

SOUTH EASTERN SYDNEY LOCAL HEALTH DISTRICT

Carers Strategy

2019-2022



A strategy to support **carers and families** caring for people who are frail aged, living with disabilities, with mental health conditions, alcohol or drug dependency, dementia, terminal illness, chronic illness or who need support

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A carer is a person who has caring responsibilities ...

they could be you, your parent, a parent, a single person, a cousin or sibling, a family friend, a person sitting on a bus... a person shopping in the supermarket, dropping children off at school, the person you smiled at in the queue... your co-worker, a worker, a volunteer, a school pupil, a student, a retiree, a newly arrived person...

Foreword

“Carers support people to live independent lives, to remain in their own homes and in their own communities. This care is fundamental to family life and our community wellbeing.”

NSW Carers Strategy 2014–2019

I am pleased to present the South Eastern Sydney Local Health District’s Carers Strategy 2019 – 2022. This strategy recognises the critically important role of carers and family members in health care. It also recognises our responsibilities as health care providers to work effectively in partnerships with carers and family members that provide care to our patients.

This strategy is our Local Health District’s response to the NSW Health Recognition and Support for Carers: Key Directions 2018-2020 which sets out our responsibilities to: inform and guide its employees to recognise and support carers; value and engage with carers as partners in care; and support employees who have caring responsibilities.

Ten percent (10%) of our population in South Eastern Sydney are carers. Every day in our health service we are in contact with carers and family members that provide care to their loved ones. However, we may not identify them as carers and they may not self identify as carers. This limits their opportunities to access the entitlements, services and supports available to support them in their caring role. It also limits their opportunities to participate in the ‘Triangle of Care’ (page 33), where carers, consumers and health care providers work together as partners in care.

As health care providers, we recognise that carers and family members that provide care have expertise in the needs and preferences of the person for whom they provide care. We recognise the responsibilities that carers hold for the wellbeing of the person for whom they provide care and that optimal health outcomes are achieved when we work together, providing carers with the information, services and supports they require to continue their caring role.

The percentage of South Eastern Sydney Local Health District employees who work and are providing care to a family member or friend is higher than the state average of 12%. We recognise that working carers need flexible workplace practices to enable them to be responsive to both their carer responsibilities and their work requirements.

Thank you to the carers, family members and health care providers who have given generously of their time to contribute to the development of the Carers Strategy 2019 – 2022. We look forward to using the strategy to improve how we work with carers and family members who provide care in our Local Health District.



Tobi Wilson
Chief Executive

Acknowledgements



South Eastern Sydney Local Health District would like to acknowledge the Traditional Custodians on whose land our facilities are located: the lands of the Dharawal, Gadigal, Wangal, Gweagal and the Bidjigal peoples. We would like to pay our respects to the Elders past, present and those of the future.

SESLHD would also like to thank Karen Edwards, Consultant, Counterpoint Consulting for her contribution to the development of the strategy, and acknowledge the generosity of those who contributed their time and spoke of their personal experiences to assist in the development of this strategy in particular, members of the Carer Strategy Steering Committee:

- Greg Stewart, Director, Primary, Integrated and Community Health (PICH)
- Tony Jackson, Deputy Director, Primary, Integrated and Community Health
- Lisa Woodland, Manager, Priority Populations
- Nicole Marchisone, Disability Strategy Manager
- Sydney Boucher, Engagement and Support Officer, Directorate Planning, Population Health and Equity (DPPHE)
- Colleen Fong, Carer Representative
- Linda Prince, Carer Representative
- Gary Sloan, Carer Representative
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- Jason Ayres, Carer Representative
- Gurdive Webster, Carer Program Manager, Priority Populations
- Alison Sneddon, Senior Health Service Planner (DPPHE)
- Joanna Politis, Former Acting Carer Program Manager
- Tim Croft, Manager, Aboriginal Health Unit
- Lauren Bray, Team Leader, Paediatric Occupational Therapy Child Youth and Family Service
- Peggy Yeomans, Deputy Head Social Work, Prince of Wales, Sydney and Sydney Eye Hospitals
- Linda Green, District Program Manager, Family & Carer Mental Health and Children of People with Mental Illness Programs
- Terry Lynch, Carer Representative
- Mary Ashton, Pastoral Care Manager, Calvary Hospital Kogarah

We would also like to sincerely thank other carers living in the District and using our services, carer support services, staff and managers working with carers in SESLHD Facilities, who provided their insights and experience for the development of the Carers Strategy.

Thank you!

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The Demography of Carers

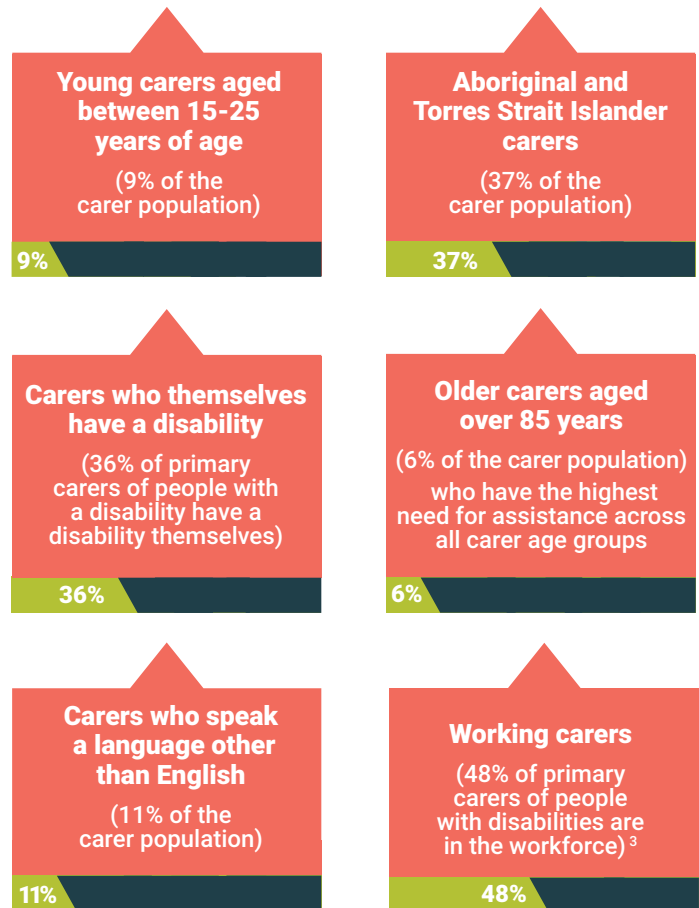
Who is a carer?

In this strategy when we talk about carers, we are including family members who may be supporting a person in need of assistance. Often, but not always, carers are spouses, parents, adult children or younger children of a person needing support. Some people are caring for more than one person.

Carers provide support to people who are frail aged, those living with lifelong disabilities, mental health conditions, alcohol or drug dependency, dementia, terminal illness, HIV or with a chronic illness. Carers can be any age and come from all walks of life. Carers may assist with activities of daily living, being a key person for transport, social support, medical appointment support or providing emotional support and assisting with decision making. They may care for a few hours a week or all day, every day, seven days a week.

Not all those who provide care to another would call themselves carers. This may be because of cultural expectations, language, or because their relationship to the person being cared for has always included an element of 'loving care', for example spouses or parents providing care^{1,2}

Vulnerable populations of carers



Source: Deloitte Access Economics, The economic value of informal care in Australia 2015, Carers Australia, June 2015

Our carers in SESLHD



In SESLHD, 10% of the population over the age of 15 years are carers with 60% of the carer population being women.



