associated with a very high workload or a non-supportive work environment. Higher scores on this scale mean that you are at higher risk for burnout.

The average score on the burnout scale is 50 (SD 10; alpha scale reliability .75). About 25% of people score above 57 and about 25% of people score below 43. If your score is below 18, this probably reflects positive feelings about your ability to be effective in your work. If you score above 57 you may wish to think about what at work makes you feel like you are not effective in your position. Your score may reflect your mood, perhaps you were having a 'bad day' or are in need of some time off. If the high score persists or if it is reflective of other worries, it may be a cause for concern.

#### Secondary Traumatic Stress

The second component of Compassion Fatigue (CF) is secondary traumatic stress (STS). It is about your work-related, secondary exposure to extremely or traumatically stressful events. Developing problems due to exposure to others' trauma is somewhat rare but does happen to many people who care for those who have experienced extremely or traumatically stressful events. For example, you may repeatedly hear stories about the traumatic things that happen to other people, commonly called Vicarious Traumatisation. You may see or provide treatment to people who have experienced horrific events. If your work puts you directly in the path of danger, due to your work as a soldier or civilian working in military medicine personnel, this is not secondary exposure, your exposure is primary. However, if you are exposed to others' traumatic events as a result of your work, such as providing care to casualties or for those in a military medical rehabilitation facility, this is secondary exposure. The symptoms of STS are usually rapid in onset and associated with a particular event. They may include being afraid, having difficulty sleeping, having images of the upsetting event pop into your mind, or avoiding things that remind you of the event.

The average score on this scale is 50 (SD 10; alpha scale reliability .81). About 25% of people score below 43 and about 25% of people score above 57. If your score is above 57, you may want to take some time to think about what at work may be frightening to you or if there is some other reason for the elevated score. While higher scores do not mean that you do have a problem, they are an indication that you may want to examine how you feel about your work and your work environment. You may wish to discuss this with your supervisor, a colleague, or a health care professional.

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# **Self-care plan**

What vision do you have for yourself in 12 months regarding your professional resilience and wellbeing? What is the plan that goes with that vision?

Here is one example of a self-care plan, but there are various formats that can be used.

Level of Intervention	What supports and energises me?	Who is involved?	What is currently in place?	What steps do I need to take now?
Personal				
Professional				
Organisational				

Review date: \_\_\_\_

Accountability to:

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# Figure List

Figure 1 - Consumer and family/carer lived experience work (Downes & Edan, 2017) Downes, L., & Edan, V. (2019). Introduction to Lived Experience Roles. Centre for Mental Health Learning. https://cmhl.org.au/sites/default/files/CMHL-Intro-to-LEW-roles-v3-20190227.pdf

Diagram - Practice Skills and Attributes - diagram developed by The Carer Perspective Supervision Framework's co-design team to reflect the Carer lived experience workforce in Carer Consultant and Carer Peer Support Worker roles

#### Figure - Triangle of Care

This figure has been adapted from - Worthington, A., & Rooney, P. (2010). The triangle of care, carers included: A guide to best practice in acute mental health care. The National Acute Care Programme, Princess Royal Trust for Carers and National Mental Health Development Unit, London.



