

Better Choices Better Health Carers in Control

Participate in Health Conference

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Presenters

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Carers

Family carers provide unpaid care and support to a partner, family member, or friend who requires assistance with various aspects of daily living as a result of chronic or acute health conditions, mental health issues, disability or aged frailty.

Impact of Caring

The role of a family carer is demanding, ongoing, physically, socially, and emotionally challenging.

The care recipient may require care support for a short time, episodically, or it may be protracted and provided over many years.

Beyond Expectations

Carers take on roles that include care tasks and responsibilities that are over and above what would normally be associated with their relationship.

Life Enhancing Investment

Carers have an ongoing relationship with the care recipient - emotionally, physically, spiritually, and historically.

Carers have an investment in the relationship, in the person, and in the future.

Working Together

Carers have practical experience and knowledge in providing care to the care recipient and they understand the day to day impact of the illness or condition.

Carers are a resource for medical practitioners and service providers.

Best care is provided when carers are included as part of the health care team.

Acknowledge and Include

Medical practitioners see their patients for a few minutes per visit and are largely reliant on what the care recipient tells them. They may not get the full picture.

Including carers in medical visits, treatments and all aspects of the care recipient's care needs will provide a complete picture.

Carer Expertise

Carers **know** the care recipient – they know the whole person and what happens behind closed doors.

Carers know:

- If the care recipient is compliant with medication regimes – and are aware of the effects
- The care recipient's limitations and the type and level of assistance required with daily living tasks, personal hygiene, mobility, etc
- The care recipient's capacity for physical, social, emotion and psychological interactions

Carer Inclusive Practice

Carers need health practitioners and service providers to acknowledge their role and to exhibit carer inclusive practice.

Inclusion means involvement!

Empowering Carers

Taking responsibility for another person's health and wellbeing on a daily basis requires a range of skills, knowledge, supports, stamina, inclusion and empowerment.

To empower and assist carers in their role we need to:

- Include carers in consultation – at all levels
- Listen to what they want and need
- Advocate for appropriate service provision
- Engage in carer inclusive practice

Respect and Recognition

Carers live with, and are affected by the care recipient's illness or condition.

Carers need respect and recognition of their skills, knowledge and expertise.

Acknowledgement and inclusion is essential.

Information

Carers also need timely and relevant information about:

- The illness or condition and what to expect
- Treatments, medications – and involvement
- The impact of illness on the family – social, emotional
- Home safety tips & OH&S techniques for carers
- Services and supports for the care recipient
- Services and supports for the carer
- Access and eligibility requirements for services and supports

Disempowerment

Carers can experience a sense of disempowerment and frustration due to a range of factors including:

- Invisibility – being treated as if they don't exist
- Not having their involvement and value acknowledged
- Exclusion from medical appointments, treatment options, care planning, etc
- Not being asked what they need or want
- Not being listened to, or their experiences validated

Disempowerment

- Not being taken seriously - being treated as if they are 'neurotic' or don't know what they are talking about
- Not having appropriate or adequate information provided early in their care journey or as the illness progresses
- Not knowing the questions to ask in order to obtain the information, support, or service required
- Jumping through hoops - red tape, assessment and eligibility processes, waiting times, getting the 'run around'

Care Role – All Consuming

The demands and pressures associated with the care role can become all consuming, infiltrating and impacting on all aspects of the carers life.

This can have negative impacts on the carers own health and wellbeing, particularly when their own needs are neglected or relegated to the bottom of the priority list.

Values, Beliefs and Expectations

Carers incorporate societal and cultural expectations into their own value and belief systems, and this will influence their decision to take on, and maintain the care role.

Expectations and Negative Impact

Sometimes expectations can be unrealistic and damaging to the carers own health and wellbeing

- It is the carer's duty
- No one else can or will do it
- Super person syndrome
- Best care is always provided in the home
- Caring is a woman's role

Assertiveness

Carers often need to develop a range of skills, and one important skill is learning to be assertive.

Assertiveness is often required in navigating health care and educational systems, recognising and effectively managing unrealistic expectations. And in accessing and accepting help and assistance.

Non Recognition

Carers do not always relate to the term *carer*, and may not even recognize the extent to which they have taken on this role.

Non recognition has implications for accessing help, services including financial and emotional support.

Carers will often say

“I’m a wife, it’s just what I do”

Relinquishing Care

Carers often remain the primary carer long after it has ceased to be the best or most appropriate option.

Relinquishing primary care of the person you have cared for, and who is a major part of your life can be very difficult.

Carers say that carer inclusive practices by residential care facilities can help to ease the emotional turmoil.

Working Together

Conference aim

To stimulate discussion, share experiences and document the evidence on how participation '*with us, not for us*', improves our health care system.

Carers Victoria's approach

To listen to carers and advocate on their behalf to all levels of government, and to provide effective programs and services to meet the needs identified by carers.

Solution Based Strategies

Strategies that carers tell us will help include:

- Listen to carers – hear what they say
- Acknowledge the role and value of carers
- Take a multifaceted approach in which carers have a voice
- Address identified needs – don't just make promises, take action

Solution Based Strategies

- Fund services at a rate that will enable them to provide flexible, quality, ongoing appropriate services
- Create flexible respite options - including residential care facilities appropriate for care recipients with various needs, including younger persons
- Provision of information and supports in a timely, user friendly and easily accessible manner

Carers Victoria

Carers Victoria offers a range of services and programs including:

- Education and training for carers
- Education and training for service providers (RTO)
- Carer Counselling Program
- Information, support and advocacy
- Policy and research

Contact Carers Victoria on 1800 242 636

or 1300 carers (1300 227 377) from 1st April 2007

In 2005 Carers Victoria became a Registered Training Organisation.

The RTO provides accredited courses to service providers to raise their awareness of carer issues and enhance their ability to provide carer inclusive practice.

Workshops for Carers

A range of educational programs and workshops have been developed for carers.

Each workshop focuses on a particular aspect of the carer's role and provides effective strategies to assist carers to incorporate their own health and wellbeing needs into their care role.

Free For Carers

Educational workshops and training programs are tailored to meet the individual needs of particular groups and are provided free of charge to carers and carer support groups throughout Victoria.

Workshop Titles

Most workshops are 2 hour sessions:

- Caring for yourself
- Moods emotions, grief and me
- Preparing for care giving
- Lasting the distance
- Humour and caring
- Planning for residential respite

Workshops Titles

More 2 hour sessions:

- When tomorrow comes – end of life care
- Building bridges or barriers – how effective is your communication style
- Surviving carer stress - condensed
- Financial information for carers
- Legal information for carers

Workshops Titles


Day programs consist of 2 sessions:

- Surviving Carer Stress
- Reacting differently - responding to emotive and manipulative behaviours

Other programs consist of 4 sessions:

- Assertiveness for carers
- Transitions

Our Vision



Caring – a personal experience,
our shared responsibility