The majority of carers are aged between 50 and 69 years (70%).



Carers of people with disabilities in SESLHD provide care for partners (38%), children (29.6%) and parents (22%).



The St George area (Georges River LGA and Rockdale LGA) has the highest percentage of carers by population across SESLHD (28% of the district population; 32% of the total carer population)³.

Source ³ SESLHD Population Profile_vulnerable and priority populations_SESLHD_ABS Census 2016.pdf

SESLHD Carers Strategy on a page

Guiding principles

Strengths based approach



Respect for carer knowledge and expertise



Access to information and support for carers



Recognition of carers as partners in care



A skilled and confident workforce engaging with carers



Organisational support for working carers

Domains of action



Goals and Outcomes

To inform and support carers throughout their caring journey

Carers are aware of the available supports and entitlements

Carers have access to experience-based advice and support in their role

Carers are accommodated in our facility design

To assist our clinicians and other staff to work in partnership with carers

Carers are routinely identified at entry into our services

Carers are routinely included in care discussions and decision-making

Our staff are confident working with carers as partners

To support our working carers in their caring roles

Our employees with caring responsibilities have access to information, support and entitlements to undertake their caring role

Our managers know the support and entitlements available for our working carers

Long-term outcomes

- Carers are recognised and supported as partners in our health service
- Employees with caring responsibilities thrive in our health service

Principles underpinning the SESLHD Carers Strategy 2019-2022



Strengths-based approach

Recognising and building on the existing strengths of carers, families and carer networks.



Respect for carer knowledge and expertise

Respecting the carer/family member as expert in the needs and care giving strategies for the person they are caring for.



Access to information and support for carers

Working with carers and families to assist them in their caring role.



Recognition of carers as partners in care

Recognising the carer/family as the third arm in the 'Triangle of Care' and working in partnership with them when the person they are caring for is receiving care in our hospitals and/or community health settings.



A skilled and confident workforce engaging with carers

Supporting staff knowledge, skills and confidence in working with carers/families as partners in care.



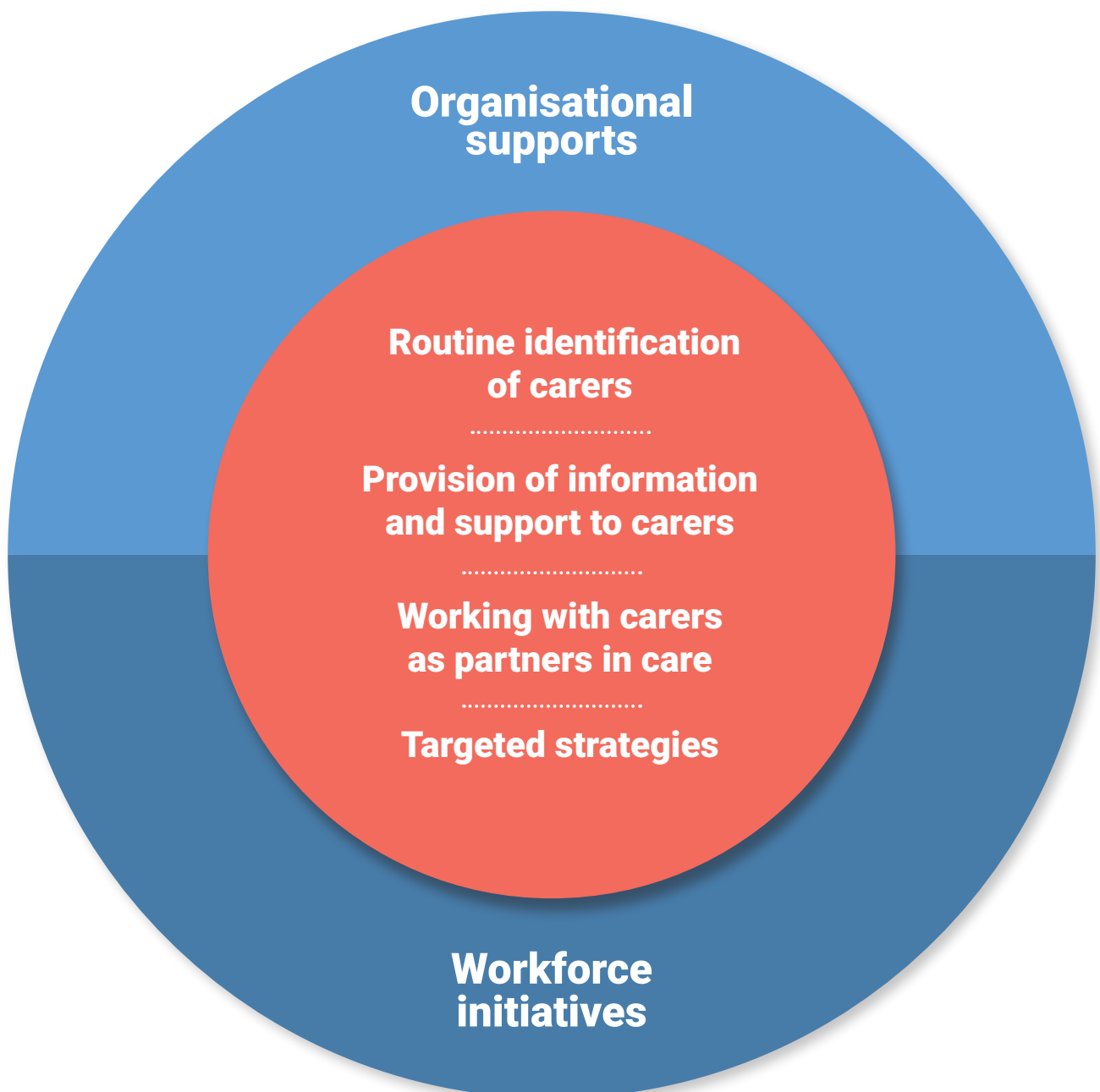
Organisational support for working carers

Being an organisation that recognises and supports employees who are carers.

Domains of action

Engagement and support for carers and family members who provide care

Figure 1



Engagement and support for all carers and family members

Engagement and support for carers & family members comprises of the following:

Routine identification of carers

We will establish a formalised process to identify carers of our patients/clients or patients/clients who are carers of others, including:

- Routinely identifying carers on intake/admission;
- Assessing the willingness and capacity of carers to partner with us in the care of the patient.

Provision of information and support to carers

We will investigate ways to ensure the systematic provision of information and support for carers & family members. We will maintain and strengthen our partnerships with community support services by:

- Investigating opportunities to enhance community-based carer support activities;
- Including community carer support providers in information channels;
- Supporting digital literacy training for carers.

Working with carers as partners in care

We will adapt our clinical processes to increase opportunities to work in partnership with carers & family members including:

- Recognising the carer as the expert in the needs and care giving strategies for the person they are caring for;
- Using tools such as the Top 5 and the Admission to Discharge (A2D) toolkit;
- Routinely communicating with carers about the clinical decisions affecting the person for whom they are providing care.

We will endeavour to allocate spaces and facilities (where possible) to support carers & family members to remain near the person for whom they have caring responsibilities.

Targeted strategies for carers and family members who are caring for someone with multiple and/or complex needs

Targeted strategies

We will investigate ways to enhance supports for carers who are caring for someone with multiple and/or complex needs, which could include:

- Establishing a carer support service to assist navigation of the health care system;
- Enhancing care coordination for patients and carers with multiple and/or complex needs.

Organisational supports for health staff to deliver engagement and support for all carers and family members

Organisational Supports

We will increase the capability within our workforce to effectively work with and provide support to families and carers including:

- Developing the knowledge, skills and confidence of our workforce to engage and support carers and families;
- Develop resources to support health staff to engage and support carers and families
- Supporting changes in practice for all staff to include carers as partners in care;
- Acting on innovative suggestions from our staff and also our carers / patients on ways of working with families and carers;
- Ensuring that consultative structures and processes are inclusive of carers.

Workforce initiatives for working carers/ carers who are employees

Workforce Initiatives

We will review and enhance workforce initiatives to support employees who have caring responsibilities.

Implementation of the Strategy

This Strategy provides a framework for each Facility and Directorate within SESLHD to articulate their contribution to our shared goals to:

- inform and support carers through their caring journey;
- assist our clinical and other staff to work with carers as partners in care; and
- support our working carers in their caring roles.

Annual implementation plans will be developed across the District and monitored by an Implementation Steering Committee. Key roles and responsibilities are outlined below:

Implementation Responsibilities

General Managers and Service Directors

-
- Identify key priorities and actions for the Facility/Directorate within the Strategy
 - Nominate representatives for the Implementation Steering Committee
 - Provide executive support for actions within the Strategy
 - Provide regular progress reports, as requested by the Implementation Steering Committee
-

Workforce Services

-
- Ensure leave entitlements for employees with caring responsibilities are understood at all levels of the organisation
 - Provide training for managers in supporting employees with caring responsibilities
 - Review workplace practices where these are creating barriers for employees with caring responsibilities
-

Primary Integrated and Community Health Directorate

-
- Chair and provide secretariat functions to the Carers Strategy Implementation Steering Committee
 - Through Priority Populations Unit:
 - ˆ Lead/coordinate District wide workforce development and capacity building initiatives
 - ˆ Provide support and advice to services and programs as required
 - ˆ Lead/coordinate District-wide initiatives/projects
-

SESLHD Carers Strategy Implementation Steering Committee

-
- Oversight of the implementation of the Carers Strategy
 - Monitor progress
 - Identify opportunities for collaboration between internal and external partners and community
-

Policy Background

Key plans and strategies relevant to planning of the SESLHD Carers Strategy include:

- SESLHD Journey to Excellence (2018-2021)
- SESLHD Equity Strategy (2015)
- NSW Carers Strategy (2014-2019)⁴
- NSW Health Recognition and Support for Carers Key Directions (2018-2020)⁵
- NSW Carers (Recognition) Act 2010 and NSW Carers Charter
- National Safety and Quality Health Service Standards - second edition (NSQHSS)

The NSW Carers Strategy

The NSW Carers Strategy is a five-year plan to improve the position of carers in NSW, which acts as a key driver for a whole of government approach to addressing the needs of carers. The NSW Carers Strategy is summarised in figure 2 below.

Figure 2:

NSW Carers Strategy summary

FOCUS AREAS →	PLANNED REFORMS	→ EXPECTED OUTCOMES
Employment & education	<ul style="list-style-type: none"> • Increase the use of existing workplace flexibility by carers and their employers • Enable carers to recognise the skills and expertise they bring to employment and training • More young carers receive support at school to transition to further education and employment 	<ul style="list-style-type: none"> Carers have choices and opportunities to participate in paid work Young carers complete school and transition to further education and employment
Carer health & Wellbeing	<ul style="list-style-type: none"> • Improve the design and delivery of services and programs in ways that make it easier for carers to look after their own health and wellbeing 	<ul style="list-style-type: none"> Carers experience good health and wellbeing
Information & Community awareness	<ul style="list-style-type: none"> • Embed and improve information for carers in the trusted systems they frequently use • Create positive media campaigns that portray carers as real people • Increase the number of people with an understanding of carers lives 	<ul style="list-style-type: none"> Carers are able to easily access information when they need it Carers feel the broader community understands their experience
Carer Engagement	<ul style="list-style-type: none"> • Continue to improve the ways we involve carers as partners in the care delivered to their loved ones • Greater involvement of carers in local decisions about the design and delivery of services 	<ul style="list-style-type: none"> Carers are involved in decisions that affect them and the people they care for
Evidence base	<ul style="list-style-type: none"> • Better use is made of the available data and research to create evidence that will shape policy and programs 	<ul style="list-style-type: none"> Carers policy and practice is informed by quality evidence

The NSW Ministry of Health is the lead agency for the NSW Carers Strategy action areas 2.1 *Easier access to health care* and 4.1 *Partners in care – health care*. The Ministry has specific programs and resources for staff working with carers and for carers themselves.

These include:

- eCARERS Learning Program – Creating a Carer Culture in NSW Health (staff training);
- Carers Compass – Carer Friendly Model of Care (model of care adapted from the UK);
- NSW Health Carer Support Services;
- NSW Family and Carer Mental Health Program;
- The Carer Line (a telephone service for carers);
- Working Carers (advice on supporting carers in the NSW Health workplace).
- Walking with Carers in NSW (information for carers on matters to do with NSW Health)

NSW Health Recognition and Support for Carers Key Directions 2018-2020

The *NSW Health Recognition and Support for Carers Key Directions 2018-2020*, describes the key directions to be taken by NSW Health entities in achieving the goals and actions within the NSW Carers Strategy 2014 – 2019 (Figure 3).

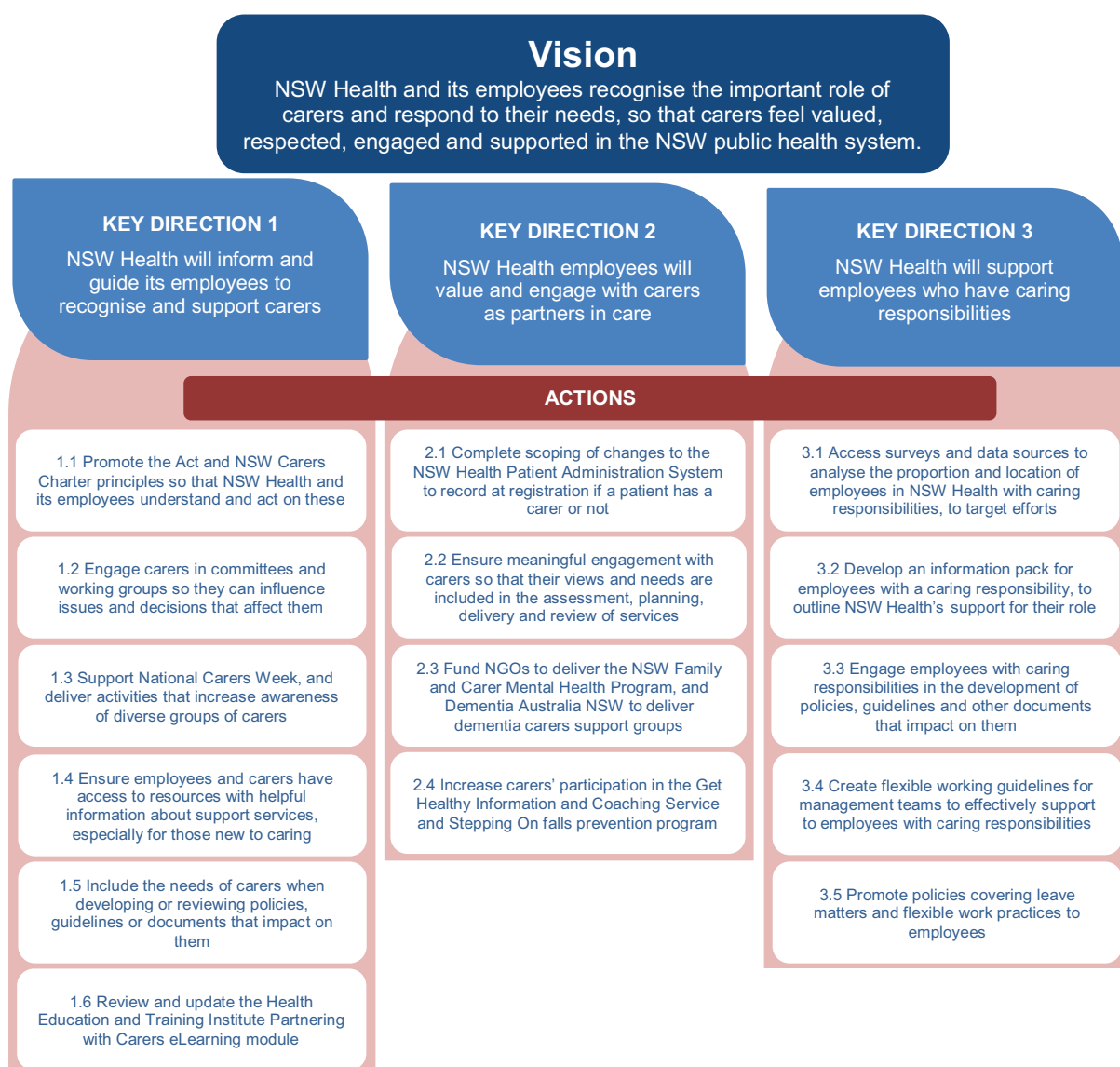
Key Direction 1: NSW Health will inform and guide its employees to recognise and support carers.

Key Direction 2: NSW Health employees will value and engage with carers as partners in care.

Key Direction 3: NSW Health will support employees who have caring responsibilities.

Figure 3:

NSW Health recognition and support for carers key directions 2018 – 2020



Guiding principles

Inclusion ➤ the diversity of carers including Aboriginal people, multicultural communities, refugees, lesbian, gay, bisexual, transgender, intersex, and young carers, is acknowledged, respected and placed at the centre when developing and implementing actions for carers

Collaboration ➤ collaboration and partnership with carers, government and non-government organisations is key to achieving a more inclusive health system and better and enduring outcomes for carers

Evidence ➤ NSW Health organisations should use tools to evaluate the impact of projects and initiatives to support the delivery of services informed by good practice

SESLHD Journey to Excellence

Carers are important to SESLHD, with the Carers Program being part of the Priority Populations Unit within the Local Health District (LHD). Planning in the LHD stems from the *Journey to Excellence* overarching Strategic Plan.

The SESLHD Strategy, *Journey to Excellence 2018 - 2021* describes the vision, purpose and strategic priorities of SESLHD. The Strategy is the foundation document for planning and prioritising SESLHD programs, clinical and corporate services.

The Strategy has five key strategic priorities:

- **Safe, person-centred and integrated care:** Everyone in our community will have access to safe, compassionate and high quality healthcare. That care should be provided either at home, or as close to home as possible.
- **Better value:** We will deliver value to our patients and community through maintaining financial sustainability and making investments consistent with our vision.
- **Community wellbeing and health equity:** We will work together with our partners to achieve health, wellbeing and equity for our shared communities.
- **Workforce wellbeing:** We will create an environment where our people will be accountable and can be happy, well and supported to reach their potential.
- **Fostering research and innovation:** We will focus on translating research and innovation into clinical service models that deliver positive health outcomes.

Key enablers to the Strategy are:

- Partnerships that deliver positive outcomes
- Relevant data and analytics
- Fit for purpose infrastructure
- Responsive information management systems
- A culture of continuous improvement



Being a carer or family member with caring responsibilities



““ It sneaks
up on you ””

““ I didn't think of
myself as a carer ””

Caring can be and often is immensely rewarding. However, it can also be frustrating, sad and limiting. For some, the carer role is unexpected and sudden, when for example, a family member or partner becomes suddenly incapacitated in an accident. In other cases, it is a gradual process, for example when a person develops dementia or has a chronic disease.

This section brings together the known evidence, with the voices of families, carers and service providers in South Eastern Sydney to describe the issues, concerns and needs of carers and of family members with caring responsibilities.

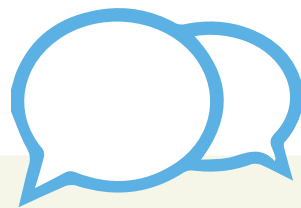
The voices of carers, families and service providers in South Eastern Sydney

Carers are not a homogenous group, and there are specific issues for different groups of carers or those caring for people with different conditions. Many people needing care have complex care needs related to multiple conditions¹.

Nevertheless, the literature is clear on stressors experienced almost universally by carers^{6,7}.

In consultations, family members, carers, carer support services and SESLHD staff identified many issues.

Family members and carers in South Eastern Sydney spoke about the need for assistance to help them negotiate the complex health, disability and aged care systems.



- **Lack of time for personal needs, leading to poorer mental and physical health**
- **Balancing the role with other demands**
- **Lack of accessible information about supports**
- **Guilt if things go wrong or the health of the person they are caring for worsens**
- **Depression and anxiety, grief and loss**
- **Fatigue and sleep disturbances**
- **Social and geographic isolation**
- **Challenges in negotiating the health, disability and aged care systems**
- **Complex digital portals which are increasingly being introduced as the default service**
- **Not being identified as a carer by health care providers**
- **Exclusion from clinical discussions**
- **Not being able to access clinicians outside of working hours**
- **A sense of powerlessness and loss of control**
- **Challenges maintaining/re-entering paid work**
- **Loss of income**

Aboriginal carers

Culturally, Aboriginal people do not necessarily see the 'caring role' as separate to their other responsibilities to family (including extended family) and community.

People from Aboriginal background are often 10 years younger than other Australians when they develop chronic illness. This impacts on their caring role as they may be managing their own health issues, while looking after grandchildren or taking on other caring responsibilities in the extended family.

Grandparents who are caring for grandchildren due to drug and alcohol, mental health conditions or family violence may find themselves more vulnerable to violence⁹.

There may be different perceptions and cultural explanations for chronic illness, mental illness and dementia in some Aboriginal communities.



- **Lack of accessible, culturally appropriate information for Aboriginal carers**
- **Aboriginal people not identifying as carers or accessing available supports**
- **Avoidance of hospital or respite care, adding to carer stress**
- **Wariness of assessment processes due to historical poor experiences with government**
- **Poor communication with carers of Aboriginal patients by clinicians**
- **Inadequate spaces for large families to visit**
- **Young Aboriginal carers looking after older relatives with chronic conditions**
- **Grandparents looking after children with complex health or behavioural issues**

Carers from culturally and linguistically diverse backgrounds

It is estimated that between 25 to 30% of carers in Australia are from CALD backgrounds⁹. In South Eastern Sydney, 11% of carers speak a language other than English at home³.

Carers from CALD backgrounds may come from a culture where caring is expected and not acknowledged as stressful or difficult. Carers may also view their caring role as positive and enabling¹⁰.

These carers may not personally identify as carers and therefore not access carer supports. Some languages and cultures do not have words or concepts for 'carer'.

Family pressures and cultural expectations may result in carers remaining invisible, unable to ask for help and unsupported.



- **Lower health literacy impacting on access to support for carers and their loved one**
- **Poor clinician understanding of the need for information to be provided for all health literacy levels**
- **Lack of carer identification by professionals**
- **Stigma associated with cultural beliefs about some illnesses in some cultures e.g. mental health condition, cancer**
- **Cultural beliefs that conflict with assessment and treatment regimes and impact on carer willingness to have the patient treated**
- **Concern about the cultural appropriateness and competency of services**
- **Access to interpreters for carers (even if the patient speaks English) if they have limited English language proficiency**
- **Lesser uptake of Centrelink carer payments, benefits and concessions**

Young carers



Young carers may be caring for a parent or a sibling. They may be caring for a parent with an early onset of a chronic condition, Young Onset Dementia (YOD), a mental health condition, drug and alcohol issues, or a motor neurone disease.

Young carers are often described as 'invisible carers' partly due to reluctance to disclose their caring role or a perception that this is a normal responsibility (especially in some Aboriginal or culturally and linguistically diverse families).

There is an increasing awareness of the impact of long term caring on the life trajectory of young people. Carers NSW have a Young Carers Program, which is designed to address many of the issues for young carers¹¹. Some key issues identified for young carers include those listed to the right^{12,13}.

- **Lower rates of study or full-time employment than other young people**
- **Fear related to inheritable conditions**
- **Physical exhaustion from manual handling**
- **Interrupted social development and social isolation**
- **No access to peer carer supports**
- **“Parenting the parent”**
- **Disrupted emotional development and maturation**
- **Grief and loss**

Older carers



As the population ages, more people are providing care to an older family member, usually a spouse or parent. Where the carer is a spouse, that person may also be experiencing the effects of ageing, with associated physical or cognitive limitations.

Nevertheless, older carers may also experience a sense of love and achievement in, for example, being able to stay with their spouse at home and maintain their relationship¹⁰.

As a parent, the carer may worry about their adult child's care needs¹⁴.

Carers over the age of 85 years are a particularly high priority group. Older carers are less likely to be aware of available services or to have the wherewithal to access them (especially where there are online gateways to navigate)¹⁵.

The National Disability Insurance Scheme (NDIS) and other online supports, such as the My Aged Care Gateway, may not be as accessible to older carers, who can become confused by the changes. Service providers face barriers in helping older carers access their information on these sites.

Older carers of adult children with disability are often worried about how their adult child, who is also ageing, will cope when they are no longer able to provide care or if they die before their child.

They may need support in planning and transitioning their adult child to other disability support services.

Working carers



One in eight Australian employees is a carer¹⁶. This is likely to increase as our population ages.

Working carers (including those from Culturally and Linguistically Diverse backgrounds) may be working in or pushed towards part-time or casual work in order to manage their caring responsibilities, but such positions are often 'insecure employment' situations.

Working carers need flexible workplace practices that support them to be responsive to their carer responsibilities and still meet their work requirements.

- **Younger working carers have families depending on their income and may not be able to reduce hours**
- **Carers are not always aware of the employee benefits available to them**
- **Employer policies may not support carers in their career development**
- **Organisational policies may support or impede caring responsibilities for workers**
- **Within the acute care setting, it is sometimes difficult to replace working carers if they need to leave the workplace suddenly**
- **There may be limited access to respite or day care**

Former carers



For many the caring role ceases due to the death or changes in response to a change in the residential status of the person they are caring for. This may be after years of intensive care, often to the detriment of other aspects of their lives.

When the caring role ends or changes, former carers can be left bereft and at sea, unsure of what to do with their life¹⁷. Life circumstances such as housing and income may be directly affected by the caring role ending.

This is a time when contact with other carers who may also have experienced this change may be helpful. Opportunities to provide peer support and share knowledge gained as a carer can also help former carers re-establish their sense of purpose^{18,19}.

- **Grief and loss**
- **Feelings of guilt associated with a change in residential status of the person they have been caring for**
- **Loss of employment skills and associated challenges in transitioning into the workforce**
- **Loss of social networks**
- **Further loss of income through cessation of carer benefits**
- **Loss of purpose**
- **Exhaustion**

Caring Roles

Caring responsibilities are taken on in many situations. Some of these are described below, although this is not an exhaustive list.

Caring for someone who is frail aged and/or living with dementia

Carers looking after a frail aged spouse are often facing health issues associated with ageing and need additional care themselves to support them to continue caring. This includes practical support and assistance to maintain their caring role²⁰. Additional psychological support for carers may be needed before and after an admission to hospital for the older person receiving care, to help with anxiety and stress²¹. Falls are a major concern for carers of a frail aged person²².

Dementia is the single greatest cause of disability in Australians over the age of 65 years, and the third leading cause of disability burden overall²³. Caring for a person with dementia impacts on carers in a multitude of ways⁷.

Hospital admissions can put additional pressure on carers, and issues for carers can arise following hospitalisation, if discharge planning does not include the carer. Things can go wrong and readmissions are more common for people living with dementia where the carer has not been involved in discharge planning²⁴.

Often the carer of a person with dementia is a spouse and experiencing cognitive or physical health limitations as well. This may limit help-seeking behaviour. Families and carers of people with dementia may not recognise and not be informed of the signs of approaching death for their loved one, resulting in them being unprepared for end of life²⁵.



- **Poorer mental and physical health, including anxiety, depression, increased risk of chronic conditions**
- **Less social connectedness, family conflict and isolation**
- **Lower quality of life**
- **Increased financial burden from increased costs and/or reduced working hours**
- **Grief and loss**

Caring at end of life

One of the most frequently identified needs of people caring for someone with a terminal illness, in addition to information and advice, is psychological support during the palliation period and after the death of the person for whom they are caring²⁶.

Symptoms at end of life can be intense and distressing for carers²⁷. Bereavement support for family members and carers is perceived as a core component of palliative care in most health services²⁸.

Carers Australia describes the following principles that should underpin support for families and carers when the person they are caring for wishes to die at home²⁷:

- Improved access to and coordination of end-of-life-care
- The engagement of carers and family in planning end-of-life care
- Advance care planning and preparation of an advance care directive
- Provision of education and supports to carers and family
- Follow-up care with bereaved carers and family



- **Depression**
- **Need for emotional support and support in preparing for the future**
- **Earlier access to, and better linkages between treatment and palliative care**
- **Grief and loss**

Caring for children with life-limiting conditions

Children with life-limiting conditions are those where the condition is diagnosed before the age of 16 years and is likely to result in them dying at a young age.

Carers and families of children with life-limiting conditions undergo intense stresses in providing ongoing care for the child²⁹. In particular trusted and trusting relationships with health care providers are important in assisting parents caring for children with life-limiting conditions to discuss treatment and make significant decisions³⁰.



- **Assistance with advance care planning**
- **High levels of communication with trusted clinicians**

Caring for someone living with a mental health condition

Mental health conditions range from mild to moderate, through to severe and enduring mental illness.

As the age of onset of some mental health conditions (e.g. psychotic illnesses) can be during adolescence or early adulthood³¹, families and carers may spend many years caring for and supporting their loved one. Children of a person living with a mental health condition may fear they will also develop a mental health condition and may experience stigma and social embarrassment³².

Families and carers are integral and active partners in mental health care. The NSW Mental Health Act requires the nomination of a designated carer and/or a designated care provider as part of case planning and treatment. There is legislation which governs the responsibilities of the health service as well as the rights of carers and family members³³.



- **Anxiety and depression**
- **Caring can be a long-term role**
- **There may be a sudden transition to the carer role after an event or diagnosis**
- **Caring fluctuates at different phases in recovery, leading to uncertainty and confusion for carers**
- **They may experience stigma and isolation**

Caring for someone living with drug and alcohol issues

Carers of a person with drug and alcohol issues are frequently family members. This may be children looking after parents with drug and alcohol issues, or parents looking after children with drug and alcohol issues. In some cases, grandparents are caring for the children of a person with drug and alcohol issues, with associated pressures related to their own health issues or financial and emotional stress³⁴. Carers and families of someone with drug and alcohol issues tend to be more socially isolated than other groups due to the stigma towards people who experience problems with alcohol and other drugs.

The psychosocial impacts of the persons problematic alcohol or other drug use, often becomes issues/concerns for the carer themselves e.g. financial problems, involvement with Police, the criminal justice system and negative impacts on relationships with family and friends.

Co-morbidity with mental health conditions is a relatively common situation. There are specific issues related to caring for a person with drug and alcohol issues^{35,36}.

Including family members in decisions regarding delivery of treatment is a complex decision, involving assessment of the relationship and its impact on the client's engagement with treatment³⁷. Drug and alcohol services work with their clients to decide when and how to involve carers and family members.



- **Unpredictability of behaviours**
- **Dealing with drug-seeking behaviours**
- **Stigma and social isolation**
- **Grief and distress**

Carers in emergency or acute care settings

The emergency and acute care environment is acknowledged as being more difficult to adapt to including families and carers, especially where there are urgent needs for clinical intervention or where carers are unable to communicate easily with clinical care providers.

Where a patient is experiencing psychological distress, has a cognitive impairment, or a condition that reduces their ability to hear, speak or understand, it is particularly important to identify if they have a carer and to work closely with their carer in delivering clinical care.

Carers often spend long hours with a patient and are an important source of information on the patient's clinical history, wants and needs. They can help the patient understand what is going on with their care and help the patient make decisions.

When planning how to communicate with a patient and carer about clinical care, the carer's language and health literacy should also be taken into account.



- **Identification of carers at presentation**
- **Routine inclusion of carers in clinical discussion, clinical handover and provision of information**
- **Recognising the role that carers may play in remaining with the patient for long periods, and accessibility for working carers.**
- **Access to quiet and friendly spaces for carers**
- **Access to on-site or nearby accommodation for carers, including rural carers using health services**
- **Access to cost-free or low-cost parking close to the hospital**
- **Access to safe, affordable transport to visit and attend health care appointments with a patient**
- **Involving the carer in transitioning from home to hospital, from hospital to hospital, from acute to sub-acute care and from hospital to home**
- **Issues for 'new' carers where an accident, event or injury has resulted in a sudden need for care, adjusting to carer role and lack of knowledge about available supports**
- **Address transfers to residential care and preparation for bereavement with carers and families**

Carers in sub-acute care, rehabilitation or community health settings

Health care providers providing palliative care, rehabilitation and 'slow stream' community-based care are more likely to be aware of family and carer needs and to interact regularly with carers. In these health services the provision of carer information and support and an understanding of carers as partners in care may have been built into their operations and into staff education.

SESLHD achievements in engaging and supporting carers



SESLHD has many clinicians and services which are passionate about engaging and supporting carers. The following are illustrative examples of some of the great work undertaken across SESLHD in recent years.

Carers Program

The Carers Program sits within the Priority Populations Unit, Primary, Integrated and Community Health Directorate of SESLHD. Achievements of the Carers Program over the past five years include:

- SESLHD profile of carers of people with disability (based on the Australian Bureau of Statistics (ABS) Survey of Disability and Carers 2015).
- Working Carers Project (2014-16) and Status Report (2018).
- Young Carers Project (2013-15) in partnership Child and Adolescent Mental Health Services - School Link and Department of Education.
- Development of referral pathways to Social Work services for carers accessing gynaecological oncology services at Royal Hospital for Women.
- Development and dissemination of information to carers, including Carers Information packs, noticeboards, newsletters and the SESLHD Carers Program internet site.
- Development and delivery of a range of education and training initiatives including nurse orientation and complex admissions forums.
- Annual Carers Week, National Aboriginal Islanders Day of Observance Committee and other local government activities

Research into the needs of carers

The Carer Program, in partnership with the South Eastern Sydney Research Hub (SEaRCH), Centre for Primary Care and Equity UNSW and others are leading two important research projects to better understand and respond to the needs of carers.

- Carers Information Needs and Technology Preferences. This study explores the information needs and technology preferences of carers who are newer to the caring role (6 months to 3 years). It is led by the Carers Program, in partnership with SEaRCH, Ministry of Health, Carers NSW and others.
- Aboriginal Carers Research Project. This study works with Aboriginal communities to explore the needs and strengths of Aboriginal carers. It is led by the Carers Program, in partnership with the Aboriginal Health Unit (AHU), SEaRCH, and community partners.

Carers as advocates

Kogarah Developmental Assessment Service (DAS) Child Youth and Family Service, employs a social worker, who is also a carer, and takes on a carer advocate role. The social worker talks to any new staff to help them develop an understanding of what it is like for families to care for a child with disability. She also maintains an email group list of carers to whom she provides updates on carer issues.

Carers of people living with a mental health condition

The SESLHD Mental Health Family and Carer Program acknowledges the significant role of families and carers, seeks to reduce barriers within the service, and promotes collaboration between clinicians, consumers, families, and carers. The program builds capacity for clinicians to work inclusively with families and carers to support consumer recovery and provides education to families and carers. In Mental Health Services in NSW and in SESLHD it is mandatory for clinicians to identify the carer for a person with a mental health condition and work actively with that carer. Identification of carers is audited for compliance.

Carer engagement in clinical and capital planning

The SESLHD Carers Strategy Steering Committee includes five carer consultants in its membership.

This exemplifies the District's commitment to engaging carers in committees and working parties providing a strategic mechanism where carers' lived experience and knowledge can inform SESLHD clinical and capital planning.

War Memorial Hospital engaged with consumers and carers in the development of the Clinical Strategic Plan 2018. The plan describes consumers and carers as "co-producers and co-designers for clinical service provision". Carers also have access to the gym on-site.

The Prince of Wales (POW) redevelopment is considering dedicated spaces for carers, including dedicated 'lounge' style space and on-site accommodation for when the person they are caring for is admitted to hospital, as well as configuring patient rooms so there is space for carers.

The St George hospital redevelopment included space and facilities in new rooms for carers to be accommodated. These initiatives were based on the Blacktown Hospital redevelopment where all new rooms had these facilities.

Admission to Discharge (A2D)

It can be challenging looking after people with intellectual disability when they are admitted to hospital, especially if they are not able to communicate their wants and needs easily. In SESLHD the A2D program supports training of hospital staff to help improve the experience of people with intellectual disability attending hospital, and supports transfer of information through the development of A2D folders for residents with disability attending hospital³⁸.

TOP 5

The TOP 5 initiative has been implemented in some hospitals in SESLHD. It is designed to improve staff awareness of the important non-clinical elements of care for patients with cognitive impairment. Clinical staff talk with carers in a structured conversation to identify and record up to five important non-clinical management strategies to help them communicate effectively with a patient and manage patient non-clinical needs or behaviours. The strategies are listed on a one-page form at the patient's bedside, where it is accessible to all staff. An evaluation showed a positive response from carers and clinicians³⁹.

REACH Program

Hospitals across SESLHD are in the process of implementing the REACH program which encourages patients and carers to alert health service staff if they become aware of a worrying change in the health of the patient. This is a NSW-wide program of information with key steps to take spelt out in an easy to read document⁴⁰.

Hospital tours and advice

New arrivals to Australia often come from very different health care systems and do not understand how our hospital system works. They may experience fear and doubt about going to hospital. Regular hospital tours for people from CALD backgrounds, including carers, introducing them to hospital services occur across many SESLHD facilities.

St George and Sutherland Social Workers hold a monthly information stall at the entry of each of the hospitals for consumers and carers. These stalls are more accessible to carers than structured carer support groups as they enable flexibility and choice for carers and still provide support as needed. The NDIS Local Area Co-coordinators (LAC's) host monthly Connection Desks in the foyers of Prince of Wales, St George and Sutherland Hospitals.

Working Carers' Forums

St George Hospital, in partnership with Sutherland Hospital and Calvary Health Care in Kogarah provides an annual Working Carer Forum for employees with caring responsibilities who work in the SESLHD. The day combines information and pampering for working carers.

Mental Health Family and Carer Program

The Program acknowledges the significant role of families and carers, seeks to reduce barriers within the service, and promotes collaboration between clinicians, consumers, families, and carers.

The Program builds capacity for clinicians to work inclusively with carers and family members to support consumer and carer recovery and provides education to families and carers.

Local opportunities for service improvement

Carers and those working with carers gave us suggestions for the things they thought could be improved in supporting carers and working with them as partners in care.

Working with carers of patients using our services

Ways in which carers can be recognised and supported when in contact with our health services were suggested for consideration in implementing the SESLHD Carers Strategy 2019-2022.

- Work to strengthen a culture in health services that recognises and values carers
- Ask three questions:
 - As a patient, do you have someone who you provide care or support too ?
 - As a patient, do you have people or a person who provides you with care or other types of support ?
 - Do you provide care or support for this patient ?
- Record carer details on any intake forms for inpatient, outpatient or community health services
- Including carers where possible in bedside handovers
- Investigating ways for carers to access clinicians outside of normal working hours
- Provide dedicated spaces for carers in hospitals
- Provide friendly child-safe areas for children and siblings of carers or patients
- Extend visiting hours for carers
- Specifically seek carer feedback, not just as part of Patient Reported Measures (PRM)
- Consider consulting with carers and families when developing new services or evaluating existing ones
- Establish a Valet Parking protocol for carers
- Instigate Carer Trolleys or other practical solutions to visit wards and provide information relevant to carers, about carer support services, carer benefits and system navigation
- Ensure staff apply the NSW Carer Charter⁴⁹ as part of patient-centred models of care
- Maintain the TOP 5 initiative and consider adaptation to other clinical environments
- Designate a specific member of the care team to support the patient's carer in negotiating the various systems and accessing support
- Review the Carer Program internet site, and other SESLHD website pages for health literacy, ease of useability and appropriateness of information (language, terminology and cultural nuances) for carers including carers from CALD backgrounds.

Recognising carers as experts/holders of key information

Carers and or family members are the experts in the day to day needs and health care history of the person for whom they have caring responsibilities. Some ways in which this expertise can be recognised include:

- Provide information on working with carers at staff orientation sessions or have a mandatory training program in Health Education Training Institute
- Include carers in the “What Matters to You?” conversation at the bedside with patients

Carers described the ways in which they maintained up to date information about the person for whom they were caring, to be used in interactions with health care providers. These ranged from one-page summaries of care needs and medications to complete histories. There may be an opportunity to assist newly identified carers with templates of carer-held information to support their interactions with health care providers

Establishing support for care navigation

There has been a lot of interest in the idea of experienced carers providing support to other carers, by sharing their hard-earned knowledge and expertise of the carer journey. Carers supported this concept strongly, recognising that many do this informally already.

There are opportunities to establish a carer support service to assist carers in the navigation of health care for the person for whom they are providing care. This would bring benefits to the patient, the carer and the health care system.

Carer support workers, with lived experience of caring, could provide information and navigation support to new carers at the time of diagnosis of the patient, or entry into the health system. Carer support workers would be provided with training and supervision for the role, with their roles and responsibilities clearly delineated in relation to members of the health care team.

Enhancing partnerships with community-based carer information and support services

Local carer support groups, provided by Community Managed Organisations, offer ongoing information and support for a range of carers. They noted in consultation the advantages of a local presence for carers, with a good knowledge of local services and easy access. This Strategy recognises the importance of these supports and those who provide them.

Some ways in which SESLHD might work in partnership with the community include:

- Enhance partnerships with local carer support services and other community groups
- Actively connect carers to local support groups and to peak bodies (e.g. Carers NSW, Dementia Australia, etc)
- Provide access to a directory of carer supports



- **Inform new carers about entitlements**
- **Help carers access NDIS/ My Aged Care/ Aged Care Assessment Team**
- **Help carers navigate the health system, including primary care and community health services**
- **Connect carers with care co-ordination services**
- **Build carer capacity and confidence in their role**

Supporting working carers/employees with caring responsibilities

SESLHD employs many working carers. Some potential improvements to how SESLHD can support its working carers are listed below:

- Provide information and education to SESLHD staff and managers on the entitlements available to working carers/employees with caring responsibilities;
- Support managers to develop work practices which enable staff to take immediate leave when required to undertake caring responsibilities;
- Hold District-wide carer events, including for working carers/employees with caring responsibilities; and
- Review implementation of policies, including flexible working arrangements, to support working carers/employees with caring responsibilities in SESLHD.

National and International examples of good practice

Examples of good practice provide an opportunity for us to think about whether those activities tested in other environments could be adapted or initiated here in South Eastern Sydney.

Carers as Peer Support Workers

In the UK, a peer support program (The Compass Worker) was trialled for carers of people with dementia who were still living at home. The program involved employing and training peer workers with lived experience of being an unpaid carer to provide a maximum of 12 peer support visits to carers, over an unlimited time period. The take-up of the service was high and surveys showed improved quality of life for participating carers¹⁸.

Carers as researchers

There are more and more opportunities for researchers to engage with consumers and carers as co-researchers. In doing so, researchers are able to gain from the lived experience and insights of carers at all stages of the study⁴¹. This approach also builds capacity within the carer population. Examples of working with carer researchers include evaluating dementia cafes⁴², developing a research training package for service users and carers⁴³ and an undertaking in mental health research⁴¹.

Valet parking

There are examples of health services addressing the issue of parking cost and distance to facilities for frail or disabled patients and carers (who may themselves be frail). For example, Children's Hospital Colorado in Denver provides free parking to patients and visitors and offers a complimentary valet service from 6.00 am to 6.00 pm⁴⁴. Griffin Hospital in Derby, Connecticut is reported to provide valet parking at the front entrance⁴⁵.

Pharmacy Carer Support

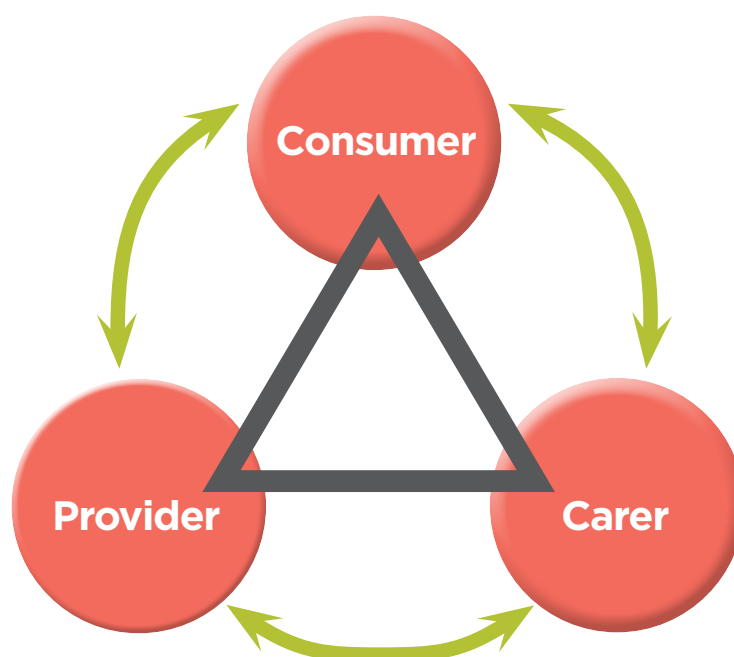
A small-scale study in South Eastern Queensland trialled a carer support program run through community pharmacies. Based on a UK trial, the program involved training pharmacy staff in carer issues and needs, and then identifying and offering support to carers who attended pharmacies for medication for the person they were caring for. The program appeared to increase community pharmacists' awareness of individual carers. Support was often sought by carers from pharmacists for 'pharmacy' tasks (such as medication administration aids) however there may also be opportunities for community pharmacy staff to signpost other carer supports in their interactions with carers⁴⁶.

The Triangle of Care – a model for engaging with carers

The Triangle of Care underpins Mental Health Service delivery in participating services in the UK. It recognises the pivotal role of carers in the lives of people living with a mental health condition, as the third arm of the triangle of service user, service provider and carer⁴⁷. The Triangle of Care has been adopted for Australian Mental Health Services (see below)⁴⁸.

Figure 4:

The Triangle of Care from *A practical guide for working with carers of people with a mental illness*, March 2016.



The Triangle of Care is supported by six principles:

1. Carers and the essential role they play are identified at first contact, or as soon as possible thereafter;
2. Staff are carer aware and trained in carer engagement strategies;
3. Policy and practice protocols regarding confidentiality and sharing of information are in place;
4. Defined staff positions are allocated for carers in all service settings;
5. A carer introduction to the service and staff is available, with a relevant range of information across the care settings; and
6. A range of carer support services are available

There are many elements of the Triangle of Care that are applicable to all services working with carers as partners in care.

Resources

For carers

Carers NSW

"Carers NSW works with all carers regardless of their age, location, life-stage or circumstances. This includes those caring for individuals with support needs relating to ageing, disability, health and mental illness."

www.carersnsw.org.au

South Eastern Sydney Local Health District

Information for Carers on the South Eastern Sydney Carers Program

www.seslhd.health.nsw.gov.au/services-clinics/directory/priority-populations/carers-program

NSW Multicultural Health Communication Service

This service provides information on a range of health issues in many different languages, and also assists with access to translation and interpreter services.

The service has developed a video resource for carers from culturally and linguistically diverse backgrounds.

www.youtube.com/watch?v=pS6sgGnaXXg

Young Carers Network (Carers Australia)

A website for young carers under the age of 25 who care for someone with an illness, disability, mental health issue or who has an alcohol or other drug problem to share their stories and opinions, attend live webinars and learn new skills.

www.youngcarersnetwork.com.au

Carer Gateway

The Australian Government is rolling out a range of new early-intervention services and support for carers in 2019.

www.carergateway.gov.au

www.carergateway.gov.au/caring-for-me
or call 1800 422 737

Australian Government Department of Human Services

Information on Carer Payment – "An income support payment if you give constant care to someone who has a severe disability, illness, or an adult who is frail and old."

www.humanservices.gov.au/individuals/services/centrelink/carer-payment

Department of Veterans Affairs

"The Department of Veterans' Affairs (DVA) understands and appreciates the role of carers and acknowledges the stress and burden involved in providing day-to-day care to veterans and war widows/ers."

www.dva.gov.au/health-and-wellbeing/home-and-care/aged-and-community-care/carers

Lifeline

A toolkit for carers of people living with mental illness.

www.lifeline.org.au/static/uploads/files/carers-of-people-with-mental-illness-wflzjutaysvm.pdf

Australian Government Fair Work Ombudsman

Sick and carer's leave (also known as personal leave or personal / carer's leave) lets an employee take time off to help them deal with personal illness, caring responsibilities and family emergencies.

www.fairwork.gov.au/leave/sick-and-carers-leave

National Disability Insurance Scheme

The NDIS provides support to eligible people with intellectual, physical, sensory, cognitive and psychosocial disability.

www.ndis.gov.au or call 1800 200 422

My Aged Care

The starting point to access Australian Government funded services

www.myagedcare.gov.au or call 1800 200 422

For health providers

South Eastern Sydney Local Health District

Information for Health Professionals on the South Eastern Sydney Carers Program.

www.seslhd.health.nsw.gov.au/services-clinics/directory/priority-populations/carers-program

Planetree

“We work with ministries of health and health-related NGOs around the world to promote person-centered care as a model for improving quality of health care and services. Through partnerships with universities in several countries, Planetree is changing the way that person-centered approaches to care are studied – and taught to future generations of healthcare professionals.

This experience and expertise that has informed global healthcare policy is the same knowledge we bring to our work guiding implementation of clients’ person-centered care strategies and tactics.”

www.planetree.org

Equal Partners in Care (EPIC) Scotland

Learning resources for workers in health, social care and other services with a role in identifying and supporting carers and young carers.

www.knowledge.scot.nhs.uk/home/portals-and-topics/equal-partners-in-care.aspx

Guide for working with carers of people with a mental health condition

“Recovery-oriented practice and service delivery recognises the unique role of personal and family relationships in promoting wellbeing, providing care, and fostering recovery across the life span, and recognises the needs of families and support givers themselves.”

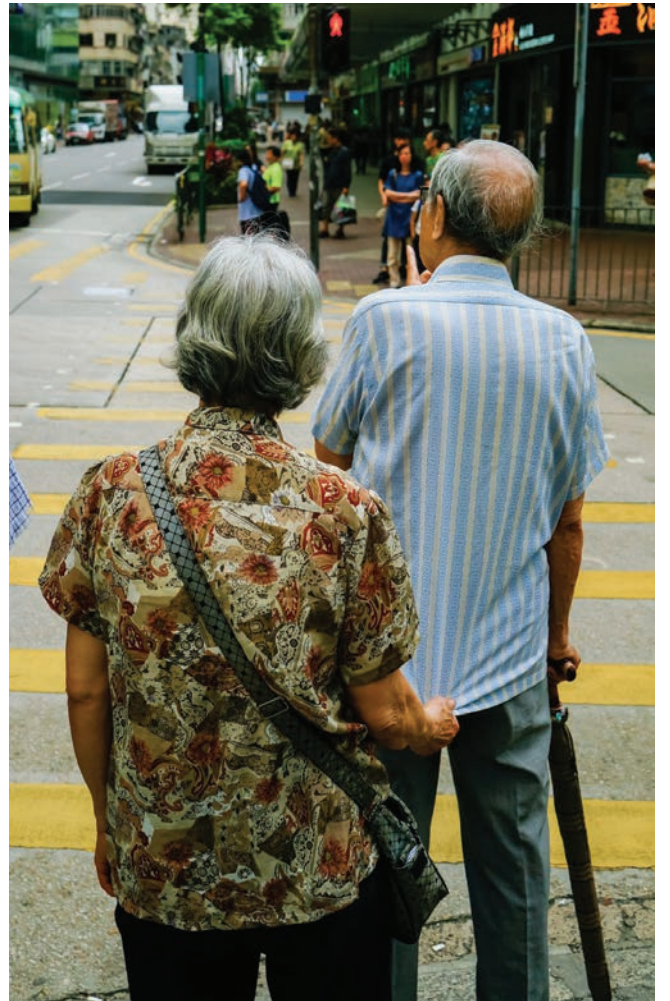
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